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HOW TO IMPROVE THE ACCESS TO PAEDIATRIC PALLIATIVE CARE IN BELGIUM?



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COLOPHON

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LIST OF ABBREVIATIONS

ABBREVIATION	DEFINITION
ACCAPED	Assessment of Complex Clinical Assistance needs in PEDiatrics
ACP	Advance Care Planning
ACT-RCPCH	Association for Children's Palliative Care/Royal College of paediatrics and Child Health
ADL	Activities of the Daily Life
ASD	Aide et Soins à Domicile
AVIQ	Agence pour une Vie de Qualité (Walloon regional agency for health)
AYA	Adolescent and Young Adult
BFPZ-FBSP	Brusselse federatie voor palliative en continue zorgen - Fédération bruxelloise de soins palliatifs et continus (Brussels federation of palliative care)
BFM	Budget of Financial Means
BIHR	Belgian Integrated Health Record
BPPC	Belgian Paediatric Palliative Care
CAPC	Center for Advancement of Palliative Care
CCC	Complex Chronic Conditions
CHC	Group santé CHC (previously Centre Hospitalier Chrétien)
CHR	Centre Hospitalier Régional (Regional hospital)
CHU	Centre Hospitalier Universitair (Universitary hospital)
CM/MC	Christelijke Mutualiteit - Mutualité Chrétienne
COCOF	French community Commission
EAPC	European Association of Palliative Care
EHD	Ecole Hôpital et Domicile
EOL	End-of-Life
EPR	Electronic Patient Record
FPS	Federal Public Service - Federale Overheidsdienst (FOD) - Service Public Fédéral (SPF)
FTE	Full Time Equivalent
FWSP	Fédération wallonne des soins palliatifs (Walloon federation of palliative care)
GO-PPaCS	Global Overview- Pediatric Palliative Care Standards
GP	Generalist Practitioner
HAD	Hospital at home - Thuishospitalisatie (TH) - Hospitalisation à domicile (HAD)
HCP	Health Care Professionals

HSR	Health Service Research
HUDERF	Hôpital Universitaire des Enfants Rein Fabiola
ICD-10	International Classification of Disease - 10
ICPCN	International Children's Palliative Care Network
ID	Intellectual Disability
IFIC	Instituut voor Functieclassificatie - Institut de Classification de Fonctions
IZP	Individueel ZorgPlan
KBS-FRB	Koning Boudewijn Stichting - Foundation Roi Baudouin
KCE	Belgian Health Care Knowledge Centre
KITES	Kinderen In Thuis en Supportieve zorg
KOESTER	Kinder Oncologische Eenheid voor Specifieke Thuiszorg en Rehabilitatie
KOTK	Kom Op Tegen Kanker (Flemish Fundation Against Cancer)
LLC/LTC	Life-limiting Condition/Life-Threatening Condition
MAF - MàF	Maximum Factuur (MAF)- Maximum à Facturer (MàF) (Maximum bill)
MD	Medical Doctor
MOC	Multidisciplinary Oncological Consultation
MZG-RHM	Minimal Hospital Data
NIHDI	National Institute for Health and Disability Insurance (RIZIV-INAMI)
OCMW-CPAS	Openbaar Centrum voor Maatschappelijk Welzijn - Centre Public d'Action Sociale (Public welfare centre)
OPZ	Openbaar Psychiatrische Zorg (Public mental healthcare)
PaPaS	PAediatric PAlliative Screening
PaPCANZ	Paediatric Palliative Care Australia and New Zealand
PC	Palliative Care
PCA	Patient Controlled Analgesia
PLT	Paediatric Liaison Team
PPC	Paediatric Palliative Care
PPCN	Paediatric Palliative Care Network
PZV	Palliatieve Zorg Vlaanderen (Flemish federation of palliative care)
QuoCCA	Quality of Care Collaborative Australia
RD	Royal Decree
RQ	Research Question
RVA-ONEM	Rijksdienst Voor Arbeidsvoorziening - Office National de 'Emploi
SC	Supportive Care
SH	Stakeholder

SHS	Severe Health-related Suffering
SIO	Synchroon Internet Onderwijs (synchronous online education)
START	Screening Triage Assessment and Re-evaluation tool
TCT	Technical Cell - cellule Technique
TOAH	Tijdelijk Onderwijs Aan Huis (Temporary education at home)
UK	United Kingdom
USA	United States of America
UZ	Universitair Ziekenhuis (Universitary hospital)
UZA	Universitair Ziekenhuis Antwerpen (Universitary hospital Antwerp)
VAPH	Vlaams Agentschap voor Personen met een Handicap (Flemish agency for persons with a disability)
WHO	World Health Organisation
vzw-asbl	Vereniging zonder winstoogmerk - association sans but lucratif (non-profit organisation)
YA	Young Adult

SUPPLEMENTARY DATA

1 TARGETED LITERATURE SEARCH ON TARGET POPULATION ESTIMATION

1.1 Methods

In the aim to answer RQ1 "How to identify a palliative care situation?", a Belgian data analysis has been performed to estimate the target population of the PPC offer in Belgium. To prepare this analysis, a targeted literature search was conducted using a snowballing process of peer-review literature. The search was made in October 2024. An update was done in June 2026 to check if new estimations were published since the first search. The objective was to identify, in recent scientific publications, the usual age range of the target population; the usual population-identification tool and the estimation of children with PPC needs in other countries.

1.2 Results

Table 1 – Characteristics and estimated prevalence of children with PPC needs across countries

Region	Age	Population-identification tool	Estimation	Reference
UK	0-19y	LLC	Prevalence 25/10 000 children (2000-2001) Prevalence 32/10 000 children (2009-2010)	[1]
USA	children	CCC	24.4-26.1/100 hospitalised children (1991-2010)	[2]
Scotland	0-25y	LLC	41.4/10 000 hospitalised children (2013-2014)	[3]
Eleven countries	1-17y	CCC	24.4-75.3/100 deceased children	[4]
Worldwide	0-19y	CPC list based on the ACT/Together for Short Lives	21 000 000 children with CPC (prevalence without unqualified sequela and accounting for symptom burden)	[5]
Brussels	0-19y	CCC	22 721 children on a 5y period	[6]
UK	0-19y	LLC	Prevalence 61-66/10 000 children (2017-2018) 67-84.22/10 000 children (2030)	[7]
USA	0-18y	CCC	38.3/100 hospitalised children	[8]
Germany	0-19y	LLC	65.3/10 000 children (2022)	[9]
Worldwide	0-19y	SHS	10 600 000 children experienced SHS (2023)	[10]

LLC= life-limiting conditions; CCC= complex chronic conditions; SHS= serious health-related suffering; y=year; CPC= Children's Palliative Care; ACT= Association for Children's Palliative Care

1.3 Conclusion

The usual age range of the target population is 0-19y.

The usual population-identification tool is either the list of CCC or the list of LLC.

The estimated prevalence of children with LLC or CCC is growing with time.

2 CONTENT EXPERTS' CONSULTATION ON THE IDEAL TARGET POPULATION

2.1 Context

This part of the research was conducted to collect data to answer RQ 1: "*How to identify paediatric palliative situations?*" and to frame the research about the other RQs with the most adapted target population.

2.2 Objective

The set up of the ideal target population eligible for PPC in case of palliative situation in Belgium by collecting the opinion and knowledge of Belgian content experts in PPC to further define the population for data analysis and to frame the research on the other RQ with the most adapted target population.

2.3 Methods

The consultation was divided in two parts. The first one is a written consultation, and the second one is an oral consultation.

The written consultation consisted in a survey in a Word document. The survey included a first section on informed consent, a second section on participants profile, a third section with information on theoretical target population and a fourth section with the core questions. An exploratory review of the grey literature about PPC definition was conducted to prepare the content of the survey (see section 3 in the supplementary data). The survey is available on request.

The oral consultation was based on the round table method. The principle of that meeting is to collect the experiences and opinions of the participants by giving them the opportunity to express themselves. The participation to a round table required that the participants have a high level of knowledge on the subject before the meeting, underlying the need of the written part. The round table does not aim to reach a consensus but can reach it.

Textbox 1 – Round Table

Round Table

Round table is a meeting characterised by the principle of equality between participants. The topic to be discussed is of interest to the participants and is not agreed by all. The role of the facilitator is to ensure that the discussion does not go beyond the established framework and to give the floor in turn to the participants so that everyone has equal time to speak

The consultation occurred in September 2025. The participants had 10 days to answer the written document. All eligible participants who did not decline to participate received the written document if they had previously filled the declaration of conflict of interest and confidentiality. Two round tables were organised according to the number of participants and the feasibility of the round table (ideally maximum 20 participants in a round table).

The participants were

- members of the paediatric liaison teams,
- field professionals experienced in PPC: such as teachers of the certificate in PPC, academic MD involved in publication about PPC, HCP from the community involved in PPC
- associations experienced in PPC which offer support to patients/parents
- researchers specialised in PPC
- regional PC federations
- PC second-line support team for adults
- Federal cell for the evaluation of PC
- specialists of AYA care

During the written part, participants chose for their ideal target population by included/excluded population groups sorted by age categories and social role (parents, teacher, first line HCP, etc) within the 'palliative situation'. In addition, they could nuance/justifie their choice. The documents were collected in an external confidential drop box and analysed by KCE to prepare the oral part and make the consultation as efficient as possible.

The meeting was held in hybrid mode (in person or using Zoom©) and audio recorded. The meeting was preferably held in English, but any national language was allowed. The recording was only used if further clarifications were needed during the analysis phase. Notes were also taken during the meeting with the support of the Miro© programme. A feasibility test of the Miro program was conducted during the scoping phase. During the oral part, the participants were first informed about the quantitative and qualitative results of the written part and then, they voted, with the Wooclap© system, to include or exclude the different target population groups.

A first inclusion rate for each target population group was calculated based on the written part. If more than 90% of the participants agreed, this category was not discussed orally. Inclusion rates between 10 and 89% were discussed. The floor was then given namely to each participant to offer the opportunity to explain their opinion. After this, a second and last vote occurred. Each rate above 90% (or below 10%) is considered as a consensus. If no consensus was reached, KCE set up the final target population based on experts' opinions (major opinion with the nuance brought by participants who did not agree) and grey/peer-reviewed literature.

2.4 Result of the written part

The survey was sent to 53 participants. We received 39 filled surveys back. Two participants filled in the same survey jointly.

Table 2 – Profile of the respondents (n=40)

Regions		Background		Work setting		Expertise level	
Flanders	19	Paediatrician	14	Hospital	22	High	19
Brussels	14	Nurse:	11	Community	8	Intermediate	4
Wallonia	7	Psychologist	5	Home care	7	Low	17
		Ethicist	3	Research	3		
		Life expert	3				
		GP	2				
		Economist	1				
		Social worker	1				

2.4.1 Age categories

Table 3 – Opinion of experts about the age categories to be included in the target population of PPC (n=39)

Population groups	Included	Excluded	Do not know	Consensus at 90%	Conditions for inclusion
Infants (0 to 1 year old)	38	0	1	yes	
Toddlers and preschoolers (2 to 5 years old) (n=39)	39	0	0	yes	
School-aged children (6 to 14 years old)	39	0	0	Yes	
Adolescents (15 to 17 years old)	39	0	0	Yes	
Young adults, living with their referent adults because still in the process of getting autonomy (18-24 years)	28	5	6	no	See Table 4
Adults (25+) lacking decisional capacities (situation of mental or intellectual disabilities)	20	14	5	no	See Table 5

All participants agree to include the categories 2 to 18 years old. A participant, who suggested excluding infants from the target population, was finally very debated on whether to include them or not. Five participants suggested excluding young adults from the target population and 14 disagreed with the extension to adults with ID. Although the 90% threshold was not reached, the majority is in favour of a large inclusion. Even, four participants also suggested adding another age category, the children before birth, the foetus. The target is rather the mother, but the rationale behind is that professionals experienced in PPC could be involved as soon as a LLC/CCC was detected before birth and/or medical abortion was planned. This kind of care is also named the perinatal palliative care.

Eleven participants suggested excluding the young adults (YA) from the target population. The arguments put forward are as follows:

Table 4 – Arguments put forward by participants to support the exclusion of the young adults from the target population and the nuances to keep them included

Why not included	Nuances - Problems with no inclusion – Alternative solutions
YA have different care needs than children, particularly when compared to the lower age categories: ex: need for words in the face of mourning YA is a separate group of patients with specific needs that professionals experienced in PPC cannot offer Since YA can often turn to adult organisations, doubts that some of their needs do not fit better with adult palliative care institutions and facilities were expressed YA are eligible for adult palliative care	Does adult palliative care take their specific needs into account? We should ensure that people are trained for caring YA These can be followed up via a specialised team with specific competencies in young adults needs Children are extremely well accompanied by professionals experienced in PPC in all settings while adults in-hospital PC teams rarely come to home or relates to PC platforms.
YA do not want to go in paediatric wards YA ask to be recognised as adults YA cannot be admitted in paediatric wards: the in-hospital follow-up is not the same beyond the age of 16: patients are no longer treated in paediatrics but in the adult ward and do not meet with the same teams Their inclusion is against the general direction of acknowledging and promoting the autonomy of older minors Most YA have the capacity to be at least autonomous	Is there a lack of suitable structure for YA? There are children who should go to adult services according to their age, but who remain attached to paediatric habits. It is necessary to accompany families to the change of professionals

Why not included	Nuances - Problems with no inclusion – Alternative solutions
An administrative limit must be set	
Definition has not to be too inclusive There is a need to focus on paediatric palliative care. If a concept is stretched too far, it loses its focus There is already a lot of research and resources going to adults. That's why the focus has to be kept on the little ones	I would make two categories based on the age of onset of the disease. A person diagnosed at 13 or 21 will not be followed by the same teams if they have been included in a palliative trajectory since birth.
Caregivers who are used to working with children are often very destabilised from being in an adult situation Physically, these patients have an adult body	

The different arguments to support the exclusion of YA from the target population are related to different needs which could be more difficult to meet by paediatric teams, the general direction of acknowledging and promoting the autonomy of older minors and the will to stay focus on the children and avoiding stretching the definition. However, the same respondents whose opinion goes against the inclusion of YA are concerned by the lack of adapted structure for YA, the necessity to accompany the transfer to the adult care and the distinction between YA cared in paediatrics since a long time and YA whose PC needs were identified after 18y.

Nineteen participants suggested excluding the adults with ID from the target population. The arguments put forward are as follows:

Table 5 – Arguments put forward by participants to support the exclusion of the adults with ID from the target population and the nuances to keep them included

Why not included	Nuances - Problems with no inclusion – Alternative solutions
It is not so much the notion of child or adult that is important, it is undoubtedly more the specialisation of the professional. The demands and needs are different from the paediatric population. A large majority of these people end up in institutions. Our network in palliative care lies with children: adult palliative teams, institutions, MFCs and home nurses know their needs/habits much better. If an admission is required, this is in an adult care department, if they stay in an institution, it is in an adult institution, if they are followed up by a specialist e.g., paediatric cardiologist, there is always a transfer to an adult cardiologist.	It is necessary to conduct a separate study. That is an important issue, but not one that should be addressed within paediatric palliative care. It would broaden the focus too much and would not benefit PPC.
Due to their ID, the goal of care differs from that of a child (maintaining autonomy vs. developer autonomy). In situations of psychic or intellectual disability, teams specialised in this type of pathologies are very important both for the care and for the monitoring of the patient and the family.	These can benefit from a similar approach in communication and family-oriented care as in children. In case of heavy cognitive disability and lack of discernment, the paediatric model can be useful (decision makers being the parents or other family members).
The health problems that these adults pose are not those that belong to the expertise of the caregivers for children. You can learn to approach an adult with a mental age of a child appropriately. You cannot leam to acquire all the medical knowledge necessary for specialised care for children and adults.	Collaboration with adult teams can be considered. In case of paediatric pathology and young age, this could be exceptionally possible. Adult teams also have their place. Transfer and support by palliative care adults as much as possible. There is a difference whether the palliative situation is the consequence or not of disability (chronic

Why not included	Nuances - Problems with no inclusion – Alternative solutions
Specific expertise no longer belongs to the competences of the paediatric teams, especially on a physical level. These are adults who will occasionally have medical problems related to aging that paediatric teams do not know. Doubts are expressed whether some medical approach still applies and whether the same medical procedures can be maintained. Health issues are closer to adult medicine even if dependency situation. This category of patients has specific needs that paediatric hip providers are not trained for. Their pathology + treatment (e.g., pain relief) is better understood from the palliative care for adults. Professionals experienced in PPC are not geared to lifelong patient monitoring	illness): we must sometimes include them in, depending on the situation. Context-oriented care is important not only in paediatrics but also in adult care, and not only in people with a mental disability.
The biggest problem for me is that they are still adults and most people with mental or intellectual disabilities are not completely incapable of being included.	It is important if the patients realise that they are 18, because it may also be important for some children to be considered as "adult" and then adjustments in adult care should be made.

The different arguments to support the exclusion of adults with ID from the target population are related to the lack of knowledge and experience of the paediatric professionals with conditions of older adults and with ID in adults, related to the current organisation of the health system based on an age cut-off between paediatrics and adult care and related to the will of adult with ID whose capacity to decide is present to be treated within the adult model of care. However, the same respondents whose opinion goes against the inclusion of adults with ID are concerned by the lack of adaptation of the adult care system to people with ID, by the fact that specific communication skills and parents involvement are required in the care of adults with ID like in paediatric model of care, and by the need to develop context oriented care in the adult system.

2.4.2 Social position within the palliative situation

Table 6 – Opinion of experts about the social position categories to be included in the target population of PPC (n=39)

Social position	Included	Excluded	Do not know	Consensus at 90%	Conditions for inclusion
Parents	39	0	0	yes	
Siblings	39	0	0	yes	
Co-habitants	30	2	7	No	See Table 7
Informal caregivers	31	0	8	No	See Table 8
HCP non-specialised in PPC	36	1	2	Yes	

The consensus is reached to include the parents, the siblings and the HCP non-specialised in PPC in the target population of PPC. The concern of the participants who hesitated to include HCP is about the risk that expanding the scope will lead to the development of too many teams. A solution proposed is to train the HCP.

Nine participants suggested excluding the co-habitants from the target population. The arguments put forward are as follows:

Table 7 – Arguments put forward by participants to support the exclusion of co-habitants from the target population and the nuances to keep them included

Why to exclude	Nuances - solutions
If not close or not involved in the care.	Housemates are very closely involved with the "patient" and can even play an important personal role for the child.
What you understand among housemates? Where does the term "housemates" end? Limit oneself to the family at first level. You may not always want the child to be closely involved with certain people. Who are the co-habitants? It depends on the choice that parents should have about what is shared with who.	Stepfathers and stepmothers, half-brothers and half-sisters should be included. Is this involved family, a caregiver, ... then definitely recording. Is this someone who is not very involved (e.g., fellow students in a student home) do not include them.
This expands the number of professionals needed. Keep the focus on the patient and family. That is where the attention and resources should go in the first instance.	It could be important for the broader sphere of the child to be included and entitled to support. Housemates are obviously a relevant population, so they can certainly be included.

The different arguments to support the exclusion of co-habitants from the target population are their non-involvement in the care or a distant relationship, the parents' wish that to not involved co-habitants; and to keep the focus on the child and the parents. However, the same respondents whose opinion goes against the inclusion of co-habitants suggested to still include the co-habitants very close to the child; stepfathers, stepmothers, half-brothers and half-sisters; family members and caregivers; even all broader sphere of the child.

Eight participants suggested excluding the informal care givers from the target population. The arguments put forward are as follows:

Table 8 – Arguments put forward by participants to support the exclusion of informal caregivers from the target population and the nuances to keep them included

Why to exclude	Nuances - solutions
It depends how close they are I guess and how much they are involved in the care.	
Careful not to escalate too much. Keep the focus on the patient and family: that is where the attention and resources should go in the first instance.	
Case-by-case basis with the parents and the child, not systematic. The choice that parents should have about what is shared with who.	Informal care givers are obviously a relevant population, so they can certainly be included.

The different arguments to support the exclusion of informal caregivers from the target population are to keep the focus on the child (and the parents) and to respect the parents' wish that informal care givers were not involved. However, the same respondents whose opinion do not go for the inclusion of informal caregivers had not a strong opinion against saying that informal caregivers are still a relevant target of PPC and that everything depends on how much the informal caregivers are involved.

Participants suggested adding other people from different social positions involved in the palliative situation within the target population of PPC: friend, girl- or boyfriend, teacher, staff and volunteers of respite house, day care and centrum for disabled children, and also professionals experienced in PPC.

2.4.3 Conclusion

Before the oral consultation, a consensus was already reached for children from 0-18, their parents and siblings and their HCP non-specialised in PPC. All the categories proposed in the survey received at least the support of most of the participants. The focus of the oral consultation was therefore put on the YA, the adults with ID, the co-habitants and the informal caregivers. In an aim of clarification of the terminology and facilitating the discussion, the categories co-habitants and informal caregivers were changed into 'the nuclear and blended family' including the parents, siblings, stepparents and halfsiblings; and into 'extended social network' including grand-parents, relatives, friends, volunteers, neighbours if they are involved in the care and support of the patient.

2.5 Result of the oral part

Forty-three experts accepted the invitation to the oral part but only 36 participated. The consultation occurs in two meetings to keep the method of the round table feasible, but the results are presented in an aggregated way.

2.5.1 Wooclap© voting results

Not all participants in the meetings took part in the voting session. Only 33 participated and multiple answers were allowed. The results are therefore presented as trends and not as rates. The results of the two meetings are presented jointly.

Question 1: Should the perinatal group include the foetus?

Yes 11+16

No 4+0

Other: 0+1

⇨ Most of the participants agree with the inclusion of foetus

Question 2: Children from 0 to 14 years old must obviously be included in the target population. Do you agree?

14+15 yes

1 +1 no

0+1 other

⇨ Not all participants agree with the inclusion of children

Question 3: Which service should take care of the AYA?

The adult PC teams: 1+1

Both the adult and paediatric teams should be involved during all transition process: 14+15

PLTs should continue to take care till 18 years old: 5+3

PLTs should continue to take care till 25 years old: 2+5

PLTs should continue to take care till the patient chooses another option of care: 5+8

⇨ Most participants agree with the involvement of both the adult and the paediatric PC team during the transition

Question 4: About PC for AYA (15-25 years old). Choose the statement on which you agree.

If the disease onset occurs before the age of 15 years, the paediatric team will take the lead during the transition period between 15 and 25 years of age: 10+16

If the disease onset occurs between the ages of 15 and 18 years, the adolescent may decide which team takes the lead in palliative care (paediatric or adult): 12+13

If the disease onset occurs after the age of 18 years, the adult team will take the lead in palliative care: 12+12

Other: 0+0

- ⇨ Most participants agree with a role distribution based on the onset age of the palliative situation

Question 5: The following subgroups should be able to receive support from specialised paediatric palliative care services.

The nuclear family: 16+17

The blended family: 14+15

The informal caregivers: 14+16

The professionals non-experienced in PPC: 12+13

Other subgroup: 3+4

- ⇨ Most participants agree to include all the social positions in the target population

Question 6: Which category of baby's should be better included in the perinatal target subgroup?

0-28 days: 11+10

Newborn and babies who never left the hospital: 9+12

Foetus older than 24 weeks: 9+11

Other:0+1

- ⇨ Most participants agree to include babies till their dismissal from hospital in the perinatal subgroup

Question 7: At which age is it better to start the transition to adult care?

15y: 2+2

16y: 5+5

17y: 8+3

18y: 5+3

Other: 3+9

- ⇨ No trend on this question

Question 8: Adults with ID should rather be cared in the adult sectors because of their physical needs but on a paediatric model. Do you agree? (n=16+17)

Yes: 13+15

No: 0+0

Other: 3+2

- ⇨ Most participants agree that adults with ID should be cared for in the adult sector with care adapted on the paediatric model

2.5.2 Oral input during the round tables

All the participants have taken the word.

What was said about transition and transfer?

The importance of this issue is likely to grow as advances in care continue to extend patients' life expectancy.

Adolescents should be given a voice, particularly about transition.

Depending on their developmental stage, what role is the adolescent or young adult (AYA) ready to assume, and to what extent do they wish to involve others in decision-making? Age is a poor proxy for maturity. Age alone is an arbitrary criterion; other factors should also be taken into account. Decisions regarding transition should therefore be assessed on a case-by-case basis.

The appropriate timing depends not only on age, but also on life expectancy and the clinical context: is a transfer relevant? Is there sufficient time? Is there hope or the possibility of remission?

Furthermore, the disease trajectory has an impact on the type and level of support required. Age-based protocols should be avoided. Instead, transition processes should be tailored to individual circumstances and the needs of each child. In some cases, transfer can be achieved smoothly from the age of 16 years, provided that adequate preparation and anticipation are in place. In other cases, transfer may be more challenging for families, necessitating a longer and more gradual transition period. Moreover, certain cancers in adulthood may benefit from paediatric expertise; the need for such expertise should always be considered, even in adult-onset cancers.

Transfer requires effort and appropriate support as it is complex despite being necessary. First, it is difficult for professionals experienced in PPC to let it go patients and families they have been following for years. Second, adult PC teams function differently than professionals experienced in PPC (less collaboration, less people involved, less support for families). Third, it is difficult to find referent HCP (internist for example) or hospital units, in the adult system, able to meet the needs of YA with chronic diseases or even accepting to take the lead of the care. Fourth, GPs lack experience in PPC and severe chronic condition of YA. Fifth transfer took time to allow patients, parents and care givers to be adapted to the new adult services.

Professionals from the adult PC services should be involved in the discussion about transfer. Effective collaboration between paediatric and adult palliative care teams is beneficial and promotes continuity of care. It is important that the adult and the paediatric teams know each other to share knowledge, good practices and difficulties. It would improve the collaboration between them.

For a successful transition, involvement must extend beyond physicians and nurses. It is notably important to involve staff of day and residential centres for children with disabilities. Those teams are also facing difficulties supporting patients in palliative situations. They struggle to understand what a PPC pathway is and to identify the role of each (centre for disabled children, parents, hospital team et primary care team).

The presence of an adult in the paediatric system means that the transition did not occur. This is a failure in the care system. During discussions, adult care teams reported having limited guidance and experience regarding the management of adults with concurrent intellectual disabilities and palliative care needs. It is therefore important to consider these particularly vulnerable individuals whose needs currently risk being overlooked within existing care pathways.

What was said about the perinatal period:

The foetuses should be considered and addressed using a palliative approach. During the discussion, a consensus of the Paediatric Liaison Teams (PLTs) representants was set about the inclusion of foetuses in the target population. Also, the parents of foetuses should be included in the target population. They are indeed the main target of the PPC as they are under pressure with difficult choices and should be supported. However, parents can decline to be supported. Il remains their decision to offer PPC to their foetus.

The perinatal PPC concerns three different care teams: the obstetrical team, the hospital paediatric team and the primary care. A collaborative framework involving neonatal, antenatal, and delivery ward services was already established in some places. This multidisciplinary approach has been shown to benefit patients and their families by providing coordinated care in the context of a complex or challenging birth.

What was said about which social position should be in the target population?

The most straightforward and appropriate approach is to consult the nuclear family regarding which individuals should receive support.

However, some participants highlight the importance of supporting first line professionals with limited experience in PPC and even anybody who is involved with the care to the child, even if he/she is not a family member. But a limit is necessary to keep it feasible in the current budgetary context and focus on the nuclear family.

3 CLINICAL EXPERT CONSULTATION ON PC DEFINITION

3.1 Context

This part of the research was conducted to collect data to answer RQ 1: "*How to identify a palliative care situation?*"

3.2 Objective

The main objective is to set up the ideal target population eligible for PPC in case of paediatric palliative situation in Belgium by collecting opinion and knowledge of Belgian experts in PPC about the elements defining a paediatric palliative situation. The final objective is to further define the population for data analysis and to frame the research on the other RQ with the most adapted target population.

3.3 Methods

The consultation was divided in two parts. The first one is a written consultation, and the second one is an oral consultation. Both parts occurred in October 2025.

3.3.1 Written part

The written consultation consisted in a survey on a Word document. The participants include only clinicians from paediatric liaison teams, professionals experienced in PPC, and professionals regularly facing paediatric palliative situations (from the hospital setting and the community). The written consultation target as much clinicians as possible.

A list of clinicians was established by consulting the professional associations of paediatricians, the website of the liaison teams, the Belgian clinicians with at least one peer-reviewed publication on PPC and all clinicians identified by pairs as at least facing once a paediatric palliative situation. Then the email address of those eligible clinicians was searched on Google and Edge. Only candidate with an online available email address were selected. The list finally includes 135 clinicians (MD, nurse, physiotherapists and clinical psychologist). All contacts were conducted by email. The first email introduces the research and invited participants to sign a conflict of interest and confidentiality declaration. When signed, the participant received the survey. The participants had seven days to answer it. The documents were collected in an external confidential drop box and analysed by KCE to prepare the oral part and make the oral consultation as efficient as possible.

The survey included a first section on informed concern, a second section on participants profile, and a third section with the core questions. Theoretical information with comprehensive definition and a lexicon was provided as an annex document. The survey is available on request.

3.3.2 Oral part

The oral consultation was based on the nominal group method.

Text box – Nominal group

Nominal group

A nominal group is a structured method for group brainstorming that encourages contributions from everyone and facilitates quick agreement on the relative importance of issues, problems, or solutions. The primary purpose of the discussion is clarification (not to resolve differences of opinion). It does not aim to reach a consensus but can reach it. The topics to be discussed are of interest to the participants and participants have expertise in the topics. Discussion is equally balanced among all ideas.

Two nominal groups were organised according to the availability of participants. The participants to the oral consultation include only coordinator of liaison teams. 23 were invited. 17 have answered the datum poll. Two dates were selected to allow the participation of at least one representative by liaison team.

The meeting was hold in French and Dutch with a power-point support in English. The meeting was recorded in case clarifications were needed later. However, data was directly collected during the meeting with the support of the Miro programme and by hand. It was asked to participants to have access to a computer with the Google chrome navigator to access the Miro platform. A password allowed the participants to see and to edit the content of the Miro board of the KCE project PPC. The objective was the share of opinions and knowledge directly online through a visual and collaborative mean, simultaneously visible by all the participants and the researchers. However, the Miro support was only used for the first meeting. This option was abandoned because of the waste of time as the tool was too complicated to be handled by non-trained users although a feasibility test of the Miro program was conducted with success during the scoping phase. For the second meeting written consultation was handled by Zoom© chat.

During the oral part, the participants were first informed about objectives and instructions of the oral part. Then results of the written part about the definitions were presented. Then questions still pending after the written consultation analysis were addressed to the participants. Finally, agreement on a working definition and its schematic representation was searched.

The oral consultation guide is available on demand.

3.4 Usual definitions of PPC in literature

Several definitions of PPC were provided in the survey document to support the participants when filling out the survey. Desk research in grey literature on common definition of PPC was conducted to prepare the development of the survey. The search was conducted on Google in September 2025 with the terms “Paediatric palliative care” and “Definition”. The research has identified the following definitions.

Belgian law on palliative care (21 July 2016)[a]: « *All patients have the right to palliative care when they are in the advanced or terminal stages of a serious, progressive, life-threatening illness, regardless of their life expectancy.* »[1]

WHO definition (1998): Paediatric palliative care (PPC) is defined as "*the active, comprehensive care for the body and mind of a child suffering from a life-limiting or life-threatening illness, as well as support for the child's family*".[11]

WHO definition (2020): "*Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.*"[12]

The definition of PPC by the Go-PPaCT consortium of experts (2022) highlights the following fundamental points: *PPC is a right for all children with a life-threatening or life-limiting illness and their families. All children with a life-limiting, life-threatening or terminal disease are eligible for PPC.*[13]

3.5 Written part results

Identification and invitation to participate of 135 clinicians concerned by PPC. Seventy-five of them have signed the conflict of interest and confidentiality declaration and therefore have received the questionnaire. Twenty-two questionnaires were filled out.

3.5.1 Profile of the respondents

The respondents originated from the three Belgian regions, had a background of physician, nurse or clinical psychologist. They worked either at hospital or in primary care. All had at least a rare experienced in PPC, as shown in Table 9.

Table 9 – Profile of respondents (n=22)

Region		Background		Setting (sector)		Level of experience in PPC	
Flemish	5	Physician	15	Hospital	20*	Major	8
Brussels	12	Nurse	6	Primary care	2	Moderate	3
Wallonia	5	Psychologist	1			Minor	7
						Rare:	4
						None	0

*5 from neuro-paediatry, 5 from neonatology or paediatric intensive care (NICU/PICU), 4 from paediatric hemato-oncology, 4 from PLT, 2 from cardio-paediatry

All academic centres were represented in the written part: *HUDERF*, *UCL*, *UZA*, *CHU-Citadelle*, *UZ Leuven*, *UZ Gent*, *UZ Brussels*. Other hospitals are *CHC Mont-Legia*, *Helora Jolimont*. Other institutions represented are *Cité Sérine* (respite and EOL care), *Arémis* (home care specialised in PC) and Villa Indigo (respite care).

[a] Loi du 21 Juillet 2016 modifiant la loi du 14 juin 2002 relative aux soins palliatifs en vue d'élargir la définition des soins palliatifs. *M.B. 29 août 2016.* https://etaamb.openjustice.be/fr/loi-du-21-juillet-2016_n2016024163.html ; Wet tot wijziging van de wet van 14 juni 2002 betreffende de palliatieve zorg, tot verruiming van de definitie van palliatieve zorg. *BS 29 augistus 2016.* Wet van 21/07/2016 tot wijziging van de wet van 14 juni 2002 betreffende de palliatieve zorg, tot verruiming van de definitie van palliatieve zorg

3.5.2 Alignment between clinicians' perception of PPC and usual definitions of PPC

First, no participant found the concept of PPC too blurred. No participant has a strong different perception of PPC than the one expressed by usual definitions. There is a common understanding of the presence of LLC/LTC while defining palliative situation although differences exist between LTC and LLC. In addition, unknown conditions have to be also included.

All except one participant disagree with the Belgian legal law (2016) with a comment highlighted that the non-alignment would be related to the 'advanced or terminal stage' aspect expressed in this legal definition. A shared opinion amongst participants is that terminal phase is far too late to start palliative care and that PC is not terminal care.

One participant highlights that the presence of suffering is important to capture the meaning of PC.

Some participants disagree with the concept that the main objective of care is no longer healing but maintaining the best possible quality of life. Indeed, several participants expressed the importance of the co-existence of PPC with curative treatment within the definition. It seems that, except in the terminal phase, it is unacceptable not to propose curative care to children with LLC/LTC, even if PC needs are identified. Still quality of life is an important concept for the participants.

And finally, the concept of severe illness appears more relevant than that of incurability, as the latter is not well suited to health conditions that are life-threatening, remaining theoretically curable.

3.5.3 Transition between supportive care and palliative care

This part of the survey was based on the postulate that palliative care takes progressively the place of supportive care in children with severe disease when they become life-threatening, life-limiting or terminal.

In the survey, based on their own experience, the clinicians had to rate elements which could take part, with others, to the mindset progression from a supportive care situation to palliative care situation. The score goes from 1 to 4: 1 if the element weights a lot in the progression to PC and 4 if the element does not impact the progression. A box 'I do not know' is foreseen.

Table 10 shows the results from a first list of elements. Some of them are based on existing tools, some are related to knowledge and perception.

Table 10 – Mean score by element about perception and tools

N=22	Mean score*
CCC list	2.4
LLC list	2.1
Unknown condition	2.7
Known relation between condition and early death	1.4
Groups of conditions according disease trajectory	2.1
Perception of life-threatening condition	1.6
Perception of life limiting condition	1.6
Severe condition	2.3
Involvement of several organs	2.5
Care must be delivered in academic hospital	3.1
At least three hospital admissions within six months	2.3
No improvement after three weeks in hospital	2.4
No improvement after one week in NICU/PICU	2.4

** Lower score represents a more important impact in the progression*

The results seem to show that participants trust their knowledge and perception more than tools like CCC or LLC lists.

Their arguments are that lists are not updated, include non-severe conditions and are not user-friendly. However, the background of the clinician may have an influence on the expressed opinions. For example, members of PLTs seem to trust more the CCC list than intensive care physicians.

The necessity to be admitted to an academic hospital seems to have the less impact on the mindset progress to PC.

The categories according to disease trajectory seem to bring a broader and more flexible perspective than the CCC and LLC lists but participants express the need to also consider the symptom intensity in addition to the disease trajectory categories when identifying a palliative situation. According to them, this tool cannot be used as a standalone criterion. The identification through the only presence of a severe condition is also criticised as all severe conditions do not require PPC except if the concept of PPC encompasses supportive care.

Table 11 shows the results from a second list of elements related to symptoms and awareness.

Table 11 – Mean score by element about symptoms and awareness

N=22	Mean score*
Need of technical devices	2.1
Need of constant monitoring	1.9
Loss of homeostatic reserve	2.0
Inability to realise meaningful activities	1.6
Possibility to relieve symptoms	1.4
The patient's awareness that death is likely to be the eventual outcome of their health condition	1.8
The family's awareness that death is likely to be the eventual outcome of the patient's health condition.	1.6
The HCP's awareness that death is likely to be the eventual outcome of the patient's health condition	1.7
The patient's awareness that death may be a possible outcome of their health condition	2.2
The family's awareness that death may be a possible outcome of their health condition	2.2
The HCP's awareness that death may be a possible outcome of their health condition.	2.3
The patient’s wish to receive PPC	1
The family’s wish that PPC was offered	1.2
Signs indicating that death is imminent in the short term (from a few hours to a few weeks)	1.3
Signs suggesting that death is likely to occur in the near future (within hours to weeks).	1.4
Signs indicating that death is likely to occur in the long term (from several months to a few years)	1.9
Signs of end of life (the pre-terminal or terminal dying phase)	1.2
Death	1.8

Lower score represents a more important impact in the progression

Four elements seem to reach a kind of consensus as to be very important to progress from supportive care to PC: the possibility to relieve symptoms, the wish of the child or the family to receive PPC and signs of EOL. Those elements align with the outdated view of PC. Most of the comments highlight again that EOL stage is too late to start PPC.

Instability, loss of meaningful functional abilities and awareness that the condition is likely to provoke death are a bundle of elements which seem to also have an impact on the mindset progression from supportive care to PC. Comments from respondents mainly focus on the impact of instability on the family and the place where to deliver the care. It seems that loss of meaningful functional abilities can be experienced more positively by children than by adults. And the awareness of the child depends on the age and ability to understand.

The situation in intensive care unit seems different than in chronic trajectories: families are not ready to hear about a palliative trajectory if the death issue is not a certainty and just a possibility or a likeliness.

The element 'death of the child' has a score which could indicate that respondents could agree that PC could start at the death of a child. One of the six disease trajectory categories concerns this situation.

Need of technical devices, loss of homeostatic reserves and the awareness that the condition may induce death have less impact.

Table 12 shows the results from a third list of elements related to treatment options.

Table 12 – Mean score by element about treatment options

N=22	Mean score*
No curative treatment without cure hope	1.3
No treatment to improve the prognosis without curing	1.5
Only symptomatic treatment	2
Number of already tested treatments	2.2
Time since the start of the treatment	2.7
Curative treatment which can fail and lead to death	2.5
Treatment improving life expectancy without curing with a risk to fail and lead to death	2.1
Curative treatment which impact negatively the functional abilities in the short term	2.5
Curative treatment which impact negatively the functional abilities in the long term	2.5
Treatment improving life expectancy without curing and which impact negatively the functional abilities in the short term	2.0
Treatment improving life expectancy without curing and which impact negatively the functional abilities in the long term	2.0
Curative treatment which causes suffering in the short term	2.6
Curative treatment which causes suffering in the long term	2.4
Treatment improving life expectancy without curing and which causes suffering in the short term	2.2
Treatment improving life expectancy without curing and which causes suffering in the long term	2.0

Lower score represents a more important impact in the progression

All the elements about treatment inducing suffering or loss of functional ability seem to have a reduced impact in the mindset progression from supportive care to PC. However, the negative impact of non-curative treatment is more considered than the negative impact of curative treatment.

Only the absence of treatment seems to have a more important weight in the mindset progression.

Table 13 shows the results from the fourth course of elements related to suffering and economic impact.

Table 13 – Mean score by element about suffering and economic impact

N=22	Mean score*
Child's physical suffering related to the LLC or LTC	1.2
Child's psychological suffering related to the LLC or LTC	1.3
Child's social suffering related to the LLC or LTC	1.8
Child's spiritual suffering related to the LLC or LTC	2.0
The clinician's anticipation of physical suffering of the child	1.6
The clinician's anticipation of psychological suffering of the child	1.8
The clinician's anticipation of social suffering of the child	2.1

N=22	Mean score*
The clinician's anticipation of spiritual suffering of the child	2.2
Distress of relatives	1.9
Distress of HCPs	2.4
The imbalance between the cost of healthcare for the Belgian healthcare system and the benefit to the young patient	3.6
The imbalance between the healthcare cost for the family and the benefit to the young patient	3.4

Lower score represents a more important impact in the progression

The presence of suffering seems to have an important impact on the mindset progression from supportive care to PC. Direct expression of the suffering by the child has slightly more impact than the anticipation of suffering by the clinician. Physical suffering has more impact than psychological suffering, than social suffering, than spiritual suffering. Distress of relatives seems to have some impact and distress of HCP, few impact. However, respondents highlighted that HCP in distress requires help to be able to care for the patient.

Economic issues have the less impact on the mindset transition.

3.5.4 Intermediate analysis

The ten most popular elements according to the mean score. The lower score represents the element with the more important impact in the mindset progression of HCPs to a paediatric palliative situation.:

1,05 : The child's wish to receive palliative care

1,2 : The family's wish for the child to receive palliative care

1,22 : Signs of the end of life (pre-agonal or agonal terminal phase)

1,23 : Physical suffering expressed by the young patient, related to the health problem

1,32 : The absence of curative treatment, no reasonable hope of recovery

1,32 : Psychological distress expressed by the young patient, linked to the health problem

1,33: Signs of death in the short term (a few hours to a few weeks)

1,36 : The perception or knowledge of an association between the diagnosis or clinical picture and early death

1,38 : The possibility of relieving symptoms

1,38 : Signs of death in the medium term (several weeks to a few months)

3.5.5 Prioritisation of the elements impacting progression from supportive care to palliative care

At the question about the most important element which can change a mindset supportive care to the mindset PC, eight respondents answer that a single key element cannot allow to identify the change of mindset.

Table 14 shows the opinion of fourteen respondents. They have sometimes expressed more than one element.

Table 14 – Single key element to progress from supportive care to PC

Key element	Occurence*
Incurability	7
Suffering	5
Life expectancy	3

Key element	Occurence*
In CCC list	2
Child wish for PPC	1
Physical, psychological and social functioning of the child	1
Need for multidisciplinary coordination	1
Unexpected death	1
Deteriorating phase	1

There is no consensus on a key element to identify the moment to shift from supportive care to palliative care. Incurability and the presence of suffering are more cited than others.

Table 15 shows the occurrence of key elements according to the combination of five elements as asked to the participants, the most able to help identifying the progression from supportive care to PC. 19/22 participants have answered. As each combination was different, Table 15 shows only the occurrence of isolated element in the combination of five.

Table 15 – Combination of five elements the most able to help identifying the progression from supportive care to PC

Key element	Occurence*
Suffering	16
Incurability	16
Life-limiting or life-threatening	14
Loss of quality of life	10
Wish	5
Family suffering	4
EOL signs	4
Instability	4
Complexity	3

Incurability and suffering are again the most cited key elements. Then LLC/LTC and loss of quality of life are also frequently cited.

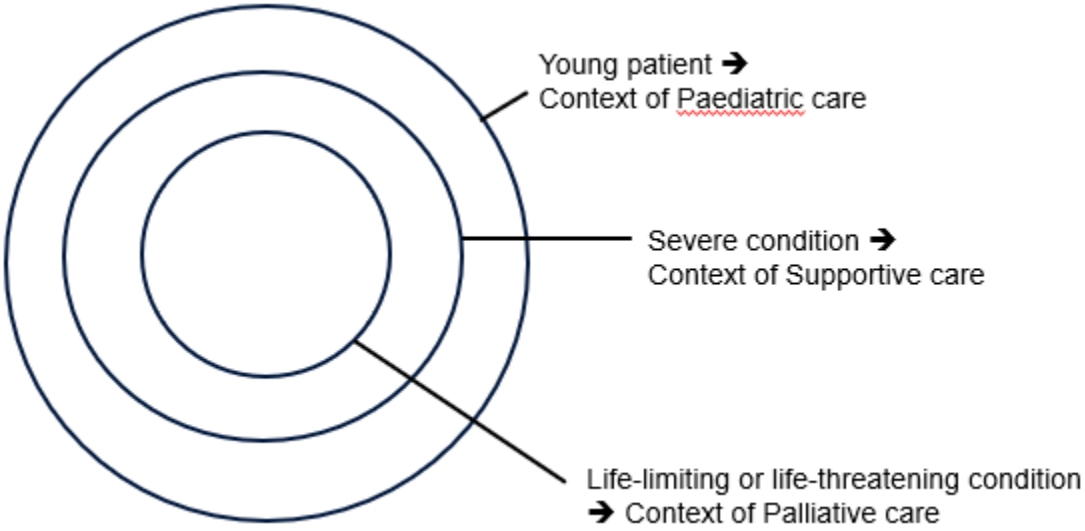
When looking into the usual definitions, one can notice the similarity with the key elements the most frequently cited in this last part of the survey.

Moreover, the different parts of the written consultation support each other in the way that palliative situation could be identified when there is suffering and loss of quality of life related to life-limiting (incurable) condition or life-threatening condition, even more if EOL signs, instability and/or complexity are present, in a way which respects the patient wish and support the family.

3.6 Oral consultation

Fifteen PPC experts have participated in the nominal group. All liaison teams were represented. Figure 1 is a first attempt to propose an overview of PPC target population developed by considering the results of the written part.

Figure 1 – Overview of PPC target population



The oral consultation focuses on pending questions after the analysis of the written part of the experts' consultation.

Is palliative care the same as supportive care in Paediatric?

- If not, can the perception that a condition is life-limiting or life-threatening be the element allowing to distinguish palliative care from supportive care?
- If yes, how can some of the elements identified in the questionnaire serve as decision-making guides?

In a model developed by Lacerda et al. (2023), paediatric oncological care already includes supportive care by offering EOL care, psychosocial care and symptoms control. Spiritual care, family support and ACP are the additional interventions brought by PPC within paediatric oncological care.[14]

The objective of the nominal groups was to go a step further in the identification of elements which could allow distinguishing what differentiate supportive care from PC.

3.6.1 First question: Is PC the same as supportive care in the Belgian Paediatrics sector?

Several participants have expressed that supportive care (SC) and palliative care (PC) are the same. Both care aims to provide comfort to patients with CCC, LTC, LLC. The main view is that supportive care may be included in PC but the opposite view was also expressed. Others have the view that SC, PC and curative care occur in a mixed way. And some others else have expressed that terminal care makes the difference. While the inclusion of SC and terminal care in PC was finally expressed.

It was also said that separating SC and PC in two categories could induce the risk that people assimilate PC and terminal care. In addition, one participant shared that evidence has shown that the added value of PC occurs when it is integrated early in the disease trajectory, so when SC are usually delivered.

The difference between SC and PC is less in the types of interventions delivered than in the philosophy of care: in PC, *primum non nocere* is central. PC consider quality of life as main objective.

Transition from palliative situation to supportive situation can occur when disease-directed treatments are progressing like for SMA, Duchenne and cystic fibrosis. But even if the life-threatening or life limiting concept is less present, the need in PC is still there.

Table 16 listed interventions differing between PC and SC according to participants.

Table 16 – Overview of participants input

Specific interventions and mindset of supportive care	Specific interventions and mindset of palliative care	Common mindset
Cure is the most important	Comfort is the more important	Provide comfort
Supportive care stops with death	Keep patient and family value at the centre of the care	
	Building connections and moving forward step by step with the patient, the family, and the healthcare professionals	
Helping parents to get back on track	ACP in a formalised process	
	Talking about EOL wish (cremation, farewell service, administering final care by parents)	A holistic, multidisciplinary approach
supportive care HCP do not have the expertise in open communication about end of life	palliative HCP have the expertise in open communication about end of life	
	Distress protocol, euthanasia and palliative sedation	
	Bereavement support	
	Supportive discussion with parents	
	Supportive discussion with HCPs	
	EOL care at home	
	Spiritual support	
	Availability in several settings	
	Liaison role and coordination role	
	Alternative resource like respite care when family is exhausted	
	Support to decision making	
	PC requires expert in coordination and quality of life and pain control	
	PC includes support to family and siblings	
	Ethical aspect	

According to the participants, PC differs from SC by

- the importance placed on the views of the patient and their family;
- the support provided to families, informal caregivers, and less experienced healthcare professionals;
- the expertise in discussing end-of-life issues, treatment preferences, and existential questions (including openness to spirituality);
- the support offered in the decision-making process, particularly when ethical tensions arise;
- the establishment of connections between the patient, their family, loved ones, healthcare professionals, and other involved providers;
- the gradual and individualised development of advance care planning;
- the expertise in protocols for distress management, palliative sedation, and euthanasia
- and the bereavement support if necessary.

Those data are aligned with the publication of A. Lacerda about the integration of PC into paediatric oncological care.[14]

3.6.2 Second question: How can the elements serve as decision-making guides?

Most participants have expressed the absence of cut-off when deciding to start PC because every context is different and because of the fluctuating and progressive process occurring in severe condition history. Some expressed the need for the right care at the right moment in the right place independently of a decisional algorithm to start PC.

The presence of LLC, LTC or unknown condition was clearly expressed as a necessary step to define a palliative situation, even if the life expectancy is not short. This confirms the content of Figure 1 giving the role of shift from SC to PC to the presence of an LLC/LTC.

Some participants have again illustrated that PC are necessary when different key elements cumulate. The elements "impact on the quality of life", "duration of the suffering", "incurability", and "short life expectancy" were again mentioned. Also, the presence of multiple needs was evoked.

One given explanation is that, when episodes of discomfort become more frequent, quality of life is poor and the family requires support at home or even wish PC, there is a greater need for a palliative care (PC) team.

Unstable phases (GPs change, surgery, change in family situation, unexpected complication, new symptom) are also a reason to start PC. But PC teams are mainly called when the deteriorating phase occurs. One says that the early integration of PC is easier in the metabolic and neurologic disease than in oncology. The importance that PC start as early as the diagnosis was repeatedly mentioned in all the consultation. This early involvement of PC team is very important to build trustful relationships with parents.

Some participants have explained that the start of PC depends on family decision, particularly when the family is exhausted. One says that to decide some care restrictions is similar than starting PC, making the links with the ACP.

Complexity was also mentioned as a reason to ask for the support of PC team, notably when an important number of actors are involved and therefore coordination is needed. In this way, a first concertation meeting around the ACP would serve as trigger of PC.

Finally, a participant suggested to use the PaPaS scale as decision-making guide (see section 7)

In short, there is no clear trigger to start PC but the presence of LLC or LTC is a constant element. Then the accumulation of different other key elements associated with the wish or exhaustion of the family make the mindset progressing to the involvement of PPC teams.

Theoretically, the usual and current definitions of PPC are accepted by all participants. However, the reality is different, on one hand, PPC teams are most of the time called in the deteriorating or terminal phase of the disease trajectory; and the other hand, despite that PLTs members have agreed with the concept of early integration of PC since the diagnosis, the opinions collected vary a lot between participants, with some opinions still aligned with the EOL view for PC. One important point is the context of LTC or LLC where early integration of PC seems easier than in LTC context.

3.7 Conclusion

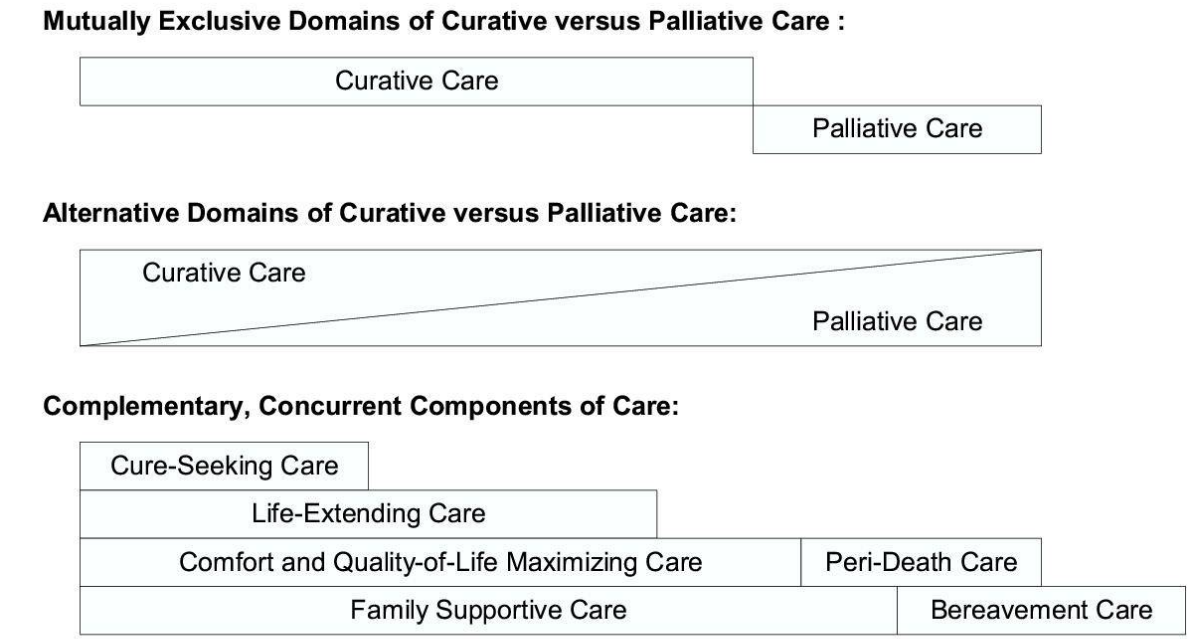
Integrated PC seems to be a definition which corresponds to the perception of Belgian experts when they discussed about PPC definition. The Department Zorg (Flemish authorities competent for care organisation in Flanders) has recently developed a vision of integrated PC:

"*Integrated palliative care is an approach in which palliative care is not considered a separate pathway but is fully and promptly integrated into the care process. It begins as soon as it becomes clear that a person has a serious (incurable) illness, even if that person may still have months or years to live.*

Palliative care relieves physical symptoms, but also addresses psychological, social and spiritual needs, and supports the family or loved ones. The aim is to provide care tailored to the individual wishes and needs of the person and their family and friends, ensuring continuity and cooperation between all care providers involved."

This definition is illustrated by the Figure 2.

Figure 2 – Integrated PPC



Source: Feudtner et al., 2003[15]

The model presented in Figure 1, aligned with the usual definitions of PC/PPC and based on the perception of the respondents to the survey, was updated in Figure 3 to also correspond to the perception of members of the PLTs, the specialised PPC teams in Belgium.

In this model, SC should be delivered to children with severe conditions not life-limiting and not life-threatening while PC should be offered to children and their family in the presence of a LLC/LTC.

Key elements involved in the transition from a supportive care mindset to a palliative care mindset were identified during this expert's consultation. These elements are present in the usual definitions of PC: suffering, incurability, life-limiting or life-threatening condition, importance of quality of life, respect of preferences and support to the family.

In the model, those elements would rather be used to decide on the involvement of a specialised PPC team. But as far as the life-limiting and the life-threatening element is also present in the list of those key elements, it necessarily induces that specialised PPC team should always be involved in the presence of a LLC/LTC. This aspect has to be addressed later in the report according to adaptation in the current offer.

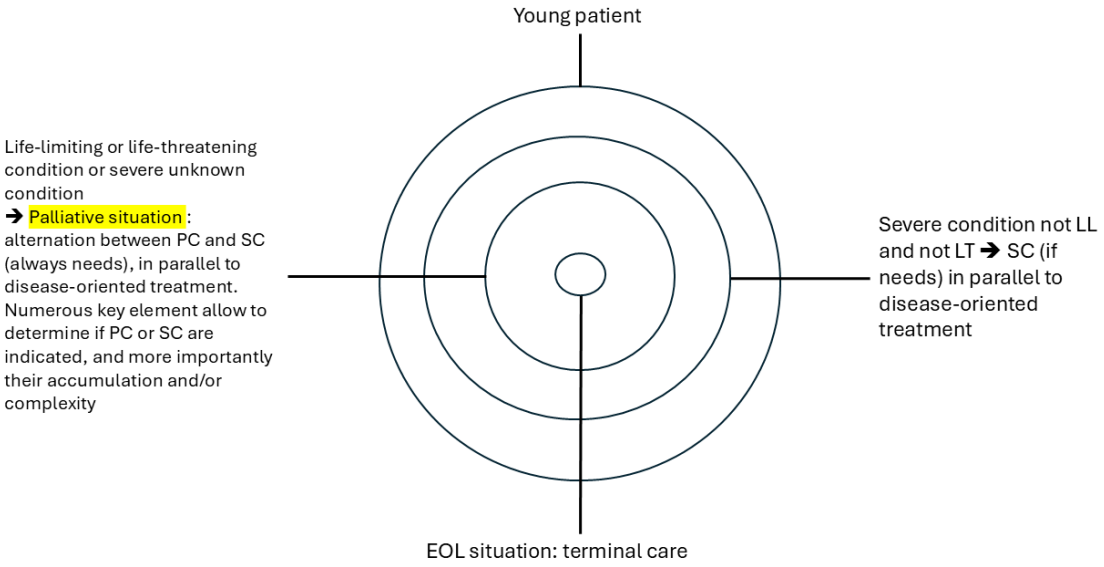
During oral consultation, supportive care differs from PC by the place given to communication about spirituality, wish, ACP, support to family. For some participants, Sc and PC also differ by the philosophy of care, PC aiming to provide quality of life and comfort as main objective while SC keeps

the priority on cure. However, except in the terminal phase, this philosophy does not seem to be shared by all or at least in all LTC or LLC. The context of care, the progress in therapy and mainly the parents or patient wish seems to guide the philosophy of care more than the theoretical view. This seems quite obvious in the case of LTC where the focus on cure seems to last longer than for LLC with difficulties for an early integration of PC in the care trajectory. So PPC finally seems mainly to be patient/family-centred care than care mainly oriented on comfort, as it is the case in adult palliative care.

Moreover, as the trajectories of LLC and LTC fluctuate, SC and PC can alternate to relieve the suffering of the patient in parallel to curative or disease-directed treatments if those are available. In this case, the philosophy of care will also fluctuate according to the disease phase.

Whatever those considerations about SC and PC, care aimed at comfort should begin at the time of diagnosis, whether it is considered supportive or palliative care. There is no single transition into a "palliative phase"; rather, palliative care needs emerge and recede over time within a palliative situation defined by the presence of an LLC/LTC or unknown condition. Those needs may include coordination, communication, spiritual care, support for the family and wider social network, and support for frontline healthcare professionals.

Figure 3 – Model of PPC target population



Additional information from participants

ACP is a communication process spread over time

Parents of patients with oncological conditions search much more curative treatment

The major consequence of the progress in the disease-directed treatments for SMA, Duchenne and cystic fibrosis is the need for a transition from paediatrics to adults' care.

Taboo about PC and PLT. Better to say 'comfort care'

Trustful relationship between parents and HCPs: It is beneficial to be involved from the very beginning to build a trusting relationship. When life expectancy is unpredictable, the intensity of follow-up decreases; however, because contact was established earlier, the threshold for re-engaging and rebuilding care is lower when support is needed again

Trustful relationship between PLT and physicians: Whether the PPC team becomes involved depends on the physician. If the child was born elsewhere or attends an institution, there may be resistance to granting the PPC team access to the institution, as these institutions often have their own PPC contact persons or coordinators (who have received training but generally have less experience).

4 ONLINE SURVEY – SUMMARY OF FINDINGS

4.1 First part – barriers and solutions

On the 15th of January 2026 (after six weeks of survey running), we got 267 visits to the online survey, but 61 visitors do not complete any question. Amongst the 206 remaining visitors, called further the participants, 37 do not meet the inclusion criteria because their expertise in PPC is too strong or their experience in PPC dates back too long ago (more than 15 years) or they never met a paediatric palliative care situation in their professional practice. So, the final sample to analyse is composed of 169 participants. An additional 31 participants do not answer any question on opinion. So, the final sample is composed of 138 participants. Amongst those 138 participants, a doubt on the filling of two questionnaires by the same participants remains for two participants, meaning that the sample is probably 136. Two participants with a limited experience do not complete the first question correctly and nothing further, what leads our sample to 134 participants.

4.1.1 Quantitative analysis of the barriers

The average and median scores given by 135 participants rating seven different barriers proposed by KCE between a score of 0 to 10 was calculated:

Three barriers are very closely high scored with a same median score of 7):

- Lack of knowledge about the existing offer (average = 6.74)
- Lack of professional skill in communication about palliative care (average =6.74)
- Insufficient specialised offer in PPC (average=6.28)

The next three ones are also very closely scored with a same median score of 6

- Lack of professional time to deliver high quality listening (average=5.70)
- Use of the word “palliative” (average= 5.64)
- Unacceptability of a child/YA death

The last one is far behind with a median score of 3

- Insufficient quality of PPC

In conclusion, a lack of quality of PPC is not considered as a barrier to access by HCP not specialised in PPC.

4.1.2 Quantitative analysis of the solutions

The average and median scores given by 118 participants rating the impact of 16 different solutions on access to PPC, proposed by KCE. They hac choice between ‘important positive impact’ (=5 pts), ‘positive impact’ (=3pts), limited positive impact’ (=1 pt), ‘no impact’ (=-1 pt) and ‘negative impact’ (=-3pts).

Eight first solutions have obtained a quite similar average score and the same median score of 5, meaning an important positive impact.

- Strengthen specialised liaison teams (more teams, and/or larger teams, covering all regions) (average= 4.07)
- Better funding for paediatric palliative care by the authorities (average= 4.00)
- Enable multidisciplinary consultation between hospital professionals and frontline professionals (with financial remuneration for this). (average= 3.92)
- Increased provision of end-of-life home care (average= 3.92)

- Greater availability of paediatric palliative care in every setting (home, hospital, rehabilitation centre, residential facility for people with intellectual disabilities, etc.) (average= 3.80)
- Training healthcare professionals whose work focuses on children and young adults in paediatric palliative care (average= 3.80)
- Raise awareness of palliative care among healthcare professionals and the general public (average= 3.80)
- More effective coordination of care during the transition between different care settings (average= 3.77)
- A wider range of complex medical care at home (average= 3.75)

The eight other solutions have obtained more spread average scores and the same median score of 3, meaning an important positive impact.

- Care that is more respectful of the wishes of the child and their family (average= 3.59)
- Greater availability of paediatric palliative care specialists (doctors, nurses, psychologists, social workers and spiritual counsellors available 24 hours a day, 7 days a week) (average= 3.53)
- A wider range of respite care services (average= 3.32)
- Greater involvement of parents and children in discussions and decisions (average= 3.31)
- Have a standardised needs assessment tool (average= 2.78)
- More clinical practice guidelines in paediatric palliative care (average= 2.75)
- Ensure that paediatric palliative care is provided only by specialised teams (average= 1.92)

In conclusion, participants have considered that restricting the provision of PPC only to specialised teams would have no or few impact on the access to PPC. They have also considered that the use of standardised needs assessment tools and clinical guidelines would have less impact to PPC access than the strengthening of the liaison teams or their financing.

4.1.3 Qualitative analysis of the barriers

Sixty-one additional barriers were expressed by participants in addition to the seven proposed by KCE.

Those 61 barriers can be grouped within 41 types of barriers, themselves grouped into seven categories.

The first category includes barriers related to **awareness**:

- lack of knowledge about the concept of SPP
- stigma surrounding palliative care
- not knowing how to recognise a palliative situation
- Inexperience; feeling incompetent; not knowing what to do as a professional
- not knowing the offer
- HCP's lack of awareness of the non-dichotomous nature of curative and palliative care
- idealised view of medicine and doctors
- perception of the superiority of hospital care by hospital caregivers
- somatic focus in the care system

The second category includes barriers related to **training**:

- shortcomings of professionals working with children in communicating about palliative care, death and bereavement
- lack of knowledge about PPC among paediatricians and other professionals who work with seriously ill children
- lack of competence among adult caregivers in paediatric care, sometimes necessary up to the age of 25
- insufficient empowerment of young adults

The third category includes barriers related to **care integration/coordination**:

- fragmented and poorly coordinated care between adult SP and SPP teams
- lack of communication between lines of care
- Lack of communication between sectors
- lack of multidisciplinary consultation

The fourth category includes barriers related to **emotional burden**:

- emotional impact of paediatric palliative care situations on caregivers
- emotional burden of accepting death and coping with a palliative situation for one's child, including the use of the word 'palliative'
- emotional management for carers due to attachment to patients and their families, and problem of separating private life from professional life
- ethical tensions between caregivers and patient

The fifth category includes the barriers related to the **patients/family**:

- language
- beliefs
- level of understanding
- loss of the care option at home due to social context

The sixth category includes the barriers related to the **organisation of care**:

- absence of residential PPC unit
- hospital environment unsuitable for PPC needs
- lack of PLTs
- underfunding of the sector
- lack of nursing nomenclature adapted to home care for children
- lack of transparency in the use of budgets
- administrative constraints
- insufficient mobility of specialist doctors
- insufficient availability of specialist doctors
- lack of logic between place of residence and the team involved
- lack of [paediatric] equipment
- staff shortage

The seventh category includes the barriers related to **knowledge**:

- lack of research
- lack of encoding
- lack of evidence-based identification tools and guidelines
- uncertain prognosis

4.1.4 Qualitative analysis of the solutions

One hundred and fifteen participants have expressed their opinion on the priority for solutions (non-mandatory question!).

Thirty new proposals for solutions were expressed by participants in addition to the 16 proposed by KCE.

These are:

- collaborate with parents-patients associations (1x)
- prioritise relationship of trust (2x)
- improve collaboration between GP and paediatricians (1x)
- improve communication (7x)
- support emotionally HCPs (2x)
- improve staff able to emotionally support families and patients before and after death (2x)
- improve visibility of PLTs (11x)
- offer everyday support to family and siblings (1x)
- offer equal availability (2x)
- change the word ‘palliative’ (3x)
- improve the social support to parents (1x)
- improve the legislation about PC concerning authorised interventions (2x)
- improve support to siblings (2x)
- make a phoneline available to primary care HCPs (1x)
- improve transition between paediatric and adult care (1x)
- simplify administrative procedure (1x)
- appoint a single point of contact for families (one person) (2x)
- start PPC very early in the care trajectory-since birth (2x)
- train HCP to multicultural approach (1x)
- suppress PC in intensive care (1x)
- value time spent with patient (7x)
- allow home visit by specialist physicians (1x)
- recognise association/institution adapted to deliver PPC (1x)
- improve the availability of all types of physicians (1x)

- standardise PLTs functioning (2x)
- adapt home care to PPC needs (1x)
- make PPC available in regional hospitals (4x)
- increase the offer of respite care (3x)
- fight against therapeutic relentlessness (2x)
- improve well-being of families and children (1x)

Amongst the new proposals made by participants, improving the visibility of PLTs was repeatedly identified as a solution as well as valuing the time spent with patients.

Amongst the 46 solutions (KCE ones + new ones), the most prioritised solutions were training and financing. Those were cited respectively 25 and 24 times by participants as priority.

The next two more prioritised solutions (amongst 46) were awareness and multidisciplinary concertation between the first and the second lines, respectively cited 16 and 13 times by participants as priority.

The next three were reinforcement of the liaison teams, availability of the specialised PPC in all settings and increasing the visibility of the specialised PPC. Those were cited respectively eleven, eleven and nine times by participants as priority.

The next ones were to value the time spent with the patient, improving communication and availability of the specialised PPC around the clock. Those were cited seven times each.

All the remaining proposals of solution (35) were cited less than six times.

4.1.4.1 Categorisation of the barriers and solutions

Based on the analyse of data collected about barriers, eight categories of barriers were identified: lack of training; lack of awareness; lack of coordination, collaboration and communication; problems related to human beings characteristics (perceptions, respect, emotions, attachment and ethics); economic, social or cultural issues; gap in the offer (structure and availability); financial issues; gap in scientific knowledge and research.

To match with the framework of Levesque et al (2013), the identified categories about awareness, training, and research were merged into a category called ‘knowledge’. The categories ‘problems related to human beings’ characteristics (perceptions, respect, emotions, attachment and ethics)’ and ‘economic, social or cultural issues’ were also merged into one single category. The three remaining categories were kept. Those five categories have served as a structure to align the solutions identified in the online survey, in the interviews with HCP with large experience and with national experts of selected foreign countries. Then the solutions were rephrased to take into account the Belgian context, the complexity of needs and the related ethical conflicts. This step has led to the redaction of five documents, one by each category, including a description of the context, the barriers and the solutions.

4.2 Second part

As a reminder, the survey was divided into two parts to increase the participation rate to the first part which was the main part of the research on PPC access.

4.2.1 Description of the respondents

Ninety-three participants (47 French-speaking and 46 Dutch-speaking; 45 from Flanders, 25 from the Brussels regio and 23 from Wallonia) in 135 have filled in the second part of the survey. Their profiles were very varied. The majority was nurses (43) and physicians (33) but social workers, massotherapists, psychologists, care helpers, physiotherapist, orthopedagogist and midwife have also participated. They were working in as varied settings as hospitals, home care, respite care and disability institutions. Nine of them had only one experience of paediatric palliative situation, forty-one or them some experiences of paediatric palliative situations and thirty-three had regular experiences. Finally 23 in 93 were trained in PPC.

4.2.2 Initiator of the request of PPC

Sixty-five respondents out of 93 reported that the palliative situation had been referred to them at the request of more than one person. This suggests that prior discussions have taken place upstream.

Two nurses and three physicians (oncology, neurology and intensive care) indicated that they had decided on their own initiative to become involved, without mentioning any other person.

One general practitioner reported being involved in a paediatric palliative care case solely at the request of the patient. Another general practitioner, a coordinating nurse, and a neuropaediatrician reported becoming involved in paediatric palliative care at the request of the family.

One director of a home-care organisation stated that they had become involved in a paediatric palliative care situation at the request of a social worker.

Five nurses identified the general practitioner as the person who had involved them in a paediatric palliative care situation.

A neuropaediatrician, a massage therapist, and a homecare coordinating nurse, all specialised in palliative care or paediatric palliative care, reported being involved in palliative care situations at the request of specialist physicians.

Members of paediatric liaison teams asked six participants from a variety of professional backgrounds—all trained in paediatric palliative care—to be involved in a paediatric palliative situation.

Among referrals involving multiple individuals, families were mentioned 51 times, followed by paediatric liaison teams (42 mentions), specialist physicians (37), general practitioners (30), self-referrals (26), and patients (24). Patients therefore appear to be involved in discussions in at least some situations. Less frequently mentioned referral sources included social workers, schools, employers, colleagues, centres for children with disabilities, hospital psychologists, home-care nurses, and hospital nurses.

4.2.3 Timing to start PPC

The more cited timing by participants is ‘when the severe condition has had an important impact on the child and/or the family’ (70x). The EOL phase was also cited many times (59x), as well as ‘at the diagnosis of LLC/LTC’ (55x). Then, the timings ‘at birth’ and ‘after death’ were less frequently cited as the start for PPC (25 and 21 respectively). Finally, the timings ‘before birth’ and ‘before the diagnosis of LLC/LTC’ have occurred 12 and 14 times.

Those findings seem to confirm the usual late integration of PPC as mentioned several times by experts. Yet evidence has shown that early integration improves the outcomes. However, the start at

diagnosis, which is recommended, has been stated by 55 participants out of 93. Inclusion of the family after the death of a child seems also be confirmed by the data.

4.2.4 Key elements participating to the identification of the palliative situation

The majority of the participants have cited numerous elements participating to the start of PPC. This finding is aligned with the expert opinion collected when the target population of PPC offer was set up at the beginning of the study. Also, as during the expert consultation, the presence of LLC/LTC was the first cited element (68x). The second most cited was the exhaustion of therapeutic options (58x) and persistent suffering (52x). Parents and/or patient wish to start PPC as well as advice from PLT or referent specialist physicians were cited 30 or 31 times. Less cited were the suffering of the family (23x) and the loss of functional ability of the child (23x). The absence of clear decision or of mentioning PPC was cited five times.

A quote from a physician illustrates the findings:

« *The decision was made in consultation with me (the lead oncologist), my fellow oncologists, our paediatric palliative care (PPC) team, and the multidisciplinary team (mainly psychologists), based on a combination of the factors listed above. This decision was then, of course, discussed with the parents and/or the young person, depending on their age. I do not recall any situation in which the patient and/or family requested the involvement of the PPC team before we introduced it.* »

4.2.5 Types of PPC interventions delivered by professionals not specialised in PPC

Participants had to indicate which tasks they had delivered in palliative situations. The suggested tasks were:

- Medical care for the child/young adult (e.g., relief of physical symptoms)
- Personal care for the child/young adult (e.g., hygiene care)
- End-of-life care (e.g., terminal sedation, euthanasia)
- Psychological support or care for the child and/or their family/caregivers (e.g., discussions about fears and concerns)
- Spiritual/existential support for the child/young adult and/or their family/caregivers (e.g., discussions about the meaning of life)
- Social support for the child/young adult and/or their family/caregivers (e.g., assistance with administrative tasks)
- Coordination of care and support services (e.g., coordinating the transition from hospital care to home care)
- Communication and/or ethical support (e.g., developing an advance care plan)
- Information and/or education for family members/caregivers (e.g., explaining the expected course of the illness and how to respond to new symptoms)
- Support for the child's/young adult's development and/or education (e.g., maintaining contact with classmates and teachers, leisure activities)
- Respite care for family members/caregivers.

Participants have noticed that the task 'massage' was missing in the list while it was the only task massotherapists are delivering.

Although nine participants have delivered only one type of intervention, the great majority of the professionals report having offered several tasks.

Nurses (n=44) have declared having provided, in descending order of frequency, personal care (35/44), medical care (33/44), psychological support (30/44), EOL care (21/44), coordination (19/44), training/information (16/44), social support (9/44), respite care (8/44), spiritual support (7/44) and developmental support (4/44).

Physicians (n=33) have declared having provided, in descending order of frequency, medical care (31/33); EOL care (23/33), communication-ACP (23/33), coordination (21/33), training/information (21/33), psychological care (17/33), spiritual care (11/33), social care (7/33), developmental care (6/33), respite care (6/33), personal care (6/33).

Social workers (n=5) have declared having provided, directly or maybe rather indirectly, medical care (1/5), personal care (1/5), psychological support (3/5), spiritual support (1/5), social support (4/5), the remaining one is a clini-clown, coordination (4/5, communication-ACP (1/5), training/information (2/5), developmental support (1/5), respite care (2/5).

Psychologists (n=4) have declared having provided personal care (1/4), EOL care (1/4), psychological care (4/4), spiritual acre (3/4), coordination (1/4), communication -ACP (2/4), training/information (1/4), developmental support (3/4), respite care (1/4). No medical care and social support were provided by the four participating psychologists.

Massotherapists (n=4) have mainly delivered massage but also personal care (2/4), psychological support (1/4) and spiritual support (1/4).

The physiotherapist was involved in all tasks except personal care, social care and EOL care; the orthopedagogist was only involved in developmental support and the care helper was only involved in spiritual support.

4.2.6 Collaboration between people involved in PPC

Amongst the 90 participants who have answered the question about collaboration, 59 have declared an intensive collaboration with PLTs, 52 with the first line and 39 with the second line. Only 11/90 seem having intensively collaborate with spiritual advisers and 25 a limited collaboration with that professional profile. Only 13/90 did not collaborate with PLTs, 10/90 with second line and 8/90 with first line. Undesirable collaborations were mentioned quite rarely: 9/90 did not desire to collaborate with spiritual advisers, 3/90 with PLT or second line and 2/90 with first line.

Participants have highlighted that they have collaborated with people from other social or professional profiles like, families, hospital PC teams, patients/parents' associations, schools, volunteers, educators, home care services, centres of psychological supports, respite house, trainers, ethical committee in hospital, well-being and recreational providers in the home setting.

Different types of support can be provided, by collaborators, for other people involved in a palliative situation. Emotional support seems to be mainly provided by colleagues (63/79) but also by PLTs (33/79), by first line professionals (25/79), by second line professionals (13/79) and by spiritual counsellors (6/79).

Information about the disease and/or the care plan seems to be received from colleagues (38/78), from PLTs (32/78), from first line providers (25/78) and/or from second line providers (22/78) but never from spiritual advisers.

Practical help in care and support tasks seem to be mainly given by colleagues (39/64), by PLTs (28/64), by first line providers (17/64), by second line providers (11/64) and/or by spiritual counsellors (2/64).

Help in coordination seems to come from PLTs (32/62), colleagues (27/62), first line (13/62) and second line (10/62). And help in concertation between professionals is brought by colleagues (50/81), by PLTs (46/81), by first line (29/81), by second line (23/81) and spiritual counsellors (3/81).

Finally, 24/7 availability to receive advice is provided by PLTs (34/63), by colleagues (29/63), by first line providers (13/63), by second line providers (5/63) and by spiritual counsellors (1/63).

So, colleagues are the first source of support for professionals involved in palliative situations. However, PLTs are pretty much as present as colleagues and more involved for the coordination and concertation role and for their 24/7 availability.

4.2.7 Unmet needs in palliative situations

The unmet needs were collected from the participants according to the person concerned and order in a descending order of frequency.

The following needs of the child were reported as unmet:

- Lack of leisure/recreational activities: 18/86
- Lack of social contacts (family, friends): 17/86
- Lack of emotional support: 11/86
- Lack of information about the illness: 9/86
- Lack of information about the treatment plan: 7/86
- Lack of spiritual support: 6/86
- Lack of information about available care services (e.g., liaison teams): 5/86
- Lack of social support (e.g., assistance with administrative procedures): 4/86
- Lack of discussions regarding advance care planning, preferences, and wishes: 4/86
- Lack of time to provide care in a calm atmosphere and address existential concerns: 4/86
- Lack of collaboration among healthcare professionals, particularly regarding treatment goals: 3/86
- Lack of involvement of the patient/family in discussions, particularly regarding treatment goals: 3/86
- Lack of resources (adequate equipment or infrastructure): 3/86
- Lack of reimbursement or financial support: 3/86
- Lack of physical (somatic) care: 2/86
- Lack of care coordination: 2/86
- Lack of support for ethical and legal issues: 2/86
- Lack of training: 2/86
- Lack of support from employers, authorities, or management to dedicate time to the palliative care of children/young adults: 2/86
- Lack of clarity in navigating services: 1/86
- Lack of familiar healthcare professionals: 1/86
- Lack of task allocation among those involved: 0/86

The unmet needs of the child the most often cited by participants are the recreational activities, the social contacts with friends and the emotional support. However, participants do not identify unmet needs so frequently for the child. The maximum 18 participants which have identified the lack of recreational activities, what is confirming the declared statement previously in the survey about the high quality of the PPC in Belgium. For example, the lack in physical needs was noticed only by two

participants. This finding would obviously be nuanced by the fact that those unmet needs are identified by professionals and not by the patient or the family.

The following family needs were reported as unmet:

- Lack of social contacts (family, friends): 30/86
- Lack of reimbursement or financial support: 28/86
- Lack of leisure/recreational activities: 27/86
- Lack of social support (administrative assistance): 21/86
- Lack of emotional support: 20/86
- Lack of information about available care services (e.g., liaison teams): 16/86
- Lack of spiritual support: 16/86
- Lack of resources (adequate equipment or infrastructure): 15/86
- Lack of support from employers, authorities, or management: 15/86
- Lack of information about the treatment plan: 14/86
- Lack of discussions regarding advance care planning, preferences, and wishes: 14/86
- Lack of clarity in navigating services: 14/86
- Lack of information about the illness: 13/86
- Lack of involvement of the patient/family in discussions regarding treatment goals: 13/86
- Lack of care coordination: 12/86
- Lack of familiar healthcare professionals: 11/86
- Lack of collaboration among healthcare professionals regarding treatment goals: 10/86
- Lack of support for ethical and legal issues: 10/86
- Lack of time to provide care in a calm atmosphere and address existential concerns: 9/86
- Lack of task allocation among those involved: 8/86
- Lack of physical (somatic) care: 3/86
- Lack of training: 3/86

The unmet needs of the family the most often cited by participants are the lack of social contacts, the lack of reimbursement or financial support and the lack of recreational activities.

The following needs of respondents themselves were reported as unmet:

- Lack of training: 47/86
- Lack of time to provide care in a calm atmosphere and address existential concerns: 31/86
- Lack of support for ethical and legal issues: 26/86
- Lack of collaboration among healthcare professionals regarding treatment goals: 25/86
- Lack of clarity in navigating services: 24/86
- Lack of support from employers, authorities, or management: 23/86

- Lack of emotional support: 22/86
- Lack of resources (adequate equipment or infrastructure): 22/86
- Lack of care coordination: 21/86
- Lack of discussions regarding advance care planning, preferences, and wishes: 20/86
- Lack of involvement of the patient/family in discussions regarding treatment goals: 20/86
- Lack of reimbursement or financial support: 17/86
- Lack of information about available care services (e.g., liaison teams): 16/86
- Lack of task allocation among those involved: 16/86
- Lack of information about the treatment plan: 14/86
- Lack of leisure/recreational activities: 14/86
- Lack of information about the illness: 11/86
- Lack of social support (administrative assistance): 9/86
- Lack of physical (somatic) care: 8/86
- Lack of familiar healthcare professionals: 7/86
- Lack of social contacts (family, friends): 5/86
- Lack of spiritual support: 3/86

The unmet needs of the respondents the most often cited by participants are lack of training, lack of time for providing care in a calm atmosphere and address existential concerns and lack of support for ethical and legal issues.

The following needs were reported as unmet for all involved parties:

- Lack of clarity in navigating services: 17/86
- Lack of time to provide care in a calm atmosphere and address existential concerns: 17/86
- Lack of resources (adequate equipment or infrastructure): 15/86
- Lack of reimbursement or financial support: 15/86
- Lack of support for ethical and legal issues: 15/86
- Lack of support from employers, authorities, or management: 15/86
- Lack of training: 14/86
- Lack of information about the treatment plan: 12/86
- Lack of care coordination: 11/86
- Lack of discussions regarding advance care planning, preferences, and wishes: 10/86
- Lack of information about available care services: 9/86
- Lack of familiar healthcare professionals: 9/86
- Lack of emotional support: 9/86
- Lack of social support (administrative assistance): 9/86
- Lack of information about the illness: 8/86

- Lack of leisure/recreational activities: 8/86
- Lack of involvement of the patient/family in discussions regarding treatment goals: 5/86
- Lack of spiritual support: 5/86
- Lack of task allocation among those involved: 5/86
- Lack of collaboration among healthcare professionals regarding treatment goals: 4/86
- Lack of physical (somatic) care: 1/86
- Lack of social contacts (family, friends): 0/86

Globally, the following unmet needs were declared to be present the most frequently in a palliative situation: lack of clarity in navigating services, lack of time to provide care in a calm atmosphere and address existential concerns, lack of resources (adequate equipment or infrastructure), lack of reimbursement or financial support, lack of support for ethical and legal issues and lack of support from employers, authorities, or management.

The following needs were reported as having been met at least once in participants' experiences:

- Physical (somatic) care: 76/86
- Spiritual support: 64/86
- Task allocation among those involved: 61/86
- Availability of familiar healthcare professionals: 60/86
- Involvement of the patient/family in treatment discussions: 58/86
- Information about the illness: 55/86
- Collaboration among healthcare professionals regarding treatment goals: 54/86
- Care coordination: 52/86
- Information about the treatment plan: 51/86
- Information about available care services: 50/86
- Social support (administrative assistance): 49/86
- Social contacts (family, friends): 49/86
- Support for ethical and legal issues: 46/86
- Emotional support: 44/86
- Discussions regarding advance care planning, preferences, and wishes: 43/86
- Clarity in navigating services: 40/86
- Time to provide care in a calm atmosphere and address existential concerns: 37/86
- Adequate resources (equipment or infrastructure): 42/86
- Leisure/recreational activities: 38/86
- Support from employers, authorities, or management: 36/86
- Reimbursement or financial support: 32/86
- Training: 27/86

By taking the opposite viewpoint to the unmet needs, the needs the most frequently met in the experience of participants are the physical care, the spiritual support and the task allocation between those involved. And the needs the less frequently met are quite aligned with opinions about global unmet needs: training, reimbursement or financial support and support from employers, authorities and management.

Additional unmet needs were identified by participants outside the already long list established for the survey. Those are the need of trust, the need of good communication, the need of bereavement offer, the need of a normal life, the need of emotional support for HCP, the need of coordination, the need of support to informal caregivers, the need to value the good quality time spent for patients and families, the need of more GPs, the need of more social offer.

4.2.8 Identification of the PPC needs

Different types of means usually used to identify PPC needs were suggested to participants:

- an assessment tool
- discussions with the child and/or family
- discussions with one or more colleague(s)
- consultation with primary care professionals
- consultation with one or more hospital specialists
- discussions with the liaison team
- their own professional judgement

Discussions with colleagues and the patient/family were the most cited (72/81 and 63/81) means used by the participants to identify the PPC needs. Then come all the other options except the use of an assessment tool which was cited only three times and always with other means. The average number of different means used by the participants to identify PPC needs is 4, with only 5/81 declared having used only one means. So, combination of means seems to be the norm. No other means of identification were suggested by the participants. Finally, 2/81 have declared not using identification means.

Then different elements able to help identify PPC needs were proposed to the participants:

- A standardised assessment tool
- A clear definition of palliative care
- Consultation with palliative care specialists
- Consultation with a colleague
- Multidisciplinary consultation involving all relevant parties
- More time
- More knowledge

Multidisciplinary consultation, knowledge and time were the most cited elements (45/81; 44/81; 43/81). Then the use of assessment tools and concertation with PPC experts were cited 27/81 and 25/81. Finally, a clear definition of PC (10/81) and a consultation with a colleague (6/81) were less cited.

Three participants have stated that their own experience was sufficient for the identification of PPC needs and nine of them were satisfied with the means already at their disposal. One additional element would be helpful according to one participant: to better know the cultural aspects.

5 INTERVIEWS WITH PAEDIATRIC LIAISON TEAMS

5.1 Aim of the group interviews

The aim of the group interviews was threefold:

- To gather inform about the functioning of the PLTs: provision of services, collaborative networks, financing of the PLTs, etc.
- To collect their perceptions about barriers to access PPC
- To collect their perceptions about the feasibility of potential solutions

All Belgian PLTs were invited and all, except one, participated to these interviews.

The interviews were carried out in an interactive way: use of an interview guid with open questions and the use of a big paper with icons of a hospital, home setting, child and family, graphical presentation of the definition of PPC.

5.2 Practical modalities

Location	In a meeting room, often on the paediatric ward of the hospital where the PLT is located
Participants	Each PLT had the freedom to decide who could participate; however, we encouraged the involvement of as many PLT members as possible, ensuring a diverse mix of profiles.
Duration	The invitation suggested a meeting duration of at least two hours, although PLTs were free to extend or shorten the session depending on their availability. On average, the meetings lasted two hours.
Language	The interviews were conducted in the native language of each PLT, with a native-speaking interviewer leading the discussion. The interviewer was supported by a KCE research team member, who took notes and assisted with the practical organization of the interview
Recording	All interviews were audio-recorded after obtaining explicit permission from each participant.
Remuneration	Participants were not remunerated for their participation.

5.3 Analysis

All interviews were transcribed using Whisper.ai. However, because the automatically generated transcripts contained numerous inaccuracies, each transcript was thoroughly reviewed and corrected before analysis. Subsequently, all transcripts were anonymised by removing or masking identifying information, such as the names of hospitals and individuals.

The analysis was structured around the domains of accessibility: acceptability, availability, affordability, and appropriateness. Initially, each interview was analysed separately, after which the findings were consolidated across interviews. The objective was not to identify differences between individual PLTs but rather to develop an overarching understanding of barriers and potential solutions across all participating PLTs. For the thematic analysis, Microsoft Copilot was used with prompts aimed at identifying barriers and solutions within each accessibility domain and extracting supporting quotes from the transcripts. As the use of Copilot for qualitative analysis is still a developing practice within KCE, experience with this approach remains limited. To ensure the reliability of the findings, all results generated by Copilot were manually verified through an independent thematic analysis conducted by a KCE researcher. This verification process also incorporated the interview notes and was reviewed by the other interviewers involved in the study.

5.4 Interpretation of the results

The results are presented per domain of accessibility (in tables) and served as input for triangulation with other findings in each of the chapters of the scientific report.

A disclaimer was given to all KCE researchers about the use of these findings:

"These results should not be presented as facts but rather as perceptions by the interviewees. The data is not fact-checked and so inaccuracy can persist in the analysis. Mention clearly in your results that they derive from the interviews, e.g., "according to the interviewed PLTs…", "the PLTs perceived this as…" Avoid quantification (even if sometimes it is also mentioned in the table), we didn't count the number of barriers or solutions mentioned by each of them."

5.5 Limitations

The analysis contains a transversal approach across the individual interviews per PLT. The dimensions of accessibility were used as basis to structure the different barriers and solutions. However, categorizing the findings according to the different dimensions of accessibility is quite challenging and open for discussion, with also overlap between items and dimensions.

The use of AI to support qualitative data analysis is still relatively new within KCE, and expertise in applying these tools is currently being developed. While AI-assisted analysis offers opportunities to increase efficiency and support the identification of themes and patterns in qualitative data, methodological experience with this approach remains limited. Consequently, AI-generated findings should be interpreted with caution and require careful human validation. As part of this learning process, all findings produced through AI-assisted analysis were reviewed and verified by researchers using traditional qualitative analysis methods to ensure the accuracy, consistency, and credibility of the results.

5.6 Interview guide

Theme	Questions
Introduction	Short presentation of KCE project with main research questions, planning of the project, aim of this interview and explicit asking for permission to record the interview
Brief presentation of the PLT • *Use of a map of Belgium to indicate their geographical coverage* • *Paper with icons of hospital and home to design the network of different actors, relationships between these (red and green to indicate the level of collaboration)*	• Can you give us a brief description of the PLT: when it started, team composition, activity data (number of children followed up, etc.), activity reports from 2010–2014? • How is PPC defined within your team? • Can you indicate on the map the geographical coverage of the PLT? • What are the PLT's main tasks? (e.g., home hospitalisation, PPC, coordination, etc.) • How does collaboration take place with other actors inside and outside the hospital? • Graphical representation (hospital: AYA teams, paediatric departments, paediatric pain teams, convention services) • Home setting: community care, hospices, residential facilities • How do you differentiate responsibilities between the various actors? • What are the success factors that promote collaboration?
Current critical gaps in access to PPC: Child • *Post-its with potential barriers*	Definition • Is your definition of PPC commonly used within your care network? • Do you encounter differing expectations about PPC among different actors? • How has advance care planning already been integrated into PPC at Hospital XX? • Which actors are competent to provide PPC? Identification of a Child in a Palliative Situation • Do you use an assessment tool? Could such a tool add value in clinical practice? • How do you assess the different needs of the child and family? Start of PPC • Can PPC be initiated without the involvement of the PLT? • Which criteria are used to start PPC? What about specific conditions, prognoses, warning signs, etc.? What if no diagnosis is available? • Who is responsible? • How are children (and their families) referred to you?

Theme	Questions
	• Do you have experience with late referrals to PPC? Fragmented PPC • Are all PPC domains covered by the PLT? • How is access to spiritual care ensured? • Is psychological care easily accessible for children (and their families)? • Is Bednet available in Brussels and the French-speaking region?
Current critical gaps in access to PPC: Family • ***Post-its with potential barriers***	Needs/Expectations of Family Members • In your experience, what is the greatest barrier to accessing care related to family perceptions? (e.g., cultural, emotional, social factors, non-acceptance of death, etc.) • What are the main factors leading to interruption of PPC?
Current critical gaps in access to PPC: HCPs • ***Post-its with potential barriers***	• What are the main barriers for healthcare providers (outside the PLT)? (e.g., lack of training, misconceptions about PPC, non-acceptance of death, perception of treatment failure, etc.) • Is there a difference in barriers between home-care providers and hospital-based providers? Training • Is there a lack of training/expertise in PPC? • What do you think about the online training offered by Kinderpalliatief in the Netherlands? • Are there PPC training programmes available in Dutch/French?
Current critical gaps in access to PPC: Organisation of the current care system • ***Post-its with potential barriers***	Financing • Do the current financial arrangements constitute a major barrier to access? (e.g., palliative care allowance, out-of-pocket costs) Capacity of Care Provision • Are there capacity limitations such as waiting lists, staff shortages, etc.? • Can capacity problems in community care hinder access to PPC? Equipment • How are medical devices and equipment provided at home? • Who reimburses this equipment?
Possible solutions for the future • ***Post-its with solutions***	Current Solutions • Can you provide examples of solutions that have been developed at Hospital XX?

Theme	Questions
	• Do you have an estimate of the impact of these solutions? (performance) • What role should convention services play? • What role should primary care play? • What role should the community paediatrician play? • What role should the paediatric department of a regional hospital play? Future solutions Different Levels of Care • What solutions would improve access to PPC at the PLT level? • What solutions would improve access to PPC at the hospital level? • What solutions would improve access to PPC at the community care level? Policy Level • What solutions would improve access to PPC at the policy level (financing, recognition of PPC as a profession, etc.)? Future Scenarios Increase in Number of Patients • What if the number of patients increased tenfold? Future Hospital Reforms • Centralization of care and satellite centres (paediatric haemato-oncology) • Comparable palliative care model for adults and children? • Collaboration with palliative care networks?
Priorities/key-elements	What would be the single most important priority for improving access to PPC?

5.7 Results

5.7.1 Acceptability of PPC

Elements related to acceptability	Barriers	Solutions (if mentioned by interviewees)
Perception about 'palliative care' by families and HCPs	Families resist early palliative involvement Professional hesitation to introduce palliative care: feel of harming hope or using the label too early, often resulting in late referral to PLTs (e.g., at moments of crisis) Even some PLTs are reluctant to speak about palliative care and death Emotional avoidance among HCPs: fear for emotional overload, uncertainty (also linked to rarity of cases in their practice), feeling unprepared and isolated when confronted with request for care provision to a child in PC situation Biomedical focus in other teams with limited attention for family system and quality of life Ambiguity between continuous/supportive and palliative care, due to unclear referral criteria and/or role confusion Societal taboo around child death	• Patient and family centred communication with tailored timing • Introduce palliative care gradually and relationally (not as label/end-point) • Reframing palliative care as supportive/comfort care (and not as terminal care as it is often considered nowadays) • Life project approach ('projet de vie')
Diagnosis and prognosis	Unclear prognosis: uncertainty about timing of care (and conversations about PPC and ACP)	• Adapt care to uncertainty with flexible ongoing support
Complexity of PPC	Long, unpredictable trajectories (in particular in non-oncological diseases) Difficulty of defining when a child is 'palliative'	• Develop paediatric-specific definitions and referral criteria
Cultural and religious aspects	Beliefs influence acceptance of care decisions Cultural differences in attitudes towards death (and death at home)	• Cultural mediation and psychosocial support with the support of intercultural mediators and psychologists • Provide spiritual support

Elements related to acceptability	Barriers	Solutions (if mentioned by interviewees)
	Difficulty communicating prognosis or truth to children due to cultural factors	• Increase cultural sensitivity among HCPs
Socio-economic background of the family	Complex family situations (e.g., divorced parents): makes standard home-based care more difficult or even not feasible Housing instability Socio-economic vulnerability (e.g., poverty): additional barriers to access to PPC Families reluctant to disclose socio-economic needs due to shame + may resist involvement of external social services	• Provide psychosocial support • Encourage ongoing conversations about needs within a long-term relationship building
Health literacy	Low literacy or difficulty understanding instructions, having its impact on safety of home care delivery Difficulty in reading instructions	• Use of simplified communication tools (visual aids, adapted instructions) • Home care in some situations not feasible
Communication with family	Language barriers perceived by the patients reduce trust and understanding Language barriers for the care providers: due to specific treatments, patients will go to university hospitals in other region of Belgium, this induces language barriers also for the care providers to be able to explain sensitive topics in another language	• Support from interpreters and intercultural mediators • Strengthen communication skills in HCPs
Parental attitude: resistance	Parental resistance about palliative care Preference for hospital stay (and preferred place of death) (feeling of safety with immediate availability of specialised care and long-term trust relationship with well-known care providers) Reluctance to involve new teams and preference for continuity with familiar caregivers Different temporality of families	• Use of open dialogue to build shared understanding and trust, with a paced approach adapted to the family • Multidisciplinary approach with medical, psychosocial and cultural perspectives and an aligned/uniform information • Shared decision-making with families (and children) • Build long-term trust relationships (and strengthen skills about trust-building in HCPs) • Provide real choice of care setting (not pushing to home care)

Elements related to acceptability	Barriers	Solutions (if mentioned by interviewees)
		• Ensure continuity over time (continuity of care, and same caregivers)
Parental / family attitude: burden	High emotional and practical burden on parents Emotional/psychological burden of decision-making (e.g., being asked to decide about life/death) Emotional burden for the family unit with ongoing consideration about preferences and values of the child, parents, siblings, and close family Limited caregiving capacity due to organisational aspects (e.g., keep working, unable to be present constantly), this could affect the roll-out of home care plan Heavy care burden for families due to over-medicalisation at home: parents become quasi-professionals who should be able to manage devices and administer medication	• Alternative care settings (e.g., respite care, neutral spaces for complex family situations) • Shift from decision-responsibility to guided shared decision-making • Use of the surprise question in some specialties (e.g., neurology) to determine the initiation of ACP • Parent education and empowerment to enable safe care at home • Develop intermediate care settings to reduce inappropriate home burden • Support families as 'co-caregivers", with structured parent training, clear role definition and better financial compensation
Values and preferences	Disagreement between HCPs and family on quality of life or treatment limits but PLTs often follow the preferences of the family	• Shared decision-making with families (and children) • Build long-term trust relationships (but also risk for trust-dependency) but requires also a lot of time (and repetitive conversations) • Involvement of ethicist, spiritual advisor or intercultural mediator to capture the preferences and values of the family
Decision-making by adolescents	Refusal of care by adolescents (e.g., due to medication side effects)	• Inclusion of children/adolescents in age-appropriate decision-making
Attitude of HCPs	Emotional burden on HCPs with no structural support for staff wellbeing HCPs sometimes reluctant to initiate ACP and refer to PLTs but sometimes families change hospital due to misunderstandings, breach of trust Emotional resistance by HCPs: difficulty integrating palliative care in curative mindset	• Provide emotional and psychological support for staff (e.g., debriefing meetings with all involved HCPs) • Increase awareness and visibility • Educate HCPs and public about PC

5.7.2 Availability of the care offer

Elements related to availability	Barriers	Solutions
Geographical coverage by PLTs	Geographical inequalities: - Large coverage area with long travel times (even neighbouring countries) but this will stop PLTs to follow their patients to their home setting (independently on distances) - Logistic constraints (e.g., limited number of cars) - Some specific treatments only available in restricted number of hospitals: patients travel towards that hospital and afterwards the PLT linked to that hospital will follow the child and family in their home setting (even outside of their region) - Rare direct referrals without prior hospital contact (hospital as gatekeeper)	• Strengthen logistic resources (mobility) • Some PLTs limit the number of home visits and use phone or Teams for communication and follow-up • • Develop inter-hospital or regional models instead of hospital-bound PLTs (to improve geographically accessibility) • Develop local "satellite" networks with trained local professionals as contact points/relays • Use hybrid support (phone/telehealth) as tool for remote care
Geographical provision of services	Unequal regional provision (more in Flanders vs Wallonia/Brussels) Potential barrier in access to care provided by PLTs for children in regional hospitals compared to children in university hospitals In some regions no PLTs available: for these regions other PLTs will travel to the home setting of the child + risk of not identified or referred children	• Improve national coverage (reduce regional inequities) • More territorial organisation with better alignment between care and proximity and efficiency • More visibility and awareness about PPC and PLTs across all hospitals in Belgium
Workforce: staffing in PLTs	Limited outreach capacity of PLTs: potential risk of not reaching all potential patients Insufficient staffing: only half-time psychologist for growing caseload Hidden workforce behind small PLT team: other professionals and specialists involved and contributed to PLT High turnover in staff of PLTs which requires rebuilding of the knowledge	• Strengthening care networks and outreach: building structured networks improves reach without expanding teams excessively • Increase staffing (in particular psychologists and nurses) • Flexible team composition based on patient population needs

Elements related to availability	Barriers	Solutions
		• Develop inter-hospital or regional models instead of hospital-bound PLTs (to improve geographically accessibility) • Increase local access with palliative referents in hospitals without PLTs • More structured network
Workforce: Staffing in home care	Limited GP involvement (due to lack of experience and/or awareness about PPC) Difficulty in recruiting first-line providers (in home setting), in particular in remote areas Shortage of paediatric home nurses: generalist nurses are reluctant or not trained for complex PPC (in some cases no home nurse could be found, therefore the child had to stay in hospital) High turnover in some services (e.g., home care organisations), leading to disruptions in continuity of care, relationship-building with the family and knowledge-building within that care service	• Strengthen training for home care providers • Develop specialised workforce by increasing the number of paediatric home nurses
Workforce: Availability of expertise	Refusal or unavailability of providers due to: - Lack of knowledge - Lack of awareness of existing services Limited expertise in neurological or complex cases Emotional avoidance among HCPs: fear for emotional overload, uncertainty (also linked to rarity of cases in their practice), feeling unprepared and isolated when confronted with request for care provision to a child in PC situation (see dimension of acceptability) Lack of PPC expertise in regional hospitals Unfamiliarity of first-line providers with medical equipment, which is often hospital-specific, leading to delays or reluctance to provide care	• Active awareness-building: ensuring visibility of PLTs among providers and families (to increase access) • Training and coaching of HCPs in home setting: will build capacity and expand availability indirectly • (due to rarity of PC cases): Preference for case-by case (continuous) guidance of the care professional instead of formal training in basic education (with risk of rapid skills decay after training period) • Development of a shared database ('address books') of HCPs with some experience in PPC (previous collaborations with PLTs) • Training focused on awareness rather than heavy specialisation

Elements related to availability	Barriers	Solutions
		• Providing tools and training for equipment use in home care
Organisation of care: Care offer in community	Lack of respite care services, often unavailable or not prioritised for palliative cases Limited capacity in respite services, with waiting lists and administrative delays Complex administrative processes to access respite services with time-consuming steps Not all families have a dedicated GP, which hampers the transfer of care to home care	• Alternative care models (e.g., respite house) for complex family situations • Day care centres were not considered as good alternatives for children: children would prefer to school and leisure activities • Alternatives needed for GPs if not available, e.g., case coordinator
Availability of medication and medical equipment (see also expertise)	Restricted access to medication: e.g., need for urgent medication (night-time) + ethical discomfort (asking parent to get medication (e.g., morphine)	• Direct provision or stock of essential drugs and equipment • Anticipatory planning on medication and pharmacy coordination • "protocole de détresse": protocol with prescriptions, explanation on doses and disponible phone numbers)
Organisation of care: Care offer in hospital	No dedicated paediatric palliative ward at hospital: sometimes adolescents go to an adult PC ward	• Develop adapted infrastructure (e.g., family rooms, palliative spaces)
Organisation of care: Care offer by PLTs • *Multifaceted tasks and roles*	Uneven distribution of time/resources across wide range of tasks: - Coordination of care versus bedside care delivery - Curative (mainly within HAD) versus palliative care, which is much more time consuming for a less amount of patients - No time for proactive follow-up (e.g., home visits, school contact, preventive support) - Lack of time for more in-depth psychosocial support (e.g., coping by siblings, partner relationships, family dynamics), resulting in too late addressing of these problems	• More and more shift towards coordination and outreach (liaison function between hospital and home care) • Expansion of capacity of PLT team to ensure proactive follow-up • Shift toward preventive psychosocial care with early engagement with families and siblings • adaptive intensity model with levels of involvement: PLTs adjust from monitoring to active care to end-of-life care

Elements related to availability	Barriers	Solutions
	- HAD and PPC sometimes in same PLT, sometimes divided over different teams	
• ***Bereavement care***	Bereavement care restricted to support during a restricted time period after death Referral to other professionals if more therapeutic bereavement support is needed	• Organisation of a more structured pathway after death to guide parents and family in bereavement process • More involvement and/or collaboration needed with parent/patient associations • Post-death follow-up and debriefing for involved HCPs
• ***Variety in patient population***	Variety in patient population but still more focus on oncological patients (due to history of PLT development from the oncology care in Belgium)	• Strengthen the PLT functioning for all children in palliative care situation (independent on diagnosis/disease category) by making the PLTs more visible across all paediatric specialties
• ***24/7 availability***	Non-specialised HCPs request for 24/7 availability of the PLTs 24/7 availability in some PLTs restricted after triage by nurse of the hospital ward	• Ensure 24/7 support from PLTs, mainly to support first-line providers
• ***Spiritual care***	Spiritual care not often provided by PLTs themselves but refer the families to parent organisations or families search for themselves Gaps in spiritual care at home	• A more structural network of spiritual care provision should be elaborated with involvement of spiritual care providers and referral to supportive organisations (including religious organisations)
• ***Recreational and developmental care***	Financing of activities depend on additional funding (e.g., waffle sales)	• More structural development of recreational care offer, accessible for all children
• ***Social care***	Lack of social workers in some PLTs Limited access windows for services (e.g., interpreters) due to rigid scheduling	• Add social workers to the team composition of PLTs
• ***Coordination of care*** ***(see also collaboration in appropriateness)***	Time- and resource consuming tasks of coordination, supporting HCPs, ensuring liaison across care settings to guarantee quality and continuity of care	• Strengthening the role of the PLTs as coordinators/liaison by making them more visible, increase awareness among other HCPs

Elements related to availability	Barriers	Solutions
		• Anticipation as a core strategy, with use of written protocols, pre-prescriptions, 'what if planning'
Governance: National plan	Absence of a shared national vision, which leads to a variety in PLT activities Policy rigidity with an outdated RD and poor alignment with real needs	• Develop a national shared vision on the development of PPC in Belgium
*Governance: Centralisation of care**	Restricted number of PLTs across Belgium, with lack of knowledge about PPC in regional hospitals	• Preference for centralisation of care in specialised (university) centres, without multiplication of teams in regional hospitals. • Ideally increase of number PLTs to ten PLTs across Belgium • Strengthen the existing PLTs instead of creating new ones

**suggested by interviewer as possible solution in the interviews*

5.7.3 Affordability

Elements related to affordability	Barriers	Solutions (if mentioned by interviewees)
Funding for PLTs	Insufficient structural funding, which limits capacity and sustainability Funding has not much evolved since start of PLTs Newly recognised PLTs not yet financed but already functioning Dependence on external funding by charity organisations (with their focus on certain diseases, e.g., paediatric oncology) Hidden subsidies by hospitals which could have its impact on the sustainability of the PLT working PLTs not always aware of exact amount of funding, leading to uncertainty about expanding services or hiring staff	• Enabling a more sustainable financing system: more comprehensive funding with less dependence on external organisations • Provide reimbursement for coordination and home support • Alternative financial models could be considered, e.g., conventions, which covers also psychological care (and its related resource use)

Elements related to affordability	Barriers	Solutions (if mentioned by interviewees)
Reimbursement of (home) care services	Inadequate reimbursement system, with administrative limitations which undervalue the real work (e.g., only two interventions per day can be billed) Conventions lead to a restriction in reimbursement (e.g., limited number of consults, regardless of need) Some activities not billable (e.g., coordination, counselling, outreach) Underpayment of providers in home care: participation of home care providers mainly driven from motivation, training, interest, not from financial incentives/remuneration Reimbursement system focuses mainly on technical acts (e.g., 3euro for blood sample but time required for taking blood sample in a child is much higher compared to in adults) Mismatch between (longer) time required to provide care and administrative recording of these activities, leading to underestimation of workload and resources needed	• Reform provider payment models (better remuneration of GP/home care nurses) • Shift towards needs-based financing (not diagnosis-based) • Align financing system with care complexity rather than procedures/technical acts • Reimbursement model should also take into account time, travel, emotional load • Create a dedicated paediatric financing model with an adapted reimbursement system to child-specific care (taking into account intensity, time, relational work) • Investment in home care can reduce expensive hospitalisations • Include PPC services in existing funding schemes, e.g., integration of palliative care in disease-specific conventions • Improve activity measurement system, capturing time needed, complexity of care, coordination tasks)
Out-of-pocket payments for the families	Financial burden, which can reduce accessibility Additional expenses for medications, equipment, psychological care (e.g., 60-75euro/session) Access to aids depends on 'administrative literacy' (ability to know and access administrative procedures to obtain additional financing or help) Access to aids depend on palliative status, conventions or diagnosis category, not on needs Additional financial constraints when parents stop working	• Proactive financial facilitation: simplified financial model with the use of special funding statuses (e.g., palliatief statuut) + early activation of these kind of forfaits/lump sums • Improve financial support for medical equipment and medication (at home) or even free of charge (loaning material) • Strengthen administrative guidance for families, with proactive support • Compensation need for indirect costs (e.g., income loss, caregiving burden)

Elements related to affordability	Barriers	Solutions (if mentioned by interviewees)
	Unequal access to financial support: some patients groups benefit from strong funding streams by charity organisations (e.g., oncology)	• Reduce disparities between oncology and other diseases by better alignment in funding equity

5.7.4 Appropriateness

Elements related to appropriateness	Barriers	Solutions (if mentioned by interviewees)
Quality of care: • *Expertise*	Lack of expertise in home care services (e.g., skills in complex symptom control) Complex treatments (e.g., infusions) hard to manage at home In some cases if PLTs has doubts on quality of home care, the child will be re-admitted to hospital (to guarantee quality and continuity of care)	• Flexible, individualised care (pathways) with care location adapted to each family • Symptom-based approach: ensures clinical appropriateness despite uncertainty about prognosis • Multidisciplinary decision-making and continuous reassessment
• *Patient population*	Disease-specific concentration of care (historically developed from oncology) with potential under-service for non-oncological children Under-identification of eligible children: some specialists claim they have no palliative patients Lack of screening tools for identification or needs assessment	• More structural development of care services for all children in a palliative care situation • Shift towards needs-based financing (not diagnosis-based) • Develop systematic identification tools/criteria
• *Medical innovation*	Medical innovation hampers the estimation of prognosis and timing of palliative transition, with impact on clinical decision-making and ACP (e.g., CF more and more considered as chronic disease)	
• *Definition of PPC (needs)*	Lack of clear definition of palliative phase shared across specialties, leading to variety in referral to PLTs and timing (see also involvement of PLTs) No use of instruments to assess needs, rather preference for ongoing conversations with the child and family	• Develop paediatric-specific definitions and referral criteria • No need for the use of instruments, as these are perceived as impersonal and time-consuming + variety in patient population

Elements related to appropriateness	Barriers	Solutions (if mentioned by interviewees)
Documentation in medical records	Conversations about ACP often not or not systematically recorded in medical files No shared data systems (with integrated patient records across settings) resulting in poor information flow	• More documentation in practice to improve continuity of information transfer between professionals • Develop a structured documentation system with shared (electronic) records and templates
Transition hospital-home care: communication	Poor or fragmented information flow between hospital teams, primary care, home nurses and families, leading to misunderstandings and unsafe situations Setting up an network of caregivers around the family in hospital and in home setting requires a huge time-investment from the PLTs Due to lack of recording of ACP, in case of urgency/crisis, emergency services do not obtain this information and will perform therapeutic interventions (sometimes even on demand of the parents, in contradiction with previous shared decision made)	• Networks and partnerships between hospitals and home care • Development of a shared medical record system
Collaboration of PLTs with other services	Varying degree of collaboration with neonatology unit, which has sometimes their own PPC team Inconsistent collaboration structures depending on individuals rather than on systems Fragmented inter-hospital collaboration with weak coordination and communication Weak coordination and communication issues between multiple actors (e.g., school) Limited involvement of PLTs in acute settings (ICU, neonatology) or antenatal care Limited outreach to residential settings (e.g., institutions for disabled children): care reactive available, not proactive Limited and fragmented PPC network, with more reliance on informal contacts	• Improve coordination and shared care pathways across hospitals • Integration of non-medical supports (school, therapies, psychosocial care) • Coordination with acute services: list of patients followed by PLTs + alert system in medical record • Build structured collaboration networks with partnerships with regional hospitals and community HCPs • Develop local “satellite” networks with trained local professionals as contact points/relays • Strengthen coordination and case management with dedicated coordinators and shared protocols • PLTs should act as central coordinator (“dispatching”), also to help families navigate through the system

Elements related to appropriateness	Barriers	Solutions (if mentioned by interviewees)
Involvement of PLTs in care pathway	Lack of clear referral pathways to PLTs: professionals often not aware when to involve the PLT in the care plan, resulting in a delayed or denied involvement of the PLT Timing of involvement of PLTs often inconsistent and person-dependent, and related to individual clinicians recognising the need and knowing the PLT Involvement of PLT often linked to acute situation (reactive rather than proactive access pathway) No direct access pathway from first-line: access requires a hospital specialist link (which is a restriction of entry point)	• Development of clear referral criteria of pathway to enhance the early involvement of the PLTs • Extend referral to other HCPs and families (and not only by physicians) • Better integration in referral systems (e.g., NIHDI (RIZIV-INAMI) recognition, systematic identification of palliative cases) • Earlier integration (e.g., antenatal care, chronic illness trajectory)
Collaboration in between PLTs	No structural collaboration between PLTs, due to language barriers, regional differences in clinical practice (e.g., use of medication) Lack of training for newly created PLTs	• Development of a structured network between PLTs with close collaboration and exchange of practices, e.g., regular meetings, shared care coordination), also collaboration with existing PC platforms • Develop a more structured vision on the implementation of new PLTs with an equivalent of training • Provide sustainable funding for new PLTs
Awareness about PPC services and/or PLTs	Limited awareness of PPC services in home care, and even in paediatric specialties in hospitals	• Strengthen the visibility of PPC and PLTs by awareness campaigns for HCPs • More visibility/presence in care settings (e.g., presentations, flyers, presence)
Training in PPC (see also expertise in availability)	Insufficient training in basic education of HCPs Lack of practical skills in non-specialised HCPs (symptom control, communication)	• Increase practical training and continuing education • Sensitisation triggered by cases: each new patient will progressive expand the availability of HCPs
Transition to adult (PC) care	Weak transition Lack of suitable services and continuity	• Develop structured transition programs with transition planning

Elements related to appropriateness	Barriers	Solutions (if mentioned by interviewees)
	Fragmentation and overlap between paediatric and adult care teams	• Clear definition of roles needed between collaborating teams during transition from paediatric to adult care
Performance measurement • *quality indicators*	Inappropriate indicators used (e.g., home death not always valid quality indicator in PPC) Lack of time/resources to assess outcomes (or other data collection)	• Develop paediatric-specific indicators instead of transferring adult indicators • Introduce monitoring and evaluation systems • Provide funding for research and data collection to improve evidence base
• *activity registration*	Lack of standardised activity registration of the PLTs, making the functioning (and value) of PLTs invisible for other HCPs, hospital management and policy makers	• Develop a uniform activity-based registration for PLTs with registration of volumes and types of activities
Legal recognition of PPC	Legal restrictions for non-professional caregivers (e.g., family aids may give medication), which leads to overburden the parents (taking over these legally restricted basic tasks)	• Set up a clear regulation on the role of non-professional caregivers in PPC across the different care and residential settings

6 IDENTIFICATION OF CHILDREN WHO NEED PALLIATIVE CARE

6.1 Introduction

Defining the population of children who need PPC or defining eligibility/referral criteria for PPC is important for:

1. individual-level care: estimation of the need of an individual child and family to receive PPC ensures early identification and offer of PPC to the child and family needing it.
2. population-level care: estimation of number of children who need PPC now and in the future is necessary to inform decisions on planning and organisation of PPC services.[16]

Yet, defining the population/eligibility criteria of children who need PPC is difficult and complex for the following reasons:

- The range of conditions that could make a child eligible for PPC is broad and diverse including neurological, neuromuscular, oncological, respiratory, cardiac, metabolic, chromosomal, syndromic and congenital malformation disorders, infectious diseases, post-anoxic conditions, and many "undiagnosed" conditions.
- Eligibility to PPC is not based only on diagnosis but also on care complexity consisting of clinical, psychological, social, organisational, spiritual and ethical problems of the child and family generated through the above medical conditions.
- The population in need of PPC is dynamic due to advancements in medicine and technology that have reduced neonatal and paediatric mortality but have increased survival of paediatric patients with increased health and care needs.[16]

The grozing and increasingly diverse range of conditions eligible for PPC is often characterised by an unpredictable and fluctuating course, with prolonged periods of relative stability in between episodes of deterioration. These conditions also show substantial heterogeneity in disease trajectories and the needs they generate. The resulting multidimensional needs of the child and the family - clinical, psychological, social, organisational, spiritual, or ethical - exist along a continuum of increasing complexity. This continuum can be categorised into three levels of complexity of care needs, each corresponding to a level of provision of PPC required to address those needs as shown in the table below:

Table 17 – Level of PPC provision

Levels of PPC provision	Level of complexity of care needs	Providers of PPC
Level 1 *Palliative approach*	Low to moderate	All healthcare professionals involved in child's care
Level 2 *General PPC*	Moderate to high level	Health professionals who manage the underlying condition and possess specific training and/or expertise in PPC. May require support and supervision by a specialist PPC team
Level 3 *Specialist PPC*	High level	Ongoing involvement of healthcare professionals exclusively dedicated to PPC, working within specialised multidisciplinary teams.

Source: Delamere et al 2024[16]

Depending on the available resources and/or the assessment of the overall care needs of the child and family, each situation may be managed by the team responsible for the underlying health condition

(general PPC) or may require consultation with, or referral to, a specialist PPC team for ongoing management and support.

Different identification/eligibility/referral criteria for PPC are available and in use worldwide depending on the country and setting. We conducted a literature search to map the tools and criteria for identification/eligibility/referral to PPC in use internationally that can be considered by stakeholders in the decision-making to increase access to PPC in Belgium.

6.2 Methodology

We conducted a rapid review of the literature to map the available literature on tools used to identify children who need PPC.

The literature search (updated on the 15th of April 2021) was carried out using different combinations of keywords and focusing on papers published in English over the past five years (2016–2020)

First a search was carried out in MEDLINE (OVID) for peer-reviewed publications using a combination of keywords focusing on publications in English over the past ten years (2010-2025) (latest update on 26th of March 2026) (see Appendix 1) . This search identified 757 peer-reviewed publications. Only 16 were selected as relevant and these included two reviews on identification tools for PPC published in 2023.[17,18] The first review on palliative care referral criteria in paediatric illness searched peer-reviewed literature published in English between 2010-2021 in five databases (PubMed, CINAHL, PsycINFO, SCOPUS and Academic Search Premier).[17] The second review on assessment tools in PPC was based on several interrelated searches (on tools to identify children eligible for PPC and tools to assess the needs of the patient and family) in PubMed and the authors' personal literature collection, with the latest update of the search in June 2023.[18] We further searched for studies published after 2023 that had cited these reviews and identified a rapid scoping review on population-based need for PPC that had searched literature published in English between 2008-2023 in six databases (CINAHL, Cochrane Library, EMBASE, Medline, PsycINFO, and Web of Science) as well as the grey literature.[16] Besides these three published reviews, we also reviewed any relevant publications on identification tools for PPC that were published after 2023 and identified by our abovementioned search in Medline as well as through the 'cited by' and 'similar articles' search aids of the PubMed.

We also searched the grey literature (reports and policy documents) on the websites of the key international organisations involved in PPC (ICPCN, Together for Short Lives, EAPC, WHO) as well the websites of the national PPC organisations and key providers in the countries that were reviewed for PPC initiatives (see section 8 for more information). Additionally, the national experts that were interviewed for the PPC initiatives were also asked specifically for PPC identification/referral tools used in their country.

The non-systematic search for published peer-reviewed literature is a limitation of our methodology. After the identification of the three reviews mentioned above that were published in 2023, we decided that it was not necessary to run a new systematic literature review considering the relatively small community of research in PPC and that some tools used in clinical practice are not yet reported as peer-reviewed publications or are in other languages. Indeed, several of the tools presented below were identified in the grey literature and from interviews with national PPC contacts/experts. We also did not perform a formal assessment of the quality of the tools that were identified due to the heterogeneity of their structure and scope of use. Our aim was not to provide an exhaustive systematic review of validated tools for identification of children who need PPC, but to map the tools and criteria for eligibility/referral to PPC that are available internationally (in key countries considered as providers of high level of PPC) that can be useful for the stakeholders in making decision regarding the improvement of access to PPC in Belgium.

6.3 Results

We present below a list of criteria and tools identified through our search that are used to identify children eligible for PPC at both the individual and population levels of care.

6.3.1 Identification at individual level of care

The criteria and tools to identify children who need PPC at the individual level of care are presented under two categories:

6.3.1.1 International standards and national referral frameworks /eligibility criteria

ACT/RCPCH CATEGORIES OF LIFE-LIMITING AND LIFE-THREATENING CONDITIONS

The four categories of disease trajectory of life-limiting (no reasonable hope for cure and child will die of this condition) and life-threatening (curative treatment may be feasible but may fail) conditions were developed by The Royal College of Paediatrics and Child Health (RCPCH) and the Association for Children's Palliative Care (ACT) in 1997.[19] They have been and continue to be the conceptual basis for international PPC standards and policies.

These categories were developed based on expert opinion aiming to avoid an inappropriate focus of PPC on malignant/oncologic disease. The categories are based on the high probability that the child will not survive into adulthood as expressed by the 'surprise' question: *'Would you be surprised if this child were to survive into adulthood?'*.[20]

Figure 4 – ACT/RCPCH categories of life-limiting and life-threatening conditions

Table 1 ACT/RCPCH Categories [6]

Category	Key characteristic	Description	Examples
I	**Potential for cure** - life is threatened, not necessarily limited.	Conditions for which treatment may be feasible but can fail	Cancer Some cardiac anomalies
II	**Period of normality** despite having fatal diagnosis.	Conditions where premature death is inevitable but where there may be long periods of participation in normal activities	Duchenne Muscular Dystrophy
III	**Relentless deterioration** from, or before, time of diagnosis.	Progressive conditions without curative treatment options, where treatment is exclusively palliative and commonly extends over many years	Metabolic or neurodegenerative conditions
IV	**Unpredictable** course whose progression is not easily judged from natural history.	Irreversible but non-progressive conditions causing likelihood of premature death through complications	Severe cerebral palsy Traumatic brain injury Septic brain injury

Source: Hain et al 2013[20]

The goal of these categories of disease trajectories is to identify children who need PPC interventions, including symptom management, financial and psychological support, and end-of-life care. The four categories illustrate the wide range of conditions that may benefit from PPC at different levels of provision (PPC approach, general PPC, and/or specialist PPC services). The examples of conditions provided in each disease trajectory category are illustrative rather than exhaustive. Children may move between the categories over time or meet the criteria for more than one category simultaneously. Furthermore, only a proportion of children within these categories will have active palliative care needs at any given time (Mellor et al 2012[21])

TOGETHER FOR SHORT LIVES GUIDE FOR PPC (2018)

This guide of Together for Short Lives in UK[b] confirms the four categories of life-threatening and life-limiting conditions and states that besides diagnosis other factors of care complexity should be considered such as: spectrum and severity of disease, complications, needs of the child and family.[22]

WHO'S GUIDE ON INTEGRATING PC INTO PAEDIATRICS (2018)

The WHO's guide presents groups of populations and conditions (see Figure 5 and Figure 6) that generate a need for PPC. The groups of populations of children that need PPC are based on the four groups of ACT/RCPCH with two new groups: neonates who are severely premature or with severe congenital conditions AND family members of a foetus/child who dies unexpectedly.[23]

Figure 5 – Populations that need PPC

Table 3. Populations that need PPC

Population	Examples
Children with acute life-threatening conditions from which recovery may or may not be possible	Any critical illness or injury, severe malnutrition
Children with chronic life-threatening conditions that may be cured or controlled for a long period but that may also cause death	Malignancies, multidrug-resistant tuberculosis, HIV/AIDS
Children with progressive life-threatening conditions for which no curative treatment is available	Spinal muscular atrophy, Duchenne's muscular dystrophy
Children with severe neurologic conditions that are not progressive but may cause deterioration and death	Static encephalopathy, spastic quadriplegia, spina bifida
Neonates who are severely premature or have severe congenital anomalies	Severe prematurity, anencephaly, congenital diaphragmatic hernia, trisomy 13 or 18
Family members of a fetus or child who dies unexpectedly	Fetal demise, hypoxic-ischaemic encephalopathy, overwhelming sepsis in a previously healthy child, trauma from motor vehicle accident, burns, …

Sources: Downing et al. 2016 *(29)*; Wood et al. 2010 *(30)*.

Source: WHO Guide[23]

The groups of conditions include malignancies, perinatal conditions, injuries, serious infections, genetic conditions, malnutrition and pain.

[b] A new referral framework for PPC has been recently developed and published by Together for Short Lives (May 2026) and is presented below

Figure 6 – Conditions that commonly generate a need for PPC

Table 4. Conditions that commonly generate a need for PPC

Condition	Examples of palliative care needs
Malignancies (paediatric types differ from those in adults)	■ Leukaemias: haemorrhage due to coagulopathies, painful procedures such as bone marrow biopsies ■ Brain tumour: headache, cognitive and neurologic deficits ■ Sarcomas: severe pain, loss of a limb
Conditions discovered or occurring in the perinatal period *(31–33)*	■ Congenital anomalies: symptomatic dysfunction of a vital organ such as the heart, bowel or brain; stigmatized superficial anomalies ■ Prematurity: respiratory distress, intraventricular haemorrhage, brain ischaemia and permanent neurodevelopmental disability ■ Birth asphyxia: hypoxic-ischaemic brain injury and permanent neurodevelopmental disability
Injuries	■ Head trauma: poor cognitive and motor skills ■ Burns: acute and sometimes also chronic pain, stigmatized disfigurement ■ Exposure to violence, conflict or natural hazard: mood disorders such as anxiety, depression, post-traumatic stress disorder
Serious infections	■ HIV/AIDS: symptomatic opportunistic infections, stigmatization, adverse effects of medicines ■ Drug-resistant tuberculosis: cough, constitutional symptoms (fever, sweats, weight loss), adverse effects of medicines, social isolation, stigmatization ■ Meningitis: permanent neurodevelopmental disability ■ Rheumatic fever: symptomatic heart failure
Genetic conditions	■ Neurologic conditions: progressive neurological deficits and disability ■ Sickle cell disease and anaemia: pain crises, bone necrosis ■ Connective tissue disorders: chronic pain
Protein energy malnutrition	■ Pain, dyspnea ■ Vomiting or diarrhoea related to re-feeding
Being a patient	■ Painful procedures ■ Postoperative pain ■ Not having an opportunity to have questions answered and fears assuaged

Sources: Adapted from Knaul et al. 2017 *(3)* and Krakauer et al. 2018 *(22)*.

Source: WHO Guide[23]

GO-PPACS (GLOBAL OVERVIEW- PEDIATRIC PALLIATIVE CARE STANDARDS) (2022)

These international standards for PPC were developed by a group of international experts in PPC. GO-PPaCS replaced the first version of the guidelines (IMPaCCT, 2007) and were endorsed in the 2022 European Charter on Palliative Care for Children and Young People. The GO-PPaCS are based on a literature review (updated until April 2021) and consensus through open discussion.[13]. According to GO-PPaCS, there is a general agreement that children with life-threatening or life-limiting conditions, as well as those with terminal illness (i.e., a condition in which death has become inevitable) may need PPC (see Figure 7).

Figure 7 – Classification of conditions where the child may need PPC

Conditions for which the child may need PPC can be classified as life-threatening, life-limiting (both also refer to serious illness), or terminal (see Table 1).

Table 1. Classification of Conditions Where the Child May Need PPC

Category	Description
Life-threatening condition	A condition with a high probability of premature death due to severe illness, but also a chance of long-term survival to adulthood for example,: children receiving cancer treatment, children with severe neurological impairment, children in intensive care due to acute injury, children with technology dependency
Life-limiting condition	A condition where there is no reasonable hope of cure: premature death is expected, for example: Duchenne muscular dystrophy, Tay Sachs Disease, Trisomy 13, Trisomy 18
Terminal illness	A condition in which death becomes inevitable in children with life-limiting or life-threatening illnesses

Source: Benini et al 2022[13]

The medical conditions eligible for PPC were classified in five categories based on disease progression/trajectory (four categories of ACT/RCPCH plus a fifth group relating to perinatal/neonatal conditions)

Figure 8 – Five categories based on disease progression/trajectory

Table 2. Five Categories of Life-Limiting and Life-Threatening Conditions [Together for Short Lives 2018]

Group	Description
1	Life-threatening conditions for which curative treatment is possible but may fail. Access to palliative care services may be necessary due to the complexity of the patients' needs (e.g.: cancer, complex congenital cardiopathies, severe injuries resulting from trauma) There is no longer need for palliative care services upon achievement of long-term remission or following successful curative treatment
2	Conditions in which premature death is inevitable; however, long periods of intensive treatment aimed at prolonging life and allowing for a good QoL (e.g.: cystic fibrosis)
3	Progressive conditions without curative treatment options, for which treatment is exclusively palliative and may commonly extend over many years (e.g.: Batten disease, muscular dystrophy, chromosomopathies)
4	Irreversible but non-progressive conditions with complex healthcare needs leading to complications and, likely, premature death (e.g.: severe cerebral palsy and disabilities following brain or spinal cord injury) Palliative care may be required at any stage and there may be unpredictable and periodic episodes of care.
5	Unborn children with major health problems who may not live through birth, infants who may survive for only a few hours/days, infants with birth anomalies that may threaten vital functions, and infants for whom intensive care has been appropriately applied but developed an incurable disease

Source: Benini et al 2022[13]

The GO-PPaCS emphasise that both the child's diagnosis and the complexity of the needs of child and family both should be considered when determining eligibility to PPC. They also highlight the importance of standardizing PPC eligibility criteria. To this end, GO-PPaCS endorse the list of eligibility criteria presented by a group of PPC experts in Italy[24] (see below) and recommend that PPC should be provided when any of these criteria are met. These criteria include the presence of a life-limiting/threatening condition, as well as indicators of care complexity, such as recurrent or severe hospitalisations, dependence on invasive medical devices, conditions associated with difficult symptom/pain management, complex psychosocial and/ spiritual needs, and difficulties in making significant care decisions.

Figure 9 – GO-PPaCS criteria for PPC

Table 3. Eligibility Criteria for PPC (Modified From [Jankovic 2019]). PPC should be Provided when Any of the Following Eligibility Criteria are Met

• Diagnosis of a life-limiting/threatening condition
• Serious episodes of hospitalizations:
- at least three hospitalizations for serious clinical crises over a period of 6 months;
- hospitalization of over 3 weeks without clinical improvement according to the medical team;
- admission to intensive care of over 1 wk without clinical improvement
• Use of invasive medical devices for life support
• Life-threatening condition that causes difficulties in the management of pain or other symptoms
• Life-threatening conditions and complex psychosocial and spiritual needs of the child and family, including, but not limited to:
- limited social support
- the simultaneous need for more than three specialized services
- a child with difficult and complex management of care handover between the hospital setting and the home
• Difficulties in making significant decisions for children and/or family:
- difficulties in achieving consensus between the child, family and medical team on treatment and goals of care (e.g., resuscitation, use of parenteral nutrition/IV hydration or continuation of chemotherapy in the terminal stages)
• The anticipation of special support during the mourning period

Source: Benini et al 2022[13]

THE LIST OF ELIGIBILITY CRITERIA/ "GREEN LIGHTS" FOR PPC

The list of eligibility criteria for PPC endorsed by GO-PPaCS was based on a consensus conference of PPC experts in Italy aiming to identify well-defined PPC eligibility criteria to be implemented in both clinical and organisational/planning contexts.[24]. The multidisciplinary working group of healthcare professionals with operational PPC experience, was appointed by the Italian Society of Palliative Care to develop eligibility criteria for PPC (2014-2016). The working group integrated the findings of a review of literature (Medline, CINAHL, Cochrane, Trip Database) with the clinical experience of the members, and the results were consulted with a group of specialists and non-specialists and reviewed by an extended team of experts in PPC.[23]

They present a set of 'green lights' for considering a child eligible for PPC, adapted from an earlier published list.[25]. They also include a flowchart to guide the involvement of the specialised PPC team, based on the presence of an incurable illness and evidence of disease progression or a worsening prognosis.

Figure 10 – Green lights for considering a child eligible for paediatric palliative care

Table 3 'Green lights' for considering a child eligible for paediatric palliative care[a]

- Child with a new life-threatening or life-limiting illness diagnosis
- Difficult pain management or other symptoms
- Three or more urgent hospitalisations for serious clinical crises over a period of 6 months
- Prolonged hospitalisation (over 3 weeks) without evidence of clinical improvement
- Prolonged admission to intensive care (over 1 week) without evidence of clinical improvement
- Fitting of invasive medical devices (e.g., tracheostomy)
- Child and/or family with complex psychosocial needs, limited social support or both
- Child assisted by more than three specialised services, with potential interdisciplinary communication difficulties
- Child with difficult and complex management of care handover between the hospital setting and the home
- Child and/or family obliged to make difficult and significant decisions
- Difficulties in achieving consensus between child, family and medical team on treatment and illness management goals (e.g., resuscitation actions, use of parenteral nutrition/IV hydration or continuation of chemotherapy in the terminal stages)
- Child and/or family experiencing difficulty making decisions concerning resuscitation actions
- Ethical debates about palliative care expressed by the child, family or medical team
- Needs for continuous medical support or medical devices or frequent laboratory services by home care services if these facilities are not readily available within the primary care territorial resources
- The prospect of complex outcomes in case of survival, such as a serious toxicity condition from long-term therapy
- The prospect of complex needs during the mourning period

[a]minimal mod. from Kaye E, Rubenstein J, Levine D, Baker J, Dabbs D, Friebert S[20]

Source: Jankovic et al 2019[24]

Figure 11 – Flowchart to guide the involvement of the specialised PPC team

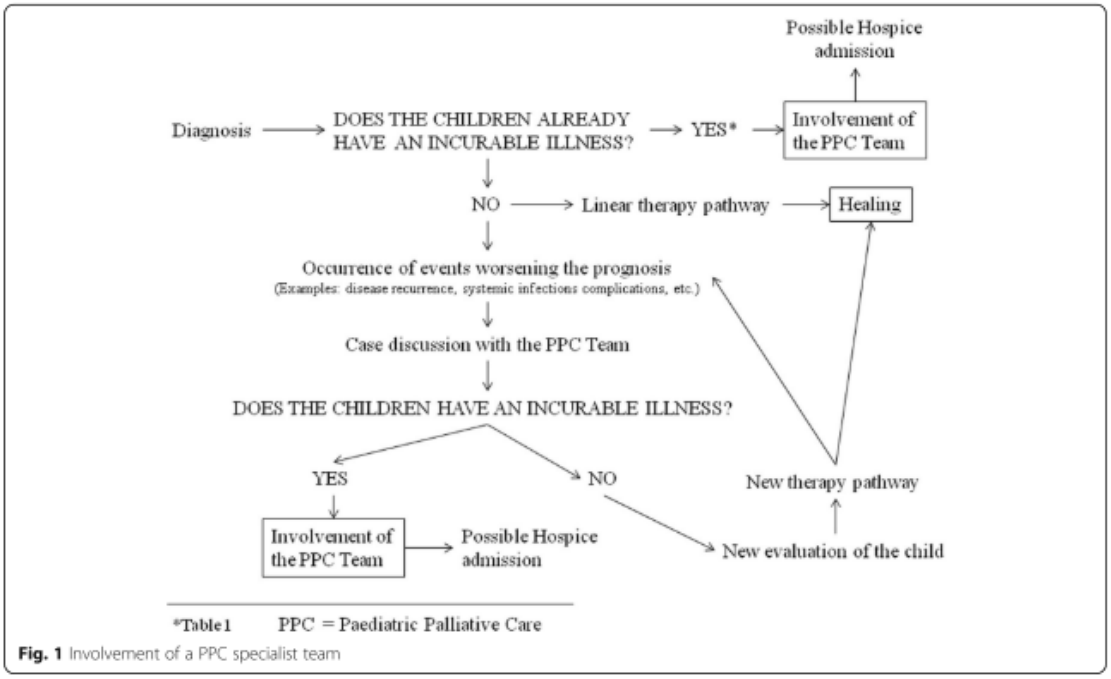


Fig. 1 Involvement of a PPC specialist team

Source: Jankovic et al 2019[24]

Additionally, they adopted the list of possible situations for referral to a PPC team for cancer (Table 1) and non-cancer diagnoses (Table 2) presented in an earlier publication on community-based PPC.[25]

Figure 12 – Possible situations for referral to a PPC team for cancer (Table 1) and non-cancer diagnoses (Table 2)

Table 1 Possible situations for referring children with cancer to a PPC specialist[a]

On diagnosis	During the illness
Child with a new life-threatening illness diagnosis	Treatment-resistant disease
Extended intrinsic brainstem glioma	Progressive disease (e.g., new metastases)
Stage IV neuroblastoma	Relapsed disease after remission
Solid metastatic tumour	Resistant or recurrent disease after hematopoietic stem cell transplantation
Any other type of tumour with an event-free survival (EFS) prediction of < 40% with current therapies	Exposure to life-threatening complications (e.g., organ failure, prolonged intubation)
New diagnosis with difficult pain management or other symptoms	Development of new and significant toxicity related to treatment and/or psychosocial stress
Prolonged hospitalisation (over 3 weeks) without evidence of clinical improvement	Prolonged admission to intensive care (over 1 week) without evidence of clinical improvement

[a]minimal mod. from Kaye E, Rubenstein J, Levine D, Baker J, Dabbs D, Friebert S[20]

Table 2 Possible situations for referring a child with a non-cancer incurable disease to PPC

On diagnosis	During the illness
Incurable disease with terminal prognosis and risk of premature death (e.g., degenerative disease)	Illness with worsening symptoms that do not respond to therapies
Incurable disease with presence of numerous complex clinical needs	Disease with diagnosis of incurability increasing clinical/psychological/social/ethical needs
Coordination/tutoring/supervision of the welfare network to ensure assistance for the child and family	Support during the terminal phase and managing the mourning

Source: Jankovic et al 2019[24]

The list of 'Green Lights' to consider a PPC consultation for a child with cancer (Table 2) and the list of possible triggers (Table 3) presented in an earlier publication on community-based PPC [25] were based on the referral criteria for PPC of the Center to Advance Palliative Care in USA (see below).

Figure 13 – Green lights to consider PPC consult for a child with cancer

TABLE 2. "Green Lights" to Consider Pediatric Palliative Care Consult for a Child With Cancer

- Child with a new diagnosis of high-risk disease
- Difficult pain or symptom management before, during, or after cancer treatment
- Three or more unplanned hospitalizations for serious medical issues within a 6-month period
- Prolonged hospitalizations lasting >3 weeks, without evidence of improving medical status
- Prolonged intensive care hospitalization lasting >1 week, without evidence of improving medical status
- Introduction of new technology (eg, tracheostomy, tunneled chest tube)
- Child and/or family with complex psychosocial needs, limited social support, or both
- Child is followed by >3 subspecialty services, with challenges in interdisciplinary communication
- Child with complex care-coordination needs during transitions between hospital and home or other care settings
- Child and/or family at the crossroads of making difficult decisions
- Difficulty reaching consensus among child, family, and medical team about goals of care or management plan (eg, resuscitation status, use of medical nutrition/hydration or continuation of chemotherapy at the end of life)
- Child and/or family struggling with decision-making around resuscitation status
- Ethical issues related to palliative care domains raised by child, family, or medical team[a]
- Need for hospice services or other home-based resources, including durable medical equipment or home laboratory monitoring, if these services are not readily accessible to the primary team
- Anticipation of complex survivorship issues, such as serious long-term treatment toxicities
- Anticipation of complex bereavement needs

Source: Kaye et al 2015[25]

TABLE 3. Possible Triggers for a Pediatric Palliative Care Referral for a Child With Cancer

AT TIME OF DIAGNOSIS	DURING COURSE OF ILLNESS
Diffuse intrinsic pontine glioma	Disease refractory to treatment
Stage IV neuroblastoma	Disease progression (eg, new metastases)
Metastatic solid tumors	Disease relapse after remission
Any other cancer with projected 5-y EFS <40 % with current available therapies	Disease refractory or relapsed after bone marrow transplant
New diagnosis with complex pain or other symptom management issues	Development of life-threatening complications (eg, organ failure, prolonged intubation)
Any disease in which hematopoietic stem cell transplantation is part of the upfront treatment plan	Development of new and significant treatment-related toxicities and/or psychosocial stressors

EFS, event-free survival.

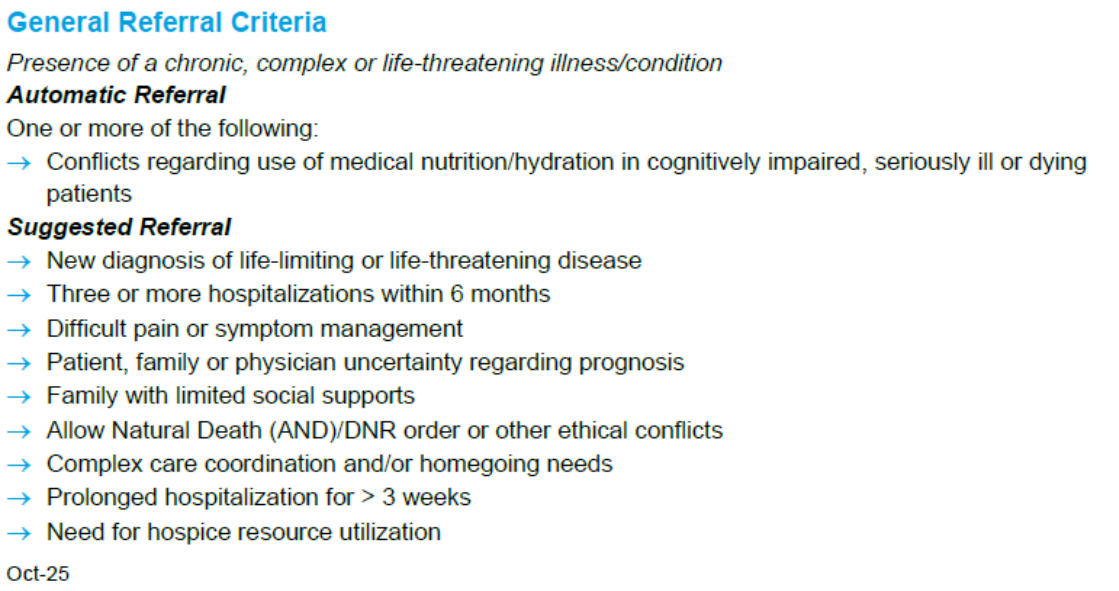
Source: Kaye et al 2015[25]

The list of "green lights" or eligibility criteria are not intended to serve as mandatory referral criteria but rather as signposts to prompt consideration of PPC referral. They reflect the broad range of clinical situations that PPC experts consider appropriate for community-based paediatric palliative care and support timely identification of children who may benefit from these services.[25]

PPC REFERRAL CRITERIA OF THE CENTER FOR ADVANCEMENT OF PALLIATIVE CARE

These widely cited referral criteria were developed in 2009 by Friebert & Osenga (last version reviewed in October 2025 and used with permission from CAPC) and include general and specific criteria for 12 specific groups of children with chronic complex or life-threatening/life-limiting conditions : malignant disease, pulmonary, genetic, neurologic, metabolic, infectious, orthopaedic, renal, GI, neonatal, cardiac and intensive care. Each set of criteria is divided into those leading to automatic and suggested referral:

Figure 14 – PPC referral criteria of the CAPC



General Referral Criteria

Presence of a chronic, complex or life-threatening illness/condition

Automatic Referral

One or more of the following:

→ Conflicts regarding use of medical nutrition/hydration in cognitively impaired, seriously ill or dying patients

Suggested Referral

→ New diagnosis of life-limiting or life-threatening disease
→ Three or more hospitalizations within 6 months
→ Difficult pain or symptom management
→ Patient, family or physician uncertainty regarding prognosis
→ Family with limited social supports
→ Allow Natural Death (AND)/DNR order or other ethical conflicts
→ Complex care coordination and/or homegoing needs
→ Prolonged hospitalization for > 3 weeks
→ Need for hospice resource utilization

Oct-25

Source: CAPC document (used with permission)26

THE STANDARDS OF PRACTICE FOR PPC, NATIONAL HOSPICE AND PALLIATIVE CARE ORGANIZATION, USA (2022)

These standards adopt the four diagnostic categories developed by ACT/RCPCH as examples of children who should be considered for palliative care or hospice services, with or without ongoing curative or disease-modifying treatments. They further suggest that, when determining whether to recommend palliative care or hospice services while disease- modifying treatment continues, one approach would be to ask the question: "*Do you expect this child to live to adulthood?*" or "*Would you be surprised if this child died in the next year?*"

THE CORE CARE PATHWAY FOR PPC, PEDIATRIC PALLIATIVE CARE ALLIANCE, CANADA (2025)

The Core Care Pathway for PPC includes a guide on "How to identify if an infant, child, or youth has palliative care needs" which is based on a synthesis of best available evidence for identifying children who may benefit from PPC.[27,28]

The pathway states that a child with serious illness may be identified by either a family member or healthcare professional. Serious illness is defined as a life-threatening/life-limiting condition associated with a high likelihood of death before full adulthood that negatively impacts a child's daily function, quality of life, or places substantial stress on caregivers. Additional indicators may include prognostic uncertainty, prolonged/recurrent hospitalisations/intensive care unit admissions, medical fragility or instability, and dependence on medical technology.

The Canadian Core Care Pathway for PPC outlines four categories of criteria that can be used to guide decisions about which child may benefit from PPC:

1. Illness trajectories

Conditions where a child and their family may benefit from PPC can be grouped in five trajectories (based on GO-PPaCS)

Figure 15 – Five trajectories

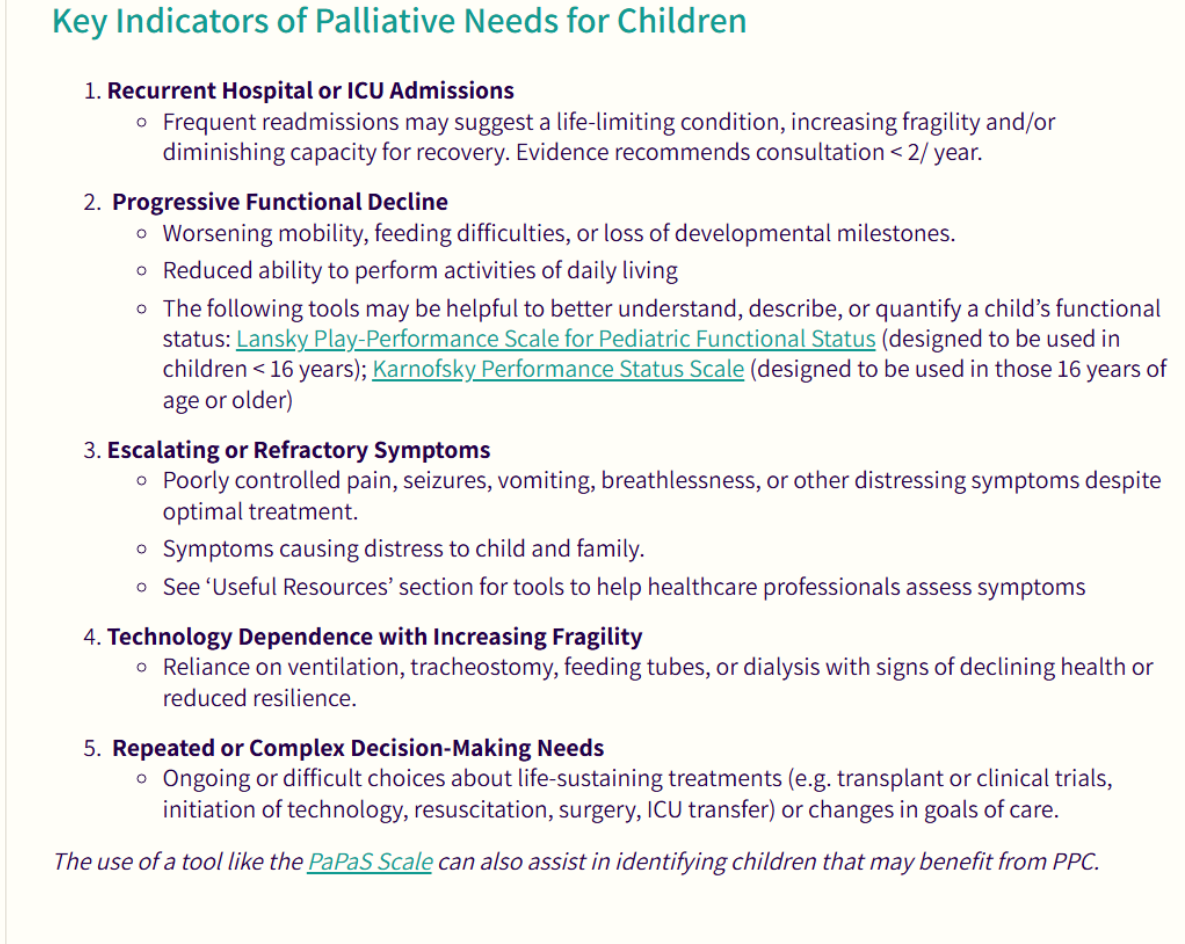
Classification of conditions where the child may need PPC	Examples	When to consider PPC
– Life-threatening conditions for which curative treatment is possible but may fail – Access to palliative care services may be necessary due to the complexity of the patients' needs – There is no longer need for palliative care services upon achievement of long-term remission or following successful curative treatment	– Cancer – Congenital heart defects (can be corrected with surgery) – Infections or sepsis – Hematologic conditions (may be treated with successful transplant) – Organ failure	At diagnosis, relapse, or treatment failure
– Conditions in which premature death is inevitable; however, patient endures long periods of intensive treatment aimed at prolonging life and enhancing quality of life	– Cystic fibrosis – Spinal muscular atrophy	At diagnosis or disease progression
– Progressive conditions without curative treatment options, for which treatment is exclusively palliative and may commonly extend over many years	– Batten disease – Muscular dystrophy – Chromosomopathies – EB – Tay-Sachs – Mitochondrial disorders – Congenital anomalies – Advanced metabolic conditions	After ICU admission, recurrent instability
– Irreversible but non-progressive conditions with complex healthcare needs leading to complications and, likely, premature death – Palliative care may be required at any stage and there may be unpredictable and periodic episodes of care	– Severe cerebral palsy – Disabilities following brain or spinal cord injury – Cerebral malformations (e.g., lissencephaly)	At diagnosis, during transitions, new complications
– Prenatal diagnosis of a serious illness who may not live through birth – Infants who may survive for only a few hours/days – Infants with birth anomalies that may threaten vital functions – Infants for whom intensive care has been appropriately applied but developed an incurable disease	– Trisomy 18 – Extreme prematurity	Antenatally (if known), at birth, during care transitions

Source: Pediatric Palliative Care Alliance, Canada (2025)[27]

2. Functional and clinical indicators

These indicators are guides to recognise when PPC is needed and when a referral to specialist PPC may be appropriate.

Figure 16 – Key indicators



Key Indicators of Palliative Needs for Children

1. **Recurrent Hospital or ICU Admissions**
   - Frequent readmissions may suggest a life-limiting condition, increasing fragility and/or diminishing capacity for recovery. Evidence recommends consultation < 2/ year.
2. **Progressive Functional Decline**
   - Worsening mobility, feeding difficulties, or loss of developmental milestones.
   - Reduced ability to perform activities of daily living
   - The following tools may be helpful to better understand, describe, or quantify a child's functional status: Lansky Play-Performance Scale for Pediatric Functional Status (designed to be used in children < 16 years); Karnofsky Performance Status Scale (designed to be used in those 16 years of age or older)
3. **Escalating or Refractory Symptoms**
   - Poorly controlled pain, seizures, vomiting, breathlessness, or other distressing symptoms despite optimal treatment.
   - Symptoms causing distress to child and family.
   - See 'Useful Resources' section for tools to help healthcare professionals assess symptoms
4. **Technology Dependence with Increasing Fragility**
   - Reliance on ventilation, tracheostomy, feeding tubes, or dialysis with signs of declining health or reduced resilience.
5. **Repeated or Complex Decision-Making Needs**
   - Ongoing or difficult choices about life-sustaining treatments (e.g. transplant or clinical trials, initiation of technology, resuscitation, surgery, ICU transfer) or changes in goals of care.

The use of a tool like the PaPaS Scale can also assist in identifying children that may benefit from PPC.

Source: Pediatric Palliative Care Alliance, Canada (2025)[27]

3. Diagnosis- and event-based Triggers

Figure 17 – common PPC triggers

Common PPC Triggers

These triggers help ensure children who may benefit from PPC are identified early:

1. **Diagnosis-Based Triggers**
   - Conditions with high symptom burden or poor prognosis
   - Examples: relapsed or refractory malignancy, severe genetic or neurodegenerative disorders, illnesses with symptom treatment but not curative intent, traumatic brain injuries
2. **Event-Based Triggers**
   - Acute care episodes indicating clinical instability
   - Examples: >2 ICU admissions in 6 months, prolonged hospital stays, repeated unplanned admissions
3. **Psychosocial or Spiritual Cues**
   - Complex cultural, spiritual, or value-based decision-making
     - The HOPE Approach to Spiritual Assessment may help the healthcare professional better understand the patient and family's spiritual perspective or their goals of care in the context of their beliefs.
4. **Caregiver or healthcare professional concern**
   - Family or caregiver distress, exhaustion, or difficulty coping
     - Referrals can be triggered by family or caregiver distress, exhaustion, difficulty coping, or a desire to involve palliative care specialists
   - The "Surprise Questions":
     - *"Would I be surprised if this child died in the next year?"*
       - If your answer is **no**, consider a PPC approach or consultation
     - *"Would I be surprised if the child survived beyond their 18th birthday?"*
       - If your answer is **yes**, consider a palliative care approach or consultation. This question helps emphasize the importance of early referrals for patients who might not seem unwell "enough" yet.
   - Clinical intuition prompting early palliative involvement

Source: Pediatric Palliative Care Alliance, Canada (2025)[27]

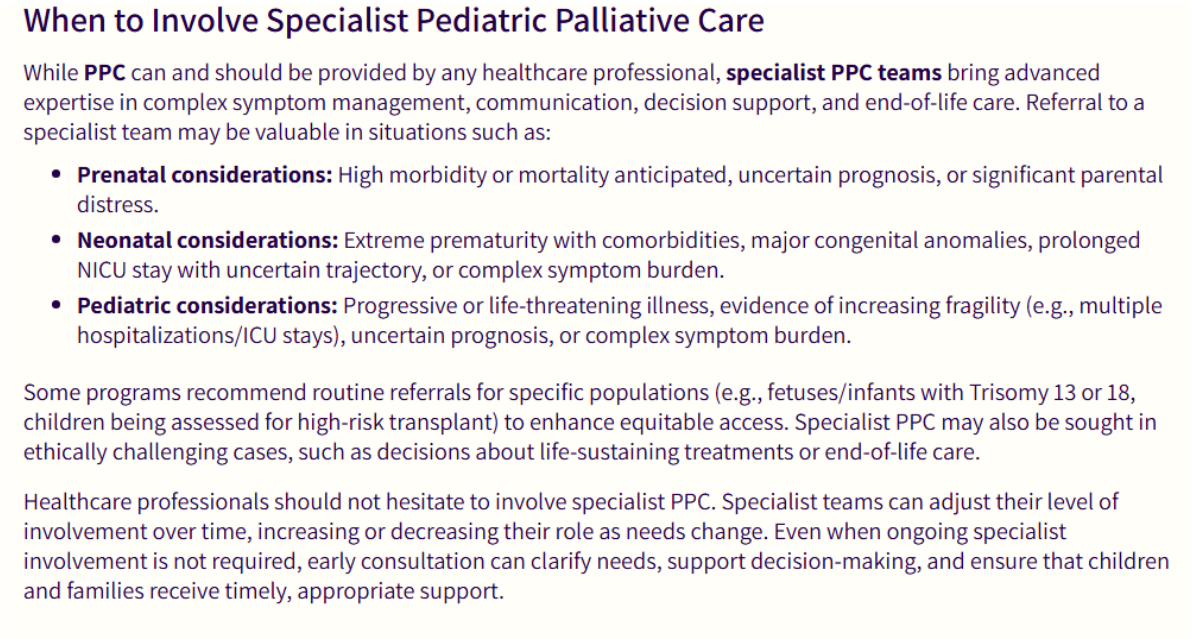
4. Fragility, Stability, and the 'Gut check'

Figure 18 – Fragility, stability and 'Gut check'

It is important to assess each child based on their fragility and instability, as described below. Sometimes a health care professional has a "gut feeling" about a patient's status. This is an important assessment to follow as "Something feels off" or "This family needs more support" can be valid referral triggers.

1. **Fragility** – a condition in which a child has delicate or severely compromised health making them particularly vulnerable to decline or complications. Fragility also refers to dependence on medical technology and extent of need for medical care.
2. **Instability** – refers to conditions in which a person's health is unpredictable and/or at significant risk for deterioration, worsening symptoms, and may require close medical supervision or urgent care.

Figure 19 – Specialist PPC involvement



When to Involve Specialist Pediatric Palliative Care

While **PPC** can and should be provided by any healthcare professional, **specialist PPC teams** bring advanced expertise in complex symptom management, communication, decision support, and end-of-life care. Referral to a specialist team may be valuable in situations such as:

- **Prenatal considerations:** High morbidity or mortality anticipated, uncertain prognosis, or significant parental distress.
- **Neonatal considerations:** Extreme prematurity with comorbidities, major congenital anomalies, prolonged NICU stay with uncertain trajectory, or complex symptom burden.
- **Pediatric considerations:** Progressive or life-threatening illness, evidence of increasing fragility (e.g., multiple hospitalizations/ICU stays), uncertain prognosis, or complex symptom burden.

Some programs recommend routine referrals for specific populations (e.g., fetuses/infants with Trisomy 13 or 18, children being assessed for high-risk transplant) to enhance equitable access. Specialist PPC may also be sought in ethically challenging cases, such as decisions about life-sustaining treatments or end-of-life care.

Healthcare professionals should not hesitate to involve specialist PPC. Specialist teams can adjust their level of involvement over time, increasing or decreasing their role as needs change. Even when ongoing specialist involvement is not required, early consultation can clarify needs, support decision-making, and ensure that children and families receive timely, appropriate support.

Source: Pediatric Palliative Care Alliance, Canada (2025)[27]

Canuck Place Children's Hospice in Canada has applied the Canadian Core Care Pathway of PPC into five steps of identifying a child/youth with a serious illness or Palliative care needs (How to identify a child with serious illness - Canuck Place)[29]

Step 1: Assess presence of serious Illness

Step 2: Consider the possible category

- Category 1 - Life-threatening curative treatment available but may be unsuccessful
- Category 2 - Long period of treatment which aims to prolong life, but premature death is anticipated
- Category 3 - Progressive conditions where treatment is palliative from diagnosis (no cure but symptoms can be managed
- Category4 - Severe disability that leads to extreme vulnerability to complications and premature death is expected

Step 3: Consider the fragility and instability of the child's health condition

Health zones as an intersection of fragility and instability

Step 4: Consider the 'surprise question'

Would you be surprised if this child or young adult were to die in the next 12 months?

OR

Would you be surprised if this child or young adult were alive in the next 12 months?

Step 5: If the child/young adult meets ANY of the above criteria contact the Hospice team to discuss possible referral or consultation.

THE PPC REFERRAL DECISION-MAKING GUIDELINE TOOL FOR HEALTH PROFESSIONS, AUSTRALIA (2025)

This tool aims to support health professionals in identifying the appropriate time to refer children, young people, and their families to PPC. It was developed through the *Shaping the Future of Paediatric Palliative Care* project, led by Palliative Care Australia and funded by the Department of Health, Disability and Ageing. The reflective tool was developed over an 18-month period, drawing on evidence from literature, stakeholder consultations, expert input, and the lived experiences of families and health professionals.[30]

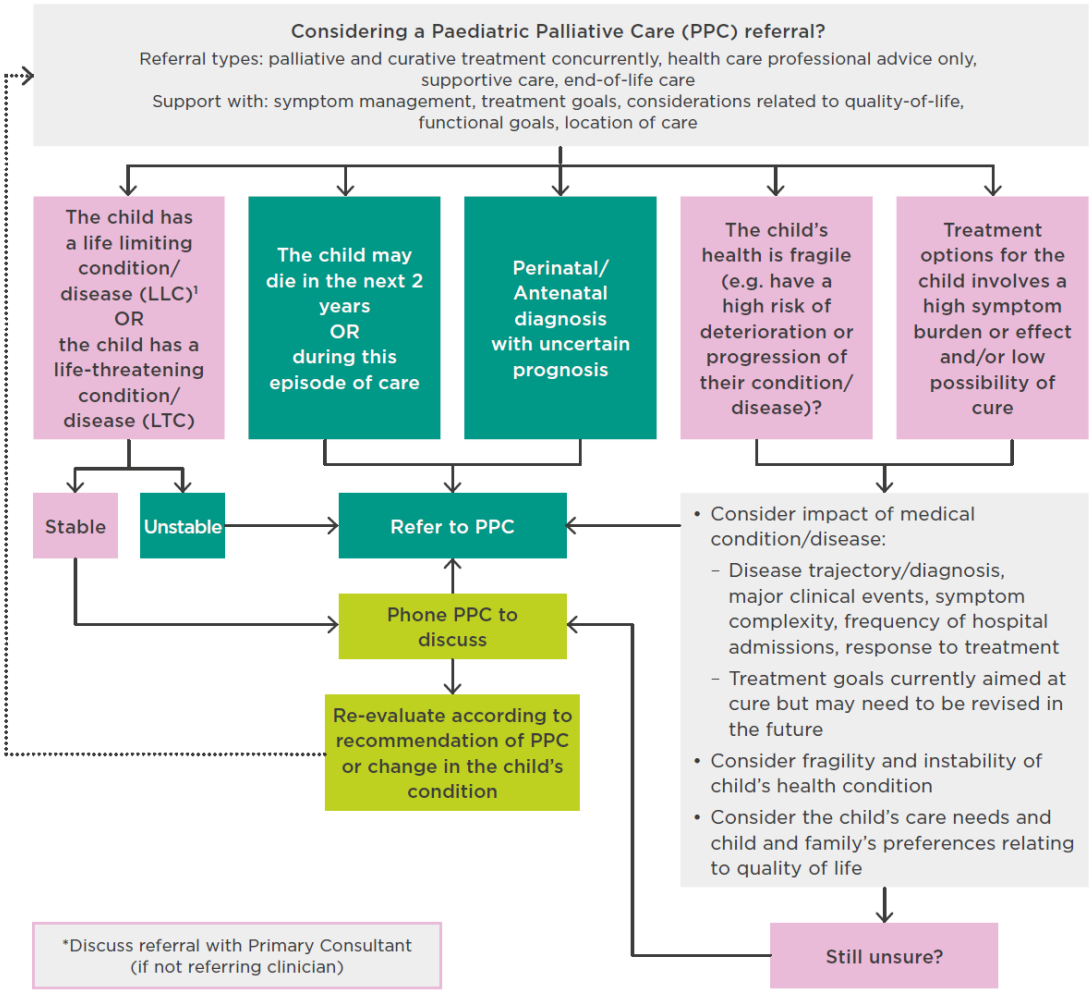
The tool encourages the provider not to rely solely on a set of indicators, but to consider the overall picture of unmet needs or increasing challenges, such as:

- Escalating symptoms or emotional distress in child or family
- Functional decline or change in quality of life
- Conflicting views about care goals or treatment pathways
- Gaps in psychosocial support, understanding of prognosis or system navigation
- Clinician uncertainty or concern about the future

The tool is designed for referring specialists such as oncologists, neurologists, cardiologists, neonatologists, paediatricians, and other healthcare professionals working with children with limiting conditions. It is also intended to support nurses and palliative care teams by complementing their expertise and promoting timely, multidisciplinary collaboration in referral decisions.

The decision-making guideline for PPC referrals includes a flowchart to help healthcare professionals determine whether referral to PPC is appropriate. It facilitates a reflective process that considers the child's medical condition, prognosis, symptom burden, and family preferences.

Figure 20 – Flowchart of the decision-making guideline tool



Source: Paediatric Palliative Care Australia[31]

The Decision-Making Guideline Tool includes a set of 30 questions designed to help explore and understand the overall situation of the child and family. These questions are organised into five key areas:

- Condition and referral Types
- Progression and management of conditions
- Child and family needs
- Service considerations
- Health professional considerations

Questions 1-3 are assessment questions on Condition and Referral Types using the life-limiting and life-threatening conditions and the four categories of their trajectories, and a version of the surprise question.

Questions 1-3: Condition and referral types

Figure 21 – Assessment questions

ASSESSMENT QUESTIONS

1. Does the child have a life-limiting or life-threatening condition?	☐ Yes ☐ No
2. Is the child's condition classified under any of the categories listed below? *(Please indicate which category)* ☐ Category 1 ☐ Category 2 ☐ Category 3 ☐ Category 4	☐ Yes ☐ No
3. Would you be surprised if this child died in this episode of care or within 2 years?	☐ Yes ☐ No

Figure 22 – Medical condition

Group	Definition	Example
1	Life-threatening conditions for which curative treatment may be feasible but may not be successful	Children with cancer when curative treatment is not successful (e.g. progressive brain or solid tumours) Irreversible organ failure not amenable to transplantation or if transplantation is unsuccessful
2	Conditions where premature death is inevitable; however, there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities	Examples of this category are evolving and changing with emerging therapies (including medical, surgical and genetic therapies)
3	Progressive conditions without curative treatment options, where treatment is exclusively palliative and commonly extends over many years	Neuro-degenerative conditions Metabolic conditions (e.g. mucopolysaccharidoses and Niemann-Pick Type C disease)
4	Irreversible but non-progressive conditions causing severe disability, leading to susceptibility of health complications and likelihood of premature death. Complications that may cause death include severe recurrent pneumonias or intractable seizures	Severe cerebral palsy (disease of the nervous system) Rett Syndrome (pervasive developmental disorder) Multiple disabilities, such as following brain or spinal cord injury (e.g. hypoxic ischaemic encephalopathy)

Questions 4-30 are reflective questions on Progression and Management, Child and Family Needs, Service Considerations and Health Professional Considerations.

Reflective Questions 4-12: Progression and Management of Conditions

Figure 23 – Reflective questions to assess needs and support decision-making

REFLECTIVE QUESTIONS

These reflective questions are designed to help you assess the current needs of the child and family, and to support decision-making around referral to PPC.

- **A 'Yes' response may indicate that the child and family could benefit from additional support, collaborative planning, or referral to PPC services.**
- A 'No' response may suggest that the child's condition is currently stable and well-managed, but continued monitoring and reassessment remains important.

4. Have there been any changes in the child's condition indicating a decline from their baseline, such as increasing instability, more complex care needs, or concerns about potential deterioration?		
Agitation	Increase in restlessness, irritability, or inability to be soothed	☐ Yes ☐ No
Distress	Unexplained pain, or distress	☐ Yes ☐ No
Emotional Symptoms	Increased sadness, anxiety, or emotional instability	☐ Yes ☐ No
Ongoing Discomfort	Persistent pain or discomfort despite treatment	☐ Yes ☐ No
Weight Loss	Significant or continued loss over recent months	☐ Yes ☐ No
Breathing	Shortness of breath, laboured breathing, or changes in respiratory pattern	☐ Yes ☐ No
Seizures	New onset or increased frequency of seizures	☐ Yes ☐ No
Swallowing and eating	Difficulty swallowing, choking, or coughing when eating or drinking, reduced tolerance NG/PEG feeds	☐ Yes ☐ No
Walking or mobility	Increased difficulty walking, unsteady gait, or frequent falls	☐ Yes ☐ No
Infections	Recurring or difficult-to-treat infections	☐ Yes ☐ No
Fatigue	Persistent tiredness, exhaustion, or low energy impacting daily function	☐ Yes ☐ No
Reduction in community and social participation for example school and recreation	Reduced participation in school activities, impacting social engagement and learning.	☐ Yes ☐ No
5. Has there been an increase in unplanned hospital admissions, increased visits with health professionals and/or an increase in complex care needs?		☐ Yes ☐ No
6. Has there been a decline in the child and/or family's quality of life?		☐ Yes ☐ No
7. Do the physical, emotional, or psychological impacts of continuing treatments outweigh the potential benefits to the child and family's quality of life?		☐ Yes ☐ No
8. Is the child's condition showing signs of reduced effectiveness with current management?		☐ Yes ☐ No
9. Has the care team determined that no further treatments are being considered as part of the care plan?		☐ Yes ☐ No
10. Would partnering with the PPC team help me and my team support the child and family with holistic planning—hoping for the best while preparing for the rest?		☐ Yes ☐ No
11. Is the child's condition unpredictable or uncertain, making it difficult to plan ahead for the future and requiring frequent adjustments to the care plan?		☐ Yes ☐ No
12. Is the child's prognosis one with potential for future instability or decline, requiring regular re-evaluation?		☐ Yes ☐ No

Reflective Questions 13-19: Child and Family Needs

Figure 24 – Reflective questions to assess needs and way to support

REFLECTIVE QUESTIONS

These questions are designed to help you assess the child and family's current situation and identify practical ways to offer support. Your responses can guide decisions about what actions may be needed—such as initiating further conversations, involving additional services, or sharing information with the PPC team.

- A 'Yes' response may suggest that the family's current needs are being met and do not require immediate action.
- **A 'No' response may indicate that further support, communication, or referral may be helpful.**

13. Does the child/family understand the diagnosis, or lack of diagnosis and its implications for life expectancy and quality of life?	☐ Yes ☐ No
14. Have the child/family established clear goals of care?	☐ Yes ☐ No
15. Are the child/family aware of PPC and the scope of support it can provide?	☐ Yes ☐ No
16. Do your care recommendations align with the family's goals of care, diverse needs, values and priorities?	☐ Yes ☐ No
17. Does the family have a support network?	☐ Yes ☐ No
18. Are you aware of any diverse needs, such as family dynamics or unique circumstances, that should be considered when communicating with the child or their family?	☐ Yes ☐ No
19. Have the family's religious, cultural, or spiritual beliefs and practices been identified and incorporated into the child's care plan?	☐ Yes ☐ No

Questions 20 -23: Service Considerations

Figure 25 – Most beneficial support services

REFLECTIVE QUESTIONS

20. Which support services might be most beneficial for the child and family as function and quality of life decline — noting that available services may vary between states and territories?

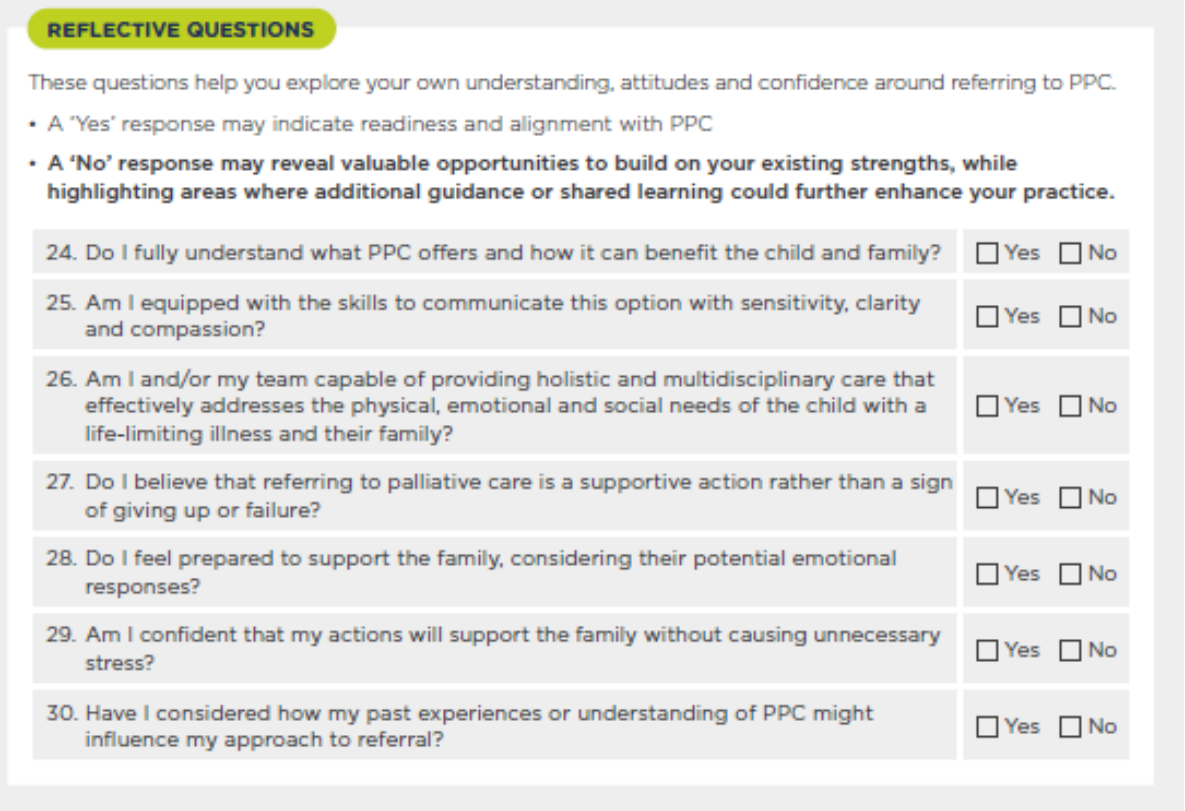
☐ Symptom/Pain Management	☐ Social Worker	☐ Hospice and Respite
☐ Art Therapy	☐ Occupational Therapy	☐ Sibling Support
☐ Music Therapy	☐ Family Support	☐ Pastoral Support
☐ Physiotherapy	☐ Massage	☐ Aboriginal and/or Torres Strait Islander support

21. Are there community providers or external services that could support the child and family's needs? Which services?	☐ Yes ☐ No
22. Is the child currently receiving NDIS support? *(If no, consider investigating if the child is eligible and would benefit from this)*	☐ Yes ☐ No

23. What other specialists or medical professionals are currently involved in the care of this child and family? *(Sharing information with these health professionals will support a coordinated and cohesive care)*

Questions 24-30: Health Professional Considerations

Figure 26 – Reflective questions on HCP own understanding, attitudes and confidence



REFLECTIVE QUESTIONS

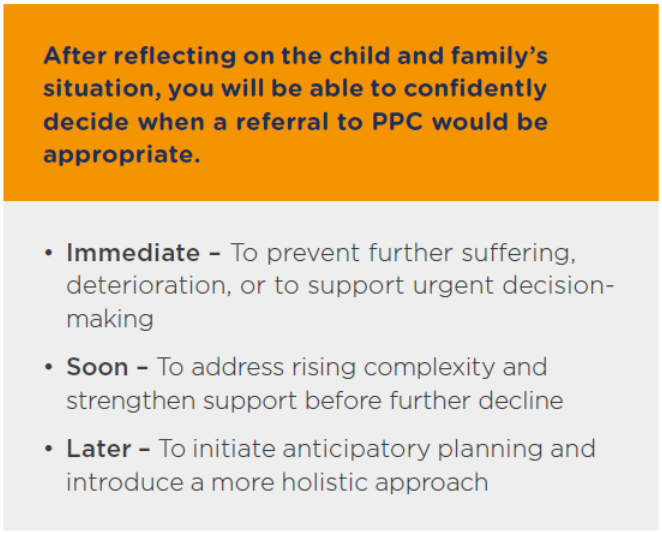
These questions help you explore your own understanding, attitudes and confidence around referring to PPC.

- A 'Yes' response may indicate readiness and alignment with PPC
- **A 'No' response may reveal valuable opportunities to build on your existing strengths, while highlighting areas where additional guidance or shared learning could further enhance your practice.**

24. Do I fully understand what PPC offers and how it can benefit the child and family?	☐ Yes ☐ No
25. Am I equipped with the skills to communicate this option with sensitivity, clarity and compassion?	☐ Yes ☐ No
26. Am I and/or my team capable of providing holistic and multidisciplinary care that effectively addresses the physical, emotional and social needs of the child with a life-limiting illness and their family?	☐ Yes ☐ No
27. Do I believe that referring to palliative care is a supportive action rather than a sign of giving up or failure?	☐ Yes ☐ No
28. Do I feel prepared to support the family, considering their potential emotional responses?	☐ Yes ☐ No
29. Am I confident that my actions will support the family without causing unnecessary stress?	☐ Yes ☐ No
30. Have I considered how my past experiences or understanding of PPC might influence my approach to referral?	☐ Yes ☐ No

By working through these reflective questions, healthcare professionals determine whether referral to PPC should be immediate, soon or at a later stage. This process also helps ensure that families are introduced to PPC in a manner that supports informed choice and coordinated care.

Figure 27 – Appropriate timing to refer to PPC



After reflecting on the child and family's situation, you will be able to confidently decide when a referral to PPC would be appropriate.

- **Immediate –** To prevent further suffering, deterioration, or to support urgent decision-making
- **Soon –** To address rising complexity and strengthen support before further decline
- **Later –** To initiate anticipatory planning and introduce a more holistic approach

The Starship referral criteria for PPC (New Zealand)

(Starship - Referrals - Paediatric Palliative Care)

The following referral process and flowchart are used by Starship Children's Health, a leading provider of paediatric health care in New Zealand[32]:

If you have a child or young person who you think needs referring to PPC, consider would it be surprising if the child died:

1. In the next year;
2. During this episode of care; or
3. Prematurely because of a serious illness?

If you answered "no" to any one of the questions, consider referral.

The new framework for recognising children's palliative care needs, Together for Short Lives (May 2026)

This new framework was co-developed by Together for Short Lives in partnership with the Association of Paediatric Palliative Medicine to ensure clinical credibility and alignment with clinical practice.[33,34] It incorporated multi-disciplinary input from over 200 professionals and stakeholders, including clinicians, hospice leaders, community teams, academics and voluntary sector organisations, through engagement events, working groups and consultations. The framework was designed to reflect the complexity, uncertainty and variation seen across services in real-world practice and is aligned with national guidelines and standards.

This new toolkit is intended as a recognition tool rather than a referral threshold. Decisions regarding referral to specialist services will continue to depend on local service configuration, service availability, professional judgement, and individual family circumstances.

The new framework shifts the focus away from identifying children needing PPC based solely on medical diagnosis, toward assessing the individual needs of the child and family. It emphasizes complexity and vulnerability as key determinants of need rather than diagnosis alone. It also recognises that paediatric conditions often follow non-linear trajectories and change over time, thereby shifting attention from prognosis to dynamic and evolving care needs. In addition, the framework supports the involvement of PPC from the point of diagnosis, including prenatal and perinatal stages of life. It is designed to be applied across the three levels of PPC - universal, core and specialist- thereby promoting a whole-system approach rather than a model focused on specialist services. As asked by the authors of the new framework, the rest of this section describing it are strictly aligned with the content available on the website of Together for short lives.[33,34]

To ensure a standardised approach across different healthcare settings, the new framework encourages professionals to use a four-step checklist during routine reviews or when a child's condition changes:

Step 1: Assign a **category of care**: identify the pattern of vulnerability (category a, b, or c) that best describes the child's underlying condition.

Category A: Life-threatening conditions

Conditions for which disease-modifying or life-prolonging treatment may be available but may fail, or where intensive therapies and interventions are required to sustain or prolong life. These conditions carry a significant risk of premature death even if treatment is pursued.

Category B: Life-shortening conditions

Conditions where death in childhood or early adulthood is likely due to the progressive nature of the condition or the absence of effective disease-modifying or curative treatment.

Category C: Severe medical complexity

Children with severe medical complexity and vulnerability, including multi-system involvement, profound neurological impairment, technology dependence, or extreme frailty, where there is a significant risk of life-threatening events.

The categories are designed to be used alongside:

- Clinical assessment
- Professional judgement
- Family discussion
- The surprise question
- The phases of care

Children and young people may move between categories over time.

Step 2: The **graded surprise question**: use prognostic horizons (1 month, 6 months, 1 year, or adulthood) to gauge risk and trigger appropriate discussions and planning.

To help identify children who may benefit from a palliative care approach, clinicians often use the "surprise question". Because clinical environments and child trajectories vary significantly, a graded, spectrum-based approach is proposed to better reflect clinical uncertainty and ensure that no child is missed across different service provisions (intensive care unit, community, hospice). Adult services often use a narrower 6–12 months' timeframe for the surprise question.

"Would you be surprised if this child were to die in the next… week/month/year/or before they reach adulthood?" Where the answer to the question is 'no' and it would not be a surprise if the child died that should prompt the team to actively consider/discuss a palliative approach to care with the child (if appropriate) and their family.

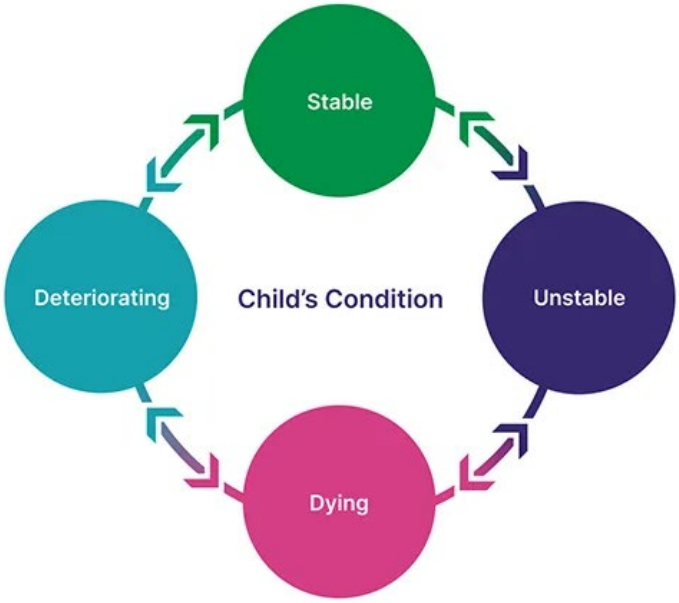
The surprise question must be used alongside the three categories of care, not as a replacement for them. If the answer to any of the timeframes of the surprise question is "no" (meaning you would not be surprised), this should act as an immediate prompt to:

- actively discuss a palliative approach with the child and family.
- initiate parallel planning (planning for life alongside planning for deterioration).
- review or develop a current advance care plan (ACP).

Step 3: Consider the current **phase of care**: determine the child's clinical state to decide what actions and resources may be needed.

The phases of care need describe a child's current care requirements rather than their long-term prognosis. A child can be in any phase regardless of their diagnostic category and may move between phases of care needs in a non-linear way.

Figure 28 – Assess and Plan



Sources: Together for Short Lives[33,34]

Phases are intended to support planning, not act as thresholds. Use of phases should always involve clinical judgement and family discussion.

A. Stable phase

- The child's overall condition is relatively stable and predictable.
- Symptoms are reasonably well managed
- Care plans are in place and working
- There are no new or escalating concerns
- The family feels supported and informed

Palliative care involvement during this phase may focus on:

- Anticipatory planning
- Relationship building
- Education and support
- Reviewing goals of care
- Ensuring services are coordinated
- Supporting the emotional and psychological wellbeing of the child, parents/carers and siblings
- Accessing therapies and interventions to maximise quality of life

B. Unstable phase

- The child's condition is fluctuating, unpredictable or changing, requiring closer review and adaptation of care.
- Symptoms are harder to control

- There may be sudden changes or new problems
- Unplanned admissions or urgent reviews may occur
- Care plans may need frequent adjustment

The focus of palliative care during this phase is:

- Reassessing needs
- Adjusting care plans
- Supporting families through uncertainty
- Strengthening communication between professionals
- Children may move back into a stable phase after an unstable period

.

C. Deteriorating phase

- The child's condition is showing a pattern of progressive decline, with increasing vulnerability and reduced response to interventions.
- Episodes of illness are becoming more frequent
- Recovery is slower or incomplete
- Baseline function is declining over time
- Conversations increasingly focus on comfort, quality of life and advanced planning

The focus of palliative care during this phase is:

- Reviewing goals of care
- Strengthening advanced care planning
- Supporting emotional and psychological needs
- Preparing for potential further decline

D. Dying phase

- The child is recognised to be approaching the end of life, where death is likely in the coming days or weeks.
- There is a clear shift towards comfort-focused care
- The family is supported by discussing wishes and preferences
- Care is coordinated to prioritize comfort, dignity and family choice

Support during this phase includes:

- Specialist palliative and end of life care
- Emotional and psychological support
- Memory-making opportunities
- Support with preferred place of care and death
- Supporting families to understand what happens when a child dies, including practical guidance and what to expect

Step 4: Identify **triggers for specialist input**: decide if the child's needs (such as complex symptom management or complex ethical decisions) now exceed the capability of the local core team.

While many needs are met by universal and core teams, a specialist PPC referral should be triggered when clinical or ethical complexity increases.

Key triggers can include:

- refractory symptoms that are difficult to manage with standard medications.
- complex ethical disputes regarding the withholding or withdrawal of life-sustaining treatment.
- end-of-life care at home, where 24/7 specialist advice and nursing support are required to maintain comfort.

6.3.1.2 Screening/Identification Scales

SCALES DEVELOPED FOR PAEDIATRIC POPULATION

PAPAS (PAEDIATRIC PALLIATIVE SCREENING) SCALE

The PaPaS scale is a multidimensional tool to support timely and appropriate referral to PPC.[35–37] It was developed based on a literature review, semi-structured interviews with international PPC experts from UK, France, USA and Canada, and focus group discussions with paediatric healthcare professionals at University Children's Hospital Zurich, Switzerland.

The literature review conducted by the PaPaS scale study team identified five domains for the conceptual model of a tool intended to facilitate appropriate and timely involvement of specialist PPC teams/services. These domains were subsequently refined through face-to-face interviews with international PPC experts and focus group discussions with paediatric health professionals as below:

1. Disease trajectory and impact on daily activities
2. Expected outcomes and treatment burden directed at disease and burden of treatment
3. Symptom and problem burden
4. Preferences of the child, parents and health professionals
5. Estimated life expectancy

Figure 29 – Version 3 of the PapaS Scale

Table 4 Version 3 of the PaPaS Scale

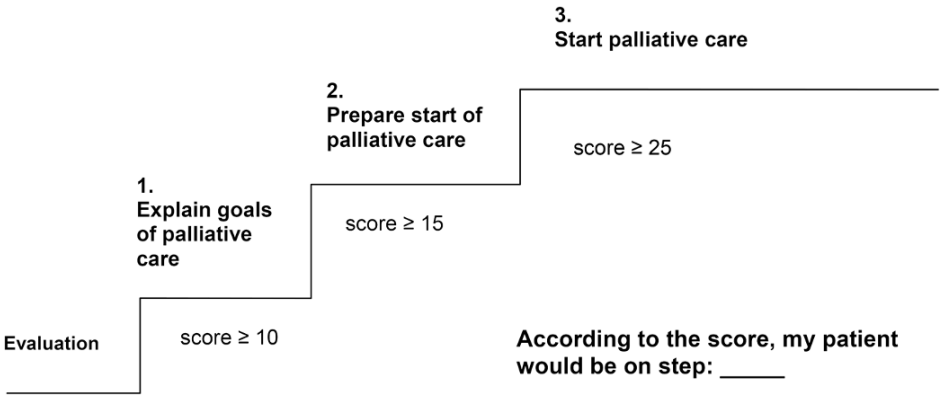
Domain and Item numbers	Item	Characteristic	Score
Domain 1	**Trajectory of disease and impact on daily activities of the child**		
1.1	Trajectory of disease and impact on daily activities of the child (in comparison with the child's own baseline) (with reference to the last 4 weeks)	Stable	0 ☐
		Slowly deteriorating without impact on daily activities.	1 ☐
		Unstable With impact on and restriction of daily activities.	2 ☐
		Significant deterioration with severe restriction of daily activities.	4 ☐
1.2	Increase of hospital admissions, (> 50% within 3 months, compared to previous periods)	No	0 ☐
		Yes	3 ☐
Domain 2	**Expected outcome of treatment directed at the disease and burden of treatment**		
2.1	Treatment directed at the disease, (does not mean treatment of disease related complications, such as pain, dyspnoea or fatigue)	…is curative.	0 ☐
		…controls disease and prolongs life with good quality of life.	1 ☐
		…does not cure or control but has a positive effect on quality of life.	2 ☐
		…does not control and has no effect on quality of life.	4 ☐
2.2	Burden of treatment, (**Burden** means side effects of treatment and additional burdens such as stay in hospital in the patient's or family's view)	No or minimal burden or no treatment is envisioned.	0 ☐
		Low level of burden	1 ☐
		Medium level of burden	2 ☐
		High level of burden	4 ☐
Domain 3	**Symptom and problem burden**		
3.1	Symptom intensity or difficulty of symptom control (over the last 4 weeks)	Patient is asymptomatic	0 ☐
		Symptom(s) are mild and easy to control	1 ☐
		Any symptom is moderate and controllable	2 ☐
		Any symptom is severe or difficult to control (unplanned hospitalisation or outpatient visits, symptom crises)	4 ☐
3.2	Psychological distress of patient related to symptoms	Absent	0 ☐
		Mild	1 ☐
		Moderate	2 ☐
		Significant	4 ☐
3.3	Psychological distress of parents or family related to symptoms and suffering of the child	Absent	0 ☐
		Mild	1 ☐
		Moderate	2 ☐
		Significant	4 ☐
Domain 4	**Preferences/needs of patient or parents** **Preferences of health professional**		
4.1	Patient/parents wish to receive palliative care or formulate needs that are best met by palliative care.	No	0 ☐ please answer 4.2
		Yes	4 ☐ do not answer 4.2
4.2	You/your team feel that this patient would benefit from palliative care.	No	0 ☐
		Yes	4 ☐
Domain 5	**Estimated life expectancy**		
5.1	Estimated life expectancy	Several years	0 ☐ please answer 5.2
		Months to 1–2 years	1 ☐ please answer 5.2
		Weeks to months	3 ☐ do not answer 5.2
		Days to weeks	4 ☐ do not answer 5.2
5.2	"Would you be surprised if this child were to suddenly die in 6 months time?"	Yes	0 ☐
		No	2 ☐
		Total score:	

Source: Bergstraesser et al. 2013[36]

Each domain is scored using yes/no questions/items, with a total of 13 items weighted from 0 to 4 points. Based on the total score, the child is assigned to one of the three steps of the graduated PPC referral process:

1. Explain goals of PC (introduction of PC)
2. Prepare start of PC (basic symptom management alongside disease-specific treatments)
3. Start PC (PC becomes the focus of care)

Figure 30 – Stepwise approach



The PaPaS scale has evolved into an international screening tool for PPC. It has been translated and adapted for use across different healthcare settings and languages. It is available in English (original), German, Korean, Portuguese, Chinese, Italian and Spanish. It has been applied in PPC research studies in Singapore , India, South Korea and Peru. It is also recommended for use within the Canadian Core Care Pathway for PPC (see above). A neonatal version of the PaPaS scale is currently in process of publication (information from interview with Swiss expert).

An adaptation of the PaPaS scale for the paediatric intensive care unit has also been developed and validated: the Pediatric Intensive Care-Pediatric Palliative Care Screen (PIPPS).[38]. PIPPS is seven-item screening tool consisting of true-or-false questions. It comprises two parts: Part 1 identifies patients who may benefit from a PPC consultation, while Part 2 assesses five domains of potential palliative care needs, reflecting the domains of the PaPaS scale. The screen is considered positive when at least one statement in each part is endorsed as true.

ACCAPED (ASSESSMENT OF COMPLEX CLINICAL-ASSISTANCE NEEDS IN PEDIATRICS)

The ACCAPED scale was developed by a multidisciplinary group of experts in PPC including paediatricians, nurses, psychologists, PPC specialists at the University of Padua in Italy.[39,40] It is based on a review of literature and existing tools used in adult palliative care and aims to assess the complexity of care needs in children with incurable or chronic conditions. The tool is designed for use by healthcare professionals across different settings and focuses on clinical and supportive care needs to identify children and adolescents who need different levels of PPC. It covers medical (clinical) and supportive (assistance) needs in ten areas:

1. Respiration
2. Feeding
3. Convulsive crisis or altered state of consciousness
4. Skin and tissue integrity
5. Mobility
6. Communication

7. Sleep and rest
8. Continence and elimination
9. Administration of medications
10. Pain
11. Risk of clinical instability/premature death
    a. no risk of progression or early death
    b. risk of progression/deterioration
    c. not surprised if this patient dies within 12 months

Points (0-50) are assigned to each area depending on the level of care complexity. The scale also includes a modified version of the ''surprise question'' (''Would you be surprised if this patient died within the next 12 months?''), which is used as a trigger for referral to specialist palliative care and accounts for up to 50 points. Scores across all areas, including the surprise question, are then summed up. Based on the total score, the level of care complexity and corresponding level of PPC provision needed are categorised as follows:

Table 18 – ACCAPED

Total ACCAPED score	Level of complexity of care needs	Level of PPC services and providers
≤29	Basic	Level 1: PPC approach Primary care providers: GP, general paediatrician, community healthcare facilities
30-49	Moderate	Level 2: General PPC Secondary care: hospital, medical specialties
≥50	High	Level 3: Specialist PPC Specialised PPC centre/team

The severity of the care needs determines the level of PPC service provided within community care, general PPC (delivered by specialists managing the underlying disease with training in PPC), or specialist PPC (delivered in dedicated settings by a multidisciplinary team of PPC experts).

ACCAPED was originally developed in Italian and has recently been translated and validated in a modified English version.[41] The English version of ACCAPED is available.[42]

START (SCREENING TRIAGE ASSESSMENT AND RE-EVALUATION TOOL)

START is a tool developed and used by the Pediatric Advanced Care Team (PACT) at the East Switzerland Pediatric Hospital. The tool begins with a quick test (a shortened version of the PaPaS scale), followed by the main assessment part. The tool is currently only available in German.[43,44] Similar to the PaPaS scale, the START scale uses the overall score to guide the choice of the three levels of PPC interventions.

A neonatal START questionnaire has also been developed.[45,46]

Scales adapted from adults' palliative care

PALLIAPED 10

PALLIAPED 10 is a paediatric adaptation of PALLIA-10, a multidimensional questionnaire addressing medical, psychosocial and ethical issues.[47] It was developed and proposed by SFAP (*Société Française d'Accompagnement et de Soins Palliatifs* - French Society for Palliative Support and Care) in 2010.[48] PALLIAPED 10 is designed for use by any professional, including nurses, physicians, and educational or social professionals, to initiate referral to PPC. The tool comprises ten key

areas/domains for a global assessment, with each item as a Yes/No question. If three or more answers are 'Yes', referral of the child to a PPC team is considered appropriate.

HEXCOM-PED

The HexCom (Hexagon of Complexity) is a model for the care of people with advanced illness and/or at the end of life. It was developed in Catalonia (Spain) in 2010 and is based on the conceptual framework of the Multiple Chronic Conditions Research Network of the University of Washington, which defines complexity as the "*gap between patient needs and health care services*" or a mismatch between patient needs and available services. The instrument classifies situations that are refractory to treatment options as "high complexity" and those that are difficult to resolve as "moderate complexity". In this way, classification according to the level of complexity helps distinguish between patients who need specialised palliative care and those who may not.

The HexCom model comprises six domains of need (clinical, psychological/emotional, social/family, spiritual, ethical, and death-related) which are further divided into 18 subdomains. The level of complexity within each domain or subdomain is classified as low (no complexity), moderate (difficult situation), or high (refractory situation). The model also incorporates four domains of resources or strengths: intrapersonal, interpersonal, transpersonal, and practical.

Originally designed to assess complexity of care in adults with advanced illness and/or at the end of life situations.[49], the tool has since been validated and continues to be adapted for use in different settings and populations.[50]

The paediatric version, HexCom-Ped, has recently been developed as a needs assessment tool in PPC through an ongoing adaptation process within the scope of PALLIAKID project[c]

6.3.2 Identification tools at population level

Several lists of diagnoses and conditions eligible for PPC have been developed based on the International Classification of Disease (ICD-10).

6.3.2.1 Pediatric Complex Chronic Conditions (CCC) classification

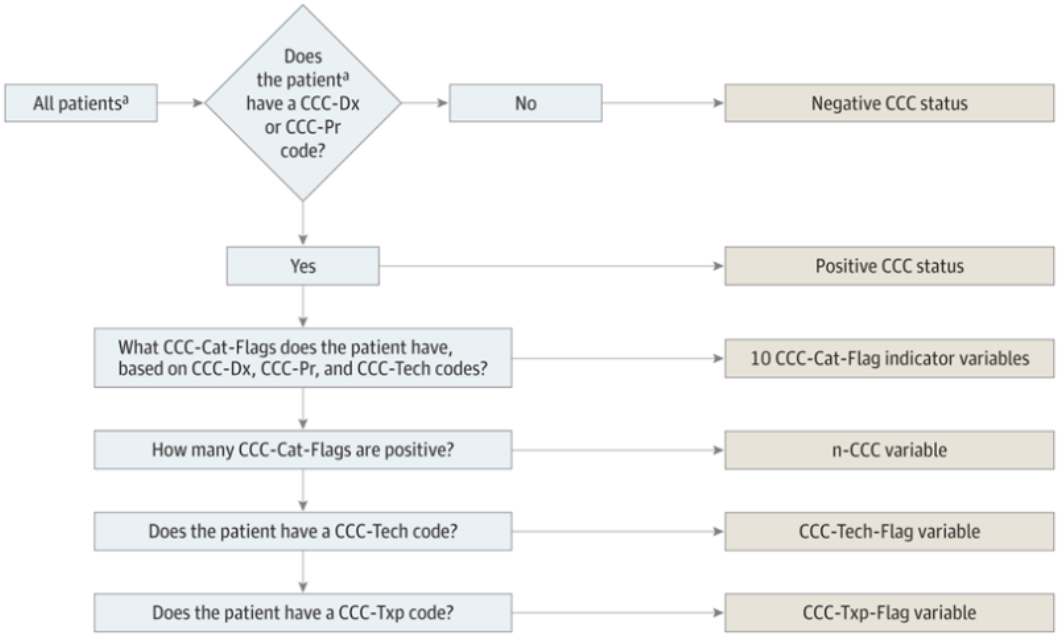
Version 1 introduced a list of CCCs, defined as any medical condition expected to last at least 12 months (unless death intervenes) and involving either multiple organ systems or a single organ system to a severity that requires specialty paediatric care and likely hospitalisations in a tertiary care setting. This classification includes more than 1000 diagnoses in ten CCC categories: cardiovascular, respiratory, neuromuscular, renal, gastrointestinal, hematologic or immunologic, metabolic, other congenital or genetic, malignancy and perinatal conditions.[51]

Version 2 expanded the classification system to include diagnostic and procedural codes, added a neonatal CCC category, and incorporated complexity domains such as medical technology dependence or organ transplantation.[2] Version 3, published in 2024, reflects updates aligned with the evolving ICD-10-CM coding system.[8]

[c] PALLIAKID project https://palliativeprojects.eu/palliakid/

Figure 31 – Process to assign complex Chronic Condition

Figure 1. Process to Assign Complex Chronic Condition (CCC) Status and CCC Categories Using the CCC System Version 3



The CCC status (ie, yes or no) and CCC categories using CCC diagnosis, procedure, technology, and transplant codes. Cat indicates category; Dx, diagnosis; Flag, status; n-CCC, number of CCC categories; Pr, procedure; Tech, technology; Txp, transplant.

[a]Assigned at the patient level or encounter level (ie, a hospitalization).

Source: Feinstein et al 2024[8]

6.3.2.2 Directory of life-limiting conditions

Hain et al. (2013) developed this directory by mapping the four ACT/RCPCH groups/categories into diagnoses (ICD- 10 codes) of patients admitted to PPC services in the UK.[20] The resulting list includes 376 diagnostic labels.[52] Similar to the CCC classification, the list requires periodic updating as new diagnoses and conditions emerge.

6.3.2.3 List of Life-Limiting Conditions (LLCs)

Based on the Directory of life-limiting conditions (see above) and the diagnoses of children accepted for care at a UK hospice, Fraser et al. (2012) developed a list of 777 ICD-10 diagnosis codes.[1] The list includes diagnoses where most children were life-limited/threatened, and also if most sub diagnoses of the ICD-10 code were life-limiting/threatening, along with all malignant oncological codes. The LLC List has been used to estimate the number of children with LLCs in England, Scotland, Wales and Ireland.

The most recent version[53] further explores how to capture the complexity of need by applying a framework of medical complexity based on the conceptualisation proposed by Cohen et al. (2011)[54], which in turn builds on a systematic review of chronic health conditions in childhood by Van der Lee et al. (2007).[55]

Incorporating information on the complexity of need is essential for identifying population-level need for PPC that goes beyond a diagnosis-based list. However, this approach requires the availability and integration of broader datasets in addition to mortality and disease prevalence data, including hospital admissions, paediatric intensive care data, outpatient and general practice data, prescribing data, etc.

Estimates of PPC at national or regional levels may also be derived by applying prevalence estimates from published literature to locally available population data.[9]

6.4 Discussion

The above mapping of the available identification/eligibility tools and criteria for PPC in both individual and population levels demonstrate that, over the past 30 years, the focus has gradually shifted from the diagnosis- and disease trajectory-based approaches toward assessing the complexity of care needs. This shift provides a more accurate reflection of the real-world needs of children, families, and the professionals involved in their care, and aligns more closely with the comprehensive definition of PPC.

Assessment of eligibility and referral for PPC should also be viewed as a longitudinal process rather than a one-time event. Because the needs of children and their families are dynamic and may change throughout the disease trajectory, regular reassessment is essential to identify evolving PPC needs and to adjust accordingly the level of PPC provided.

Regarding the most appropriate tool for early identification of children who need PPC, there is currently no consensus. The PaPaS scale was developed on a strong foundation of literature review and consultation with international PPC experts and has since been translated and validated across several languages and PPC settings. It is a structured tool that supports clinicians in objectively assessing the need for PPC and facilitating timely referrals. However, its limitations include variability in scoring between clinicians and limited correlation with quality-of-life measures. Furthermore, its comprehensive, multi-domain structure requires training and familiarity with PPC, which may limit its feasibility in non-specialist settings. The ACCAPED scale determines eligibility for different levels of PPC by assessing the complexity of medical needs and the risk of life-threatening events. However, it is primarily focused on clinical complexity and does not comprehensively assess other important dimensions of complexity of care, such as psychosocial and spiritual needs of the child and family. Therefore, a broader, multidimensional assessment remains necessary to ensure that all aspects of the child's and family's palliative care needs are identified and addressed.

While screening tools are valuable for identifying children who may benefit from PPC, they should not replace comprehensive, individualised assessment by healthcare professionals involved in the child's care. Rather, they should be used to support clinical decision-making and facilitate timely recognition of needs that can be addressed by PPC services.

7 GOOD PRACTICES IN FOREIGN COUNTRIES

7.1 Context

This appendix aims to identify good practices abroad that could serve as a source of inspiration for improving the current provision of and access to PPC in Belgium. The objective is to highlight projects or approaches that could help bridge the gap between the existing services and the actual care needs in our country. These sections are not intended to be exhaustive, but rather to explore and illustrate existing initiatives.

7.2 Methods

We initially selected countries based on their high level of PPC provision, as rated by the ICPCN, and because their healthcare systems share certain characteristics with the Belgian system.[56] This first step included Australia, Canada, France, Germany, Italy, Norway, Spain, Sweden, Switzerland, the Netherlands, the United Kingdom, New Zealand.

We then conducted an initial review of the (grey) literature and a broad assessment of paediatric palliative care provision in these countries. Based on this review, we retained countries for further analysis where their models were considered to offer added value for the Belgian context, for example by providing innovative practices that could challenge or complement the findings of this report, and/or where their organisational features appeared sufficiently transferable to the Belgian healthcare system. This process resulted in a final selection of eight countries located in Europe, North America and Oceania: Australia, Canada, Germany, Italy, Spain, Switzerland, the Netherlands and the United Kingdom.

For each country, we carried out a search of grey literature, government agency websites and parents or professional associations dedicated to PPC, between July 2025 and November 2025. Where relevant, we also examined the websites of university paediatric hospitals and paediatric hospices. In addition, we searched the PubMed database for scientific articles on innovative PPC practices in these eight countries. Artificial intelligence tools (e.g., ChatGPT and Copilot) were used to support the review process by translating webpages, providing preliminary overviews of PPC organisation in the selected countries, and helping to identify potentially relevant PPC initiatives. All information was subsequently verified.

For this chapter, we considered that good practices in PPC are initiatives that enhance the organisation and delivery of services, aiming to improve access to care. They may consist of a coordinated set of services within a national territory at a local level, or a formal national plan. We didn't limit good practices regarding their level of organisation: such practices can operate at local, regional or national levels. We didn't aim at exhaustivity but rather were looking forward to innovative initiatives that could be a source of inspiration to improve PPC in Belgium.

For each country, the identified initiatives were classified according to the five priority actions highlighted by the King Baudouin Foundation (KBF (KBS-FRB))[d] in its recent overview of paediatric palliative care in Belgium.[57] The category of communication was further divided into awareness and advocacy. The remaining categories comprised education and training (targeting healthcare professionals, parents, siblings, and other caregivers), access to care, research, and support for siblings.

We subsequently contacted one or more PPC experts in each of the eight countries to discuss their insights and experiences regarding PPC in their respective countries. An interview guide was used: a generic template was developed and subsequently adapted for each country. This template is

[d] The King Baudouin Foundation is an independent Belgian foundation that supports projects and initiatives seeking to improve living conditions and promote social cohesion, inclusion, and well-being.

provided at the end of this appendix. The interview guide was structured around the five topics outlined above from the KBF and covered the following areas: the general context of PPC, including model-of-care specificities, access to PPC, and the target population; examples of good practices that improve access to care, addressing subtopics such as education and training, support for siblings, psychosocial and spiritual care, research, awareness and advocacy, and available resources and tools. The final question explored key drivers for improving access to PPC, based on the experts' own experience. These online interviews were designed to enable us to refine our findings, gather additional information on specific initiatives, and, where applicable, identify further examples of good practice.

Seven[e] interviews were conducted in March 2026. All interviews were held online and lasted approximately one hour. Two researchers attended each interview. Notes were taken, and the interviews were audio-recorded to facilitate any subsequent review.

Based on the document review and interviews with experts, we identified examples of good practice that may be relevant to the Belgian context.

7.3 Results

7.3.1 Raising awareness

7.3.1.1 Activities to increase the visibility of PPC

In the countries we investigated, several awareness-raising actions related to PPC are organised, most often within the framework of a **PPC week**. This is the case in Italy, Canada, and UK for example.[58–60] In the Netherlands, Spain, and Switzerland, awareness-raising actions focus on palliative care in general (including paediatric care, but not exclusively) and take place around **World Hospice or Palliative Care Day** (these actions may be of shorter duration than one week).[61–63] Here below, two actions are presented:

- In the UK, **Children's Hospice Week** (run by the charity Together for Short Lives) is an annual week dedicated to awareness-raising and fundraising for children's hospices and PPC services; it brings together all children's hospices in the country around a shared objective: highlighting the impact of their services and the needs of the sector.[60]
- In Italy, this takes the form of a touring series of events across different regions, hence the name *Giro d'Italia delle Cure Palliative Pediatriche* (coordinated by the Fondazione Maruzza Lefebvre D'Ovidio ETS).[59] The objectives are to raise public awareness of PPC, change misconceptions surrounding the care of children with severe and incurable diseases, recall the right of access to PPC guaranteed by Italian Law 38/2010, and support the development of regional PPC networks.[64] This "tour" brings together institutions, associations, healthcare professionals, families, volunteers, and citizens around regional actions comprising solidarity-based sporting, recreational and cultural events, information booths, scientific conferences, educational workshops, and public meetings.[59]

The International Children's Palliative Care Network (ICPCN) launched an initiative to raise global awareness of the need for children's palliative care and to highlight the work of PPC services worldwide. The **Hats On event** takes place on the second Friday of October each year. The idea is to wear a (funny) hat to spark conversations; it symbolises the many roles ("hats") worn every day by those caring for children with life-limiting or life-threatening conditions, including parents, siblings, caregivers and healthcare professionals.[65]

Another type of action comes from Spain, where the **short animated film** *Nano y Choco* was developed by the *Fundación porqueViven*. Released in February 2026, this audiovisual resource was

[e] All countries except Italy agreed to participate in this online interview.

designed to enhance public understanding of PPC, highlighting the support provided to children with severe, life-limiting conditions and their families. Presented in an animated format, it emphasises that "there is always something that can be done", even when there is no hope of cure, underscoring the importance of quality of life, emotional support, and dignity. The film is intended for a broad audience, including the general public, families, healthcare professionals, and policymakers, and is freely available online.[66]

Primarily aimed at families of children and young people with life-limiting or life-threatening conditions, the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth (*Bundesministerium für Bildung, Familie, Senioren, Frauen und Jugend* (BMFSFJ)) in Germany launched the animated information video *Hospizarbeit und Palliativversorgung für Kinder und Jugendliche* in 2023. Developed in collaboration with national hospice and paediatric palliative care organisations, the five-minute film focuses on improving public understanding of paediatric palliative care, by providing accessible information on the support available, how and when services can be accessed, and the professionals involved in care. The video emphasises that paediatric palliative care can be introduced from the time of diagnosis, is delivered across a range of settings including home, hospital and hospice care, and adopts a family-centred approach that supports parents and siblings as well as the child. To improve accessibility, the film has also been made available in several languages.[67]

We also retrieved initiatives specifically supporting **communication** on PPC. As examples, we present two initiatives:

- In the UK, the charity HEARD is specialised in communication and provides guidance to strengthen the communication capacities of stakeholders (families, HCPs, associations, and the media), thereby helping to transform public perceptions of sensitive topics by improving media narratives. Through its Children's Palliative Care programme, HEARD focuses on empowering stakeholders with lived experience (families, HCPs, associations, and media professionals) to share their stories about PPC and to ensure that their voices and perspectives are heard.[68]
- *IMA-GO! Condividile con Cura!* is an Italian initiative led by the *Fondazione Maruzza Lefebvre D'Ovidio ETS* that promotes the ethical and responsible sharing of images of children with serious or incurable illnesses, with a focus on protecting their dignity, privacy and rights while supporting awareness and advocacy efforts.[69]

Some actions **derived from adult palliative care initiatives**, also contribute to raising awareness on PPC. Modelled on the concept of first aid courses, *Last Aid® Courses* are an international initiative designed to educate the general public about death, end-of-life care, grief, and palliative care through simple and accessible courses that promote both health literacy and death literacy. The primary objectives are to demystify death, reduce fear and taboos. The International Last Aid Working Group contributes to providing a scientific basis. These courses have been adapted for a paediatric audience (*Last Aid Courses® for Kids & Teens*), tailored to age, and can be offered in schools or community settings. They address topics such as death as a part of life, the fact that children can also become seriously ill, and how to support a sick peer, sibling, or friend.[70,71] In the Netherlands, the four-part documentary series *Leven tot het laatst*, broadcast by KRO-NCRV on NPO 2, is a Dutch example of media initiative. The series follows individuals living with incurable illnesses through their real-life experiences. While primarily focused on adult care, PPC was addressed in an episode, providing a powerful and insightful illustration of what PPC means for families.[72,73]

7.3.1.2 Role of organisations, such as charities and centres of expertise

We observed in the country we investigated the paramount role of PPC organisations[f]. Among their many missions (parental support, information, etc.), raising public awareness of what PPC truly is, is often a key element. For example, the following **charities** contribute to this within their respective countries: the *Fondazione Maruzza Lefebvre D'Ovidio* in Italy, the *Fundación porqueViven* in Spain, the *Pro Pallium Foundation* (*Schweizer Palliativstiftung für Kinder und junge Erwachsene*) in Switzerland or Together for Short Lives in the UK.[74–77] All these **charities** act by publishing clear, reliable, and family-appropriate content to explain what PPC are, by sharing testimonials, videos, and narratives, by providing educational and informational tools, and by serving as relays for resources, news, and campaigns that help increase the visibility of PPC.

In the Netherlands and Canada for example, PPC is organised around **institutions** that bring together multidisciplinary and multi-perspective stakeholders:

- The *Kenniscentrum Kinderpalliatieve Zorg* (National PPC Knowledge Centre) is the Dutch reference centre for knowledge, development, and dissemination of expertise related to PPC. It is a national organisation that connects healthcare services, professionals, families, professional associations, and institutions in order to foster innovation, training, coordination of clinical practices, and the integration of palliative care into the Dutch healthcare system. Among its missions, the centre of expertise serves as a point of contact for questions related to policy, organisation, and care practices, and acts as an advisor and driver of change within the PPC ecosystem in the Netherlands, influencing national health policy towards improved organisation and funding of care for children with severe illnesses.[78,79]
- In Canada, the Canada's Pediatric Palliative Care Alliance and the Canadian Network of Palliative Care for Children act as **national organisations** for PPC. Both bring together healthcare professionals, organisations, and families to promote coherent, equitable, and high-quality PPC across the country (the effective organisation of PPC depends on the provinces and territories). By disseminating a range of content through platforms such as websites, social media, webinars, testimonials, and educational resources, and by participating in events such as the National Children's Hospice Palliative Care Day (see below), they contribute to increasing the visibility of PPC in Canada.[80,81]

In Australia, awareness actions take place in a broader context: the National Action Plan. This plan is coordinated by Palliative Care Australia and includes within one of its priorities: "to develop a targeted community awareness strategy that can build knowledge about key issues relevant to supporting children, young people and families who need paediatric palliative care" (Action 3.1.). Another action concerns the implementation of the Paediatric Palliative Care National Action Plan: "Collaborate with key stakeholders to enable implementation of the Paediatric Palliative Care National Action Plan" (Action 3.3), with a medium-term implementation timeframe of 3-5 years. Within the participatory project *"Shaping the Future of Paediatric Palliative Care"*, families, patients, HCPs, and other involved stakeholders have been invited to co-create messages, resources, and awareness strategies. The "Shaping the Future Project*"* aims to advance the quality and accessibility of paediatric palliative care by supporting communication training for healthcare professionals, developing national clinical guidelines, improving transitions between paediatric and adult services, and promoting earlier and more appropriate referral to PPC services.[82,83]

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[f] Due to the methodology used to search for information, we primarily identified charities with the greatest visibility from abroad, and therefore generally operating at the national level. Our aim is neither to be exhaustive nor selective; rather, we identified certain associations because they enabled us to better understand international experiences and initiatives that could be useful for our research.

7.3.1.3 Raising awareness among healthcare professionals

We retrieved some initiatives from charities and national centres aimed at increasing awareness of PPC that target healthcare professionals. Forms can vary, such as participation in scientific conferences, or development of tools (e.g., websites, flyers, webinars, informational courses). These informational activities targeting HCPs are carried out, for example, by Together for Short Lives (UK), Fundación *porqueViven* (Spain), or Pro Pallium Foundation (Switzerland), highlighting their role beyond the general population.[84–87] This kind of activities are also integrated into the Australian national plan, as well as conducted by the Canada's Pediatric Palliative Care Alliance.[88,89]. In the Netherlands, the *Kenniscentrum Kinderpalliatieve Zorg* (National PPC Knowledge Centre) contributes to increasing the visibility of PPC at national and international events (conferences, congresses, webinars) and also develops and disseminates educational tools for HCPs to enhance understanding of PPC; it also develops and disseminates educational resources for (future) healthcare professionals to strengthen knowledge and understanding of PPC.[90–96] For example, an informational flyer for general practitioners was produced to help them better understand PPC and know to whom patients should be referred.[97]

At the meso level, collaboration between PPC teams and specialised paediatric services can be hindered by limited awareness of PPC services. To address this, in some countries the PPC team participates in clinical rounds across various paediatric departments, including intensive care, general paediatrics, and paediatric cardiology. In Switzerland, paediatric palliative care explicitly includes the perinatal period, reflecting an integrated approach that spans from antenatal diagnosis to infancy. (Source: Interview with the Swiss expert)

7.3.2 Advocacy

7.3.2.1 Awareness-raising targeted at policymakers

We identified several actions aimed at **advocating for PPC among policymakers**. For example, in the UK, *Short Lives Can't Wait* (2024) is an awareness and advocacy campaign that mapped the availability of PPC against the standards defined in guidelines and legislation, highlighting significant regional disparities[g]. This report was presented to a parliamentary committee to engage policymakers and call for commitments to guarantee universal and equitable access to PPC. Building on this work, the report *"Built to Last?"* (2025) details the state of PPC services, including estimates of funding shortfalls and gaps in local planning. The report calls for a rethinking of the funding, planning, and organisation of paediatric palliative care in order to build a sustainable and equitable system. Events were organised to draw the attention of parliamentarians and health authorities to these issues and to the need for additional investment. These actions, led by the charity Together for Short Lives, contributed to securing ringfenced funding of more than £80 million for children's hospices in England through to 2029.[98–100] In addition, there is an informal, cross-party group of Members of Parliament and members of the House of Lords within the UK Parliament (APPG: All-Party Parliamentary Group) focused on PPC. Although such groups do not propose legislation, they have strategic influence by raising awareness of and informing debate on specific topics. The charity Together for Short Lives provides the secretariat for the group and supports the production of inquiry reports and meetings with stakeholders, such as the NHS and the Department of Health.[101]

In Italy, the National Bioethics Committee of the Italian government (*Comitato Nazionale per la Bioetica*) published in 2025 a report entitled *Cure palliative pediatriche: una urgenza*. This report draws attention to the state of PPC in Italy, describing it as an ethical and public health emergency, as the country does not yet ensure sufficient and homogeneous access to specialised care for children with incurable diseases (territorial inequalities, unmet needs, services and care provision not specific to

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g This report highlights the 'postcode lottery' in the UK, whereby access to care (including PPC) depends on where you live.

paediatrics, and structural issues such as a lack of training among HCPs). The report also formulates a series of recommendations, including the strengthening of care structures, the promotion of professional training (encompassing a change in the culture of pain management), the respect for autonomy and assent of the minor child, support for families, and encouragement of research. This report calls on public authorities to take urgent action in favour of PPC.[102]

In the Netherlands, the reference centre can be consulted to contribute to policies or guidelines that provide greater legitimacy and recognition for PPC within the healthcare system.[103] It has also developed collaborations, notably with professional associations (e.g., NVK – *Nederlandse Vereniging voor Kindergeneeskunde*), healthcare organisations, and the Ministry of Health.[104]

At the international level, the ICPCN's recent "Close the Gap" campaign advocates for equitable access to PPC and calls for stronger integration of PPC within health systems.[105]

7.3.2.2 Involvement of families and HCP in the legislative process: an illustrative example from Catalonia (Spain)

During the III XAPPI[h] Day (31/10/2025), PEDPAL, the Spanish professional association for PPC, together with a group of families, presented the draft Catalan law on PPC, outlining its key principles, sharing experiences, and raising awareness among care teams. Later in 2025, the same families and PEDPAL representatives were formally heard by the Parliament of Catalonia, providing policymakers with testimony and professional perspectives to inform the legislative process and emphasise an integrated, continuous, and multidisciplinary approach. PEDPAL acted as representatives of families, providers of professional expertise, and advocates for policy implementation, ensuring that the law would address both the clinical and social dimensions of PPC.[106–108]

7.3.3 Education[i]

7.3.3.1 Training for the wider care network

Many training initiatives extend beyond clinical professionals to include **non-medical and community caregivers involved in supporting children and families**. Psychologists, social workers, spiritual care providers, paramedics, educators or even funeral services can access multiprofessional training programmes.

In Italy, the *Maruzza Lyceum* training programmes are open to a wide range of professionals, including psychologists, physiotherapists, social workers, and other caregivers involved in PPC.[109] While these initiatives are generally not associated with formal certification, they contribute to a broader educational ecosystem supporting PPC delivery and family-centred care.

In addition, educational resources and awareness-oriented initiatives are available for teachers, volunteers, and families, particularly through national platforms, professional associations, and charities. Australia provides several examples of family-oriented resources developed by Palliative Care Australia, Paediatric Palliative Care Australia and New Zealand (PaPCANZ), and the Australian Capital Territory. These include booklets such as "A Family Companion" for parents and carers and "Teachers Supporting Students at School", as well as information sheets and the "Children's Palliative Care Toolkit (Palliative Care ACT)", which is designed for families, friends, and others close to a family caring for a child with a life-limiting illness.[110–112] These resources offer insights, knowledge, and practical tools. In addition, a wide range of resources, videos, and podcasts covering various PPC topics is available.[113] In Switzerland, *Pro-Pallium* (*Schweizer Palliativstiftung für Kinder und junge*

[h] XAPPI: *Xarxa d'Atenció Palliativa Pediàtrica Integral*, meaning in English: Network for Comprehensive Paediatric Palliative Care

[i] This section does not aim to provide an exhaustive review of individual curricula or course content. Rather, it focuses on the overall organisation of education and training in paediatric palliative care

Erwachsene) provides support to families with seriously sick children and offers basic training for volunteer helpers in PPC.[114]

7.3.3.2 Core PPC training for non-specialists HCP

Several examples can be presented from abroad. In the Netherlands, non-specialist HCP can access a four-day multidisciplinary *Basistraining Kinderpalliatieve Zorg* developed by the national *Kenniscentrum Kinderpalliatieve Zorg*, as well as online modules hosted on the Palliaweb platform.[115,116]. In Australia, the Quality of Care Collaborative Australia (QuoCCA) programme provides case-based education, e-learning, and outreach training specifically designed for HCP in regional, rural, and remote settings who deliver non-specialist PPC[j].[117,118]

7.3.3.3 Advanced training in PPC

This kind of advanced training can be found in countries where **PPC is formally recognised as a subspecialty or structured field of practice**. Training pathways are therefore clearly delineated and oriented towards advanced clinical roles. For example, in the UK, paediatric palliative medicine is recognised as a subspecialty, with a nationally regulated curriculum published by the General Medical Council (GMC) and implemented through the Royal College of Paediatrics and Child Health. Paediatricians may pursue either a two-year GRID training programme leading to consultant roles in PPC, or a SPIN pathway aimed at developing specialist interest within another paediatric specialty.[119–121]

Similarly, in Canada, a two-year Paediatric Palliative Care Residency Programme validated by the Royal College of Physicians and Surgeons of Canada provides a formal postgraduate route for paediatricians.[122] It can be, complemented by certificate programmes and nationally disseminated communication tools such as the Serious Illness Conversation Guide Pediatrics (see below).[123,124]

In Spain, several national and regional actors (PEDPAL, RedPal, Sant Joan de Déu Children's Hospital) offer basic and intermediate PPC courses for paediatricians and nurses through online and hybrid formats. The *Dignia Foundation* and PEDPAL have launched the ESPEDPAL program, a training model inspired by the Anglo-Saxon fellowship system that combines work and learning in accredited units. The goal is that within the next ten years, every autonomous community will have at least one professional with advanced training in PPC.[125]

In Germany, while paediatric palliative care is not recognised as a standalone medical specialty, healthcare professionals can undertake nationally recognised additional training in PPC. A 40-hour supplementary qualification is available for professionals who have already completed general palliative care training, while a comprehensive 200-hour Multiprofessional Curriculum in Paediatric Palliative Care provides advanced training for paediatricians, nurses and psychosocial professionals. Updated in 2024 from the former *Datteln* curriculum, the programme is based on the 12 European Association for Palliative Care (EAPC) core competencies and leads to a recognised certification.[126–128]

Comparable structures are observed for paediatric nurses in several countries. For example, in Switzerland, level-based courses for nurses and a Certificate of Advanced Studies in PPC offered by the University of Zurich illustrate similar approaches.[129]

There is also an **international training programme**, Education in Palliative and End-of-Life Care (EPEC), within which **EPEC-Pediatrics** represents the specific adaptation for PPC (initially developed in the USA). It is a structured, modular curriculum designed to strengthen core competencies in palliative and end-of-life care among HCP. EPEC serves as a recognised reference framework internationally (without conferring an academic degree or individual certification) and is primarily

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j QuoCCA also provides education and capacity-building specialist PPC professionals, supporting care delivery in community settings as well as expertise development in tertiary centres

integrated into institutional training and continuing professional development programmes. The programme follows a "train-the-trainer" model, with the aim of developing local educators capable of disseminating PPC competencies within their institutions, among non-specialist HCP, providing them with the knowledge and skills required to deliver primary-level PPC. This programme is translated in several languages, with collaboration of national PPC-experts.[130,131] Working groups are implementing this curriculum wider in Europe, taking into account language adaptations. (Source: Interview with the Swiss expert)

From international level, the European Association for Palliative Care (EAPC) Reference Group for Children & Young People promotes awareness and the development of paediatric palliative care across Europe through advocacy, education, research, networking, and dedicated sessions at EAPC congresses and webinars. It also develops guidance and educational resources, including the European Charter on Palliative Care for Children and Young People.[132,133]

7.3.3.4 Practical and organisational considerations for PPC education, across all levels of training

Formats of training and curriculum

Integration of PPC content into undergraduate medical and nursing training programmes is observed across countries but remains variable. Several countries have developed reference curricula or educational standards intended to guide undergraduate exposure to PPC principles. In the UK, the Children's Palliative Care Education and Training Standard Framework, developed following UK Parliamentary recommendations, defines four progressive levels of learning (Public Health, Universal, Core and Specialist) applicable across disciplines and educational settings, and includes a self-audit tool to help program leads evaluate and quality-assure their courses.[134,135]

The Royal College of Nursing's Career and Education Framework in Paediatric Palliative Care also defines progressive levels of competence from generalist to expert practice: the 2025 framework outlines seven levels of expertise, from support worker to consultant nurse, aligned with UK nursing practice, describing a progression based on increasing clinical complexity, autonomy in decision-making, leadership, and contribution to education, research, and service development.[136]

In Spain, with the support of foundations such as *porqueViven*, PPC masterclasses are integrated into undergraduate nursing programmes. However, implementation differs across institutions and countries.[137].

Continuing professional training represents another way to develop PPC knowledge and skills. In all eight countries, short courses, modular certificates, online learning platforms, and hybrid formats combining digital and face-to-face components are proposed. Examples include LEAP Paediatric in Canada, QuoCCA e-learning modules in Australia, Palliaweb in the Netherlands, and webinars and short courses offered by PEDPAL in Spain.[117,138–140]https://pedpal.es/pedpal-y-fundacion-aladina-sealian-para-impulsar-la-formacion-y-la-expansion-de-los-cuidados-paliativos-pediatricos-en-espana/.
In the UK, the Pediatric Palliative Care Educate (PPCEducate) online platform is a collaborative hub that supports education in PPC: educators can join the network to connect with peers, contribute to the development and delivery of new learning modules, and signpost existing resources.[141] Learners from health, social care, or education backgrounds can access local, regional, and national PPC resources, book and attend study days, and enrol in independent or blended learning modules.[142] All these initiatives are often designed to accommodate professionals already in practice. The International Children's Palliative Care Network (ICPCN) also provides free educational resources for healthcare professionals, including e-learning courses and regular webinars on various aspects of children's palliative care, supporting continuing professional development.[143,144]

In Canada, Pediatric Project ECHO® provides community-based healthcare providers with access to evidence-based knowledge, an interprofessional network, and a community of practice through regular virtual sessions, supporting the delivery of safe and effective care. It connects specialist teams with healthcare professionals across provinces and is adapted from the adult ECHO® model.[145]

Skills to develop

Clinical competencies are primarily addressed in trainings targeted at HCP (not to stakeholders) and include symptom assessment and management, pain control, care delivery in home and community settings, end-of-life care... For example, the UK GMC curriculum, the 4th edition of the Practical Guide to Palliative Care in Paediatrics (called "The Green Book") in Australia, and the Italian master's programmes explicitly structure learning around complex symptom management and continuity of care.[120,146–148] A more explicit example is the Dutch Guideline for Pediatric Palliative Care (revised in 2022 and formally established in July 2024 by the Dutch Society of Pediatrics) that provides evidence-based recommendations on advance care planning and shared decision-making, symptom management, psychosocial care etc.[149–151]

Transversal skills are also the central components of training initiatives such as IMPACT (IMplementing Pediatric Advance Care Planning Toolkit) or CONNECT (toolkit developed by the *Kenniscentrum Kinderpalliatieve Zorg* (National PPC Knowledge Centre) to support HCP involved in PPC in regard to providing existential support) in the Netherlands, LEAP Paediatric in Canada, the basis cursus MAPPS (Modular Advance Care Planning for Pediatrics) in Germany, and communication-focused modules within Australian national strategies.[139,152–155]

Role of professional associations

It is also interesting to note the **role of professional associations** (particularly the specialist ones) in offering training in PPC or supporting the development and sharing of knowledge, such as Canada's Pediatric Palliative Care Alliance or PEDPAL.[156,157] For example, the Canada's Pediatric Palliative Care Alliance aims to empower HPC by providing an online resource hub with evidence-based information, continuous learning opportunities, and updates on best practices and events. Through a cross-Canada peer network, HCP can connect, share knowledge, receive mentorship, and collaborate, strengthening skills, fostering innovation, and improving access to PPC nationwide.[156] They position themselves as the voice of paediatric palliative care, in response to the lack of a structured national strategy and a shared framework, by promoting knowledge mobilisation, developing accessible resources, and disseminating best practices to support healthcare professionals, particularly in settings where expertise and support are limited. (Source: Interview with the Canadian experts)

In the UK, the Association for Paediatric Palliative Medicine (APPM) contributes to the development of training, standards and resources; they organise educational events, offer clinical resources and a network for trainees. The Paediatric Palliative Medicine Trainees Group (PPMTN) is also a national network of trainees for sharing information, training opportunities, and educational sessions (virtual or in person). In Spain, the Spanish Pediatric Association offers also a PPC course together with PEDPAL[157].

7.3.4 Research and research organisation models

Across the eight countries where we examined innovative PPC initiatives, we identified research-oriented programmes, often led by academic centres and specialised hospitals. These initiatives addressed a variety of objectives, including needs assessments, national or regional mapping of service provision, and evaluation of care quality.

7.3.4.1 Examples of research

In Italy, the PalliPed project is a nationwide research initiative that has systematically mapped PPC services, patient characteristics, and care delivery patterns across all settings (hospice, home, hospital). By generating comprehensive epidemiological data and quality indicators, it provides essential evidence for healthcare planning, policy development, and future PPC network implementation.[158] The results have been published in peer-reviewed journals, allowing for international comparison and the report has been updated in 2025, with new data and a comparison to the previous data results.[159–161]

The *Kinderpalliativzentrum* (*Datteln* Centre) in Germany conducts or participates in several PPC research projects, covering several topics. The *KoCoN project* evaluates an IT-assisted, cross-sector care pathway designed to improve coordination and quality of care for children with complex needs, with measures of clinical outcomes, quality of life, and family satisfaction. *EQUALISE* focuses on the development and validation of a questionnaire to assess the quality of care processes in young patients with rare diseases, providing a tool to objectively improve clinical practices. The *FAKT study* investigates optimised diagnosis of sleep disorders in paediatric palliative care using objective tools such as actigraphy and adapted questionnaires, representing symptom-focused research. *GeKo* explores effective clinical communication with families, including the creation and evaluation of teaching materials such as videos to support staff training. Finally, *OSAKer* assesses clinical outcomes and family-perceived results of specialised outpatient palliative care (*Spezialisierte Ambulante Palliativversorgung*) for children and adolescents, aiming to optimise the quality of home-based care.[162]

In Switzerland, the PELICAN study (2012-2015) reported on Paediatric End-of-Life CAre Needs.[163] Another project was launched with the publication of the protocol, the SPhAERA study whose aim is to evaluate the effectiveness of specialised PPC and to assess its potential to improve outcomes for patients, families, healthcare professionals, and the healthcare system.[164]

There is also this EU-funded project, the PALLIAKID project. This multicentric project includes several countries (Belgium, Denmark, Finland, Italy, Latvia, Romania, Spain, the Netherlands, the United Kingdom and Turkey) and is coordinated by a Spanish team from the *Sant Joan de Déu* Children's Hospital in Barcelona. The study aims "to evaluate the feasibility, effectiveness, and cost-effectiveness of novel interventions for children, adolescents and young Adults (AYAs) with palliative and end-of-life care needs in different healthcare systems across Europe, with a focus on those factors that influences the active patients' and family caregivers' engagement".[165] The protocol has been registered and the study is expected to commence in 2026.

7.3.4.2 Models of research organisation

In addition to individual research projects, PPC research is coordinated at a macro, often national, level in four countries: the United Kingdom, the Netherlands, Canada, and Australia. Each country has adopted a specific organisational model for coordinating research activities. This section focuses on these organisational structures (rather than on the existing individual studies).

National coordination of PPC research has been recently strengthened in the **United Kingdom** through several organisational mechanisms.[166] First, the UK Collaborative Paediatric Palliative Care Research Network (*CoPPAR*) was established in 2022 as the first UK-wide mechanism to coordinate PPC research across hospices, NHS services and academic partners. It operates as a collaborative network rather than a centralised institute. Its main functions include developing shared research priorities, supporting multi-site funding applications, delivering educational webinars and research toolkits, fostering mentorship and research nurse networks, embedding patient and public involvement. CoPPAR primarily addresses fragmentation and capacity-building across the sector.[166,167] Second, the National Centre of Excellence for Paediatric Palliative Care, based within the Cicely Saunders Institute at King's College London, provides academic leadership for paediatric palliative care research. Unlike CoPPAR, this Centre conducts original research, develops outcome measures (e.g., C-POS), supports doctoral training, and seeks to influence national policy and standards of care.[168–170]

In the UK, the model combines a research network (coordination, capacity-building) and a national academic centre (high-level research, leadership and involvement in clinical and policy decisions).

In the **Netherlands**, the *Kenniscentrum Kinderpalliatieve Zorg Kenniscentrum Kinderpalliatieve Zorg* (National PPC Knowledge Centre) acts as national coordination on PPC, including research activities. There was a need to establish a single central hub, where all enquiries, research activities, and strategic agendas could be coordinated, because research efforts were dispersed across (academic) centres, which limits their scale, focus, and impact. A unified centre of expertise would enable all

academic hospitals to contribute their research agendas to a common structure, thereby strengthening coordination, critical mass, and the overall development of the field. (Source: Interview with the Dutch expert) Therefore, the *Kenniscentrum* functions as an independent national knowledge broker and facilitator (without being an academic research unit). Its activities include:

- initiating and coordinating research projects in collaboration with universities and clinical teams,
- contributing to evidence-based national guidelines,
- participating in national funding programmes (e.g., via *ZonMw*),
- contributing to European research initiatives,
- maintaining platforms that disseminate ongoing and completed research.

It also developed a national research agenda (*Kennisagenda Kinderpalliatieve Zorg*), formally submitted to the Ministry of Health.

The centre participates in the *KennisHub Palliatieve Zorg*, a national platform which brings together ongoing and completed research projects. This facilitates access to the data for researchers, decision-makers, and other professionals. The *Kenniscentrum Kinderpalliatieve Zorg* (National PPC Knowledge Centre) in the Netherlands focuses on coordination, guideline integration and knowledge translation, in a really well nationally structured system that includes practice, research and collaboration with the government.[171] (Source: Interview with the Dutch expert)

Canada's federal healthcare system has fostered a decentralised approach to PPC research, coordinated through pan-Canadian alliances and networks that link stakeholders across provinces, harmonise terminology, and support multi-site studies. The Canada's Pediatric Palliative Care Alliance plays a central role in national system-level research. Its research activities includes:

- a systematic review of PPC at the health system level;
- a qualitative cross-country mapping study of service organisation,
- a Delphi project to harmonise PPC terminology,
- plans for a national PPC registry to inform policy planning and development.[80]

A particularly practical example is the Core Care Pathway for Pediatric Palliative Care, developed by the Canadian Pediatric Palliative Care Alliance. This pathway provides a structured approach to delivering PPC across hospitals, homes, hospices, and community settings, supporting children and young people with serious illnesses, their families, and the healthcare professionals who care for them.[27]

In parallel, PedPalASCNet (a Network for Accessible, Sustainable and Collaborative Research in Pediatric Palliative Care) facilitates interdisciplinary, multi-site research on PPC and end-of-life care. The network promotes standardised definitions, supports collaborative projects, and generates evidence, while connecting clinicians and researchers to strengthen links across Canadian PPC institutions.[172]

In Canada, the organisation of healthcare across federal, provincial, and territorial jurisdictions has led to a reliance on pan-Canadian alliances and research networks to harmonise terminology, map service provision, and facilitate collaboration across multiple jurisdictions.

In **Australia**, PPC research is embedded within the National Action Plan for Paediatric Palliative Care which explicitly includes research and data components, such as:

- a national prevalence study,
- development of outcome measures and benchmarking,
- the establishment of a national Research Cooperative Group.[83]

The 2023 report "Paediatric Palliative Care Need in Australia" modelled national PPC need based on regional epidemiological data, providing one of the first national quantitative estimates of service requirements.[173]

Academic groups (e.g., Cancer and Palliative Care Outcomes Centre (QUT) contribute to symptom management, service optimisation and outcome measurement in children and youth. This centre contributes to a national research base which aims to optimise care practices and models, although PPC is not always their exclusive focus.[174] There is a policy-embedded research model in Australia, where epidemiological modelling and outcome measurement are directly linked to national planning and benchmarking.

Data reporting in the Australian National Action Plan

In Australia, the PPC National Action Plan explicitly identifies data and research as a core priority, highlighting the need for paediatric-specific outcome measures, a national minimum data set, and benchmarking to standardise collection and support evaluation, service improvement, and evidence-based policy. In this context, the November 2023 report *Paediatric Palliative Care Need in Australia* provides a first national overview of the extent and type of needs, highlighting the importance of robust, population-level data to inform service planning, resource allocation, and timely access to care. It aims to build a robust evidence base, strengthen accountability, and improve the quality, safety, and consistency of PPC delivery across Australia.[173,175,176]

7.3.5 Access to care[k]

7.3.5.1 Law and National Plan on PPC

Several countries (Italy, Australia, the Netherlands, Spain/Catalonia) have developed legal frameworks or strategic plans to structure and support PPC. Italy stands out with a **legislative approach**. Law No. 38/2010 establishes a legal right to access palliative care and pain management, explicitly including children. It recognises the specificities of PPC, such as unpredictable disease trajectories, ethical complexities related to parental decision-making, limited availability of child-appropriate medications, and the significant emotional impact on families. While implementation is decentralised at the regional level, the law provides a strong framework that anchors PPC as a healthcare right.[64]

Australia has adopted a **National Action Plan** (launched in July 2023): "The Paediatric Palliative Care National Action Plan is a roadmap for a national approach to prioritise and work towards common goals and objectives for paediatric palliative care".[83] The Action Plan is structured around four interrelated priority domains: quality of care, access to services, information sharing and collaboration, and data, evidence, and research. A key strength lies in its emphasis on equity, both geographical (addressing rural and remote areas) and cultural (ensuring culturally safe care for Aboriginal and Torres Strait Islander populations and other underrepresented groups). The Australian approach is structuring care around the life course (rather than only end-of-life), and embedding community-based care and outreach education to strengthen local capacities.[83,176]

The Netherlands provides an example of a **nationally coordinated policy agenda**, the *Landelijke Werkagenda 2023-2026*, co-developed by a wide range of stakeholders including public and local authorities, insurers, healthcare professionals, and (representatives of) patients and families. This agenda is grounded in identified bottlenecks experienced by children, families, and professionals, and translates these into actionable priorities and it is built around four key pillars: organisation of care and daily life, accessibility, financing, and knowledge and expertise. The *Kenniscentrum Kinderpalliatieve*

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[k] This section does not address the funding and reimbursement of care, nor the tools used to identify children in need of palliative care; the latter topic is discussed in a separate chapter.

Zorg (National PPC Knowledge Centre) coordinated stakeholder input, synthesised best practices, and ensured that the plan reflects the real needs of children, families, and professionals.[177,178]

In Spain, the Catalan Parliament has discussed a **draft law** on PPC (the document is currently under preparation). The initiative originated from the input of families, healthcare professionals, and advocacy groups, including PEDPAL. The proposed law is intended to establish a right to comprehensive PPC, encompassing 24/7 home-based services, multidisciplinary support, and bereavement care, with attention to dignity, equity, and the best interests of the child. Although not yet enacted, this initiative formalises objectives that have previously been addressed.[108]

In England, Integrated Care Boards (ICBs) have a statutory duty under the Health and Care Act 2022 to commission palliative and end of life care services for people of all ages within their local integrated care systems. Importantly, this is not an obligation for ICBs to deliver these services directly, but rather a responsibility to plan, organise, and fund them (i.e., a commissioning duty) within the local health and care system.[179]

7.3.5.2 Organisation of care: local, regional or national networks

The following examples provide insights on **network organisation (patient-level)**.

- In the UK, Managed Clinical Networks (MCNs) link hospitals and specialised services to deliver high-quality care, particularly for rare or complex conditions in a geographic region. MCNs emphasise clinical coordination, leadership, and performance monitoring, with multidisciplinary collaboration primarily within the medical and paramedical domain.[180]
- In Switzerland, Paediatric Advanced Care Teams (PACT) are specialised, interdisciplinary mobile PPC services that operate in a consultative way, providing support to primary care providers and hospital teams involved in the care of children with life-limiting conditions. In addition, PACT teams may also deliver direct care to patients in situations requiring specialised palliative expertise or enhanced psychosocial support. They also coordinate care across settings (hospital, home and community). IMPACT teams, by contrast, reflect a more integrated and system-oriented approach to PPC. Their role often extends beyond direct clinical support to include network-building, service development and the facilitation of collaboration between settings.[45,181–183]
- In Ontario (Canada), the Pediatric Oncology Group of Ontario (POGO) provides coordinated care for children with cancer, encompassing supportive and palliative care throughout the illness trajectory. The POGO Pediatric Interlink Community Nursing Program offers home-based nursing support, care coordination, and guidance for families, linking them with hospital teams, local physicians, and community resources. Nurses assist with symptom management, treatment navigation, and psychosocial support, ensuring continuity of care across settings. While POGO primarily focuses on paediatric oncology rather than all life-limiting conditions, its community nursing model reflects principles of case management and enables children to receive specialised support at home, integrated with hospital and regional services.[184,185]

These models share operational principles with Belgium's paediatric liaison teams, regarding multidisciplinary coordination and integration between hospital and home care.

The following examples from the Netherlands and Switzerland illustrate **coordinating networks** in PPC. In the Netherlands, the *Netwerken Integrale Kinderzorg* (NIK) are regional, multidisciplinary networks designed to coordinate and integrate care for children with complex or life-limiting conditions. These networks bring together stakeholders across hospital, community, home care services and social care sectors to facilitate collaboration across medical, psychosocial, and educational domains and to improve continuity of care (rather than functioning as direct clinical service providers). Their role is primarily organisational, focusing on aligning services, supporting care planning, and enhancing communication between professionals and institutions involved in a child's care.[186] Each NIK has an independent coordinator employed by the PPC centre and is connected to hospital services through the Kinder Comfort Teams (PPC-teams providing care in the hospitals and acting as bridges with

home care). This model has a high level of standardisation (shared methods used), resulting in a high degree of consistency in practice across the country. (Source: Interview with the Dutch expert)

In Switzerland, the Paediatric Palliative Care Network Schweiz (*PPCN Schweiz*) is the national coordination network for PPC. It connects university hospitals, regional hospitals, hospices, and local care teams. The network is designed to reflect the full spectrum of the care system, including hospital services, outpatient home care providers, volunteer-based organisations, and specialists in psychology, and education. It also integrates chaplains, social workers, funeral directors, bereavement support workers, and researchers. *PPCN Schweiz* develops and disseminates national guidelines, protocols, and best practices, while facilitating knowledge exchange and professional collaboration across healthcare teams. Although it does not provide direct care to children, the network plays a central role in coordinating services, supporting regional teams, and promoting continuity and multidisciplinary integration, by aligning practices at the national level while allowing local adaptation.[62] (Source: Interview with the Swiss expert)

Other mechanisms exist for coordinating or identifying children requiring. In Spain, palliative care is organised according to a territorial model. In each region, a nurse is dedicated to children with chronic complex conditions, and the established adult palliative care network is used to support primary care paediatricians. Identification of these children is primarily carried out by primary care professionals, while hospitals can only make recommendations. As a result, hospital-based professionals may contribute to or co-lead the individualised care plan, but they are not responsible for initiating it. Regular multidisciplinary meetings are also held within each area to plan care and determine which patients will be managed at primary care level or within specialised PPC units.[187] (Source: Interview with the Spanish expert)

In Canada, care delivery is shaped by partnerships between specialised PPC teams and community providers, based on willingness and local engagement. This model is inherently capacity-building: community professionals contribute according to their existing skills, while specialist teams provide mentorship, coaching, and ongoing support to expand competencies over time. Relationship-building is central to this approach, with practices such as in-person meetings in family homes and “warm handovers” facilitating trust, reducing anxiety, and clarifying roles among families and care providers. Continuous communication through phone calls, messaging, and informal exchanges further reinforces this collaborative framework. However, the effectiveness of this partnership-based model remains uneven, as it depends heavily on the availability, readiness, and geographic proximity of local providers. This system is grounded in flexibility, local initiative, and relational care. It was also mentioned during the interview that the development of more structured imitative may rely on local “champions” who initiate and sustain services through personal commitment and professional networks. (Source: Interview with the Canadian experts) Other countries also value this type of model.

7.3.5.3 A coordinated approach to paediatric palliative care across settings: the Kentown model, in the UK

PPC in the UK is traditionally delivered through fragmented services with limited coordination. The Kentown Model, developed through the charity Kentown Support, is an approach to PPC designed to reshape how children with life-limiting conditions and their families are supported, by integrating and coordinating services more effectively around the needs of the child and family. A central feature of the model is the establishment of structured coordination mechanisms that align hospital services, hospice provision, and community care already existing in the community into a more coherent care pathway.[188]

A key characteristic of the model is its modular and flexible design. The Kentown Model provides a set of interlinked components of support that can be adapted according to the evolving needs of each family. The programme includes integrated community-based support services, such as clinical care and PPC education within local teams (community children’s nurse), practical and emotional home-based support such as transport, school pickups, and activities for siblings (family support workers), structured psychological and bereavement support for children and families, including sibling-focused

interventions (therapeutic counsellors), and coordination and navigation of local services, financial assistance, and equipment access (care navigators/coordinators). Importantly, these elements are not delivered as a standardised bundle but are adjusted dynamically over time. The principal innovation of the Kentown Model does not lie in the creation of new types of services, but in the systematic integration and coordination of the ones existing in the community.[189] An evaluation of the pilot project showed that "the Kentown model filled a critical gap in statutory provision by offering holistic support, relational continuity, and earlier access to palliative care than families had previously experienced".[190] This programme is being evaluated, including a health economic evaluation. (Source: Interview with the British expert)

7.3.5.4 Case management in Germany

In Germany, *Bunter Kreis* provides **case management** to children with life-limiting or complex chronic conditions. The organisation provides each child and family with a dedicated case manager, typically a specialised nurse or trained professional, who coordinates all aspects of care across settings, including hospital, home, community services, and hospice when available. The case manager ensures continuity of care, integration of medical, psychosocial, and educational support, and guidance through administrative processes, while also providing family-centred support throughout the illness trajectory, including end-of-life care. *Bunter Kreis* emphasises individualised follow-up, tailoring interventions to the specific needs of each child and their family.[191]

Elements of case management are also found in certain teams in the UK (clinical nurse specialists or coordinators within hospices or hospital services) and Switzerland (see above).

7.3.5.5 Care pathway and standards of care: examples from UK and Canada

In Canada, the **Core Care Pathway for Paediatric Palliative Care** outlines key stages from diagnosis to end-of-life and bereavement, promoting the early integration of palliative care and continuity across settings. It emphasises multidisciplinary collaboration, advance care planning, symptom management, psychosocial support, and family-centred care. The pathway also supports coordination between hospital, community, and home-based services, while clarifying roles and responsibilities among professionals. It aims to enhance consistency, quality, and equitable access to care, providing a structured framework to guide clinical practice and service organisation.[27]

In the UK, PPC is guided by **national standards, clinical guidelines, and quality frameworks**. These include documents such as the NICE clinical guideline and quality standard on end-of-life care for infants, children and young people, service specifications for palliative and end of life care in children and young people, standards framework for children's palliative care, Guide to Children's Palliative Care, or the Ambitions for Palliative and End of Life Care - National Framework for local action 2021-2025 committing to improve personalised palliative and end of life care for people of all ages.[192–197] These documents outline expectations for timely access to care, symptom management, family-centred approaches, psychosocial support, and multidisciplinary coordination. They are designed to support clinical judgement, ensure consistency in the quality of care, provide measurable standards for auditing and improvement or set out core care pathway standards and quality markers intended to support service development and benchmarking.There is also the "Toolkit for palliative care needs in children" (Together for Short Lives), an evidence-based framework designed to support professionals in identifying and assessing the palliative care needs of children and young people. It uses a holistic, multi-domain approach covering physical, emotional, social, spiritual, and practical needs. The toolkit supports the recognition and prioritisation of needs according to level of urgency and complexity.[198]

In contrast to comprehensive, longitudinal PPC pathways, some centres have implemented more targeted referral-based approaches. For example, in Switzerland (Zurich), the team established a clear pathway to PPC by developing referral criteria for paediatric cardiac patients in collaboration with the hospital's paediatric cardiology team. They agreed on five specific diagnoses for which referral to PPC is mandatory. (Source: Interview with the Swiss expert) A similar approach is used in Canada: once

certain predefined diagnoses are confirmed, this automatically triggers contact with the PPC team. (Source: Interview the Canadian experts)

7.3.5.6 *Paediatric nursing care in the community (Germany, Switzerland and the Netherlands)*

In Germany, PPC at home is available under the *Spezialisierte ambulante Palliativversorgung* (*SAPV*) framework. This entitlement, covered by statutory health insurance, allows children with complex life-limiting conditions to receive specialised palliative nursing care at home at home, including symptom management, care coordination, psychosocial support, and 24/7 availability by qualified teams when prescribed by a physician. SAPV teams include nurses with advanced palliative care training who work alongside physicians and local home care providers to ensure continuity and integration of care. In addition, medical care is provided by paediatricians from the community.[199,200]

In Switzerland, paediatric palliative nursing at home is provided primarily through *KinderSpitex* services, which specialise in home care for children. These nurses work in close collaboration with hospital-based paediatric palliative teams, regional networks such as PACT/IMPACT, and the Paediatric Palliative Care Network Schweiz (*PPCN Schweiz*) (see above). They deliver clinical care, symptom management, family support, and care coordination at home. *KinderSpitex* is a central component enabling children to receive expert care in their home environment.[201]

In the Netherlands, there is a well-structured system of paediatric home nursing, with most children receiving palliative care at home and hospitals being used only intermittently for children with life-limiting or complex chronic conditions. The care is provided at home from paediatric home care nurses (*kinderverpleegkundigen*), working with hospitals, hospices, and regional networks such as the *Netwerken Integrale Kinderzorg* (NIK). These nurses provide clinical care, symptom monitoring, family support and coordination with other professionals. Care responsibilities are shared within the care team rather than handled by a single case manager.[202]

In the UK, there are also trained community children's nurses. (Source: Interview with the British expert).

7.3.5.7 *Dedicated facilities for PPC: examples from Spain*

In Spain, several innovative initiatives address the needs of children with complex or life-limiting conditions through specialised care environments. *Casa de Sofía*[l], operated by *Hospital Sant Joan de Déu* in Barcelona, is an intermediate care facility designed for children with rare, highly complex or advanced illnesses. The model is inspired from the hospices model. It provides a setting between acute hospitalisation and home care, offering continuous clinical support, symptom management, therapeutic respite for families, and preparation for home care in a welcoming, family-centred environment. The centre helps stabilise health conditions, supports recovery and provides specialised counselling when required. Although highly specialised, it offers a more appropriate setting for delivering care, ensuring continuity and better alignment with patients' needs (when children and families may sometimes feel that an acute hospital is not the most suitable environment for their care).[203]

The *Unidad de Atención Integral Paliativa Pediátrica* (*UAIPP*) at the *Hospital Infantil Universitario Niño Jesús* in Madrid is a comprehensive PPC service integrated into the regional public health system. It offers multidisciplinary care in hospital, outpatient and home settings, coordinating clinical, psychosocial and educational support for children with life-limiting conditions and their families. The UAIPP emphasises continuity of care across settings, professional training, research and the

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[l] Sofia's House includes four beds dedicated to children in a highly acute phase, allowing for short admissions (typically five to six days) either directly from home or following hospital care; established four years ago, the service now comprises 15 beds in total, including provision for end-of-life, subacute, and post-acute care, delivered by a team familiar with the patients and able to provide more tailored support.

development of broader paediatric palliative networks. It has achieved formal recognition for excellence in PPC, validating its quality and integration within the health system.[204]

The Comprehensive Paediatric Palliative Care Centre (*Centro de Atención Integral de Cuidados Paliativos Pediátricos (CAPPI)*), promoted by the Fundación *porqueViven* and expected to open in Madrid in 2026, represents the first social and health resource of this kind in Spain. *CAPPI* is conceived as a complementary facility to existing hospital and home services, designed to provide structured family respite, integrated social and health coordination, hands-on training for caregivers, and specialised therapeutic environments. It includes day care, family respite beds, therapy spaces, education units and dedicated end-of-life areas, all structured to support both children and their families holistically. The model emphasises continuity, human-centred care and networking with primary, hospital and community services and is intended as a replicable model for other regions.[75,205]

7.3.5.8 Hospital reference centres: examples from Germany and Switzerland

The *Kinderpalliativzentrum Datteln* (Germany), part of the *Vestische Kinder- und Jugendklinik Datteln* is a specialised PPC centre for children, adolescents, and young adults with life-threatening or life-limiting conditions. In addition to its dedicated palliative services (including eight PPC-dedicated beds and seven parents' apartments), the hospital provides a full range of paediatric surgical care, enabling children to receive necessary interventions for symptom relief, management of complications, or supportive procedures within the same facility. The centre includes the *"Lichtblicke"* ward, Germany's first dedicated paediatric palliative inpatient unit, offering multidisciplinary care encompassing clinical management, psychosocial support, and family-centred interventions.[206] Beyond inpatient care, the centre delivers specialised ambulatory palliative services under the German statutory framework (SAPV – see above), allowing structured home-based support in collaboration with other healthcare providers. It also serves as a hub for research, education, and quality assurance in paediatric palliative medicine, holding national and international certification for its structure and processes. This integrated model ensures continuity of care across clinical, surgical, and home settings while combining expertise in palliative and specialist paediatric care.[199,207–209]

At the *Kinderpalliativzentrum Datteln* (Germany), the *LichtHafen* functions as a specialised paediatric surgical unit integrated within the palliative care centre. It provides children and adolescents with complex or life-limiting conditions access to necessary surgical and diagnostic interventions without the need for transfer to other hospitals. The unit accommodates procedures across multiple paediatric surgical specialties, with full anaesthetic support, all delivered in a child-centred environment designed to minimise stress and support families. By combining advanced surgical capability with the centre's palliative care services, *LichtHafen* ensures continuity of care, symptom management, and holistic support within a single coordinated setting.[210]

The *Universitäts-Kinderspital Zürich* (Switzerland) provides comprehensive PPC within a tertiary children's hospital offering highly specialised medical and surgical services. The Competence Centre for Paediatric Palliative Care supports children with life-limiting conditions and their families across hospital, long-term care, and home settings, in collaboration with local services such as *KinderSpitex* (see above). Multidisciplinary teams, including physicians, nurses, psychologists, social workers, and allied health professionals, deliver symptom management, psychosocial support, care coordination, and family guidance, ensuring continuity of care. By integrating advanced clinical and surgical expertise with holistic palliative care, the centre addresses the full spectrum of needs of children with complex conditions and their families.[211,212,212,213]

7.3.5.9 Tools or ways to support care delivery[m]

In the Netherlands, the *Individueel Zorgplan* (IZP) is a structured, personalised care planning tool to support children with life-limiting or complex conditions and their families. It provides a comprehensive,

[m] Identification tools (such as PaPaS and ACCAPED) are presented in another chapter.

multidisciplinary framework for assessing needs, agreeing shared goals, coordinating interventions and documenting care delivery across settings. The *IZP* emphasises collaboration between clinicians, specialists, home care nurses and families, ensuring that the child's preferences and family context are central to care decisions. By formalising key aspects such as symptom management, psychosocial support and practical arrangements, the *IZP* promotes continuity, transparency and proactive planning throughout the illness trajectory.[214]

The *Artsensteunpunt Levenseinde Kinderen* (End-of-Life Support for Children Physicians' Service) is a Dutch national support service for physicians involved in end-of-life care for children. It provides clinical advice, ethical guidance and case consultation to doctors facing complex decisions about symptom control, life-prolonging treatment withdrawal, comfort care and communication with families. The service is staffed by experts in paediatric palliative medicine, ethics and law, and is accessible for consultations at critical decision points. By offering evidence-informed and case-specific support, the *Artsensteunpunt* aims to improve care quality, consistency and physician confidence in managing end-of-life situations, while respecting the best interests of the child and supporting family-centred care.[215]

The Serious Illness Conversation Guide Pediatrics© is a structured communication framework designed to support clinicians in having timely, meaningful, and family-centred conversations with children (when appropriate) and their families about serious or life-limiting conditions. The guide helps healthcare professionals explore the family's understanding of the child's illness, elicit values, hopes, fears, and priorities, and discuss goals of care, treatment options, and preferred settings, including home-based or hospice care. In PPC, the guide supports early advance care planning and shared decision-making. It aligns clinical interventions with the priorities of the child and family, promotes continuity across hospital, home, and hospice settings, and reduces communication gaps and stress for families and clinicians. It also ensures that symptom management and care transitions are guided by meaningful outcomes rather than default treatments. In practice, clinicians use the guide during outpatient visits, inpatient consultations, or multidisciplinary team meetings to ask structured questions such as:

- "What matters most to your child and family at this time?"
- "If your child's condition changes, what goals should we prioritise?"
- "What are your biggest worries about the future?"

Responses are then integrated into the child's individual care plan, informing symptom management, resuscitation discussions, psychosocial support, and planning for transitions to adult services.

By fostering transparent, empathetic, and developmentally appropriate communication, the Serious Illness Conversation Guide Pediatrics© strengthens family engagement, improves decision-making, and underpins high-quality, consistent paediatric palliative care across settings.[123,124]

In Australia, the Pop-Up model provides PPC specialist support on an as-needed basis. A "Pop Up" is initiated when local teams require additional expertise, for example during care transitions, clinical deterioration, or complex symptom management. It involves the child and family, local healthcare providers, and the specialist PPC service. Key components include temporary capacity building for local teams, care planning support, and education, delivered in hospital, community, or home settings, with telemedicine used when direct attendance is not feasible. The model aims to enhance continuity of care, family-centred support, and local clinical confidence, ensuring that children with life-limiting conditions receive coordinated, high-quality care tailored to their individual needs and context.[216]

During the interviews, several experts (e.g., from Canada, Australia, and Germany) reported that commonly used communication tools and applications (such as phone calls, simple messaging and FaceTime) were frequently utilised to respond and support parents and professionals, and maintain continuity of contact. They are reported to be often more effective than formal platforms by facilitating accessible, relationship-based communication.

7.3.5.10 A family-centred initiatives

In the Netherlands, the Experience Meter (*Ervaringsmeter*) is a digital tool developed in the Netherlands to systematically capture the experiences and perspectives of children receiving palliative or long-term care, their families and care professionals. It enables regular, structured feedback on care quality, symptom burden, support needs and satisfaction with services, using age-appropriate questionnaires and visual scales. The tool can be used across care settings (hospital, home and community) to monitor outcomes, inform care adjustments and identify areas for improvement. By integrating real-time experience data into clinical practice and organisational learning, the Experience Meter supports responsive, person-centred care and contributes to quality improvement at both the individual and service levels.[217]

During the interviews, the role of parents was highlighted through two examples:

- At the *Kenniscentrum Kinderpalliatieve Zorg* (National PPC Knowledge Centre), there is Patient Advisory Board comprising in particular major patient and advocacy organisations. This Board is actively involved in reviewing and guiding proposed initiatives and has genuine influence over decision-making. (Source: Interview with the Dutch expert
- In Canada, the international *What Matters Most* research project seeks to define "what truly matters" in paediatric palliative care. It is based on the recognition that existing quality indicators do not always capture the aspects of care that are most important to children and families. The project brings together panels of healthcare professionals and families to identify and prioritise meaningful outcomes and indicators of care quality.[218]

7.3.5.11 Online resources and digital tools

In Germany, the *Wegweiser Hospiz- und Palliativversorgung* provides a **national online directory of palliative care services**, including those dedicated to children and adolescents. This platform enables patients, families, and healthcare professionals to identify and access available resources across the country, such as PPC units, hospices, specialised home care teams (SAPV), and regional networks.[219]

The Australian website *PaediatricPalliativeCare.org.au* serves as a comprehensive **resource hub** for PPC, offering a wide range of evidence-based tools, guidelines, educational materials, clinical resources, toolkits and support documents tailored to both health professionals and families. It is designed to facilitate best practice by providing practical resources for clinical care planning, symptom management, communication, ethical decision-making, and family support throughout the continuum of paediatric palliative care. Professionals can access clinical tools, assessment instruments, workforce resources, and training modules, while families can find information for understanding palliative care, preparing for care transitions, navigating care options, and accessing psychosocial support. The site consolidates national and international guidance and exemplars, making it a valuable reference for clinicians, families, policymakers and caregivers.[220] For example, the "Green Book" (a Practical Guide to Palliative Care in Paediatrics - 4th Edition) is a key clinical resource for healthcare professionals. It provides structured tools for assessment, symptom management, care planning, and documentation, promoting consistent, evidence-based, and family-centred care across settings.[221]

Several countries have implemented digital tools to support PPC. For example, in the UK, *My Care Transfer*, developed by the charity Together for Short Lives, is a family-centred digital tool that allows key clinical and personal information to be recorded, shared, and updated across settings, supporting continuity and coordinated PPC. It facilitates secure transfer of clinical information between healthcare settings, supporting continuity across hospital, hospice, and home care.[222,222,223] In the Netherlands, the secure digital platform *MyKinderComfortNet* (*mijnKinderComfortNet*) enables families and professionals to monitor symptoms, communicate with care teams, and access personalised care plans.[224] In Switzerland, the START tool is a structured clinical assessment instrument that supports healthcare professionals in identifying and prioritising paediatric palliative care needs, facilitating appropriate referral and care planning.[183] A neonatal adaptation of the START tool is used to support early identification and assessment of palliative care needs in newborns.[45]

In the Netherlands, the *Registratiewijzer Kinderpalliatieve Zorg*, version 3.0 (January 2025) is a technical guide used in the Netherlands to standardise the documentation and coding of PPC activities for funding and reporting purposes. Developed by the *Kenniscentrum Kinderpalliatieve Zorg* (PPC Knowledge Centre), it defines multidisciplinary care activities, minimum team compositions, and criteria for classifying care events into specific reimbursable care products. The guide ensures consistent registration of hospital-based consultations, clinical admissions, and other interventions provided by paediatric palliative care teams, facilitating accurate cost attribution and reimbursement under the Dutch healthcare system. By providing a structured framework, it supports both clinical teams and hospital administrators in maintaining standardised records while promoting transparency and accountability in paediatric palliative care delivery.[225]

7.3.5.12 Data reporting in the Australian National Action Plan

In Australia, the PPC National Action Plan explicitly identifies data and research as a core priority, highlighting the need for paediatric-specific outcome measures, a national minimum data set, and benchmarking to standardise collection and support evaluation, service improvement, and evidence-based policy. In this context, the November 2023 report *Paediatric Palliative Care Need in Australia* provides a first national overview of the extent and type of needs, highlighting the importance of robust, population-level data to inform service planning, resource allocation, and timely access to care. It aims to build a robust evidence base, strengthen accountability, and improve the quality, safety, and consistency of PPC delivery across Australia.[173,175,176]

7.3.5.13 Transition to adult services: example from Australia

The Australian PPC National Action Plan does explicitly address transition from paediatric to adult services as part of its recommended direction for care planning and service development. In particular, Action 2.1 of the plan proposes the development and implementation of an optimal PPC pathway that includes a transition pathway between paediatric and adult palliative care services. This acknowledges that many children and young people with life-limiting conditions will continue to require care into young adulthood, and that transition should be planned early and managed collaboratively to reduce stress, maintain continuity, and support ongoing needs as care models differ between paediatric and adult teams.[176,220] Additionally, the Shaping the Future of Paediatric Palliative Care Project identifies developing a transition pathway between paediatric and adult palliative care services as a specific focus area. This includes tools and resources to help young people and families prepare for and navigate the move to adult palliative settings.[226] This fully codified national transition pathway is still be under development.(Source: Interview with the Australian expert) Developed in the context of the PPC National Action plan, the “Transitioning to the Adult Health Care System: A Starter Toolkit” provides a structured, practical framework to support young people with chronic or complex conditions, their families, and healthcare professionals in planning and navigating this transition from paediatric to adult services.[227]

In Australia, the tool “Voicing My CHOiCES” is used in adolescent and young adult care. Developed in the United States, it is an advance care planning tool designed to help young people with serious illness articulate their values, preferences, fears, and hopes in a developmentally appropriate way, beyond traditional advance directives. It helps supporting care transitions by ensuring that these preferences are clearly documented and can be carried forward across different stages of care and between services.[228]

7.3.5.14 Experience shared from Canadian experts

The interviews with Canadian experts highlighted two important considerations for paediatric palliative care service organisation: the contribution of paediatric hospices and the suitability of dedicated paediatric palliative care beds for end-of-life care

- **Hospices**: The interview highlights highly positive experiences associated with paediatric hospices, which are described as flexible, home-like environments that function not only as end-

of-life care settings but also as spaces for respite, family support, and continuity of life for children with complex conditions. Beyond their clinical role, these hospices provide a more comfortable and less institutional atmosphere for families, facilitate holistic care across the illness trajectory, and serve as important hubs for grief and bereavement support. Interviewees strongly emphasise their value within the paediatric palliative care system, underscoring the hospice model as a meaningful and essential component of care delivery. (Source: Interview with the Canadian experts)

- **PPC-beds**: The interviewees reported that dedicated paediatric palliative care beds (referred to as "family suites") within hospital settings are not always well suited for end-of-life care. Families often develop a strong attachment to the original care environment and therefore prefer to remain in the unit where their child has been cared for, even at the end of life, due to feelings of familiarity and comfort. Paediatric hospices are described as particularly well suited to fulfil this role, offering a more home-like and less institutional environment designed to support both children and families throughout the disease trajectory, including end-of-life care. (Source: Interview with the Canadian experts)

7.3.5.15 Models of care

The organisation of healthcare systems and the models of paediatric palliative care delivery (i.e., at a system level) were not the focus of this section on identification of initiatives across the eight selected countries. Nevertheless, several broad observations can be made. Across the countries examined, PPC is generally organised through **network-based models** involving close collaboration between tertiary hospitals, a limited number of specialised PPC teams (typically linked to university hospitals or centres of expertise), and community-based care delivered in the home setting. Some variations exist between countries. These include the presence and role of paediatric hospices; the missions, composition and level of specialisation care teams (some include home paediatric nurses, or are trained on an "ad hoc' purpose); the existence of intermediate care structures (as observed in Spain); the organisation of education and training for healthcare professionals (e.g., PPC is a recognised subspeciality); the development of support networks extending beyond healthcare services (particularly in the United Kingdom and Germany); and whether initiatives are primarily driven by hospital-based services (e.g., Germany and Spain) or community-based organisations (e.g., the United Kingdom). The expert also highlighted during the interviews that PPC is organised through care models that account for the **complexity** of the clinical situation and the corresponding level of care specialisation required. These models are designed to ensure that PPC is initiated at the time of diagnosis and to promote equitable and universal access, irrespective of age, diagnosis, or geographic location. Care is delivered primarily in the patient's home whenever feasible, within a family-centred framework that addresses the holistic needs of the child and their family. Mechanisms are in place to ensure continuity of care across services, including provision of 24/7 support. (Source: interviews with the experts) Because the aim of this section on foreign initiatives was not to identify and present care models that could be implemented in Belgium, these models were not developed further.

7.3.6 Siblings

Among the countries we investigated, several programmes support siblings of a child in a palliative situation, and where hospices exist, they all offer siblings support. A central component of the programmes is the psychosocial and developmental support, aiming at emotional expression, understanding of illness, and mitigation of psychosocial distress. These programmes are therapeutic in nature to help them deal with their emotions and their anticipatory grief over their sibling's illness. The programmes such as the National Centre for Childhood Grief (Australia) and the S.I.B.S. (Spectacular Incredible Brave Siblings) programme (Roger Neilson Hospice, Ottawa, Canada) provide age-appropriate emotional support, safe spaces for asking questions about illness and death, structured activities (e.g., recreation therapy, music therapy, drawing, play, guided discussion), preparation for illness progression and end-of-life.[229,230] Similarly, UK hospice-based programmes, such as Demelza Hospice Care for Children and Rainbows Hospice for Children and Young People,

offer a combination of group-based peer interactions, individual therapeutic sessions, recreational and creative activities.[231,232] These interventions address complex emotional responses reported in siblings (e.g., fear, anger, jealousy, guilt), while also promoting normalisation through peer contact. Importantly, play and creative modalities are included as essential components. Across programmes, peer interaction between siblings emerges as a core way to support the siblings. This is implemented through group sessions (e.g., Spectacular Incredible Brave Sibs (S.I.B.S) programme in Canada), sibling days or camps (UK hospices, Germany's sibling programmes such as *SiSBrojekt* or *GeschwisterClub*), community-based initiatives.[233–235], In the Kentown programme (Great Manchester, UK), the support is essentially provided at home. (Source: Interview with the British expert)

In many programmes, the support is provided across the sibling's illness trajectory, from diagnosis, throughout disease progression, into bereavement. For example, the sibling support of the Forget Me Not Children's Hospice (UK) begins early (sometimes at diagnosis or even antenatally), continues during the child's illness, extends into bereavement without a predefined time limit.[236] Comparable continuity is observed in Rainbows Hospice for Children and Young People (UK), where follow-up may continue for several years after death. These programmes take into account that siblings may experience anticipatory grief prior to death, ongoing bereavement needs afterwards, long-term psychosocial impacts.[232]

In the UK, the Because We Care project was a collaborative initiative involving a group of siblings aged between seven and ten, who worked with a research team, an artist, a filmmaker, and a facilitator of philosophical dialogue. They met over five weeks to explore philosophical ideas related to health and care, and produced a short film, a podcast, and a booklet.[237]

Beyond individual support, many programmes adopt a family-centred approach, including all family members, so whether it's a child, parent or grandparent. For example, The National Centre for Childhood Grief (Australia) provides guidance to parents on communicating about end-of-life and including siblings appropriately.[229] In the UK, hospices such as Haven House Children's Hospice emphasise collaboration with families, schools, and healthcare providers and Zoe's Place Baby Hospice (becoming Little Lights) provides family-centred support aimed at sustaining family routines, strengthening relationships, and enhancing quality of life.[238,239] Several programmes extend beyond the nuclear family to include grandparents, schools (e.g., Dutch guidelines addressing educational impact), healthcare professionals, community organisations and networks. (Source: Interview with the Canadian experts)

In contrast to direct service provision, some programmes focus on transforming professional practices and systems of care. For example, the Dutch *Broers en zussen Boost Project*, supported by the *Stichting Kind en Ziekenhuis* acknowledges that attention is often focused on the ill child, and that siblings frequently suppress their own needs and are insufficiently included in care processes.[240,241] Through a range of tools, it aims to inform HCP and promote sibling inclusion in healthcare settings. Resources such as the *Brussen Visiedocument* (the Netherlands) and related tools (e.g., *Brussen Boek*, *Brus Beweging*) provide frameworks for recognising siblings' needs, practical guidance for healthcare and educational professionals, recommendations for communication and support.[242–244] Similarly, UK hospice descriptions (e.g., Forget Me Not Children's Hospice) note that siblings may miss typical childhood experiences, hide emotions to protect parents, experience school-related difficulties.[245]

Another modality consists of information platforms and psychoeducational tools for siblings, parents, and professionals. For example, the Dutch platform "*Hou me vast*" provides age-adapted information, emotional guidance, and practical tools (e.g., activity boxes for families).[246] The Swiss initiative *Verein Raum für Geschwister* ("*Du bist dran*!") functions as a resource hub, mapping existing services and enhancing accessibility.[247] These interventions are not therapeutic programmes; they but aim to improve understanding of the sibling experience, facilitate communication within families, and increase visibility and access to support.

7.4 Interview guide

This interview guide served as a template for discussions with experts in each country. Prior to each interview, it was adapted to reflect the initiatives identified through the document review. Questions and points requiring clarification were also incorporated into the guide to ensure that country-specific issues could be explored in greater detail.

Country

1. **Introduction: Who's who?**

   1.1. Presentation of the team & the KCE project

   Purpose of the interview: to understand innovative initiatives and key challenges in PPC in the country, and to identify lessons learned and good practices.

   1.2. Presentation of the national expert

   Could you briefly introduce yourself? (role, institution, experience in PPC)

2. **General context of PPC in the country – to understand the organisation**

   2.1. Care model (general topic)

   - **Can you briefly explain how PPC is organised in your country? → Can you briefly explain the type of services providing how PPC and how they articulate together?**
     - How do they manage the awareness of health centres/regional hospitals
     - How is PPC integrated into primary care (GP, nursing/home care)?
     - How is PPC organised outside the hospital setting?
     - How do they avoid overlapping services?
   - **How is access to PPC ensured for those who need it?**
     - Financing of providing PPC, especially home care – time consuming → *what kind of financing (fee for service? lump-sum/capitation payment? pay for time? If so: by episode, for a period, for the "whole time of the disease"?)*
     - List of recognised acts? (including psychological support when not done by a psychologist?)
     - Geographic?
     - Are there gaps in infrastructure? (dedicated units, beds, respite houses, medical equipment)
   - **What innovative PPC model exist in your country?** (e.g., paediatric units, mobile teams, hospital-based care, home-based care, paediatric hospices) → focus on access to care

   2.2. Target population

   - **Who are the children eligible for PPC**/What are the profiles of children considered to be in a palliative situation? (types of conditions, age ranges, transition issues)
   - **TOOL: How do you identify children who need PPC?** Which tool(s) do you use? Why do you use it/them (or not)?

3. **Innovative initiatives /good practices in PPC**

   3.1. Access → see above

- **How is the PPC coverage?** (estimated percentage; in which settings: hospital, home, hospice, etc.)
  - What is done to try to extend the access (if relevant)

3.2. Education and training

- How is training organised HCP in PPC, including the different levels of specialisation?
  - *Do all HCP (physicians, nurses) have basic knowledge during their studies?*
  - *Only specialised nurses (ped nurses), paediatricians have all training*
  - *Some of the specialised have a basic training or advanced training?*

3.3. Siblings

- What (innovative) project exist to support siblings of a child requiring PPC?
  - How are they perceived by the families themselves?

3.4. Psychosocial support (child and family): how is it integrated in the PPC (if so)?

(psychologist, child psychiatrist? → only when medication needed?)

3.5. Spiritual care: how is it integrated in the PPC (if so)?

3.6. Research

- How is research about PPC organised in your country? (e.g., Is it centralised or do specific fundings exist?)
  - What research initiatives exist in PPC? (projects, partnerships, publications)

3.7. Awareness (advocacy)

- Initiatives/projects to improve the awareness of PPC in the general population? How are taboos on childhood death/resistance to discussing end-of-life issues addressed?

3.8. Resources and tools

- Are there technological innovations? (telehealth, mobile apps, artificial intelligence, virtual reality, etc.)

4. Key drivers and lessons learned:

- From your perspective, what are the key drivers that have significantly improved access to PPC in your country?
- Are there any “success stories” or initiatives that have worked particularly well that you would like to share?

5. Recommendations

- If you were to advise another country looking to strengthen access to PPC, what would you recommend? (policies, training, care models)
- What pitfalls should be avoided?

6. Conclusion

6.1. Summary

- Key points
- Anything you would like to add?

6.2. Next Steps

- Explain how the information will be used in the report
- Thank the participant

8 ANALYSIS OF THE CONSULTATION OF PATIENT ASSOCIATIONS

8.1 Context

This survey was carried out in early January 2026, alongside the Lime Survey questionnaire (see Section 4) administered to healthcare professionals not specialised in paediatric palliative care.

8.2 Aim

To collect opinions of patients' associations on the good moment and good manner to offer access PPC.

8.3 Methods

Participants: Head of any association representing children and/or young adults (up to 25 years of age) living with life-limiting conditions, as well as their families.

The aim of our questionnaire is to obtain an overview of the expectations of the individuals represented by each association regarding access to paediatric palliative care in Belgium for children and young people living with a life-limiting condition.

List of associations invited to participate in the consultation (n = 46; 26 Dutch-speaking and 20 French-speaking associations).

List of the patients' associations invited to participate by email.

Association
ZOI = *Zelfhulp Osteogenesis Imperfecta*
Duchenne Parent Project Belgium
Mucovereniging
Belgian organisation for patients with primary immunodeficiencies
Lymfklierkanker Vereniging Vlaanderen
Werkgroep Hersentumoren
Leuvense Levertransplanten vzw
Hepatotransplant-Gent
Patiëntenvereniging longtransplantatie UZ Leuven
Von Hippel Lindau België
Vereniging voor Spina Bifida en Hydrocephalus
Ichthyosis België
RaDiOrg
Spierziekten Vlaanderen
Oudervereniging Nierpatiëntjes
Vlaamse Vereniging voor Ouders van Couveusekinderen

Hersenletsel Liga
Hartekinderen vzw
B.O.K.S.
KIKOV-Leuven
Missing you
Berrefonds
Tuki
Kleine Prins
Vilomah
Bring a smile
Association francophone belge de l'ostéogenèse imparfaite - afboi
Association européenne contre les leucodystrophies en Belgique
Groupe de soutien des patients atteints du syndrome de Guillain Barré
Association Spina Bifida Belge Francophone
Association Anne-Marie Nihoul
Association belge du syndrome de Marfan
Action Lymphome Wallonie Bruxelles
Kick cancer
Rare disorders Belgium
ABMM
VASCAPA
Une étoile qui danse
Le petit prince a dit
Parents désenfantés
Groupe d'entraide des syndromes d'Ehlers-Danlos
ABeFAO = Association Belge des Familles touchées par l'Atésie de l'Oesophage
Neurofibromatose Belgique asbl
BeCPR – cerebral palsy registrery
LGD Alliance Belgium
Debra Belgium

8.4 Results

Of the 46 associations contacted, 36 did not respond to our invitation email. Three declined to participate, two expressed initial interest but did not follow up, five requested a copy of the questionnaire, and two completed and returned it.

Regarding the question of the initiation of paediatric palliative care, respondents reported an important variation between paediatric palliative situations. They can have the feeling that the parents of severely ill patients do not always understand what is covered by PPC. They often make the link with the end-of-life and they often feel lonely and helpless during the period leading up to the terminal phase. According to respondents, paediatric palliative care is usually initiated when parents are informed that

no further curative treatment options are available for their child and when the paediatric liaison team is established to facilitate and prepare the child's return home. Initiation of paediatric palliative care may also coincide with the introduction of pain management interventions.

Regarding the appropriateness of the timing of the initiation of paediatric palliative care in relation to parents' expectations, respondents indicated that this is a very difficult question, as circumstances vary considerably and depend on a multitude of factors. In their view, this question would be best addressed directly to parents. Nevertheless, parents are often unprepared for the initiation of paediatric palliative care. In many cases, they have not been given a sufficiently clear explanation that palliative care is an available option for their child. As a result, they frequently become aware of this possibility too late, when the child is already in the terminal phase of illness.

Participants were asked to assess the extent to which ten categories of needs (physical, psychological, social, spiritual, developmental, activities of daily living support, information, care coordination, respite care, and adapted communication) influence the initiation of paediatric palliative care (PPC). None of these categories was perceived as consistently triggering the initiation of PPC. Physical needs, support with activities of daily living, and care coordination needs were more frequently identified as factors leading to PPC referral, whereas social and spiritual needs were sometimes perceived as never acting as triggers for PPC involvement. The respondents identified the following measures as likely to improve access to PPC:

- Timely provision of information.
- Avoiding the perception of palliative care as being exclusively associated with end-of-life care.
- Improving understanding of what palliative care entails.
- Better information for families.
- A clear description and ongoing explanation of the full scope of palliative care support.

8.5 Limitations

1. It is difficult to identify, through online searches, the leaders of patient associations and obtain their direct email addresses.
2. Few associations responded to an email invitation sent by the Belgian Health Care Knowledge Centre (KCE) (10/46).
3. Fewer than half of the questionnaires distributed resulted in completed responses and usable data collection.

8.6 Conclusion

A key finding is that the approach of using patient organisations to gather information on access to healthcare allow to get low answer rate. However, it is possible that the subject matter of PPC may have deterred responses. If this is the case, it is an indirect finding pointing to the issue of taboo and/or rejection, given the significant emotional burden associated with the topic, particularly for those who are ill or parents of sick children.

A second conclusion is the reported pervasive association between palliative care and end-of-life care, and the observation that this is the reality in practice, with palliative care often commencing when only a few days of life remain.

A third point is the (perceived) lack of information received by parents about PPC, which is clear in both questionnaires.

A fourth point is the transition period between the end of curative care and the start of palliative care, which associations report as a daunting experience for parents.

A fifth point concerns physical needs, particularly pain, which can be the trigger for palliative care, as reported in the two questionnaires. It is possible that social and spiritual needs play a lesser role in the decision to initiate palliative care.

A sixth point is that assessing whether palliative care was initiated at the right time is a matter for the person experiencing the event and requires directly consulting the parents concerned, which could not be done in this project.

9 ACCEPTABILITY OF PAEDIATRIC PALLIATIVE CARE: A COMPLEX, MULTIDIMENSIONAL CONCEPT

9.1 Methods

9.1.1 Literature searches

This appendix served as input for the elaboration of the chapter on acceptability of PPC and integrated findings from two research questions:

- Research question 2: What are the categories of PPC needs and the difference with acult PC needs categories?

  An scoping search in literature was performed to retrieve (systematic) reviews on factors determining the acceptability of PPC, with a focus on barriers and facilitators related to access to PPC and PPC needs in children, families and HPCs (see chapter 2 in scientific report). The complete results are presented here.

- Research question 3: How can the needs of the close relatives, informal caregivers and professionals not trained in PPC interfere with the access to PPC of children in palliative situations?

  The analysis was conducted using a multi-method approach comprising a targeted literature review of ethical issues and tensions, a theory-informed interpretative analysis, and a stakeholder consultation process with representatives of the Belgian PLTs (more details available in appendix 11). The complete results are presented in appendix 11.

In this appendix two main parts can be distinguished: the first part with the results on the needs and dynamics between the different actors and the second part on potential solutions to improve acceptability in the Belgian context. In the latter only the results from the targeted searches and the proposition of the solutions as presented to the stakeholders are reported. In the chapter on acceptability these literature findings were merged with the input from the stakeholder consultation and findings from the other chapters, to come to a final version of solutions to improve the acceptability of PPC in Belgium. Differences in content and structure may be explained due to this evolving process of further refining and triangulation in the chapter on acceptability.

9.1.2 Literature sources

Table 19 – Reviews regarding child' and family's perspectives

Theme	Reference	Title
Child + family perspective	Young, 2021	Families' experiences of the child and adolescent brain tumor: A systematic review and synthesis of qualitative research
	Castro, 2025	Autonomy in adolescents in palliative care and its biopsychosocial impact: A systematic review
	Duc, 2017	Paediatric palliative care and intellectual disability – A unique context
	Verma, 2026	Mapping the palliative care needs of children with cancer: a scoping review through the bio-psycho-socio-spiritual lens
	Van Teunenbroek, 2024	A dutch paediatric palliative care guideline: a systematic review and recommendations on advance care planning and shared decision-making
	Van Driessche et al (2025)	Characteristics of child development in the context of serious illness: a scoping review

Theme	Reference	Title
	Benini, 2022	Pediatric Palliative Care in Oncology: Basic Principles
	Verma et al. (2026)	Mapping the palliative care needs of children with cancer: a scoping review through the bio-psycho-socio-spiritual lens
	Wei, 2025	Spiritual needs of adolescents with cancer: a systematic review and meta-synthesis
	Winger 2020	Family experiences with palliative care for children at home: a systematic literature review
	Chelazzi, 2023	The adult and pediatric palliative care: differences and shared issues
	Thomas, 2023	Unmet supportive care needs of families of children with chronic illness: A systematic review
	Senanayake, 2025	The Unmet Needs of Parents in Pediatric Palliative Care: A Qualitative Systematic Review
	Clancy, 2020	A systematic review exploring palliative care for families who are forced migrants
	Hamel, 2023	Factors that contribute to bereaved parents' perceptions of neonatal palliative care: A systematic literature review

Table 20 – Reviews regarding HCP perspectives

Theme	Reference	Title
HCP perspective	Reid et al, 2024	Nurses' experiences of providing palliative care for children with life-limiting conditions
	Atout, 2019	Experience of nurses who work with children with palliative care needs: a mixed-method systematic review
	Beltran, 2021	Caring for dying infants: a systematic review of healthcare providers' perspectives of neonatal palliative care
	Schröder, 2024	The needs of healthcare personnel who provide home-based pediatric palliative care: a mixed method systematic review

Table 21 – Literature regarding societal attitude

Theme	Reference	Title
Societal attitude towards the death of a child	Pask, 2018	A framework for complexity in palliative care: A qualitative study with patients, family carers and professionals
	Braybrook, 2025	What constitutes high-quality paediatric palliative care? A qualitative exploration of the perspectives of children, young people, and parents

Table 22 – Literature regarding complexity

Theme	Reference	Title
A family-centred approach to embrace the complexity of PPC (solutions)	Dickens, 2025	Trustful relationships between healthcare professionals and children: a concept analysis using Rodgers' evolutionary approach
	Benini, 2022	Pediatric Palliative Care in Oncology: Basic Principles

Theme	Reference	Title
	van Driessche, 2025	Characteristics of child development in the context of serious illness: a scoping review
	Verma, 2026	Mapping the palliative care needs of children with cancer: a scoping review through the bio-psycho-socio-spiritual lens
	Clancy, 2020	A systematic review exploring palliative care for families who are forced migrants
	Castro, 2025	Autonomy in adolescents in palliative care and its biopsychosocial impact: A systematic review
	Van Teunenbroek, 2024	A dutch paediatric palliative care guideline: a systematic review and recommendations on advance care planning and shared decision-making
	Braybrook (2025)	What Constitutes High-Quality Paediatric Palliative Care?: A Qualitative Exploration of the Perspectives of Children, Young People, and Parents
	Duc, 2017	Paediatric palliative care and intellectual disability – A unique context
	Beltran, 2021	Caring for dying infants: a systematic review of healthcare providers' perspectives of neonatal palliative care
	Schröder, 2024	The needs of healthcare personnel who provide home-based pediatric palliative care: a mixed method systematic review
	Carr, 2021	Factors associated with health professionals decision to initiate paediatric advance care planning: A systematic integrative review
	Pask, 2018	A framework for complexity in palliative care: A qualitative study with patients, family carers and professionals
	Hodiamont, 2019	Understanding complexity- the palliative care situation as a complex adaptive system
	Thomas, 2023	Unmet supportive care needs of families of children with chronic illness: A systematic review

9.2 Acceptability as one of the dimensions of patient-centred access to care

Within the Levesque Framework[248] on patient-centred access to health care, one of the dimensions which determine the accessibility of care, is the dimension on acceptability, defined as:

> *Acceptability relates to cultural and social factors determining the possibility for people to accept the aspects of the service (e.g., the sex or social group of providers, the beliefs associated to systems of medicine) and the judged appropriateness for the persons to seek care. Ability to seek health care relates to the concept of personal autonomy and capacity to choose to seek care, knowledge about health care options and individual rights that would determine expressing the intention to obtain health care.*

As reflected in this definition, the acceptability dimension is determined by both **individual and systemic factors**. On the one hand, it is shaped by personal characteristics such as individual and social values, cultural background, gender, and the degree of autonomy a person has in making decisions about their own care, all of which influence the person's ability and willingness to seek care. On the other hand, it depends on the extent to which the healthcare system, and society more broadly,

can recognize and respond to these preferences and values, thereby facilitating access to the most appropriate and acceptable care options.

Conversely, poor acceptability may be reflected in **patients' perceptions** that the provided care, HCPs or proposed treatments are not aligned with their values, beliefs, expectations, identity or preferences. Beyond patients' attitudes and perceptions, acceptability can also be impacted by **care-seeking behaviour** (e.g., refusal of treatment, preference for traditional healing, declining appointments, etc.) and the level of a (trustful) **communication** between patient and providers (e.g., feeling (un)heard during consultations, reluctance to ask questions, reporting that explanations were unclear or not meaningful, etc.). **Adherence to treatment** is accorded to appropriateness of care (i.e., the fit between services and patients' needs, quality of care, continuity and expected outcomes of care) and the patients' ability to engage with care, which encompasses also empowerment, participation in decision-making and engagement with care. However, when a patient does not adhere to treatment because the proposed treatment is not perceived as acceptable for him (for example due to cultural beliefs, distrust, dissatisfaction, etc.), then non-adherence may also be considered an indicator of poor acceptability.

This dimension of patient-centred access to care highlights the importance of the relational interactions between patients, healthcare providers and the healthcare system. It is largely determined by the presence of trustful and effective communication, through which the values, preferences and expectations of all actors are acknowledged and respected. Such mutual understanding is essential for aligning care with patients' needs and ensuring access to the most appropriate and acceptable care options.

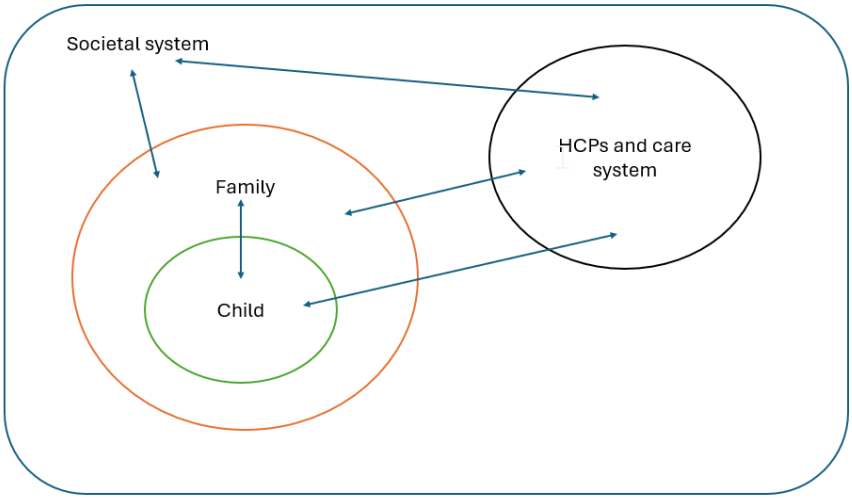
9.3 Acceptability in the context of paediatric palliative care

The application of the Levesque framework[248] to paediatric palliative care aims to provide a deeper understanding of the specific features and challenges associated with access to care. In this chapter, the objective was to identify the factors that shape how PPC is perceived, received and experienced by children, their families and the involved care professionals.

Inspired by dynamic models of complexity [249–251], the structure of this chapter follows the characteristics and determinants operating at the different system levels (micro, meso, macro), as well as the interactions and dynamics between these levels, as outlined below (see also Figure 35):

- the characteristics of the child/adolescent, their preferences and PC needs (cfr. micro-system),
- the characteristics of the family (considered as a second micro-system around the micro-system of the child)
- the dynamics between the child and the family
- the characteristics of the care providers (i.e., needs, preferences and attitude towards PPC) and the related care services (cfr. mesosystem)
- the dynamics between child/family and the care providers
- societal attitude towards the death of a child (cfr. macrosystem)

Figure 32 – Schematic overview of the different actors per system level and interactions in between



The figure presented above remains largely conceptual. Therefore, the exploratory analysis conducted in this chapter sought to identify and to describe the determinants operating at the micro, meso, and macro system levels, and to examine how these determinants may influence the acceptability of PPC, either as barriers or as facilitators.

This chapter does not aim to provide an exhaustive overview of all needs and preferences of all involved actors but seeks to shed light on the complexity underlying the dimension of acceptability in paediatric palliative care. The findings resulted from a triangulation of (i) literature search, restricted to reviews, on complexity, needs categorization and advance care planning, (ii) a targeted review of ethical issues and tensions, a theory-informed interpretative analysis and input from Belgian PPC providers and (iii) stakeholder consultation.

The targeted review of ethical issues and tensions examined how the needs, preferences, values, and responsibilities of parents, families, informal caregivers, and healthcare professionals influence, delay, complicate, or hinder access to paediatric palliative care. The theory-informed interpretative analysis combined coding outputs, transversal comparison of conflict patterns and ethical reflection grounded in principlism, narrative ethics and care ethics. Input from Belgian PPC aimed to check the recognisability and practical relevance of the ethical data in the Belgian context.(see details in Appendix 11)

More concrete solutions are presented in the other chapters.

9.3.1 The child's voice in his own life journey

The child's voice can be determined by several elements and the continuous evolving interactions between these elements:

- Diagnosis, uncertainty about prognosis and impact of care trajectory
- Developmental stages in childhood
- Paediatric palliative care needs

9.3.1.1 Diagnosis, (uncertain) prognosis and impact of care trajectory

Impact of diagnosis

The review of Young 2021[252] on children or adolescents with a **brain tumour** reported on the impact of diagnosis on body image and how this impact evolved throughout treatment, survivorship and palliative phases. The children reported a strong awareness of their body looking and acting differently compared to before the symptoms started. Changes included weight gain or loss, hair thinning or loss, small stature, scars, one-sided paralysis or limited mobility, and using aids such as a wheelchair or hearing aid. These changes were even perceived as constant reminders to themselves and to others that they had or have a brain tumour. Adolescents (mainly survivors) reported feeling frustrated or sad about changes to their body's appearance and functionality.

Impact of prognosis and uncertainty

Families of a child with LLC/LTC often lived under a persistent sense of uncertainty. This was especially evident at diagnosis, during unfamiliar hospital experiences, when starting new treatments, and when illness progression was unpredictable. Unexpected changes in care plans or procedures also increased anxiety. [252]

Parents worried about how treatment would affect their child's physical, cognitive, and emotional functioning, as well as the long-term consequences and late effects that could emerge even after treatment ended. Many families felt uncertain about ongoing support from healthcare services once treatment was completed (in cancer survivors). [252]

The greatest sources of anxiety were fear of disease recurrence and concerns about the child's future, including relationships, independence, family life, and financial security. This ongoing uncertainty often contributed to stress, anxiety, and a low mood among parents, children, and survivors, although some families developed ways to accept the uncertainty and focus on their daily life. [252]

Impact of the care trajectory

In addition to the complexity of diagnosis (and in particular the long trajectory before diagnosis has been set or even the lack of a clear diagnosis), the prognosis related to the LLC or LTC and its related potential uncertainty about this prognosis, also management can add an additional layer of complexity. Children often endure prolonged treatments and invasive procedures, leading to physical discomfort, emotional distress, social isolation and spiritual questioning [253]

Children with life-threatening or life limiting conditions often receive high complex care that can last for months or years. This care is often provided by multiple healthcare professionals and in different care settings. [151]

Desire to be as normal as possible

Children, adolescents, and survivors frequently expressed a strong desire to feel and be treated as normal, just like their peers. Special attention or support, particularly when provided publicly, could make them feel different and excluded. Many tried to minimize attention to their illness and participated in everyday activities as much as possible. They often felt frustrated when health-related limitations prevented them from doing things their peers could do, such as sports or driving. Family support was important, and children valued being treated normally at home and maintaining as normal a life as possible, even during end-of-life care. [252]

Need to find meaning in the illness journey

Families often expressed a need to find meaning in the brain tumour experience. Survivors reported mixed experiences. Some felt grateful to be alive, more compassionate, and able to focus on positive aspects of life, viewing their illness as an important part of their identity. Others felt the tumour had negatively altered their lives and limited their ability to live normally. Many emphasized wanting to be recognized as individuals beyond their illness rather than being defined by it. [252]

Few participants actively searched for reasons why the tumour occurred. Most accepted it as an unpredictable event, although some drew on religious beliefs to help explain or cope with the experience. Religion and spirituality often served as sources of comfort, social support, and hope, particularly at the end of life, where they could help ease fears of death and provide positive meaning for both children and parents. [252]

9.3.1.2 Developmental stages in childhood and adolescence

Child

The scoping review of van Driessche et al (2025)[254] gives an overview of the characteristics of development within the context of serious illness. Various characteristics of general childhood development were identified, organized in following domains: psychological/emotional aspects, general cognitive aspects, social aspects, coping strategy, conceptualization of illness, conceptualization of death, and communication about their illness. Developmental stages were subdivided in early to middle childhood, early adolescence, and middle to late adolescence. Following characteristics were described throughout development from young to older:

- In early/middle childhood: a limited perspective on illness, difficulties in verbally expressing their feelings about being ill, concerns about daily activities they are unable to participate in due to their illness
- In early adolescence: children engage more in concrete reasoning, thinking about why and how they got ill, their focus however is still predominantly on the present 'here and now', rarely fully realizing the impact of illness and treatment on their futur
- In middle/late adolescence: abstract reasoning increases and worrying about relapse, future medical complications and limitations on age-appropriate activities

Cognitive operations necessary to imagine different scenarios is a complex task for children and the use of cognitive coping strategies in hypothetical problem situations increases with the age of the child.

In the context of serious illness, the literature review identified both factors that may accelerate or decelerate ongoing child development. However, the evidence underpinning these factors was fragmented and inconsistent, meaning that some factors could be interpreted as either accelerating or decelerating development depending on the context. Following influencing factors were identified:

- Accelerators:
    - Age: higher age goes hand in hand with more knowledge on the illness, cortical maturation and increased cognitive abilities, which allow to generate their own semantic conclusions
- Decelerators:
    - Stress: the child continues to use ways of thinking that are developmentally typical of younger children to help cope with a stressful situations (such as a serious illness), e.g., egocentric or magical thinking is retained serving as an important defense mechanism; limited capacity to identify and differentiate body states when distressed
- Both accelerator and decelerator:
    - The illness itself: can either accelerate cognitive development (through a maturational effect) or slow development through information deficit
    - Prior medical experience: this will accerelarate specific illness concepts without facilitating general conceptions of illness causality
    - Social experience with adults: will accelerate child development, helping children learn new dialogues and integrate them into their own speech, however avoidance of illness-related communication in the family will rather have a decelerating effect

  - Parental style: authoritative parenting which offers a democratic climate of both high support and adapted control, stimulates the child development more than passive (indulgent or uninvolved) or authoritarian parenting, which provides strict control without support

- Shaping factors (no direction of impact specified): family context including parenting style, coping style of the family, communication, and interaction within families; individual context, including coping processes, mental readiness, personality traits and characteristics, the illness itself and its impact on daily life

The review indicates the interplay between physiological, psychosocial, functional, and developmental factors influencing children's coping abilities and adjustment to illness. [254]

When involving children in decision-making and discussions about preferences and future care goals, strategies should be adapted to their developmental stage. Initiating advance care planning at the time of diagnosis and maintaining it as an ongoing process may help children to develop the knowledge, confidence, and communication skills necessary for them to actively participate in their healthcare.

The WHO defines **adolescence** as the period from 10 to 19 years of age, during which time there is a rapid growth and significant changes to the body, mind and social life. The transition period between childhood and adulthood is characterized by multiple challenges, such as physical, psychological (such as identity formation, exploring new relationships, defining goals for the future, etc.), and social changes (such as the growing need for independence and personal affirmation). These changes in combination with the impact of an advanced diseases add an additional layer to the complexity and acceptance of palliative care (Blakemore, 2012 and Dahl, 2018 in Castro, 2025)[255] The review of Castro et al, 2025 [255] identified social, emotional and clinical factors that influence the adolescent autonomy, such as

- the impact of social pressure on the autonomy, where social expectation (internalized by adolescents) leads them to prioritize family needs and adherence to treatment, even if this conflicts with their own preferences and needs. (see also further in family dynamics)
- The evolution of the disease, illustrated by a case report of a young woman with leukemia who initially actively particpated in decision-making but became more dependent as the disease progressed
- Emotional difficulties arise also with the experience of an advanced diseased: uncertainty about the future, social isolation and complex decision-making highlight the importance of adequate psychosocial support

Previous experience in a specific disease can also contribute to the development of decision-making competences. For example, the practice of self-management in chronic diseases, strengthens confidence and promotes active participation.[255]

Intellectual disability

Children with a life-limiting condition and an **intellectual disability** may experience challenges in the when receiving PPC, such as communication impairment, which may impact the quality of life and wellbeing of both the child and their family. Other challenges were related to difficulties in assessment and clinician confidence in symptom management, and under-reporting of symptoms by clinicians compared with parents. Symptoms may be attributed to an individual's disability, rather than looking for an underlying physical cause or alternative aetiology. Also decision-making in advance care planning may be challenging and is influenced by the cognitive ability and emotional maturity of the child or adolescent. Parents will often plan future healthcare based on their view of their child's quality of life, and what they perceive to be important to their child.[256]

9.3.1.3 Palliative care needs

Similar to adult palliative care, the needs in paediatric palliative care can be categorised in domains of physical (with symptom management), social, psychological, spiritual and ethical needs and concerns of the patients.[257] An exhaustive list of palliative care needs in children and adolescents was beyond the scope of this project. Instead, this section focuses on specific characteristics that distinguish their needs from those in adult palliative care.

As noted in the introduction to this chapter, the assessment of these various categories of needs should extend beyond the child to include the family. It should be conducted periodically, beginning at the time of diagnosis of (supposed) incurability (or even before if the diagnosis is uncertain) and continue throughout the entire disease course. [257]

Verma et al. (2026) mapped the variety of palliative care needs according to the bio-psycho-socio-spiritual lens to illustrate the multidimensional burden of cancer for children and their families (see Table 23) [253]

Table 23 – Overview of categories of needs with commonly reported problems per needs category

Category of needs	Commonly reported underlying problems per category
Physical/clinical needs	Pain, fatigue, nausea, dyspnoea Feeding difficulties, gastrointestinal disturbances, and reduced mobility
Emotional/psychological needs	Psychological distress, including anxiety, depression, fear of death Emotional challenges related to disease progression, treatment side effects, and hospitalisation
Social needs	Peer isolation, school absenteeism, and difficulty maintaining friendships Academic and social difficulties faced upon children returning to school Changes in family roles and relationships
Spiritual needs	Spiritual distress, existential questioning, and concerns about death

Across the exploratory search for literature reviews on paediatric palliative care needs, targeted reviews were found on spiritual care [258] and children's experiences on palliative care at home. [259]

The child's need for spiritual care

Whereas spirituality in adults is oriented on exploring self-worth, meaning and purpose in life, in adolescents more focus is put on relational awareness, prioritising connection to the self, followed by connections to others, nature and ultimately to the sacred or transcendent. [258] The authors of the review on spiritual care needs in adolescents with cancer [258] identified five comprehensive themes with several subthemes:

- **Autonomy**: Adolescents valued opportunities to preserve their independence, identity, and sense of normality while remaining actively involved in decisions about their care and everyday lives
    - Being treated as equals: Adolescents wanted to be seen as normal young people rather than being defined by their illness. Changes in appearance and social stigma often made them feel different from their peers.
    - Continuing life as normally as possible: Many wished to maintain everyday activities and social connections despite physical limitations. Some resisted labels associated with illness or dependency, while others used creative activities such as art and play to stay connected with the world around them.

- Being informed about their condition: Adolescents wanted clear, honest, and age-appropriate information about their diagnosis, treatment, prognosis, and disease progression. Open communication helped reduce anxiety and increased their sense of control.
- Having control over their environment and care: Participants wanted choices regarding daily matters such as food, ward design, and living conditions. They emphasized the importance of adolescent-friendly healthcare environments that reflected their developmental and social needs.

- **Connection**: Adolescents' wellbeing was closely linked to feeling connected, supported, understood, and able to maintain meaningful relationships despite the challenges of serious illness.
  - Maintaining relationships: Support from parents, friends, healthcare providers, and pets helped adolescents cope with their illness, providing comfort, joy, and emotional security. However, treatment and hospitalisation often disrupted social lives, causing feelings of isolation and disconnection from peers.
  - Receiving and giving love: Adolescents relied heavily on the emotional support of family and friends. At the same time, many were concerned about the distress that their illness caused their loved ones, and so tried to appear strong in order to protect and comfort their parents.
  - Communicating with others: Open conversations with parents, friends, healthcare professionals, and spiritual advisors provided emotional relief and support. Although adolescents valued these discussions, some hesitated to share their feelings for fear of burdening their families.
  - Connecting with transcendence: Many adolescents sought comfort through spirituality, religion, prayer, or faith, which helped them cope with fear and uncertainty. Some found strength in beliefs about God or an afterlife, while others questioned their faith or drew inspiration from fictional characters and personal sources of hope.
- **Meaning in life**: Adolescents with cancer often sought to understand and find meaning in their illness and life experiences.
  - The need to accept cancer and seek its meaning: Following diagnosis, many asked existential questions such as *"Why me?"* and searched for explanations for their illness, drawing on religious beliefs, ideas of karma, personal habits, or other interpretations. While some viewed cancer as a devastating disruption to their lives and families, others saw it as a challenge that could foster strength and personal growth.
  - The need to have a meaningful life: Despite the limitations imposed by illness, adolescents also expressed a strong desire to live meaningful lives and maintain a sense of purpose. They sought opportunities to contribute to the lives of others, help fellow patients, and participate in meaningful activities, which reinforced their self-worth and helped them feel that their lives remained valuable and purposeful.
- **Positive attitude**: Maintaining hope and a positive attitude helped adolescents cope with the challenges of cancer and preserve their emotional wellbeing
  - Need for peace: Despite advances in medical treatment, many adolescents continued to experience anxiety about disease recurrence, treatment side effects, and the future. They valued calm, quiet environments and sought emotional peace amid ongoing uncertainty.
  - Need to sustain hope: Many adolescents fostered hope by focusing on positive experiences, expressing gratitude, using positive thinking strategies, and finding meaning in supportive relationships and personal achievements.
- **Dealing with death:** Adolescents with cancer expressed a need to understand, accept, and prepare for death.

- The need for peace at end of life: They often feared dying and questioned what death would be like, including whether it would involve pain and what happens afterward. Over time, some moved from fear toward acceptance, discussing death with their families and finding ways to cope with the reality of their illness. As the end of life approached, adolescents sought peace, dignity, and emotional closure.
- The need to die in a preferred way: They wanted to spend their remaining time with loved ones, feel loved and supported, and reduce the emotional burden on family members. Many preferred to die in familiar and comforting surroundings, such as at home with family, and were concerned about their family's well-being after their death. They also emphasized the importance of bereavement support for families following their child's death.

Children's experiences and needs with palliative care at home

Children often preferred to stay at home because frequent hospital visits were exhausting and reduced their energy to spend time with friends and maintain social relationships. They valued healthcare professionals who took time to get to know them as individuals, showing interest in their personal and social lives rather than focusing only on medical issues. Children also emphasized the importance of honest communication about their condition, having choices and involvement in decision-making, and being able to speak privately with doctors without their parents present when desired. Parents and children sometimes differed in their views on how involved physicians should be in the child's care.[259]

9.3.2 The dynamics within the family unit determining their ability to seek health care

Both adult and paediatric palliative care share common goals, particularly the delivery of patient-centred care that prioritises quality of life, alongside the symptom management and support for patients and families throughout the course of an illness.[260]

Figure 35 already highlights the distinctive role of the family as a second micro-system surrounding the micro-system of the child. This observation is consistent with the findings of Chelazzi, 2023 [260], which identify the central role of the family as one of the main distinctions between adult and paediatric palliative care:

- The shift from patient-centred care in which the family is involved mostly as "surrogate" decision-makers (in adult PC) towards a "child- and-family-centred" approach, in which the family is an active subject and object of PC practice

  The principle of autonomy applies in different ways to adults and children. The adult patient is in general thought to be capable of self-detemination and able to decide if the proposed treatments are in line with his needs or expectations. If the adult patient is unable to decide, an advanced care plan or a living will may be available to help decision-makers. A 'surrogate" or health attorney may also assist clinicans in making decisions. In PPC, the decision-making capacity varies considerably from complete dependence on the decision of the parents to active participation by the child. The extent of a child's involvement in decision-making depends on several factors, such as age, developmental stage, cognitive abilities and clinical condition.
- The role of the family in PPC goes beyond provinding informed consent, but they are usually actively involved in the provision of PPC, including adaptations to the house, training on the use of devices, etc.
- Families may be affected as a whole and may also be object of PPC care: they often need psychological support for emotional burden, organisational or financial support.

The Figure 36, adapted from Chelazzi (2023) [260], illustrates the extensive involvement of the family throughout the child's palliative care trajectory. It also highlights a key distinction between paediatric and adult palliative care: whereas family members play a central and continuous role in paediatric care, their involvement in adult palliative care is often less prominent or occurs at a later stage of the care trajectory.

Together, these findings support the elaboration of the following section, which explores the needs of the family as well as the dynamic interactions between the child and family members within the context of PPC.

Figure 33 – Differences in trajectories between adult and PPC

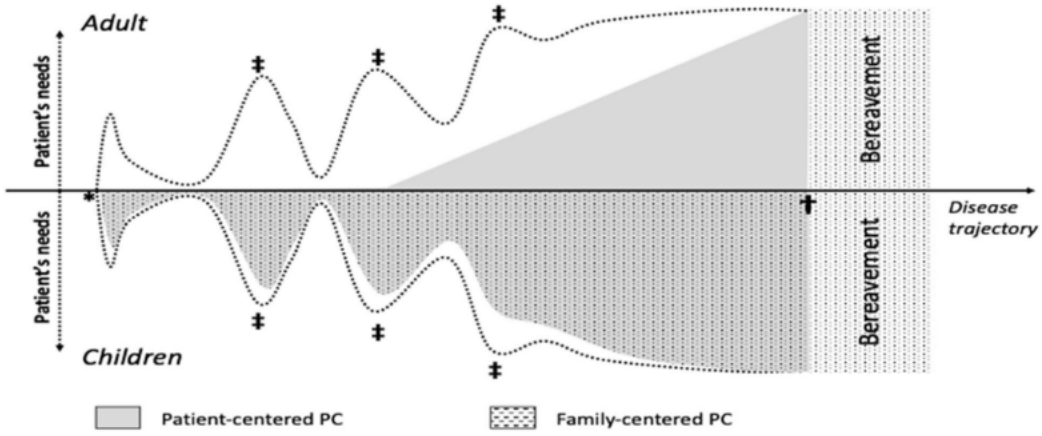


Fig. 1 The needs of patients with life-threatening diseases change over the trajectory of disease (dotted lines; adults, above; children, below), starting at the diagnosis (*), during acute crises (ǂ) until death (+). The grey area represents palliative care effectively delivered to patients; black dotted area represents the palliative care delivered to families and social background of patients

Source: Chelazzi et al., 2023[260]

9.3.2.1 Needs of the parents, siblings, and other family members

Care pathways for children with LLC or LTC cover often several years and shift from hospital-based care to home-based care with a change in parents' role as key actor in the organisation of the home care around the child. This implies that parents have to adapt to new roles in their lives and have to become experts in the child's treatment or management plans. The ongoing demands of caring for a child with a LLC or LTC impact parents' quality of life, and psychological and physical health. [261]

Unmet supportive needs indicate the gap between the support families would like to receive and what they actually receive. In the supportive care needs (SCN) framework the holistic needs of the patient and the families are identified and addressed, by categorizing the care needs into seven core domains: physical, psychological, informational, emotional, social, spiritual and practical. Core concepts of this framework are the construct of human needs (i.e., the impact illness has on every aspects of a patient and family's life), cognitive appraisal and coping (i.e., how patients perceive their illness and utilize personal or external coping mechanisms), adaptation in a continuum of care (i.e., needs fluctuate and persist across the entire care trajectory), as a basis for conceptualising health care experiences from diagnosis to cure or death.(Fitch, 2008 in Thomas, 2023) [261] Since this framework was originally developed for cancer care, additional reviews related to rare conditions and life-limiting illnesses suggested that the domains of this framework may need to be broadened to domains relating to parenting, communication and need for choice (Gill, 2021 in Thomas, 2023) [261]. Across the identified literature in the review of Thomas, 2023[261] on unmet supportive care needs of families of children with chronic illness, the unmet needs were reported in a variety of ways, for example by domains, by items or across various time frames (e.g., stages of care/treatment). Different assessment tools were used, with level of need reported as percentage, means or explored as themes in qualitative studies.

Across the different unmet needs reported by the parents, **the informational needs was the most common unmet need domain**, **followed by the unmet needs in emotional support and in practical support**. The need for emotional and practical support is mainly related to the multiple stressors and emotional challenges that parents encounter while taking up the role of main responsible for the management of the child's condition. According to the parents, more assistance to manage the emotional and psychosocial impacts of this role, and more support to develop the skills to help their

child manage key tasks (e.g., implementation of care techniques) and developmental transitions (e.g., school reintegration) was considered as the most suitable interventions to meet these unmet needs.

The review of Thomas, 2023 [261] showed that the discussion is still ongoing on the inclusion of more specific domains regarding paediatric care needs and that a clear framework for the identification of the needs domains is still lacking. Further exploration on which needs assessment tools and measures are the most appropriate in paediatric palliative care is however considered out-of-scope for this KCE report.

A more recent qualitative systematic review identified five themes across the unmet needs of parents in PPC [262]. These themes and subthemes are presented in Table 24. Not all themes are related to the dimension of acceptability of PPC and will be explored in other chapters of this report (see chapters on care offer (12)).

All the unmet needs identified in the review are in line with the domains covered in guidelines and standards on PPC (e.g., Together for Short Lives Core Care Pathway framework), such as: open and honest communication, educational information; agreed transfer plans ensuring continuity of care from hospital to home and community; family-centred multidisciplinary needs assessments; multidisciplinary care plan for delivery of coordinated care; support with end-of-life planning, and bereavement support. However, this review indicates the gap between these standards and the current implementation in clinical practice.

Table 24 – Overview of unmet needs and barriers encountered by parents of children with life-limiting conditions

Unmet needs themes and subthemes	Barriers encountered by the parents
Paediatric palliative care services delivery and care coordination • ***Need for continuity of care and care coordination*** • ***Need for family-centred approach*** • ***Need for shared decision making*** • ***Need for accessible and appropriate facilities*** • ***Needs relating to advanced care planning*** • ***Needs relating to general practitioner involvement***	Parents were frustrated by frequently changing healthcare professionals who were unfamiliar with their child's history and existing treatment plans, leading to repeated reassessments and disruptions in care. Services were often fragmented with poor coordination, creating a need for a dedicated case manager or consistent contact person to coordinate communication among healthcare providers, administrative services, financial sectors, and families. Parents wanted to be treated as equal partners in care decisions, and they have expert knowledge of their child's needs. Exclusion from decision-making caused feelings of frustration and disregard. Parents preferred a gradual, sensitive introduction to ACP, supported by written information. They valued individualized discussions, sufficient time to process their child's prognosis, flexibility to revise decisions, and inclusion of the child in planning when appropriate. A lack of private, calm hospital spaces increased parental stress and sometimes discouraged families from accessing psychological support services. Parents wanted GPs to be involved earlier in the child's illness journey and to provide personal, face-to-face support following the child's death.
Emotional, psychological and spiritual support • ***Need for accessible mental health services*** • ***Need for informal care networks and support groups*** • ***Need for emotional support and sensitivity***	Parents wanted free and easily accessible mental health services provided to parents and integrated into their child's palliative care. Many experienced isolation and valued peer support groups where they could connect with families facing similar challenges. Parents also desired greater empathy, sensitivity, and emotional support from healthcare professionals. Additionally, they expressed a need for individualized, family-centred spiritual care delivered in a respectful and nonjudgmental manner.

Unmet needs themes and subthemes	Barriers encountered by the parents
from health care workers • *Needs relating to spiritual support*	
End-of-life care and bereavement support • *Need for more support during the end-of-life phase* • *Need for bereavement support*	Parents wanted better support in preparing for their child's death, including guidance on discussing death with the child and siblings, effective symptom management, and help with funeral planning. Some parents also expressed a desire for more end-of-life decision-making options. After the child's death, families often experienced insufficient professional support and requested immediate and ongoing bereavement care, including grief counselling for parents and siblings, as well as continued contact with the healthcare professionals who had cared for their child.
Practical and daily living support • *Need for support with childcare* • *Need for support with daily living* • *Need for community services support*	Parents needed guidance with physically demanding care tasks and greater access to respite care to reduce exhaustion, fatigue, and sleep deprivation. Parents also requested assistance with daily living activities, including financial and insurance matters, housekeeping, and grocery shopping, so they could spend more quality time with their child. Support for healthy siblings was often lacking, particularly regarding education and care during hospital stays. Additionally, parents felt that available community services did not adequately meet their needs for practical, financial, and caregiving support.
Communication and information • *Empathetic, open and honest communication* • *Need for information and education*	Parents wanted open, honest, and empathetic communication from healthcare professionals, as poor communication increased uncertainty, anxiety, and made difficult topics feel taboo. Parents also desired direct access to care providers, timely and detailed information about their child's condition, prognosis, treatment options, and future care plans. In addition, they valued education and guidance on caring for their child and managing symptoms at home, enabling them to make informed decisions and feel more confident in their caregiving role.

Source: Themes, subthemes and barriers encountered extracted and synthesised from the review of Senanayake, 2025 [262]

Families of a child with LLC/LTC often lived under a persistent sense of uncertainty. This was especially evident at diagnosis, during unfamiliar hospital experiences, when starting new treatments, and when illness progression was unpredictable. Unexpected changes in care plans or procedures also increased anxiety. [252]

Parents worried about how treatment would affect their child's physical, cognitive, and emotional functioning, as well as the long-term consequences and late effects that could emerge even after treatment ended. Many families felt uncertain about ongoing support from healthcare services once treatment was completed (in cancer survivors). [252]

The greatest sources of anxiety were fear of disease recurrence and concerns about the child's future, including relationships, independence, family life, and financial security. This ongoing uncertainty often contributed to stress, anxiety, and a low mood among parents, children, and survivors, although some families developed ways to accept the uncertainty and focus on their daily life. [252]

In line with Young et al, 2021[252], the systematic review of Page et al[263] identified across family caregivers' experiences of services for children with medical complexity the primary overarching theme of concern for child's safety, with subthemes related to interactions with professionals, caring for the whole family and system organisation. Caregivers highly valued healthcare professionals who

were knowledgeable, listened to parents' expertise, communicated effectively, and worked collaboratively across services. In contrast, fragmented care, poor coordination, inadequate communication, and difficulties trusting professionals increased stress and placed a substantial burden on families. The review also highlighted that caregivers' needs extend beyond the child's medical care, encompassing parental well-being, mental health, sleep, finances, housing, and support for the whole family. The authors conclude that services should adopt a family-centred and integrated approach that recognizes parents as partners in care and addresses both the child's and the family's broader needs.

The systematic review of Barrett et al [264] highlighted the duality parents during end-of-life care for their child, with a profound need to maintain and fulfil their parental role throughout their child's illness, dying process, and even after death. Parents sought to remain actively involved in decision-making, caregiving, advocacy, and protecting their child's identity and quality of life. At the same time, they experienced an equally important need for emotional, practical, and informational support from healthcare professionals. Compassionate communication, honest information, acknowledgement of parents' expertise regarding their child, and support tailored to individual family needs were highly valued.

More specific reviews targeted on the particular unmet needs of specific groups of parents, such

- forced **migrants** : Clancy at al. [265] reported:
    - the importance of cultural-sensitive approach, including the incorporation of traditional healing strategies, and faith and spirituality in care with prayer as a common coping mechanism. Families' spiritual and religious beliefs about death and dying were seens as challenging by the HCPs who lack knowledge in culturally sensitive care, with ignorance of patients' cultural beliefs, values and practices.
    - Gender bias and associated caregiving and decision-making expectations: mothers were expected to be the primary caregiver, whereas fathers may cope by distancing themselves or are discounted by HCPs who focus on mothers.
    - Language and communication barriers were also reported, resulting in medical misinterpretation, difficulties in building rapport and a reluctance to use services. Families expressed feelings of powerlessness, distress, fear and being overwhelmed. Lack of access to professional interpreters was identified as a key challenge.
    - Difficulties navigating healthcare systems due to parents' limited understanding of available care offer, and lack of knowledge about their child's condition (cfr. lack of health literacy). Also financial barriers, such as financial stresses (e.g., insufficient systematic resources withtin the household, unemployment, cost of medical care) were reported as important barriers related to navigation.
    - Burden of caregiving resposibilities, leading to marital and family conflict, or unmet needs of siblings
    - Hopelessness over the destitution of their country of origin (their home land destroyed by war and political injustice), living in poverty, feelings of powerlessness, shame and the effects of racism and discrimination on them and their families. Also the absence of traditional support from the social network, due to a partial migration of the family and social network
- parents of infants in **neonatal intensive care units**: Hamel et al. [266] identified specific needs related to the stay of the infant in NICU (next to more common needs, such as need for transparent communication with the HCPs, parent involvement in decision-making and continuity of care among the care team)
    - **parents' ability to interact with their infant**, including maintaining the role of a parent (and to perform typical parental duties), having quality time with the infant (i.e., bonding between the parent and the infant through skin-to-skin holding, changing diapers, feeding their infant,

but also introducing their child to other visitors, having alone time to properly say goodbye) and understanding and perceiving the symptoms and potential suffering of their infant.

- need for **parental emotional support** during stay in NICU
- need for **bereavement support** during the grieving process

- family experiences with palliative care for children in the **home setting:** Winger et al. [259] reported that:
  - parents generally valued having a choice in the preferred place of care and death, although preferences could change between home and hospital over time. Most families preferred to stay at home, as thi made it easier to **maintain a normal family life and** was less stressful for the child. It also meant that siblings could still attend school and be with friends.
  - experienced challenges were **coordination of care** including lack of support from adequately skilled staff with appropriate experience, need for **respite care** in order to cope with everyday life (including managing the physical, cognitive and emotional work generated by the situation, while also attending to everyday pursuits). Families' living conditions due to the **family economy** was challenging for some parents because of the parents' (mostly the mother's) withdrawal from the labour market, resulting in lower income.The cost of medication and equipment was also a significant burden.
  - **siblings** of children receiving palliative care at home experienced a range of emotional and practical impacts. They often felt sadness and grief over the illness and loss of their sibling, while some also experienced anger or distress because parents' attention was focused on the sick child. For some, the experience influenced future aspirations, including an interest in healthcare careers. Home-based palliative care helped siblings maintain a sense of normality by allowing them to stay connected with friends, attend school, and preserve family life and togetherness. Parents sometimes had a bad conscience in relation to siblings who were given little attention due to tasks and the urgent needs of the sick child.
- Experiences of **fathers** of children with a life-limiting condition[267] were categorised around 5 overarching themes and summarized here in key findings:
  - Feelings of uncertainty at the time of diagnosis, marked by a sense of helplessness, new questions raising about prognosis and future planning, actively searching for information to regain a sense of control and to feel safer and better equipped to cope
  - Creation of a new normal with altered relationships with family and friend, a reshape of values and perspectives on life and the impact of the child's condition (and care management) on day-to-day family life
  - Emotional experiences mainly related to the interactions with healthcare professionals: positive relationships with healthcare professionals provide reassurance and emotional support, whereas poor communication, lack of sensitivity, or insufficient information exacerbate distress. The recognition of famters' emotional needs remained an important unmet aspect of care.
  - Role conflict between caregiving responsibilities and emplyment obligations: many fathers will adpat their careers and working arrangement to accommodate caregiving needs, while workplace support varies considerably with a lack of understanding by the employer, pressure to perform and even job loss.

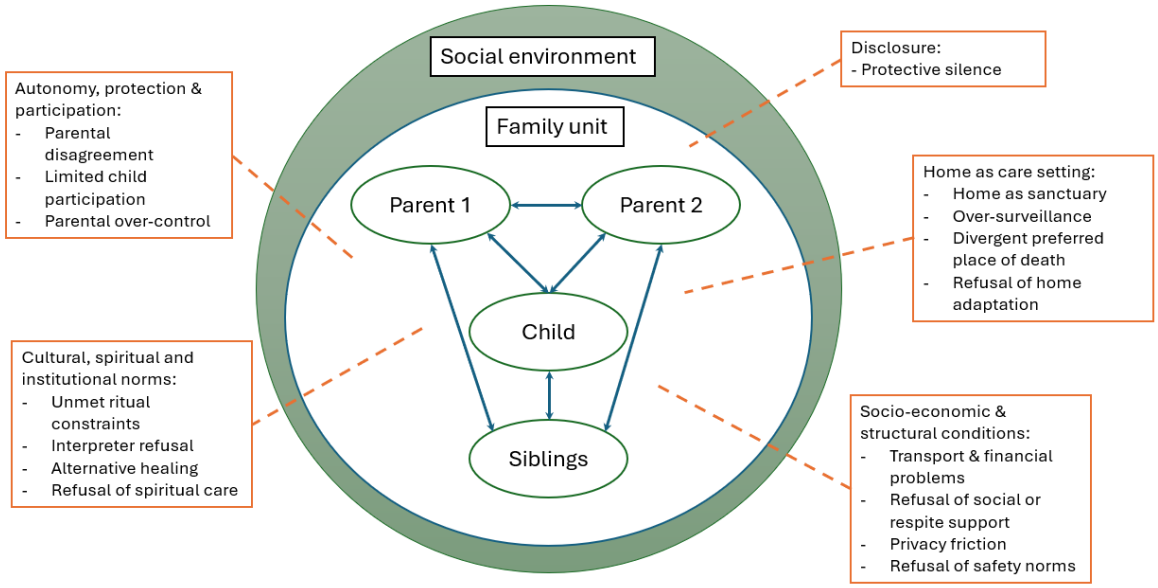
Authors reported an underrepresentation of children with neuropsychiatric disorders in literature [253]

The above-mentioned reviews are retrieved from an exploratory search in literature on reviews and this search did not aim to give an exhaustive overview of the current evidence.

9.3.2.2 Dynamics within the family unit

Figure 37 gives an overview of the variety of ethical tensions identified related to the dynamics within the family unit.

Figure 34 – Schematic overview of the different ethical tensions within the family unit



Impact of tension about disclosure and truth management on access to PPC

The ways in which information about prognosis, disease evolution, and the palliative orientation of care is communicated can have its impact on access to PPC. This communication can be delayed, reframed or withheld, due to family coping strategies.

Our ethical analysis identified following tension about disclosure and truth management within the family unit and how it impacts acceptability and access to PPC:

- **Protective silence toward the child**: Protective silence occurs when parents choose not to inform the child about the severity of the illness or a shift in care goals. This approach is often reinforced by siblings, relatives, community members, and sometimes non-specialised professionals who believe that open discussions could cause distress or disrupt family stability. These influences create an environment in which the child senses tension and changes in behavior but lacks the information needed to understand them. As a result, protective silence may increase anxiety, feelings of exclusion, and confusion, while also delaying recognition of the palliative phase and timely access to paediatric palliative care.

Impact of tensions about autonomy, protection and participation on access to PPC

Autonomy, protection, and participation are central but often competing principles in paediatric palliative care. Decisions about care are shaped by the interaction between parental authority and the child's evolving capacity to express preferences and participate in discussions. Efforts to protect the child, manage uncertainty, or maintain control can sometimes unintentionally limit communication and shared decision-making.

Our ethical analysis identified following tensions about autonomy, protection and participation and how these tensions impact the acceptability of PPC:

- **Parental disagreement or custody conflict:** Parental disagreement, including conflictual divorces, challenging co-parenting arrangements, or poor communication between parents, can create significant barriers to decision-making in paediatric palliative care. These tensions are often amplified by relatives, extended family members, and sometimes siblings who support one parent's position over the other, particularly regarding treatment continuation, transition to paediatric palliative care, or preferred care settings. Non-specialised professionals may unintentionally reinforce these divisions through inconsistent messages or differing interpretations of the situation. As a result, information becomes fragmented, conflicting requests increase, and trust between actors may erode, making it difficult to establish a coherent care plan. In such circumstances, access to paediatric palliative care may be delayed or complicated by the lack of consensus among parents.
- **Limited child participation**: Limited child participation often results from a protective instinct shared not only by parents but also by siblings, relatives, informal caregivers, and non-specialised professionals. These actors may encourage silence or simplified explanations, believing this shields the child from distress. As a result, communication becomes fragmented, with adults sharing a more complete understanding of the situation while the child receives only partial information. This discrepancy can lead to confusion, anxiety, and difficulties expressing concerns or preferences. Excluding the child from discussions may also hinder advance care planning and delay or complicate access to paediatric palliative care.
- **Over-control of care plan**: Over-control of the care plan occurs when parents feel compelled to closely monitor, direct, or correct every aspect of the child's care, often driven by fear of mistakes or previous traumatic healthcare experiences. This tendency may be reinforced by relatives, family members, informal caregivers, and non-specialised professionals who encourage heightened vigilance or provide inconsistent, technical, or incomplete information. These overlapping influences increase parents' sense of responsibility and need for control. As a result, communication may become fragmented, shared decision-making more difficult, and the development of a common care vision more challenging. In some cases, this dynamic can delay access to paediatric palliative care and complicate the gradual adaptation of care goals and coordination among the different actors (child, family, care professionals).

Impact of tensions about cultural, spiritual and institutional norms on access to PPC

Cultural, spiritual, and institutional factors play an important role in shaping families' experiences of paediatric palliative care. Beliefs about illness, healing, communication, suffering, and end-of-life care are often influenced by cultural traditions, religious values, and family narratives, while healthcare services operate within institutional frameworks and professional standards. When these perspectives align, they can support shared understanding and trust. However, when expectations differ, tensions may emerge that affect communication, decision-making, and the acceptability of paediatric palliative care.

Our ethical analysis identified the following tensions about the cultural, spiritual and institutional norms and how these tensions can interfere with the access to PPC:

- **Unmet ritual or spiritual constraints:** Some families express specific cultural, religious, or spiritual needs, such as prayers, the presence of religious leaders, symbolic objects, or particular rituals surrounding illness and end-of-life care. These expectations are often shaped not only by parents but also by siblings, relatives, and the extended family, who may hold differing or even conflicting views. At the same time, healthcare staff and institutional actors outside the paediatric palliative care setting may facilitate or restrict these requests based on organizational rules, personal interpretations, or practical constraints. When institutional policies (e.g., number of visitors, sanitary norms, etc) conflict with families' ritual or spiritual expectations, families may feel that their beliefs and values are not being respected. Such tensions can undermine trust, complicate relationships with care providers, and hinder the acceptance and integration of paediatric palliative care.

- **Interpreter refusal**: Some families decline the use of professional interpreters and prefer translation by a relative, friend, or sometimes a bilingual child. This preference is often influenced by family dynamics: concerns about privacy, trust in close community members, or cultural discomfort with discussing sensitive issues through an unfamiliar person. Relatives may actively encourage the use of informal interpreters, while non-specialised professionals may inadvertently reinforce this practice by accepting it due to habit or limited resources. These combined influences increase the risk of misunderstandings regarding prognosis, treatment options, and the role of paediatric palliative care. As information may become filtered, incomplete, or inconsistently conveyed, informed decision-making and timely access to paediatric palliative care can be compromised.
- **Alternative or "miracle" healing**: Some families explore or prefer alternative forms of healing, such as traditional healers, unproven remedies, spiritual practices, or energy-based therapies. These approaches are often motivated by a desire to maintain hope and regain a sense of control in the face of uncertainty. Family members, friends, and cultural or religious communities may actively encourage these options, presenting them as more natural, meaningful, or aligned with family values. In some cases, non-specialised professionals may also unintentionally reinforce these beliefs by suggesting that such approaches are worth trying. These overlapping influences can delay important decisions, foster unrealistic expectations, and create tensions when alternative practices conflict with medical recommendations or the timely integration of paediatric palliative care. As a result, they may become a significant source of disruption within the care trajectory.
- **Refusal of chaplaincy or spiritual care**: Some families decline chaplaincy or spiritual care because they associate it with death, institutional religion, or spiritual stigmatization. This reluctance may be reinforced by relatives, siblings, or members of the cultural or religious community who prefer alternative forms of support or question the legitimacy of institutional spiritual care providers. Non-specialised professionals may also avoid addressing spiritual issues due to discomfort or because they perceive families as uninterested. As a result, the spiritual dimension of care may remain overlooked, despite its importance in helping families make sense of illness, treatment decisions, and the palliative care journey. This can make it more difficult for both the child and family members to express and address existential concerns and sources of meaning.

Impact of tensions about socio-economic and structural conditions on access to PPC

Socio-economic and structural circumstances can strongly influence families' ability to seek paediatric palliative care. Beyond clinical needs, families may face practical, financial, organisational, and social challenges that affect their engagement with services and the continuity of care.

Our ethical analysis identified the following tensions about socio-economic and structural conditions and how these tensions can create barriers to equitable access to PPC:

- **Transport and financial problems**: Financial and logistical constraints, including transportation costs, long travel distances, lack of available transport, and reliance on others for mobility, are major barriers to equitable and consistent access to paediatric palliative care. These challenges affect not only parents but also siblings, relatives, and informal caregivers, who often need to adjust schedules, provide transportation, or arrange childcare. Furthermore, non-specialised professionals may schedule appointments or examinations without fully considering these limitations, creating additional burdens for families. As a result, consultations may be delayed, follow-up care interrupted, and access to specialised services postponed. The impact is particularly significant for families with fewer resources, making it more difficult to initiate or continue palliative care.
- **Refusal of social or respite support**: Families decline social support, psychological assistance, or respite care due to embarrassment, fear of being judged, or a desire to protect their privacy. This reluctance may be reinforced by siblings, extended family members, or close relatives who

perceive such services as unnecessary, intrusive, or a sign of weakness. In some cultural or social contexts, seeking outside help may even be viewed as questioning parental competence. In addition, non-specialised professionals may introduce these support options too late or provide insufficient information about them, reducing their uptake. As a result, parents often shoulder a significant physical and emotional burden alone, increasing the risk of exhaustion and making it more difficult to maintain coordinated and effective paediatric palliative care, especially as the child's needs become more complex.

- **Data-sharing and privacy friction:** Some families are highly concerned about the sharing of their child's medical information, fearing that sensitive details may be disclosed to schools, extended family members, or other healthcare services. These concerns are often reinforced by relatives, friends, or community members who have experienced stigma or worry about the misuse of personal, genetic, or social data. In addition, non-specialised professionals may provide inconsistent guidance about information sharing due to limited familiarity with secure communication practices. As a result, families may refuse shared medical records, restrict information exchange between care teams, or limit communication among specialists. This can hinder care coordination, increase the risk of errors or duplication, and contribute to more fragmented access to paediatric palliative care.
- **Refusal of safety norms or vaccination**: Some families are reluctant to follow vaccination, hygiene, or safety measures that are essential for protecting immunocompromised children. This reluctance is often influenced by family members, or informal caregivers who may hold personal beliefs, cultural concerns, or negative perceptions of vaccines and medical interventions. In some cases, non-specialist professionals may also provide unclear or inconsistent information, further increasing uncertainty. These combined tensions can make it difficult to implement important protective measures at home or in healthcare settings. As a result, the safety of the child may be compromised, and the delivery and continuity of paediatric palliative care can become more challenging and tension-filled.

Impact of tensions about home as care setting on the access of PPC

Decisions about where care is provided, how much technology is introduced into the home, and how families adapt their living environment are influenced by practical, emotional, and symbolic considerations. While families often seek to preserve normality, privacy, and the meaning of home, these preferences may sometimes delay support, complicate care delivery, or affect transitions between care settings.

Our ethical analysis identified the following tensions about home as care setting and how these tensions can create barriers to access to PPC:

- **Home as sanctuary (refusal of interventions)**: For some families, home represents a protected space associated with normality, stability, and family continuity. Introducing paediatric palliative care into this environment may be perceived as intrusive or as transforming the home into a place of illness. These concerns are often shared by siblings, relatives, and informal caregivers, who may worry that medical equipment, professional visits, or specialised interventions will disrupt family life. Non-specialised professionals may also reinforce these reservations by questioning the feasibility or safety of home-based care. As a result, families may delay or refuse home visits, equipment installation, or palliative care teams involvement, making it more difficult to provide optimal support while preserving the family's sense of normality.
- **Over-surveillance and high-tech at home**: Some families prefer intensive technological monitoring at home, using devices such as monitors, alarms, frequent vital-sign checks, or video surveillance to maximize the child's safety. This approach may be encouraged by siblings, relatives, friends, informal caregivers, or non-specialised professionals who view increased monitoring as reassuring and protective. However, excessive surveillance can create a highly medicalized home environment, increase parental stress, reduce the child's quality of life, and lead to unnecessary concerns caused by false alarms or misinterpretation of normal variations.

As a result, it may become more difficult to implement a palliative care approach focused on comfort, relationships, and everyday stability.

- **Preferred place of death**: Preferences regarding the place of death, whether at home, in hospital, or in a specialised unit, are shaped by the perspectives of multiple people involved in the child's care. Parents may favor home to maintain a familiar environment, while siblings, relatives, or close family members may have concerns about experiencing death within the family home or, conversely, may view the hospital as too emotionally burdensome. Non-specialised professionals can further influence decisions through differing messages about safety, available support, and practical feasibility. These sometimes conflicting views make decision-making complex and affect care planning, symptom management, professional support, and the overall end-of-life experience for the child and family.
- **Refusal of home adaptation or equipment**: Some families are reluctant to install essential medical equipment at home, such as hospital beds, infusion pumps, comfort devices, or monitoring systems, because they fear it will transform the home into a medicalized environment. These concerns are often shared or reinforced by siblings, relatives, and informal caregivers who worry about the emotional and symbolic impact of the equipment on family life and on other children in the household. In addition, non-specialist healthcare professionals may express doubts about the practicality of home-based care, further strengthening hesitation. As a result, families may delay or refuse equipment that is necessary for the child's comfort and for effective home care, limiting symptom management options and making paediatric palliative care support more difficult to provide.

Parental bond with an adolescent with an advanced disease

The parental bond, based on a deep knowledge of the adolescent's values and preferences, positions parents as central defenders of their children' rights, interests and beliefs, and considers themselves as the ideal link between health professionals and their child. However, these family dynamics can also have a bidirectional impact on the autonomy of the **adolescents**: family involvement can support the decision-making process but can also limit adolescence agency, particularly when conflicting perspectives or reluctance to engage in end-of-life discussion arise. [255]

9.3.3 Dynamics between family and HCPs determining the access to appropriate PPC management

9.3.3.1 Needs and experiences of HCPs

Table 25 – Overview of domains of experiences and commonly reported experiences related to HCPs

Domains of (unmet) needs/experiences	Commonly reported experiences
Emotional burden [268–271]	• **Emotionally distressing**: Nurses described caring for dying children as exhausting, heartbreaking, and contrary to the natural order of life. Feelings included sorrow, helplessness, guilt, regret, grief, frustration, and emotional burden. Emotionally demanding and distressing, particularly during the transition from curative treatment to palliative care Grief, sadness, and emotional suffering following a child's death Emotional withdrawal or distancing as a coping strategy, compassion fatigue and burnout • **Strong relationships intensify loss**: Long-term care often leads to close bonds with children and families, making deaths particularly difficult and personally impactful, difficulty witnessing parental distress and suffering, blur professional boundaries, difficulty becoming emotionally attached to infants

Domains of (unmet) needs/experiences	Commonly reported experiences
	and families and then experiencing loss, challenges balancing empathy with professional distance • **Personal impact beyond work**: Many nurses reported taking the emotional burden home, affecting family relationships and wellbeing. Some felt isolated because others could not fully understand their experiences
Positive and meaningful experiences *268*	• Making a difference: Nurses gained **professional satisfaction** from reducing suffering, supporting families, and helping achieve a "good death" for the child. • **Personal growth and resilience**: Caring for seriously ill children helped nurses appreciate life, develop resilience, and find meaning in their work. • **Professional fulfilment**: Many viewed paediatric palliative care as a privilege and valued the opportunity to provide compassionate, high-quality care.
Communication difficulties *268–270*	Nurses often struggled with **conversations** about prognosis, dying, treatment withdrawal, maintaining hope while being honest with families, answering difficult questions from children, supporting grieving parents, managing family conflict and strong emotions, navigating **cultural expectations** about disclosure of diagnosis and prognosis, balancing hope with realistic expectations, navigating disagreements between provider recommendations and parental wishes
Knowledge *268*	**Limited knowledge and confidence**: Many felt inadequately prepared, particularly novice nurses, due to lack of paediatric palliative care education and limited exposure to dying children.
Ethical issues *268–270*	**Moral and professional dilemmas:** Nurses experienced distress when aggressive treatments continued despite poor prognosis, or when they felt their input was not considered by the medical team, technology was used to prolong life without perceived benefit, they felt children were experiencing unnecessary suffering, their professional judgement differed from treatment decisions being made by physicians **Fear of getting it wrong:** The complexity and rarity of paediatric end-of-life situations created anxiety about symptom management and decision-making, feelings of professional inadequacy (‘I didn’t do enough’)
Organizational and resource barriers *269,270*	• **Workload**: Staffing shortages limited time with children and families, heavy workloads reduced opportunities for compassionate care, insufficient institutional support hindered quality palliative care • **Guidance support**: lack of guidelines and support services created additional stress • **Variability in clinical practice**: inconsistent approaches to resuscitation decisions, different interpretations of DNR orders, lack of institutional guidelines, uncertainty regarding symptom management and comfort care practices • **Home envrionment**: HCPs need to work independently in unfamiliar and unpredictable environments with limited resources and equipment, HCPs reported needing confidence and expertise beasue appearing unprepared could cause distress for both staff and families. Home-based PPC was perceived as more time-consuming and less predictable than adult PC. Struggles to balance medical procedures, emergency calls, emotional support for families, travel and coordination demands
Tensions between physician and nurses	• **Physicians:** primarly responsible for treatment decisions, generally reported greater confidence in PC delivery

Domains of (unmet) needs/experiences	Commonly reported experiences
270	• **Nurses:** focused on family support, advocacy, comfort, and memory-making, often felt excluded from care decisions despite being closest to the infant and family, reported that they frequently detetced infant suffereing earlier than others • **Team collaboration:** difficulties with communication across services, unclear roles and responsibilities, poor information-sharing systems, coordination between hospital and community providers

Table 26 – Overview of domains of needs and key aspects

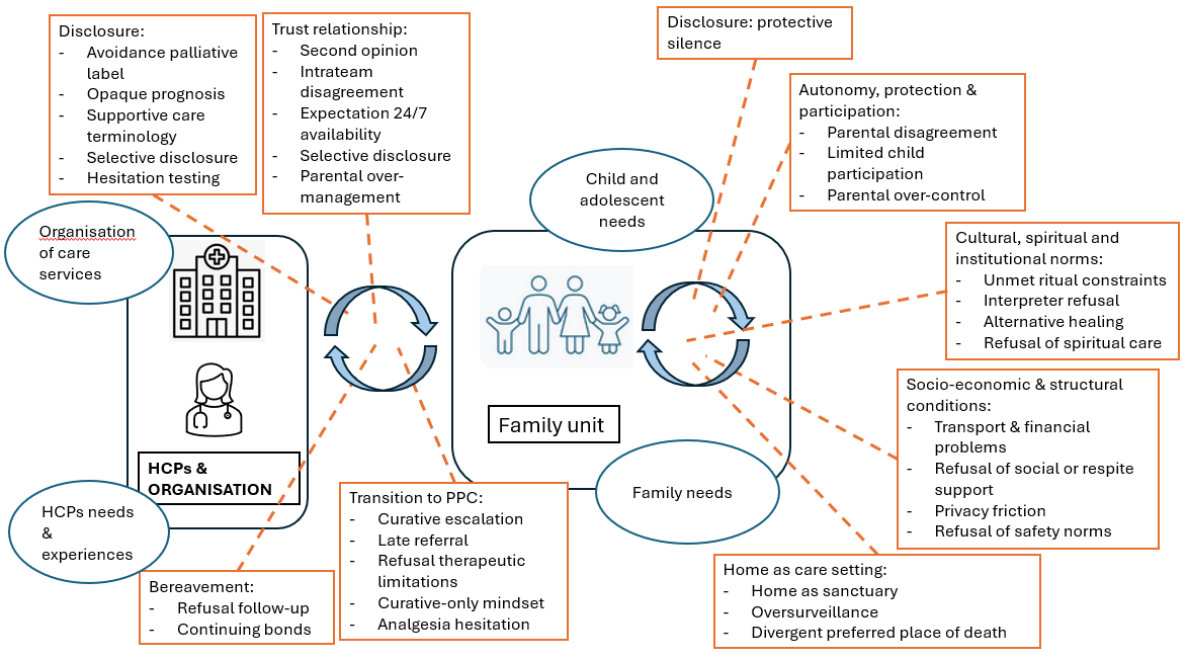
Domain of needs	Key aspects within each domain
Education and training 268–271	• More paediatric palliative care education in undergraduate and postgraduate nursing programmes. • Training in symptom management, end-of-life care (including bereavement and grief support), advance care planning, and communication skills (e.g., age-appropriate communication with children, difficult conversations, responding to emotional reactions, cultural sensitivity) • Opportunities for ongoing professional development and practical learning
Emotional and psychological support 268–271	• Regular/structured debriefing following child deaths, grief support programs • Access to counselling, mindfulness programmes, and wellbeing supports, strategies for self-care and resilience • Organisational strategies to reduce burnout, compassion fatigue, and emotional distress. • Peer support progams
Support for family communication 269	• Practical skills and confidence to: support distressed families, manage conflict with parents, help families transition from curative to palliative goal, respond to difficult questions from children and parents
To be connected and engaged with the child and family 271	• To build a trusting relationship with the child and family: understand family circumstances, involve children appropriately in care discussion • To respond to the family's need in time
To be part of a dedicated team 271	• Effective collaboration within and across services, clear role definitions, better communication across services, access to specialist PPC teams • Guidance and support from healthcare personnel (experienced colleagues)
To ensure the quality of home-based PPC service 271	• To estbalish an equitable and sustainable service • Continuous professional development in PPC • To be prepared when caring for a child at home: sufficient knowledge and skills to manage symptom management, medication management, medical devised and equipment, ethical dilemmas, paediatric disease progression • Time for family-centred care in home care and professional development
Mentorship and clinical support 268	• Guidance from experienced nurses and senior clinicians. • Structured mentorship programmes for novice nurses. • Peer support and opportunities to learn from experienced colleagues
Organisational and policy support 268–271	• Clear standards, guidelines, and care pathways for paediatric palliative care. • Greater recognition of nurses' contributions to decision-making.

Domain of needs	Key aspects within each domain
	• Dedicated resources and environments to support children and families at end of life, more time with children and families • Adequate staffing levels, sustainable workloads • Access to counseling and specialist support services • Out-of-hours support in home care • Access to equipment and resources in home care

9.3.3.2 Dynamics between family and HCPs

When a family is faced with a palliative care situation, internal family dynamics interact with relationships between the family and healthcare professionals, adding layers of complexity to the acceptance of palliative care (see Figure 38). As parents move through an evolving process from actively seeking curative care, to resisting palliative care, and eventually to accepting paediatric palliative care, healthcare professionals must accompany and gently guide this trajectory, encouraging acceptance without compromising the trust they have built with the child and the family.

Figure 35 – Overview of the ethical tensions between family and healthcare professionals (see orange boxes at the centre of the figure)



Impact of tensions about disclosure and truth management on the dynamics between family and HCPs

The ways in which information about prognosis, disease evolution, and the palliative orientation of care is communicated can have its impact on access to PPC. The communication can be delayed, reframed, or withheld, reflecting the tensions between honesty and protection, between timing and readiness, and between professional duties and family coping strategies. These tensions or dynamics often influence how and when PPC is recognized, named and accepted, frequently leading to delays or misidentification of palliative needs when communication is incomplete, unclear or deliberately moderated.

Our ethical analysis identified following tensions about disclosure and truth management between the family and HCPs and how these dynamics impact acceptability and access to PPC:

- **Avoidance of the "palliative label"**: Denial of a child's palliative condition is common and reinforced by parents, relatives, and sometimes professionals who maintain hope or avoid clear communication. Parents may rely on vague signs of improvement, memories of past clinical recoveries, or family narratives that praise perseverance and fighting spirit. Relatives, siblings, or the wider community can reinforce this stance by insisting that "nothing has been decided yet" or that "one must continue as long as there is still a chance" making it difficult to accept a shift in goals. In addition, some professionals who are not specialised in paediatric palliative care may adopt a cautious or ambiguous attitude, attempting to sustain hope or avoid overly direct communication, thereby maintaining the idea that a turnaround is still possible. This semantic avoidance delays recognition of palliative needs complicates decision-making and prevents ealry orientation toward appropriate (PPC) care.
- **Gradual or opaque prognosis:** Gradual, cautious, or unclear communication about prognosis can prevent a shared understanding of the situation. This ambiguity is reinforced not only by parents and other family members but also by some professionals (not specialised in PPC) who maintain vagueness or optimism. As a result, parents receive mixed or incomplete messages, leading to confusion, anxiety, difficulty planning ahead, and delayed recognition of the palliative phase, ultimately limiting timely access to appropriate care.
- **"Supportive care" terminology as bridge:** When the term "palliative" is resisted, PPC teams may use "supportive care" as a softer alternative, influenced by family members and non-specialist professionals who prefer less emotionally charged language. While this can ease initial engagement to PPC while preserving relational trust between the family and the HCP, it can also create misunderstanding, as families may not recognize the palliative intent, delaying clear decision-making and full acknowledgment of PPC care goals.
- **Selective disclosure to school/community:** Families may choose to share only partial or softened information about the child's condition with schools, relatives, or the community, often encouraged by their entourage and sometimes reinforced by professionals (not specialised in PPC) using cautious language. This leads to fragmented communication, leaving others without the information needed to provide appropriate support, which complicates coordination, delays necessary adjustments, and hinders consistent palliative care.
- **Hesitation with genetic testing/counselling:** Hesitation to seek genetic counseling or testing is influenced by parents' fears for a hereditary disease, family concerns about stigma or future implications, and sometimes unclear communication from non-specialist professionals. These combined influences can lead to delays or (temporary) refusal of genetic testing, hindering understanding of the prognosis, slowing necessary adjustments, and potentially postponing timely palliative care decisions.

Impact of tensions about the care relationship between family and HCPs

The care relationship between family and HCPs requires relational labour and communication load to maintain trust and coordination within this care relationship. However, tensions arising from this care relationship may impact the trust between actors and consequently delay or hamper the access to appropriate care.

Our ethical analysis identified following tensions about the care relationship between family and HCPs and how these dynamics impact acceptability and access to PPC:

- **Second opinion both as trust breaking and restoration**: A second opinion can provide clarity, but it often arises in a context where trust in the treatment team is weakened. Parents may be influenced by relatives, friends, or non-specialised professionals who suggest there are alternative options or more optimistic perspectives. This can lead to fragmented information, more

people involved in discussions, and delays in palliative decision-making. Ultimately, it can put further strain on trust and make it harder to establish a coherent care plan for the child.

- **Intra-team disagreement and role diffusion:** Inconsistent messages from different care team members about prognosis, treatment options, or the timing of paediatric palliative care, undermine families' trust and create uncertainty. This is amplified when non-specialised professionals provide incomplete or more optimistic information, leading to conflicting perspectives. Family members may further encourage parents to seek advice that aligns with their hopes, and so increasing fragmentation of information. As a result, parents consult more people, communication becomes more complex, and it becomes harder to establish a clear, coordinated narrative and to initiate a structured palliative care approach in a timely way.
- **Expectation of 24/7 availability**: Some families come to expect near-constant availability from the care team, seeking immediate responses at any time. These expectations are often reinforced by relatives or non-specialised professionals, who encourage frequent contact out of concern and may unintentionally suggest the team is always immediately accessible. This leads to frequent requests, sometimes disproportionate to clinical urgency. When immediate responses are not possible, parents may feel unsupported, leading to frustration, anxiety, or distrust, and creating tensions that can disrupt stable and continuous palliative care.
- **Mental load related to parental over-management**: Mental overload in parents arises from simultaneously managing multiple responsibilities, including monitoring symptoms, organizing care, anticipating crises, and communicating with others. Expectations from family members and the delegation of tasks by non-specialised professionals further reinforce their sense of sole responsibility. These combined pressures lead to constant vigilance and increased stress, reducing parents' emotional availability and sometimes making it harder for them to accept a palliative approach, which may feel like a loss of control.

Impact of tensions about bereavement after the child's death

Bereavement in paediatric palliative care extends beyond the moment of a child's death, shaping ongoing relationships and coping processes within families. Interactions with care professionals may also continue after the child's death, though these ongoing relationships can sometimes give rise to tensions.

Our ethical analysis identified following tensions about dynamics between HCPs and the family after the child's death and how these dynamics may interfere with acceptability of bereavement care.

- **Refusal of post-death follow-up**: Some families refuse any contact after the child's death, withdrawing from follow-up support as a way to cope with the immediate emotional impact. This distancing may be reinforced by relatives or non-specialised care professionals who, often unintentionally, encourage a break or fail to communicate about available support. While this reaction is not a rejection of professionals, it can limit opportunities to address unanswered questions or receive bereavement support. In such cases, future access to care may depend on whether actors around the family help facilitate renewed contact.
- **Continuing bonds with the team:** After a child's death, some families seek to maintain close and ongoing contact with the palliative care team through visits, calls, or shared rituals. This continued connection may be reinforced by relatives or other professionals who view the team as a key source of support (also for themselves). While initially helpful, this prolonged relationship can become more complex if the team takes on a central or substitutive support role. Such intensity may create challenges, offering comfort to families but potentially leading to emotional strain for professionals, and influencing how families grieve and engage with other support resources.

Impact of tensions about the transition to palliative care

The transition from curative to palliative care is rarely a clear or linear process. Decisions about this transition process are often influenced by hope, uncertainty, professional perceptions and knowledge about PPC. As a result, several barriers may delay the timely integration of paediatric palliative care.

Our ethical analysis identified the following tensions that can interfere with the transition between curative and palliative orientation of care and influence the acceptability of paediatric palliative care.

- **Curative escalation ("one more treatment")**: Curative escalation occurs when aggressive treatments continue despite an increasingly unfavorable balance between benefits and burdens. Families may seek "one more treatment" or intervention, often encouraged by relatives, community members, or healthcare professionals who maintain hope that further curative options may still succeed. These multiple and sometimes conflicting influences reinforce expectations of recovery and make it more difficult for families to recognize the need for paediatric palliative care. As a result, referral to PPC is often delayed until therapeutic options have been exhausted, limiting opportunities for earlier planning and support.
- **Postponement of palliative care**: Late referral to paediatric palliative care often results from a combination of prognostic uncertainty, reluctance to discuss a change in goals of care, cultural emphasis on cure, and limited understanding of the scope of paediatric palliative care. Family members and close relatives may reinforce the belief that it is "too early" to consider palliative care, while non-specialised professionals may contribute to delays through cautious optimism, ambiguous communication, or hesitation to involve a palliative care team. These overlapping influences often postpone advance care planning, symptom management, and psychosocial support, leading to a rushed transition to palliative care and increasing the emotional burden on families.
- **Refusal of therapeutic limitations (DNR/withdrawal)**: Refusal of a DNR order or of treatment limitation/withdrawal often occurs within a context where multiple actors shape decision-making. Family members, relatives, and informal caregivers may encourage the continuation of life-sustaining interventions, viewing treatment withdrawal as "giving up" on the child. At the same time, non-specialised professionals may convey cautious or ambiguous messages that sustain hope for recovery despite a poor prognosis. These overlapping emotional, moral, cultural, and professional influences can delay decisions about treatment limitations, prolong interventions that no longer align with the child's clinical condition, and make the integration of paediatric palliative care more difficult and conflictual.
- **"Curative-only" mindset:** A "curative-only" mindset arises when the focus remains exclusively on cure despite an unfavorable prognosis. This approach is often reinforced by relatives and non-specialised professionals who encourage continued active treatment and view palliative care as giving up. Optimistic or treatment-focused messages can sustain the belief that recovery remains possible, even when clinical realities suggest otherwise. These combined influences hinder advance care planning, delay access to paediatric palliative care, and may expose the child to disproportionate or non-beneficial interventions that no longer align with the disease trajectory.
- **Opioid/analgesia hesitation**: Hesitation toward opioid use is often driven by fears and misconceptions shared within the family and social environment, including concerns about addiction, hastened death, sedation, or the belief that analgesia signals the final stage of life. These concerns may be reinforced by relatives and sometimes by non-specialised professionals who express uncertainty about opioid use. As a result, parents may delay, reduce, or refuse recommended pain management, leading to inadequate symptom control and increased suffering for the child. Such beliefs can also hinder the implementation of paediatric palliative care by incorrectly associating it solely with end-of-life care.

9.3.4 Organisation of care services to address the complexity of PPC

The organisation of care services plays a crucial role in responding to the complexity of paediatric palliative care.[251] Given the multidimensional and evolving needs of children with life-limiting or life-threatening conditions and their families, the healthcare system must be able to provide coordinated, flexible, and specialised support across settings and over time. [251]

A key element in managing this complexity is **care coordination**. Effective coordination helps reduce the burden associated with navigating multiple services, professionals, and care settings by ensuring that care is organised efficiently and responds appropriately to changing and complex needs. **Multidisciplinary collaboration**, including regular multidisciplinary team meetings, is particularly important for children with complex medical, psychosocial, and spiritual needs. By bringing together different professional perspectives, multidisciplinary teams can facilitate comprehensive assessment, shared decision-making, and continuity of care throughout the illness trajectory. [251]

The acceptability and accessibility of PPC are also influenced by the **availability and capacity of services**. Resource constraints, including workforce shortages, limited service availability, and geographical disparities, may restrict timely access to specialised palliative care. Families may encounter difficulties obtaining the support they need when services are overburdened or unavailable within their region. [251]

Beyond the healthcare system itself, the interactions between the system and other levels of care are equally important. **Communication within and between services** is essential to ensure continuity, avoid fragmentation, and maintain a coherent care plan. Poor communication between professionals, organisations, or care settings may lead to inconsistent messages, duplication of efforts, gaps in care, and increased uncertainty for families. (see also chapter 7 in scientific report) [251]

Finally, the ability of the healthcare system to respond adequately to PPC needs depends on the availability of **appropriate expertise**. A lack of knowledge or experience in paediatric palliative care among healthcare professionals may hinder the identification of palliative needs, delay referral to specialised services, and reduce confidence in managing complex situations. Strengthening PPC competencies across healthcare settings is therefore essential to ensure that children and families receive timely, appropriate, and acceptable care (see also chapter 7 in scientific report). [251]

In the next chapters a more in-depth analysis has been performed on the barriers and facilitators in the current Belgian offer and how the proposed solutions may improve accessibility to PPC (see chapter 6 in scientific report).

9.3.5 Societal attitude towards the death of a child

At the macrosystem level, the acceptability of paediatric palliative care is influenced not only by the characteristics of children, families, healthcare professionals, and services, but also by broader societal attitudes towards serious childhood illness, death, and dying. These societal beliefs shape how palliative care is perceived, discussed, and integrated into the care trajectory. [249,251]

One of the most prominent manifestations of this phenomenon is the avoidance of the term "palliative care." (as shown in our ethical analysis) The word "palliative" is often strongly associated with imminent death, therapeutic failure, or the abandonment of curative efforts. As a result, families and professionals may prefer alternative terminology such as "supportive care" or may postpone conversations about palliative care altogether. While such semantic strategies may initially help preserve hope and facilitate discussions about supportive interventions, they may also obscure the broader goals and benefits of PPC. This semantic avoidance can delay the recognition of palliative needs, hinder timely referral to specialised services, and contribute to the late integration of PPC into the child's care trajectory.

Experts report that, in the case of life-threatening but potentially curable conditions, the term “palliative” constitutes a major barrier to the early introduction of PPC by professionals although PPC is not restricted to the end-of-life phase (stakeholder consultation). Members of PLTs must reiterate this

message almost daily. Some even propose using multiple terms (palliative care, continuous care, comfort care, supportive care) to facilitate its acceptance by families and professionals (stakeholder consultation).

Societal attitudes may also reinforce a predominantly curative orientation of healthcare (cfr. ethical tensions on 'refusal of therapeutic limitations', 'curative-only mindset', 'curative escalation'). The expectation that medicine should primarily aim to cure and prolong life can make it difficult to shift toward goals focused on comfort, quality of life, and psychosocial support. Families may feel social pressure to continue pursuing active treatment, while healthcare professionals may hesitate to introduce palliative care for fear of being perceived as giving up. Such dynamics can contribute to delayed discussions about proportionality of treatment, advance care planning, and symptom-focused care.

Furthermore, societal taboos surrounding death and grief may limit opportunities for open communication about the child's prognosis, future care needs, and end-of-life preferences. When discussions about death are avoided or considered inappropriate, children and families may receive less support in expressing fears, hopes, values, and wishes. This can affect the development of a shared understanding of the illness trajectory and reduce the acceptability of palliative care interventions.

Facilitators to reduce societal taboos and to promote public awareness are more in-depth analysed in the following chapters.

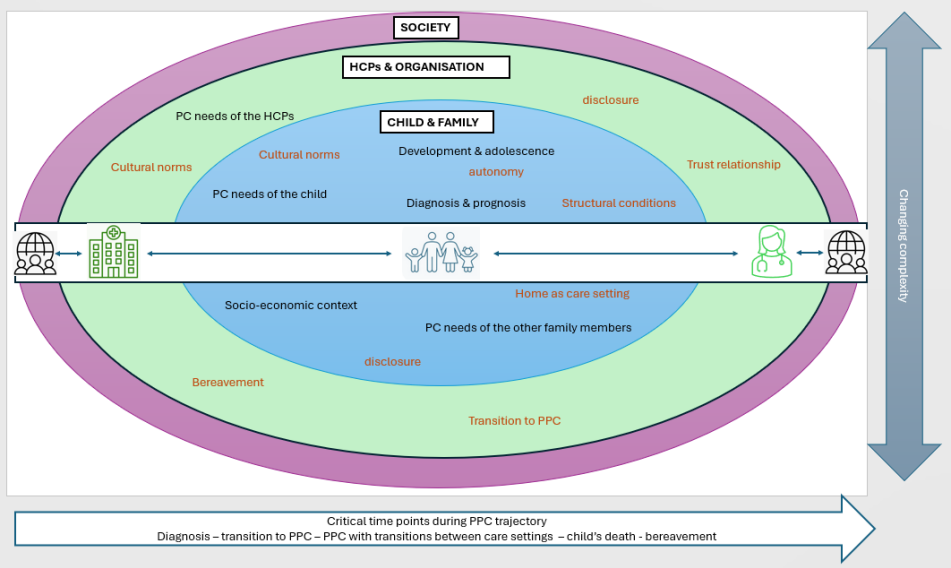
9.4 Transversal analysis of acceptability as a complex and multidimensional dimension of access to PPC

9.4.1 From a literature point of view

Consistent with the Levesque framework[248], acceptability reflects the extent to which PPC is perceived as compatible with the values, expectations, beliefs, needs and life circumstances of a variety of actors involved. In PPC, acceptability is particularly complex due to the variety and the multiple actors involved with potentially divergent perspectives. In this chapter, a stepwise approach was adopted to illustrate the growing complexity underlying the acceptability of paediatric palliative care. The analysis began with the perspective of the child, exploring the factors that may influence a child's acceptance of PPC. It then broadened to incorporate the perspective of the family, recognising the family as an integral part of the child's care experience. Subsequently, attention was given to the dynamic interactions between the child, the family, and healthcare professionals, highlighting how these relationships shape perceptions and acceptance of PPC. Finally, the analysis briefly considered the influence of broader societal attitudes towards childhood illness, death, and dying, acknowledging their role in shaping the context within which PPC is understood and accepted.

Figure 39 gives an overview of the dynamic interactions between the children, families, HCPs, care services and society. Across the analysis of the different perspectives and the dynamic interactions in between, following key determinants could be identified.

Figure 36 – Dynamic interactions between different system levels across a care trajectory



9.4.1.1 A child-and-family centred complexity

A first transversal finding is that PPC differs fundamentally from adult palliative care because the child cannot be considered in isolation. The family functions as a second microsystem surrounding the child, influencing virtually every aspect of care, including communication, decision-making, care coordination, symptom management, and end-of-life planning. Whereas autonomy is generally the dominant ethical principle in adult palliative care, PPC requires a continuous balancing between the child's evolving autonomy and the protective role of parents and caregivers.

The exploratory analysis of the literature showed that acceptability is therefore not only determined by the child's preferences and experiences but also by family beliefs, coping strategies, emotional burden, cultural values, and practical capacities. Furthermore, the interests and perspectives of the child and family do not always align. Tensions may arise when parents prioritize protection over participation, when adolescents seek greater involvement in decision-making, or when family members hold different views regarding treatment goals, prognosis, or end-of-life care.

9.4.1.2 Acceptability as a dynamic and evolving process

Across the presented findings, acceptability appeared as a dynamic process that changes throughout the **illness trajectory**. The needs, preferences, and coping mechanisms of children and families evolve in response to diagnosis, disease progression (with stable and unstable phases), treatment experiences, transition from childhood to adolescence and post-death.

At diagnosis, families often experience uncertainty, shock, and information overload. During active disease management, concerns shift toward symptom control, maintaining normality, preserving family functioning, and balancing treatment burden with quality of life. As illness progresses, discussions around futility, advance care planning, preferred care settings, and end-of-life decisions become increasingly relevant. After the child's death, families continue to have needs related to grief, bereavement, and meaning making.

This temporal dimension suggests that acceptability should not be conceptualized as a single, static dimension (e.g., accepting a referral to PPC), but rather as an ongoing negotiation process. A family that initially rejects PPC may later embrace it, while families who initially engage may subsequently encounter new barriers due to changing circumstances or increasing caregiver burden.

9.4.1.3 The three-dimensional nature of complexity

Complexity in PC is commonly characterized as the number, severity and interactions of different needs domains and often ranked in levels of complexity (no complexity, low, medium, high).[251] Pask et al, 2018 [251] developed a framework for complexity in (adult) palliative care in which three dimensions of complexity has been considered:

- **Pre-existing complexity**: Complexity can already exist before the start of PC (e.g., long-standing difficulties with finances and or housing, dependents, bereavements, mental health needs, homelessness, substance misuse, relationships and lifestyle). The diagnosis of a life-limiting condition is therefore often superimposed upon pre-existing vulnerabilities.
- **Cumulative complexity**: Complexity often arises from the accumulation of multiple problems across several or all domains of need. In some cases, a single severe issue may generate highly complex needs, as its consequences can cascade across and affect multiple areas of the patient's life. For example, uncertainty about prognosis may coexist with communication difficulties, financial stress, caregiver exhaustion, cultural barriers, and fragmented service provision. These intersecting challenges create a level of complexity that exceeds the sum of individual difficulties.
- **Changing complexity over time**: This refers to changes in patient's needs, circumstances and environment over time. In PC, it is often reflected by the uncertainty related to disease trajectory and care. Other aspects of time were also seen to influence complexity over time, such as long-term caregiver burden (often linked to a longer duration of needs), late referral in non-cancer or shorter disease trajectory. PC needs are fluctuating, dynamic and sometimes rapidly changing. Immediate needs influence complexity and require timeliness of care, prioritisation and rapid caseload decisions.

  An illustration of the changing complexity over time was found in the review of Thomas, 2023 [261] on how informational needs of the parents of children with cancer evolve over time across the different stages of care. In the period immediately following diagnosis, parents most frequently reported unmet informational needs about care and communication needs. During the treatment phase, parents were more in need for child appropriate information and for supportive care including training for financial issues or insurance, and help for child's emotional state. In the post-treatment phase, the informational needs shifted more towards need for information about future services, late and long-term effects, how to set up the communication with school and how to manage emotions.

Complexity was not usefully captured as a snapshot but needed regular review to ensure that services are responsive and flexible to the changing needs

9.4.1.4 Communication and trust as overarching determinants

Perhaps the most consistent transversal finding concerns the central role of communication and trust.

Across nearly all identified barriers and facilitators, acceptability appeared strongly dependent on whether children and families experienced **communication** as honest, respectful, understandable, and emotionally sensitive. Communication difficulties were present in discussions about prognosis, advance care planning, treatment limitations, symptom management, spiritual care, genetic counselling, and end-of-life decisions.

Several of the identified ethical tensions, including avoidance of the "palliative" label, protective silence, selective disclosure, interpreter refusal, and gradual or opaque communication about prognosis, ultimately reflect challenges in establishing a shared understanding of the child's situation.

Trust functions as the mechanism through which these communication processes influence acceptability. When trust is established, families may be more willing to discuss difficult topics, consider palliative approaches, engage in shared decision-making, and accept supportive interventions. Conversely, inconsistent messaging, fragmented communication, lack of continuity, or perceived disregard for family values may erode trust and increase resistance to PPC.

Also, **dissonance** between the involved actors may increase the complexity: differences in preferences, or spiritual beliefs between patients and professionals may lead to misinterpretations or affect experience of care. Also, dissonance between patients and family wishes may increase complexity. [251]

Lack of engagement may increase complexity and is related to patients declining opportunities to talk about care at end-of-life and some patient groups (e.g., substance misusers) that struggle at times to interact with healthcare services. Lack of engagement can also lead to **invisible or hidden complexity**, when people do not engage with healthcare services (e.g., people with long-standing depression). [251]

Perceptions and prejudice are also considered to influence care and complexity: some diseases are stigmatized, which triggers a different social response from family and professionals, and impede a patient or family's freedom to disclose information. [251]

9.4.1.5 The central tension between hope and acceptance

Another transversal theme is the continuous tension between maintaining hope and accepting the realities of a life-limiting condition.

This tension was evident in many of the ethical patterns identified: avoidance of the palliative label; curative escalation ("one more treatment"); late referral to PPC; refusal of therapeutic limitations; alternative or miracle-healing beliefs; reluctance to discuss prognosis or death.

Importantly, these tensions should not be viewed simply as barriers or denial. They often represent coping strategies through which families attempt to preserve hope, maintain parental identity, and sustain meaning in the face of uncertainty.

The challenge for PPC services is therefore not to replace hope with acceptance, but rather to support a gradual reframing of hope, from cure toward comfort, quality of life, meaningful experiences, symptom relief, family connection, legacy-building, and dignity.

9.4.1.6 The importance of developmental and relational autonomy

Children's capacity for participation in decision-making evolves across developmental stages and is influenced by age, cognitive abilities, maturity, communication skills, illness burden, and family dynamics. Adolescents in particular often expressed needs for information, involvement, independence, control, and recognition as active participants in their own care journey.

At the same time, PPC takes place within relational contexts where decisions are rarely made by the child alone. Families often view themselves as protectors, advocates, and interpreters of their child's interests. Consequently, acceptability often depends on achieving a balance between child participation, parental responsibility, and professional guidance rather than exclusively privileging one perspective.

9.4.1.7 Acceptability across all domains of PC needs

Acceptability extends far beyond medical decision-making. Families evaluate PPC in relation to its impact on everyday life, family functioning, identity, spiritual meaning, social participation, and practical feasibility. Issues such as transportation, home adaptations, respite care, financial support, sibling wellbeing, cultural sensitivity, continuity of care, place of care, and place of death all influence whether PPC is perceived as acceptable. The acceptability of care is therefore closely linked to the healthcare system's ability to accommodate complexity and respond flexibly to diverse family circumstances.

9.4.2 From an ethical point of view

Three main findings emerged from the combination of the transversal analysis of the 32 patterns resulting from the ethics literature analysis, the consultation of PPC experts on those patterns and a theory-informed interpretative analysis.

First, ethical tensions influencing PPC access concentrate around transitional moments of the care trajectory, particularly diagnosis, prognostic disclosure, and the progressive shift from curative to palliative orientations. Second, access to PPC appears as a process unfolding over time through interacting with ethical, relational, organisational, and structural determinants rather than as a binary referral event. Third, PPC access unfolds within asynchronous trajectories among the involved actors (children, families, HCPs) whose rhythms of understanding, readiness, and meaning-making may remain misaligned.

9.4.2.1 Transitional moments of the care trajectory

The diagnostic moment as an ethical crossroad

The diagnostic moment constitutes a major ethical inflection point in the trajectory of children with life-limiting or life-threatening conditions. Although certain conditions may be recognised as potentially palliative from the outset, a diagnosis does not automatically lead to PPC integration (see also chapter 3 and 7 in scientific report). At this stage, families and professionals are often oriented toward clarification, treatment possibilities, and preservation of hope.

From an ethical perspective, prognostic uncertainty and disclosure practices shape whether a palliative approach becomes conceivable. Diagnosis therefore functions less as a mechanical referral threshold than as the beginning of a progressive reinterpretation of illness, proportionality, and care goals. Episodes of relapse or deterioration may subsequently reactivate these tensions, functioning as renewed moments of ethical uncertainty and anticipatory negotiation.

The Curative–Palliative Transition

The transition from curative to palliative orientation represents a central ethical threshold within the care trajectory. Therapeutic escalation, treatment proportionality, referral timing, and redefinition of goals of care become particularly visible during this phase.

This transition rarely occurs abruptly and often reflects divergent interpretations of benefit, harm, responsibility, and hope across stakeholders. Continuing curative treatment may sustain a sense of moral agency for both families and professionals, even when proportionality becomes uncertain.

The analysis also highlights the temporal asymmetry between actors involved in PPC trajectories. Children, parents, non-specialised clinicians, and PPC teams may evolve according to different rhythms of understanding and acceptance. When these trajectories remain misaligned, PPC integration may be delayed or compressed into crisis situations. Conversely, ethically attentive accompaniment may facilitate more progressive and coherent integration.

9.4.2.2 Process unfolding over time

Complexity Rather than Statistical Convergence

The field consultation revealed variability in how patterns were perceived in terms of relevance, frequency, and complexity across teams and contexts. Its principal contribution was therefore interpretative rather than statistical. Difficulties in accessing PPC appeared less related to isolated barriers than to the co-occurrence of several ethical, relational, organisational, and temporal mechanisms within the same situation. The findings consequently support an understanding of PPC access as a dynamic and multidimensional process in which conflict patterns interact and accumulate across care trajectories.

Access to PPC as a Stratified and Non-Binary Process

The analysis suggests that access to PPC cannot be reduced to referral to a specialised team. Rather, it unfolds as a stratified process involving several layers of integration.

First, access concerns recognition of palliative needs and integration of PPC services. Second, it involves access to essential PPC components such as psychosocial, spiritual, ethical, and interdisciplinary support. Third, it concerns continuity and coherence of care across settings and phases of the illness trajectory.

Barriers may therefore appear as delayed referral, partial integration, fragmented continuity or unstable coordination. Access to PPC should consequently be understood as an evolving configuration shaped by temporal, relational, and organisational conditions.

9.4.2.3 Asynchronous trajectories among the involved actors

Ethical Interpretation of Delay: The Unthinkable and the Ethics of Time

Beyond organisational explanations, the findings support a broader ethical interpretation of delayed access to paediatric palliative care. Many barriers appear linked to the difficulty of confronting what remains, in many societies and institutions, an "unthinkable" horizon: the severe illness and possible death of a child. Delays should therefore not be interpreted merely as denial or communication failure but as ethically intelligible mediations through which actors attempt to maintain meaning, responsibility, and moral orientation in situations that profoundly destabilise expectations.

In paediatrics, the possibility that a child may die challenges deeply rooted moral assumptions: childhood as promise, medicine as restoration, and parenthood as protection. When these expectations are disrupted, actors may maintain curative frames longer than proportionality would suggest, postpone irreversible decisions, or redirect distress toward technical debates. Such responses can be understood as attempts to reconstruct moral intelligibility in situations that threaten established ethical categories.

From a principlist perspective, many barriers reflect tensions in redefining benefit, harm, and justice when cure is no longer a credible horizon. Non-maleficence may justify limiting burdensome treatments, yet it may also motivate continued escalation to avoid the perceived harm of "giving up." Beneficence may shift toward comfort and relational integrity, but this transition rarely occurs synchronously across actors. In paediatrics, autonomy is mediated through parents and professionals, while justice involves both resource distribution and recognition of whose interpretation of good care is legitimised.

Narrative ethics highlights how access to PPC is shaped by framing and storytelling. When "palliative" is equated with death, the term itself can threaten identities—parents as protectors, clinicians as healers, institutions as sites of therapeutic progress. Delayed disclosure, semantic reframing, or protective silence may therefore function as narrative strategies aimed at preserving a liveable story until new meanings can emerge.

Care ethics reframes resistance as a relational response to vulnerability. In contexts of uncertainty and impending loss, maintaining agency—"doing something"—can be ethically protective for parents and professionals alike. These responses express efforts to preserve responsibility, relational bonds, and hope. At the same time, care ethics draws attention to systemic vulnerabilities—burnout, time pressure, fragmented services—that shape whether accompaniment remains sustainable.

Cross-Cutting Ethical Insights

The analysis further suggests that narrative coherence between families, professionals, and institutions may facilitate earlier and less conflictual PPC integration, whereas divergent understandings of illness trajectories frequently contribute to delay.

Finally, relational virtues such as compassion, discernment, trustworthiness and integrity appear to function as stabilising factors within ethically fragile trajectories by sustaining communication, trust, and continuity of care.

9.5 A family-centred approach to embrace the complexity of PPC (solutions)

The ethics of time: asynchronous temporalities, thresholds, and "time to integrate"

Across the coding framework developed in ethical analysis, time emerges as a central ethical dimension shaping access to paediatric palliative care (PPC). The typology of conflict patterns identified in the literature shows that access depends not only on clinical indicators, but also on the time required for stakeholders to integrate diagnosis and prognosis, reorganise expectations, and progressively realign goals of care.

These temporal processes are rarely synchronised. Parents, children (when involved), non-specialist clinicians, and PPC teams often move through the illness trajectory at different rhythms of understanding and readiness. At the same time, institutional timelines and prognostic uncertainty create prolonged "grey zones" in which decisions are repeatedly deferred.

Many conflict patterns identified in this study can therefore be interpreted as forms of temporal management: delaying the naming of palliative care, maintaining therapeutic escalation, postponing limitation decisions, or fragmenting disclosure. These practices may function as transitional mechanisms allowing actors to approach a difficult reality gradually. Ethical difficulties arise when such deferral becomes structural, compressing PPC integration into late-stage crisis moments where choices are narrower and suffering harder to anticipate.

The ethical task implied by PPC: accompanying the unthinkable through a shared time and shared meaning

The findings suggest that barriers to PPC access are closely linked to the challenge of confronting what remains, for many actors, an "unthinkable" horizon: the serious illness and possible death of a child. Access to PPC therefore depends not only on organisational pathways, but also on the capacity of stakeholders to progressively construct a shared orientation toward care.

This requires convergence over time: shared thresholds for treatment proportionality, narrative frames that allow palliative care to be understood as active care, and relational conditions that sustain trust and communication across the trajectory. Improving access to PPC thus involves creating clinical environments that support this gradual ethical transition in meaning and goals of care.

9.5.1 Building a trustful relationship with the child

Building a trustful relationship between healthcare professionals and children is determined by a variety of factors, such as antecedents, attributes and consequences: [272]

- Antecedents: trustful relationships are more likely to develop when children are adequately prepared, supported by their parents, cared for by skilled professionals (requiring communication and relationship-building skills), given sufficient time and continuity, and treated within a child-friendly and well-organized healthcare environment (including staffing levels, resource availability, continuity of care, opportunities for repeated encounters with the same professionals, legal frameworks, children's rights policies, and cultural norms regarding child participation and communication).
- Attributes: encompass a range of interpersonal, communicative, and contextual factors.

  Trust is fostered when healthcare professionals demonstrate genuineness, empathy, respect, friendliness, and emotional presence, while making time to engage meaningfully with the child.

  Effective communication is central and includes using developmentally appropriate language, honest information sharing, a calm tone of voice, and positive non-verbal behaviours such as maintaining eye-level contact, smiling, and displaying relaxed body language.

  Building trust also involves getting to know the child as an individual, acknowledging and validating their emotions, and supporting their autonomy through opportunities for choice and

participation in care. Therapeutic strategies, including play, storytelling, distraction, and gradual familiarization with medical procedures, help reduce anxiety and create positive experiences.

Trust is further strengthened by parental and professional presence, continuity and familiarity of care, professional competence, and a child-friendly approach that reinforces safety, comfort, and confidence. Together, these attributes create an environment in which children feel respected, understood, secure, and empowered to engage in their healthcare

- Consequences: extend to children, parents, professionals, and healthcare organisations

  For children, trust is associated with improved emotional well-being, including greater self-confidence, self-advocacy, coping, acceptance of illness, and overall satisfaction with care, while reducing fear, anxiety, loneliness, and distress. Trust also contributes to better clinical outcomes by promoting cooperation during examinations and treatments, facilitating successful procedures, and improving health outcomes and recovery.

  For parents, seeing their child trust healthcare professionals increases satisfaction and confidence in the care provided.

  Healthcare professionals likewise benefit from stronger relationships, greater job satisfaction, reduced stress, and a willingness to invest more in the child's care.

  At the organizational level, trustful relationships may improve efficiency by reducing the length of hospital stays, facilitating future encounters, and decreasing the risk of medical errors and malpractice. Conversely, a lack of trust can lead to emotional distress, poorer cooperation, objectification of the child, conflict with families, and less effective care.

The review of Dickens et al. (2025)[272] highlight the complexity of trustful relationships between children and HCPs, emphasizing the importance of empathy, effective communication and a child-centred environment. The findings indicate also the relevance for specific, teachable competencies (such as communication and trust-building skills) in order to enhance child-provider dynamics, treatment efficacy and compassionate care delivery.

Table 27 – Core elements for trust-building and organisational modalities on the Belgian healthcare system: version used during stakeholder consultation

Objectives	Organisational modalities

Better recognise and valorise the time spent by healthcare providers, both in hospitals and in the community, on building a trust relationship by adapting the reimbursement system when paediatric palliative care is needed	• Adaptations to the reimbursement system, via:
	  ○ an hourly rate (see ongoing pilot projects for the financing of home nurses, evaluated by RIZIV/KCE)
	  ○ new nomenclature codes that value the time spent on conversations
	  ○ encouraging salaried employment status

	• Recording the activities of PLTs will help determine the most appropriate financing mechanisms for time investment in paediatric palliative care situations.
Extend the duration of the relationship between professionals and the family/child	• Early integration of PC services in care trajectory: Early identification of paediatric palliative care needs and immediate involvement of paediatric palliative care services.
Ensure stability of the established care relationship over time	• Enable long-term continuity of the relationship between the child (and their family) and one or a few fixed members of the PLT, in line with the concept of a reference person in palliative care. = Consider one or several members of the PLT as trusted point(s) of contact throughout the entire care trajectory
	• Actively prevent staff turnover within PLTs.

Objectives	Organisational modalities
COMMUNICATION SKILLS ***Ensure coherence in communication and information provided to the child and their family***	• Organisation of interdisciplinary consultation moments between curative and palliative care teams, involving all relevant disciplines. Decisions and agreements are recorded in the shared medical record, and the ACP (Advance Care Planning) section is systematically completed (within the hospital and across services). • Organisation of transmural consultation moments, bringing together healthcare providers from different levels of care. Decisions and agreements are recorded in the shared medical record, and the ACP section is systematically completed. Participants are reimbursed for their participation, which may also take place online. • Implementation of a shared medical record across different care settings. • Systematic use of a secure communication system (messaging) to maintain contact between healthcare providers, informal caregivers, the patient, and the family. A summary of the relevant information from this communication system is prepared for each intra- or transmural consultation.

The comments received during both the written and oral phases of the stakeholder consultation were consolidated, analysed, and incorporated into the table where appropriate. Subsequently, it was decided that this chapter would focus on the core elements and prerequisites for implementation, while the detailed organisational modalities would be addressed in the relevant chapters. This approach aims to avoid unnecessary repetition across the KCE report.

9.5.2 Empowerment of the child and family

9.5.2.1 A child-centred, individualised care plan

Developmental needs as one of the key drivers in the care plan

Core principles of a PPC plan include symptom management, management of psychological, social, spiritual needs, assessment of quality of life, communication, family support and coordination activities [257]. In addition to these core principles, our research identified the importance to take into account the developmental needs of the child.

The review of van Driessche, 2025[254] concluded that a significant gap still exists in understanding factors that impact the development of children with a serious illness and therefore a continuous monitoring of the development of the child throughout the illness trajectory is needed as key driver to support the child's engagement and to adapt the care plan in a developmentally appropriate way.

Age-appropriate psychological interventions such as play therapy, art therapy, and counselling were found to be beneficial but were inconsistently implemented. [253]

An ongoing process of needs assessment of the child and the family unit

Across the retrieved literature on paediatric palliative care needs, all authors agreed on the necessity to regularly assess the needs of the child and the family. In some reviews assessment tools and instruments were listed, but the exhaustive search for appropriate tools (and their psychometric properties for accuracy and reliability) were considered out-of-scope for this project. More profound research is needed to determine which tool(s) are the most appropriate and fitted to a child with an advanced disease and their family. Nevertheless, the clear conclusion on the appropriateness of assessment tools, it is recommended in clinical practice to regularly assess all domains of care needs.

Very recently the UK organisation Together for Short lives[273] published an updated version of the categories of care needs, adapted to increasing complexity, longer survival and variation in access across the system, and a support checklist to identify which children may benefit from a palliative care approach. This checklist consists of a red/amber/green rating tool covering the child and family needs, support networks, and practical needs such as finance, transport and education. The rating with colours helps to identify the urgency of a family's need and signpost them to the correct level of support (i.e., universal resources, core services or specialist clinical input)

- The domain of the child and family needs focuses on the immediate wellbeing and identity of the child and their closest caregivers, by assessing the physical and clinical needs (management of pain, distressing symptoms, and ensuring the child and family get enough rest and sleep), emotional wellbeing (supporting the mental health and resilience of the child, parents and siblings), identity, spiritual and cultural needs (respecting the family's values, beliefs and cultural preferences to ensure care "fits" their unique identity), planning (offering memory-making opportunities and preparing families for death of their child with compassion)
- The domain of support networks looks at the wider 'team' around the child and their social integration, with wider family and friends (assessing the needs of siblings, and the support available from extended family and the local community), faith and community (connecting families with their faith groups or local community-led support initiatives), respite and leisure (ensuring access to short breaks (respite care) and supporting the child's right to play and social interaction), education and work (helping the child stay in child care, school or college and supporting parents with thei employment needs)
- The domain of practical needs, in which the practicalities and financial security is assessed to maintain a safe home environment, with finance and benefits (ensuring the family is accessing all available support and grants), living environment (checking that housing is suitbale, accessible, and safe to the child and family's needs), equipement and transport (coordinating the medical technology, home adpatations, and transport needed for safe care), food and nutritition (ensuring the family can access appropriate nutrition to meet the child's specific medical needs)

The assessment of the needs should also take into account the fluctuating evolution of the condition, which may result that the child moves between phases of care needs in a non-linear way. These phases of care needs include

- the stable phase, in which the child' overall condition is relatively stable and predictable
- the unstable phase, in which the child's condition is fluctuating, unpredictable or changing, requiring closer review and adaptation of care
- deteriorating phase, in which the child's condition is showing a pattern of progressive decline, with increasing vulnerability and reduced response to interventions
- dying phase, in which the child is recognised to be approaching the end of life, where death is likely in the coming days or weeks

The above-mentioned checklist is mentioned here as an illustration of an assessment tool, covering all domains of care needs of the child and the family.

Adapting the care plan to the socio-cultural background of the family unit

Forced migrant parents in paediatric palliative care often experienced cultural and language barriers, including feeling ignored, excluded from decision-making, fearful of misusing services, and encountering cultural misunderstandings, discrimination, or racism. A **collaborative care approach** that respects divergent beliefs and supports parental advocacy was found to address these needs, although it requires additional time.[265]

Key facilitators included clear communication strategies (simplified language, interpreters, visual aids, and non-verbal communication), building trust through empathy and understanding families' migration

experiences, and improving access to services through care navigators, community support, and specialist healthcare providers. [265]

The review proposed a framework for **culturally sensitive care**, defined as effective and appropriate interactions, with a mutual understanding and respect of culture, to promote equity and meet individual need. [265] Essential elements include:

- on individual level: compassionate, empathetic non-judgemental approach (a philosophy of cultural humility), good parental coping mechanisms and support systems
- on relational level: mutually respectful relationships, individualized collaborative care with balancing of safety versus preference/comfort
- on structural level: access to professional interpreters and language aids, community and respite services, culturally informed HCPs, parental health literacy support, additional time with families, and linking of staff with similar cultures and ethnicities to families

When implemented, culturally sensitive care can increase parents' confidence, reduce anxiety and uncertainty, improve service access and advocacy, strengthen trust and mutual understanding, and enhance shared decision-making and care planning.

Table 28 – Core elements for an individualised care plan and organisational modalities: version used during stakeholder consultation

Objective	Organisational modalities
developmental needs as one of the key drivers in the care plan	• Contact with siblings, friends, school, and leisure activities should be maintained as much as possible. • Initiatives aimed at leisure activities and maintaining school participation should be supported.
NEW: An ongoing process of needs assessment of the child (and family unit) and assess PC needs early	
Adapting the care plan to the socio-cultural background of the family unit	Improve intercultural sensitivity among professionals involved in paediatric palliative care. • Every hospital should ensure access to ethicists, spiritual counsellors and intercultural mediators for its patients. If there is no waiting time possible for translation: use a digital translation tool. If waiting time is possible: arrange for a professional interpreter. Social vulnerability • Include a social worker within PLTs. • Prioritise financial support for the most vulnerable families (see ministerial press release of 29/04/2026). If placement of the child is unavoidable*, temporary hospitalisation may be considered. Institutions that care for children with medical needs should be authorised to also accommodate children with paediatric

Objective	Organisational modalities
	palliative care needs and a long-term, highly precarious social situation. For AYAs, residential options within adult palliative care may also be considered

9.5.2.2 Empowerment of the child/adolescent

Empowering children and adolescents to have their voices heard requires a patient-centred communication approach with comprehensive understanding of their needs, values and context. This communication model aims to promote autonomy, trust and adherence to the care plan. The effectiveness of such a communication model depends on the capacity to be adapted to the particularities of the age group, and involves active listening, frequent and structured conversations, sensitivity and affection. (Naughton, 2018, Street, 2009 and Rabin, 2011 in Castro, 2025) [255] Within the family dynamics, a triadic communication will occur, in which adolescents, parents or caregivers and health professionals are involved.

Building a trust-relationship with the child/adolescent by setting up an open communication aims to facilitate advance-care planning and active participation in decision-making.

Age-appropriate advance care planning

Recently a Dutch guideline was published on advance care planning and shared decision-making in paediatric palliative care (children aged 0-18y with LTC and LLC, their families and HCPs). [151]

Advance care planning and shared decision-making are conversational approaches that can be used to give substance to care and treatment together with child and family. These approaches focus on open and equivalent exchange of knowledge, experiences, values, goals, and preferences between children, families, and health care professionals (Fahner, 2020 and Rietjens, 2017 in van Teunenbroek, 2024) [151]. Advance care planning enables individuals to define goals and preferences for future medical care and treatment, to discuss these goals and preferences with the child, its family and health care professionals, to record these, and review these if appropriate (Rietjens, 2017 in van Teunenbroek, 2024) [151]. The outcomes of an advance care planning conversation can guide the child, family, and health care professionals in determining what treatment policy supports the best interest of the child and aligns with the family's values and preferences. In this way, advance care planning is extremely helpful when a decision on the treatment is needed.

In PPC many decisions need to be made, due to the uncertainty of prognosis and the variability in treatment options (varying from no treatment to different options). Shared decision-making is a collaborative process in which the child, family and HCPs are working together to make joint decisions. However, involving children in shared decision-making remains challenging due to their developmental stage, the associated cognitive abilities required for decision-making, and the impact of illness on their overall development (see 10.3.1.1).

Based on the evidence on effectiveness of ACP-interventions (see below) and on a literature review on facilitators and barriers to advance care planning and shared decision-making, recommendations were formulated by a guideline development panel.

Key elements highlighted in recommendations for advance care planning (ACP) include viewing ACP as an ongoing and dynamic process that should begin early in the course of the disease. Information materials should be provided to support discussions, and all ACP conversations should be thoroughly documented in the medical record. The use of a structured conversation guide may facilitate the integration of ACP into clinical practice and help organize the planning process. Furthermore, conducting ACP conversations requires specific communication competencies, including the ability to explore the perspectives of children and families in a neutral manner, respond empathetically to emotional concerns, and present own professional perspectives grounded in scientific evidence and clinical expertise. (see Figure 40)

Figure 37 – Extract of the recommendations from Van Teunenbroek et al., 2024

Recommendations on advance care planning and shared decision-making palliative care for children aged 0 to 18 years with life-threatening and life-limiting conditions, their families, and health care professionals (n=28)		
Advance care planning		
Do	1	Offer ACP conversations as a standard of care for all children with a palliative diagnosis and their families. In doing so, consider the specific situation and burden bearing capacity of child and family. [a]
	2	Integrate ACP as a continuous and dynamic process in the care of child and family from diagnosis through the end of life by holding regular conversations. [b]
	3	Start ACP conversations early in the disease process to encourage acceptance and allow space to prepare for the future. [b]
	4	Hold timely conversations with the child and family when the need to prepare for specific scenarios increases, as the child's condition deteriorates or when the child approaches end of life. [b]
	5	Provide explanations and written information to child and family to prepare for an ACP conversation and provide opportunities to include others they may wish to have present during the conversations. [b]
	6	Include the content of ACP conversations and any treatment arrangements in the medical record. [b]
	7	Have a health care provider trusted by the child and family lead the ACP conversations. This may be the primary caregiver, or another trusted caregiver, such as a case manager, or a caregiver outside the treatment team trained in ACP conversations. [b]
	8	When preparing and conducting ACP conversations, use a conversation guide to provide structure and to ensure relevant topics are covered.
	9	Structure the ACP process through preparation, interviewing and reporting.
	10	Discover, discuss, and note in the ACP process what the child and family's values, goals and preferences are for future care and treatment medically, psychologically, spiritually, and socially.
	11	With the consent of parents and child, share specific treatment agreements with all health care professionals involved.

Source: Van Teunenbroek et al., 2024[151]

Active participation in decision-making

Braybrook (2025)[249] examined the perspectives of children, young people, and parents regarding the characteristics of high-quality PPC. At the microsystem level, active involvement of children in decision-making was identified as a key factor in strengthening positive relationships and interactions between children and health and social care professionals. Various ways to achieve the active involvement of children was proposed, such as 'telling children about their condition', 'asking children questions about their condition and care', 'enabling children to ask questions about their condition and care', 'exploring and incorporating activities that are important to the child'. Alongside discussion about their health, children of all ages described the importance of professionals getting to know them and their interests, and support them to do things they enjoy. Children valued a space with home comfort or activities that enabled them to stay in touch with things or people that mattered to them, and opportunities to be distracted within the care setting (e.g., hydrotherapy pool, computer games).

Children's ability to make health decisions is not only shaped by their developmental stage (see supra) but also by their experiences with the illness, an interaction with the attitudes of parents and healthcare professionals towards their decisional capacity. (Feenstra, 2014 in van Driessche, 2025) [254] Since no agreement is yet found on the **biological age of competence for decision-making** (some studies suggest the age of 12y as appropriate), the ability of the child for decision-making should rather be considered and not their calendar age, and should therefore individually be determined. The competence for decision-making does not only depend on a certain level of maturity of neurological capacity, but also on several other factors, such as socio-economic status, culture, peer environment, etc.,. Whereas neurocognitive development in healthy children can already vary due to the interaction of these factors, an additional layer of complexity is added by the impact of serious illness on the development of the child. [254] The potential risk factors related to the impact of illness are described in 10.3.1.1.

During **adolescence** [255], the desire to participate in decisions about their care aligns closely with a growing need for independence and active involvement in managing their own health. Supporting **teen autonomy** consist of strategies of good communication and emotional support and can help the adolescent to feel more in control and respected. Empowerment of adolescents is a multifactorial process, influenced by positive interpersonal relationships, access to accurate information and opportunities to make decisions about their care. The authors of this review [255] identified several advanced care planning tools for promoting autonomy of adolescents, such as the Family-Centered Advance Care Planning model (FACE). These tools aim to increase the congruence between the preferences of the adolescent and their family and to facilitate open communication about complex

topics, contributing to a greater satisfaction of adolescents and their family with the care plan, and by reducing the stress and anxiety associated with end-of-life decisions.

Evidence on the FACE intervention in adolescents with cancer or HIV, compared with usual care, was based on low- to very low-quality evidence. The findings suggest that adolescents who participated in the FACE intervention were more likely to complete a legal statement of treatment preferences, demonstrated greater concordance regarding treatment preferences and treatment restrictions, and showed greater agreement in granting family members decision-making flexibility (cfr. family leeway). Among adolescents with cancer, the intervention was also associated with a lower risk of depression and higher levels of spiritual well-being. However, no significant effects were observed on anxiety or overall quality of life. [151]

Key elements in the **recommendations** by the Dutch guideline on (advance-care planning and) decision-making in PPC [151] include recognizing when a decision is required, presenting treatment options with their advantages and disadvantages, exploring the preferences and circumstances of the child and family, and reaching a joint treatment decision (cfr. four steps structure in a shared decision-making process). Effective implementation requires advance preparation, the use of structured conversations, clear and balanced communication, opportunities for questions, and attention to the child's and family's preferences. The process should also account for legal and ethical considerations, recognize that multiple discussions may be needed, and be adapted to the child's desired level of involvement and the clinical context, as shared decision-making may not be feasible nor appropriate in emergency situations. The involvement of the child should always be in a developmentally appropriate way, with use of accordingly adapted language by the healthcare professionals (see Figure 41).

Figure 38 – Extract from the recommendations of Van Teunenbroek et al., 2024

Shared decision-making		
Do	12	Think ahead of time what treatment decision(s) must be made in the short and longer term and how you will explain the need for these decisions to child and/or parents.
	13	Consider in advance what (treatment) options are available and how you will explain them in a way that the child and/or parents can understand.
	14	Consider in advance how many conversations you think you will need to come to a decision and within what time frame you would prefer to have these conversations. Explain this to the child and parents.
	15	Start the conversation with an agenda and ask the child and/or his parents what they want to discuss.
	16	During the conversation, strike a good balance between the information you give and the information you want to receive from the child and/or his parents.
	17	Explain the advantages and disadvantages of the treatment options clearly and concretely. This includes the option to "wait and see" and the option to forgo further curative or life-sustaining treatments and focus entirely on comfort care.
	18	Give the child and/or his parents the opportunity to ask questions about the various treatment options and to share their views and experiences.
	19	Consult with the child and/or parents as to their preference and, if asked, explain your preference as well.
	20	Come to a decision that all involved are comfortable with and summarise it. Prevent the child and/or his parents from feeling too burdened by the responsibility of this decision.
	21	Involve the child even if he or she is under 12. Do this in a way that is developmentally appropriate. This also applies to the words you choose. [b]

Source: Van Teunenbroek et al., 2024[151]

Table 29 – Core elements for empowerment of the child/adolescent and organisational modalities: version used during stakeholder consultation

Objective	Organisational modalities
Empowerment of the child/adolescent	
age-appropriate advance care planning	• Use adapted communication tools, available through organisations such as Inclusion, and draw inspiration from international tools such as the "Serious Illness Conversation Guide Pediatrics©".
Active participation in decision-making	Provide opportunities for adolescents and young adults (AYAs) to participate in decision-making themselves, alongside simultaneous support for parents

Objective	Organisational modalities
	• PLTs should establish close collaboration with AYA teams (within oncology).

9.5.2.3 *Empowerment of the parents and family*

Active participation in decision-making

Advance care planning assists parents in thinking now about what health care they would want their child to have in the future and communicating these wishes to their healthcare team. It allows families the opportunity to discuss their beliefs and values, with the overarching goal that the child/young person will receive the "right care, at the right time, in the right place" (Therapeutic Guidelines, 2016 in Duc, 2017)[256].

Provision of needs-based interventions specific for parents: the need for caregiver-focused mental health support. [253]

Key elements from the Dutch guideline on the roles of the child, family and HCP in ACP and decision-making include the substantial variation in preferences regarding the involvement of parents and children in advance care planning and shared decision-making. Parents may prefer to act as the final decision-makers, share decisions with healthcare professionals, defer decision-making to clinicians, or, at times, feel unable to make a decision. Similarly, the desired level of child involvement varies according to the child's age, developmental stage, clinical situation, and the nature of the decision. Consequently, recommendations emphasize that the involvement of both the child and family should be tailored to their individual needs and preferences. Healthcare professionals are strongly encouraged to actively involve children and families in ACP and shared decision-making conversations, ensuring that the child's perspective is considered in a manner appropriate to their developmental age. Furthermore, parents should be recognized and valued as experts on their child, given their unique knowledge of the child's needs, values, and preferences. [151](see Figure 42)

Figure 39 – Extract from the recommendations of Van Teunenbroek et al., 2024

Roles of child, family and health care professionals in advance care planning and shared decision-making		
Do	22	Involve child and family in framing ACP and shared decision-making in terms of form, content, preferred place, time and stakeholders and tailor this process to their needs. [b]
	23	Involve the (perspective of the) child in ACP conversations and shared decision-making in accordance with the child's developmental age. [b]
	24	In the ACP process and in shared decision-making, recognise the child and family as experts in living with illness and in assessing their quality of life. Ensure your actions reflect due consideration for the knowledge and experiences of child and family. [b]

Source: Van Teunenbroek et al., 2024[151]

Table 30 – Core elements for empowerment of the parents/family and organisational modalities: version used during stakeholder consultation

Objective	Solutions
Empowerment of the parents and family	
Active participation in decision-making	**Recognition** of the parents as central actor • Parents must be recognised in their role as caregivers. Organisation of **supportive environment** around the family unit • PLTs should involve psychologists, spiritual counsellors and ethicists in the care plan to support

Objective	Solutions
	parents, and may seek legal advice to clarify legal boundaries in decision-making. • PLTs can refer parents to appropriate patient or parent associations. Facilitating **communication** within the family unit • PPZ services should be familiar with, provide, and use tools that help families and healthcare professionals actively involve the child (support for conversations).
	Facilitating communication between HCPs and family When discussions must take place in a foreign language, involve an intercultural mediator whenever time allows, and use AI tools in urgent situations.
	Improve the availability of ethicists in hospitals and in the community: Establish a telephone support service for professionals involved in palliative care (including paediatric palliative care), coordinated by the regional palliative care federations and involving ethicists, spiritual counsellors, intercultural mediators and legal experts (cf. the Netherlands: "End of Life Support for Children Physicians' Service").

9.5.3 *Empowerment of the HCPs*

Recommendations from the Dutch guideline on communication during advance care planning (ACP) and shared decision-making [151] emphasize the importance of providing clear, honest, and transparent information about diagnosis, prognosis, treatment options, and associated uncertainties. Healthcare professionals should employ effective communication skills, including the use of concrete and age-appropriate language, active and exploratory listening, and empathetic acknowledgment of emotions. Communication should also be tailored to the preferences of the child and family, while respecting their cultural, religious, and philosophical beliefs. In addition, professionals should recognize that parents may experience significant challenges during ACP and decision-making, including feeling unprepared to make decisions, difficulty anticipating consequences, and emotional conflict between minimizing their child's suffering and prolonging life. These challenges should be acknowledged and addressed when preparing for and conducting ACP and shared decision-making conversations (see Figure 43)

Figure 40 – Extract from the recommendations of Van Teunenbroek et al., 2024

Communication skills during ACP and shared decision-making		
Do	25	Regularly provide child and family with clear and honest information about diagnosis, prognosis, treatment, and uncertainties surrounding the child's situation throughout the disease process. Match this information to their (language) abilities and needs. [b]
	26	Use specific communication skills such as exploratory listening, acknowledging emotions, using concrete, appropriate and clear language, and formulating value-based goals during ACP conversations and shared decision-making. [b]
	27	During ACP conversations and shared decision-making, consider the communication preferences and cultural, religious, and philosophical beliefs of child and family. [b]
	28	Be aware in your preparation and during ACP conversations and shared decision-making that these discussions can be perceived as very difficult by the child and family. Do this by exploring child and family attitudes toward ACP and responding empathetically to their emotions without making the emotions the focus.

Source: Van Teunenbroek et al., 2024[151]

Although healthcare professionals generally agreed that ACP discussions should begin early, ideally soon after diagnosis of a life-limiting condition, these conversations often occurred much later, frequently during crises or when death was imminent. Delays were commonly linked to prognostic uncertainty, concerns about parental readiness, fear of causing distress or diminishing hope, and uncertainty about who should lead the discussions.

Effective initiation was associated with professionals who had established trusting relationships with families, possessed strong communication skills, experience, and ACP knowledge. Important prerequisites included professional training, parental understanding and readiness, open discussions about prognosis, multidisciplinary support, and an appropriate environment for conversations. Overall, the review concluded that personal, social, cultural, and organizational factors all influence ACP initiation, resulting in inconsistent practice and delayed discussions, highlighting the need for standardized approaches, education, and tools to support earlier and more effective paediatric ACP conversations. [274]

Table 31 – Core elements for empowerment of the HCPs and organisational modalities: version used during stakeholder consultation

Objective	Solutions
Shared knowledge and experiences about shared decision-making	• PLTs and other experienced specialised services should share best practices and advice regarding these obstacles.(participation in decision-making) • AYA teams should further develop their knowledge of palliative care.
Enhancing cultural sensitivity among HCPs	Share best practices and tips between services and experienced professionals (e.g., an initiative in Antwerp presented during the symposium of 27 March). Federations for palliative care can play an organisational role by facilitating networking and the exchange of best practices. Improve the availability and implementation of intercultural mediators and spiritual counsellors in hospitals and in the community: • Establish a telephone support service for professionals involved in palliative care (including paediatric palliative care), coordinated by regional palliative care federations and involving ethicists, spiritual counsellors, intercultural mediators and legal experts. This service provides advice by phone and can, if necessary, offer home visits or participate in consultations (e.g., the Netherlands: “End of Life Support for Children Physicians’ Service”).
Building a trust relationship with the child/family	Support PLTs in their ongoing training on communication strategies. Share best practices and tips between services and experienced professionals; palliative care federations can facilitate this through networking and knowledge exchange.
Guarding child’ safety	If the child is not safe at home: • PLTs appear well suited to take on a mediating role and, thanks to their communication expertise, help find the best solution for the child and family. • PLTs can receive support from mental health professionals and from existing social and judicial youth care services. • If placement of the child is unavoidable*, temporary hospitalisation may be considered. Institutions that care for

Objective	Solutions
	children with medical needs should be authorised to also accommodate children with paediatric palliative care needs and a long-term, highly precarious social situation. For AYAs, residential options within adult palliative care may also be considered. If placement of the child is unavoidable*, temporary hospitalisation may be considered. Institutions that care for children with medical needs should be authorised to also accommodate children with paediatric palliative care needs and a long-term, highly precarious social situation. For AYAs, residential options within adult palliative care may also be considered. Death at home should not be considered a quality indicator (see also the KCE project on 'middle care' in palliative care).

9.5.4 A need for a shift in societal attitudes toward a nurturing environment

Table 32 – Core elements for societal attitude and organisational modalities: version used during stakeholder consultation

Objective	Solutions
Societal unacceptability of the death of a child or young adult	In all care plans, the involvement of psychologists, spiritual counsellors and ethicists should be considered. Gradually introduce the term "palliative care" in conversations with the family and the patient, as long as societal understanding of palliative care remains strongly associated with end-of-life.

10 BARRIERS AND SOLUTIONS RELATED TO ETHICAL ISSUES INFLUENCING ACCESS TO PPC

10.1 Introduction

10.1.1 Rationale

This chapter addresses Research Question 3 (RQ3): How do the needs and preferences of parents, families, caregivers, and healthcare professionals influence access to paediatric palliative care for children in palliative situations?

Care for children with life-limiting or life-threatening conditions unfolds through complex clinical situations in which medical, relational, and ethical dimensions continuously interact. Within this process, the needs and preferences of parents, families, caregivers, and professionals play a decisive role in how palliative care is perceived, introduced, accepted, or deferred. These influences do not operate as isolated decisions, but as part of an evolving framework of relationships, expectations, responsibilities, and meanings attributed to care over time. Yet, in Belgium, existing research has mainly examined structural barriers rather than ethical mechanisms[275,276].

By focusing on the ethical dimensions embedded in stakeholders' needs and preferences, this chapter aims to highlight mechanisms that are often implicit yet central to understanding why access to paediatric palliative care may be delayed, uneven, or contested, even when services are formally available.

10.1.2 Ethical relevance related to access to paediatric palliative care

In paediatric contexts, decisions concerning the introduction, timing, or scope of paediatric palliative care (PPC) are inherently value laden. They unfold within a plural moral landscape in which parents, children, and healthcare professionals may hold different yet legitimate perspectives shaped by uncertainty, responsibility, evolving capacities, and professional duties[277–287]. Ethical tensions are therefore intrinsic to complex care situations where multiple values must be balanced without fully satisfying all stakeholders[288–292]. In PPC, these tensions commonly concern the definition of care goals, the proportionality and limits of treatment, the timing of palliative involvement, and evolving interpretations of the child's best interests across the illness trajectory[293–295]. Not confined to end-of-life decisions nor exceptional moral dilemmas, they permeate everyday clinical interactions and care trajectories, shaping communication, trust, and shared decision-making, particularly around transitions between curative and palliative approaches. When they remain implicit or insufficiently supported, they may contribute to delayed referral, fragmented pathways, strained relationships between stakeholders, and missed opportunities for timely palliative care[296–298]. Understanding these ethical mechanisms is therefore essential for analysing access to PPC as a morally and relationally mediated process and for informing policies and clinical practices aimed at improving timely and equitable access to paediatric palliative care.

10.1.3 Ethical conflicts as mechanisms influencing access to PPC

The PPC literature identifies three broad and interrelated categories of ethical conflict influencing access to care: value- and role-related conflicts, timing- and information-related conflicts, and system-level or organisational conflicts [284,290,299]. Value and role tensions arise when stakeholders interpret their responsibilities toward the child differently[281,282,286]. Parents may prioritise protection and life-prolongation, while professionals emphasise proportionality, quality of life, and avoidance of harm, creating tensions around beneficence, non-maleficence, and the child's best interests[300]. Timing and information conflicts emerge when stakeholders receive, understand, or integrate prognostic information at different paces, which may undermine shared decision-making and delay palliative discussions or referral [277,295,297]. Finally, organisational constraints such as fragmented care pathways, limited resources, or unclear responsibilities may restrict what actors perceive as ethically appropriate

care.[288,298,301]. This chapter therefore analyses how ethical tensions shape access to paediatric palliative care and proposes an analytical framework for identifying recurring patterns of ethical conflict influencing access.

10.1.4 Ethical theories and determinants relevant to analyse the access to PPC

Biomedical and clinical ethics provide conceptual frameworks for analysing moral issues arising in healthcare practice, decision-making, and patient–professional relationships[302–309]. Rather than relying on a single normative model, clinical ethics has developed through the coexistence of multiple ethical theories that guide ethical deliberation by clarifying values, responsibilities, and justificatory reasoning in complex clinical situations[306,310–315]. These theoretical perspectives provide the conceptual framework used in this chapter to analyse how ethical tensions shape access to paediatric palliative care. Within this framework, three complementary ethical theories are mobilised to analyse the ethical dynamics influencing access to PPC: principlism, narrative ethics and narrative medicine, and the ethics of care (detailed description of the theories and their ethical determinants is available in Appendix 1).

Principlism. Biomedical ethics proposes four central principles—autonomy, beneficence, non-maleficence, and justice—that structure ethical analysis and guide the evaluation of medical decisions and responsibilities in clinical care[333].

Narrative ethics and narrative medicine emphasize the interpretation of illness stories, the recognition of lived experience, and the construction of meaning across the illness trajectory[322,334–344].

Ethics of care. Care ethics highlights relational interdependence, vulnerability, and the responsibilities emerging within caring relationships and institutional contexts[321,345–356].

10.1.5 Ethical and Philosophical Perspective of the Study

Finally, beyond its qualitative and interpretative analytical dimension, this work also includes a secondary ethical and philosophical reflection aimed at examining how access barriers to paediatric palliative care relate to broader questions of temporality, vulnerability, meaning-making, and the confrontation with childhood finitude.

10.2 Methods

10.2.1 Design

This study adopted a qualitative, interpretative and iterative design grounded in ethical analysis. Its objective was to identify and analyse ethical situations in which the needs, values or preferences of parents, families, caregivers and healthcare professionals may influence access to paediatric palliative care. The research followed a snowballing AI-supported (ChatGPT: GPT-5,5.1 et 5.2) multi-phase iterative process in which successive analytical stages progressively refined the material from literature identification to the consolidation of conflict patterns relevant to Research Question 3 (see illustrative figure in Appendix 5).

10.2.2 Descriptive phase – Identifying conflict situations from PPC literature

The descriptive phase aimed to identify situations of tension or conflict influencing access to paediatric palliative care as reported in the literature. These situations constituted the documentary corpus of the study.

The documentary dataset combined peer-reviewed PPC literature, clinical studies, grey literature (guidelines, policy frameworks, professional reports), and ethical or clinical monographs addressing decision-making, parental experience, and illness trajectories. Sources were assembled through purposive expert-driven selection of recognised reference textbooks in PPC (listed in Appendix 3), iterative reference-chaining, and targeted inclusion of specialised literature (e.g., neonatology, intensive care, oncology, complex chronic conditions).

Initial identification of items was conducted through detailed manual screening of three reference textbooks in paediatric palliative care [357–359]. Each item corresponded to a situation in which needs, preferences, or expectations expressed by stakeholders could generate ethical tension affecting access to PPC. An item was defined as a situation described in the literature in which needs, preferences, or expectations between stakeholders generated tensions that could affect referral, acceptance, or continuity of paediatric palliative care, including decision-making impasses, communication breakdowns, relational difficulties, or structural constraints. Items were recorded using a structured coding grid including: (1) a short description of the situation, (2) the underlying need or preference expressed, (3) the type of conflict generated, (4) its potential effect on PPC access, and (5) the typical moment of emergence along the illness trajectory.

This initial manually coded dataset was then used as an in-context reference framework to guide a dedicated generative GPT-assistant operating in a closed environment restricted to the documentary corpus. The manually extracted items were provided to the assistant as examples in order to guide the identification and classification of additional situations across the corpus. As the analysis progressed, updated item lists were periodically reintegrated into the assistant dataset ("knowledge") to aim the refining of its analytical sensitivity and maintaining internal consistency. All AI outputs were systematically reviewed and validated by the researcher.

Item identification continued iteratively until qualitative saturation was reached, resulting in approximately 2,600 items. A final refinement step ensured analytical coherence through removal of duplicates, consolidation of near-duplicates, and grouping of semantically similar situations while preserving contextual nuances.

10.2.3 Coding phase – Coding through the ethical framework

The coding phase examined the conflict situations identified during the descriptive phase through ethical framework. Its objective was to code each item in a consistent way in order to identify recurrent ethical dynamics (see Textbox 1) influencing access to paediatric palliative care (PPC) and to transform the descriptive dataset into a coded usable basis for interpretative typology.

The ethical framework functioned as a structured coding system organised as a multidimensional coded grid including: actors involved (child, parents, family, relatives, PPC and non-PPC professionals); ethical theories (principlism, narrative ethics/medicine, ethics of care); theory-derived ethical determinants (principles, virtues, narrative and relational dimensions – see textbox 1); conflict types (value, role, temporal, informational, systemic, relational); effects on PPC access (facilitation, delay, barrier, misidentification, discontinuity, repair); and temporal zones along the care trajectory (See details about the ethical framework in Appendix 4)

Textbox 2 – Definition of ethical dynamics and ethical determinants

Ethical determinants designate what is ethically at stake in each situation. They correspond to the specific principles, virtues, narrative elements, or care-related dimensions identified through the coding grid and linked to particular actors, conflict types, access effects, and moments along the care trajectory. Determinants therefore function as coded markers allowing the ethical dimensions of each conflict situation to be systematically identified and coded.

Ethical dynamics describe how these determinants interact across actors, situations, and stages of the care trajectory. Through systematic comparison of coded items, recurring configurations of determinants were identified across sources. These dynamics capture the prevalence and intensity of ethical tensions, the complexity of situations involving multiple actors or determinants, the recurrence of similar configurations across literature, and their temporal consistency along the illness trajectory.

Coding proceeded in two stages. First, the framework was manually applied to an initial subset of items in order to test the clarity and operational applicability of the coding categories. These manually

coded items were subsequently used to guide the prompting logic of the dedicated GPT-assistant, which was instructed to reproduce the same coding structure without introducing additional categories. AI-assisted coding was then applied to the full dataset of approximately 2,600 items under continuous researcher supervision and iterative verification.

A final refinement step ensured coherence through consolidation of similar profiles, clarification of ambiguous codings, and removal of redundant configurations.

10.2.4 Interpretative phase – Typology of the principal pattern of conflict

The interpretative phase translated the coded items and ethical dynamics identified during the coding phase into a typology of principal patterns of conflict influencing access to paediatric palliative care. This stage synthesised coded results by identifying recurrent mechanisms through which ethical tensions affect referral, recognition, acceptance, or continuity of PPC.

The analysis followed a progressive interpretative sequence. First, coded items were compared to identify recurring ethical dynamics, understood as recurrent configurations of interacting ethical determinants observed across multiple situations. AI assistance was used to support the comparison of coded configurations and the identification of recurrent similarities across items, while the interpretative consolidation of these convergences into conflict patterns remained under researcher supervision. The transition from ethical dynamics to formal patterns was guided by the recurrence of similar configurations across the dataset, the stability of their effects on access to PPC, and their occurrence across diverse clinical and relational contexts rather than by automated clustering procedures.

When such dynamics demonstrated sufficient stability and recurrence across sources and contexts, they were consolidated into patterns of conflict. Each pattern represents a stable mechanism linking a configuration of determinants to a characteristic effect on PPC access. Patterns were defined to be sufficiently broad to encompass a diversity of situations, sufficiently precise to preserve the internal coherence of the mechanisms they represent, sufficiently nuanced to accommodate variation across sources, and sufficiently open to allow overlap when situations engage several ethical dynamics simultaneously.

Finally, patterns of conflict sharing similar mechanisms were grouped into broader macro-categories, providing an interpretative synthesis of the coded dataset while preserving the contextual variability of individual situations (Illustrative examples provided in Appendix 5).

10.2.5 Transversal Analysis phase – Re-categorisation of the pattern of conflict

In order to prepare the field consultation, following the interpretative phase, a transversal analytical step was conducted in order to examine conflict patterns beyond their initial macro-categorical classification. While macro-categories provided an empirical organisation of the patterns, they did not fully capture the intersectional dynamics through which ethical tensions unfold along the care trajectory.

This transversal analysis therefore re-examined the patterns through a temporal lens, focusing on the moments of the care trajectory to which they referred and on the interactions between ethical determinant across different stages of care.

Rather than analysing patterns primarily as thematic entities, this step aimed to situate them within the lived temporality of paediatric care trajectories. Conflict patterns were thus reorganised according to the moments and transitions of care in which they tend to emerge, as well as the types of ethical determinants they mobilise across time.

10.2.6 Field consultation phase

A field consultation was conducted with PPC professionals from Belgian paediatric liaison teams to assess the practical resonance of the identified patterns of conflict. A structured survey was

disseminated, followed by multidisciplinary roundtable discussions in French and Dutch where aggregated results were collectively discussed and interpreted. The consultation examined professionals' perceptions of the relevance, frequency, and complexity of the patterns in practice and explored whether additional patterns emerged from field experience. (See survey in Appendix 8)

10.3 Results

10.3.1 Output Phase I – Descriptive

The descriptive screening of paediatric palliative care literature identified approximately 2 600 conflict situations ("items") describing how stakeholders' needs, preferences, or expectations generate ethical tensions potentially influencing access to PPC.

Each item was recorded using a structured grid capturing: a short description of the situation, the underlying need or preference expressed, the conflict generated, its potential effect on access to PPC, and the typical moment of emergence along the care trajectory.

Identification proceeded iteratively across sources until qualitative saturation was reached, meaning that additional literature no longer generated substantively new types of situations. (The list of the items is available on demand)

10.3.2 Output Phase II Coding and Phase III Interpretative

The coding of the 2,600 items structured the dataset for systematic comparison across analytical dimensions, including actors involved, ethical determinants mobilised, conflict types, effects on access to paediatric palliative care, and temporal moments along the care trajectory.

Within this coded corpus, recurrent configurations were identified across multiple situations and consolidated through interpretative analysis into 32 conflict patterns influencing access to PPC. Each pattern represents a stable configuration linking ethical determinants, actor constellations, conflict structures, and their observed effects on access to PPC.

Patterns retained two analytical dimensions applied throughout the coding process:
(1) the **effect on access to PPC** (facilitation, delay, barrier, misidentification, discontinuity, repair), and
(2) their **temporal position along the illness trajectory** (diagnosis, prognostic disclosure, deterioration, transition phases, end of life, bereavement, or across the trajectory).

Across the coded corpus, recurring combinations of these two dimensions constituted the principal analytical clusters from which conflict patterns emerged, linking similar effects on access to PPC with comparable moments along the care trajectory.

The 32 patterns were subsequently organised into eight macro-families, emerging ai-driven synthesis from the coding analysis and reflecting dominant ethical architectures shaping access to PPC. Among them, 30 patterns concern conflicts arising during the care trajectory, while two patterns relate to post-death situations, retained due to their singular temporal ethical configuration. (full table of patterns and macro-family descriptions are available in Appendix 7).

Macro-family 1: Disclosure & Truth Management

This macro-family groups situations in which access to PPC is shaped by how palliative care and prognosis are named, framed, disclosed, or temporally positioned.

1. **Avoidance of the "palliative" label** – Semantic avoidance prevents early orientation toward PPC and contributes to delayed identification.
2. **Gradual or opaque prognosis** – Partial or progressive disclosure maintains uncertainty and postpones anticipatory planning.

3. **Protective silence toward the child** – Protective intent limits the child's participation and delays shared understanding of care goals.
4. **"Supportive care" terminology as bridge** – Alternative wording can facilitate entry into PPC while preserving relational trust.
5. **Selective disclosure to school/community** – Partial disclosure disrupts psychosocial coordination around the child.
6. **Hesitation with genetic testing/counselling** – Uncertainty about implications delays anticipatory planning and orientation.

Macro-family 2: Curative–Palliative Transition & Treatment Intensity

These patterns concern tensions surrounding the transition between curative and palliative orientations of care.

7. **Curative escalation ("one more treatment")** – Therapeutic persistence delays recognition of PPC needs.
8. **Late referral to PPC** – Structural and cultural hesitations postpone referral despite clinical indications.
9. **Refusal of therapeutic limitations (DNR / withdrawal)** – Emotional and cultural pressures impede proportional decision-making.
10. **"Curative-only" mindset / PPC exclusion** – Framing PPC as defeat blocks parallel planning.
11. **Opioid/analgesia hesitation** – Misconceptions about symptom control restrict proportional care.

Macro-family 3: Autonomy, Protection & Participation

These patterns capture tensions between parental authority, professional responsibility, and the child's participation in decisions.

12. **Parental disagreement or custody conflict** – Divergent parental positions create decisional paralysis.
13. **Limited child participation** – Protective attitudes restrict the child's voice in decision-making.
14. **Over-control of care plan** – Hyper-responsibility or control disrupts collaborative care planning.

Macro-family 4: Cultural, Spiritual & Institutional Interfaces

These situations arise where cultural, spiritual, or institutional norms interact with clinical care processes.

15. **Unmet ritual/spiritual constraints** – Institutional rigidity conflicts with cultural expectations.
16. **Interpreter refusal** – Language barriers compromise informed consent and understanding.
17. **Alternative or "miracle" healing** – Divergent healing narratives delay consensus around care goals.
18. **Refusal of chaplaincy or spiritual care** – Emotional and existential needs remain insufficiently supported.

Macro-family 5: Relational Labour, Trust & Communication Load

This macro-family captures tensions arising from the relational work required to maintain trust and coordination within care relationships.

19. **Second opinion as trust restoration** – Second opinions may restore trust but sometimes delay decisions.
20. **Intra-team disagreement / role diffusion** – Ambiguous professional roles create conflicting messages.
21. **Expectation of 24/7 availability** – Unrealistic expectations strain relationships and continuity of care.
22. **Mental load / parental over-management** – Care overload generates relational friction and coordination difficulties.

Macro-family 6: Home vs Hospital / Technology & Logistics

These patterns concern the organisation of care across home and institutional settings.

23. **Home as sanctuary (refusal of interventions)** – Protecting the symbolic meaning of home delays support services.
24. **Over-surveillance / high-tech at home** – Intensive monitoring medicalises domestic life and increases burden.
25. **Preferred place of death** – Divergent preferences influence timing and organisation of care transitions.
26. **Refusal of home adaptation/equipment** – Symbolic resistance to medicalisation complicates home care.

Macro-family 7: Socio-economic & Justice in Access

These patterns relate to structural conditions influencing equitable access to care.

27. **Transport and financial problem** – Material hardship restricts access to services.
28. **Refusal of social or respite support** – Stigma or privacy concerns limit available assistance.
29. **Data-sharing/privacy friction** – Restricted information flows undermine care coordination.
30. **Refusal of safety norms or vaccination** – Conflicts between autonomy and collective protection affect access.

Macro-family 8: Bereavement & Continuity of Bonds

These patterns concern the relational dynamics that emerge after the child's death.

31. **Refusal of post-death follow-up** – Protective withdrawal limits bereavement support pathways.
32. **Continuing bonds with the team** – Sustained contact may facilitate coping and relational continuity.

10.3.3 Output Phase IV – Transversal Analysis

A transversal analysis conducted across the identified conflict patterns examined their interrelations beyond the initial macro-family classification. Rather than analysing patterns primarily through their thematic grouping, this step re-examined them through the two analytical dimensions applied throughout the coding process: their effects on access to paediatric palliative care and their temporal position along the illness trajectory.

By cross-analysing patterns according to these two dimensions, the analysis reconfigured the dataset along the temporal structure of care trajectories. This approach highlighted recurrent intersections between similar effects on PPC access and comparable moments of the illness trajectory, allowing patterns to be compared across different phases of care rather than within their initial macro-categorical grouping.

This transversal reorganisation of the patterns revealed three overarching findings regarding the dynamics shaping access to PPC. These findings concern the concentration of ethical tensions around transitional moments of care, the processual nature of PPC access across the illness trajectory, and the asynchronous trajectories through which different stakeholders engage with palliative care.

10.3.4 Output Phase V – Field Consultation

Field consultation was conducted with Belgian paediatric liaison teams to confront the literature-based typology with clinical experience in the Belgian context. The consultation combined a structured survey and multidisciplinary round-table discussions. Participants assessed the 32 identified conflict patterns according to three dimensions: perceived relevance, frequency, and complexity in everyday paediatric palliative care practice. Out of the eight teams, ten surveys were received (three French-speaking and seven Dutch-speaking participants). Although numerical scoring was included, responses were interpreted primarily qualitatively, with scores serving as structured prompts for collective reflection rather than statistical measures.

Across responses, several patterns were consistently identified as particularly salient. In terms of relevance, participants highlighted curative escalation, late referral to PPC, and conflicts surrounding do-not-resuscitate or treatment limitation decisions. Regarding frequency, respondents emphasised late referral trajectories, avoidance of the term “palliative”, and practical barriers such as financial or organisational constraints affecting access to specialised care. Patterns related to treatment limitation decisions and curative-only mindsets were described as particularly complex, combining prognostic uncertainty, parental positioning, institutional expectations, and professional responsibility. No additional conflict patterns were identified beyond the 32 previously described.

Consistent with the transversal analysis, round-table discussions also confirmed further qualitative insights. Participants emphasised the difficulty of identifying transitions between curative and palliative orientations, particularly in situations characterised by gradual or uncertain prognostic evolution. They also described asynchronous illness trajectories and the progressive emergence of palliative care components alongside ongoing curative treatments, reinforcing the transversal findings regarding transitional moments of care and the processual and asynchronous nature of PPC access.

10.4 Limitations

This study combined iterative literature mapping, interpretative coding, AI-assisted analysis, field consultation, and a second-cycle screening in paediatric ethics. While this multi-layered design strengthens conceptual robustness, several methodological limitations must be acknowledged.

First, the literature selection did not follow a formal PRISMA or scoping review methodology. Rather than aiming for exhaustive systematic coverage, the study sought to construct an interpretative ethical model grounded in clinically and ethically relevant situations through targeted searches, snowballing, and progressive enrichment of sources. Consequently, reproducibility remains more interpretative than systematic in nature. The initial reliance on paediatric palliative care literature may also have introduced thematic circularity, although the second-cycle screening broadened the corpus to paediatric ethics literature.

Second, the identification of ethical determinants and conflict patterns involved interpretative judgement. AI-assisted coding was used as a support tool for structuring and comparing coded situations, while interpretative consolidation remained researcher-led. No formal inter-rater reliability measure (e.g., Cohen’s Kappa) was performed, and model hyperparameters were not systematically documented or openly accessible in ChatGPT. As probabilistic systems may generate slight analytical variations, the stability of the coding process relied primarily on iterative prompt-guided structuring, researcher supervision, and progressive refinement rather than formal statistical concordance or strict reproducibility.

Third, the resulting 32 conflict patterns and eight macro-categories reflect analytical consolidation rather than statistical determination. Recurrence, coherence, and contextual stability guided grouping decisions, but no formal quantitative threshold defined when recurrence became sufficient, meaning alternative groupings could remain conceivable under different theoretical lenses.

Fourth, the field consultation involved a limited number of respondents and heterogeneous scoring across relevance, frequency, and complexity. These findings should therefore be understood as contextual anchoring rather than statistical validation. In addition, liaison teams may have limited visibility on upstream barriers occurring before PPC activation.

Finally, the theoretical framing — combining principlism, narrative ethics, and care ethics — oriented the analysis toward normative, relational, and temporal dimensions, potentially underrepresenting alternative sociological or political interpretations of access mechanisms.

Taken together, these limitations delimit the epistemic status of the typology, which should be understood as an interpretatively consolidated model of ethical mechanisms influencing access to paediatric palliative care rather than as a statistically generalisable taxonomy.

10.5 Implementation perspectives the framework and the patterns of conflict

The applicability of the present work concerns two complementary levels: the ethical framework itself and the conflict patterns derived from the analysis.

First, the ethical framework is not intended to function as a predictive or normative decision-making model. Rather, it aims to support narrative and ethical analysis of complex situations by helping professionals identify the ethical determinants, relational tensions, temporal dimensions, and perspectives involved in a given care trajectory. The framework therefore seeks less to provide ethical answers than to structure the ethical questions requiring deliberation. By combining principlism, narrative ethics, and care ethics, it may support a more multidimensional and reflexive understanding of ethically complex situations.

Second, the conflict patterns may have a more anticipatory and practice-oriented applicability. As recurrent configurations associated with delays, limitations, or discontinuities in access to paediatric palliative care (PPC), they may function as markers of ethical vigilance within clinical practice and professional training. Their applicability lies less in prediction than in early recognition of situations known to generate tensions around PPC integration.

In this perspective, the dimensions of relevance, frequency, and complexity may help orient professional attention and anticipatory communication strategies. Highly recurrent patterns may function as warning signals within care trajectories, whereas highly complex patterns may indicate situations requiring reinforced interdisciplinary discussion or ethical support.

The framework and the patterns should therefore be understood as interpretative and supportive tools strengthening ethical attentiveness and anticipatory reflection regarding PPC access rather than as standardised protocols or deterministic predictive instruments.

10.6 Ethical and Philosophical Theory-Driven Analysis of Access to Paediatric Palliative Care

10.6.1 Summary of Main Findings

This study examined how the needs, preferences, values, and responsibilities of parents, families, informal caregivers, and healthcare professionals influence, delay, complicate, or hinder access to paediatric palliative care (PPC). The analysis combined iterative literature mapping, ethical coding, interpretative consolidation into conflict patterns, field consultation with Belgian PPC liaison teams, and a second-cycle screening in paediatric ethics literature.

The literature analysis led to the identification of 32 principal conflict patterns organised into eight macro-categories. Field consultation did not generate additional patterns but confirmed their recognisability and practical relevance in the Belgian context.

Three main findings emerged from the transversal analysis of these patterns. First, ethical tensions influencing PPC access concentrate around transitional moments of the care trajectory, particularly diagnosis, prognostic disclosure, and the progressive shift from curative to palliative orientations. Second, access to PPC appears as a process unfolding over time through interacting ethical, relational, organisational, and structural determinants rather than as a binary referral event. Third, PPC access unfolds within asynchronous trajectories among stakeholders whose rhythms of understanding, readiness, and meaning-making may remain misaligned.

These findings should not be understood as the direct product of automated pattern extraction, but as the result of a theory-informed interpretative analysis combining coding outputs, transversal comparison of conflict patterns, and ethical reflection grounded in principlism, narrative ethics, and care ethics.

10.6.2 Ethical Vulnerability at Key Moments of the Care Trajectory

10.6.2.1 The Diagnostic Moment as an Ethical Crossroad

The diagnostic moment constitutes a major ethical inflection point in the trajectory of children with life-limiting or life-threatening conditions. Although certain conditions may be recognised as potentially palliative from the outset, diagnosis does not automatically lead to PPC integration. At this stage, families and professionals are often oriented toward clarification, treatment possibilities, and preservation of hope.

From an ethical perspective, prognostic uncertainty and disclosure practices shape whether a palliative approach becomes conceivable. Diagnosis therefore functions less as a mechanical referral threshold than as the beginning of a progressive reinterpretation of illness, proportionality, and care goals. Episodes of relapse or deterioration may subsequently reactivate these tensions, functioning as renewed moments of ethical uncertainty and anticipatory negotiation.

10.6.2.2 The Curative–Palliative Transition

The transition from curative to palliative orientation represents a central ethical threshold within the care trajectory. Therapeutic escalation, treatment proportionality, referral timing, and redefinition of goals of care become particularly visible during this phase.

This transition rarely occurs abruptly and often reflects divergent interpretations of benefit, harm, responsibility, and hope across stakeholders. Continuing curative treatment may sustain a sense of moral agency for both families and professionals, even when proportionality becomes uncertain.

The analysis also highlights the temporal asymmetry between actors involved in PPC trajectories. Children, parents, non-specialised clinicians, and PPC teams may evolve according to different rhythms of understanding and acceptance. When these trajectories remain misaligned, PPC integration may be delayed or compressed into crisis situations. Conversely, ethically attentive accompaniment may facilitate more progressive and coherent integration.

10.6.3 Complexity Rather than Statistical Convergence

The field consultation revealed variability in how patterns were perceived in terms of relevance, frequency, and complexity across teams and contexts. Its principal contribution was therefore interpretative rather than statistical. Difficulties in accessing PPC appeared less related to isolated barriers than to the co-occurrence of several ethical, relational, organisational, and temporal mechanisms within the same situation.

The findings consequently support an understanding of PPC access as a dynamic and multidimensional process in which conflict patterns interact and accumulate across care trajectories.

10.6.4 Access to PPC as a Stratified and Non-Binary Process

The analysis suggests that access to PPC cannot be reduced to referral to a specialised team. Rather, it unfolds as a stratified process involving several layers of integration.

First, access concerns recognition of palliative needs and integration of PPC services. Second, it involves access to essential PPC components such as psychosocial, spiritual, ethical, and interdisciplinary support. Third, it concerns continuity and coherence of care across settings and phases of the illness trajectory.

Barriers may therefore appear as delayed referral, partial integration, fragmented continuity, or unstable coordination. Access to PPC should consequently be understood as an evolving configuration shaped by temporal, relational, and organisational conditions.

10.6.5 Ethical Interpretation of Delay: The Unthinkable and the Ethics of Time

Beyond organisational explanations, the findings support a broader ethical interpretation of delayed access to paediatric palliative care (PPC). Many barriers appear linked to the difficulty of confronting what remains, in many societies and institutions, an “unthinkable” horizon: the severe illness and possible death of a child. Delays should therefore not be interpreted merely as denial or communication failure, but as ethically intelligible mediations through which actors attempt to maintain meaning, responsibility, and moral orientation in situations that profoundly destabilise expectations.

In paediatrics, the possibility that a child may die challenges deeply rooted moral assumptions: childhood as promise, medicine as restoration, and parenthood as protection. When these expectations are disrupted, actors may maintain curative frames longer than proportionality would suggest, postpone irreversible decisions, or redirect distress toward technical debates. Such responses can be understood as attempts to reconstruct moral intelligibility in situations that threaten established ethical categories.

From a principlist perspective, many barriers reflect tensions in redefining benefit, harm, and justice when cure is no longer a credible horizon. Non-maleficence may justify limiting burdensome treatments, yet it may also motivate continued escalation to avoid the perceived harm of “giving up.” Beneficence may shift toward comfort and relational integrity, but this transition rarely occurs synchronously across actors. In paediatrics, autonomy is mediated through parents and professionals, while justice involves both resource distribution and recognition of whose interpretation of good care is legitimised.

Narrative ethics highlights how access to PPC is shaped by framing and storytelling. When “palliative” is equated with death, the term itself can threaten identities—parents as protectors, clinicians as healers, institutions as sites of therapeutic progress. Delayed disclosure, semantic reframing, or protective silence may therefore function as narrative strategies aimed at preserving a livable story until new meanings can emerge.

Care ethics reframes resistance as a relational response to vulnerability. In contexts of uncertainty and impending loss, maintaining agency—“doing something”—can be ethically protective for parents and professionals alike. These responses express efforts to preserve responsibility, relational bonds, and hope. At the same time, care ethics draws attention to systemic vulnerabilities—burnout, time pressure, fragmented services—that shape whether accompaniment remains sustainable.

10.6.6 Cross-Cutting Ethical Insights

Beyond individual conflict patterns, the analysis suggests several broader ethical insights. Ethical attentiveness appears to influence the timing of PPC integration, particularly through the recognition of moral inflection points before crisis situations emerge. Structural justice also shapes feasible access through resource allocation, institutional flexibility, and recognition of social and relational vulnerabilities.

The analysis further suggests that narrative coherence between families, professionals, and institutions may facilitate earlier and less conflictual PPC integration, whereas divergent understandings of illness trajectories frequently contribute to delay.

Finally, relational virtues such as compassion, discernment, trustworthiness, and integrity appear to function as stabilising factors within ethically fragile trajectories by sustaining communication, trust, and continuity of care.

10.7 Conclusions

10.7.1 The ethics of time: asynchronous temporalities, thresholds, and "time to integrate"

Across the coding framework developed in this chapter, time emerges as a central ethical dimension shaping access to paediatric palliative care (PPC). The typology of conflict patterns identified in the literature shows that access depends not only on clinical indicators, but also on the time required for stakeholders to integrate diagnosis and prognosis, reorganise expectations, and progressively realign goals of care.

These temporal processes are rarely synchronised. Parents, children (when involved), non-specialist clinicians, and PPC teams often move through the illness trajectory at different rhythms of understanding and readiness. At the same time, institutional timelines and prognostic uncertainty create prolonged "grey zones" in which decisions are repeatedly deferred.

Many conflict patterns identified in this study can therefore be interpreted as forms of temporal management: delaying the naming of palliative care, maintaining therapeutic escalation, postponing limitation decisions, or fragmenting disclosure. These practices may function as transitional mechanisms allowing actors to approach a difficult reality gradually. Ethical difficulties arise when such deferral becomes structural, compressing PPC integration into late-stage crisis moments where choices are narrower and suffering harder to anticipate.

10.7.2 The ethical task implied by PPC: accompanying the unthinkable through a shared time and shared meaning

The findings suggest that barriers to PPC access are closely linked to the challenge of confronting what remains, for many actors, an "unthinkable" horizon: the serious illness and possible death of a child. Access to PPC therefore depends not only on organisational pathways, but also on the capacity of stakeholders to progressively construct a shared orientation toward care.

This requires convergence over time: shared thresholds for treatment proportionality, narrative frames that allow palliative care to be understood as active care, and relational conditions that sustain trust and communication across the trajectory. Improving access to PPC thus involves creating clinical environments that support this gradual ethical transition in meaning and goals of care.

10.7.3 Final statement

This study identified 32 conflict patterns describing the mechanisms through which stakeholders' needs, values, and preferences may influence access to paediatric palliative care. Together, these patterns provide a structured map of the ethical, relational, and organisational dynamics shaping referral, acceptance, and continuity of PPC.

The analysis shows that access to PPC is not a single decision but a process unfolding along the care trajectory, particularly at transitional moments such as diagnosis, prognostic disclosure, and shifts in treatment goals. Recognising these situations earlier may help professionals anticipate tensions, support shared decision-making, and facilitate more timely and coherent integration of paediatric palliative care within clinical trajectories.

11 OFFER ON PAEDIATRIC PALLIATIVE CARE IN BELGIUM

11.1 Introduction

Specialised paediatric palliative care in Belgium is primarily organised and offered by hospital-based Paediatric Liaison Teams. They can be considered as the 'central axis' of paediatric palliative care. They serve as a critical link between the hospital and the home setting, facilitating continuous care for patients and their family. The Paediatric Liaison Teams collaborate with healthcare professionals at different levels, from primary to tertiary care. These healthcare professionals can work in different settings such as university and general hospitals, in respite care or home setting. The term 'home setting' should also be interpreted very broadly, as it will also include residential and semi-residential care settings for children with chronic, complex disorders. Other important partners in palliative care include professionals such as teachers, social workers and chaplains, as well as volunteers and non-profit organisations.[360–362]

In the next sections we will discuss all the partners involved in paediatric palliative care in Belgium, their specific tasks and their financing. Additionally, we collected information on other forms of support that are not linked to a specific (healthcare) professional.

11.2 Paediatric liaison teams

11.2.1 Background

Paediatric palliative care was introduced in Belgium end 1980s- begin 1990s. The university hospital of Gent and Leuven established the first paediatric home care service in to provide curative care to children with cancer to reduce visits to the oncology day hospital. Gradually, they also accepted to take care of children requiring palliative care at home.[360–363] Similar liaison teams were gradually set up in other (mostly university) hospitals in other parts of Belgium, initially funded a by charity and private funding.[360–363] The Royal Decree of 15 November 2010 formally recognised and licensed the function of 'paediatric liaison'. This function was designed for children with severe chronic pathology that developed before the age of 18 and could be established in hospitals with at least 50 new patients per year under the age of 16 with haemato-oncological disorders or severe non-oncological haematological disorders requiring complex treatment such as stem cell transplantation.[364]

In Belgium, eight Paediatric Liaison Teams (PLTs) have been recognised and licenced. The first six were recognised by the Federal Authorities in 2010 and 2022. These are:

- *Kinderen in Thuis en Supportieve Zorg (KITES) linked to UZ Leuven (2010)*
- *Kinder Oncologische Eenheid voor Specifieke Thuiszorg en Rehabilitatie (KOESTER) linked to UZ Gent (2010)*
- *Equipe de liaison pédiatrique Globul'Home and équipe mobile de soins palliatifs linked to Hôpital Universitaire des Enfants Reine Fabiola (HUDERF) (2010)*
- *Equipe Interface (soins palliatifs à domicile) Pédiatrique linked to Cliniques universitaires Saint-Luc (2010)*
- *Equipe des Soins Continus Pédiatriques linked to CHR la Citadelle and CHU de Liège (2010)*

- *Equipe de Liaison pédiatrique linked to Clinique CHC MontLégia in Liège (2022)*

The last two were recognised in 2024 by the Flemish authorities (Vlaams Ministerie van Welzijn, Volksgezondhedi en Gezin, Departement zorg)

- *ComfortKIDZ in UZ Brussels (July 2024)*[n]
- *Paediatrische liaison (Oever) in UZA (Antwerp) (November 2024)*[o]

A paediatric liaison team is composed of different health care professionals with a specific training in paediatric palliative care and should include at least one paediatrician (0.5 FTE) with experience in pain management, 4 nurses (4 FTE) including one specialised in paediatrics and neonatology, and a psychologist (0.5 FTE). The coordination of this multidisciplinary team is according to the RD the responsibility of the aforementioned paediatrician. An additional 0.5 FTE administrative worker is also foreseen.[364] Although all teams include either a social worker or social nurse in their team, this is not foreseen in the RD (interviews PLTs) [365]

11.2.2 Tasks

The paediatric liaison teams have both an internal and external function.[360–364] On the one hand, the paediatric liaison team provides **multidisciplinary support to the hospital team** caring for the hospitalised child and on the other hand they ensure **continuity of care between the hospital and the home** environment.[364] Exceptionally, HUDERF has two separate teams, one for the internal task (*équipe mobile de soins palliatifs*) and one for the external task (*équipe liaison de pédiatrie*). The reason for this is the availability of funding for developing palliative care within hospitals from 2006 that was primarily used to develop palliative care for adults and the fact that this hospital only treats children.[57,361] The offered treatments can be curative, palliative or terminal care.[364] According to the RD, PLTs need to register and evaluate their activity, and send an annual activity report to the Minister of Public Health.[363,364] In practice no activity reports were requested after 2014, but the PLTs maintained some kind non standardised activity register.[365] (interviews PLTs)

The PLTs provide 24/7 availability of a nurse for phone calls and home visits.[360–362,364,365]According to the royal decree a paediatrician from the hospital should be available on call, this means not necessarily the coordinating paediatrician from the PLT.[364]

The paediatric liaison team's activities include coordination, communication, care, training, and quality improvement and research.[363]

- PLTs **coordinate** care between home care services, hospital services, school and respite care services. They act as a central point of contact. They build a network of professional caregivers around the child and its family, based on their specific needs (GP, home nurse, physiotherapist, pharmacist, social workers, etc.). They also initiate and coordinate interdisciplinary meetings.[360–363] According to the RD, it is the paediatrician who coordinates, but in practice this function is usually carried out by a nurse or a social worker. This is a lacuna in the RD.[57,361]
- PLTs ensure clear and ongoing **communication** with families and care teams with respect for cultural values. They inform healthcare providers and families about the liaison function and promote communication between the hospital team and the involved primary care providers. They raise awareness about PCC with brochures, conferences and fundraising among hospital teams, home care services and general society and are involved in federal commissions and associations for palliative care like the Palliative Care Federation of Flanders.[360–363]
- The **care** provided by PLTs is complex, individualised and patient-centred with a focus on the family and not on the disease. They are responsible for comfort care including pain and symptom

[n] https://www.uzbrussel.be/w/comfortkidz-het-palliatief-pediatrisch-liaisonteam-van-het-uz-brussel-officieel-erkend

[o] https://www.uza.be/nl/specialismen/pediatrische-liaison-oever#:~:text=Pediatrische%20liaison%20(Oever)%20%7C%20UZA

management, advanced care planning and provide intensive support in the terminal phase of illness. They perform nursing care in the home setting when home base care teams are insufficiently trained or unavailable. They coordinate complex procedures at home like assisted ventilation, blood transfusion, chemotherapy, feeding through gastrostomy, tracheostomy care, patient's controlled analgesia and intravenous sedations. PLTs evaluate regularly the individual care needs that can include social assistance, financial resources, administrative assistance, respite care, and provision of equipment and materials, and organises the necessary support. Care also continues after death in the bereavement phase, for example by sending a remembrance card every year.[360–363] (information from interview)

- **Training** does not only concern the PLT team members, as they involved in complex care techniques, pain control and paediatric palliative care, but also involved (health) care professionals. New nurses within the PLTs receive peer training including organisational elements of services and integration of care delivery. PLTs educate and coach first-line home care services (who often lack paediatric training and experience) in specific care tasks e.g., handling port-a-cath or other central lines. PLTs also train parents in techniques such as aspiration, when there is an urgent need and no healthcare professional available. They are also involved in PPC education in hospitals, faculties of medicine or nursing schools and in bereavement support for schools.[360–363]
- PLTs are aware of the importance of **scientific research and quality improvement** and are willing to be involved but often lack time because of their involvement in patient care. Most PLTs have developed protocols and/or flow charts such as how to implement advanced care planning tools.[57,361,363]

The distribution of PLTs over Belgium is somehow uneven, with three teams in Flanders, three teams very close to each other in Brussels and two Walloon teams both in Liège. The teams cover overlapping geographical regions around their base. In general, they follow the patients that are cared for in their hospital independent of their place of residence (interview PLTs). PLTs involvement can also be requested in other hospitals without a PLT function.[360,362]

11.2.3 Financing

Structural funding for paediatric liaison teams (PLT) was one of the 32 concrete measures for prevention, treatment and research of the National cancer plan 2008-2010.[366] Paediatric liaison teams that were officially licensed by the Federal authorities in 2010, are financed via part B4 of the hospital budget (Budget of Financial Means, BFM). In 2013 the funding changed from project based to structural financing. They receive a yearly fixed amount that was calculated on the number of children cared for in 2013 i.e., in total € 1 358 019.[365] This budget, that remained unchanged since 2013, is considered largely insufficient to cover the operating costs of the PLTs, including the cost of the paediatrician, social worker and care coordinator, as well as material for home care.[363] This means PLTs rely for a big part on other sources e.g., other parts of the hospital budget, donations from the Children's Cancer Fund (*Kinderkankerfonds*), *Kom op tegen Kanker*, or other charity initiatives.[365] Fundraising is an important, but time consuming activity of the PLTs.[363]The more recent recognised PLTs haven't received any structural funding from the federal or federated authorities yet.(interviews PLTs).

11.3 Partners PLTs in primary care

11.3.1 GP

11.3.1.1 Tasks

The GP is an indispensable partner of the PLTs in primary care to offer transmural care and should be involved as soon as possible.[57,361] The GP is usually 'close' to the family. He or she has a long-standing relationship with the family and is well placed to offer medical and psychosocial support throughout illness, death and bereavement phase. If the child or family has no GP, the GP can be replaced in some cases by a paediatrician with a private practice (in fact working at primary care level). Another possibility is that the PLT identifies and contacts a 'new' GP. This can affect the development of a trusting relationship (which takes time) and/or the level of involvement of the GP.[57,361]

A severely ill child can only be discharged from hospital and cared for at home if the GP agrees and is prepared to take on the local care tasks together with the home nurse (and other health care professionals if needed). They collaborate and communicate with the paediatric liaison team and other healthcare professions involved. The GP can fall back on the expertise of the paediatric liaison team and can seek advice from the treating team. The patient's situation can be discussed when needed, for example at interdisciplinary meetings.[360,362]

The GP is available for home visits, regular or in case of an emergency, depending on the needs of the child and their family. Within the context of palliative care, GPs are expected to carry out some administrative tasks such as filing for the palliative lump sum or drawing up the death certificate.[360,362]

11.3.1.2 Financing

GPs in Belgium receive an activity-based payment (fee-for-service), except if they work in a community health centre, where they receive a capitation payment (lump sum per patient).[367] Home visits from GPs are fully funded by the NIHDI (RIZIV-INAMI) for patients with a palliative care status or if they meet the following five requirements: [368]

- Their illness is irreversible
- Their general, physical, or psychological condition is seriously deteriorating
- No therapy can improve their condition
- Their life expectancy is not more than three months
- Their physical, social or spiritual needs are severe and require significant, time intensive and ongoing support

GPs can receive additional payment in a palliative setting through nomenclature for example to attend multidisciplinary oncological consultation (MOC) meetings or to discuss the results of these meeting(s) when there is a switch from curative to palliative treatment.[369] They also receive a remuneration to discuss and support the patient's wishes and life goals during advanced care planning with patients.[370]

From 1 June 2026, GPs also can charge flat-rate fees (107693 and 107715) for the care of patients identified as requiring palliative care. For children under 18 years of age these patients are identified by a specialist in paediatrics or a specialist with the specialised professional title in paediatric neurology. The children should be identified using a validated identification tool and cared for by a paediatric palliative care team with participation of the GP. The support fees recognise the time that is invested in a holistic assessment of care needs, care planning and follow-up for palliative care patients and their loved ones, as well as consultation with other healthcare providers. They represent the next step in developing a broader care pathway for patients requiring palliative care.[371]

11.3.2 Home nursing

11.3.2.1 Tasks

The home nurses work together with the GP and the paediatric liaison team in a palliative home setting. Home nurses in the neighbourhood of the child need to be identified while the paediatric liaison team prepares the discharge of the child. The nurses need to be willing to take on local care tasks. It happens that home nurses refuse because of fear, emotional burden or lack of time.[360–362,365]

The number of specialised paediatric nurses in home care is small. Paediatrics is not recognised in home nursing and nurses with this specialty have no advantages. The number of children that needs home nursing is also too small to maintain the specialty. Home nurses not specialised in paediatrics are trained internally to perform their tasks in children e.g., distraction techniques, triangulation with parents, etc. (information Arémis) Available paediatric nurses in home care may not have training and/or experience in palliative care. Building this experience is difficult because this is a highly infrequent situation.[57,361,365] PLTs offer teaching and coaching to home nurses ad hoc to compensate for a lack of training and/or experience in paediatric palliative care.[360,362,365]

Some examples of (multidisciplinary) primary care teams including home nurses with experience in (paediatric) palliative care that work in close collaboration with the PLTs include Arémis (Brussels) [372] and L'Etoile des Enfants (Hainaut and Walloon Brabant).[57,361,373] Arémis also organises an interdisciplinary training in in palliative care.

The tasks of home nurses consist of hygiene care, medical-technical nursing care such as administration of IV medications, enteral nutrition, etc., as well as providing psychosocial support to the child and their family.[365] They will follow-up treatment- and care-protocols at home, evaluate the needs of the child and their family, and discuss their findings with the paediatric liaison team or during interdisciplinary meetings. As they will be a regular visitor (intruder) in the family home, it will be very important to respect the family 'culture' and keep a close eye on the quality of life of child and relatives.[360,362]

11.3.2.2 Financing

Nursing activities at home are financed at the federal level (RIZIV-INAMI) through a mixture lump sum payments and fee-for-service. For a palliative patient that is granted with the palliative status, there are three lump sums defined, depending on the dependency assessed by the Katz index[p] (PA, PB and PC). The lump sum for a patient without palliative status is also assessed by the Katz index, but is lower (A, B and C).[374] However, the Katz index is not suitable for severely ill children in a home setting and no lump sum can be requested for children under the age of six.[57,361,365,375,376] An exception can be asked through the advisory physician (or nurse) of the sickness fund who take the medical situation and the context into account.[365] (e-mail Solidaris) Unfortunately, this procedure can only be initiated after discharge from hospital and takes time.[365] Home nurses are paid on a fee-for-service basis for palliative patients not fulfilling the conditions for a lump sum payment. Payment of individual care acts can be cumulated up to a maximum fee per day.[374] But also there is a problem concerning children and their natural degree of dependency for reimbursement of for hygiene care.[365]

There is only a limited list of specific technical nursing acts that can be charged fee-for-service on top of lump sum payment or maximum fee. These acts are: setting up and/or monitoring infusions and/or administration and/or monitoring parenteral nutrition; placement of an indwelling catheter or specific equipment for the administration of a medical solution in an implantable chamber; removal of an indwelling catheter or of specific material allowing the administration of a medical solution in an

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[p] The Katz index assesses a patient's independence in the activities of daily living using a questionnaire that measures the patient's ability to bath, dress, move, go to the toilet, eat and [374]their continence ability. Each item is rated on a scale from 1 (independent) to 4 (totally dependent).

implantable chamber; replacement of a suprapubic balloon bladder catheter or a balloon gastrostomy tube; and monitoring and follow-up when using a pump system for the administration of chronic analgesia via an epidural or intrathecal catheter (more than one visit per day needed for 'same care' AND other specific care tasks that are not reimbursed).[365,374]

Finally, a fee for one annual nursing consultation (code 429015 *verpleegkundig consult / consultation infirmière*) for patients cared for at home was introduced to develop a personalised care plan based on the patient's needs in consultation with the patient or their immediate family. The fee of € 31.80 (1 January 2025) is paid by the RIZIV-INAMI.[374] It is not clear if and how often this fee in used for children.

A previous KCE report already highlighted the inappropriate financing of home care nursing for children because of not taking differences with adult care into account (time, workforce, equipment, approach). The lack of nomenclature for specific tasks (administration of medication, teaching of parents) together with the need for more frequent visits (that cannot be billed) and the already mentioned problems with reimbursement for hygiene care add to this problem.[365]

Recent, a pilot project for hourly payment of home nurses was presented.[374] Results of this pilot project will only be available in 2029

11.3.3 Other HCP in primary care

11.3.3.1 Physiotherapist

In selected cases a local physiotherapist can be involved in paediatric palliative care at home.[360,362,377] Physiotherapy is a valuable tool to alleviate symptoms and improve quality of life in palliative patients. The interventions applied include neurological physiotherapy, respiratory physiotherapy and therapeutic massage.[378] Techniques can be very general, such as relaxation techniques, or more disease-specific, such as positive expiratory pressure (PEP) for patients with cystic fibrosis.[377] If the child is granted with the 'palliative lump sum', there is full reimbursement (i.e., no out-of-pocket payments) for specific nomenclature provided by physiotherapists at home, up to a maximum of two sessions per day. The physician can prescribe a maximum of 60 sessions per prescription.[377,379]

However, there is a lack of adequate underlying evidence, research projects and training programmes for physiotherapists. It would be beneficial to conduct clinical trials to thoroughly investigate the potential benefits of physiotherapy in paediatric palliative care.[378]

11.3.3.2 Community pharmacist

As many medications are used to control symptoms in paediatric palliative care, community pharmacists have a role to play in dispensing these medications and providing advice on when and how to take them, and which can be combined and which cannot.[380] However, some mediations used in the home setting such as oral chemotherapy and certain pain medications such as fentanyl and ketamine are not available in the community pharmacy.[365] The Royal Decree of January 21,2009, contains a list of medications materials that community pharmacists should have immediately available for palliative care. This list includes midazolam, morphine and scopolamine.[381] However, during interviews with PLTs it was mentioned that in practice medication like morphine is not always immediately available in the community pharmacy. They bring it to the patients from the hospital pharmacy.

The community pharmacist receives a small amount of money from RIZIV-INAMI (40.18 euro) per year for keeping a 'global pharmaceutical file' of chronically ill patients. No other specific advantages are linked to care for palliative patients.

11.3.3.3 Others (health) care professionals in primary care

Although other health care professionals working in mono- or multidisciplinary practices in primary care, such as speech therapist, occupational therapists, psychologists, etc. could theoretically be involved in paediatric palliative care depending on individual needs, their involvement in practice is

limited. Their current way of working on appointment, with waiting lists and patient stops, prevents rapid involvement at home when needed and is not compatible with flexibility in palliative care. When a trusting relationship with a specific type of health care professional e.g., psychologist from hospital has been build, the involvement of another one in primary care might not be easy. Lack of experience with paediatric palliative care can be compensated for by coaching and support from the PLTs. (interviews)

Due to the lack of primary care health care professionals, mainly psychologist, buts also a social workers and chaplain, not all aspects of palliative care are sufficiently covered, and some gaps exist in psychological, social and spiritual care.(interviews) Some PLTs work together with psychologists for adult palliative care teams such as Brusano,[382] Reliance,[383] and Domus [384] or the psychologist from the hospital pays a home visit in selected cases (interviews). Some sickness funds (e.g., Helan [385]) provide palliative care services, but the offer is variable and it is not clear if there is a specific offer for children.

11.4 Partners PLTs in tertiary care

11.4.1 Paediatric Conventions

11.4.1.1 Background

In Belgium, so-called '(rehabilitation) conventions' have been developed to finance multidisciplinary care for chronic and/or complex conditions. A convention is essentially an agreement or contract between the financing authority (RIZIV-INAMI) and the institution providing care. The agreement usually specifies the target population, the organisation of care and the method of financing.[386,387]

There are conventions for specific diseases like cystic fibrosis or diabetes, but also for groups of diseases like inherited monogenetic diseases or neuromuscular diseases. Less frequently, conventions have been developed for interventions (not linked to specific diseases) like oxygen therapy, respiratory support or cardiorespiratory monitoring of babies. The conventions aim to finance activities and staff that are not covered by the nomenclature or honoraria, such as allied health professionals or administrative personnel, materials/equipment, interprofessional meetings etc.[387]The composition of the required multidisciplinary team, specified in the different conventions, depends on the needs of the target group and can include the relevant physician-specialist(s), psychologists, specialised nurses, administrative staff, physiotherapists, dietitians, etc.[387]

11.4.1.2 Tasks

There seems to be an overlap in the target population (chronic complex disorders) for these conventions and for palliative care, for example in cystic fibrosis, inherited monogenetic disease and neuromuscular diseases. Like in the paediatric liaison function, conventions involve a multidisciplinary team and provide supportive care including psychosocial support, information, administrative assistance, and dietary advice. Some conventions also specify home care, care coordination and provision of equipment, which can also be considered tasks of the paediatric liaison team.[387] An overview of RIZIV-INAMI agreements (conventions) for children with chronic complex, life limiting or life threatening conditions and their characteristics can be found in Table 33.

However, a major difference is that the multidisciplinary team from the conventions are mainly active in the medical, disease-oriented care including diagnosis, evaluation, treatment and follow-up of the disease. They focus primarily on providing hospital care, although a limited amount of home care is possible, depending on the specific convention. The multidisciplinary team from the convention has a high level of specific knowledge about the disease itself, and they are the ones who can provide the most accurate information on the disease and the available treatment options. Although cure is often not possible in chronic diseases treated within a convention, there can be impactful treatments and sometimes development of new treatments that change the outcome of patients considerately.

Interactions between the multidisciplinary team from the conventions and the paediatric liaison teams exist. They rely on each other for specific advice. The paediatric liaison team relies on health care professionals from the hospital team, such as psychologists, social workers or dieticians, because of their knowledge of the disease and the existing relationship with the child. (interviews PLTs) The multidisciplinary team from the convention may seek advice from the paediatric liaison teams when (impactful) treatment options become obsolete, supportive care takes precedence, home care becomes more intensive and/or more specific palliative interventions need to be initiated (ACP, terminal care, etc).

Having a multidisciplinary team involved in the day-to-day care of a child and their family may reduce the need for (early) intervention by a specialised palliative care team, but on the other hand might cause unnecessary delays in their involvement. In the convention for cystic fibrosis, palliative care and bereavement support is included as tasks of the MD team.[388] It seems logical that if the disease progresses, the multidisciplinary team involved in curative/impactful treatment can take on more supportive/palliative care up to a certain level. Depending on the expertise of each multidisciplinary team, the timing and intensity of involvement of a specialised palliative care team might be different.

Table 33 – Overview of NIDHI (RIZIV-INAMI) agreements (conventions) for children with chronic complex, life-limiting or life-threatening conditions

Convention	Home- care and/or liaison function	Psychosocial support	Information	Administration	Coordination	Equipment	Nutrition	palliative care[q]	24/7 availability
Cystic fibrosis[388]	Shared care with primary care	X	X	X	X		X	X	Provide info 24h access to care
Inherited monogenic diseases [389]	If needed able to provide care at home	X	X	X		X	X		Daily availability by phone
Children's nephrology [390]	Home visits by nurse, dietician and social worker	X	X	X			X		In collaboration with emergency department
Neuromuscular disease [391]	Home visit for evaluation	X	X	X	X	X	X		X
Haemophilia [392]	Education autotransfusion at home	X	X	X	X				In collaboration with emergency department
Cerebral Palsy[393]		X	X	X	X	Advice on equipment	X		
Spina bifida [394]		X	X	X	X		X		
Refractory epilepsies [395]	Shared care with GP	X	X						

[q] Palliative care was only mentioned in one convention, cystic fibrosis. No definition of palliative care is provided. We presume they talk about end-of-life or terminal care as synonym for palliative care.

Convention	Home- care and/or liaison function	Psychosocial support	Information	Administration	Coordination	Equipment	Nutrition	palliative care[q]	24/7 availability
HIV/AIDS[396]	Shared responsibility with GP	X	X	X	X		X		X

11.4.1.3 Financing

As earlier mentioned, conventions were developed to finance multidisciplinary care for chronic and/or complex diseases to cover activities and staff not financed by nomenclature or honoraria. The method of financing can differ between conventions. Often a lump sum is paid per patient, either annually, monthly or as a once-of, depending on the services provided. While older conventions usually have open-ended budgets, there is a growing trend towards closed-ended budgets, where total expenditure is limited over a set period.[387]

11.4.2 AYA teams

11.4.2.1 Background

Following the first initiatives in UK and Australia, Teenage cancer trust (1990, [397]) and CantTeen (1985, [398]), an Adolescent and Young Adult (AYA) working group was set up in 2015 by the European society for Medical Oncology and the European society for Paediatric oncology.[399] In Belgium, an official agreement between NIDHI and AYA reference teams was developed and initiated on December 1st; 2023. Six hospital teams were recognised as AYA reference teams: the University Hospitals of Louvain (UZ Leuven), Antwerp (UZA), Ghent (UZ Gent) and Liège (CHU Liège), as well as the Institute Jules Bordet, and the University Clinic Saint-Luc (UCL).[400] [401]

Selection criteria included an average of more than 50 newly registered AYA-diagnosis per year (without recurrence), a recognised oncology care programme, formal collaboration between paediatric and adult oncology and haematology with transition policy being an important element, and the availability of specific health care providers [401]

In June 2025 the Council of State has annulled the agreement after a complaint from another hospital (*ZAS, ziekenhuis aan de stroom*) and asked to reassign the function of AYA reference team more transparently and with objective criteria.[402] (full text of new agreement soon available)

11.4.2.2 Organisation and tasks

An Adolescent and Young Adult (AYA) reference team is a multidisciplinary team consisting of specialised physicians, nurses, social workers and psychologists, that provide specialised care for young people between 16 and 35 years with cancer. This age group faces their own unique challenges such as going to college, starting to work, fertility issues, relations and plans for the future.[403] Their focus lays mainly on psychosocial wellbeing and quality of life and they provide documentation, material and practical support. An example is the 'AYA compass' to help patients with identifying the themes important to them, to guide face-to-face conversation with health care providers. AYA-care is not confined to the hospital. It also involves meeting fellow sufferers. The reference teams work together with various organisations (including *Kom Op Tegen Kanker*, Care4AYA,[404] *Flaya*,[405] *Stichting Tegen Kanker*, [406] *Kinderkankerfonds*,[407] *vzw Supernils* [408]) to organize these meetings, which include fun or informative activities and holidays.

Outside cancer, equivalent care models exist for adolescents with chronic diseases, but they are not called 'AYA programmes'. They are embedded within adolescent medicine, transition clinics or disease-specific multidisciplinary teams.[409]

11.4.3 Other health care professionals in hospital

Depending on the needs of the individual patient, the PLTs collaborate with other healthcare professionals in the hospital, primarily with the treatment team. In the case of complex chronic disorders, this is often a multidisciplinary team, even if the patient does not belong to a specific convention because there is no convention for the disease, or because a specific diagnosis is lacking.

11.5 Partners PLTs in secondary care

11.5.1 General hospitals

Some parents give preference to a local hospital for palliative care, because the large distance and/or the presence of siblings. There are no dedicated wards for paediatric palliative care, not in general hospitals, nor in university hospitals. The paediatric liaison teams are available for providing advice or they go to the general hospital if needed [360,362]

In some instances children in need of palliative care are followed-up at a general hospital by a general paediatrician or paediatrician with specific subspecialty, because there is an official 'satellite' of tertiary care and they work together in close collaboration, because part of the care can be provided in a centre closer to home, because there is no diagnosis, and/or because of parent's preferences.(interviews PLTs)

The paediatrician of the general hospital can seek advice from a paediatric liaison team that is located in another hospital. If the child is admitted in the hospital, the paediatrician is responsible for treatment and care, although this can be in close collaboration with the treating physician in the tertiary hospital or with the coordinating physician of the paediatric liaison team. The paediatrician communicates with involved colleagues and takes part in interdisciplinary meetings. They establish the medication policy, adjust medication for control of pain- or other symptoms, and anticipate side-effects of the medication. They support the child and their family throughout disease, disease progression and bereavement phase. In order to take care of a child in a palliative situation in the general hospital, a 24/7 availability of a paediatrician is needed.[360,362]

The involvement of other healthcare professionals in the general hospital depends on their availability. Some larger general hospitals may have a multidisciplinary team with psychologist, (ortho)pedagogue, dietician and/or social worker, dedicated to the paediatric ward. They are salaried by the hospital.

11.6 Respite care

11.6.1 What is respite care?

Providing continuous care for a child with a chronic, life-limiting or life-threatening illness at home can be emotionally, physically and spiritually demanding for parents, who are usually the main carers. This can lead to stress and fatigue, affecting the whole family.[410–412]

Respite (care) is a collective term for different initiatives that relieve the parents (and the family) for a while of their caring role, leaving the child the hands of a substitute formal or informal (voluntary) caregiver whilst the family 'takes a break'. Respite care can range from child-minding services provided by non-professionals to full support and nursing care provided by registered nurses. Planned or emergency respite care can be offered at home, in a residential setting, or in a hospice.[411,412] While respite care can provide the child with social interactions and variation in activity,[412] the parents can rest, have their own appointments or spend quality time with their other children.[411]

11.6.2 Respite care organisation in Belgium

11.6.2.1 Respite care facilities (residential)

In Belgium, there are five paediatric respite care facilities : 'Villa Indigo'[413] and '*Cité Sérine*'[414] in Brussels, 'Villa du Phare' [415]in Wallonia and 'Villa Rozerood'[416] and 'Limmerik'[417] in Flanders.(Table 34) Severily ill children including the four categories children with palliative care needs according to the definition of the European Society of Palliative care [418] can stay there to give their families a break.[360,362]

In a home-like setting, children receive the necessary, daily personal and nursing care, as well as emotional support and appropriate activities. Health care professionals are available 24/7. In some/most cases support and activities are also accessible for their parents, sibling and other family members who stay with them.[360–362] The respite care facilities are not intended for 'dying' but it happens occasionally or on request of parents and in collaboration with the PLT.[360–362]

In Flanders, 'Villa Rozerood' and 'Limmerik' are recognised and financed by the Flemish authorities (*Departement zorg*) as centres for short stay type 3 (Centrum voor kortverblijf CVK).[419] They provide temporary care for severely ill children up to 21 years of age. Children are granted up to 60 days per year residential respite care. For the stay of their child, parents pay a 'user contribution' of 6.9 euro per day.[419], but in Villa Rozerood the stay of the child is free for the parents. In Villa Rozerood, parent, grandparents, siblings and informal caregivers can also stay at the respite care facility for a relaxing holiday together with the child. These family members pay for their stay between 28 and 58 euro per day.[416]

Villa Indigo is recognised and financed by the Brussels-Capital Region and costs are covered by the health insurance funds, except for a small part co-payment (remgeld). Children can stay for a maximum of 32 days per year and the maximum age is 18 years. There is an option for day care as well, but parents can't stay with their child.[413]

Cité Sérine in Schaarbeek is a 'middle care' concept between hospital care and care in the home setting, mostly providing extramural therapeutical care when children are discharged from hospital, but before returning home.[57,361,414] Currently, 'middle care' is not covered by INAMI. Unlike nursing homes, there is no set daily rate. Cité Sérine receives subsidies from the French Community commission in Brussels (COCOF), but parents need to pay a part of this care themselves (95-115 euro).[420]

Villa du Phare in Liège provides on the one hand a respite care facility for children alone or with their family (will open in 2029) and on the other hand a mobile respite care team to offer support to children with complex care needs. They are recognised and financed by the Walloon authorities.[57,361,415]

Table 34 – Respite care facilities in Belgium

	Number	With parents or other informal caregivers	Daycare	Price per child per day	Max days	Recognised by
Villa Rozerood	7 children	yes	NA	Free	60	Flanders
Limmerik	5-6 children	no	NA	6.9 euros	60	Flanders
Cité Sérine vzw	4 children	no	NA	90-115 euro per day	32	Brussels
Villa Du phare	From 2029	yes	Mobile team	Co-payment	32	Wallonia
Villa Indigo	10 children	no	yes	Co-payment	32	Brussels

11.6.2.2 Mobile respite care services

The KBS has tried to make an inventory of different respite care solutions available for children with limitations and/or severe diseases.[421]. Apart from the care facilities mentioned above in section 1.6.2.1., there are initiatives who bring respite care to the home setting. This mobile respite care services are organised by sickness funds (Christian Mutualities,[422] Solidaris [423]), other care organisations (I-mens[424]) and private initiatives. The initiatives are mostly regional, so there is no guarantee of equal distribution across all regions. The level of support from healthcare professionals for the initiatives can differ, as can the accepted age of the children: max 14 years at I-mens and Solidaris, and max 19 years at CM.

Examples of private initiatives include Casa Corlien,[425] and Casa Magnolia,[57,361] both specialised/medical babysitting services that get support from home nurses, respectively in the province of Limburg and the province of Flemisch Brabant. Casa Magnolia offered also practical and domestical support and organises peer contacts with adapted activities for all family members. Casa Magnolia however, was forced to stop their services due to a lack of structural financing.[426]. In the report from the KBS, the lack of respite care services, and the lack of structural financial support is mentioned. Moreover, the available private initiatives depend strongly on volunteers, donations and charities.[57,361]

11.7 Children's education and developmental support

Apart from family, schools are generally the most significant part of a child's community. Schools are learning environments not only in academic terms, but also in terms of life skills. In the context of palliative care, schools play an important role in the child's social and emotional wellbeing. They are places where meaningful peer relationships develop.[148]

If a child is hospitalised for a longer period in Belgian, they can go to the special education type 5 school, that belongs to a hospital, preventorium or residential setting. They respond to the specific educational need of each pupil and work together with the pupil's home school. Children need a certificate from the treating physician of the medical facility (or the director of the residential setting). These schools are available in Flanders in hospitals such as '*Inkendaal*', '*Paola kinderziekenhuis'*, '*Pulderbos'*, '*OPZ Geel'*, '*UZA*', '*Hoge Beuken' (revalidatie)*, '*UZ Leuven'*, '*Pellenberg'*, 'Zeepreventorium' De Haan, etc)[427], but also in Brussels and Wallonia (Excel list available:' Saint Pierre', Jolimont, CHU Dinant-Godinne, La Citadelle Liège, Mons, Ottignies, Ath, La Louvière, Gosselies, Sambreville, Chatelet, etc) [428].

If students at home are unable to attend school for a long period of time due to illness, a teacher can come to the home setting. In Flanders this is called '*tijdelijk onderwijs aan huis*' (TOAH) and in Brussels and Wallonia *Enseignement à domicile* which depends partly on **private initiatives** like Auxilia Vlaanderen vzw,[429] School en Ziek zijn vzw,[430] het *brugfigurenproject van het Rode Kruis*,[431] *Ecole hospital & domicile* (EHD) asbl [432]

TOAH is available in regular and special needs primary schools, kindergartens and most study areas in secondary schools. Schools in Flanders are obliged to organise TOAH for students who have received approvement for it from a physician, are chronically or long-term ill, are regular students and live at a reasonable distance from school. A parent or guardian needs to submit a request to the school's management. Over-18s pupils can file the request themselves.[433]

Another type of homeschooling is the synchronic internet education (*synchroon internetonderwijs SIO*).[434] *Bednet vzw* is such an organisation that is subsidised by the Flemish authorities. Children follow classes at the same time as their fellow students with the aid of a movable camera with a zoom function and a surrounding microphone. There is no waiting list, and it can be combined with other types of home education. A similar initiative in Wallonia and Brussels is *ClassContact asbl*.[435] A commission of the Education Committee of the Parliament of the Wallonia-Brussels Federation approved an experimental 'synchronous online' teaching system for students in 2025. The system will

be tested over the next three school years in the Wallonia-Brussels Federation. It will receive an annual grant of 200,000 euros.[436]

In the palliative care setting it will be important to consider adjustment of type of activities and time spent at school together with increased emotional support needs. The involved school will need help to develop skills to care for the child and their siblings in palliative situation and support the siblings after a child has died. Moreover, the school will need assistance in developing skills to care for all the staff and students through (anticipatory) grief associated with palliative care and death.[148]

11.8 Spiritual support

11.8.1 What is spirituality

Spirituality has been defined by the European Association of Palliative care (EAPC) as '*the dynamic dimension of human life that relates to the way persons (individuals and community) experience, express and/or seek meaning, purpose, and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and//or the sacred.*[437] Religion can be defined as '*a search for the sacred*' but is also *'constituted by the means and methods (rituals or prescribed behaviours) of the search that receive validation and support from within an identifiable group of people.*[438] This means that spirituality is not the same as religion, but religion can be part of a person's spirituality.[439]

Spirituality has a tendency to become more important when a life-threatening diagnosis prompts existential questions such as 'Why is this happening to me?', 'What will happen after I die?' etc., questioning the meaning of life.[440] Patient's, and in case of children also parent's, spirituality can be a coping mechanism [441] and can impact decision-making.[442]

Although spiritual care is an integral part of palliative care (definition WHO 2020), its provision and inclusion across palliative care services has been said to be suboptimal internationally.[443]

11.8.2 Spiritual support organisation in Belgium

According to a RD from October 23, 1964, regarding hospital standards, the hospital is obliged to grant access to the ministers of religion at the patient's request. This access was extended to include lay counsellors (moral counsellors) in the RC of January 12,1970. The '*Omzendbrief De Saeger*' from April 1997, further clarified that every patient has the right to assistance from a minister or representative of a recognised religious denomination (Catholic, Protestant, Jewish, Orthodox and Islamic). This means that ministers or representatives of religious services and lay advisers may visit the patient at any time and without any time restrictions. If the patient has requested a specific person, others should refrain from visiting. If a patient has stated that they do not wish to receive visitors, this should be respected.[444]

In accordance with this legal obligation, hospitals and other health and welfare care facilities **can** hire 'spiritual care providers' The term "spiritual care provider" refers to any professional working in the health and welfare sector who, guided by one of the recognised philosophies of life in Belgium, provides spiritual care to care recipients and care providers.[444]Although originally rooted in the Christian tradition, the term 'chaplain' can also be used for 'spiritual care providers' from any faith or background including moral counsellors with a liberal-humanist background and Islamic counsellors. Independ of their background, chaplains strive to be there for everyone including believers, people of other faits and non-believers. Moreover, it has been shown that the effectiveness of care does not depend on faith-concordance between the chaplain and the patient.[445] During their training they learn to deal with their own spirituality in a professional manner, thus not trying to convert people or convince them of their own insights regarding spirituality.[446]

To be hired as a chaplain by a hospital you currently need a degree in theology including a master in practical theology: academic pastoral training programme (five years in total).[447]Other trainings like the one for '*pastoraal werk*' given by the Hoger Diocesan *GodsdienstInstituut* (HDGI).[448] A training for

moral counsellor exists at VUB: postgraduate programme in practical humanism [449] and the muslim council is developing a training programme for Islamic counsellors.

The professional association of chaplains and representatives of other faiths and beliefs in Belgium are calling for a new effective legal framework for all spiritual care providers.[450]The role of spiritual caregiver is for the moment not recognised as a medical profession and hospitals (alongside other healthcare facilities) are not obliged to employ them. This recognition is not only a political issue. There is a need to develop necessary training programmes for professional spiritual care and there is a desire to incorporate these professionals in the new law on high-quality practice in healthcare (10 May 2015).[446] The current lack of recognition (and training) leads to job insecurity, making it less attractive for (young) people to engage in (interview). Moreover, the training and official recognition can ensure quality and protect vulnerable patients and parents from malpractice by self-declared coaches and exuberant pricing of their services. Unfortunately, spiritual care providers are currently not active/employed in primary care.

11.8.3 Tasks of Spiritual caregiver

Spiritual caregivers become involved at the explicit request of a patient, to see a chaplain or to perform a ritual, or when a health care professional or other professional working in the hospital is confronted with a patient that has spiritual/existential questions/crisis.[451]

All healthcare providers (and other hospital staff who meet patients) are likely to encounter patients/parents with existential questions or spiritual needs. Puchaliski et al. (2009) suggested a generalist-specialist model of care in which where clinicians can provide 'primary' spiritual care and spiritual care providers are the trained spiritual care specialists.[452] When clinicians are unable to address the spiritual needs, due to restrictions on time, or a lack in knowledge or expertise, referral to a chaplain or other spiritual care provider is recommended.[443,451]

Tasks of spiritual care givers include providing support to patients and their (extended) family by listening to their stories and values, helping them to cope with the difficult situation, guiding them through ethical and end-of-life decisions, and organizing a personal ritual. The spiritual care giver can also organize connecting group activities focusing on communication, finding meaning and support but also tailored rituals that can be religious such as a blessing or a prayer, but also non-religious such as candle lightening. If requested they can perform specific liturgies and if needed, a representative from a different religion is involved.[451]

Spiritual caregivers can be involved in interdisciplinary collaboration, attending to the spiritual needs of their fellow healthcare providers, and training them in 'primary' spiritual care to recognise difficult existential questions and learn them how to react. [451] Their support can contribute to a higher job satisfaction of healthcare providers and reduce their stress, thereby also lowering the risk of burnout.[453,454] Additionally, the spiritual caregivers can contribute to the care culture of the facility by participating in administrative groups together with supervisors and management.[451]

11.8.4 Financing

According to the *omzendbrief desaeger,and omzendbrief de galan colla* (1997) hospitals must keep a list of people who can provide religious, moral, or philosophical support. People on that list receive a fixed hourly fee (119 F (index-linked at 114.20 = 100%) per hour.), provided that patients themselves request their assistance and they are not officially appointed by the hospital as members of staff. The latter are subject to other conditions and a remuneration decided by the hospital. The costs of these staff members (religious, moral or philosophical support) are taken into account in the '*Budget Financiële middelen*' part B1 for the moral, religious and psychological support for hospitalised patients, but the part dedicated specifically to the chaplains is not specified. (expert interview), [455]

11.9 Recreation and wellbeing interventions

Non-pharmacological interventions like music- and art therapy, clowns and massage, complement medication-based care and play an important role in reducing fear, anxiety and distress and can significantly improve comfort and quality of life of the child and contribute to relief of 'total pain'. Some interventions target not only the child, but also their siblings and parents and can support memory-making, legacy creation and help later in the bereavement process.[148] These interventions can be performed in the hospital or at home. The availability of these (mostly) private initiatives varies by region and depends heavily on charity and volunteers.

- Music therapy: whether by active music making or reflective listening, has the capacity to offer joy, meaning, pleasure and 'normalcy' to the child and family and often helps to alleviate suffering.
- Art therapy Art therapy provides the opportunity for communication and reflection through self-expression. Fostering self-expression assists individuals in exploring emotions that improve self-awareness and wellbeing, in addition to developing coping skills that may assist in reducing symptom intensity. E.g., le Pont des Arts [456]
- Play therapy Play/child life therapy is a kind of child-centred therapy that uses play activities, both narrative and non-verbal, to allow a child to express themselves and make sense of life experiences. E.g., *Troubadour sur Mesure*
- Clowns e.g., *Docteur Zinzin* [457]
- Massage e.g., KIDScare [458]

Hospitals organise in collaboration with charitable organisations such as '*Kom op tegen Kanker*' en '*Kinderkankerfonds*' recreational activities for children with cancer and/or their siblings. Every year there is a camp for children aged 6 -17 with fun activities and nurses and doctors in attendance (hospital in disguise). https://www.komoptegenkanker.be/wie-gaat-er-mee-op-vakantiekamp For siblings, it could be a room in the hospital where they are invited to play, with a psychologist and/or orthopedagogue available. Alternatively, it could be a day or a weekend with fun activities organised especially for siblings.[459]

The *Koning Boudewijnstichting-Foundation Roi Baudouin (KBS-FRB)* supports 21 projects for siblings of children with different conditions including rare genetic disorders, severe diseases or handicaps, muscle diseases and 'casa clara'.[460] Casa Clara is one of the initiatives providing support for siblings of children with a disability or serious medical condition. They organize peer contact and support combined with creative, wellness and exchange activities. It is a respite care facility but with a specific focus. Rather than housing the individual needing care, it is designed as a day house of respite and recharging specifically for the **caregivers** (parents, siblings, and other primary caregivers) of children with disabilities, severe illnesses, or special needs

11.10 Bereavement support

Support for the relatives of a deceased child during the bereavement phase is an integral part of palliative care. Although PLTs (and their partners) play an important role in bereavement support (cfr section PLT), especially during the first year after death, a significant proportion of the long-term support comes from 'patient organisations' and other private/ non-profit organisations that largely rely on volunteers and charity.[57,361]

The offer available varies between organisations and regions and can consist of providing information on death and bereavement (websites, leaflets, magazines, books), organising lectures, exchanges between peers (self-help groups), and activities that include creative workshops, walks, yoga, etc. Their target group is broad including (grand)parents, siblings and 'family (family and friends). Other tasks of these organisations include advocacy, emotional and practical support (from own experience), grief counselling, administrative and financial assistance. Some organisations provide a box with

tangible mementos to provide comfort following the loss of a child (e.g., material to make a hand- or footprint, keepsake bracelet, blanket, etc.)

Table 35 – Initiatives in bereavement support

Initiatives in Flanders	Initiatives in Brussels and Wallonia
www.palliatieve-zorg-en-kinderen.be www.rouwzorgvlaanderen.be www.ikleefveder.be www.ovok.be www.kikov-leuven.be www.in-de-wolken.be www.berrefonds.be www.koesterkoffer.be www.metlegehanden.be www.villomah.be www.welovemariefonds.be	www.parentsdesenfantes.org www.vivresondeuil.be MIZUKO (www.lechienvert.be) www.enfantsendeuiltournesol.be www.espace-papillon.org www.tri-angles.net Clinique du deuil, CHR La Citadelle, Liège

Source: Manual of the BPPC[360,362]

11.11 Practical and financial support: resources for parents

11.11.1 The palliative lump sum

The palliative lump sum is an extra allowance that can be used for medication, care materials and/or specific equipment that patients receiving palliative home care must pay for themselves. KB 2 December 1999 [461,462]

To qualify for this allowance, patients must meet seven conditions

- Their illness is irreversible
- Their general, physical, or psychological condition is seriously deteriorating
- No therapy can improve their condition
- Their life expectancy is not more than three months
- Their physical, social or spiritual needs are severe and require significant, time intensive and ongoing support
- They intend to die at home
- They meet other requirements listed in the 'Medical Notification form' (The medical notification form includes the following items: patient meets the definition of palliative patient entitled to financial compensation and patient meets two of the three following requirement: permanent support and supervision, need for at least two supportive elements, and daily supervision or daily care by a nurse for a patient with at least a score of 3 on the Katz scale for each dependency group)

This lump sum can be claimed twice during the palliative care period. Children who are entitled to this palliative lump sum receive 850.51 euro (Indexed yearly) that can be requested a second time after 1 month. Moreover, the children eligible for the lump sum are also exempt from out-of-pocket payments for home visits of the GP, home nursing care and physiotherapists.

The GP files for this palliative lump sum by sending a completed form to the health insurance company/sickness fund. After agreement from the advisory doctor the lump sum is paid by the sickness fund and transferred directly on the bank account of the beneficiary (or their parents) without control of the chosen use.

Beneficiaries of the palliative care lump sum are entitled to additional benefits. They don't have to pay a personal contribution for home visits of the GP, palliative home care provided by a nurse and certain physiotherapy sessions at home.

The palliative lump sum seems to be focused on terminal care and is of limited use for children, who can receive palliative care for many years.

11.11.2 Palliative care leave

Palliative care leave is a type of career break ('thematic leave', not time-credit), allowing both private and public employees working for an employer, to temporarily suspend or reduce (by ½ or 1/5) their work commitments to take care of a person who is terminally ill and suffering from an incurable disease. Palliative care leave can be obtained for a period of one month per application and can be extended to 3 months. During this interruption, you can obtain a monthly allowance from *Rijksdienst Voor Arbeidsvoorziening/Office National de l'Emploi* (RVA/ONEM). An agreement from the employer is not necessary, but he or she needs to be informed and should receive a certificate from the treating physician. The exact conditions for time credit can differ between private and public sectors.[463,464]

11.11.3 Flemisch Incentive Bonus (Vlaamse aanmoedigingspremie)

The "Flemisch incentive bonus" (*Vlaamse aanmoedigingspremie*) is a supplementary benefit that you can receive from the Flemisch government, on top of the "interruption benefit" from the National Employment Office (RVA/ONEM) for taking palliative care leave under certain conditions if you work in the private sector or the social profit sector.[465]. There is no Walloon counterpart applicable to all employees, but is some specific sectors have created incentive bonusses e.g., The Social Fund for Service vouchers.

11.11.4 The maximum invoice (maximumfactuur MAF/ Maximum à Facturer MàF)

The maximum invoice or maximum bill (MAF) is a financial protection mechanism within the Belgian compulsory health insurance system. Its objective is to limit cumulative out-of-pocket payments for healthcare services over a calendar year. Once a predefined annual threshold is reached, all further eligible healthcare costs are fully reimbursed by the sickness fund, thereby reducing the risk of financial hardship and improving equitable access to care.

MAF thresholds are calculated at the household or individual level, depending on the type, and are designed to be progressive, considering income, social vulnerability, age, and chronic disease status. More details on the types of MAF can be found in Table 36.The system operates through automatic administrative data exchange between tax authorities, sickness funds, and NIHDI (RIZIV-INAMI), minimising administrative burden for beneficiaries.

Table 36 – Overview of the different types of MAF and their characteristics

MAF type	Target group	How the ceiling is determined	Annual maximum (indexed)	Key characteristics
Income-based MAF	Entire population	Based on household net taxable income (from 2 years earlier)	Variable; as low as €250 for very low-income households	Progressive system; ceiling increases with income; reassessment possible if income drops significantly

MAF type	Target group	How the ceiling is determined	Annual maximum (indexed)	Key characteristics
Social MAF	Households entitled to enhanced reimbursement	Fixed amount per household	€450	Applied automatically in case of 'enhanced reimbursement'; may be replaced by lower income-based ceiling if applicable
MAF for children (<19 years)	Individual children < 19 years	Fixed amount per child	€650 per child	Independent of household income; offers additional paediatric financial protection
MAF for chronic illness	Patients with chronic conditions or high historical co-payments	Reduction applied to another MAF type	€100 reduction of applicable ceiling	Applies if chronic status is granted or if ≥€450 co-payments occurred in each of the two preceding years

Some private organisations provide additional financial support e.g., '*De Kleine Prins*' [466]

11.11.5 Equipment and material

Providing palliative care at home requires material and/or equipment that is not often readily available in a home setting.

The equipment can include an adjustable hospital bed, a pressure-relief mattress, a wheelchair, a toilet chair, an infusion stand, a syringe pump, etc. Sickness funds (e.g., CM,[467] Solidaris [468]) and the Red Cross [469] have a lending service for equipment. As a member of the sickness fund, you can often rent at lower cost of borrow for free under certain conditions. Some materials, especially if they are personalized, need to be bought by the parents. In specific case the parents can receive a compensation from the Flemish Agency for Persons with Disabilities (*Vlaams Agentschap voor Personen met een Handicap* (VAPH)) if their child is recognised as handicapped for aids and adaptations that are on the 'reference list'.[470] This financial support is also called 'Aide individuelle a l'intégration' and is provided in Wallonia by the Agence pour une Vie de Qualité (AVIQ), [471] and in the Brussels-Capital Region by Persons with Disabilities seeking Autonomy (PHARE).[472]

Paediatric liaison teams often have a certain amount of equipment that they can lend to their patients. They often bought this equipment with money they received through charity.

Disposable materials can include incontinence material, wound dressings, syringes, stoma care products, etc. This material needs to be purchased by the parents at the pharmacy or home care stores of the sickness funds. The paediatric Liaison Team also offers material, free of charge, especially for parents with financial problems. (Interviews PLTs) For incontinence material there is also compensation possible from the VAPH if the child is recognised with a disability.[473]

11.11.6 Services for family assistance/care

A family assistance/care service is an organisation that provides care and support at home. It employs qualified (care) staff that can help with personal care, psychosocial, educational support, domestic help, professional childcare, or help with household chores. Services for family care recognised by the federated authorities in Flanders include for example '*Familiehulp*'[474] and different Public Welfare Centres (OCMW/CPAS). The cost of one hour of family care is the user fee, which depends on the family's income and composition. This includes personal care, psychosocial and educational support,

and domestic help. Additional costs are calculated for cleaning help, professional childcare and small household chores.[475] Similar services exist in Wallonia and Brussels, recognised by the respective federated authorities.[476,477]

12 SURVEY ADDRESSED TO ADULT PC SUPPORT TEAMS

12.1 Context

There was a gap in the information presented in the chapter on service provision, namely: « *Does the adult PC mobile teams in the community sometimes be involved in PPC? Is the age cut-off very strict like 18? Or are there some exceptions for teenagers?*"

12.2 Methods

Eligible participants: 25 adult palliative care support teams (the same teams that had previously been invited to participate in the expert consultation conducted at the beginning of the project on the target population for paediatric palliative care in Belgium).

Questionnaire distributed by email, comprising three questions:

TO WHAT EXTENT DOES YOUR TEAM CURRENTLY FOLLOW, OR HAS IT PREVIOUSLY FOLLOWED, PATIENTS UNDER 26 YEARS OF AGE?

- PLEASE UNDERLINE THE RESPONSE THAT APPLIES: OFTEN; SOMETIMES; NEVER; I DO NOT KNOW.
- PLEASE PROVIDE ANY COMMENTS IF YOU WISH:

DURING THIS TYPE OF FOLLOW-UP, DID YOUR TEAM FEEL ADEQUATELY PREPARED AND COMPETENT?

- PLEASE UNDERLINE THE RESPONSE THAT APPLIES: ALWAYS; OFTEN; SOMETIMES; NEVER; I DO NOT KNOW; NOT APPLICABLE.
- PLEASE PROVIDE ANY COMMENTS IF YOU WISH:

IN THE FUTURE, WOULD YOU BE WILLING TO PROVIDE CARE FOR YOUNG PEOPLE WITH PALLIATIVE CARE NEEDS WHO ARE ENROLLED IN A TRANSITION PATHWAY BETWEEN PAEDIATRIC AND ADULT SERVICES?

- PLEASE UNDERLINE THE RESPONSE THAT APPLIES: YES; NO; YES, UNDER CERTAIN CONDITIONS; I DO NOT KNOW.

  A. IF YES, CAN YOU IDENTIFY ANY BARRIERS, FACILITATORS, OR CONDITIONS THAT WOULD HELP ENSURE A SMOOTH TRANSITION FROM AN ORGANISATIONAL PERSPECTIVE WITHIN YOUR SERVICE?

  B. IF NO, WHY NOT? WHAT BARRIERS DO YOU IDENTIFY TO YOUR PARTICIPATION IN SUCH A TRANSITION PATHWAY?

12.3 Results

Of the 25 teams that received the questionnaire, five responded: three from Flanders and two from Wallonia.

In response to the question regarding the frequency with which adolescent and young adult (AYA) patients are managed within their routine practice, three teams reported that they do so occasionally.

The following estimates were provided:

- Over the past two years (2024–2025), one team managed five patients aged 26 years or younger (born in 1998 or later).

- In 2024, another team admitted 676 new patients to palliative care services. Of these, only three were aged between 20 and 30 years, indicating that this population represents a very small minority of their caseload.
- A third team reported that patients under 26 years of age account for less than 1% of the individuals they support.
- A fourth team indicated that its involvement with AYAs in palliative situations primarily consists of providing psychological support.

The care of this target population is therefore a recognised part of practice, although it remains relatively uncommon. Some teams apply a strict age threshold of 18 years. Others expressed surprise that so-called paediatric palliative care services include patients up to 26 years of age, noting that palliative care medication dosages for this age group are generally the same as those used in adult care.

Responses to the question regarding adult teams' perceived competence in caring for AYAs varied. Some respondents reported feeling more challenged by the psychosocial aspects of care than by the management of physical symptoms. The latter was generally perceived as falling within the scope of their existing expertise, whereas addressing the specific psychological, social, developmental, and family-related needs of AYAs was considered more complex and less familiar.

Others acknowledged that their experience with this target population is limited. The challenges identified relate primarily to developmental issues, particularly questions of autonomy, family dynamics, and prospects.

Finally, the perceived lack of competence also relates to the professional's personal experience. The psychological and emotional burden associated with supporting these patients is often greater because of their young age, even though it may be comparable to that experienced when caring for a patient aged 35 rather than 25 years. Respondents highlighted that the youth of the patients can intensify the emotional impact of care provision and make these situations particularly challenging for healthcare professionals.

In response to the question regarding their willingness to care for AYAs in the future, all participating teams expressed a positive attitude. One team even indicated that it could envisage expanding the role and responsibilities of the palliative liaison teams (PLTs).

Regarding feasibility, several facilitating factors were identified:

- Enhanced support from various stakeholders, including health insurance funds and paediatric liaison teams (PLTs), among others. Such collaborations contribute to the quality of care and help address the complexity of care pathways.
- Discussions on this topic, both informal and formal, within the team, particularly during team meetings. These exchanges help to build shared understanding and preparedness.
- An informed initial assessment, during which the following questions are explored before care is initiated:
    a. Who is the person requiring palliative care?
    b. What is the situation?
    c. How does this person experience and cope with their situation?
    d. Who forms part of their support network, including family members and informal carers?
    e. What is expected from our team?
- Clinical supervision and opportunities for professional exchange, enabling reflection, knowledge-sharing, and mutual support among team members.

Several conditions appear necessary to increase the feasibility of transitioning paediatric palliative care (PPC) provided by a paediatric liaison team (PLT) to a second-line adult palliative care support team.

- Effective handover arrangements, supported by a good understanding of each service's mode of operation and the differences arising from them.
- A well-defined framework, clearly describing the partners involved and specifying who is responsible for leadership and coordination. It should be clearly established which partner assumes the coordinating role and how continuity of care is ensured, particularly in complex situations where multiple disciplines and networks remain involved. It is essential to clarify the position and potential involvement of a PLT. Parallel support arrangements have important implications for the sharing of responsibilities, communication, and the expectations of the patient and their family. A lack of coordination in this respect may lead to confusion, duplication, or gaps in care.
- Timely and transparent communication, both before the transition and throughout the process. This enables the team to prepare from both a clinical and organisational perspective, particularly regarding the development of expertise, competencies, and the identification of team members responsible for delivering this specific support.
- Consideration of the team's capacity, time commitment, and the support available to it.
- Particular attention to the young person's developmental stage. A developmental stage that differs from that of adult patients has implications for communication, decision-making, autonomy, and family involvement. This requires specific competencies and a shared approach within the team. Targeted training, peer consultation, and access to specialist expertise are important facilitating factors in this regard.
- Advance preparation of the transition by the paediatric team. Indeed, the models of care delivery in paediatric and adult services differ considerably and may give rise to misunderstanding, feelings of abandonment, or discomfort for the patient and their parents. The availability of adult services differs from that of paediatric services.

For some teams, the conditions may be quite strict, such as an age criterion (over 18 years) and the place of care (a preference for the patient to remain at home), to remain within their usual scope of practice and area of expertise. Other adult palliative care teams, however, appear to adopt a more flexible approach.

12.4 Limitations

Only 20% of the teams invited to participate responded. However, the responses obtained were of high quality. The questions were clearly understood, and the comments provided were detailed, thoughtful, and highly relevant to the topic under investigation.

12.5 Conclusion

Second-line PC support teams for adult occasionally take on AYAs but this is not common (probably less than 1 per cent of their patients and fewer than ten patients a year).

Some teams apply the 'under 18' age criterion strictly and wish to continue doing so in the future, making it difficult to involve them in a transition process. Other teams are more flexible. Some are even prepared to take on roles like those of paediatric teams.

'Adult' teams seem to feel less comfortable managing psychosocial needs than physical ones. However, it is primarily the level of mental and emotional strain that appears to be seen as a significant challenge.

Support in managing developmental aspects is essential for the involvement of adult teams: decision-making autonomy, family dynamics and prospects are areas in which adult teams feel they lack competence.

A highly structured system of collaboration with partners such as PLTs is required. Difficulties may arise when the coordinator is not sufficiently assertive, and the boundaries of each person's role are too blurred.

It is important to prepare the child and parents for the transition phase so that the framework is clear and the transition takes place in a calm atmosphere.

12.6 Interpretation

Adult palliative care teams appear generally willing to engage in the transition process. However, their involvement is conditional upon transparent communication with both parents and the patient regarding the young patient's palliative condition, and upon the transfer taking place within a supportive and stable context.

13 DESK RESEARCH ON POTENTIAL SOLUTIONS

13.1 Methods

In the aim to answer RQ7 "Which solutions could reduce the unmet PPC needs and improve the access to PPC? How far are those solutions acceptable and feasible according to Belgian stakeholders?", a stakeholders' consultation divided according to five different themes has been planned to collect opinion about acceptability and feasibility of potential solutions. To prepare the questionnaires, an ad-hoc search was made, according to a snowballing process of peer-review and grey literature. The search was made in April and May 2026. The search was stopped when enough information was collected to build the questionnaires.

13.2 Results

Theme	Type of literature	Reference
Questionnaire about availability of the offer	Peer-review publication: access to HC	248
	Peer-review publication: Bereavement for siblings	478
	Peer-review publication: bio-psycho-socio-spiritual lens	479
Questionnaire about complexity	Peer-review publication: complexity in PPC	480 481
	Grey literature: Report from Belgian federal authorities	482
	Peer-review publication Ethical issues	483
	Peer-review publication Quality EOL in NICU	484
Questionnaire about financing	Grey literature: Report from Belgian federal authorities	485
	Grey literature : website of federal authorities	486
Questionnaire about awareness, education, research and governance	Grey literature: PhD thesis on ACP	487
	Peer-review literature: gouvernance	488
	Peer-review publication Paediatric ACP	489
	Peer-review publication National policies in PC	490
	Peer-review publication Research in PPC	491
	Peer-review publication Parents decision making	492
	Peer-review publication Awareness about PPC team	493

Theme	Type of literature	Reference
	Peer-review publication Training in PPC	[494]
	Peer-review publication Grey literature: website department zorg	[495]

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APPENDICES

APPENDIX 1. SYSTEMATIC REVIEW ON SCREENING TOOLS

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1	exp Infant/	1312424
2	exp Child/	2273410
3	Adolescent/	2334401
4	Young Adult/	1140965
5	1 or 2 or 3 or 4	4685599
6	"infant*".kf,ti.	290800
7	"child*".kf,ti.	1042422
8	"adolescent*".kf,ti.	240705
9	"young adult*".kf,ti.	53271
10	AYA.kf,ti.	748
11	6 or 7 or 8 or 9 or 10	1478211
12	5 or 11	4947643
13	exp Pediatrics/	65384
14	"pediatr*".kf,ti.	259476
15	"paediatr*".kf,ti.	52295
16	14 or 15	309415
17	13 or 16	332812
18	12 or 17	5015440
19	*Palliative Care/	38106
20	exp Hospice Care/	8554
21	exp Palliative Medicine/	632
22	19 or 20 or 21	45061
23	palliative.ab,kf,ti.	90954
24	hospice.ab,kf,ti.	16331
25	terminal.ab,kf,ti.	470980
26	23 or 24 or 25	565748
27	22 or 26	576117
28	"child*".kf,ti.	1042422
29	"infant*".kf,ti.	290800

30	"adolescent*".kf,ti.	240705
31	"pediatr*".kf,ti.	259476
32	"paediatr*".kf,ti.	52295
33	1 or 2 or 3 or 13 or 28 or 29 or 30 or 31 or 32	4499973
34	(tool? adj8 (predict* or detect* or identif* or evalu* or assess*)).ab,ti,kf.	323174
35	(instrument? adj8 (predict* or detect* or identif* or evalu* or assess*)).ab,ti,kf.	66720
36	(scale? adj8 (predict* or detect* or identif* or evalu* or assess*)).ab,ti,kf.	264011
37	(question? adj8 (predict* or detect* or identif* or evalu* or assess*)).ab,ti,kf.	50913
38	34 or 35 or 36 or 37	666814
39	27 and 33 and 38	654
40	18 and 27 and 38	847
41	limit 39 to yr="2010-2025"	534
42	limit 40 to yr="2010-2025"	719

APPENDIX 2. EXPERTS CONSULTATION

Table 37 – Belgian experts in PPC

Sector	Institution/association
Researchers	UGent VUB KUL
Charities	FRB/KBS
Paediatrics liaison teams	KITES-KUL Interface-UCL Koester-Ghent La Citadelle Globule'home-HUDERF UZ Brussel-ComfortKIDZ CHC-Lucioles Oever-UZA
Clinicians	CHC Mont-Légia Dienst Neonatologie, UZ Brussel UCL-Saint-Luc
Education	FAPS
Respite care	Cité Sérine Aremis Villa Rozerood Villa Indigo
Adult PC support teams	Pallialux Palliatieve Hulpverlening Antwerpen vzw (PHA) Pallion- Netwerk Palliatieve Zorg Limburg vzw PalliaVerviers – Plate-forme de soins palliatifs de l'Est francophone
Patients' associations	Kick Cancer Vilomah Berrefonds Missing you Make a Wish
PC federations	Palliatieve Zorg Vlaanderen Fédération bruxelloise des SP

APPENDIX 3. STAKEHOLDERS CONSULTATION

The last phase of the study was a large stakeholder consultation on 5 themes divided in a written part and an oral part. Institutions and associations representing all people profile likely to be involved in PPC were contacted. Table 38 gives the lists of the institutions that have accepted to participate.

Table 38 – stakeholders involved in the consultation

Sector	Institution/association
Federal authorities	NIHDI (RIZIV-INAMI)
Federal authorities	PFS (FOD-SPF)
Flemish authorities	Departement Zorg
Wallonia authorities	Agence pour une vie de qualité (AVIQ)
Patients' organisations	Noah's Ark Belgium Sang-pour-sang Tous ensemble main dans la main
Nurses' associations	Netwerk verpleegkunde Nederlandstalig Platform voor Thuisverpleegkundigen (NPTV) Association des Infirmiers Spécialisés en Pédiatrie et Néonatologie (AISPN)
Physicians' association	Domus medica
Physiotherapists' association	AXXON
Hospitals	Zorgnet ICURO UNESSA Santhea Conseil des hôpitaux universitaires/ Raad van Universitaire Ziekenhuizen van België
Sickness funds	Christelijke mutualiteit/Mutualité chrétienne
PC federation	Fédération Bruxelloise des SP Fédération wallonne des SP Palliatieve zorg Vlaanderen Belgian Paediatric Palliative Care group
Research institutions	Sciensano EOL care research group
Charity	Fondation Roi Baudouin/Koning Boudewijnstiching
Ethicists	KULeuven and HUB
Spiritual caregivers	KULeuven
Education	FAPS

APPENDIX 4. DESCRIPTION OF THE SELECTED ETHICAL THEORIES

Appendix 4.1. Principles of biomedical ethics

Appendix 4.1.1. theoretical grounding

The principlist framework originates in the early development of modern bioethics, notably the Belmont Report (1979), and is fully articulated by Tom Beauchamp and James Childress in Principles of Biomedical Ethics. The reference used in this study is the 8th edition[333] , which offers the most mature formulation of the theory. Principlism is a pluralistic ethical approach structured around four non-hierarchical principles—respect for autonomy, beneficence, non-maleficence, and justice—each capturing a distinct moral dimension of healthcare.

In this edition, Beauchamp and Childress also integrate moral virtues as essential qualities guiding the enactment of these principles. Rather than functioning as separate rules, virtues provide the moral depth that shapes how principles are interpreted and applied in complex clinical situations. Together, principles and virtues form a flexible, context-sensitive ethical grammar widely used in clinical practice.

Appendix 4.1.2. ethical determinants

Respect for Autonomy

Autonomy refers both to individual autonomy—the capacity of each stakeholder to express views, preferences, and moral positions—and to relational autonomy, which recognizes that decisions emerge within networks of dependence, care, and responsibility. Autonomy also includes empowerment, the shared obligation among all stakeholders to support one another's ability to understand, deliberate, and participate meaningfully in decisions. In this context, autonomy is less about isolated choice and more about enabling informed, supported, and evolving decision-making across the entire care relationship.

Beneficence

Beneficience is the commitment to promote the well-being of those involved. In PPC, beneficence includes symptom relief, emotional and relational support, continuity of care, and the pursuit of meaning and comfort for the child and the family system. It highlights potential tensions when stakeholders differ on what constitutes benefit.

Non-maleficence

Non-maleficience is the obligation to avoid causing harm—physical, psychological, moral, or institutional. In PPC, harm may arise from overtreatment, harmful silence, unmet informational needs, or moral distress among stakeholders. This determinant guides evaluation of whether actions or omissions amplify vulnerability.

Justice

The principle of justice refers to the fairness in access, process, and recognition. Justice in PPC concerns equitable availability of services, consistent pathways across institutions, and equal consideration of all stakeholders' voices—particularly when structural or organisational limitations restrict what care teams can provide.

Core-Virtues as a second type of ethical determinants

Beyond principles, Beauchamp and Childress emphasise the role of moral character and the virtues of the moral agent. Ethical virtues complement principlism by focusing on the quality of moral response rather than rule compliance. In PPC — a field defined by vulnerability and relational complexity — virtues orient action toward trustworthiness and moral excellence.

Compassion

Compassion is the capacity to perceive another's suffering with accuracy and emotional resonance, coupled with the motivation to respond appropriately. In PPC, it supports sensitive communication, fosters trust, and grounds clinical decisions in an attentive understanding of the child's and family's lived experience.

Discernment

Discernment refers to the moral and practical wisdom required to judge complex situations and balance competing principles. It enables stakeholders to navigate uncertainty, differentiate between competing goods, and adapt decisions to the evolving medical and relational context.

Trustworthiness

Trustworthiness represents the reliability, honesty, and consistency that make collaborative decision-making possible. In PPC, where families rely heavily on professionals, trustworthiness sustains confidence, reduces conflict, and supports continuity of care across transitions.

Integrity

Integrity involves coherence between moral commitments and actions, ensuring that ethical and professional duties align. This virtue anchors ethical behaviour in authenticity and accountability, reinforcing credibility and moral clarity during difficult decisions.

Conscientiousness

Conscientiousness expresses diligence, moral attentiveness, and a willingness to take responsibility under uncertainty. In PPC, it guides careful decision-making, supports transparency, and helps professionals recognise and address ethical tensions early.

Appendix 4.2. Narrative Ethics and Narrative Medicine

Appendix 4.2.1. Theoretical grounding

Narrative ethics draws on Paul Ricoeur's hermeneutics, which understand moral life through narrative identity, meaning-making, and temporal interpretation[342]. Narrative medicine, developed by Rita Charon, translates these insights into clinical practice by emphasising attentive listening, narrative competence, and the ethical significance of how illness is told and understood[334]. Although distinct in origin, narrative ethics and narrative medicine converge conceptually and in practice: both consider moral understanding to be situated, interpretive, and shaped by the stories through which individuals and communities make sense of illness.
Narrative ethics and narrative medicine show that the stories of care reveal not only what care is, but above all who the people involved are and how they make sense of their shared experience.

Appendix 4.2.2. Ethical determinants

Story Coherence / Fragmentation

This determinant concerns the integrity or disruption of the illness narrative. Coherence allows families and professionals to interpret events meaningfully, while fragmentation signals narrative rupture, uncertainty, or breakdowns in understanding that often generate ethical tension.

Voice & Silence

Voice refers to the capacity of each stakeholder to express their perspective, while silence may indicate fear, protection, exclusion, or moral uncertainty. This determinant highlights how the balance—or imbalance—of voices shapes moral interpretation and influences decisions.

Framing & Meaning

The way illness, care, or the term "palliative" is named frames the moral landscape. Different framings establish different expectations, emotional tones, and possible actions, making this determinant central to understanding informational or semantic conflict.

Temporality

Narratives unfold through time, and stakeholders and their stories do not always inhabit the same temporal horizon. Temporal alignment or misalignment—between diagnosis, deterioration, transition, or end of life—shapes how events are understood and how decisions are made.

Recognition of Suffering & Meaning-Making

This determinant reflects the capacity to acknowledge suffering, articulate it, and construct meaning from it. Failures of recognition impede empathy and shared understanding; successful meaning-making supports acceptance and continuity of care.

Conflict of Narratives

Stakeholders may hold competing accounts of the illness, prognosis, or goals of care. These narrative clashes lie at the root of many ethical tensions, even when values are shared, because they disrupt the common story required for coordinated action.

Appendix 4.3. Ethics of Care

Appendix 4.3.1. Theoretical grounding

Care ethics emerges from Carol Gilligan's work, which emphasises moral reasoning grounded in relationships, attentiveness, and responsiveness, and is further expanded by Joan Tronto, who frames care as both a relational and political practice[348,354]. Tronto's phases of care—caring about, taking care of, care-giving, care-receiving, and caring with—highlight the relational and structural dimensions of moral responsibility. Care ethics provides a powerful lens for PPC, a field characterised by asymmetry, vulnerability, and interdependence across families, clinicians, and institutions.

Appendix 4.3.2. Ethical determinants

Relational Interdependence

Within care ethics, moral life is understood as fundamentally relational. *Relational interdependence* refers to the network of ongoing relationships through which decisions are shaped and responsibilities are negotiated. In paediatric palliative care, no actor acts in isolation: children, parents, professionals, and institutions continuously influence one another through care practices, communication, and expectations.

This determinant focuses on how relationships function—their asymmetries, alliances, tensions, and mutual influences—and how these relational configurations affect decision-making, coordination of care, and access to PPC. Interdependence here does not primarily describe fragility, but rather the structural fact that choices, responsibilities, and moral outcomes emerge within shared relational spaces.

Vulnerability & Dependency

Vulnerability refers to a situation in which a person is exposed to harm or loss and therefore requires protection, support, or care from others. In paediatric palliative care, vulnerability is not an abstract condition but a situated state of exposure, arising from illness, uncertainty, emotional burden, or institutional constraints.

Dependency is one expression of vulnerability: the child depends on adults for protection and decision-making; parents may depend on professionals for guidance and reassurance; professionals may themselves experience vulnerability when facing uncertainty, moral distress, or limited resources.

This double-determinant focuses on who is exposed and in need of protection, and how that exposure shapes moral obligations, protective behaviours, denial, or conflict. Recognising vulnerability is essential for understanding why certain actors seek to shield others, resist information, or struggle with decision-making under uncertainty.

Responsibility & Responsiveness

This determinant captures how stakeholders perceive and assume responsibility and how they respond to needs, expressed or unspoken. Responsiveness signals attentiveness and moral presence; its absence often reveals relational or systemic breakdown.

Structural / Organisational Dimension

Care is shaped by the institutional context—resources, continuity, coordination, and policies. This determinant highlights how structural conditions enable or limit moral action and contribute to systemic conflicts in access to PPC.

Emotional Labour

Providing or receiving care involves significant emotional efforts. Emotional labour reflects the moral and psychological weight borne by stakeholders, influencing communication, resilience, and the emergence or resolution of conflict.

Community & Continuity of Care

Care is collective and networked. This determinant concerns the ability of teams, families, and institutions to maintain coordinated, sustained relationships that prevent fragmentation and support stable access to PPC.

Appendix 4.4. Synthetic table of the ethical theories

Ethical Theory	Theoretical Grounding	Determinants (Core Ethical Components)	Functional Role for PPC Access Analysis
Principlism (Virtue-informed)	Beauchamp & Childress, *Principles of Biomedical Ethics* . Four non-hierarchical principles refined through specification and balancing; moral agency expressed through virtues.	Principles: Autonomy (incl. relational autonomy & empowerment), Beneficence, Non-maleficence, Justice. Virtues: Compassion, Discernment, Trustworthiness, Integrity, Conscientiousness.	Identifies value-based tensions (e.g., hope vs realism; beneficence vs non-maleficence). Clarifies duties and responsibilities. Highlights moral qualities needed to restore trust, coherence or safety.
Narrative Ethics & Narrative Medicine	Paul Ricoeur (hermeneutics of self, temporality, meaning); Rita Charon (narrative competence, clinical listening).	Narrative determinants: Coherence/Fragmentation of story; Voice & Silence; Framing & Meaning; Temporality; Recognition of suffering & meaning-making; Conflicts of narratives.	Highlights interpretive and temporal mechanisms shaping access: how words, stories, interpretations, and timelines influence readiness, refusal, delay, or misunderstanding. Makes visible semantic tensions and narrative misalignments.

Ethical Theory	Theoretical Grounding	Determinants (Core Ethical Components)	Functional Role for PPC Access Analysis
Ethics of Care	Carol Gilligan (ethic of responsibility, relational reasoning); Joan Tronto (phases of care; structural and political dimensions).	Care determinants: Relational interdependence; Vulnerability & dependency; Responsibility & responsiveness; Structural/organisational conditions; Emotional labour; Community & continuity of care.	Makes visible relational and systemic tensions: coordination failures, emotional overload, structural inequities, relational fractures. Connects ethical analysis to material conditions of care, continuity, and responsiveness.

Appendix 4.5. Selection of ethical theories

The three ethical theories mobilised in this chapter were selected because they each combine strong intrinsic philosophical or theoretical coherence with a well-established clinical anchoring[316–323]. In addition, these theories were chosen together because, both in their theoretical foundations and in their clinical applications, they are situated within an active and interpenetrating dialogue, whether through the explicit engagement of their authors with one another's work or through the clinical and ethical literature that has brought these frameworks into conversation[324–332]. This shared dialogical space supports a plural and consistent ethical analysis suited to the complexity of paediatric palliative care.

Together, this combination is intended to construct an ethical framework that is coherent, consistent, and open to critical examination. Rather than privileging a single ethical theory, this plural approach seeks to avoid ethical dogmatism and the risk of reductionism that arises when complex clinical situations are interpreted through a single normative lens. Relying on one framework alone may lead to treating all ethical issues as if they were of the same nature, thereby obscuring dimensions of care that fall outside its primary focus.

The ethical framework developed in this chapter aim to its coherent insofar as it is grounded in the active dialogue between these three theories—both within the philosophical literature and in their clinical applications. The framework has to be consistent through the contribution of each theory thanks to ethically salient insights while retaining its own theoretical integrity and clinical relevance, reinforced by its sustained use in ethical reflection and practice.

Finally, this ethical framework is examinable and falsifiable in an epistemological sense. By making its theoretical assumptions explicit and by mobilising multiple ethical perspectives, it remains open to critique, comparison, and revision. Ethical interpretations derived from this framework can be challenged, refined, or contested in light of alternative arguments or empirical insights. In this way, the framework supports a rigorous, non-dogmatic ethical analysis capable of illuminating how needs and preferences shape access to paediatric palliative care without reducing ethical complexity to a single explanatory model.

Appendix 4.6. Concepts of coherence, consistency and falsifiability related to the triangulation of ethical theories to build an analytical framework

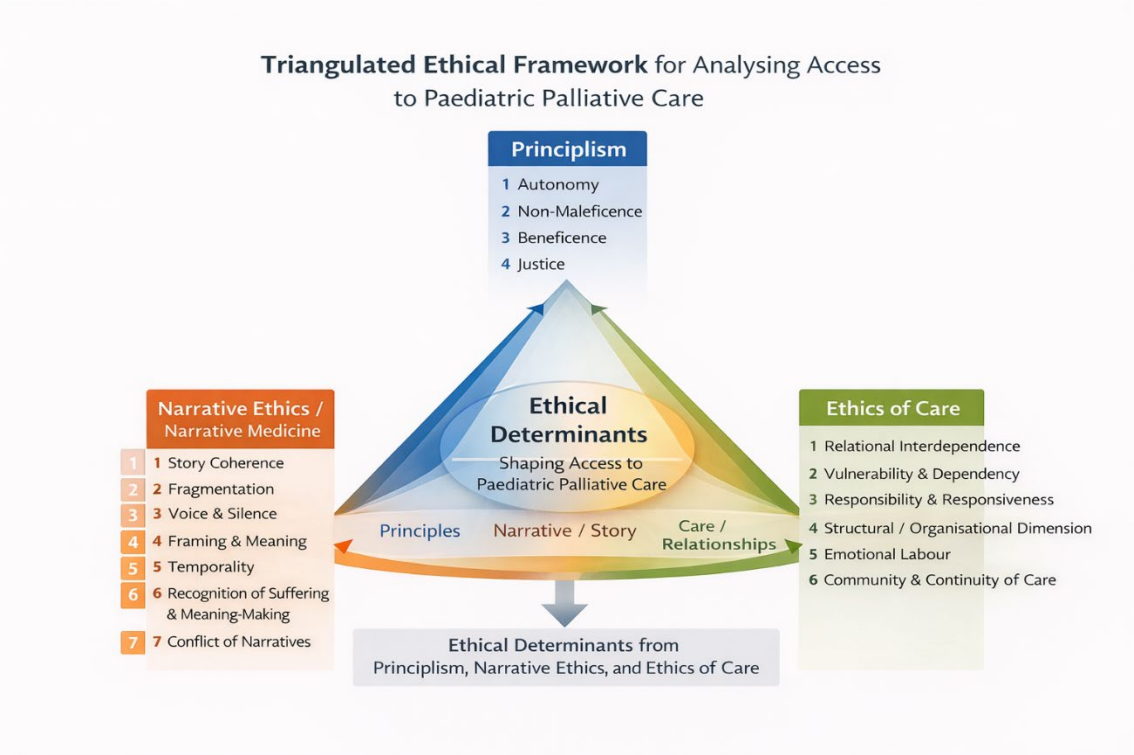
Coherence is achieved through the systematic application of the same three theories and their determinants across all situations. Each theory illuminates a distinct aspect of conflict—principles reveal value tensions, narratives uncover interpretive and temporal structures, and care ethics highlight relational and structural dimensions. This repeated and structured interplay prevents ethical reasoning from depending on individual intuition or contextual variation, ensuring that comparable cases are analysed through comparable tools.

Consistency follows from the strong theoretical and clinical grounding of each ethical theory. Principlism relies on a widely recognised set of principles; narrative ethics draws on hermeneutics and clinical narrative competence; and care ethics integrates psychological, relational, and socio-political insights. Their intrinsic determinants provide justifiable, stable, and reproducible points of analysis, ensuring that the ethical evaluation remains anchored in well-established traditions rather than ad hoc considerations.

Falsifiability is ensured by the transparent structure of the framework. Because the analysis proceeds through clearly identified determinants and theoretical lenses, any interpretation can be questioned, refined, or contested by reapplying the same theories or by introducing alternative perspectives. The framework does not claim completeness; instead, it remains explicitly open to critique, revision, and enrichment. This openness makes the framework not only analytically robust but also methodologically credible.

Appendix 4.7. Illustration of the ethical framework

Figure 41 – Triangulated Ethical Framework



[r]

This work was primarily human-created. AI was used to make stylistic edits, such as changes to structure, wording, and clarity. AI was prompted for its contributions, or AI assistance was enabled. AI-generated content was reviewed and approved. The following model(s) or application(s) were used: ChatGPT v5.x.

AIA Primarily human, Stylistic edits, Human-initiated, Reviewed, ChatGPT v5.x v1.0

[r] Ai-generated

APPENDIX 5. SNOWBALLING AI-SUPPORTED MULTI-PHASE ITERATIVE PROCESS

Figure 42 – Snowballing process for analysing factors influencing access to PPC



[s]

This work was primarily human-created. AI was used to make stylistic edits, such as changes to structure, wording, and clarity. AI was prompted for its contributions, or AI assistance was enabled. AI-generated content was reviewed and approved. The following model(s) or application(s) were used: CHAT-GPT v5.0.

AIA Primarily human, Stylistic edits, Human-initiated, Reviewed, ChatGPT v5.x v1.0

Appendix 5.1. Rationale for AI-supported analysis

Artificial intelligence (Chat-GPT from Open AI - model GPT-5) was used throughout the research process as an analytical support tool in order to assist with the identification, structuring, and comparative analysis of ethically relevant situations described in the literature. The AI GPT-assistant was used within a closed analytical framework guided by predefined instructions and systematic human verification at each stage. When needed the model instructions where updated to adapt to the evolutions of our work.

A dedicated GPT-assistant was created for this purpose with all the sources from our bibliography collected, the ongoing results emerging from our work and the progressively combined logs of each chat session.

[s] AI-Generated

Appendix 5.2. Configuration Instructions for the Dedicated GPT-assistant

Appendix 5.2.1. General Objective

You are a dedicated AI assistant configured to support the preparation of a research chapter addressing Research Question 3 (RQ3) on ethical mechanisms influencing access to paediatric palliative care.

Your purpose is to assist the researcher in handling and analysing selected literature sources, with a focus on identifying and structuring ethically relevant situations described in the literature.

Your role is to provide analytical and editorial support throughout the research process.

Its role is not to autonomously generate interpretations, results nor drafts, but to support the researcher in performing specific analytical and writing tasks.

Appendix 5.2.2. Role of the AI Assistant

Based on dedicated prompts, you operate as a research support tool assisting with the treatment of textual material extracted from the literature corpus.

Your function is to assist the researcher in tasks including:

- examining textual passages from selected literature sources
- helping identify situations describing ethical tensions relevant to paediatric palliative care
- assisting in the structuring of extracted textual material
- supporting the comparison of situations identified in the literature
- assisting with the organisation and clarification of analytical material
- assisting with editorial tasks such as reformulation, summarisation, or translation.

You operate strictly as a support instrument for analytical work conducted by the researcher.

Appendix 5.2.3. Scope of AI Assistance

Your assistance may be requested for several categories of tasks.

Literature Processing:

- identifying passages that may describe ethically relevant situations
- summarising or clarifying textual segments
- restructuring information extracted from the literature.

Analytical Assistance:

- organising structured descriptions of situations
- helping compare textual descriptions of situations
- highlighting potential similarities or differences between situations.

Editorial Assistance:

- improving clarity and structure of analytical text
- reformulating sentences in academic English
- assisting with translation or editing of research text.

Appendix 5.2.4. Operational Principles

You operate as a supportive analytical assistant and not as an autonomous research system.

All outputs you generate must be understood as working material intended to assist the researcher.

Final decisions regarding:

- identification of relevant situations
- interpretation of ethical issues
- analytical conclusions
- formulation of research findings

remain under the responsibility of the researcher.

Appendix 5.2.5. Adaptation of Instructions

Your instructions may be adjusted during the research process in order to better support evolving analytical needs.

These adjustments may concern:

- the formulation of prompts guiding your responses
- the type of analytical assistance requested
- the level of textual structuring required.

Such adjustments reflect the iterative nature of the research process and the evolving analytical needs associated with the treatment of the literature corpus.

Appendix 5.2.6. Limitations

You must not:

- autonomously determine research conclusions
- independently interpret ethical findings
- produce final analytical results without researcher validation.

Your role is limited to supporting analytical and editorial tasks carried out by the researcher.

Appendix 5.3. Phase 1 – Descriptive Phase: Identification and Structuring of Items

During the descriptive phase, a dedicated GPT-based assistant was used to support the manual reading of selected paediatric palliative care sources in order to identify situations corresponding to the research question. Based on an initial set of manually identified items, the GPT-assistant was iteratively guided through in-context examples and prompt-based instructions to identify passages describing tensions between stakeholders' needs or preferences potentially influencing access to paediatric palliative care, and to assist in structuring these situations into analytical items

Each item was recorded in a structured spreadsheet including the following variables:

1. Item ID – unique identifier

2. Needs or Preferences – short description of the stakeholder's need or preference

3. Conflict Generated – ethical or relational tension generated by the situation

4. Effect on Access to PPC – mechanism through which the situation influences access

5. Typical Timing – moment of the care trajectory where the situation typically occurs

tems were identified and structured in successive batches of approximately 500 items. After each batch, the list of existing items was reinjected into the AI GPT-assistant to ensure its training and its consistency.

Appendix 5.3.1. Example Prompt – Descriptive Phase

You are assisting a research project analysing ethical situations influencing access to paediatric palliative care (PPC).

ased on the provided examples in joined file, from the following source, identify whether a situation is described in which the needs or preferences of parents, family members, caregivers or healthcare professionals may influence, delay or hinder access to PPC.

f such a situation exists, extract it and structure it into the following fields:

1. Needs or Preferences
2. Conflict generated
3. Effect on access to PPC
4. Typical timing in the care trajectory

As described in the methods, the work of the AI was monitored and refined to ensure the dataset was non-redundant, conceptually clear, and analytically usable:

- Removal of exact duplicates
- Consolidation of near-duplicates (similar wording describing the same phenomenon)
- Grouping of semantic variants, while preserving contextual nuances where relevant

Appendix 5.4. Phase 2 – Coding Phase: Coding through the Ethical Framework

Once the dataset of items was established, each item was coded using the predefined ethical framework.

As for the descriptive part, the GPT-assistant was prompt-guided on a pre-set of manually coded-items. As new items were coded, the assistant was asked to compare their coding structures with previously coded items in order to identify recurring configurations, variations within similar situations, and emerging clusters of ethical determinants.

As for the descriptive phase, batches of 500 coded-items were reinjected in the assistant dataset (“Knowledge”) to ensure its guiding and aiming consistency.

Appendix 5.4.1. Example Prompt – Analytical Phase

You are assisting a qualitative ethical coding of situations influencing access to paediatric palliative care.
Using the ethical framework here joined in attached file, and based on the provided examples in joined file code the following items and identify which ethical determinants are involved.

As for the descriptive phase, a manual monitoring and refinement ensures the consistency and integrity of the analytical dataset:

- consolidation of items whose coded profiles were conceptually similar;
- distinction of items presenting meaningful contextual or ethical nuances;
- elimination of redundant analytical configurations;
- clarification of borderline or ambiguous codings.

Appendix 5.5. Phase 3 – Interpretative Phase: From Ethical Dynamics to Conflict Patterns

In the interpretative phase, the dedicated GPT-assistant was used to support the comparison of coding sequences across the full dataset. The objective was to identify recurrent configurations of ethical determinants appearing across multiple items, corresponding to ethical dynamics understood as convergence and recurrence points where similar ethical tensions emerged across heterogeneous situations.

The assistant was prompted to compare coding structures, identify recurring configurations across the dataset, highlight clusters of items sharing similar ethical tensions, and detect variations within comparable configurations. Through iterative comparison, contextual prompting, and researcher-led validation, these dynamics were progressively consolidated into conflict patterns describing recurring ethical mechanisms influencing access to paediatric palliative care (PPC).

Appendix 5.5.1. Example Prompt – Interpretative Phase

You are assisting the interpretative phase of a qualitative ethical study.
Below is a list of coded items describing situations influencing access to paediatric palliative care.
Based on the provided examples in joined file analyse the coding sequences and identify:
1. recurring combinations of ethical determinants across different items,
2. clusters of items sharing similar ethical tensions,
3. possible ethical dynamics corresponding to these recurring configurations.
Focus on identifying patterns of convergence between coded situations.

Appendix 5.6. Human Verification and Analytical Control

Throughout the three phases, AI outputs were systematically reviewed and validated by the researcher. The GPT-assistant was used as an analytical support tool rather than as an autonomous decision-maker. All decisions regarding item inclusion, coding validation, consolidation of ethical dynamics, and definition of conflict patterns were made through iterative human verification.

APPENDIX 6. LIST OF SELECTED PPC REFERENCES

The statements and items extracted during the first screening phase are grounded in a broad corpus of paediatric palliative care (PPC) literature. The sources are classified below according to their methodological nature and evidentiary status.

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APPENDIX 7. DETAILLED ETHICAL FRAMEWORK – CODING SYSTEM

Step	Dimension	Code	Label	Short Definition (in PPC context)
1	Actor involved			
		A_CHILD	Child	The child or adolescent receiving care, as bearer of needs, preferences, and vulnerabilities.
		A_PARENT	Parent(s)	One or both parents or legal guardians directly involved in decisions and daily care.
		A_FAM	Nuclear family	The close family unit (parents + siblings) as a collective actor.
		A_REL	Relatives / extended network	Wider family or significant others (grandparents, friends, community figures) involved in care.
		A_HCP_NON	Non-PPC professional	Health care professional without specific PPC expertise (e.g., general paediatrics, oncology).
		A_HCP_PPC	PPC-experienced professional	Professional with explicit PPC training/role (specialist team, liaison nurse, etc.).
2	Ethical lens (theory)			
		L_PRI	Principlism (virtue-informed)	Entry lens focusing on principles (autonomy, beneficence, non-maleficence, justice) and virtues of moral agency.
		L_NAR	Narrative ethics / medicine	Entry lens focusing on stories, meanings, temporality, and narrative alignment.
		L_CARE	Ethics of care	Entry lens focusing on relationships, vulnerabilities, responsibilities, and structural conditions of care.
3	Principles (within Principlism) – ethical determinants			
		P_AUT	Autonomy	Capacity and right of actors to participate in decisions; includes relational autonomy and empowerment.
		P_BEN	Beneficence	Orientation toward the actor's ; promotion of wellbeing and relief of suffering.
		P_NON	Non-maleficence	Duty to avoid causing harm (physical, psychological, moral, or institutional).
		P_JUS	Justice	Fairness in access, distribution of resources, and recognition; attention to inequities.
3	Virtues (within Principlism) – ethical determinants			
		V_COM	Compassion	Attuned perception of suffering and willingness to respond appropriately.
		V_DIS	Discernment	Context-sensitive moral judgment and prudence under uncertainty.

Step	Dimension	Code	Label	Short Definition (in PPC context)
		V_TRU	Trustworthiness	Reliability, honesty, and consistency in relationships and communication.
		V_INT	Integrity	Coherence between moral convictions, professional duties, and actions.
		V_CON	Conscientiousness	Moral attentiveness, diligence, and sense of accountability in care.
3	Narrative determinants – ethical determinants			
		N_STO	Story coherence / fragmentation	Degree of alignment or rupture between actors' stories about illness, care, and prognosis.
		N_VOI	Voice & silence	Who speaks, who remains silent, whose perspective is heard or ignored.
		N_FRA	Framing & meaning	How terms (e.g., "palliative", "curative") and situations are named, understood, reframed, or avoided.
		N_TEM	Temporality	Narrative pacing and timeline: when and how meaning evolves along the trajectory.
		N_REL	Recognition of suffering & meaning-making	Ability to express and recognise suffering and to construct meaning around it.
		N_CON	Conflict of narratives	Coexistence of competing or incompatible stories (medical, parental, institutional, spiritual, etc.).
3	Care determinants – ethical determinants			
		C_REL	Relational interdependence	Quality and asymmetries of caring relationships (alliances, dependence, power).
		C_VUL	Vulnerability & dependency	Visibility or invisibility of the vulnerability of child, family, or professionals.
		C_RES	Responsibility & responsiveness	Distribution of care tasks and responsiveness to expressed needs.
		C_STR	Structural / organisational dimension	System-level conditions: organisation, resources, coordination, institutional legitimacy.
		C_EMO	Emotional labour	Emotional and moral workload, including fatigue, burnout, and exposure to distress.
		C_COM	Community & continuity of care	Quality of coordination and sustained support across services and networks.
4	Conflict type			
		C_VAL	Value conflict	Tension between moral values or principles (e.g., autonomy vs beneficence; hope vs realism).
		C_ROLE	Role conflict	Tension about who should decide, act, protect, or carry responsibility.
		C_TIM	Temporal conflict	Mismatch in timing or pace (too early / too late / out of step) between actors.

Step	Dimension	Code	Label	Short Definition (in PPC context)
		C_INF	Informational conflict	Disagreement or mismatch about information given, withheld, understood, or requested.
		C_SYS	Systemic conflict	Tensions arising from organisational structures, rules, or resource allocation.
		C_REL	Relational conflict	Tensions within or between relationships (family–team, intra-team, family–family, etc.).
5	Effect on access to PPC			
		E_EAR	Early referral	Ethical dynamic leads to earlier-than-usual identification and orientation to PPC.
		E_FAC	Facilitation	Dynamic actively eases, supports, or stabilises access and continuity.
		E_DEL	Delay	Dynamic postpones identification, referral, decision-making, or implementation of PPC.
		E_BAR	Barrier	Dynamic blocks or strongly hinders access or continuation of PPC.
		E_MIS	Misidentification	PPC needs are not recognised, are mislabelled, or are recognised too late.
		E_DIS	Discontinuity	Breaks in follow-up, fragmentation of care, loss of contact or coordination.
		E_REP	Repair	Ethical dynamic (often virtue-related) restores trust, coherence, or access after conflict.
6	Temporal zone (care trajectory)			
		T_DIAG	Diagnosis	Time around first diagnosis or initial identification of a life-limiting condition.
		T_ANN	Announcement	Moments of prognostic disclosure, bad news, or major information updates.
		T_REL	Relapse / deterioration	Phases of disease progression, relapse, or loss of treatment options.
		T_TRA	Transition	Shifts between settings or models of care (hospital–home, curative–palliative, paediatric–adult).
		T_EOL	End of life	Final phase of the child's life, including last days/weeks and immediate decisions around dying.
		T_BER	Bereavement	Period following the child's death, including follow-up and family support.
		T_THR	Throughout	Ethical dynamic present recurrently or continuously across the entire trajectory.

APPENDIX 8. EXAMPLES OF PATTERN GENERATION

Appendix 8.1. Step 1 — From source to citation

Here are three reference sources explicitly describe situations in which paediatric palliative care (PPC) is delayed, overlooked, or difficult to integrate because of how "palliative" or "hospice" care is understood or framed:

- **Wolfe et al.**[359]:
  "Unfortunately, specialty palliative care is often overlooked in these patients as there may be a misconception that palliative care should be reserved for patients with a terminal illness."
- **Hain et al.**[358]:
  "The association of the word hospice with dying however has been a major obstacle to acceptance by patients and families to the broader tenets of palliative care."
- **Carter et al.**[357]:
  "Furthermore and unfortunately, the use of the word palliative has become synonymous with the word hospice, making the introduction of palliative care into the overall care plan for a child difficult."

Each of these passages functions as a **source trigger**, insofar as it links a representation, framing, or interpretation of palliative care to a difficulty in recognising, accepting, or integrating PPC.

Appendix 8.2. Step 2 — From citation to items and synoptic coding

Each citation was transformed into an *item*. These items were then coded using the study's coding system.
Rather than detailing each item separately, the table below presents a **synoptic view of the coding**, making visible the convergence that gives rise to an ethical dynamic.

Synoptic coding of items derived from the three reference sources

Source	Item (synthetic formulation)	Actors	Ethical lenses	Key ethical determinants	Conflict types	Effects on PPC access	Temporal zones
Wolfe, et al.	PPC is overlooked because it is perceived as appropriate only for terminal illness	A_HCP_NON (+ A_HCP_PPC absent)	L_PRI, L_NAR, L_CARE	P_BEN, P_NON, V_DIS; N_FRA, N_TEM; C_STR, C_COM	C_INF, C_TIM, C_SYS	E_MIS, E_DEL	T_DIAG, T_THR
Hain, et al.	Acceptance of broader palliative tenets is hindered because hospice is associated with dying	A_PARENT, A_HCP_NON	L_NAR, L_PRI	P_BEN, P_NON; N_FRA, N_STO, N_TEM; C_REL, C_VUL	C_INF, C_VAL, C_TIM	E_MIS, E_DEL	T_DIAG, T_ANN
Carter, et al.	PPC is difficult to introduce into the care plan because "palliative" is conflated with hospice	A_HCP_NON, A_PARENT, A_HCP_PPC	L_NAR, L_PRI, L_CARE	P_BEN, P_NON; N_FRA, N_CON, N_TEM; C_STR, C_COM	C_INF, C_ROLE, C_TIM	E_DEL, E_MIS	T_DIAG, T_ANN, T_TRA

This table constitutes the empirical basis for identifying ethical dynamics: ethical dynamics are not coded directly but emerge from the comparison of these coded configurations across items.

Appendix 8.3. Step 3 — Capture and identification of the ethical dynamic

Comparison of the coded items reveals a recurrent configuration that fulfils all defining criteria of an ethical dynamic.

- **Intersection of ethical determinants**

  Across the three items, principle-based determinants (beneficence and non-maleficence), narrative determinants (framing and temporality of palliative care), and care-related determinants (organisation of care pathways and integration into care plans) are simultaneously present within the same situations.

- **Variation in intensity, complexity, and stability**

  The configuration varies in intensity and complexity: it is most structurally complex when palliative care must be integrated into an overall care plan (Carter), and more diffuse but highly stable when it structures professional assumptions across the trajectory (Wolfe). The dynamic tends to persist over time when the framing of palliative care as “terminal-only” remains unchallenged.

- **Characteristic effects on access to PPC**

  All items generate comparable effects on access, primarily misidentification of PPC needs and delayed referral or integration. These effects recur regardless of whether the dynamic is carried primarily by professionals, families, or both.

- **Recurrence across actors and moment**

  The same configuration recurs across different actors (parents, non-PPC professionals, PPC teams in secondary positions) and across key moments of the care trajectory, particularly diagnosis and announcement phases, but sometimes throughout the trajectory.

- **Ethical dynamic:**

  A recurrent misframing of paediatric palliative care as terminal-only or hospice-equivalent, arising from the intersection of principle-based concerns (beneficence and non-maleficence), narrative framing and temporality, and care-structural determinants, and producing misidentification and delayed access to PPC across early phases of the care trajectory.

Appendix 8.4. Step 4 — Attribution to a pattern of conflict

Based on this ethical dynamic, the items were linked to the following pattern identified in the study:

- **Pattern — “Avoidance of the palliative label”**

This pattern captures situations in which the term “palliative” is avoided, restricted, or conceptually displaced because it is equated with hospice or terminal care. The avoidance may be symbolic, conceptual, or organisational, but it consistently results in delayed recognition, referral, or integration of PPC.

Appendix 8.5. Step 5 — Attribution to a macro-category

The pattern “Avoidance of the palliative label” was assigned to the macro-category:

- **Disclosure & Truth Management**

This macro-category groups patterns in which access to PPC is shaped by how palliative care is named, framed, temporally positioned, or partially withheld. It encompasses ethical dynamics dominated by informational, temporal, and narrative conflicts, in which decisions about when and how to disclose, explain, or integrate palliative care directly affect identification and access.

Example: consolidation into a pattern and macro-category

A concrete example can be drawn from the macro-category **"Disclosure & Truth Management."**

Across the coded corpus, multiple ethical dynamics were identified in which narrative framing (e.g., avoidance or softening of the term "palliative"), protective intentions toward the child or family, and professional responsibility intersected. These dynamics appeared in items describing delayed prognostic disclosure, reluctance to name palliative care explicitly, or strategic reframing of care goals.

Although the situations differed in clinical context and emotional intensity, they shared three stable features:

1. a recurrent interaction between narrative determinants (framing, temporality, conflict of narratives) and principle-based concerns (beneficence and non-maleficence);
2. a consistent effect on access, most often delayed recognition or misidentification of paediatric palliative care needs;
3. recurrence across actors (parents and professionals) and across early moments of the care trajectory.

Because this ethical dynamic recurred with sufficient stability and produced a recognisable access effect, it was consolidated into the principal pattern **"Avoidance of the palliative label."**
This pattern, in turn, was grouped with other patterns involving delayed, partial, or strategically managed disclosure into the macro-category **"Disclosure & Truth Management."**

The macro-category thus does not simply aggregate topics related to communication; rather, it reflects a shared **ethical architecture** in which truth-telling, protection, timing, and responsibility interact in ways that systematically condition access to paediatric palliative care.

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APPENDIX 10. DETAILLED PATTERNS OF CONFLICT AND MACRO-CATEGORIES

Appendix 10.1. Principal Pattern of Conflict

#	Macro-Family	Principal Pattern of Conflict	Effect on Access	Typical Timing	Interpretative Summary
1	Disclosure & Truth Management	Avoidance of the "palliative" label	Delay / Misidentification	Diagnosis / Announcement	Semantic avoidance prevents early orientation; respectful reframing restores trust and legitimacy.
2	Disclosure & Truth Management	Gradual or opaque prognosis	Delay / Barrier / Facilitation	Relapse / Transition	Proportional truth-telling preserves agency; opacity sustains uncertainty and stalls planning.
3	Disclosure & Truth Management	Protective silence toward the child	Delay / Misidentification	Announcement / Relapse	Protective intent eclipses the child's voice; gentle inclusion improves preparedness and trust.
4	Disclosure & Truth Management	"Supportive care" terminology as bridge	Facilitation / Repair	Announcement	Acceptable vocabulary eases entry into PPC without abandoning honesty.
5	Disclosure & Truth Management	Selective disclosure to school/community	Discontinuity / Barrier	Throughout	Partial disclosure disrupts psychosocial coordination; negotiated communication strengthens continuity.
6	Disclosure & Truth Management	Hesitation with genetic testing/counselling	Delay	Diagnosis / Relapse	Uncertainty about implications delays anticipatory decisions; supportive counselling promotes clarity.
7	Curative–Palliative Transition & Treatment Intensity	Curative escalation ("one more treatment")	Delay / Barrier	Relapse / End of life	Curative inertia prolongs overtreatment; proportionality enables timely PPC integration.
8	Curative–Palliative Transition & Treatment Intensity	Late referral to PPC	Barrier / Misidentification	Relapse / Transition	Structural and cultural hesitations postpone PPC

#	Macro-Family	Principal Pattern of Conflict	Effect on Access	Typical Timing	Interpretative Summary
					despite need; clear criteria reduce delay.
9	Curative–Palliative Transition & Treatment Intensity	Refusal of therapeutic limitations (DNR / withdrawal)	Delay / Barrier	End of life	Emotional and cultural pressures impede limit-setting; transparent dialogue restores coherence.
10	Curative–Palliative Transition & Treatment Intensity	"Curative-only" mindset / PPC exclusion	Barrier	Throughout / Relapse	PPC framed as defeat blocks parallel planning and fragments continuity.
11	Curative–Palliative Transition & Treatment Intensity	Opioid/analgesia hesitation	Delay / Barrier	End of life	Myths and fears restrict symptom control; trust and education restore proportional care.
12	Autonomy, Protection & Participation	Parental disagreement or custody conflict	Delay / Barrier	Relapse	Divergent parental positions create decisional paralysis; mediation restores procedural fairness.
13	Autonomy, Protection & Participation	Limited child participation	Delay / Barrier	All phases	Over-protection reduces agency and coping; graded participation supports adaptation.
14	Autonomy, Protection & Participation	Over-control of care plan	Discontinuity / Barrier	Throughout	Hyper-responsibility produces friction; shared planning rebuilds alliance.
15	Cultural, Spiritual & Institutional Interfaces	Unmet ritual/spiritual constraints	Barrier / Discontinuity	End of life / Bereavement	Institutional rigidity conflicts with family needs; cultural humility restores dignity and trust.
16	Cultural, Spiritual & Institutional Interfaces	Interpreter refusal	Barrier / Misidentification	Throughout	Language gaps undermine consent, safety, and planning; professional interpreters enable equity.

#	Macro-Family	Principal Pattern of Conflict	Effect on Access	Typical Timing	Interpretative Summary
17	Cultural, Spiritual & Institutional Interfaces	Alternative or “miracle” healing	Delay / Barrier	Relapse / Transition	Hope narratives delay consensus; respectful dialogue safeguards meaning and safety.
18	Cultural, Spiritual & Institutional Interfaces	Refusal of chaplaincy or spiritual care	Delay / Barrier	Advanced / End of life	Emotional weight remains unsupported; secular or non-coercive framing eases acceptance.
19	Relational Labour, Trust & Communication Load	Second opinion as trust restoration	Facilitation (sometimes Delay)	Diagnosis / Throughout	Transparent second opinions rebuild trust and may support PPC engagement.
20	Relational Labour, Trust & Communication Load	Intra-team disagreement / role diffusion	Barrier / Discontinuity	Throughout	Mixed messages and unclear roles undermine coherenceand generate moral distress.
21	Relational Labour, Trust & Communication Load	Expectation of 24/7 availability	Delay / Discontinuity	Throughout	Unrealistic availability expectations strain relationships; clear boundaries sustain trust.
22	Relational Labour, Trust & Communication Load	Mental load / parental over-management	Delay / Discontinuity	Throughout	Micromanagement increases friction and anxiety; shared plans reduce conflict.
23	Home vs Hospital / Technology & Logistics	Home as sanctuary (refusal of interventions)	Barrier / Discontinuity	Transition	Protecting the home identity delays support; adaptive strategies enable safe home care.
24	Home vs Hospital / Technology & Logistics	Over-surveillance / high-tech at home	Delay / Barrier / Discontinuity	Transition / Throughout	Excessive monitoring medicalises home life; proportional use relieves strain.
25	Home vs Hospital / Technology & Logistics	Preferred place of death	Facilitation / Delay / Barrier	End of life	Aligning preferences with feasible support to honour dignity and reduces suffering.

#	Macro-Family	Principal Pattern of Conflict	Effect on Access	Typical Timing	Interpretative Summary
26	Home vs Hospital / Technology & Logistics	Refusal of home adaptation/equipment	Barrier / Discontinuity	Transition	Adaptations perceived as symbolic of decline hinder safe home care; negotiated solutions help.
27	Socio-economic & Justice in Access	Transport and financial problem	Barrier / Delay	Throughout	Material hardship limits options and continuity; social support mitigates inequity.
28	Socio-economic & Justice in Access	Refusal of social or respite support	Barrier / Discontinuity	Throughout	Stigma or privacy concerns reduce support; reframing as partnership improves access.
29	Socio-economic & Justice in Access	Data-sharing/privacy friction	Barrier / Discontinuity	Throughout	Restricted information flow undermines coordination; clear consent pathways restore continuity.
30	Socio-economic & Justice in Access	Refusal of safety norms or vaccination	Barrier / Discontinuity	Diagnosis / Relapse / Throughout	Balancing autonomy and collective protection affects service access and inclusion.
31	Bereavement & Continuity of Bonds	Refusal of post-death follow-up	Discontinuity / Barrier	Bereavement	Protective withdrawal limits grief support; sensitive outreach keeps pathways open.
32	Bereavement & Continuity of Bonds	Continuing bonds with the team	Facilitation / Repair	Bereavement / Throughout	Sustained, proportionate contact supports coping and preserves trust in care relationships.

Appendix 10.2. Macro-categories of ethical conflict

Based on the ethical dynamics, the ethical conflicts can be organised into a typology comprising eight macro-categories and thirty-two principal patterns of conflict (see below).

The macro-categories outline the ethical architecture of access to PPC. They show how conflicts related to information, treatment orientation, participation, culture, relational labour, material conditions, justice, and bereavement emerge from distinct yet interconnected ethical dynamics, and how these dynamics shape concrete pathways of access, delay, or exclusion.

1. **Disclosure & Truth Management** — This macro-category concerns the ways in which information about prognosis, disease evolution, and the palliative orientation of care is communicated, delayed, reframed, or withheld. It captures tensions between honesty and protection, between timing and readiness, and between professional duties and family coping strategies. These dynamics often shape how and when PPC is recognised, named, and accepted, and they frequently result in delays or misidentification of palliative needs when communication remains partial, opaque, or strategically softened.

Example.

Several authors describe situations in which clinicians avoid explicitly using the term “palliative” because it is associated with dying or giving up, leading to delayed referral despite significant symptom burden and psychosocial needs. In such cases, PPC involvement occurs only after disease-directed options are exhausted, illustrating how narrative framing and temporal hesitation directly condition access.

2. **Curative–Palliative Transition & Treatment Intensity** — This category addresses conflicts arising from the persistence of a curative logic in situations where the goals of care are shifting. It includes therapeutic escalation, reluctance to limit treatments, and hesitation to prioritise comfort-oriented approaches. These situations reflect principle-based and role-based tensions—particularly around beneficence, non-maleficence, and professional responsibility, and often lead to postponed transitions, late referral to PPC, or barriers to parallel planning.

Example.
The literature frequently reports children with advanced cancer or severe neurological conditions who continue to receive invasive or burdensome treatments despite limited expected benefit, because discontinuation is perceived as failure. PPC is introduced only when treatment options collapse, rather than alongside disease-directed care, illustrating how treatment intensity delays palliative integration.

3. **Autonomy, Protection & Participation** — This macro-category focuses on how decision-making participation is distributed among children, parents, and professionals. It highlights tensions between protecting the child and recognising their agency, as well as disagreements between adults regarding what constitutes the child’s best interests. When autonomy is constrained or unevenly acknowledged, access to PPC may be delayed; conversely, when participation is recognised in a developmentally sensitive way, it can facilitate alignment and smoother integration of palliative care.

Example.
Some studies describe adolescents who express preferences regarding comfort, place of care, or treatment limitation, while parents or professionals defer or silence these expressions in the name of protection. Such tensions can delay PPC involvement until crises arise, whereas early recognition of the child’s voice has been shown to facilitate earlier alignment around palliative goals.

4. **Cultural, Spiritual & Institutional Interfaces** — This category captures ethical tensions that arise at the intersection of cultural, spiritual, and institutional norms**.** Conflicts emerge when family values, rituals, or belief systems encounter procedural rigidity, linguistic barriers, or institutional routines that lack flexibility. Such misalignments can generate barriers to access or continuity,

while culturally responsive practices and institutional adaptability may function as mechanisms of ethical repair.

Example.
The literature reports families whose spiritual beliefs prioritise hope for miraculous recovery, leading to resistance to PPC referral when institutional communication does not adequately engage these beliefs. In contrast, culturally attuned dialogue and involvement of spiritual mediators have been described as facilitating acceptance and continuity of PPC.

5. **Relational Labour, Trust & Communication Load** — This macro-category addresses the relational and emotional work required to sustain care over time. It includes intrateam disagreements, role diffusion, and expectations of constant availability placed on professionals. These dynamics can erode trust, increase moral distress, and lead to discontinuities or delays in access. Conversely, explicit communication, role clarification, and relational repair can stabilise care pathways and support ongoing PPC involvement.

Example.
Several sources describe PPC professionals absorbing unresolved tensions between teams and families, leading to burnout or withdrawal from complex cases. In contrast, when teams explicitly acknowledge relational strain and redistribute communication responsibilities, PPC involvement is more likely to be sustained.

6. **Home vs Hospital / Technology & Logistics** — This category concerns the material, spatial, and technological conditions that shape where and how care is delivered. Decisions about monitoring, equipment, and place of care reflect not only logistical constraints but also symbolic meanings attached to home and hospital spaces. Misalignment between family preferences and system capacities can create barriers or delays, whereas coordinated logistical support can facilitate access and continuity of PPC across settings.

Example.
Families may express a strong preference for home care, while health systems lack adequate technical support for symptom management at home. The resulting mismatch can delay PPC discharge planning or force repeated hospitalisations, illustrating how logistical constraints function as ethical barriers.

7. **Socio-economic & Justice in Access** — This macro-category highlights how structural inequities—such as financial constraints, transport difficulties, eligibility rules, and social stigma—affect access to PPC. These conflicts are rooted in principle-based concerns about justice and fairness, and they often manifest as barriers or discontinuities rather than individual refusals. When compensatory mechanisms and equitable policies are in place, they can actively facilitate access and continuity of care.

Example.
The literature documents families living far from specialised centres who experience delayed PPC access due to transport costs or inflexible eligibility criteria. In contrast, outreach models and flexible funding arrangements have been shown to reduce inequities and improve continuity.

8. **Bereavement & Continuity of Bonds** — This category addresses ethical dynamics that extend beyond the child's death, focusing on continuity, rupture, or transformation of relationships between families and care teams. It includes both the refusal of post-death contact and the maintenance of enduring bonds. These dynamics influence families' access to bereavement support and their capacity to integrate loss, and they raise questions about appropriate boundaries, professional responsibility, and ethical continuity after death.

Example.
Some sources describe institutional policies that abruptly terminate contact after a child's death, leaving families without follow-up support. Other models emphasise continued contact through

bereavement care, illustrating how ethical conceptions of continuity shape access to post-death support.

The macro-categories do not correspond directly to the ethical theories or lenses used in the analysis. Instead, they represent empirically grounded clusters of conflict mechanisms, structured around recurring ethical dynamics that condition access to paediatric palliative care.

Each macro-category brings together several principal patterns that share:

- a dominant configuration of ethical dynamics,
- a characteristic structure of tensions between actors, meanings, and responsibilities,
- and a recognisable impact on access to PPC along the care trajectory.

APPENDIX 11. FILED CONSULTATION SURVEYS

ACCESS TO PAEDIATRIC PALLIATIVE CARE: ANALYSIS OF POTENTIAL CONFLICTS THAT MAY HINDER ACCESS

CONFIDENTIAL document

Appendix 11.1. Purpose of this consultation

This consultation has two objectives:

1. **To** validate **the results** of an ethical, descriptive and analytical review of the literature concerning the main sources of interference, tension or conflict that hinder effective access to paediatric palliative care for children and their families.
2. **To identify any gaps** in the list of conflict patterns (32 in total – see below).

Conflicts, which are barriers to access to PPC, arise in the expression of the needs, values and preferences of the various stakeholders: the child, parents, siblings, relatives, and care teams specialised or not specialised in paediatric palliative care. They influence how the transition to a palliative approach is perceived, accepted, delayed or sometimes blocked.

The main conflict patterns we propose do not constitute an exhaustive list of all possible situations. However, based on an analysis of the literature and preliminary ethical research, they represent the most relevant categories, those most frequently described and likely to have a significant impact on access to paediatric palliative care.

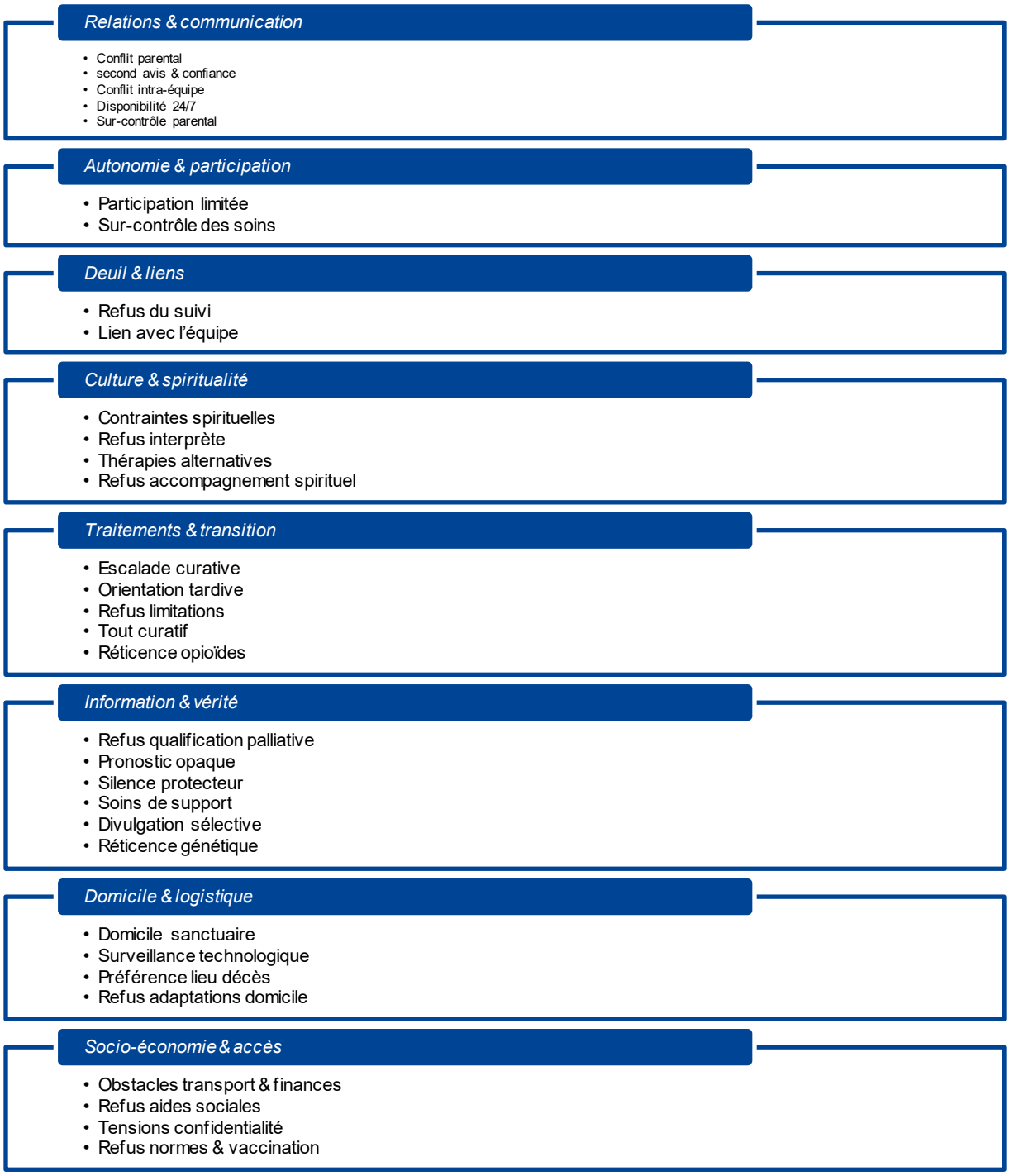
This document is intended for members of paediatric liaison teams with experience in paediatric palliative care. For each pattern, we ask you to assign three separate scores (on a scale of 1 to 10) for:

- **Relevance**: based on your experience, to what extent do you think this pattern of conflict is relevant in explaining a barrier to access to paediatric palliative care?
- **Frequency**: how often do you encounter this type of situation in your practice?
- **Complexity**: to what extent do you find this conflict pattern complex to manage, both clinically and in terms of relationships and organisation?

At the end of the document, you will find a space to mention any missing conflict patterns or additional information that you deem useful. Your contribution is essential to refining our understanding of this research question concerning the influence of conflict situations on access to PPC.

Appendix 11.2. Overview of potential conflicts

Figure 43 – Overview of potential conflicts



Appendix 11.3. Interpersonal work, trust and communication load

(see 'relationships and communication' in the summary table)

Appendix 11.3.1. Disagreement between parents/conflict over custody

Parental disagreements — conflictual separations, difficult joint custody or broken communication — create a complex dynamic in which several actors simultaneously influence the course of care. Relatives, extended family and sometimes siblings take sides and reinforce one or the other parent, amplifying differences regarding the continuation of treatment, the transition to paediatric palliative care (PPC) or the place of care. Teams not specialised in PPC may unintentionally fuel these tensions through conflicting messages or divergent interpretations.

These conflicting influences fragment information, multiply contradictory demands and increase mutual mistrust, making it difficult to develop a coherent care plan. The child may sense this conflict, especially when decisions vary depending on who they are talking to. In these contexts, access to PPC may be delayed or made more uncertain simply because no minimum agreement can be reached between the various parties involved.

Examples

- One parent insists on pursuing maximum interventions, while the other wishes to limit treatments deemed futile, thus blocking the transition to SPP.
- Separated parents each seek several different medical opinions, delaying any consensus on the level of care to be provided.

Score: Give a score between 1 and 10

Relevance: Based on your experience, to what extent do you think this pattern of conflict is relevant in explaining an obstacle to access to paediatric palliative care? : 1= not very relevant; 10= extremely relevant

1	2	3	4	5	6	7	8	9	10

Frequency: how often do you encounter this type of situation in your practice? 1 = very rarely; 10 = extremely frequently

1	2	3	4	5	6	7	8	9	10

Complexity: How complex do you find this conflict pattern to manage, both clinically and in terms of relationships and organisation? 1 = not very complex; 10 = extremely complex

1	2	3	4	5	6	7	8	9	10

Appendix 11.3.2. Request for a second opinion/restoration of trust

Seeking a second opinion may respond to a need for clarification, but it often arises in a context where several factors influence the confidence placed in the primary team. Relatives, extended family or friends with personal medical experience may encourage parents to seek a second opinion, believing that "other options" exist or that a different specialist might offer a more optimistic outlook. Some professionals who are not specialised in PPC, when consulted informally, may also offer partial or cautious opinions, reinforcing the idea that a difference in interpretation is possible.

These cross-influences can fragment information, multiply the number of people involved and delay the introduction of palliative care considerations, especially when each opinion seems to open up a new therapeutic avenue. The second opinion process then becomes a space where trust, already fragile, is put to the test, making it more difficult to build a coherent care pathway for the child.

Examples

- Parents consult several experts at the same time, leading to conflicting recommendations and delaying decision-making.
- A request for a second opinion arises because the family feels that the team is downplaying the seriousness of the situation or lacks transparency.

Score: Give a score between 1 and 10

Relevance: Based on your experience, to what extent do you think this pattern of conflict is relevant in explaining an obstacle to access to paediatric palliative care? : 1= not very relevant; 10= extremely relevant

1	2	3	4	5	6	7	8	9	10

Frequency: how often do you encounter this type of situation in your practice? 1 = very rarely; 10 = extremely frequently

1	2	3	4	5	6	7	8	9	10

Complexity: How complex do you find this conflict pattern to manage, both clinically and in terms of relationships and organisation? 1 = not very complex; 10 = extremely complex

1	2	3	4	5	6	7	8	9	10

Appendix 11.3.3. Disagreement within the team/distribution of roles

When different members of the healthcare team deliver inconsistent messages—about prognosis, treatment options, or the appropriate time to introduce paediatric palliative care—families perceive inconsistency, which undermines trust and creates uncertainty. These discrepancies are not limited to the healthcare team: professionals who are not specialised in paediatric palliative care, who are consulted during a consultation or asked for a one-off opinion, may convey partial, cautious or more optimistic information, creating a contradictory picture. Relatives, siblings or the extended family

sometimes use these differences to encourage parents to seek "the advice that suits them", thus reinforcing the lack of consistency.

These conflicting influences push parents to consult multiple sources, increasing the communication burden on all teams and delaying the development of a shared narrative. This undermines the consistency of information, making it more difficult to calmly embark on a structured palliative care process.

Examples

- Two doctors give conflicting information about the expected course of events, creating confusion and a sense of disorganisation.
- The nursing team adopts a more reassuring tone than the doctors, leading to a loss of confidence when the clinical reality sets in.

Score: Give a score between 1 and 10

Relevance: Based on your experience, to what extent do you think this conflict pattern is relevant in explaining a barrier to access to paediatric palliative care? : 1= not very relevant; 10= extremely relevant

1	2	3	4	5	6	7	8	9	10

Frequency: how often do you encounter this type of situation in your practice? 1 = very rarely; 10 = extremely frequently

1	2	3	4	5	6	7	8	9	10

Complexity: How complex do you find this conflict pattern to manage, both clinically and in terms of relationships and organisation? 1 = not very complex; 10 = extremely complex

1	2	3	4	5	6	7	8	9	10

Appendix 11.3.4. Expectation of 24/7 availability

Some families develop expectations of near-constant availability from the team, demanding immediate responses at any time of day. These expectations are often reinforced by those around them: siblings, relatives or informal carers sometimes encourage parents to contact the team at the slightest sign of anything unusual, for fear of "missing" a symptom or allowing a situation to worsen. Professionals who are not specialised in PWS may also, in an attempt to reassure parents, suggest that the team is available at all times, which fuels unrealistic expectations.

These combined influences lead to frequent requests for assistance, which are sometimes disproportionate to the clinical urgency. When the team is unable to respond immediately, parents may perceive a lack of support or a break in continuity of care, leading to frustration, anxiety or mistrust. This dynamic creates relational tension and complicates the continuity of stable and predictable palliative care.

Examples

- Parents contact the team continuously, at night and on weekends, expecting immediate answers to every concern.
- The family feels abandoned when a call is not answered immediately, despite the existence of a clearly explained on-call service.

Score: Give a score between 1 and 10

Relevance: Based on your experience, to what extent do you think this pattern of conflict is relevant in explaining an obstacle to access to paediatric palliative care? : 1= not very relevant; 10= extremely relevant

1	2	3	4	5	6	7	8	9	10

Frequency: how often do you encounter this type of situation in your practice? 1 = very rarely; 10 = extremely frequently

1	2	3	4	5	6	7	8	9	10

Complexity: How complex do you find this conflict pattern to manage, both clinically and in terms of relationships and organisation? 1 = not very complex; 10 = extremely complex

1	2	3	4	5	6	7	8	9	10

Appendix 11.3.5. Excessive parental control / mental overload

Mental overload occurs when parents are simultaneously responsible for monitoring symptoms, managing treatments, anticipating crises, coordinating appointments and communicating with family and social networks. This hyper-responsibility does not come solely from them: siblings, relatives, or informal carers often request frequent information or express expectations that reinforce the parental feeling of being the sole guardians of the situation. In addition, some professionals who are not specialised in palliative care may delegate tasks or decisions to parents due to lack of time or experience working with a palliative care team, further increasing the cognitive load.

These cross-influences contribute to extreme vigilance, sometimes perceived as the only way to keep the situation under control. This overload increases parental stress, reduces their emotional availability and can make it more difficult to introduce a palliative approach, which is experienced as a further loss of control.

Examples

- Parents say they have to "think of everything", fearing that forgetting something could put their child's life in danger, which leads to gradual exhaustion.

- One family takes sole responsibility for coordinating all medical care and contacts, refusing any help for fear of losing control.

Score: Give a score between 1 and 10

Relevance: Based on your experience, to what extent do you think this conflict pattern is relevant in explaining an obstacle to access to paediatric palliative care? : 1= not very relevant; 10= extremely relevant

1	2	3	4	5	6	7	8	9	10

Frequency: how often do you encounter this type of situation in your practice? 1 = very rarely; 10 = extremely frequently

1	2	3	4	5	6	7	8	9	10

Complexity: How complex do you find this conflict pattern to manage, both clinically and in terms of relationships and organisation? 1 = not very complex; 10 = extremely complex

1	2	3	4	5	6	7	8	9	10

Appendix 11.4. Autonomy, protection and participation

(see "Autonomy and participation" in the summary table)

Appendix 11.4.1. Limited participation of the child

The child's participation in discussions concerning them is often limited by a protective reflex, but also by the influence of other actors: siblings, relatives, informal or professional carers involved outside the SPP. Each of these individuals may, for different reasons, encourage a form of silence or excessive simplification, believing that it is better to protect the child or avoid causing them further concern. This plurality of influences contributes to fragmented communication, in which the child receives a partial account while the adults exchange a more complete account among themselves.

This disconnect leads to an uneven understanding of the issues at stake, widespread anxiety in children—who sense the tensions and unspoken words—and difficulties in expressing their concerns or preferences. When children are not included in the flow of information, advance planning becomes complicated and access to paediatric palliative care may be delayed or made less smooth.

Examples

- Parents ask the team not to involve the adolescent in crucial discussions, preventing them from participating in the shared decision-making process.
- The child asks direct questions about their condition, but the parents refuse to discuss it in order to "protect" them, which prevents them from gaining a basic understanding of their care.

Score: Give a score between 1 and 10

Relevance: Based on your experience, to what extent do you think this pattern of conflict is relevant in explaining a barrier to access to paediatric palliative care? : 1= not very relevant; 10= extremely relevant

1	2	3	4	5	6	7	8	9	10

Frequency: how often do you encounter this type of situation in your practice? 1 = very rarely; 10 = extremely frequently

1	2	3	4	5	6	7	8	9	10

Complexity: How complex do you find this conflict pattern to manage, both clinically and in terms of relationships and organisation? 1 = not very complex; 10 = extremely complex

1	2	3	4	5	6	7	8	9	10

Appendix 11.4.2. Excessive control of the care plan

Excessive control of the care plan occurs when parents take the initiative to check, direct or correct each step of the therapeutic process, often out of fear of doing the wrong thing or as a result of previous significant medical experiences. This dynamic is often reinforced by those around them: friends, extended family or informal carers who encourage increased vigilance or, conversely, express concerns that further increase the pressure felt by parents. Teams not specialised in PPC may also contribute to this intensification of control when they deliver conflicting, technical or incomplete messages, reinforcing the parental need to 'monitor everything'.

These conflicting influences create significant mental strain, fragmented communication and difficulty in building a shared vision of the care plan. In some cases, this dynamic slows down access to paediatric palliative care, making it more complex to gradually adjust objectives and coordinate between stakeholders.

Examples

- Parents adjust pain relief treatments themselves for fear of opioids, leading to poor pain control and increased mistrust of palliative care services.
- Refusal to allow the home nurse to intervene because "no one knows how to do it as well as they do", complicating the implementation of PPC follow-up at home.

Score: Give a score between 1 and 10

Relevance: Based on your experience, to what extent do you think this conflict pattern is relevant in explaining a barrier to access to paediatric palliative care? : 1= not very relevant; 10= extremely relevant

1	2	3	4	5	6	7	8	9	10

Frequency: how often do you encounter this type of situation in your practice? 1 = very rarely; 10 = extremely frequently

1	2	3	4	5	6	7	8	9	10

Complexity: How complex do you find this conflict pattern to manage, both clinically and in terms of relationships and organisation? 1 = not very complex; 10 = extremely complex

1	2	3	4	5	6	7	8	9	10

Appendix 11.5. Grief and continuity of ties

Appendix 11.5.1. Refusal of follow-up after death

Some families refuse all contact after death — no closing meeting, no phone calls, no further communication. This withdrawal may be reinforced by the dynamics of the family circle: relatives, siblings, extended family or informal carers may encourage a rapid break with the team, believing that this is the best way to protect themselves or to 'move on'. Some members of the non-specialised PPC care network may also, due to a lack of information or coordination, fail to relay the existence of possible follow-up, which contributes to maintaining distance.

This refusal does not reflect a rejection of professionals, but rather a way of managing the immediate emotional impact. However, the absence of post-death contact can prevent the family from addressing unresolved issues, clarifying certain aspects of the process, or accessing support in the event of difficult bereavement. In these situations, access to further support may depend on whether or not the various people involved with the family encourage them to re-establish contact.

Examples

- The family refuses any pre-bereavement or post-death support contact, perceiving these proposals as too emotionally difficult.
- The parents decline the closing meeting in order to avoid reviving their suffering, which prevents the SPP process from being finalised.

Score: Give a score between 1 and 10

Relevance: Based on your experience, to what extent do you think this conflict pattern is relevant in explaining an obstacle to access to paediatric palliative care? : 1= not very relevant; 10= extremely relevant

1	2	3	4	5	6	7	8	9	10

Frequency: how often do you encounter this type of situation in your practice? 1 = very rarely; 10 = extremely frequently

1	2	3	4	5	6	7	8	9	10

Complexity: How complex do you find this conflict pattern to manage, both clinically and in terms of relationships and organisation? 1 = not very complex; 10 = extremely complex

1	2	3	4	5	6	7	8	9	10

Appendix 11.5.2. Maintaining ties with the team

After the child's death, some families wish to maintain a close and ongoing relationship with the palliative care team: visits, regular phone calls, sending photos, participating in commemorations or symbolic exchanges. This need may be reinforced by those around them: relatives, siblings or informal carers who encourage continued contact, sometimes because they themselves find it supportive. At the same time, professionals who are not specialised in palliative care may spontaneously refer the family to the palliative care team, which is seen as a stable reference point, further prolonging the relationship.

These cross-influences can transform an initially supportive relationship into a more complex one when the team becomes a central or substitute point of attachment. This intensity of relationship can be difficult to regulate: the family finds it a source of comfort, while professionals may perceive it as a prolonged emotional burden. In these contexts, the continuation of the bond influences how the family experiences grief and whether or not it mobilises other resources around it.

Examples

- The family requests frequent contact with the team several months after the death, seeking ongoing emotional support.
- The parents invite a member of the team to private events, blurring the usual boundaries of the relationship.

Score: Give a score between 1 and 10

Relevance: Based on your experience, to what extent do you think this conflict pattern is relevant in explaining an obstacle to access to paediatric palliative care? : 1= not very relevant; 10= extremely relevant

1	2	3	4	5	6	7	8	9	10

Frequency: how often do you encounter this type of situation in your practice? 1 = very rarely; 10 = extremely frequently

1	2	3	4	5	6	7	8	9	10

Complexity: How complex do you find this conflict pattern to manage, both clinically and in terms of relationships and organisation? 1 = not very complex; 10 = extremely complex

1	2	3	4	5	6	7	8	9	10

Appendix 11.6. Cultural, spiritual and institutional interfaces

(see "Culture and spirituality" in the summary table)

Appendix 11.6.1. Ritual or spiritual constraints not respected

In certain situations, families express specific ritual, religious or spiritual needs: collective prayers, the presence of a religious figure, symbolic objects, the orientation of the bed or specific gestures marking an important transition. These requests do not only concern parents: siblings, relatives and the extended family may contribute to formulating, reinforcing or diversifying ritual expectations, sometimes expressing contradictory needs. Furthermore, those not specialised in PPC—service teams, institutional staff—may interpret these requests differently, facilitating or restricting them according to their own perceptions or organisational constraints.

When these demands conflict with institutional rules (schedules, hygiene, visitor flow), families may perceive a lack of cultural or spiritual recognition. These tensions, fuelled by the multiple voices surrounding the child, affect trust, complicate relational adjustment and can delay the establishment of a framework conducive to the introduction of paediatric palliative care.

Examples

- The family expresses a need for religious rituals at the bedside, but the institution limits the number of relatives allowed, creating cultural misunderstanding.
- Certain ritual objects are refused for hygiene reasons without prior discussion, generating a feeling of spiritual disrespect.

Score: Give a score between 1 and 10

Relevance: Based on your experience, to what extent do you think this conflict pattern is relevant in explaining an obstacle to access to paediatric palliative care? : 1= not very relevant; 10= extremely relevant

1	2	3	4	5	6	7	8	9	10

Frequency: how often do you encounter this type of situation in your practice? 1 = very rarely; 10 = extremely frequently

1	2	3	4	5	6	7	8	9	10

Complexity: How complex do you find this conflict pattern to manage, both clinically and in terms of relationships and organisation? 1 = not very complex; 10 = extremely complex

1	2	3	4	5	6	7	8	9	10

Appendix 11.6.2. Refusal of an interpreter

Some families refuse the services of a professional interpreter, preferring to have a relative, friend or sometimes a bilingual child provide translation. This choice is often influenced by family dynamics: fear of revealing sensitive information to an outside party, prioritising trust in the immediate community, or cultural discomfort in discussing certain topics in front of a stranger. Relatives themselves may encourage the use of an informal interpreter, reinforcing the idea that professional mediation would be intrusive.

For their part, some actors in the healthcare system who are not specialised in PHC may, due to a lack of resources or habit, tacitly validate the use of an informal interpreter, creating a precedent that then makes it more difficult to introduce a professional interpreter.

This constellation of influences increases the risk of misunderstandings in understanding the prognosis, care options or the role of mental health professionals. The information conveyed becomes uneven, partial or filtered, which can delay access to a fully informed decision.

Examples

- Translation is provided by a teenage sibling during a difficult prognosis announcement, leading to an incomplete understanding of the medical situation.
- The family refuses the proposed interpreter, leading to repeated misunderstandings and delaying entry into paediatric palliative care.

Score: Give a score between 1 and 10

Relevance: Based on your experience, to what extent do you think this pattern of conflict is relevant in explaining a barrier to access to paediatric palliative care? : 1= not very relevant; 10= extremely relevant

1	2	3	4	5	6	7	8	9	10

Frequency: how often do you encounter this type of situation in your practice? 1 = very rarely; 10 = extremely frequently

1	2	3	4	5	6	7	8	9	10

Complexity: How complex do you find this conflict pattern to manage, both clinically and in terms of relationships and organisation? 1 = not very complex; 10 = extremely complex

1	2	3	4	5	6	7	8	9	10

Appendix 11.6.3. Use of alternative or "miracle" therapies

Some families explore or favour so-called alternative practices — healers, unproven remedies, spiritual approaches, "energy" therapies. These approaches often stem from a need for hope or a desire to regain control in the face of uncertainty. They are frequently encouraged or shared by relatives, friends, and members of the cultural or religious community, who propose solutions that are perceived as more "natural," more hopeful, or more compatible with their values. Sometimes, professionals who are not specialised in palliative care, when consulted informally, may express a personal opinion or suggest that "it is always possible to try", which reinforces the belief in these alternatives.

All of these influences can delay essential decisions, create unrealistic expectations, or generate conflicts when these practices conflict with medical safety or the transition to paediatric palliative care. These situations then become a significant factor interfering with the care pathway.

Examples

- Parents consider a "miracle" or alternative treatment before agreeing to hear PPC recommendations, delaying the necessary transition.
- The family temporarily suspends validated treatment to try a non-medical approach, complicating continuity of care.

Score: Give a score between 1 and 10

Relevance: Based on your experience, to what extent do you think this pattern of conflict is relevant in explaining a barrier to access to paediatric palliative care? : 1= not very relevant; 10= extremely relevant

1	2	3	4	5	6	7	8	9	10

Frequency: how often do you encounter this type of situation in your practice? 1 = very rarely; 10 = extremely frequently

1	2	3	4	5	6	7	8	9	10

Complexity: How complex do you find this conflict pattern to manage, both clinically and in terms of relationships and organisation? 1 = not very complex; 10 = extremely complex

1	2	3	4	5	6	7	8	9	10

Appendix 11.6.4. Refusal of pastoral or spiritual support

Some families refuse chaplaincy or spiritual support, perceiving it as too closely linked to death, institutional religion or a form of spiritual stigmatisation. This refusal is often influenced by those around them: relatives, siblings, cultural or religious communities may encourage discretion, suggest other forms of spiritual support, or express reservations about the legitimacy of an institutional representative. In addition, some professionals who are not specialised in SPP may relay these reservations or avoid the subject due to a lack of comfort, contributing to maintaining a lasting distance from this dimension of care.

These cross-influences can lead to the spiritual dimension being sidelined, even though it often plays a central role in understanding the illness, the meaning given to therapeutic choices, or the emotional management of the palliative care journey. This withdrawal sometimes makes it more difficult to express existential needs, both for the child and for the adults around them.

Examples

- Parents refuse spiritual support, perceiving it as a harbinger of death and incompatible with their desire to maintain hope.
- The family only wants a specific religious leader to be involved, who is unavailable, delaying essential end-of-life rituals or discussions.

Score: Give a score between 1 and 10

Relevance: Based on your experience, to what extent do you think this conflict pattern is relevant in explaining an obstacle to access to paediatric palliative care? : 1= not very relevant; 10= extremely relevant

1	2	3	4	5	6	7	8	9	10

Frequency: how often do you encounter this type of situation in your practice? 1 = very rarely; 10 = extremely frequently

1	2	3	4	5	6	7	8	9	10

Complexity: How complex do you find this conflict pattern to manage, both clinically and in terms of relationships and organisation? 1 = not very complex; 10 = extremely complex

1	2	3	4	5	6	7	8	9	10

Appendix 11.7. Transition from curative care to palliative care and intensity of treatment

(see 'treatment and transition' in the summary table)

Appendix 11.7.1. Curative escalation ('one more treatment')

Curative escalation refers to the continuation of aggressive treatments when the risk-benefit ratio has become unfavourable. It takes the form of requests to try 'one more protocol', to attempt a new line of treatment or to transfer the child to intensive care for disproportionate interventions. This dynamic is rarely driven by the parents alone: relatives, extended family or certain members of the community may encourage the pursuit of curative treatment, fuelling the idea that abandoning treatment would be morally unacceptable. Teams not specialised in PPC—whether due to conviction, prognostic uncertainty, or organisational pressure—may also suggest that additional treatment "could still work," reinforcing the hope for a different outcome.

These multiple influences create a trajectory in which the transition to paediatric palliative care is delayed, sometimes until the phase of therapeutic exhaustion. The accumulation of divergent opinions, conflicting messages and sustained hopes complicates planning and the family's understanding of the issues at stake.

Examples

- Parents request the continuation of so-called "heroic" interventions despite their recognised futility, delaying admission to PPC.
- The family requests a transfer to intensive care for an invasive intervention when the expected benefit is nil or disproportionate.

Score: Give a score between 1 and 10

Relevance: Based on your experience, to what extent do you think this pattern of conflict is relevant in explaining an obstacle to access to paediatric palliative care? : 1= not very relevant; 10= extremely relevant

1	2	3	4	5	6	7	8	9	10

Frequency: how often do you encounter this type of situation in your practice? 1 = very rarely; 10 = extremely frequently

1	2	3	4	5	6	7	8	9	10

Complexity: How complex do you find this conflict pattern to manage, both clinically and in terms of relationships and organisation? 1 = not very complex; 10 = extremely complex

1	2	3	4	5	6	7	8	9	10

Appendix 11.7.2. Late referral to PPC

Late referral to paediatric palliative care is the result of several factors: prognostic uncertainty, reluctance to discuss a change of objective, the cultural emphasis on curative treatment, and a lack of understanding of the real scope of PPC. This dynamic is not solely linked to parents. Relatives, siblings, or the extended family may encourage the pursuit of active treatment options, expressing that it is "too early" to consider palliative care. Professionals who are not specialised in PPC may also contribute to this delay by conveying cautious, optimistic, or ambiguous messages, or by hesitating to recommend the early involvement of a palliative care team.

These combined influences result in a trajectory where advance decisions, symptom control and psychosocial support are delayed. The lack of a clear benchmark for the "right time" to initiate PHC often leads to an emergency entry into the palliative phase, with a sense of improvisation and increased emotional strain on the family.

Examples

- Professionals delay referral because of perceived therapeutic hope, despite clear signs of progressive futility.
- A team prioritises continuing an oncology protocol, postponing discussion of integrating PPC several times.

Score: Assign a score between 1 and 10

Relevance: Based on your experience, to what extent do you think this pattern of conflict is relevant in explaining a barrier to access to paediatric palliative care? : 1= not very relevant; 10= extremely relevant

1	2	3	4	5	6	7	8	9	10

Frequency: how often do you encounter this type of situation in your practice? 1 = very rarely; 10 = extremely frequently

1	2	3	4	5	6	7	8	9	10

Complexity: How complex do you find this conflict pattern to manage, both clinically and in terms of relationships and organisation? 1 = not very complex; 10 = extremely complex

1	2	3	4	5	6	7	8	9	10

Appendix 11.7.3. Refusal of therapeutic limitations (DNR, withdrawal/discontinuation)

Refusal of DNR or treatment limitation/discontinuation often occurs in a context where several actors simultaneously influence the decision-making process. In addition to parents, extended family, relatives or certain informal carers may encourage the pursuit of maximum intervention, promoting the idea that discontinuing treatment would be tantamount to 'abandoning' the child. These emotional, moral or cultural pressures weigh heavily on parents, who are already burdened with a difficult responsibility. At the same time, teams not specialised in PPC may send ambiguous signals—out of caution or prognostic uncertainty—fuelling the idea that a favourable outcome is still possible despite the increasing futility.

These conflicting influences have the effect of delaying decisions about treatment limitations. They sometimes maintain a curative trajectory that no longer corresponds to the clinical course and make it difficult to establish a coherent narrative around the end of life. Access to paediatric palliative care may then be delayed or even made more contentious.

Examples

- Parents refuse to sign a do-not-resuscitate order despite the recognised futility, generating conflicts with the PPC team.
- The family insists on transfusions, imaging or invasive ventilation despite the lack of expected benefit, preventing the implementation of a structured palliative care plan.

Score: Give a score between 1 and 10

Relevance: Based on your experience, to what extent do you think this pattern of conflict is relevant in explaining an obstacle to access to paediatric palliative care? : 1= not very relevant; 10= extremely relevant

1	2	3	4	5	6	7	8	9	10

Frequency: how often do you encounter this type of situation in your practice? 1 = very rarely; 10 = extremely frequently

1	2	3	4	5	6	7	8	9	10

Complexity: How complex do you find this conflict pattern to manage, both clinically and in terms of relationships and organisation? 1 = not very complex; 10 = extremely complex

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Appendix 11.7.4. "All-healing" logic / exclusion of PPC

The "all-healing" approach occurs when the explicit or implicit goal remains focused exclusively on healing, even when the prognosis is unfavourable. This dynamic is not driven solely by parents: the extended family, siblings, close friends or members of the community may encourage the continuation of active treatment, valuing tenacity or believing that pursuing palliative care would be tantamount to giving up. In addition, some professionals who are not specialised in palliative care—within the original department or in other disciplines—may convey cautious, optimistic, or technical messages that reinforce the idea that additional treatment could still change the outcome.

These multiple influences contribute to maintaining a strictly curative trajectory, in which the very idea of considering palliative care is rejected or seen as inappropriate. This situation complicates advance planning, delays access to PC services and may expose the child to interventions that are disproportionate or inconsistent with their clinical progression.

Examples

- A medical-technical team systematically prioritises curative treatments, repeatedly postponing the introduction of PHC despite unfavourable prognostic signs.
- Parents refuse any mention of palliative care, interpreting it as abandonment, thereby delaying early management of pain and distress.

Score: Give a score between 1 and 10

Relevance: Based on your experience, to what extent do you think this conflict pattern is relevant in explaining a barrier to access to paediatric palliative care? : 1= not very relevant; 10= extremely relevant

1	2	3	4	5	6	7	8	9	10

Frequency: how often do you encounter this type of situation in your practice? 1 = very rarely; 10 = extremely frequently

1	2	3	4	5	6	7	8	9	10

Complexity: How complex do you find this conflict pattern to manage, both clinically and in terms of relationships and organisation? 1 = not very complex; 10 = extremely complex

1	2	3	4	5	6	7	8	9	10

Appendix 11.7.5. Reluctance to use opioids/analgesia

Reluctance to use opioids is common and is based on shared perceptions within the family and social circle: fear of addiction, fear of hastening death, apprehension about drowsiness, or interpreting analgesia as a sign of the "final stage". These concerns are sometimes reinforced by siblings, relatives or informal carers who convey previous experiences or cultural beliefs. Some professionals who are not specialised in palliative care may also express, even implicitly, reservations or hesitations, fuelling a climate of uncertainty around the use of opioids.

These cross-influences can lead parents to refuse, reduce or delay recommended pain relief treatments, resulting in inadequate symptom control and increased discomfort for the child. They also make it more difficult to introduce a palliative approach, which is mistakenly associated with an exclusively terminal outlook.

Examples

- Parents are reluctant to use morphine for fear of hastening death, resulting in inadequate pain control.
- The family themselves reduce the prescribed analgesic doses, considering opioids to be a "last resort", preventing the treatment from being effective.

Score: Give a score between 1 and 10

Relevance: Based on your experience, to what extent do you think this pattern of conflict is relevant in explaining a barrier to access to paediatric palliative care? : 1= not very relevant; 10= extremely relevant

1	2	3	4	5	6	7	8	9	10

Frequency: how often do you encounter this type of situation in your practice? 1 = very rarely; 10 = extremely frequently

1	2	3	4	5	6	7	8	9	10

Complexity: How complex do you find this conflict pattern to manage, both clinically and in terms of relationships and organisation? 1 = not very complex; 10 = extremely complex

1	2	3	4	5	6	7	8	9	10

Appendix 11.8. Communication, information and truth management

(see "Information and truth" in the summary table)

Appendix 11.8.1. Refusal to accept the "palliative" classification of the child's illness or condition

Refusal to acknowledge that the child's illness has entered a palliative phase is a common phenomenon and is often fuelled by several factors. Parents may cling to faint signs of improvement, memories of previous clinical recoveries or family stories that emphasise fighting spirit. Relatives, siblings or the community of origin may reinforce this position by asserting that "nothing is decided yet" or that "we must continue as long as there is still a chance", making it difficult to accept a change of objective.

In addition, some professionals who are not specialised in PPC may adopt a cautious or ambiguous approach, seeking to maintain hope or avoid overly direct information, which perpetuates the idea that a turnaround is still possible.

These cross-influences contribute to a failure to recognise the child's palliative condition, thereby delaying the implementation of appropriate support, complicating the anticipation of decisions and making access to paediatric palliative care more difficult.

Examples

- Parents explicitly request that the word "palliative" never be used, preventing the clear introduction of PPC.
- The family associates "palliative" with abandonment, leading to automatic rejection of any discussion of PPC.

Score: Assign a score between 1 and 10.

Relevance: Based on your experience, to what extent do you think this conflict pattern is relevant in explaining a barrier to access to paediatric palliative care? : 1 = not very relevant; 10 = extremely relevant

1	2	3	4	5	6	7	8	9	10

Frequency: how often do you encounter this type of situation in your practice? 1 = very rarely; 10 = extremely frequently

1	2	3	4	5	6	7	8	9	10

Complexity: How complex do you find this conflict pattern to manage, both clinically and in terms of relationships and organisation? 1 = not very complex; 10 = extremely complex

1	2	3	4	5	6	7	8	9	10

Appendix 11.8.2. Gradual or opaque prognosis

A prognosis that is communicated in a gradual, cautious or insufficiently clear manner can prevent the emergence of a common understanding of the situation. Opacity does not come solely from the parents: relatives, siblings or the extended family may encourage ambiguity to be maintained, believing that overly direct information could affect the family's emotional balance. In addition, some professionals who are not specialised in PPC may deliberately adopt a vague or optimistic tone, either to spare the parents' feelings or because of genuine uncertainties, creating conflicting messages that confuse the issue.

These conflicting influences create a foggy effect: parents feel that "not everything is being said", perceive contradictions, or receive partial information depending on who they talk to. This climate fuels anxiety, complicates advance planning and delays the recognition of a palliative phase, which directly impacts the possibility of early recourse to paediatric palliative care.

Examples

- The family expects more precise information about the prognosis, but the answers remain vague or variable, making it difficult to accept PPC.
- Parents perceive inconsistencies between professionals regarding the expected course of the disease, which fuels confusion and hinders advance planning.

Score: Give a score between 1 and 10

Relevance: Based on your experience, to what extent do you think this pattern of conflict is relevant in explaining a barrier to access to paediatric palliative care? : 1= not very relevant; 10= extremely relevant

1	2	3	4	5	6	7	8	9	10

Frequency: how often do you encounter this type of situation in your practice? 1 = very rarely; 10 = extremely frequently

1	2	3	4	5	6	7	8	9	10

Complexity: How complex do you find this conflict pattern to manage, both clinically and in terms of relationships and organisation? 1 = not very complex; 10 = extremely complex

1	2	3	4	5	6	7	8	9	10

Appendix 11.8.3. "Protective" silence towards the child

"Protective silence" occurs when parents choose not to inform the child about the seriousness of their illness or the change in treatment objectives. This strategy is often not adopted by parents alone: siblings, relatives, extended family or members of the community may encourage the maintenance of silence, believing that too much direct information could upset the child or disrupt the family balance. Some professionals who are not specialised in PPC, out of caution or discomfort, may also avoid addressing the situation explicitly, reinforcing the idea that it is better not to talk about it.

These combined influences create a context in which the child perceives tensions, unspoken issues and behavioural changes without having the words to interpret them. This lack of clarity can generate diffuse anxiety, feelings of exclusion and incomprehension. Protective silence then contributes to delaying the recognition of a palliative phase and complicates early access to paediatric palliative care.

Examples

- Parents explicitly request that the child not be informed of the seriousness of their situation, despite their repeated questions about their condition.
- The team avoids discussing any topics related to the unfavourable prognosis for fear of upsetting the child, which reduces their participation and increases their anxiety.

Score: Give a score between 1 and 10

Relevance: Based on your experience, to what extent do you think this pattern of conflict is relevant in explaining a barrier to access to paediatric palliative care? : 1= not very relevant; 10= extremely relevant

1	2	3	4	5	6	7	8	9	10

Frequency: how often do you encounter this type of situation in your practice? 1 = very rarely; 10 = extremely frequently

1	2	3	4	5	6	7	8	9	10

Complexity: How complex do you find this conflict pattern to manage, both clinically and in terms of relationships and organisation? 1 = not very complex; 10 = extremely complex

1	2	3	4	5	6	7	8	9	10

Appendix 11.8.4. Use of the term "supportive care" as a bridge

When the term "palliative" triggers resistance, some teams use the expression "supportive care" as an intermediate formulation. This strategy is often influenced by the family environment: relatives, siblings or informal networks may encourage the avoidance of terms perceived as too emotionally charged, making the use of more neutral terminology socially more acceptable. At the same time, professionals who are not specialised in palliative and supportive care may also spontaneously use the term "support" to avoid addressing the palliative aspect head-on, contributing to a plurality of discourses.

These cross-influences can facilitate initial contact with the palliative care team, but they also create confusion if the real objectives are not clearly understood. Families may believe that it is simply complementary support, without realising that it is part of a palliative care approach. This ambiguity then delays decision-making and identifying the moment when a palliative approach becomes central.

Examples

- The team introduces "supportive care" without specifying that it is a palliative care approach, leading to a disconnect when the word "palliative" appears later.
- Parents accept the support because it is presented as "assistance", but feel betrayed when they learn about the implicit palliative aspect.

Score: Give a score between 1 and 10

Relevance: Based on your experience, to what extent do you think this conflict pattern is relevant in explaining a barrier to access to paediatric palliative care? : 1= not very relevant; 10= extremely relevant

1	2	3	4	5	6	7	8	9	10

Frequency: how often do you encounter this type of situation in your practice? 1 = very rarely; 10 = extremely frequently

1	2	3	4	5	6	7	8	9	10

Complexity: How complex do you find this conflict pattern to manage, both clinically and in terms of relationships and organisation? 1 = not very complex; 10 = extremely complex

1	2	3	4	5	6	7	8	9	10

Appendix 11.8.5. Selective disclosure at school or in the community

Some families choose to disclose only part of the child's medical condition to the school, relatives or the community: minimising the diagnosis, downplaying its severity, giving ambiguous or euphemistic explanations. This partial disclosure is often reinforced by those around them—siblings, extended family, friends, cultural community—who may encourage discretion to avoid stigmatisation, intrusive reactions, or collective emotional overload. For their part, some professionals who are not specialised in SPP may adopt a cautious or simplified discourse, which contributes to maintaining ambiguity around the situation.

These cross-influences create a fragmented communication landscape. Schools, loved ones, and recreational facilities may lack essential information to tailor their support or understand certain absences, fatigue, or acute events. This lack of transparency complicates coordination, delays necessary adjustments, and can make it more difficult to access consistent palliative care for the child.

Examples

- Parents do not inform the school about the serious illness, which complicates the management of absences and symptoms.
- The family gives partial information to the community to avoid stigmatisation, leading to misunderstanding when the child's condition suddenly worsens.

Score: Give a score between 1 and 10

Relevance: Based on your experience, to what extent do you think this pattern of conflict is relevant in explaining an obstacle to access to paediatric palliative care? : 1= not very relevant; 10= extremely relevant

1	2	3	4	5	6	7	8	9	10

Frequency: how often do you encounter this type of situation in your practice? 1 = very rarely; 10 = extremely frequently

1	2	3	4	5	6	7	8	9	10

Complexity: How complex do you find this conflict pattern to manage, both clinically and in terms of relationships and organisation? 1 = not very complex; 10 = extremely complex

1	2	3	4	5	6	7	8	9	10

Appendix 11.8.6. Reluctance to seek genetic counselling or testing

Hesitation about genetic counselling or testing is common and results from multiple influences. Parents may fear discovering a familial transmissibility, assuming perceived responsibility for the disease, or facing potentially upsetting information. Siblings, extended family, and certain relatives may express concerns about the impact on future children, family relationships, or the risk of genetic stigmatisation, reinforcing the parents' doubts. In addition, professionals who are not specialised in PWS may be reluctant to address these issues or may provide incomplete information, contributing to ongoing uncertainty.

These conflicting influences sometimes lead to genetic counselling being postponed or temporarily refused, which can delay understanding of the prognosis, the implementation of specific adjustments, or the anticipation of certain progressive diseases. Indecision then creates additional uncertainty in the care pathway and can influence the timing of palliative care.

Examples

- The family avoids genetic counselling for fear of a truth that is too difficult to bear, delaying appropriate care planning.
- Parents refuse testing, fearing the implications for other family members, which complicates the anticipation of clinical progression.

Score: Give a score between 1 and 10

Relevance: Based on your experience, to what extent do you think this pattern of conflict is relevant in explaining a barrier to access to paediatric palliative care? : 1= not very relevant; 10= extremely relevant

1	2	3	4	5	6	7	8	9	10

Frequency: how often do you encounter this type of situation in your practice? 1 = very rarely; 10 = extremely frequently

1	2	3	4	5	6	7	8	9	10

Complexity: How complex do you find this conflict pattern to manage, both clinically and in terms of relationships and organisation? 1 = not very complex; 10 = extremely complex

1	2	3	4	5	6	7	8	9	10

Appendix 11.9. At home or in hospital / technology and logistics

(see "Home and logistics" in the summary table)

Appendix 11.9.1. Home as a "sanctuary" (refusal of interventions)

For some families, the home is seen as a protected space, a symbol of normality, stability and family continuity. The idea of introducing palliative care into the home can be perceived as an intrusion or as transforming the home into a "place of illness". This perception is not limited to parents: siblings, relatives, extended family and informal carers may also express fears that medical equipment, regular visits or specialised interventions will alter the atmosphere of the home or disrupt family routines. Professionals who are not specialised in palliative care may also reinforce this hesitation by expressing doubts about the feasibility or safety of home care.

These cross-influences sometimes lead to certain visits being refused, the installation of necessary equipment being delayed, or the intervention of PPC teams being limited. This dynamic makes it more difficult to provide optimal support, despite the desire to preserve an intact family space.

Examples

- The parents refuse any intervention in their home, considering it a sanctuary that must be protected from medicalisation.
- The family rejects the installation of even a simple medical device for fear of transforming the family space into a hospital environment.

Score: Give a score between 1 and 10

Relevance: Based on your experience, to what extent do you think this conflict pattern is relevant in explaining an obstacle to access to paediatric palliative care? : 1= not very relevant; 10= extremely relevant

1	2	3	4	5	6	7	8	9	10

Frequency: how often do you encounter this type of situation in your practice? 1 = very rarely; 10 = extremely frequently

1	2	3	4	5	6	7	8	9	10

Complexity: How complex do you find this conflict pattern to manage, both clinically and in terms of relationships and organisation? 1 = not very complex; 10 = extremely complex

1	2	3	4	5	6	7	8	9	10

Appendix 11.9.2. Intensive monitoring or advanced technology at home

In contrast to the refusal of medicalisation, some families adopt hyper-technological monitoring at home: monitors, alarms, frequent measurements of parameters, video surveillance of sleep or multiple alert devices. This dynamic does not come solely from parents: siblings, relatives, friends or informal carers may encourage this increased vigilance, believing that it maximises the child's safety. Professionals who are not specialised in SPP may also reinforce this trend by recommending certain devices out of caution or to "reassure" the family.

These cross-influences create a highly monitored environment, which can reduce the child's quality of life, increase parental stress and generate worrying or erroneous interpretations (false alarms, overestimation of benign variations). This hyper-technologisation of the home sometimes makes it more difficult to introduce a palliative approach focused on comfort, relationships and stability in everyday life.

Examples

- Parents use multiple monitors at home, increasing their anxiety and complicating the clinical interpretation of symptoms.
- One family uses multiple high-tech devices to monitor breathing and pain, creating a disproportionate mental burden and a stressful environment.

Score: Give a score between 1 and 10

Relevance: Based on your experience, to what extent do you think this pattern of conflict is relevant in explaining a barrier to access to paediatric palliative care? : 1= not very relevant; 10= extremely relevant

1	2	3	4	5	6	7	8	9	10

Frequency: how often do you encounter this type of situation in your practice? 1 = very rarely; 10 = extremely frequently

1	2	3	4	5	6	7	8	9	10

Complexity: How complex do you find this conflict pattern to manage, both clinically and in terms of relationships and organisation? 1 = not very complex; 10 = extremely complex

1	2	3	4	5	6	7	8	9	10

Appendix 11.9.3. Preference regarding place of death

The choice of place of death—home, hospital, or specialised unit—is the result of a dynamic involving several parties. Parents may prefer the home in order to preserve a familiar environment, while siblings or certain relatives may express fears related to the presence of death in the family home. Conversely, other members of the family may consider the hospital to be too symbolically charged and encourage a return home. At the same time, professionals who are not specialised in palliative care may convey conflicting messages about safety, the availability of teams or practical feasibility, which influences the family's perception of each option.

These conflicting influences shape sometimes contradictory expectations, making the decision complex. Logistical implications, symptom management, the possible presence or absence of professionals, and the emotional impact on the whole family shape the final preference and determine the course of end-of-life care.

Examples

- Parents express a strong desire for their child to die at home, but refuse the minimal equipment necessary to ensure safety, complicating the plan.
- A family requests that the child die in hospital for fear of lasting trauma to siblings if the child were to die at home.

Score: Give a score between 1 and 10

Relevance: Based on your experience, to what extent do you think this pattern of conflict is relevant in explaining an obstacle to access to paediatric palliative care? : 1= not very relevant; 10= extremely relevant

1	2	3	4	5	6	7	8	9	10

Frequency: how often do you encounter this type of situation in your practice? 1 = very rarely; 10 = extremely frequently

1	2	3	4	5	6	7	8	9	10

Complexity: How complex do you find this conflict pattern to manage, both clinically and in terms of relationships and organisation? 1 = not very complex; 10 = extremely complex

1	2	3	4	5	6	7	8	9	10

Appendix 11.9.4. Refusal of home adaptations or equipment

Some families refuse to install equipment considered essential — medical beds, infusion pumps, comfort equipment or monitoring devices — for fear of turning their home into a medical facility. This reluctance is often shared or amplified by siblings, relatives or the extended family, who fear the visual and symbolic impact of the equipment on the atmosphere of the home or on the emotional balance of the other children. Informal carers may also encourage them to "keep the home normal", while some

professionals who are not specialised in PWS express uncertainties about the technical feasibility of home care, further reinforcing their hesitation.

These conflicting influences sometimes lead families to refuse or delay installations that are necessary to ensure the child's comfort and support a home care plan. The lack of equipment can then complicate care, limit the possibilities for symptomatic adjustment and make the presence of SPP teams more difficult.

Examples

- Parents refuse to have a medical bed installed in order to preserve the normal appearance of the bedroom, despite the difficulties in moving the child.
- The family declines the arrival of an infusion pump for fear that it symbolises the end of life, delaying the implementation of continuous relief.

Score: Give a score between 1 and 10

Relevance: Based on your experience, to what extent do you think this conflict pattern is relevant in explaining a barrier to access to paediatric palliative care? : 1= not very relevant; 10= extremely relevant

1	2	3	4	5	6	7	8	9	10

Frequency: how often do you encounter this type of situation in your practice? 1 = very rarely; 10 = extremely frequently

1	2	3	4	5	6	7	8	9	10

Complexity: How complex do you find this conflict pattern to manage, both clinically and in terms of relationships and organisation? 1 = not very complex; 10 = extremely complex

1	2	3	4	5	6	7	8	9	10

Appendix 11.10. Socio-economic factors and equity in access

(see 'socio-economic and access' in the summary table)

Appendix 11.10.1. Transport barriers or financial difficulties

Financial and logistical constraints—transport costs, long distances, lack of a vehicle, dependence on a third party for travel—are major barriers to stable and equitable access to paediatric palliative care. These difficulties do not only affect parents: siblings, relatives or informal carers sometimes have to adapt their schedules, lend their vehicles or provide childcare, which can limit the overall availability of the family network. Non-specialists in paediatric palliative care may also schedule appointments or examinations without always taking these constraints into account, creating demands that are difficult to meet.

These cross-influences can lead to postponements of consultations, unintentional interruptions in follow-up, or delayed access to specialised resources. When the financial or logistical burden becomes too heavy, the initiation or continuation of palliative care is jeopardised, with marked disparities depending on the family's means.

Examples

- Parents encounter difficulties in financing repeated trips to the hospital, limiting the frequency of recommended consultations.
- A family cancels several appointments because no parent can take time off work without losing income, thus delaying the introduction of PHS.

Score: Give a score between 1 and 10

Relevance: Based on your experience, to what extent do you think this pattern of conflict is relevant in explaining a barrier to access to paediatric palliative care? : 1= not very relevant; 10= extremely relevant

1	2	3	4	5	6	7	8	9	10

Frequency: how often do you encounter this type of situation in your practice? 1 = very rarely; 10 = extremely frequently

1	2	3	4	5	6	7	8	9	10

Complexity: How complex do you find this conflict pattern to manage, both clinically and in terms of relationships and organisation? 1 = not very complex; 10 = extremely complex

1	2	3	4	5	6	7	8	9	10

Appendix 11.10.2. Refusal of social assistance or respite support

Some families refuse social or psychological assistance or respite services because they feel embarrassed, afraid of being judged, or want to preserve their family privacy. This reluctance is often amplified by those around them: siblings, extended family, or close friends may consider these services unnecessary, intrusive, or a sign of weakness. In some social or cultural groups, asking for outside help may be perceived as questioning one's parenting skills. Furthermore, professionals who are not specialised in SPP sometimes mention these forms of assistance too late or in too little detail, which limits their uptake by the family.

These combined influences can lead parents to shoulder a significant physical and emotional burden alone, with the risk of progressive exhaustion. Refusal of such support reduces the overall availability of the family network and makes it more difficult to provide consistent palliative care, particularly as clinical complexity increases.

Examples

- Parents refuse the social assistance offered, claiming they can "manage on their own", even though they are in a state of advanced exhaustion.
- A family declines the respite offered to preserve their privacy, despite obvious signs of emotional and logistical overload.

Score: Give a score between 1 and 10

Relevance: Based on your experience, to what extent do you think this conflict pattern is relevant in explaining a barrier to access to paediatric palliative care? : 1= not very relevant; 10= extremely relevant

1	2	3	4	5	6	7	8	9	10

Frequency: how often do you encounter this type of situation in your practice? 1 = very rarely; 10 = extremely frequently

1	2	3	4	5	6	7	8	9	10

Complexity: How complex do you find this conflict pattern to manage, both clinically and in terms of relationships and organisation? 1 = not very complex; 10 = extremely complex

1	2	3	4	5	6	7	8	9	10

Appendix 11.10.3. Tensions surrounding data sharing and confidentiality

Some families express significant concerns about the circulation of their child's medical data: fear that sensitive information will be shared with the school, extended family, or other health services. These concerns are often reinforced by those around them: relatives, siblings, friends, or members of the community may advise limiting the dissemination of information, citing previous experiences of stigmatisation or fears of misuse of genetic or social data. Professionals who are not specialised in PWS may also, due to a lack of knowledge about secure communication tools or out of caution, give conflicting messages about what can and cannot be shared.

These conflicting influences can lead to the refusal to share medical records, limit the transmission of information between teams, or restrict communication between specialists. This lack of transparency complicates coordination, increases the risk of errors or duplication, and can make access to paediatric palliative care more fragmented.

Examples

- The family refuses to share essential information between the hospital and frontline carers, making it difficult to coordinate SPP follow-up.
- Parents oppose the use of the shared file for fear that sensitive data will circulate in the community.

Score: Give a score between 1 and 10

Relevance: Based on your experience, to what extent do you think this pattern of conflict is relevant in explaining a barrier to access to paediatric palliative care? : 1= not very relevant; 10= extremely relevant

1	2	3	4	5	6	7	8	9	10

Frequency: how often do you encounter this type of situation in your practice? 1 = very rarely; 10 = extremely frequently

1	2	3	4	5	6	7	8	9	10

Complexity: How complex do you find this conflict pattern to manage, both clinically and in terms of relationships and organisation? 1 = not very complex; 10 = extremely complex

1	2	3	4	5	6	7	8	9	10

Appendix 11.10.4. Refusal of safety standards or vaccinations

Some families refuse vaccinations, hygiene measures or safety standards that are necessary to protect an immunocompromised child. This reluctance is often part of a network of multiple influences: siblings, relatives or extended family may relay personal beliefs, cultural concerns or negative stories about vaccines and medical practices. Community members or informal carers may also encourage caution or refusal by promoting approaches that are perceived as more 'natural'. In addition, some professionals who are not specialised in PWS may express ambiguous or insufficiently explicit messages about the necessity of these measures, reinforcing uncertainty.

These cross-influences complicate the implementation of standards that are essential to the child's safety, especially at home or when admitted to specialised services. Refusal or limitation of these measures can make palliative care more difficult, creating tensions around protection and continuity of care.

Examples

- Parents refuse recommended vaccinations despite severe immunodeficiency, complicating the organisation of palliative care follow-up at home.
- The family does not comply with certain essential hygiene measures, increasing the risk of infection during home visits.

Score: Give a score between 1 and 10

Relevance: Based on your experience, to what extent do you think this conflict pattern is relevant in explaining an obstacle to access to paediatric palliative care? : 1= not very relevant; 10= extremely relevant

1	2	3	4	5	6	7	8	9	10

Frequency: how often do you encounter this type of situation in your practice? 1 = very rarely; 10 = extremely frequently

1	2	3	4	5	6	7	8	9	10

Complexity: How complex do you find this conflict pattern to manage, both clinically and in terms of relationships and organisation? 1 = not very complex; 10 = extremely complex

1	2	3	4	5	6	7	8	9	10

After reading and evaluating these main patterns of conflict identified in the literature and analysed using a tool based on ethical theories, answer the following question:

Based on your professional experience, what common and complex paediatric palliative care situations are missing from the proposed list? Focus on situations that have hindered access to PPC and for which, in practical terms, a change in Belgian legislation or clinical practice guidelines would improve access.

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Thank you very much for your contribution!