

SYNTHESIS

SUPPORT FOR INFORMAL CAREGIVERS – AN EXPLORATORY ANALYSIS





Belgian Health Care Knowledge Centre

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■ FORWARD

The relationship between a dependent person and the person who chooses to care for them, generally known as an "informal caregiver", is quite unique. First, it is unparalleled in terms of the dyad between the caregiver and care recipient and of the context in which they interact. Second, it is jam-packed full of feelings, emotions and values that define the essence of being human. These issues may be verging on "the existential", but they still need to be grounded, and it is clear that support measures are required in the day-to-day lives of caregivers. These support measures are needed to allow them fulfil a choice that comes out of the kindness of their heart, albeit without "leaning on them" into making decisions that are not right for them and without distorting the essence of a relationship that is based on affection, gratuity, solidarity perceived as natural and for granted.

First and foremost, there is an urgent need for consistent, up-to-date information on the various forms of support available for informal caregivers. This information may help to reduce the trepidation that can set in when facing with an urgent choice – or even with an unavoidable one – to "jump into the breach". Furthermore, it is vital that caregivers are not "penalised" for making that choice – legally, socially or fiscally. The means required to support caregivers in what they do need to be put in place; they currently shoulder by far and away the lion's share of care provided to people with a reduced degree of functional capacity. Their contribution to the society goes beyond economic considerations, as they provide a link for the handing down of history and of "living together". In this day and age, with society marked by an ageing population, we need them more than ever.

We would like to thank the teams of researchers from Yellow Window, from the university of Antwerpen and of the Université Catholique de Louvain for bringing us the stories and experiences of informal caregivers that allowed us to recognise their essential role. Our deepest gratitude also goes to the informal caregivers, who despite enormous time constraints, did not hesitate to share the experiences that enriched the content of this report.

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■ ABSTRACT

BACKGROUND

How to better support informal caregivers is a concern increasingly present among health and social care professionals, sickness funds, federal and regional authorities and researchers. Indeed, care provided by family members, friends and neighbours remains a central and essential piece of the long-term care system. Yet, the availability of informal caregivers may decline because of changes in the society such as the growing integration of women in the labour market, the new family structures and the declining family size. In addition, providing informal care may have negative consequences on people's physical and psychological health and may affect their participation in the labour market. Not surprisingly, how to support informal caregivers is an important part of the current discussions – both on a national and an international level – on how to ensure the sustainability of the long-term care system.

AIM OF THE STUDY

The present research aims at discussing the advantages and shortcomings of available support measures for informal caregivers looking after dependent older people. We focused on measures established in the current macro-institutional context, in Belgium and in four other European countries (i.e. France, Germany, The Netherlands and Luxembourg).



METHODS

Evidence on support measure uptake, on expenditures for informal caregivers programs and on their impact was obtained via a review of the literature on the macro-institutional context in which support measures are implemented in the different countries. A structured review of the Belgian literature on informal caregivers' needs and experiences with policies was also performed. In addition, an empirical qualitative research, using a case-study design aimed at illustrating the experience of informal caregivers with support measures within the boundaries of their national or regional context. Cases were selected on the basis of the geographical residence of informal caregivers: Belgium (with Flanders, Wallonia and Brussels considered as separate cases), France, Germany, the Netherlands and Luxembourg. Health and social care professionals were contacted to recruit a total of 37 informal caregivers looking after dependent older people.

RESULTS

The results emphasise the complexity of the environment in which support policies for informal caregivers are implemented.

Depending on the country and environment, support measures can include financial compensation to the informal caregiver for their care work, access to social security benefits, to leave policies and to respite and psycho-social support. We found little to no data on the number and on the socioeconomic characteristics of informal caregivers who are using them.

For Belgium, financial compensation for informal caregivers is limited, as social security benefits are not necessarily covered during care periods and the cash-for-care allowances (*Vlaamse zorgverzekering and the Allocation pour l'aide aux personnes – tegemoetkoming voor hulp aan bejaarden*) are seldom used for compensating the informal caregiver. A caregiver allowance (*mantelzorgpremie*) is available in some municipalities and provinces in Flanders and is rather seen as a form of recognition for the informal caregiver's work than being a financial compensation at the level of a salary. A well-established system of leaves from work exists in Belgium. However, little information was found on the extent to which work leaves provide a long-term solution for people who want to combine work

and care responsibilities. Finally, while respite care and psycho-social support is available from different sources, informal caregivers do not necessarily have access to those services. An important finding is that barriers in the access to information on support measures for the informal caregiver and for dependent older persons may hinder their use and even the extent to which informal caregivers can look after dependent older persons. In addition, the access to information seems to be related to the informal caregivers' socioeconomic characteristics.

CONCLUSION

The evidence in this report invites for a coherent policy on support measures for informal caregivers that needs to be discussed beyond the borders of the health care system. Support measures for informal caregivers may have an influence in different sectors of the economy and, in return, on the overall social security system. This report provides some insights in the complexity of the unintended policy trade-offs of the different support policies for informal caregivers. Those trade-offs need to be fully evaluated in line with what is (will be) expected from informal caregivers, in order to implement a coherent policy to support them.

At the level of the health care sector, the discussion on a policy to support informal caregivers cannot be separated from a vision on how to improve the provision of formal care in the community in a complex and fragmented health and social care system. The first step is to improve the access to information for all informal caregivers and their families, avoiding that it depends on their capacity to navigate the system. The second step is to acknowledge that the choice made by dependent older people between different care arrangements differs between different groups in society and as consequence determines the care demands faced by informal caregivers.

Beyond the health care sector, it calls for a societal debate on the social risks associated with the provision of informal care, and on how society can respond to those risks and ensure the same level of social protection for all citizens.



■ SYNTHESIS

TABLE OF CONTENTS

■	FORWORD.....	1
■	ABSTRACT.....	2
■	SYNTHESIS.....	4
1.	BACKGROUND.....	6
2.	OBJECTIVES, SCOPE AND METHODS.....	7
2.1.	OBJECTIVES AND SCOPE.....	7
2.2.	METHODS.....	7
3.	RESULTS OF THE LITERATURE REVIEW: THE COMPLEX ENVIROMENT OF SUPPORT POLICIES FOR INFORMAL CAREGIVERS.....	8
3.1.	GENERAL CONTEXT IN DIFFERENT COUNTRIES.....	8
3.2.	ASSESSING THE SUPPORT MEASURES TO AVOID LOSS OF INCOME, OF SOCIAL SECURITY BENEFITS OR OF EMPLOYMENT.....	9
3.2.1.	Financial compensation for informal care.....	9
3.2.2.	Social security benefits.....	10
3.2.3.	Impact of financial compensation for informal caregivers.....	11
3.2.4.	Leave arrangements and flexible working arrangements.....	12
3.3.	ASSESSING RESPITE CARE AND PSYCHOSOCIAL SUPPORT.....	15
3.3.1.	Use and uptake of respite care and psychosocial support.....	15
3.3.2.	The impact of support interventions on informal caregivers.....	15
3.3.3.	The barriers limiting the use of support intervention for informal caregivers.....	15
4.	CAREGIVER NEEDS AND EXPERIENCES IN BELGIUM.....	16
4.1.	INFORMATION NEEDS OF INFORMAL CAREGIVERS.....	16
4.2.	NEEDS AND EXPECTATIONS REGARDING PROFESSIONAL HELP AND RESPITE CARE.....	16
4.3.	NEEDS FOR RECOGNITION.....	16
5.	RESULTS OF THE CASE STUDIES.....	17
5.1.	DESCRIPTION OF THE STUDY SAMPLE.....	17
5.1.1.	The reasons to care.....	17
5.1.2.	What informal caregivers do.....	18



- 5.2. ARE INFORMAL CAREGIVERS AWARE OF THE EXISTING SUPPORT MEASURES?18
 - 5.2.1. What do they know?18
 - 5.2.2. Who provides information?18
- 5.3. DO INFORMAL CAREGIVERS BENEFIT FROM EXISTING SUPPORT MEASURES AND HOW? .19
 - 5.3.1. Financial compensation, social contributions and leave policies.....19
 - 5.3.2. Measures on respite care and psychosocial support.....20
 - 5.3.3. The importance of support measures for the dependent older person.....20
- 5.4. WHAT IMPACT/EFFECT DO THESE SUPPORT MEASURES HAVE ON THE CONTINUITY OF CARE FOR THE DEPENDENT OLDER PERSON AND ON THE RISK FOR INSTITUTIONALIZATION?21
 - 5.4.1. Continuity of care21
 - 5.4.2. Institutionalization.....21
- 6. DISCUSSION22**
- 6.1. LESSONS FROM THE MACRO-INSTITUTIONAL CONTEXT ON SUPPORT FOR INFORMAL CAREGIVERS.....22
- 6.2. ARE INFORMAL CAREGIVERS AWARE OF THE EXISTING SUPPORT MEASURES?22
- 6.3. DO INFORMAL CAREGIVERS BENEFIT FROM EXISTING SUPPORT MEASURES AND HOW? .23
 - 6.3.1. Financial compensation, social contributions and leave policies.....23
 - 6.3.2. Respite care and psychosocial support24
- 6.4. WHAT IMPACT/EFFECT DO THESE SUPPORT MEASURES HAVE ON THE CONTINUITY OF CARE AND ON THE RISK FOR INSTITUTIONALIZATION?.....24
- 7. CONCLUSION25**
- **RECOMMENDATIONS.....28**
- **REFERENCES.....30**



1. BACKGROUND

The European population is aging very rapidly, and the number of very old people in particular will increase drastically in the coming decades. This demographic trend is expected to increase the need and consumption of long-term care in Europe over time. Within the large debate on long-term care needs and provision, three findings are particularly consistent. First, long-term care provided at home is preferred over institutional care. Second, in all European countries care provided by family members, friends and neighbours remains a central and essential piece of the long-term care system. Yet, the availability of informal caregivers may decline because of changes in society such as the growing integration of women in the labour market, the new family structures and the declining family size. Third, providing informal care may have negative consequences on people's physical and psychological health and may affect their labour market participation. Not surprisingly, how to support informal caregivers is an important part of the current discussions on how to ensure the sustainability of the long-term care system.

In line with the international debate, concerns on how to better support informal caregivers are increasingly present in Belgium among health and social care professionals, sickness funds, federal and regional authorities and researchers. While this concern is not new, it tends nowadays to evolve towards an open discussion on whether the informal caregivers should be more formally recognised as an actor in his own right of the long-term care system.

Box 1 – Long-term care for dependent older people: definitions of and differences between formal and informal care

According to the Organisation for Economic Co-operation and Development (OECD), **long-term care (LTC)** is defined as “a range of services required by persons with a reduced degree of functional capacity, physical or cognitive, and who are consequently dependent for an extended period of time on help with basic activities of daily living (ADL)”.¹ **Long-term care (LTC) includes both formal and informal care.**

Formal care refers to care services provided to dependent people by health and social care professionals in the context of formal employment regulations.

Informal care in this study refers to the care or support given to a dependent older person by a family member, friend, or acquaintance in a solidarity-based relationship. This relationship is “based on mutual help and moral obligation within families and social networks. Informal caregivers' work can be unpaid or remunerated” in some way.² Informal care in this report does not include paid care work provided by people outside of the solidarity-oriented relationship.

People providing informal care are referred in this study as **informal caregivers**. Informal caregivers may be involved in a variety of tasks, ranging from personal care (e.g. bathing, dressing), to preparing medications, providing surveillance and managing and coordinating formal care services.



2. OBJECTIVES, SCOPE AND METHODS

2.1. Objectives and scope

The present research aims at discussing the advantages and shortcomings of available support measures for informal caregivers as established in the current macro-institutional context in Belgium and in four European countries sharing a similar organizational structure and of the level of financial generosity³ (i.e. France, Germany, The Netherlands and Luxembourg).

The scope of this report is the support measures for people looking after dependent older people. The organisation of support measures for people looking after adults or children with disabilities is not addressed. The research aims at providing evidence concerning the following research questions:

1. What are the support measures available for informal caregivers in selected countries? Is there information available at the national level on support measures uptake, expenditures on programs for informal caregivers and on their impact?
2. Are informal caregivers aware of the existing support measures?
3. Do informal caregivers benefit from existing support measures and how?
4. What is the impact/effect of these support measures for informal caregivers on the continuity of care for the dependent older person and the subsequent impact on the institutionalization process?

2.2. Methods

First, a literature review was performed. Evidence at the national level on support measures uptake, expenditures on programs for informal caregivers and their impact was obtained via a review of the literature on the macro-institutional context in which support measures are implemented in the different countries. A structured review of the Belgian scientific and grey literature on informal caregivers' needs and experiences with policies was also performed.

Second, an empirical qualitative research, using a case-study design was performed. Its aim was to get a better understanding of the experience of

informal caregivers with these support measures. Health and social care professionals were contacted and they were asked to recruit primary informal caregivers, i.e. people considered as being the most involved in the care provided to a dependent older person. The included population had a relatively balanced distribution in terms of family relationship (spouses vs. children), trajectories in the labour-market and uptake of formal care services. We excluded dependent older persons in palliative care, having been hospitalised in the past four weeks and having an acute disease.

Cases were selected on the basis of the geographical residence of the informal caregiver: Belgium (with Flanders, Wallonia and Brussels considered to be separate cases), France, Germany, the Netherlands and Luxembourg. The Brussels case reflects the reality of non-native Belgian dependent older people and their informal caregivers. A detailed description of the methods used can be found in the scientific report.



3. RESULTS OF THE LITERATURE REVIEW: THE COMPLEX ENVIRONMENT OF SUPPORT POLICIES FOR INFORMAL CAREGIVERS

3.1. General context in different countries

There is a wide agreement that supporting informal caregivers is essential in order to allow them to fulfil their caring role without compromising their own health or their income. However, the way that support is actually provided does not correspond with one single pathway. Support measures are included in several sectors of the social security system (e.g. pension, unemployment, compulsory insurance for medical care), which may make it difficult to establish one single and coherent strategy to cover the needs of informal caregivers. The available support measures can be categorised into:

- those aiming to avoid or to reduce loss of income (e.g. financial compensation for the care work), access social security benefits (e.g. pension and unemployment contributions), or employment (e.g. leaves and flexible work arrangements);
- and those aiming at improving the health of informal caregivers (respite care and psychosocial support).

Hereafter, we give an overview on what is available to informal caregivers in each country (see also Table 1). A detailed description of policies including all eligibility requirements can be found in the Chapter 3 of the scientific report.

Germany

Informal caregivers receive benefits from the long-term care insurance (*Soziale Pflegeversicherung*). They can receive a yearly lump-sum to cover expenses for respite care (up to maximum of 1550 euros in 2013), training courses and counselling, coverage of social contributions during unpaid care leaves and pension contributions. Informal caregivers who were in paid employment before the care period can choose to continue paying, on a voluntary basis, contributions for unemployment (as pension

contributions are paid by the long-term care insurance). For informal caregivers in paid employment, an unpaid leave (*Pflegezeitgesetz*) and flexible work arrangement (*familienpflegezeit*) may be used to combine care and work responsibilities. The benefits are available to informal caregivers who look after a dependent person on a non-commercial basis for at least fourteen hours per week.

Recently, Germany also implemented a global policy on psychosocial support and guidance via information centres (*Pflegestützpunkte*).

Luxemburg

In Luxembourg, the Dependency insurance (*Assurance dépendence*) pays pension contributions for one informal caregiver per dependent person. In addition, the Dependency insurance may include respite care, within the scope of the care plan established for the dependent older person.

The Netherlands

The informal caregiver can receive a caregiver allowance (*Mantelzorgcompliment*) amounting to 200 euros per year. Respite care can be financed by the long-term care insurance (*Algemene Wet Bijzondere Ziektekosten (AWBZ)*) linked to the benefits provided to the dependent older person. During the care period, people leaving the labour market (or being unemployed) may be exempted from the duty to look for employment. In addition, care periods may be taken into account when calculating unemployment benefits and in the career-length requirement for pensions (via the *Mantelzorgforfait*).

France

For employed caregivers, an unpaid leave (*congé de soutien familial*) may be used to combine care and work responsibilities. During the unpaid leave, pension contributions are paid by the social insurance for informal caregivers with a low income.

An increase in the number of day care places to provide respite care for informal caregivers is planned. In addition, there are several structured initiatives at the level of the departments and municipalities providing information as well as coordination of services, providing advice and guidance regarding the different types of assistance available. These initiatives are financed by the state and by local authorities.



Belgium

In Belgium, support for informal caregivers is scattered over federal and regional authorities, provinces and municipalities. People who are in paid employment have access to a well-established system of leave schemes. Most employees in Belgium have access to specific paid leaves to care for a seriously ill family member up to the second degree^a. In addition, other existing leave arrangements, not specific to caring for an ill person, can be used to temporarily exit the labour market, but their main objective is not defined in terms of a care need. During the paid leave periods, payment of social contributions is provided by the social security. People receiving an unemployment allowance may be exempted from the duty to look for employment and can refuse a job offer when being in a *difficult family situation*. The National employment office (Office nationale de l'emploi – Rijksdienst voor Arbeidsvoorziening) approves or refuses the access to this benefit (*dispense liée à difficultés sociales et familiales – vrijstelling voor sociale of familiale moeilijkheden*).

A caregiver allowance (*mantelzorgpremie*) is available at the level of several Flemish local authorities (provinces and municipalities). Each local authority sets the eligibility requirements and the amount attributed to the informal caregiver.

Respite care is available in residential care facilities and by other initiatives from different actors, such as sitting home-respite care provided by the sickness funds. Different regional and local organisations and institutions (social services of the sickness funds, informal caregiver associations, social services of the hospitals, public municipal welfare centres, etc) provide information to informal caregivers.

^a Two types of leaves : a) *Crédit-temps avec motif: Assistance ou octroi de soins à un membre du ménage ou de la famille gravement malade assister ou octroyer des soins à un membre du ménage ou de la famille - Tijdskrediet met motief verlot voor medische bijstand: Bijstand of verzorging aan een zwaar ziek gezins- of familielid.* b) *Congé pour assistance médicale – verlot voor medische bijstand*

Cash-for-care allowances

Besides the policies mentioned above, all countries have implemented cash-for-care allowances, directly paid to the dependent person allowing them to choose to some extent how to cover their care needs. These cash payments may be used to financially compensate the informal caregiver. A detailed description on the role of cash-for-care allowances in the selected countries to pay informal caregivers is provided in section 3.2.1.

3.2. Assessing the support measures to avoid loss of income, of social security benefits or of employment

In this section, we provide an overview of the measures aiming to avoid or to reduce loss of income (e.g. financial compensation for the care work of informal caregivers), access to social security benefits (e.g. pension and unemployment contributions), or employment (e.g. leaves and flexible work arrangements).

3.2.1. Financial compensation for informal care

Two different types of payments were identified in the countries studied: caregiver allowances and cash-for-care allowances paid directly to the dependent older person.

Caregiver allowance

A caregiver allowance is usually a small amount provided to informal caregivers, rather as a form of recognition for their work than as a financial compensation at the level of a salary.⁴ It is available in some municipalities and provinces in Flanders (*mantelzorgpremie*) and The Netherlands (*mantelzorgcompliment*). In both cases, the caregiver allowance gradually became increasingly popular, and, as a consequence, the amount granted has been reduced in The Netherlands and in some cases in Flanders.

Studies have shown that, although caregivers appreciate this kind of recognition, it is not a driver to become a caregiver. An evaluation of the Dutch allowance showed that to ensure a high uptake for this benefit, the policy needs to be sufficiently well known, both to professionals in different care services and to the users, and, consequently, that it should be amply advertised. In certain situations, users did not apply for this scheme because of the complex eligibility criteria or because the amount was not deemed worth the administrative burden.



In the Netherlands, the allocated budget is around 65 million euros per year. In Belgium, little data were available on the amounts allocated by the municipalities.

Cash-for-care allowances paid to the dependent older person

Cash-for-care allowances include cash transfers to dependent people (care recipients), the household or the family caregiver, to pay for, purchase or obtain care services.¹ When paid to the dependent older person, the choice to compensate the informal caregiver remains at the discretion of the dependent elderly. In all countries included in our study, cash-for-care allowances are paid directly to the dependent older person (see Table 1).

In Belgium, there are two parallel systems:

- the Flemish care insurance (*Vlaamse zorgverzekering*) grants, a monthly lump-sum granted to severely dependent individuals;
- the (till June 2014 still federal) allowance for a dependent older person (*allocation pour l'aide aux personnes âgées – tegemoetkoming voor hulp aan bejaarden*), attributed to individuals aged 65 years or older who suffer from a disability or from an age-related illness; it is dependent on the degree of disability and the income level.

Available data indicate that only few dependent older people use the cash-for-care allowance to financially compensate their informal caregivers (see Table 1). Compensation to informal caregivers seems to take most often a “non-formalized” form, even in countries with regulation allowing the implementation of a labour contract between the dependent older person and the informal caregiver. Moreover, the recruitment of a family member by the dependent older person does not seem to be really pursued by the authorities either. In Luxembourg, a recent evaluation points out that it is not an explicit objective of the system to recognise the informal caregiver as a formal employee, as it will raise the cost of the long-term care insurance. A recent evaluation on the German system concluded that payments in cash to informal caregivers are not to be considered as a remuneration for a service, but rather as means to promote care in the normal environment of the dependent person.

Little information was found on the socioeconomic characteristics and on the number of informal caregivers who benefit from financial compensation from the dependent older person, or on the amount and type of care that is provided. In France, there is some evidence that mostly women benefit from this type of compensation and that a labour contract is most often established between the dependent older person and a child or a child-in-law. Nevertheless, the financial remuneration paid to the informal caregiver does not seem to compensate for the volume of services delivered by them.

In Belgium, France and The Netherlands, informal caregivers without a contract are not entitled to social security contributions for pensions and unemployment, except when using a leave arrangement. In contrast, in Germany and Luxembourg informal caregivers are eligible for social contributions for pensions that limit to some extent the economic consequences when giving up or partially reducing a paid job.

3.2.2. Social security benefits

In Belgium, France and The Netherlands informal caregivers are entitled to pension benefits if they have a contract with the care-receiver, but there is hardly any information on the uptake or the amounts at stake.

In Germany and Luxembourg, an increasing number of caregivers benefit from pension contributions (see Table 1). In 2012, in Germany, the total budget was 0.9 billion euros.

Little is known on the socioeconomic characteristics of the beneficiaries. The only information available for Germany and Luxembourg is that more than 90 per cent of them are women. Whether pension contributions benefit all informal caregivers entitled to this financial resource remains an open question. Moreover, little is known on the extent to which these benefits really compensate for lost income.

For unemployment benefits, no evidence on uptake or its impact on caregivers could be found either.



Box 2 – How can cash-for-care allowances paid to the dependent be used to financially compensate the informal caregiver?

The Flemish care insurance (*Vlaamse zorgverzekering*) and the allowance for a dependent older person (*allocation pour l'aide aux personnes âgées – tegemoetkoming voor hulp aan bejaarden – (APA – THAB)*) do not explicitly foresee the establishment of a labour contract between the dependent older person and the informal caregiver.

In France, the personalized autonomy allowance (*Allocation personnalisée d'autonomie (APA)*) is granted to individuals whose dependency level corresponds to a given level on the AGGIR scale (*Autonomie, gérontologique, groupes iso-ressources*). The dependent older person can sign a labour contract with the informal caregiver (except the spouse), and the APA can be used to pay the salary. The labour contract must comply with the collective agreements of the labour law for home employees and employers, which implies that the informal caregiver benefits from all social rights.

In the Netherlands, the dependent person may opt for a cash-for-care allowance (*Persoongebonden budget*) to cover their care needs. In this case, a care contract (*zorgovereenkomst*) between the dependent older person and the informal caregiver can take two modalities: either a labour contract or a care agreement (*zorgovereenkomst met een freelancer or zorgovereenkomst met een partner of familielid*). Only if a labour contract is signed between the parties, the minimum legal wage must be paid. The dependent person is not obliged to cover social security benefits for the informal caregiver. However, the care period may be taken into account when calculating social security benefits (unemployment and career-length requirement for pensions) via the *Mantelzorgforfait*.

In Germany, a dependent person can receive a given amount of cash (*Pflegegeld*) when only informal care is provided. The establishment of a labour contract between the dependent older person and the informal caregiver is not explicitly foreseen. However, informal caregivers may benefit from social security benefits even if a labour contract is not signed.

In Luxembourg, a shared care plan (*plan de partage*) establishes what will be done by the informal caregiver and by formal care providers. Based on what the informal caregiver does, the dependent older person can receive benefits in cash (*prestation en espèces*) that can be used to compensate the informal caregiver. The shared care plan is not a formal contract but the dependent older person may choose to sign a labour contract with the caregiver, except if the caregiver is the spouse. The dependent older person (the employer) pays a minimum salary, social contributions for unemployment and health care while the dependency insurance is in charge of the contribution for pension. Informal caregivers may benefit from pension contribution even if a labour contract is not signed.

3.2.3. Impact of financial compensation for informal caregivers

Implementing a financial compensation for informal caregivers as a means to cover care needs for the elderly may come with non negligible policy trade-offs.

The *caregiver allowance* aims at recognizing the role of informal caregivers who look after a dependent older person. From what we learn on the uptake and on the perception by informal caregivers, it seems that this type of policy attains its objective. Seen as a form of recognition, the allowance has little impact on the decision whether or not to provide care.

The evaluation of cash-for-care allowances as a means to compensate an informal caregiver is more complex. First, it remains an open question whether paying an informal caregiver may affect the solidarity-based relationship with the dependent older person. Second, the choice for cash-for-care allowances instead of using formal services may be related to the socioeconomic background of families. Dependent people from less privileged backgrounds more often opt for cash benefits than for formal services. Without formal services, the care needs of these dependent people may solely be covered by their informal caregivers. Third, a labour contract with the dependent older person can create a poverty-trap for informal caregivers, as it might be a low-paid job which can affect his/her future income (i.e., pension). In addition, informal caregivers accepting such a contract are more likely to belong to less privileged backgrounds



and face larger constraints to re-enter the labour market when the labour contract comes to an end. Finally, cash-for-care allowances are usually set at a low level, making them not sufficient to compensate the informal caregiver.

On the other hand, we should not overlook the positive aspects. For some informal caregivers, a compensation for their care work may be the only option available to improve their living conditions and also may be in line with their own personal values. All of this should also take into account that informal caregivers may on the one hand know the person in need of care best and thus can give person-centred care, but on the other hand, they are usually not trained to give more specialised forms of care.

Similar arguments for and against also apply to the payment of social contributions, but the case seems a little more compelling here. These policies mostly give incentives to people from low socioeconomic backgrounds to provide care at the risk of endangering their labour market participation. Yet, not paying social contributions during care periods may lead to losing social entitlements such as unemployment and pension benefits, leading to a double penalty, as they may lose both current income and future pensions.

3.2.4. Leave arrangements and flexible working arrangements

Belgium is the only country in our sample where most employees have a legal right to paid leave to care for a dependent individual. Belgium's leave policies seem to be generous compared to that of other countries. There are currently few studies available on how these leaves influence the provision of informal care. Evidence from Belgium studies points out that informal caregivers not often use the leaves available to them. Between 2007 and 2012, the number of people using the medical assistance leave increased from 5554 to 11 443. While other leaves available in Belgium (i.e., time-credit and career-interruption leave) may also be used to provide care, the reasons behind their use cannot be retrieved from the National employment office database (NEO – ONEM – RVA).

In other countries, some studies report that short-term leaves (usually used for personal emergencies) are seen as a last resort when people can no longer cope with their care and work responsibilities. Before turning to these leaves, caregivers reported using first their free-time (i.e., non-working time) to provide care. In addition, there is some evidence that caregivers tend to avoid the use of unpaid leaves.



Table 1 – Summary of support measures to avoid loss of income, of social security benefits or of employment

Type of measure	Belgium	France	The Netherlands	Germany	Luxembourg
Caregivers' allowance	<i>Mantelzorgpremie</i> (only in Flanders) Beneficiaries in 2012: 30 242	No	<i>Mantelzorgcompliment</i> Beneficiaries in 2012: 377 313	No	No
Dependent elderly using the cash-for-care allowance to compensate the caregiver	<i>Vlaamse zorgverzekering</i> Beneficiaries in 2006: 20% <i>Allocation pour l'aide aux personnes âgées – (APA – THAB)</i> Beneficiaries: N.A.	<i>Allocation personnalisée d'autonomie (APA)</i> Beneficiaries 2008: 16%	<i>Persoonsgebonden budget</i> Beneficiaries in 2006: 33%	<i>Pflegegeld</i> Beneficiaries : N.A.	<i>Prestation en espèces</i> Since the beginning of the dependency insurance: 496 people received a labour contract
Pension contributions	Limited. When: leave from work or if a labour contract is signed Beneficiaries: N.A.	Limited. When: leave from work or if a labour contract is signed Beneficiaries: N.A.	<i>Mantelzorgforfait</i> When: paid to informal caregivers if they are compensated via the <i>Persoonsgebonden budget</i> Beneficiaries: N.A.	Paid to informal caregivers (subjected to certain eligibility) Beneficiaries, 2012: 414 000 actively insured	Paid to informal caregivers (subjected to certain eligibility) Beneficiaries, since the establishment of the measure: 2545
Unemployment benefits for caregivers	Extension of rights: No duty to look for employment, refuse a job offer and no need to be inscribed as looking for employment. Beneficiaries: N.A.	No Beneficiaries: N.A.	<i>Mantelzorgforfait</i> paid to informal caregivers if they are compensated via the <i>Persoonsgebonden budget</i> Extension of rights: No duty to look for employment Beneficiaries: N.A.	Unemployment benefits are granted when in unpaid leave. Unemployment contributions can be paid on a voluntary basis by the informal caregiver. Beneficiaries: N.A.	No



Specific paid work leave	Yes Beneficiaries in 2012: 11 443	No	No	No	No	No
Specific unpaid work leave	Available via collective agreements Beneficiaries: N.A.	<i>Congé de soutien familial</i> Beneficiaries: N.A.	Available via collective agreements Beneficiaries: N.A.	<i>Pflegezeitgesetz</i> Beneficiaries: N.A.	Available via collective agreements Beneficiaries: N.A.	
Flexible arrangements	work Yes, through use of part-time leave Beneficiaries: N.A.	No, but available via collective agreements Beneficiaries: N.A.	No, but available via collective agreements Beneficiaries: N.A.	<i>Familienpflegezeit</i> Beneficiaries: N.A.	No, but available via collective agreements Beneficiaries: N.A.	

Source: Information was first retrieved from one of the following sources: Colombo et al.(2011)¹, Triantafilou et al. (2010)⁵, Lundsgaard (2005)⁶, Riedel et al.⁷ and Gasior et al.(2012)⁸. Other sources used to update or to verify available information were: Belgium⁹⁻¹¹, France¹²⁻¹⁵, Germany¹⁶⁻²¹ Luxembourg^{22, 23}, The Netherlands²⁴⁻²⁷; N.A. information not available. Data on the table corresponds to the most recent identified in the literature.



3.3. Assessing respite care and psychosocial support

In this section, we provide an overview of the measures aiming at reducing poor health outcomes among informal caregivers available in the form of respite care and psychosocial support.

3.3.1. Use and uptake of respite care and psychosocial support

In all countries, efforts have been made to increase the number of places in day care centres and other forms of short-term stays providing occasionally or more regularly some respite to informal caregivers.

In Germany, the uptake of the respite care lump-sum has constantly increased from 45 491 users in 2005 to 74 210 in 2012. However, uptake remains low, and we estimate that less than 5 per cent of all informal caregivers have benefited from the respite care lump-sum. Similarly, in Luxembourg, the number of hours of support activities provided in non-residential centres doubled between 2005 and 2010. According to the evaluation report of the dependency insurance, this could be interpreted as an increase in use of respite care in day care centres. However, no information was found for the other countries, nor on the occupancy rate or on the socioeconomic characteristics of the families and users of respite care.

Each of the countries studied, one way or another implemented policies of psychosocial support and guidance. In Germany, the development of information centres *Pflegestützpunkte* at a national level, responded to the need to have a single and well defined point of access to information on the long-term care system. An evaluation of this policy is ongoing and the first results provide interesting insights in the impact of this national policy. First, it appears to be difficult to evaluate the proportion of the population in need of support who actually received it from the information centres (policy uptake). This is related to the difficulty of evaluating how many caregivers are in need of support (target population). Second, it was reported that higher educated people and people in paid employment compose the majority of those who ask for support and counselling. The authors point out that more targeted strategies may be needed to reach people from less privileged backgrounds and from ethnic minorities.

In Luxembourg, informal caregivers can receive training and support via the long-term care insurance and from home care providers. Yet, support

is seldom provided (or asked for) since less than 5% of individuals entitled to benefits, received psychological support.

In the Netherlands, municipalities are in charge of the support and information activities for all citizens. Their role will be reinforced from 2015 onwards, as more responsibilities with respect to the support to dependent older people and their informal caregivers will be transferred.

In France and Belgium, finally, support and training is provided from multiple local initiatives and different care providers, with much variability in the type of support and the cost per session. Moreover, the different initiatives and the information that they provide seem to be poorly coordinated. Currently, data on access to these initiatives is limited.

3.3.2. The impact of support interventions on informal caregivers

It is widely acknowledged that policies to relieve stress from caregivers are essential to allow them to cope with their care responsibilities. However, it is not always straightforward to implement policies that can effectively target caregivers' health. Studies point out that such interventions tend to have small positive effects. Family caregivers generally feel satisfied and grateful about the professional support and feel less burdened or depressed in the short time follow-up period. But, again, even if these interventions are available, informal caregivers may not always use them.

3.3.3. The barriers limiting the use of support intervention for informal caregivers

Barriers for the use of respite care services include the personal background and preferences of caregivers, the quality of the relationship between the caregiver and the care-receiver, and the acceptability of services in the eyes of both the care-recipient and the caregiver. Informal caregivers from middle and high socioeconomic backgrounds are more likely to use the different forms of support available to them than people from less privileged backgrounds. The knowledge of and availability of services were also reported as influencing the uptake of respite care. Concerns about the quality of care provided, the cost of the services, and waiting lists were also cited among the reasons limiting their uptake.



4. CAREGIVER NEEDS AND EXPERIENCES IN BELGIUM

The following section provides an overview of results of the literature review of Belgian studies related to informal caregivers. More details can be found in Chapter 2 of the scientific report.

4.1. Information needs of informal caregivers

Caregivers' need for information primarily relates to the dependent elder's illness or health status and its evolution, or to practical issues and financial rewards. Moreover, the need is in general higher in the beginning of the care process or when the care situation, the financial benefits or the supply of services change.

Since the social services of hospitals and sickness funds are often the first contact points at the start of a home care process, these services are expected to provide the 'crucial' information or refer to the relevant information source. Another key person is the general practitioner, who is expected to be able to inform on the dependent older person's health status and its probable evolution, to refer to relevant information sources and to help with the administrative procedures needed to get financial benefits. Informal caregivers stress the necessity of being proactively informed instead of having to search themselves, which is experienced as very burdensome.

Another bottleneck in the information collection is the perceived lack of centralisation. Information is often provided by different players involved in the care process and is perceived as incoherent.

4.2. Needs and expectations regarding professional help and respite care

Informal caregivers express the need for more modalities of respite care and home care, particularly when caring for people with dementia or older persons with depressive symptoms. Yet, in practice, they rather feel reluctant to appeal for professional help (including also home care services), often appealing to respite care in an ultimate stage or at a critical moment in the care situation. They also experience making use of external help as an extra burden.

Barriers for the use of professional help relate to psychological aspects and attitudes of care-receivers and their informal caregivers as well as to the organisation of professional help (e.g. no transport to the day centre, the burden of administrative admission procedures). Attitude barriers for care-receivers include the idea that care should be based on family solidarity, the feeling of loss of privacy and independency, the difficulty to accept the situation and the difficulty to accept new care providers, along with feelings of shame towards formal care providers. Informal caregivers also express that lack of use of support alternatives is related to feelings of guilt towards the dependent person or a feeling that they do not comply with social expectations.

Among the organisational barriers, the lack of knowledge or information on the services, the financial accessibility, the eligibility restrictions, the burden of the administrative procedures and the lack of transportation to the day care centre are mentioned as hindering factors. Input from third parties, such as professionals or acquaintances providing information on professional help or working in the elderly sector can help overcome the barriers.

The financial and informational accessibility, the availability in terms of quantity and continuity, the skills and competences of the care provider and the recognition of the caregiver as a partner in care determine how the quality of the professional care will be perceived.



4.3. Needs for recognition

Informal caregivers express the need for a reward from the care receiver, mainly in terms of appreciation or gratitude. Financial rewards from the government, such as the *mantelzorgpremie* in Flanders are appreciated by informal caregivers, although money is not a driver for the care provided. In principle, cash-for-care allowances can be used to remunerate the informal caregiver. Although the *Vlaamse zorgverzekering* was primarily introduced to enable dependent older people to cover the non-medical costs, transfer of money by the older person to the informal caregiver is limited: only 20% of the older people benefiting from the *Vlaamse zorgverzekering* financially compensate the caregiver (data from 2006). Whether the APA – THAB is used to compensate the informal caregiver remains an open question, as we found no data on this subject. It has to be noted, however, that caregivers who live together with the dependent older person will often benefit indirectly from an amount paid in cash as this will be added to the household budget.

Box 3 – Towards a more coherent view on the role of informal caregivers in Belgium: discussion of a status

At the time of writing this report, political discussions are ongoing to grant a legal status to the informal caregiver. In a bill of law, recognition of the informal caregiver by her/his sickness fund is foreseen as a first step.²⁸ Particular social rights or guarantees linked to the status of informal caregivers are to be elaborated in a next phase. Several social partners and stakeholders and the regions authorities gave an advice on the text. Concerns such as the risk for a stop in the investment in services for home care, competition between professional care providers and informal caregivers, inequality between recognised and non-recognised caregivers, etc. were ventilated by the advising bodies. It also needs to be noted that the current draft bill and the existing regional legislation are not aligned; for instance, different scales are used for needs assessment and the definitions of the notion caregiver vary.

5. RESULTS OF THE CASE STUDIES

This section presents the results of the case-study analysis by comparing the findings from Belgium with the findings from France, The Netherlands, Germany and Luxembourg. At least five primary informal caregivers were interviewed in each country (or region in Belgium) summing up to 37 informal caregivers. A mix of spouses and child caregivers were included in the sample. The Brussels case reflects the reality of non-native Belgian dependent older people and their informal caregivers, originating from Turkey, Morocco or Romania. Health and care professionals recruited informal caregivers who they considered being involved in common care situations. Obviously, their specific experiences cannot reflect the overall picture of informal care in each country; but nevertheless the results allow the researcher to test whether the first explanations emerging from one case are robust enough when applied to other cases, in order to construct an empirically based description of the issue investigated. Based on these experiences, we can learn about the barriers and success factors that influence the uptake and impact of the different policies.

5.1. Description of the study sample

The average age of the informal caregiver, with spouse/partner relationship and with the dependent older person is 77 years. The mean age for non-spouse informal caregivers is 53 years. Regarding job occupation the sample is quite heterogeneous, except for Luxembourg where the sample is older and therefore all informal caregivers were retired. All informal caregivers had family ties with the dependent older person, except in one case in France. In the Netherlands, Germany, Wallonia and France, a mix of co-residence status with child(-in-law) informal caregiver was present. In Brussels, all daughters providing care lived with the dependent older person.

5.1.1. The reasons to care

What caregivers do, and why they do it, seems to be related to one single objective: to ensure the well-being of the dependent older person and to allow them to stay at home for as long as possible. Informal caregivers in the sample reported being helped by other family members and friends, but these are less intensely involved in the caregiving



5.1.2. What informal caregivers do

From our data, it seems that the informal caregivers in all countries do as much as possible without professional help. Yet, we can see a difference in perspectives depending on the financial situation and on whether the informal caregiver is still in the labour force. In those cases in which they are still working, they do look for more professional help.

Informal caregivers have a variety of tasks ranging from daily household activities, administration, and surveillance up to (in rare occasions) medical care. Noteworthy, informal caregivers coordinate, at least to some extent, the care, both medical and non-medical and often make sure the dependent person complies with medication. Compared with spouse-caregivers, non-spouse caregivers are not very keen on providing personal care, which is transferred to health and social professionals. However, the non-native informal caregivers living in Brussels felt that personal care should be provided to a maximum extent by themselves.

5.2. Are informal caregivers aware of the existing support measures?

5.2.1. What do they know?

In our Belgian sample (Flanders, Wallonia, and Brussels), if the informal caregivers were aware of policy measures, they knew mostly about formal care services for the dependent older person.

“Je ne crois même pas que cela existe, je le saurais » (Wallonia)

Even then, the knowledge level and therefore the access to services were highly heterogeneous and dependent on the informal caregiver's socioeconomic characteristics. The informal caregivers do not actively seek for information about these issues because they worry about the financial implications, except when they still participate in the labour market. Moreover, access to information seems to be difficult and often fragmented. Informal caregivers seem to look for help for themselves as a last resource when the formal support system for the dependent older person is no longer sufficient. Not surprisingly, they are rarely aware that respite care may be available.

“Het is echt uitzoeken en rondbellen en te weten komen. En dan links en rechts bij lotgenoten met dezelfde problematiek, dezelfde situatie

en dan geraak je daar wel uit. Het is echt volhouden, nog eens een papier invullen” (Flanders)

The couple formed by the informal caregiver and the dependent person, the so-called dyad, living in the other countries (i.e., France, Luxembourg, the Netherlands, and Germany), informal caregivers are well-informed about support measures for the dependent older person. In contrast, compared to informal caregivers living in Belgium, they seem to be more aware of the existing policy measures to support themselves. No clear relationship between socioeconomic status and awareness of support measures was seen in the dyads living in these countries.

5.2.2. Who provides information?

In Belgium, when respondents received information, it was provided at discharge from the hospital by social workers and in moments of crisis, when help was needed urgently. In Wallonia and Brussels, the informal caregiver mentioned the central role of the general practitioner (GP) for giving information.

In the other countries, information sources are similar to those mentioned by informal caregivers in Belgium (i.e., GPs, hospital health and social workers). In addition to these information sources, information is also provided by workers from agencies dealing with the provision of benefits (in-cash and/or in-kind) granted to the elderly because of their dependency level.

Information provided is not limited to benefits for the dependent older person but also includes support measures for the informal caregiver. For instance, in The Netherlands, informal caregivers are well aware of existing measures (i.e., *mantelzorgcompliment*, unpaid leaves, and respite care) to support them.

As pointed out by informal caregivers in The Netherlands and France, supplementary information can be sought through the internet. For France, information found on the internet was pointed out to be not user-friendly and incomplete.



5.3. Do informal caregivers benefit from existing support measures and how?

5.3.1. Financial compensation, social contributions and leave policies

Caregiver's allowance

In Flanders, the informal caregiver and the dependent older person do not make a distinction between the *mantelzorgpremie* and the *Vlaamse zorgverzekering* although both originally served a different goal. In our dyads in Flanders, the caregiver's allowance was not provided in the city/village of most of our respondents.

“Het bedrag is niet overal gelijk. Op de ene plaats krijgen ze 50 euro, op de andere 20 euro. Dat is een groot verschil. En hier krijgen ze niets.” (Flanders)

In The Netherlands, the caregiver's allowance was quoted as 'a nice to have', but did not seem to make a real difference in the degree to which their caregiver role is recognised and appreciated or in the coverage of their expenses.

Cash-for-care allowances used to compensate the informal caregiver

There was no mention of a labour contract between any of the informal caregivers and the dependent older people. Informal caregivers were not financially compensated by the dependent older person, except for one person in France who partially benefited from financial compensation via the *Allocation personnalisée d'autonomie*. In line with this, no reference was made to the *Vlaamse zorgverzekering* or the *Allocation pour l'aide aux personnes âgées – Tegemoetkoming voor hulp aan bejaarden* as a means to compensate the caregiver. In Belgium, informal caregivers pointed out that both allowances were mostly used to cover the dependent older person's daily expenses and to a lesser extent to cover formal care services.

For some caregivers, the financial compensation was judged insufficient compared to the bureaucracy for obtaining the benefits.

“On a introduit une demande auprès de l'APA, aide pour personnes âgées... on a dû aller chercher un document à la maison communale

qu'on a dû faire remplir par le Dr V. et commencer toutes les démarches... J'ai tout complété moi-même avec l'aide du Dr. V.” (Brussels)

When discussing cash-for-care allowances provided to the dependent older person, such benefits are usually perceived by the informal caregiver (in the different countries) as a means to cover household expenses.

The dyads without financial problems saw the allowances as “a nice to have” while others relied on this payment to cover household expenses and in some cases to cover the cost of formal care services.

“Ils vivent relativement bien, ils ne sont pas dans le besoin, mais si on doit faire appel à un garde-malade et à toute la panoplie, je ne crois pas qu'il pourrait s'en sortir... De l'APA, il reçoit 343 euros, cela permet de couvrir les frais médicaux, parce qu'il en a déjà pour presque 300 euros de médicaments par mois. Il a 300 euros par mois pour le centre de jour, et comme il n'a que 900 euros de pension, donc si on doit faire appel à un garde-malade ou à un aidant, il n'a plus rien à manger...” (Brussels)

Leave arrangements and flexible working arrangements

In Belgium, flexible working hours are used to keep the formal support system in balance, and leave policies are used to fill gaps in the continuity of care provided by formal services. Also, the informal caregivers interviewed mentioned that having a flexible work schedule was enough to cope with the care needs.

“Het is een beetje een vast schema, maar je kon er wel flexibel in zijn. Ze hebben op het werk er extra op gezien, dat ik kon wisselen met de collega's. Het zijn heel lieve collega's, ze hebben er rekening mee gehouden.” (Flanders)

For the informal caregivers interviewed in other countries, access to leaves is limited (e.g., short-time leaves, unpaid leaves) or non-existent; therefore, the informal caregiver used the short-term leaves only in emergencies to cover unexpected care demands. In France, one caregiver used a complex arrangement to reduce the work schedule: an unpaid leave was combined with partial financial compensation from the *Allocation personnalisée d'autonomie*. The drawback from this arrangement was that the financial compensation did not cover the income loss; therefore, the informal



caregiver faced a difficult financial situation. In Germany, two informal caregivers were still working when care first started. The first one took an unpaid leave but eventually had to quit her job because she could no longer combine work and caring. The other became self-employed so that she could arrange her own work schedule, and she judged the available measures for flexible work arrangements to be unrealistic and unhelpful.

5.3.2. Measures on respite care and psychosocial support

Informal caregivers reported that when respite care alternatives were available, they were seldomly adapted to the informal caregiver and/or the dependent older person needs or preferences. For other informal caregivers and dependent older people, it appeared as simply not acceptable to use these types of services. Hesitancy appears to be due to lack of trust and to the strong relationship between the informal caregiver and the dependent older person. Informal caregivers do not like to entrust the care of their family to non family members for their personal benefit. Use of respite care at home seems even more problematic among non-native Belgian caregivers because they do not want health or care professionals coming into their homes to do something they can do themselves.

When some respite is needed, the other informal caregivers are the first resource contacted. Only in Belgium, some informal caregivers willing to use respite care (in particular amongst those living in Wallonia and among non-native informal caregivers), reported that the cost of services limited their access.

“Il est allé quelques fois au centre de jour. Il aimait bien, mais il fallait le déposer. Il y avait l'autobus, mais souvent ils oubliaient de le mettre dans le journalier, on me téléphonait et je devais me précipiter pour aller le chercher... et puis cela coûtait 30 euros par jour environ. C'est très cher, parce qu'il arrive à 10h du matin, à midi il mange peu, et l'après-midi, il dort. Alors, pourquoi payer 30 euros ? ” (Wallonia)

However, when respite care seems to be adapted to the dependent older person's and informal caregiver's needs, it is welcomed and does provide solutions. In Luxembourg, a service in which someone comes to the dependent older person's house to look after the dependent older person for some time was mentioned as a valid alternative to respite care in a facility. In Germany, respite care was only used in emergencies, for

example when the informal caregiver fell ill. In Germany, long waiting lists hindered access to respite care services.

None of the interviewed caregivers made a reference to the policies about psychosocial support. It was even mentioned by two French informal caregivers that these services were missing altogether.

5.3.3. The importance of support measures for the dependent older person

In most dyads in Belgium, the formal services for the dependent older person are the only source of support for informal caregivers. Informal caregivers expressed that, access to formal care services or to cash-for-care allowances for the dependent older person, is hindered by how difficult it is to find one's way in the system as well as by the cost of services. However, all of the dependent older people received some form of formal care within their home. Among informal caregivers having a lower level of education and not working, navigating the system and, therefore, getting access to formal services for the dependent older person seems to be even more difficult. Informal caregivers in Belgium reported being worried about the financial implications of using more formal help and tried to postpone it as long as possible. The language barrier of non-native dependent older persons living in Brussels is an additional problem for informal caregivers as they need to cope with all the administrative issues surrounding access to formal care. Moreover, the cultural background of non-native dependent older persons living in Brussels may lead the informal caregiver to provide most of the care even if formal services are available.

“Elle ne sait pas lire, elle ne sait pas écrire, elle ne sait pas parler en français. Partout où elle allait, j'étais l'interprète: docteur, mutuelle, banque, partout elle avait besoin de moi. J'étais toujours à côté d'elle.” (Brussels)

Informal caregivers in our case study from France, Luxembourg, and The Netherlands did not explicitly mention that the cost of formal care limited access to services for the dependent older person. In Germany, some informal caregivers criticised the cost of formal care, especially because in one of the cases, the informal caregiver was liable to pay for the dependent older person's institutionalisation. In France, for people in our sample who are not eligible for the *Allocation personnalisée d'autonomie*



due to an income exceeding the established threshold, access to care services can be even more difficult, in the absence of a care plan. Yet, dyads with higher incomes in this case turned to other solutions such as vouchers (*Chèque Emploi Universel (CESU)*), which can be used to pay for domestic aids.

5.4. What impact/effect do these support measures have on the continuity of care for the dependent older person and on the risk for institutionalization?

5.4.1. Continuity of care

In all countries, formal home care is available and is used to some extent by the dependent older person. Informal caregivers interviewed play, at least to some extent, an essential role in arranging and managing formal care for dependent older person, including coordinating and arranging care.. When they can no longer fulfil this role, other family members, friends, and neighbours are called in to ensure the continuity of care. The coordination of care comes at a high cost for some caregivers, in particular when the supply of formal care is fragmented between different services, and when those services do not communicate with each other. To some extent most informal caregivers mentioned that the turnover of health and care professionals disrupted the continuity of care. Even when continuity of care seemed manageable; informal caregivers are aware of the delicate balance and rely on personal networks in emergency situations.

“ Cette année, je suis allée en vacances à la mer avec le petit. Je m’installe à peine, je mets mon transat, je mets ma couverture, je reçois un coup de fil de l’assistante sociale de la mutuelle qui me téléphonait pour me dire qu’elle ne savait pas assurer les trois jours semaine pendant que j’étais à la mer... elle avait eu un couac avec son personnel... je croyais que j’allais mourir, et alors, pas d’humanité, pas une seule excuse...” (Wallonia)

For working informal caregivers, flexible work arrangements seem to be an essential element in ensuring the continuity of care. To a lesser extent, caregivers reported that leaves from work also help to cover unexpected higher care needs. However, leaves are seen as an emergency tool as they are usually not paid (except in Belgium) and can be used only to cover short periods of time. In some cases, informal caregivers on sick

leave reported that this time-out from work allowed them to care for the dependent older person.

“Ik heb het voordeel gehad van een jaar thuis te zijn. In die zin, van dat principe kon ik wel binnenstappen. Kon ik wel eens meegaan naar de dokter” (Flanders)

Lack of continuity of care (e.g., if the informal caregiver becomes ill, if something happens because they are also often elderly) can cause a collapse in the already fragile system and institutionalisation might become necessary.

5.4.2. Institutionalization

In all countries, the informal caregiver and the dependent older person prefer at-home care to institutionalisation. Living at home gave the dependent older person a higher level of autonomy, while feeling at home and staying in the known social environment. Concerns about the care provided in institutions were also cited by some ICGs as a reason to try to avoid this. In Belgium, the informal caregiver and the dependent older person also mentioned that there are enormous waiting lists for institutionalisation. The cost of a nursing home was also cited as a reason to avoid institutionalisation for as long as possible. All informal caregivers acknowledge that formal care services are essential to allow the dependent older person to live at home for as long as possible and therefore appreciate these services. In all countries, institutionalisation seems unavoidable at some point, either when surveillance becomes unmanageable, when the health of the informal caregiver is at stake, or when the informal caregiver can no longer combine care and work responsibilities.

“Dan was het huis ook niet meer aangepast, de verpleegster zei, dat douchen wordt moeilijk om elke keer in de bak te stappen. En dan was het ook niet in orde met de brandverzekering, het was nog met een gaskachel, en de verluchting was niet in orde.” (Flanders)



6. DISCUSSION

The present research aimed at discussing the advantages and shortcomings of available support measures for informal caregivers as established in the current macro-institutional context in Belgium and in four other European countries (i.e., France, Germany, The Netherlands, and Luxembourg). To this end, a literature search was performed and 37 caregivers were interviewed. The qualitative research in this report aimed at improving the understanding of this complex issue. The findings from our case studies reflect in many aspects what was found in the literature. The lessons learned through the eyes of the informal caregivers do provide important insights on the factors that hinder and enhance the impact of the different policies.

6.1. Lessons from the macro-institutional context on support for informal caregivers

Based on the analysis of policies in the different countries, it is not possible to say that one country provides more or less global support to informal caregivers than another. The types of support differ between the countries and there is little to no evidence on the number and on the socioeconomic characteristics of informal caregivers who are using them.

Germany and Luxembourg have the most comprehensive data on uptake of policies. However, even for these countries little evidence was found on the profile of informal caregivers who receive benefits. We cannot rule out that the complex framework in which multiple authorities are involved in providing services to informal caregivers hinders the transparency about what services are available. In addition, while this study focused on support policies for informal caregivers we have to keep in mind that formal care for the dependent older person indirectly benefits the informal caregiver. As such, a direct comparison between the systems in the different countries may need to include cost and availability of formal home care, which is beyond the scope of this report.

But, even in the light of these limitations, some general remarks can be made.

In Belgium, any financial compensation for informal caregivers of dependent older people is basically a non-formalised support measure, as it is not explicitly foreseen that a labour contract between the informal

caregiver and the beneficiary be signed. Benefits in-cash currently available in Belgium represent a symbolic recognition of the work of the informal caregivers but, with minor exceptions, are neither a driver for informal care nor an incentive to appeal for more professional help. The current design of benefits in-cash provided to dependent older people most certainly provides the household with financial resources to cover everyday life expenses. However, they are unlikely to compensate the informal care giver for an eventual income loss relating to their care activities. This holds for the care insurance (*Vlaamse zorgverzekering*) and caregiver's allowance (*mantelzorgpremie*) in Flanders, as well as for the allowance for a dependent older person (*Allocation pour l'aide aux personnes âgées – tegemoetkoming voor hulp aan bejaarden*) available at a national level.

In Belgium, gaps in the access to social security benefits for informal caregivers exist as care periods are not taken into account when calculating unemployment benefits and in the career-length requirement for pensions. Gaps in the access to respite care and psychosocial support may also exist even if these services are available from different sources. However, access to these services is not guaranteed nor a right for informal caregivers.

Compared to the other countries studied, employed caregivers can rely on a number of leave policies, including paid leaves to care for ill relatives. This is certainly a positive point. However, lack of data on the uptake of these policies and the socioeconomic characteristics of informal caregivers limit the evaluation of their impact. This equally holds for the use of respite care, psychosocial support and of available job leaves in Belgium. The same also holds for the other countries, therefore we cannot provide a final statement on whether some countries provide more generous benefits than others.



6.2. Are informal caregivers aware of the existing support measures?

The results from the case studies are in line with what was already reported in literature: caregivers' need for information primarily concerns the dependent elder's illness or health status and its evolution. Only in a second instance, and often in extreme situations, informal caregivers seek for information on support for themselves. The fragmented structure of the system and the need to contact different health and social care providers are important barriers to obtain this information, in particular among caregivers from low socioeconomic backgrounds. Unequal access to information will directly lead to unequal access to formal care services.

As shown in the Belgian literature, caregivers need to be proactively informed instead of having to search for information. Making access to information easy and organised is the first step to allow informal caregivers to navigate the system. Too often, patients and caregivers receive the first information on existing services at hospital discharge. We therefore hypothesise that providing information earlier during the care process and reducing inequities in its access, may reduce an existing burden among informal caregivers, in particular among those from less privileged backgrounds.

6.3. Do informal caregivers benefit from existing support measures and how?

6.3.1. *Financial compensation, social contributions and leave policies*

Caregiver's allowance

The sheer availability of a caregiver's allowance does not seem to trigger or maintain the provision of informal care. Rather, it is seen as a 'nice to have' and a form of recognition, but the amount most often is rather low. Moreover, access is fragmented and quite unequal in Belgium, as only a limited number of municipalities or provinces do offer a caregiver's allowance. And even if it is available, the awareness among caregivers may be poor. If such a policy is pursued, we could learn from the Dutch experience: it is important to maintain simple eligibility requirements, have

ample advertising and avoid overly complex bureaucratic procedures in order to reach the largest number of caregivers.

Cash-for-care allowances paid to the dependent older person

In all countries, there are cash-for-care allowances to compensate for the costs relating to autonomy loss of the elderly. From the literature we know that cash-for-care allowances are only seldom used to pay a salary or to provide a financial compensation to the informal caregiver. This equally holds for countries where it is foreseen to sign a labour contract between the dependent older person and the informal caregiver (France, the Netherlands and Luxembourg) and where this framework does not exist (Belgium and Germany). In none of the countries, the policy makers have the intention to turn informal caregivers into employees. The goal rather is to support informal care and to keep the dependent older person longer at home.

Social security benefits

The discussion about whether to compensate the informal caregivers is also related to the coverage of social security benefits. Even if the dependent older person compensates the caregiver, this situation does not necessarily imply (except when there is a labour contract) that pension or unemployment contributions are covered. There is very limited information available on the impact of social security contributions for informal caregivers, except that the number of informal caregiver who benefit from pension contributions has increased in Luxembourg and in Germany. In addition, this policy benefits mostly women, but this might merely reflect the gender distribution among caregivers.

Providing financial compensation for informal caregivers may have non-intended and important consequences. A combination of a care-related-salary and coverage of social contribution for informal caregivers, may preferentially stimulate people from low socioeconomic backgrounds to exit the labour market or not to look for employment in order to provide care.



Flexible work arrangements and leaves

A well-established system of leaves from work exists in Belgium. The literature provides little evidence on their use except that working informal caregivers do not systematically apply for these benefits. The working informal caregivers interviewed in Belgium appreciated and used the leaves, and such leaves had a positive effect on the continuity of care. In other countries, short-term leaves are used for emergencies, often as a last resort.

For working informal caregivers, job leaves play a complementary role to the formal services provided to the dependent older person. In addition, informal caregivers reported, both in the literature and in our case studies, that work flexibility is a key condition to be able to combine work and care responsibilities. It is worth noting that some of the interviewed informal caregivers told us that going on sick leave also allowed them to provide care, so sick leave was used as a solution for a social problem.

In Belgium, it would be important to more fully understand the extent to which work leaves provide a long-term solution for people who want to combine work and care responsibilities. In addition, we should identify whether a social gradient in the use of leaves exists. Today, there is no information about this issue.

6.3.2. Respite care and psychosocial support

In terms of respite care and psychosocial support, the literature has pointed out that: a *one size-fits-all policy* for dependent older people and their caregivers does not seem to exist. Respite care often is a last option and we cannot but wonder whether it arrives too late during the care process. Not surprisingly, the case studies fully reflect this finding. Not only adjusting respite care to the needs and preferences of different types of informal caregivers and dependent older people is an issue of concern. In addition, the cost of services was reported to limit access to respite care for Belgian informal caregivers.

None of the interviewed caregivers in the different countries referred to policies on psychosocial support. Two French informal caregivers mentioned that these services were altogether missing.

6.4. What impact/effect do these support measures have on the continuity of care and on the risk for institutionalization?

In literature, as well as in the case-studies, we saw that both the informal caregiver and the dependent older person prefer care at home rather than in an institution. When considering formal home care services, informal caregivers interviewed are always involved to some extent in the coordination of care. Without a doubt, all informal caregivers we interviewed play an essential role in arranging and managing that the care needs of the dependent older person are covered on a daily basis. It should be noted, that not all informal caregivers may be able to manage or to maintain a support system. In Belgium, informal caregivers from less privileged backgrounds or with a small or no support network may be disadvantaged: they both are less likely to dispose of all necessary information in order to be able to obtain and manage formal care services and the cost of formal care may be more of a barrier for them.

The current report did not aim at evaluating the institutionalisation process in Belgium; however, some findings from the case-studies open a door for further debate. First, institutionalisation seems unavoidable at some point, either when surveillance becomes unmanageable, when the health of the informal caregiver is at stake, or when the informal caregiver can no longer combine care and work responsibilities. Yet, appropriate support for informal caregivers including both the measures directed to them and formal care services for the dependent older person may delay institutionalisation. Second, informal caregivers in Belgium reported being worried about waiting list and about the costs of residential care facilities. Third, a gradual transition for the dependent older person from being at the home to being institutionalised does not seem to be envisaged. Whether the latter is not possible because affordable and accessible intermediate solution (such as homes in an adapted environment) are lacking or because informal caregivers are not prepared for this gradual step remains an open question.

Limitations of the report

This report aimed at identifying key elements to improve caregivers support in Belgium in the light of experiences in different countries. A certain number of limitations must be mentioned:



- For Belgium, we included dyads from Wallonia, Brussels, and Flanders, but not from the German-speaking region.
- The literature search was not a systematic review. A scoping review was done for two reasons. First, as support measures for informal caregivers cover several policy areas (labour, social rights, etc.) their evaluation also goes beyond the health care sector. Second, given the limited timing for the project and its exploratory character, the scoping review allowed a view on available studies for the large number of policies discussed in this report. At the time of writing of this report, the evaluation of alternative forms of care for older people and the impact for informal caregivers were being carried out.(in the 'Protocol 3' study). A part of the answers related to the impact of support measures for the dependent older person and the informal caregiver might be found in the results of the Protocol 3 study.
- Even though a homogenous blueprint for the recruitment of participants was designed, problems with recruitment in different countries did not allow the researchers to completely follow this initial strategy. But, we think to have sufficiently covered the spectrum of caregivers looking out for dependent older people.
- Since participation was voluntary, a selection bias is possible. However, it is unclear whether this selection bias influences the perception of caregivers to support measures.
- We did not include dyads living in Belgium who benefited from services that provide coordination of care, such as the Integrated Home Care Services (*Geïntegreerde Diensten voor Thuisverzorging-services Intégrés de Soins à Domicile*), the Centres de Coordination de Soins et Services à Domicile (CCSSD), and the Samenwerkingsinitiatieven in de Eerstelijnsgezondheidszorg (SEL). However, while the population covered by those services has increased, it probably remains small with respect to the total number of dependent older people.
- The project did not discuss the care process per se, nor its implication for working caregivers, nor the impact on their health. The departure point of the research is that support measures are needed because of the possible negative consequences of caregiving on people.

7. CONCLUSION

Public support to informal caregivers is a complex issue. First, each caregiving situation is unique. Therefore, a single support strategy cannot be beneficial to all informal caregivers. Second, measures to provide informal caregivers with support are scattered in different sectors of the social security system. Third, it is important to note that when discussing support measures with the informal caregivers, in all countries, they automatically linked such support to formal care services for the dependent older person. Moreover, while the scope of the research focussed on measures supporting the informal caregivers, it became apparent in our case studies to what large extent the support measures are complementary to professional home care services. Without appropriate formal care at home, support measures for the informal caregiver may prove to be just a drop of water in an ocean of needs.

Information and fragmentation of the system: the need for a clear road map for informal caregivers

The findings in this report provide a clear signal that the way that information is currently provided needs to be improved. However, it does neither imply that currently no appropriate channels exist nor that all informal caregivers are not well informed. Yet, it reflects the difficulty to navigate the very fragmented system between health and care providers, between federal authorities, regional authorities and even within municipalities. Based on the findings of this study, we cannot discuss the short-comings and advantages of the current structure. Even so, the bottom line for the informal caregiver is that he or she has to deal with multiple professionals and will not necessarily be able to find the appropriate information on services for the dependent older person and for themselves. The lack of a well-known information channel adapted to all informal caregivers and their families will preclude the use of services even if they are available and affordable.

Equity issues

The ability to look for information appears to be related to the informal caregiver's socioeconomic characteristics (e.g., education level, labour market participation, language proficiency). In the current fragmented system; people with a high socio-economic status may be more prepared than people with a low socio-economic status to find information and



therefore to use available support services. For non-native families living in Brussels, the language barrier may add an additional obstacle, when confronted with the administrative hassle surrounding access to formal care. Moreover, the cultural background of non-native dependent older people living in Brussels may lead the informal caregiver to provide most of the care even if formal services are available.

Making informal care a paid job? A difficult question

Based on the evidence in this study and on its exploratory nature, we cannot judge whether paying for the care of informal caregivers would be a good policy for Belgium. But we learned a number of things. The caregiver allowance and the cash-for-care allowance are responding to different policy objectives. The caregiver allowance fully plays its recognition role; however, it has little impact on the decision whether or not to provide care. The evaluation on cash-for-care allowances as means to compensate an informal caregiver is more complex as it may come with non-negligible policy trade-offs.

The current design of benefits in-cash (*Vlaamse zorgverzekering and Allocation d'aide aux personnes – tegemoetkoming voor hulp aan bejaarden (APA – THAB)*) in Belgium provided to dependent older people most certainly provides the household with additional financial resources to cover everyday life expenses and to lesser extent to appeal for more professional help or to compensate the informal caregiver. Policy-makers should be aware that the preference for in-cash versus in-kind benefits depends on the socioeconomic status of the people. To a certain extent, people in financially difficult situations might opt for cash benefits and not use formal services. In return, refraining to use formal services eventually may imply an increased risk of overburdening. For these informal caregivers, a compensation for their care work may be the only option available to improve their living conditions. Yet, a paid care job can become a poverty-trap for the informal caregivers, as it might be a low-paid job which can affect his/her future income (i.e., pension). Last but not least, although the care work of the informal caregiver is essential, it is unlikely it can totally substitute the work by formal care professionals.

Making respite care and psycho-social support work: the need for tailor-made solutions

Access to respite care depends on three factors: (1) knowledge of and availability of services that are (2) adapted to the informal caregiver and the dependent older person needs and preferences, (3) at an affordable cost. There clearly is a need to enhance the financial accessibility and the appropriateness in relation to needs of shorter-period types of respite care as well as to develop services better adapted to dependent individuals and their informal caregivers. Moreover, psycho-social support should be offered proactively as informal caregivers will seldom ask for help for themselves.

Making leave policies and flexible work arrangements a good solution: they exist but are they really used?

It is important to take into account that informal caregivers will probably first use their free-time (i.e., non-working time) or, if available, use flexible work arrangements to provide care, before using the more formal job leave schemes available to them. As not all workers may benefit from flexible work arrangements, the official leaves as established in Belgium are a way to grant to all informal caregivers the possibility to adapt their working schedule. However, it would be important to more fully understand the extent to which work leaves provide a long-term solution for people who want to combine work and care responsibilities. In addition, we should identify whether a social gradient in the use of leaves exists. Today, there is no information about this issue.

The evidence presented in this report inevitably brings us back to the findings of the KCE position paper on chronic care.²⁹ First, general practitioners and other primary health care practitioners may play a more central role in the identification of precarious care situations, as well as in the assessment of the needs of the informal caregiver and the dependent older person. Existing tools such as the general medical record (GMD – DMG) and BelRAI could help physicians and other care workers to better support informal caregivers and dependent older people. Second, there is a need to extend affordable and differentiated respite care services. Third, studies should examine how intermediate living structures for dependent elderly may ease the role of informal caregivers and may provide a more gradual process from being cared for at home to being institutionalised. Fourth, informal caregivers on an everyday basis deal with the complex



home care system in Belgium. This situation can be improved by enhancing the coordination of home care providers from the health and social care sector. This calls for setting strategies at a micro and macro level. At a micro level, case managers in close collaboration with other health and social care providers (e.g. GP, nurses) can help to coordinate home care services and provide needed coordination support to dependent older people and their informal caregivers. At a macro level, this situation calls for improvements in the coordination between the health and social care sectors, which today are extremely fragmented in Belgium. In this sense, it would be important to set up a combined knowledge base, including health care services and social care services offered by federal, regional and local authorities. This could allow all involved actors to have a better view on who is providing services, on how many home care services are being provided to dependent people and their families, and on possible gaps in the system.

In line with the need for coordination at a macro level, the evidence in this report invites for a coherent policy on support measures for informal caregivers that goes beyond the borders of the health care system. A successful policy to maintain dependent older people in their home may not be achieved without defining the role of informal caregivers in the long-term care sector. The ongoing discussion on the creation of a legal status for informal caregivers is certainly a big step forward. This project is to be followed by a law encompassing the possible advantages and rights (at social, legal and/or fiscal) that will be linked to this "status". The status should be a requirement and a facilitator to access a coherent and more standardised supply of services and social protection. The bill encompasses people with a high degree of dependency, but at this stage, the concept of dependency is still too broadly defined.

Whatever the nature of entitlements and benefits granted to informal caregivers (either by the federal level through the legislation referred to above, by the regions or by the municipalities), it should be ensured that caring for a dependent person remains a positive choice, and not to undermine the "voluntary" nature of this choice. The next step is to set up an open societal debate about which policy measures should be prioritised and implemented in order to effectively support informal caregivers in the future.



■ RECOMMENDATIONS^b

To the Interministerial Conference Public Health and to all competent authorities at the federal, regional and local level

Status for informal caregivers

- A societal debate on the role of informal caregivers in the long-term care system should be carried out (which include formal and informal care) before deciding which financial compensations or advantages should be granted, in particular to people obtaining the informal caregivers' status. A detailed evaluation of inequalities and policy trade-offs relating to the impact and to the consequences of different benefits, entitlements and obligations outlined in this report should be made available to fuel this debate:
 - flexible work arrangements and leaves ;
 - financial compensations and access to social rights;
 - access to respite care and psycho-social support.

To sickness funds, patients and informal caregivers associations and all concerned or competent authorities

- In order to improve the access to information, currently provided by multiple initiatives and sources, but insufficiently known, used or coordinated, a performing platform should be developed linking these different sources and identifying gaps.
 - The project should bring together all actors from the health and social care sector, from the associative world and from the federal and regional level. The Interministerial Conference could play a leading role, in line with the initiatives developed in the context of the care for chronic patients;
 - The project should create a centralised platform (web-based) that includes all relevant sources of information about practical aspects related to the informal caregivers role and about formal services, aids, advantages, etc available to fulfil their role;
 - Multiple "gateways" to access this platform should be envisaged and include the existing networks;
 - In order to ensure the readability of the information, professionals in the field of communication should be associated to the project.

^b The KCE has sole responsibility for the recommendations.



To professionals looking after dependent people who are cared for by informal caregivers

- The dependent person's care plan should include a section for the informal caregiver. The section should take into account the characteristics of the dyad (informal caregiver-care-receiver) and of their shared environment in order to support and recognise informal caregivers and to protect their needs and health. The care plan for the informal caregiver should be set up ideally in collaboration with the dependent person by a formal health or care professional or by a care coordinator. The professional involved in the care plan should be fully informed about the different services available. For highly dependent people, case managers or discharge managers could be involved in implementing this care plan;
- The above-mentioned professionals could also help informal caregivers to identify appropriate information and to coordinate health and social home care services required for each specific care situation;
- Respite, psychosocial support and training should be proactively proposed to informal caregivers. These services should be adapted to the needs and the preferences of informal caregivers and of dependent older people;
- Training programs should be integrated into the academic curriculum of health and social care professionals in order to promote a partnership with informal caregivers and to screen precarious situations where caring for a dependent older person may prove to be extremely difficult for informal caregivers.

Recommendations for further research

- Policymakers could better appraise care needs of dependent people and of their informal caregivers through the implementation of a database linking information on different cash-for-care allowances, on services in kind (formal health and care services) with care needs of dependent people, evaluated with appropriate tool such as the BelRai;
- To evaluate the functioning of different case management structures of health and social care services (case managers, discharge managers, SISD – GDT, CCSSD, SEL, etc.) and to evaluate their contribution in the care management for dependent older people and their informal caregivers.



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