

SUPPORT FOR INFORMAL CAREGIVERS – AN EXPLORATORY ANALYSIS



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GLOSSARY

WORD	DEFINITION	SOURCE
Informal caregiver	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. Informal care in this report does not include paid care work provided by people outside of the solidarity-oriented relationship. Also addressed as carer (OECD)	Escobedo et al.
Long-term care	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 or help with basic activities of daily living.	OECD
Domestic aid	Help with instrumental activities of daily living (IADL), such as using the telephone, shopping, food preparation, housekeeping, transportation, taking medication and financial administration.	Genet et al.
Personal care (services)	Providing assistance with dressing, feeding, washing and toileting, and getting in or out of bed.	Genet et al.
Technical nursing	Activities such as assistance with putting on prostheses or elastic stockings; changing stomas and urinal bags; help with bladder catheter/ catheterization; skin care; disinfection and prevention of bedsores; oxygen administration; and giving intravenous injections.	Genet et al.
Supportive nursing	Provision of health information and education.	Genet et al.
Dependent older person	Vulnerable elderly Individuals needing help with IADL or ADL activities on a long-term basis. The age threshold above which the vulnerable individual is considered as “elderly” may vary according to countries, age (60 or 65 years old) or be linked to access to benefits.	
Residential care	Facilities (or institutions) other than hospitals which provide	Genet et al.



	accommodation and a long-term care package.	
Home care	Care provided at home by professionals after a formal needs assessment. "Care" means domestic aid services, personal care and supportive, technical and rehabilitative nursing.	Genet et al.
Cash-for-care allowance	Include cash transfers to care recipients, the household or the family caregiver, to pay for, purchase or obtain care services. They can also include payments directed to informal carers Also addressed as cash-for-care benefits or cash benefits.	OECD
Caregiver allowance	Program typically providing a small stipend and not designed to compensate the family caregiver. They recognize family caregivers unpaid effort and stress.	Polivka
Rehabilitative nursing	Occupational therapy or physiotherapy.	Genet et al.
Community care	See home care.	

Source: Genet et al. (2011)¹, Colombo et. al.(2011)², Polivka (2001)³ and Escobedo (2004)⁴



LIST OF ABBREVIATIONS

ABBREVIATION	DEFINITION
ADL	Activities of Daily Living
AGGIR	Autonomie Gérontologique Groupes Iso-Ressources
APA	Allocation personnalisée d'autonomie
APA – THAB	Allocation pour l'aide aux personnes âgées – Tegemoetkoming voor hulp aan bejaarden
AWBZ	Algemene Wet Bijzondere Ziektekosten
BESADL	Belgian Evaluation Scale for Activities of Daily Living (adapted Katz scale)
CBGS	Centrum voor Bevolkings- en Gezinsstudie The survey Zorg in Vlaanderen is often referenced as the CBGS
CDV – CSJ	Centre for daycare – Centra voor dagverzorging – Centre de soins de jours
ECHP	European Community Household Panel Panel de démographie familiale Panel Studie van Belgische Huishoudens
FPS	Federal Public Service
GDT – SISD	Integrated Services for Home Care – Geïntegreerde Diensten voor Thuisverzorging - Services Intégrés de Soins à Domicile
GMD – DMG	Global medical record – Globaal Medisch Dossier – Dossier Médical Global
IADL	Instrumental Activities in Daily Living
LOVO	Leefsituatie Onderzoek Vlaamse Ouderen survey
LTC	Long-term care
LTCI	Long-term care insurance
NADES	The National Dementia Economic Study
NEO – ONEM – RVA	National employment office – Office nationale de l'emploi – Rijksdienst voor Arbeidsvoorziening
OCDE	Organisation for Economic Cooperation and Development
OCMW – CPAS	Public Centre for Social Welfare – Openbare Centra voor Maatschappelijk Welzijn – Centre Public d'Aide Sociale
PNG	New Care Guidance Law (Pflege-Neuausrichtungs-Gesetz)
RIZIV – INAMI	National Institute for Health and Disability Insurance – Rijksinstituut voor Ziekte- en



	Invaliditeitsverzekering – Institut National d'Assurance Maladie-Invalidité
ROB – MR	Elderly Care Homes – Rustoorden voor bejaarden – Maison de repos
RVT – MRS	Nursing home – Rust- en verzorgingstehuizen – Maison de repos et de soins
SCV-survey	Sociaal-culturele verschuivingen in Vlaanderen survey
SHARE	Survey of Health, Ageing and Retirement in Europe



■ SCIENTIFIC REPORT

How to use this document?

This Scientific Report is not intended to be read as a stand-alone document, but as a complement to the Synthesis of this study. It gives a detailed account of the methods and results of each of the scientific building blocks underpinning the messages rendered in the Synthesis.

The context, problem description, as well as the discussion of the results and the conclusions are to be found in the Synthesis.

The Synthesis is published as a separate document on our web site. It can be accessed from the same referral page as the current document.

1 INTRODUCTION

1.1 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)”.²

Long-term care (LTC) includes both formal and informal care.

Long-term care can be distinguished from **curative and rehabilitative health care** in that it aims at compensating for a lasting disability while the two latter aim at changing a medical condition.⁵ However in practice, the boundaries between long-term care, curative and rehabilitation health services can be blurred.¹

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.⁴ 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 emotional support, to personal care (e.g. bathing, dressing), to preparing medications, providing surveillance and managing and coordinating formal care services. There is not a single profile of informal caregivers as their role varies with the nature of the impairment of the dependent older person and according to their own characteristics.

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

Against this background, the KCE received different research proposals around issues concerning caregivers’ experience and the support measures existing for them. The support measures for informal caregivers go beyond the health care system. Providing informal care can have an impact on people’s labour market participation and as such, policy reforms in the employment sector may be needed to conciliate care and work responsibilities. In addition, during care periods, not paying social contributions may lead to losing social entitlements such as unemployment and pension benefits.

During the summer of 2013, the KCE set up an exploratory project to overview available measures to support informal caregivers.

1.2 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 generosity⁶ (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 four main research questions:



1. What are the support measures available for informal caregivers in selected countries? Is there information available at the national level on policy 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 has been 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?

1.3 Methods

In a first stage, a literature review was performed. Evidence at the national level on policy 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 separate structured review of the Belgian scientific and grey literature on informal caregivers' needs and experiences with policies was also performed.

In a second stage, 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 policies. 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 different chapter of this scientific report.

1.4 Structure of the report

The chapters of this report are structured as follows:

- Chapter 2 provides a broad overview of the results of studies regarding Belgian informal caregivers.
- Chapter 3 describes in detail policy measures to financially and psychologically support informal caregivers in a selection (i.e. Belgium, France, Germany, The Netherlands and Luxembourg). The chapter also includes and discussion on uptake and cost policy of policy measure and to their impact on caregivers.
- Chapter 4 provides empirical evidence on the effects and experiences regarding policy measures among 37 informal caregivers living in the different countries included in the international comparison.



2 RESEARCH ON CAREGIVERS IN BELGIUM

Relevant literature on provision of informal care and its consequences on the lives of informal caregivers can be found in different fields including economics, sociology and medical sciences. The aim of this section is to provide a broad overview of the results of studies regarding Belgian informal caregivers. As the studies are heterogeneous and seldom provide information exclusively for caregivers of older people, general trends were identified. European studies have tried to provide a similar overview. However, Belgium was never included.^{7,8}

In order to provide the most complete overview, studies on the impact of providing informal care among Belgian caregivers were identified via a two-step procedure. First, websites from tertiary education institutions were searched using one of the following key terms: informal care, care, caregiver, *mantelzorg*, *aidant proche* and *aidant informel*. This allowed us to identify both publishes articles in national and international journals as well as research reports (grey literature). Criteria for inclusion included availability of information on socio-economic characteristics of informal caregivers and the impact of care activities on informal caregivers' health, labour market participation and income. Moreover, studies regarding informal care in residential setting were not included. Second, two Belgian experts reviewed the list of publications identified in the first step in order to verify that relevant studies were included. The Appendix 1 in the report supplement includes a detailed description of selected studies.

We focused on studies and reports published after 2005. Whenever results from recent publications were based on earlier reports, reference to the original source was mentioned.

2.1 Surveys identified used in studies on informal care in Belgium

Eleven national surveys were identified from the review of Belgian studies on informal care. Six out of the eleven national surveys provide information on informal care based on national or regional representative population samples (Panel Study of Belgian Households (PSBH)^a, Socio-Economic Survey of 2001 (SEE)^b, Living conditions of Flemish elderly (LOVO_1)^c, Care in Flanders (CGBS)^d, and the 2008 and 2011 Socio-cultural changes in Flanders (SCV)^e). All regional surveys cover Flemish municipalities. These surveys can be used to assess prevalence of informal care in the general population.

In addition to the national surveys, three European surveys also provide information of informal care (the Eurobarometer 2007, the European Community Household Panel (ECHP 1994-2002) and the Ageing and Retirement in Europe survey (SHARE 2004-2012). The PSBH was integrated according to the standards of the European Community Household Panel (ECHP) since its third wave.⁹ The PSBH includes more questions than the standard ECHP questionnaire. In order to avoid repetitions, only the PSBH characteristics are discussed. Information based on the SHARE survey and on the Eurobarometer is presented in Chapter 3 along with the description of policy measures for informal caregivers in Belgium, France, Germany, Luxembourg and the Netherlands.

^a In French "Panel de démographie familiale" in Dutch "Panel Studie van Belgische Huishoudens"

^b In French "Enquête socio-économique" in Dutch "Socio-economische Enquête"

^c In Dutch "LeefsituatieOnderzoek Vlaamse Ouderen".

^d In Dutch "Zorg in Vlaanderen". The survey is often referenced after the institution who made it (In Dutch "Centrum voor Bevolkings- en Gezinsstudie" survey –CBGS).

^e In Dutch "Sociaal-culturele verschuivingen in Vlaanderen".



Five more surveys provide additional information on informal caregivers only. Two caregiver self-identification surveys Informal care in Flanders (in Dutch “*Mantelzorg in Vlaanderen*”) and Listening to caregivers to better support them (in French “*Ecouter les aidants proches pour mieux les soutenir*”) provided information on registered informal caregivers at the Flemish care insurance and on informal caregivers in Wallonia. Two additional disability based surveys provide information on caregivers from individuals suffering from dementia (The National Dementia Economic Study (NADES) and the Qualidem study). The Qualidem study elaborated consensus guidelines related to the support of caregivers caring for older persons suffering from dementia. The guidelines are developed through systematic literature review, expert review, feasibility check in practice and validation by a steering group. The NADES study assesses the socio-economic consequences of dementia in Belgium. The functional status of 140 community dwelling patients was recorded and analysed. Finally, the survey from the Flemish Elderly care study (in Dutch “*Vlaamse Ouderen Zorg Studie*”) (VOSZ)) provides information on the characteristics, the care experiences and the needs of informal caregivers of frail elderly people. The study contains data from the period 2009-2010 for a sample of 487 elderly and 320 informal caregivers. Results based on caregiver’s surveys should be analyzed taking into account whether the sample focuses on a specific group (e.g. caregivers from adults with dementia or highly involved caregivers only) or whether it provides a wide perspective on multiple situations faced by caregivers. In addition, it may be possible that caregivers who face the most care demands may be more likely to participate in the survey as a way to express their needs. For instance, Heylen and Mortelmans (2006)¹⁰ pointed out that when comparing people looking out for ill individuals in a population based survey (Care in Flanders) vs. those in participating to the caregiver survey in Flanders (Informal care in Flanders), a higher proportion of highly involved caregivers was found in the former than in the latter. Yet the opposite also holds as highly involved caregivers may be too busy (or too tired) to participate in such a survey. This could be particularly the case for informal caregivers of older people who tend to be older themselves and older people are less likely to participate in surveys. Finally, as for all surveys participation rate may be related to socio-economic factors, as it has been shown that persons with higher socio-economic status are more likely to

participate in different type of studies.¹¹ Because these surveys provide information among informal caregivers only, the data available cannot be used to assess socio-economic differences between caregivers and non-caregivers in the general population. **Informal care in Belgium: results from representative population based survey**

Estimations of the number and of the characteristics of informal caregivers are in the heart of the debate whenever discussions on interventions are put forward in the policy agenda. The availability of national surveys estimating the prevalence of informal caregiving in the general population and the consequences of the care tasks on their daily life is certainly a point of concern. However, national surveys usually have different approaches to ascertaining the number of informal caregivers, concerning the definition of the care tasks and of the intensity of the care provided.

Several authors have tried to compare results on the prevalence of informal care from different surveys.¹²⁻¹⁴ In this section, we build on their efforts and differences and similarities from the different national surveys are appraised based on Giovannetti et al. (2010)¹⁵ framework for the classification of representative, population-based surveys on informal care. This framework allows understanding how survey characteristics influence estimates on the prevalence of informal care and on the intensity of the care provided.

2.2.1 Characteristics of national or regional representative population based surveys

The sample frame for all surveys is based on addresses extracted from the national registry. Only the SCV surveys provide data on informal care after 2005. In all surveys, informal care is considered outside the scope of the work related environment (non-paid activity) or as voluntary work (except for the Census 2001 where the latter is not explicitly mentioned).

In all the surveys, individuals are asked whether they provide care to individuals suffering from an illness or disability. Three surveys also mention “old age” along with illness or disability as the reason why care is provided (PSBH and the two SCV surveys). In addition, three surveys asked participants whether they received informal care themselves and who provided it (PSBH, LOVO_1 and CGBS). Five out of the six surveys provide information on the link between the caregiver and care-receiver as



well as on whether they share the same household. None of the surveys restrict the care provided to individuals living in the community.

Four surveys addressed young adults (broadly aged 15 years or older), adults and older people (PSBH, Census (2001) and the two SCV surveys). Only LOVO_1 and CBGS limited the population in the survey to older people and to adults of working age, respectively.

The biggest differences between the surveys rely on the definition of the care provided (based on the need for help of the care-receiver), of the reference period over which care has been provided and of the intensity of the care provided. First, only four surveys define the type of care provided in terms of specific activities of daily living (ADL) and of instrumental activities of daily living (IADL) (PSBH, LOVO_1, CBGS and SCV of 2011) and categories defined for ADL/IADL identification are not homogenous. Giovannetti et al. (2010) separated in their analysis the definition of disability from the care provided by informal caregivers. However, in the Belgian surveys both notions are confounded. Second, intensity of care is also measured using multiple definitions that vary from the number of hours of care per week, to the number of ADL/IADL tasks or the number years since care has been provided (see exact definition in (Table 1). Third, based on the available variables on the care intensity, studies provide different definition for highly and less involved caregivers. Finally, four surveys included “the last twelve months” as the reference period during which care has been provided. This does neither imply that informal care has only been provided during the last year not that is has been a permanent activity during the last twelve months. Only the CGBS includes a concept of long-lasting care provision, as informal care should have been provided in relation with a care need that has lasted for more than a month. Overall, given that the Belgian surveys use different definitions of informal care and target different populations direct comparisons of results should be performed with caution.

Box 2 Elements that need to be taken into account to obtain greater consistency in the measurement of informal care

Consistent estimates on the prevalence of informal care are needed in order to monitor the consequences of looking after dependent people and to implement policies to support them: The following elements may influence in different ways the estimates on informal care obtained from different surveys:

Type of survey: Compared with health and care surveys, general surveys often include a large number of questions on multiple topics of which few tackle health and informal care issues. Respondents may overlook health and care questions and therefore may fail to identify themselves as caregivers. Therefore, general surveys may yield in lower prevalence estimates of informal care than health and care surveys.

Caregiver identification protocol: How the informal caregiver is identified (e.g. self-identification vs. identifies by the care-receiver) may influence prevalence estimates, but also the measures on the level of their overall involvement in the care provided. For instance, compared to caregivers extracted from a population based survey, those recruited via a caregiver association are more likely to provide more hours of care.

Criteria to define caregiving and/or disability: Multiple criteria are used to define caregiver’s involvement and may influence in opposite ways prevalence estimates. Without a detailed definition *on the type of help provided (ADL or IADL activities)*, some people may fail to recognize themselves as informal caregivers (e.g. providing guidance). Therefore, prevalence of informal care may be underestimated. Without a clear definition of *the reference period and the reason for assistance* (when and why does the care period start), people may confound informal care tasks with previously provided normative assistance (e.g. division of household chores before that the care-receiver became dependent). In return, this may lead to overestimate the prevalence of informal caregivers or the intensity of the care provided.



In order to fully assess the **intensity of the care** provided multiple measures may be needed. This is due to the fact that the caregiving process (and its burden) depends of multiple factors that cannot be solely measured by the time spent caring. The type of activities performed (e.g. personal care, surveillance, coordination of care) as well as psychosocial conditions will determine the overall care load

Table 1 – Representative, population base surveys containing information on informal care in Belgium

	NATIONAL			REGIONAL		
	PSBH ¹ (1992-2002)	SEE ² (2001)	LOVO_1 ³ (2001)	CBGS ⁴ (2003)	SCV ⁵ (2008)	SCV ⁵ (2011)
Type of survey	<i>General survey</i> on socio-demographic characteristics and living conditions of the population	<i>General survey</i> on socio-demographic characteristics and living conditions of the population	Collecting information on the daily life of the elderly population	Collecting information on different aspects of health and care in the population	Collecting information of values and attitudes of Flemish people regarding social policy issues	Collecting information of values and attitudes of Flemish people regarding social policy issues
Survey design						
• Survey design and mode	Longitudinal panel, face-to-face or self-administrated questionnaire	Cross-sectional, self-administered questionnaire	Cross-sectional	Cross-sectional, self-administered postal questionnaire	Cross-sectional, face-to-face administrated questionnaire	Cross-sectional, face-to-face administrated questionnaire
• Sample frame	National registry	National registry	National registry	National registry	National registry	National registry
• Sample Units	Individuals and households	Individuals and households	Individuals	Individuals	Individuals	Individuals
• Sampling design	Two-stage sampling with municipalities systematically selected within each of the 275 clusters and addresses of heads of households selected within each cluster	Total resident population	Representative sample of Belgian elderly aged 50-90 years old living in Flemish municipalities	Population-based stratified sample according to Dutch speaking Belgians according to province, urbanization, gender and data of birth	Population-based representative sample of Dutch speaking Belgians in Flanders and Brussels	Population-based representative sample of Dutch speaking residents in Flanders and Brussels



	NATIONAL			REGIONAL		
	PSBH ¹ (1992-2002)	SEE ² (2001)	LOVO ¹³ (2001)	CBGS ⁴ (2003)	SCV ⁵ (2008)	SCV ⁵ (2011)
Caregiver identification protocol						
• Who identifies the caregiver	Informal caregiver or care-receiver	Informal caregiver	Informal caregiver or care-receiver	Informal caregiver or care-receiver	Informal caregiver	Informal caregiver
• Who is interviewed	Informal caregiver or care-receiver (not necessarily linked to each other)	Informal caregiver	Informal caregiver or care-receiver (not necessarily linked to each other)	Informal caregiver or care-receiver (not necessarily linked to each other)	Informal caregiver	Informal caregiver
• Population from which the care-receiver is dawn	Elderly, sick or disable people	Individuals suffering from an illness, ailment or permanent disability	Individuals aged 55-90 years reporting needing help to carry some tasks	Ill, disable or individuals intensity of the care in need of care for at least one month	Ill, disable or older people	Ill, disable or older people
• Population from which the caregiver is dawn	Individuals aged 16 years or older	Individuals aged 15 years or older	Individuals aged 55-90 years	Dutch speaking Belgians living in Flanders aged 25-64 years	Dutch speaking Belgians living in Flanders and Brussels Individuals aged 18-84 years old	Dutch speaking residents of Flanders and Brussels Individuals aged 18 years or older
Criteria to define caregiving and /or disability						
• Activities of daily living (ADL)	Personal care, help to eat or drink,	-	Dressing, bathing, feet care	Help with eating, dressing, and bathing, using toilets or incontinence equipment.	-	Go outside the household, moving around in the house, dressing and bathing
• Instrumental activities of daily living (IADL)	Hot meals, medication, laundry, domestic aid	-	Prepare warm drinks, prepare meals, doing light housework, doing heavy housework, cleaning clothes, ironing, taking out the garbage, shopping, managing household tasks, gardening and administrative work bringing garbage tasks and doing shopping	Medication, house cleaning, cleaning clothes, domestic animals care, shopping, task inside and outside the household, preparing meals and cleaning , organizing	-	Doing light housework, doing heavy housework, doing administrative tasks and doing shopping
• Support	Listening to the care-receiver problems	-		Listening, support, transport or guidance for doctor appointments, family visits, shopping	-	Transport or guidance for doctor appointments, emotional support and taking care or provide supervision



	NATIONAL			REGIONAL		
	PSBH ¹ (1992-2002)	SEE ² (2001)	LOVO_1 ³ (2001)	CBGS ⁴ (2003)	SCV ⁵ (2008)	SCV ⁵ (2011)
• Reason for assistance	Because of old age, illness or disability (without pay and not voluntary work)	Because of illness, ailment or permanent disability	Carrying specific activities with the help of a third person	Because of illness, disability, old age care was provided for at least one month (without pay and not voluntary work)	Because of illness, disability, old age	Because illness, disability or old age (without pay) and not voluntary work
• Intensity of informal care	Total number of hours of care per week	At least once a week (but not every day) Every day: Less than 30 min More than 30 min but less than 2 hours More than 2 hours but less than 4 hours More than 4 hours	Care-receiver responds: not precisely defined ("usually") when the Caregiver: Regularly, occasionally, rarely or never	Frequency was measured for each task Once or more a week Once or more a month One or several times in the last 12 months	Never Once a year Several times per year Monthly Several times per month Weekly Daily	Number of years that care has been provided
• Reference period	-	-	Last 12 months	Last 12 months (but care need lasted for more than a month)	Last 12 months	Last 12 months
Definition of the caregiver and care-receiver relation	Member of the household (yes/no) Partner, parent(-in-la), other family member or person outside the family for non-cohabitant children	Member of the household, family member outside the household or friend or neighbour	Partner, daughter (in-law), son(in-law) or grand-children	Member of the household, family member outside the household or friend or neighbour	-	Partner, parent(-in-la), grand-parent, sister or brother (in-law) other family member or not related Distance between the care-giver and care-receiver residence
List of publications using the data	13, 16-18	19-22, 23, 24	25-27	28, 29-32	14	33

Source:¹ PSBH: Panel Study of Belgian Households, ² Socio-Economic Survey of 200, ³LOVO_1 Living conditions of Flemish elderly, ⁴CBGS: Centrum voor Bevolkings- en Gezinsstudie, survey Care in Flanders, ⁵SCV: Socio-cultural changes in Flanders survey.



2.2.1.1 *Prevalence of informal care based on population based surveys*

According to the 2001 SEE data, almost one out of ten (9.4%) Belgian residents aged 15 years or older provides informal care.^f Approximately half of the caregivers responded that care was provided every week but not on a daily basis. Deboosere et al.¹⁹ argue that some regional differences exist, with a lower proportion of informal caregivers in Flanders (8.8%) than in Wallonia (10.4%) and Brussels (9.6%). Results based on the 2001 SEE, are the only ones available for all of Belgium.

Several surveys have tackled the provision of informal care among Flemish speaking Belgians residing in Flanders (in some cases also of those living in Brussels).^{14, 30-33} Based on the LOVO_1 survey, Vanderleyden (2006)³⁴ reported that 26% of Flemish adults aged 55 years to 90 years provide informal care. Among the population of working age (25-64 years), the survey "Care in Flanders" is used to provide estimates on prevalence of informal care according to the caregivers care load (the number and the type of tasks performed).^{28, 29, 32} According to Vanbrabant and Craeynest³⁵, almost two thirds of the respondents are involved in care activities. They estimated that 19% of the respondents are highly involved in the care provided to an ill person. Less involved informal caregivers account for 45% of the respondents.³⁵ Finally, according to data from SCV of 2008, almost one out of five (18.0%) Dutch speaking Belgians in Flanders and Brussels aged 18 to 90 years provide care on a daily or weekly basis.¹⁴ Estimates based on the SCV survey of 2011 are even higher, with almost one out of four (23.4%) of the respondents having provided informal care during the last 12 months.³³

Different studies use different definitions of informal care and target different populations, therefore direct comparisons of results are not appropriate. For instance, the SCV of 2008 and 2011 used different definitions of informal care (that of 2011 being broader than that of 2008), therefore it cannot be concluded that the proportion of informal caregivers increased between 2008 and 2011. The prevalence for 2008 includes

individuals providing care on a regular basis (weekly or daily) and the prevalence for 2011 includes all individuals having provided care in the last twelve months. Vanderleyden and Moons (2012)³³ also reported different prevalence estimates for 2011 when they included people currently providing care or people having provided care in the last twelve months. All studies showed that the provision of informal care is not a rare (isolated) phenomenon. However, a perspective on the evolution of care activities is missing. Lack of a single definition for informal care represents a challenge when attempting to compare estimates based on the different sources. The prevalence estimates based on the 2001 SEE seemed to be in general lower than those of other studies. This may be related to the fact that in this general survey, people looking after a relative or a friend may fail to identify themselves as caregivers.³⁶ On the contrary, the CBGS, the LOVO_1 and the SCV of 2011 surveys target health and care related issues, defining a subject area more clearly for the respondents. Therefore, smaller differences in prevalence estimates among these surveys were found.

2.2.1.2 *Are the socio-economic characteristics of informal caregivers different from that of non-caregivers?*

In this section, we focus on whether consistent trends regarding the characteristics of informal caregivers and the impact of informal caregiving can be identified in the Belgian literature. This type of analysis was chosen over a direct comparison of estimates as the latter may prove to be uninformative. Indeed, discrepancies in estimates do not reflect errors relating to how informal care is measured but rather differences in the scope on what informal care is. Moreover, existing trends identified in the different studies provide an interesting insight to the association between socio-economic characteristics (namely education and employment) and the provision of informal care. However, the cross-sectional nature of these data cannot disentangle the causality between socio-economic characteristics (such as education or employment) and caregiving.

^f For this section a detailed table is available in the Appendix 1 in the report supplement



Gender and age

Three main and consistent trends were found in all studies. First, all studies reported that the proportion of caregivers is higher among women than among men, in particular among people who provide care on a regular basis.^{14, 19, 33, 37} For instance, according to the 2001 SEE data, the proportion of women and men aged 45-64 providing care amounts to 16.4% and 10.3%, respectively. Second, the relationship between age and the proportion of people who provide care on a regular basis follows an inverted U-shaped pattern.^{14, 19, 22, 33, 34, 37, 38} The proportion of caregivers increases with age to attain a record high among middle-aged adults (often around the age category comprehended between the 45 to 64 years old) and then decreases in the older age groups. The inverted U-shaped pattern might be related to a higher demand for care from dependent older people to their middle-age family members (in particular from adult children). In line with this, Bracke et al. (2008)¹⁶ pointed out that working age women and men are more likely to care for their parents, as they get older. Vanderleyden et al. (2012)³³ also reported that a large proportion of informal caregivers report caring for their parents because of old age disability. Adult children play an important role in caring for their older parents, however among older married couples, the main informal caregiver is usually the partner.³⁹ Two studies^{19, 34} depicted a small nuanced in the gendered picture of care as the proportion of caregivers is higher among men than among women in the older age groups. Third, compared to men a higher proportion of women provide care outside the household.^{19, 28, 33}

Education and labour force participation

Differences in labour force participation between caregivers and non-caregivers may be closely linked to differences in work patterns between men and women, with opportunities for early retirement and for part-time work. Moreover, two different situations must be considered: i) How does labour market participation influence individual choices when people face care demands? ii) How do care demands affect individual choices concerning their labour market participation? For education, multiple questions can also arise: i) Does education attainment determine whether to provide care? ii) Does education attainment determine how individuals

will face care demands? While cross-sectional data⁹ from studies included in this chapter cannot provide a definite answer to these questions, some important findings must be mentioned.

Three studies found that caregivers are more likely to be economically inactive individuals than non-caregivers.^{14, 19, 33} In contrast to this result, Heylen and Mortelmans (2006)³⁷ argue that after controlling for all socio-economic characteristics, no differences remain in the association between labour market participation and caregiving among Flemish people aged 25-64 years.

As with labour market participation, the association between education attainment status and the provision of informal care follows a puzzled structure. Deboosere et al. (2006)¹⁹ reported that compared with people with low education attainment, people with higher education attainment are more likely to provide informal care. Yet, after controlling for all socio-economic characteristics studies based on CBGS¹⁰ and on the SCV surveys^{14, 33} provided a more nuanced picture as no statistical significant association was found between the education attainment and the provision of informal care.

More consistent results were found when the association between level of involvement in care activities and education attainment or labour market participation were analysed. Compared with less involved caregivers, highly involved caregivers (as defined by each study) are more likely to have a low education attainment and to be economically inactive.^{10, 14, 19, 35}

⁹ Masuy (2009)¹⁷ builds on these issues using a pooled sample of women from the European Community household Panel (including Belgium). However, estimates for Belgium were not reported.



2.3 Caregiver's experiences and impact of caregiving

2.3.1 *Are there difference in the socio-economic characteristics of highly and less involved caregivers among informal caregivers?*

In both the *Informal care in Flanders* and in the *Listening to caregivers to better support them* surveys, the majority of respondents are women. Results based on both surveys are in line with three main findings from population based survey as highly involved caregivers are more likely to be women, to have a low education attainment and to be economically inactive. In addition, Casman et al. argued that compared with caregivers reporting not having financial problems, those who reported being in a difficult economic situation spend more time looking out for a dependent individual, provide almost all personal and domestic care, report being more often depressed and needing respite care.^{10, 40}

2.3.2 *Caregiver burden and the impact on the subjective health of the caregiver*

The caregiver burden can be described as the perceived impact of caregiving on the caregiver's physical, psychological, social and/or financial status. Studies show that, overall, caregivers report to experience a high burden²⁹, with even higher scores in caregivers taking care of persons with dementia.^{41, 42} The care burden is predicted by the way caregivers perceive their caring role, deal with problematic situations and experience feelings of control and depression rather than the objective workload.⁴¹ Care receiver characteristics can also impact the perceived burden of care. Yet, for older people with dementia, the level of cognitive impairment seems to have a more moderate impact than the functional level.⁴³ Although burden in dementia caregivers is an important motivation for institutionalisation, the unmanageable behavioural disturbances are the main reason for the final decision to institutionalise the elderly.⁴⁴ Apart from caregiver and care receiver characteristics, a good relationship between both is of primordial importance for the perceived burden of care. People with dementia or older persons with depressive symptoms as well as their informal caregivers experience in general a warm, reciprocal relationship.^{45, 46} In population studies, a higher care burden is most often associated with providing more care tasks and is most often present

among partner caregivers than among other caregivers.³³ In addition, compared with less involved informal caregiver, highly involved informal caregivers tend to report being in poor health.^{19, 21, 22, 34}

Caregiving places a heavy burden on the general health of caregivers, particularly on mental health.⁴⁶ Caregivers suffer more frequently from depression than the general population of the same age.⁴¹ The prevalence of depression is even higher for caregivers taking care of persons with dementia than the caregivers of other chronically ill relatives and non-caregivers.^{43, 44} The impact of dementia on the caregiver is associated with the characteristics of the person with dementia, the characteristics of the caregiver, the relationship between them, contextual factors such as the financial situation and the social network and characteristics of the professional care situation.⁴⁷ Rather than objective characteristics and the mental and physical state of the person with dementia, however, heavy burden, low problem solving coping behaviour and high emotional coping behaviour of the caregiver are associated with an increased risk for depression.⁴¹

The care burden can also have an impact on the physical health of the caregiver, in particular for older caregivers with an already weakened health status. The interruption of sleep or physical efforts related to the washing, clothing and lifting of the elder can lead to physical complaints.⁴⁸

2.3.3 *Perception of positive and negative care experiences*

Caregivers experience positive as well as negative aspects related to the caregiving. Both positive and negative feelings are more frequent when caregiver and care receiver are cohabiting. Although the overall care experience is specific for each situation and each individual caregiver, in general positive feelings are relatively more experienced than negative feelings.^{46, 49} Caregiving gives sense to the caregivers' life.³⁶ Moreover caregivers reveal to have discovered their "strong capacities", are more confident in the contact with others, feel closer with the family and experience a closer relationship with friends. Most of them feel useful in the relationship with the elder and appreciate the company of the elder.

Feelings of dependency towards the elder, expressed in less contact with family and friends, is the most important negative care experience in general and is more present with caregivers cohabiting with the care receiver, caregivers taking care of older people with dementia, in case of



high need for assistance in daily life activities and in case of decreasing social contact of the caregiver. Caregivers also experience stigma, disturbing behaviour of the elder, negative effects on family life and problems with professional help. Furthermore, caregivers also deal with feelings of uncertainty related to the financial consequences if the elder's situation gets worse and with the prospect of bereavement.

2.3.4 *Perceived needs and expectations of caregivers*

Caregivers' needs cannot be summarised in a general and exhaustive list. Depending on different aspects such as the specific care situation and the intensity of care, the caregiver and the elder's characteristics, needs vary. In general, needs and expectations of caregivers are related to information and advice, emotional support, practical or instrumental support, material or financial support, social support or network, respite care and self-care.⁴⁷

2.3.5 *Information needs of caregivers*

Information needs primarily relate to the care receiver's illness or the health status and its evolution, practical issues and financial rewards.⁵⁰ Only a minority of the caregivers express the need for information or education regarding the relation and the care for the elder.⁴⁶ The information need is in general higher in the beginning of the care process, when the care situation of the dependent older person or the caregiver changes or in case of changes in legislation on financial awards or changes in the offer of services.

Expectations on the type of information differ according to the person or organisation intervening in the care process.³⁸ Since the social services of hospitals and the 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 health status and its probable evolution, to refer to relevant information sources and to help with the composition of the dossier needed to get financial rewards. Sickness funds are expected to provide information on services they offer and on financial rewards whereas home nurses are primarily supposed to provide practical caring information. From the government side, caregivers expect information on rewards.³⁸

Barriers and possible success factors related to information transfer are linked to different dimensions: the characteristics and situation of the information provider, the format and content of the message, the information channel and the situation of the receiver.^{38, 50} The socio-economic characteristic of informal caregivers are also associated with needs for information. Caregivers in a financially difficult situation report need more information on legal aspect as well as the formal services available.⁴⁰

Experiences with the information provision of the different players are mixed and highly depend on the knowledge and awareness of the respective information provider.

Information obtained during peer groups meetings is highly appreciated and is estimated to be correct and to the point. Caregivers suggest to organise these meetings regularly and not only in the evening.

The perceived quality of the information depends on the complete, relevant, specific and correct character. Yet, written information is often experienced to be too difficult. Caregivers stress the necessity of being proactively informed instead of a search by themselves, which is experienced as a heavy burden. The lack of home visits is often cited. Caregivers also report to be not aware where to get the information. Information is often provided by different players involved in the care process for the care receiver, though centralisation is lacking. Caregivers' suggestions regard a central information point, a central telephone number and the diffusion of information via diverse channels such as newspapers, regional/local gazettes, television, etc. Internet was seldom used by the older caregivers.^{38, 50}



2.3.6 Needs and expectations with regard to professional help and respite care

Caregivers of people with dementia or older persons with depressive symptoms frequently express the need for more modalities of respite care and home care.⁴⁶ Yet, in practice, they rather feel reluctant to appeal for professional help, often appealing to respite care in an ultimate stage or in a critical moment in the care situation and experience a higher burden if they use help.^{47, 51} From a trial conducted by Schoenmakers et. al. it appeared that carers are sufficiently surrounded by professional support, but want to feel more supported.⁴² Needs for respite care are also often mentioned among caregivers of non-demented people.⁴⁰

Barriers for the use of professional help relate to psychological aspects and attitudes of care receivers and caregivers as well as to the organisation of professional help.⁵² Resistance of the care receivers stems from the idea that care should be based on family solidarity, the feeling of loss of privacy and independency and the difficult acceptance and feelings of shame.⁵³ Some caregivers expressed that formal services are not used because the care-receiver does not want to.³³ Caregivers also experience feelings of guilt towards the care receiver or feelings of not complying with social expectations. Organisational aspects hamper the use of professional help as well. The lack of knowledge or information on the services, the lack of a diagnosis, the financial accessibility, the eligibility procedures (miscalling of the needs, the burden of the administrative procedures) and physical elements (e.g. no transport to the day centre) are mentioned as hindering factors. Input from third parties, such as professionals or relatives providing information on professional help or working on the elder can help overcoming the barriers.

The perceived quality of professional help is determined by the financial and informational accessibility, the availability in terms of quantity and continuity. Furthermore, reliability, limited variation in care providers, respect for structure and timing aligned to the care receiver's home situation and the skills and competences of the help providers play a role. Caregivers also report the need to participate and to be recognised as a partner in care.⁵³

For residential respite care, such as revalidations centres, the presence of the partner, the distance from home, the organisation of exercise enabling the independency at home are the most important, native speaking personnel, revalidation support, physiotherapy and equivalent care to hospital care are crucial factors. Moreover, there is substantial need for preliminary advice on the offer and practical information from the general practitioner or the social service of the sickness fund.⁵⁴

2.3.7 Needs for recognition

Caregivers express the need for a reward from the care receiver, mainly in terms of appreciation or gratitude and to a minor extent financial rewards or small gifts. Rewarding of informal care in general is perceived as more likely if the caregiver cohabits with the care receiver whereas, the need for a financial reward is most expressed by caregivers caring for a parent. Practice seems to be consistent with the expectations.³⁰ Financial rewards are more present in care situations where the caregiver and the care receiver cohabit and in the care for a parent or another sibling. This is not to be interpreted as a marketing of care, however, but rather as a contribution on household charges or a general compensation for the care.³⁰

Rewards for the caregiver from the government are embraced by almost all caregivers. A large majority prefers financial rewards.²⁹ In practice, however, solely the local/provincial caregiver allowance is directly paid to the informal caregiver. Informal caregivers appreciate this kind of rewarding but it is not a driver to be a caregiver.⁵² Yet, caregivers in the working population claim to be more often involved in informal caregiving if it was financially rewarded.³⁰ The Flemish Care Insurance contribution was primarily introduced to enable dependent older people to cover the non-medical costs, such as the support by the informal caregiver. However, the financial rewards from the Flemish Care Insurance, being paid to the care receiver are likely to be transferred to the informal caregiver to a very limited extent.³⁰ This finding is confirmed by a study of the *Hoger Instituut voor de Arbeid*: only 20% of the people benefiting from the Flemish Care Insurance allowance financially compensate the caregiver.⁵⁵ It has to be noted, however, that caregivers who live together with the dependent elder will often benefit indirectly from the allowance as it will be added to the household budget.⁵⁶ Overall, the Flemish Care Insurance mainly impacts



the subjective feeling of financial security. There is hardly an increase, however, in the provision of formal and informal care due to the allowance of the Flemish Care Insurance.⁵⁵

2.3.8 *How to support caregivers?*

There is no magic solution with regard to the support of the caregiver. As the components of the care burden are multifactorial and thus depend on the individual situation, a generic approach is not feasible. Furthermore, care needs are not always made explicit by the caregiver or are not clear for the caregiver him- or herself. Therefore, primary care providers as they are often aware of the particular care situation, have the task to assess the care needs of both the caregiver and the care receiver⁴⁶ The use of an instrument for needs assessment can be a step forward to the explicit a systematic needs assessment and support of caregivers.⁴⁸ The BelRAI, a web based system for needs assessment that is currently tested for implementation by the Federal government could play a role in the future. The evaluation of the care situation is rather independent of the discipline, as long as the health care professional is skilled in communication techniques and is sufficiently familiar with the particularities of the care burden for caregivers for demented elderly. Furthermore, if the assessment is done by different health care providers, it is important that information is coordinated.⁴⁷

3 INTERNATIONAL COMPARISON OF SUPPORT MEASURES FOR INFORMAL CAREGIVERS IN BELGIUM

3.1 Introduction

This chapter aims at providing a detailed description of policy measures to support informal caregivers in a selection of European countries. To have a sound understanding of the background in which informal care and its policy measures are imbedded, a description of the organization and financing of long term care in general is provided (section 3.3). Then an overview of the main characteristics of informal caregivers in the selected countries is described (section 3.4). The policy measures for informal caregivers are described in sections 3.5 and 3.6. Finally, Information on policy measures with respect to their uptake, cost and their impact is discussed in section 3.7.

3.2 Methods

The country selection for the international comparison was based in one recent typology developed in the Assessing Needs of Care in European Nations study (ANCIEN).⁶ Kraus et al. classified the long-term care system based on its organizational structure and on the level of financial generosity (see Box 4).

According to this classification, countries sharing similar characteristics over these two aspects include Belgium, Denmark, France, Germany, the Netherlands and Sweden. These countries combine profound organizational depth as well as a high level of financial generosity. To avoid language barriers during the search for information, Denmark and Sweden were not included for further review. In addition to the already selected countries (Belgium, France, The Netherlands and Germany), Luxembourg was also included in the sample because a recent report on the performance of the long-term care system was identified.⁵⁷



Box 3 – A typology of long-term care systems in Europe

Within the ANCIEN study, which looked at 21 countries, the long-term care (LTC) system characteristics were summarized under the headings ‘organizational depth’ and ‘financial generosity’.

Organizational depth represents the way the system is organized as was defined using 6 variables: accessibility of care (means-testing access and entitlements), availability of cash benefits, the freedom that patients have to choose and organize their care (choice of provider), rules for quality insurance of formal care providers and integration/coordination of long-term care services.

Financial generosity takes into account public expenditures for LTC as a share of GDP and cost sharing. Public expenditures for LTC as a share of GDP can be seen as a measure of the generosity of an LTC system. The more a country spends on LTC, the more services and service capacity are hypothetically available. Cost sharing describes the financial burden of private households/care recipients for LTC services.

Source: Kraus et al. (2010)⁵⁴

A classical research for information was performed using a three-step analysis:

- First, we searched for projects financed by the European Commission and the OCDE on informal care or on the long-term care system for dependent older people. Based on these reports, the macro and institutional context in which support measures are implemented in the different countries was established (see Appendix 3 in the supplement for a list of the projects identified). A list of benefits (in cash and in kind) for caregivers was set. National authorities’ websites were visited to validate and to update information up to August 2013.
- Second, in addition to projects identified in the first step, national authorities’ websites were searched to identify evidence on uptake, expenditure in programs to support informal caregivers and on evaluation on national/regional level for informal caregivers.

Simultaneously, a scoping review in Ovid Medline and Econlit was performed (see Appendix 3 in the supplement).

- Third, information collected in the two first steps was validated by national experts (see Appendix 3 in the supplement).

3.3 Who is involved in financing formal services for long-term care?

Although this study focuses on informal care, it is important to frame it within long-term care and to distinguish it from formal care. Thus, this section will start with clarifying these concepts. On the other hand, the discussion of benefits for informal caregivers cannot take place without a general understanding of how long-term care is designed in each country. Therefore, in this section, a general overview of actors involved in financing formal services in each country is also provided. We specifically aim at identifying how the articulation between budgets from the health, long-term care insurance and social care sectors cover formal services, in particular for home care services. Benefits for caregivers will be discussed in detail in the remaining sections of the chapter.

Box 4 – Terminology used for home care services

Home care: care provided at home by professionals after a formal needs assessment. “Care” means **domestic aid services, personal care and supportive, technical and rehabilitative nursing**. Care provided at home is also addressed as community care.

Domestic aid: help with instrumental activities of daily living (IADL), such as using the telephone, shopping, food preparation, housekeeping, transportation, taking medication and financial administration.

Personal care services: providing assistance with dressing, feeding, washing and toileting, and getting in or out of bed. Personal care is sometimes addressed as nursing care.

Supportive nursing: provision of health information and education.



Technical nursing: activities such as assistance with putting on prostheses or elastic stockings; changing stomas and urinal bags; help with bladder catheter/ catheterization; skin care; disinfection and prevention of bedsores; oxygen administration and giving intravenous injections.

Rehabilitative nursing: occupational therapy or physiotherapy.

Residential care: facilities (or institutions) other than hospitals which provide accommodation and a long-term care package.

Source: Genet et al. (2012)¹

Recent works analysing long-term care systems in terms of benefits (i.e. range of services or benefits in cash and in kind), coverage (i.e. rules limiting entitlement to benefits) and responsibilities in provision and financing of services clearly point out that long-term care systems do not follow a single model, making it rather difficult to understand how dependent older people are being cared for in different countries.^{1, 2, 58} This is particularly true when analysing how dependent older people are being cared for in the community. The “home care package” may cover a wide spectrum of services from basic domestic help to rehabilitation services. In addition, personal care services aiming at providing assistance with dressing, feeding, washing and toileting, and getting in or out of bed can be in combined with technical nursing activities such as skin care or wound dressing. The combination of personal care with technical nursing makes it sometimes difficult to determine which institution is in charge of providing a certain type of care. While personal care is usually covered by social care services, technical nursing is usually covered by health care services. Not surprisingly, comparable home care data seems difficult to gather, in part because of the lack of a homogenous definition of which services are provided and needed to support loss of autonomy for individuals residing in the community.

In the following section, formal home care services refer to professional domestic aid services, personal care and supportive, technical and rehabilitative nursing as defined by Genet et al. (2012)¹. Care provided by informal caregivers to dependent older people or benefits for informal

caregivers are not mentioned in this section as a detailed analysis of these measures is provided in other sections of this chapter.

In this section, residential care refers to care provided in facilities (or institutions) other than hospitals which offer accommodation and a long-term care package.² Residential care facilities can provide short- or long-term care accommodation for dependent individuals. Usually care provided in these institutions is a combination of personal care and health care (technical nursing, surveillance).

3.3.1.1 Belgium

The public long-term care system consists of a wide range of benefits mostly in kind, organized at the federal, regional and municipal levels. Long-term care services provided through the statutory health insurance (Rijksinstituut voor Ziekte- en Invaliditeitsverzekering – Institut National d’Assurance Maladie-Invalidité (INAMI RIZIV)) system covers nursing care, residential care and part of personal care to dependent persons, mainly financed with social security contributions and to a lesser extent by taxes.^h The statutory health insurances also partly finances non-medical expenses of chronically ill persons by means of different allowances: annual allowance for the use of incontinence material, annual care allowance, palliative care allowance, and allowance for persons in a vegetative or minimally responsive state. The communities and regions finance other services such as domestic aid and delivery of meals-on-wheels, among others.

A whole range of long-term care services is organized and provided at the regional level. The regional governments have issued decrees that regulate several issues related to LTC services: certification of facilities such as nursing homes, short-term beds, day care centres, services for domestic aid and personal care services, sitting services, hosting services, among others. Overall, these services are to a large extent financed by taxes and to a lesser extent by out-of-pocket expenditures and specific contributions.

^h A more detailed description of the Belgian Long-term care system can be found in the Appendix 2 in the report supplement.



There are two major cash-for-care allowances targeted at alleviating the financial burden of dependency incurred by LTC recipients. First, 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. Because this allowance is means-tested, it is partially designed as an income replacement.⁵⁹ Since 1 December 2012, the allowance varies from €549.15 to €6589.77. Second, the Flemish care insurance (*Vlaamse zorgverzekering*) grants a monthly lump-sum (€ 130 per month in 2013) to severely dependent individuals living in the community or in a residential facility, irrespectively of their income level. Dependency level can be assessed using different dependency scales (e.g. *Basis Eerste Lijnsprofielschaal (BELprofielschaal)*, *KATZ-scale*). The allowance is automatically paid to severely dependent individuals who receive home care services from recognized social and health care home services (in Dutch “*erkende dienst voor gezinszorg of aanvullende thuiszorg*” or from “*erkend erkende dienst voor logistieke hulp*”). Eligibility is limited to the Flemish territory, with residents of the Brussels Capital Region being allowed to opt in.

Needs assessment

The eligibility for nursing care and the intensity of care (dependency of the elderly), and the corresponding level of financial intervention by the federal health insurance system, is determined by the treating nurse using the Belgian Evaluation Scale for Activities of Daily Living (BESADL), which is adapted from the Katz scale. The tool evaluates the six original domains of the ‘Index of ADL’: bathing (personal hygiene), dressing, transfer, toileting, continence, and eating (feeding). Each function is scored 1 (no help) to 4 (complete help), a higher score indicating higher dependency. A care plan needs to be included in the nursing file. The minimum content of the care plan concerns the planned nursing activities, the frequency and the timing. The evaluation of the provided care needs to be registered based on the items of the BESADL scale. This can result in a prolongation, adaptation or ending of the care plan or a revision of the needed care.

Different scales for the needs assessment are currently being used by domestic aid and personal care services from the Flemish and the French Community and for the Brussels region. In the German speaking Community, needs assessment is done by a case manager. In the near

(foreseen 1 June 2017), a single scale the so called “BelRai” will be used for need assessment in all regions and communities in Belgium. The Belgian version of the Resident Assessment Instrument (RAI), the BelRAI is a web-based system for needs assessment that will be implemented for chronic care patients, home care services and nursing homes.

Home care

The statutory health insurance reimburses home nursing to persons with low to severe ADL limitations and/or cognitive limitations, irrespectively of their age. Care provided by home nurses includes technical nursing interventions and basic nursing care. The latter partly overlaps with care provided by personal care services, which are subsidized by the regional governments. Basic nursing care is financed via a per diem lump sum system. Medical prescription is not required. For technical nursing interventions financing is foreseen via a fee-for-service system. This requires a doctor's prescription, with a maximum day-limit. The financing of the providers is not based on their qualification levels. However, some specific nursing interventions are only reimbursed when they are performed by specialized nurses. Regulations for nursing care delivery at home allow the third-party payer system. Generally, the level of co-payments of the patient for home nursing is (approximately) 25% of the tariff. For some nursing interventions, patients do not have to contribute, e.g. the lump sum payments for specific nursing interventions in diabetic patients, or payments for nursing interventions in palliative patients.

With regard to domestic aid and personal care services subsidized by the regional governments, yearly quotas limit the volume of subsidized care hours that accredited organizations can provide. The quota of subsidised hours per service differs per region according to the competent government. Users of home care services are required to pay user charges. The hourly fee depends on the user's income and household composition. Yet, in the different legislations, there are differences in the elements taken into account for the calculation of the income.

The diversification of LTC services is being accompanied by several initiatives to improve the collaboration between care providers in different settings (residential, semi-residential, at home) and to provide patient-oriented integrated services. Financed at the federal level, the Integrated Services for Home Care (“*Geïntegreerde Diensten voor Thuisverzorging*” (GDTs) or *Services Intégrés de Soins à Domicile (SISDs)*”) coordinate the



provision of care in rather broadly defined geographical areas. These services organise primarily complex care situations and facilitate multidisciplinary co-operation between primary care providers, mainly general practitioners, nurses and paramedical professionals. Any patient, informal caregiver or care provider can initiate a multidisciplinary consultation that will serve to draft a care plan aligning the different care interventions.

The care plan includes the proposed care, the status of the functioning in daily life, a description of the formal and informal care network and the tasks to be performed by the different caregivers and healthcare professionals. Home care is further coordinated by 'Primary Care Cooperation Initiatives' (samenwerkingsinitiatieven eerstelijnszorg) in Flanders and by 'Coordination Centres for Home Care Services' (Centres de Coordination de Soins et Services à Domicile, or CSSDs) in Wallonia. In addition to home care coordination initiatives, special programmes and so-called care circuits have been created to streamline the provision of care as patients move between care settings.

Residential care

Day care centres and short stay centres provide nursing and personal care services for older persons with moderate to severe ADL or cognitive limitations that still live at home but (temporarily) lack adequate informal care, or whose caregivers need respite time. In day care centres, older persons are taken care of during one or more weekdays, but they spend the night at home. Short-stay centres provide residential services to older persons for a limited time period to temporarily alleviate the burden of informal caregivers. Additionally, no or low-care older people can stay in 'service flats' and similar accommodation which combine individual living arrangements with collective facilities (meals-on-wheels, home help, etc.). In the residential sector, homes for the elderly (In Dutch "*Woonzorgcentra*" previously called *Rustoord*, in French "*Maisons de repos pour personnes âgées*" in German "*Altenwohnheime*") provide nursing and personal care as well as living facilities for dependent older people. Older persons who are strongly dependent on care but who do not need permanent hospital treatment are admitted to nursing homes (In Dutch "*Rust-en verzorgingstehuis*", in French "*Maison de repos et de soins*" French, and in German "*Pflegewohnheime*"). The board and lodging costs are covered by dependent people and their families and in exceptional

cases, dependent people can rely on the help from Public municipal welfare centre (in Dutch "*Openbare Centra voor Maatschappelijk Welzijn (OCMW)*" in French "*Centre Public d'Aide Sociale Public Centres for Social Welfare (CPAS)*") The statutory health insurance covers health care expenses (including a part of the cost of health professionals working in the institutions). Public municipal welfare centres (*OCMW CPAS*) (abbreviated as *OCMW* in Dutch and *CPAS* in French), and both non-profit and for-profit private organizations organize residential care services.

3.3.1.2 France

In France, the main actors in the provision of long-term care are the statutory health insurance, the social care system via the allowance for the autonomy (in French "*Allocation personnalisée d'autonomie (APA)*") and to a lesser extent the state.⁶⁰⁻⁶²

Policy for elderly people is fragmented among the health and social care sectors as well as between provision of services among public and private care providers.⁶³ Families must cover remaining non-reimbursed expenses and use of private insurance towards the risk of dependency remains marginally used in France.⁶⁴ All private insurance policies in France are designed as a fix lump-sum. Therefore, expenses coverage is not related to the services costs.^{62, 64}

The French health care system is based on social insurance with universal coverage. This fundamental principle implies that, only in exceptional cases, coverage of services is targeted to specific populations.⁶¹ Dependent older people are not considered as a specific population and, as a consequence, coverage of health care expenses is related to their medical condition and not their dependency level. The Social care system based on tax funding finances health insurance. The second key players in financing long-term care are the departments and the National Solidarity Fund for Autonomy (CNSA). Both entities are responsible for financing the personalized autonomy allowance implemented in 2002 (in French "*Allocation personnalisée d'autonomie (APA)*"). The APA Departments finance almost 70% of the APA and are in charge of the planning and the coordination of the allowance. Funding for the APA comes from taxes and from employer's social contributions (for the CNSA). Finally, the state role resides in planning LTC policy, through quantitative and qualitative targets implemented with all involved partners.



Needs assessment

The medico-social team of the General Council and the coordinating physician assess dependency using the “*Autonomie, gérontologique, groupes iso-ressources* (AGGIR) for elderly living in the community and in an institution, respectively. The AGGIR scale is used nationwide and is composed of six groups of dependency, with the level one and six representing the most and of the least dependent individuals, respectively.

Home care

Dependency related needs are addressed, however, via specific rehabilitative nursing and technical nursing acts included in the French nomenclature for professional acts (in French “*nomenclature des actes professionnels (NGAP)*”). The statutory health insurance (in French “*Assurance Maladie*”) reimburses personal care prescribed by the physician and provided by nurses under the Nursing care acts (in French “*Actes infirmiers de Soins (AIS)*”) or by Home nursing care services (in French “*service de soins infirmiers à domicile (SSIAD)*”). SSIADs can arrange provision of technical nursing, personal care as well as domestic aid. Personal care is provided in 99% of the cases by nurse aids (in French “*aides-soignants*”) and not by the nurses who cover all the technical nursing.^{60 155} While SSIAD are financed by the health insurance, authorization for new SSIAD places is delivered by the regional committee of the social and medico-social organization (in French “*Comité régional d’organisation sociale et médicosociale (Crosms)*”). Domestic aid can also be provided by personal assistants and other domestic aid services (in French “*services d’Aide et d’Accompagnement à Domicile (SAAD)*”).⁶⁵

The APA is granted to dependent individuals aged 60 years or older residing in the community or in an institution. The APA is granted to individuals whose dependency level corresponds to the AGGIR groups one to four. The final amount received by the dependent older person depends on their dependency level, the cost related to the aid plan (“*plan d’aide*”) proposed by the medico-social team and their income (see Table 2). The dependent older people whose resources exceed €734.66 a month pay an income related co-payment. The aid plan can include technical aids, adaptation of housing, meals-on-wheels, household help or remuneration for the informal caregiver. In 2013, the APA benefits were capped to €1304.84, €1118.43, €838.82 and €559.22 in the AGGIR level one, two, three and four, respectively. Less dependent individuals

(AGGIR five and six) can receive social household help.⁶⁶ People who do not qualify for the APA (e.g. having an income above the maximum thresholds) may recruit home or personal assistants and beneficiate from tax exemption. However, a care plan they will not beneficiate of a care plan define by health and care professionals from the departments.

Table 2 – Dependent elderly participation in the cost of the aid plan of the APA (2013)

Monthly Income (Euro)	Participation
Less than 734.66	None
Higher than 734.66 and less than 2927. 66	$C \times [(I - 734,66 \text{ €}) / 2193 \text{ €}] \times B\%$
Higher than 2 927.66	90% *C

Source: Ministère des affaires⁶⁶. C stands for cost aid plan, I stands for income and B stands for percentage varying from 0 to 90%. APA stands for the Allocation personnalisée d’autonomie (France).

The state exempts older people of the payment of social contributions for domestic aid workers and grants a tax-deduction or a tax-credit on the salaries for the domestic and family aid employees paid via the French vouchers system (in French “*cheque employ service universel*”).⁶⁶

Residential care

Financing of residential institutions (in French “*Établissement d’hébergement pour personnes âgées dépendantes (EPAHD)*”) is divided into three main parts in France. First, board and lodging costs are covered by older people and their families and in exceptional cases, older people can rely on the help from the Solidarity housing allowance (ASH) (*Allocation de Solidarité pour l’hébergement*). Second, the health insurance covers health care expenses (including a part of the cost of health professionals working in the institutions) according to fixed scales based predetermined rules. Finally, the APA (therefore the departments and the CNSA) and older people’s APA related co-payments cover the costs of services and surveillance services needed for the acts of daily living which are not related to the health care services provided to the dependent older person.



3.3.1.3 The Netherlands

As early as 1968, the Netherlands introduced a system of public long-term care insurance to cover the needs of dependent older people as well as of individuals suffering from chronic illnesses. The Exceptional Medical Expenses Act (AWBZ) (in Dutch “*Algemene Wet Bijzondere Ziektekosten*”) initially covered the cost of residential care for elderly and for mentally handicapped individuals and of hospital admissions of more than one year.^{67, 68} The AWBZ is the first of the three so-called compartments (in Dutch “*compartimenten*”) of the Dutch health insurance system. The second compartment, regulated by the Health Insurance Act (Zvw) (in Dutch “*Zorgverzekeringswet*”), includes the basic health insurance for curative medical care and short-term care (e.g. care provided by general practitioners (GP), specialists, pharmaceuticals, etc.). Both compartments constitute the mandatory health insurance programs and provide universal coverageⁱ for the Dutch population. The third compartment consists of the complementary voluntary health insurance (VHI) for services not covered by the AWBZ and the Zvw.⁶⁸ Individuals participate in the cost of long-term care through different cost-sharing arrangements for community and institutional services. Besides the AWBZ, municipalities (in Dutch “*gemeente*”) play an important role in long-term care as they are in charge of providing social support^j. Since 2000, major reforms to the AWBZ have been undertaken. A brief overview of the current system and of the forthcoming changes is presented in the following section.

Needs assessment

Every request for benefits needs to be assessed by the Centre for Care Assessment (In Dutch “*Centrum Indicatiestelling Zorg (CIZ)*”). The CIZ evaluates needs for care arisen from different health conditions and disabilities as well as based on the living conditions of each individual. Living conditions include the need for care that exceeds the usual care provided by the individual’s social network along with other care sources. The CIZ determines the level of care provided by the AWBZ (in cash and

in kind, or both) in the community or in an institution. Broadly, the choice over receiving in kind or in cash benefits comes to the dependent person. The cash-for-care allowance corresponds to 75% of the amount of the cost of the services in kind.⁶⁹

Home care

The AWBZ currently covers personal care, technical nursing (such as wound care and injections), domestic aid (such as supervising activities), rehabilitation, stays in long-term care facilities and some forms of short-stays.⁷⁰ Coverage from the AWBZ is not restricted according to age and benefits are granted in kind and in cash. Dependent individuals may benefit from a cash-for-care allowance (in Dutch “*Persoongebonden budget*”) to cover the care needs established according to the CIZ. Since 2007, the Social Support Act (WMO) (in Dutch “*Wet maatschappelijke ondersteuning*”) transferred some responsibilities from the Exceptional Medical Expenses Act (AWBZ) to municipalities in order to enhance coordination of social care and welfare assistance.⁶⁷ Each municipality implements their own support program that includes, among others, domestic help, mobility aids (e.g. wheelchairs) and home adaptations not covered by the AWBZ. Benefits from WMO are also subjected to the CIZ assessment.

The Intensive Long-term Care Act (LIW) (in Dutch “*Wetsontwerp Langdurige Intensieve Zorg*”) will guide the changes in community and residential care and will replace the Exceptional Medical Expenses Act (AWBZ). Transfer in responsibilities from the current AWBZ to the municipalities (under the WMO) and to health insurance (under the Zvv) aim to guarantee the quality of life for dependent older people and disabled people who need care and to enhance patient responsibility and participation. As will be stipulated in the Social Support Act (WMO), personal care, support, short-stays and transport will be in charge of the municipalities from 1 January 2015 onwards.⁷¹ In addition, the health insurance will cover technical nursing (not covering personal care as it will be WMO’s responsibility), rehabilitation, long-term mental health care and case-manager nurses (in Dutch “*wijkverpleegkundigen*”).⁷¹

ⁱ Two groups are not covered, the persons refusing to be insured on grounds of religious beliefs or their philosophy of life and members of the armed forces⁶⁸

^j Social support was earlier in charge of the AWBZ



Residential care

The costs of publicly financed homes for the elderly and nursing homes (in Dutch “*Verpleeghuizen*” and “*verzorgingshuizen*”, respectively) are covered via a combination of income related cost-sharing arrangements for patients and the severity-of-care packages (in Dutch, “*zorgzwaartepakketten*” (ZZPs)) by the AWBZ. Currently, lodging cost is covered along with medical cost in these institutions by the AWBZ. However, from 2014 onwards, the government will implement new arrangements so that lodging cost will be directly paid to residential facilities by its residents. Dependent elderly can also cover the cost of private residential facilities with their cash-for-care allowance. In this case, the cash-for-care allowance is allocated in the severity-of-care package.

3.3.1.4 Germany

In 1995, Germany introduced the mandatory and universal system of long-term insurance (LTCI) (in German “*Die Soziale Pflegeversicherung*”) as the fifth pillar of the social insurance system (after health, accident, pension and unemployment insurance).⁷²⁻⁷⁴ Long-term care insurance is compulsory. Insured individuals via the Statutory Health Insurance (in German “*Gesetzlichen Krankenversicherung*”) are automatically insured under the social long-term insurance. Persons insured on the private health insurance program are obliged to buy private long-term care insurance. Individuals participate in the cost of long-term care via out-of-pocket expenses as cost of services usually exceeds the amount of benefits granted.^{73, 74} The Statutory Health Insurance covers medical needs for older people living in community and residential care institutions. In 2012, the government introduced the New Care Guidance Act (in German “*Pflege-Neuausrichtungs-Gesetz – PNG*”) in order to reform the long-term care insurance.⁷⁵ The key elements of the reform include enhancing the access to benefits for individuals suffering from dementia, enhancing flexibility in access to services in kind and in cash, establishing new care forms to improve home care, strengthening the principle of “rehabilitation before care” (into force since 2008), increasing support to informal caregivers, improving the evaluation procedure relating to whether a need for care exists and promoting medical care in residential care institutions by establishing cooperation agreements with physicians.

Needs assessment

According to the legal framework of the LTCI, need for long-term care arises when physical or psychological conditions or a disability require major and regular help to carry out everyday activities for more than six months. The Medical Review Board (in German “*Medizinischer Dienst der Krankenkassen*”) of the Statutory Health Insurance is responsible for assessing care needs.^{72, 73} The Medical Review Board designates geriatric-trained nurses or physicians to undertake the needs assessment based on limitations to perform activities of daily living (ADL) as well as to perform instrumental activities of daily living (IADL). Care needs are then classified into three levels (I great needs for care, II heavy care needs and III critical needs for care) according to the overall time needed to cover the care needs, the time spent in providing basic care (in German “*Grundpflege*”) and on the weekly need for domestic aid. Hardship cases are defined as situations where dependency needs are classified in category III but where more help is needed (in terms of time of care and if care must be provided by different persons). The Statutory Health Insurance may in principle be also involved in health and care provided at home when prescribed by a physician.

Home care

Benefits from the long-term care insurance are based on the three levels of care and can be granted in cash, in kind or as a combination of both. Since 1 January 2013, the level of benefits are classified into four groups (from level zero to level three) reflecting the additional benefits granted to people suffering from dementia. If only informal care is provided, a specific amount is paid and the dependent older person (usually referred to as “*Pflegegeld*”). If formal care services are used to cover care needs individuals receive the “*Pflegesachleistung*”. (see Table 3 hereafter for the exact amounts).

The long-term care insurance does not cover technical nursing (in German “*Behandlungspflege*”). Medical prescription of technical nursing and in general of health and care services at home (in German “*Häusliche Krankenpflege*”) is regulated by and under the responsibility of the Statutory Health insurance. In principle, health and care services covered by Statutory Health Insurance can be prescribed for a maximum period of four weeks (per episode of illness).⁷⁶ However, if a medical need exists, the period can be extended after approval of the medical services (in



German “*Medizinische Dienst*”). Prescription of technical nursing combined with personal care and domestic care is possible as long as the dependent person is not entitled to benefits from the long-term care insurance.⁷⁶

Table 3 – Amount of benefits for dependent people for home care in Germany (2013)

Type of benefits		Care level			
		0	1	2	3
In cash (Pflegegeld)	People with physical needs	-	235	440	700
	People with considerable care needs (dementia)	120	305 (235+70)	525 (440+85)	700
In kind (Pflegesachleistung)	People with physical needs	-	450	1100	1550 (and up to 1918)
	People with considerable care needs (dementia)	225	665 (450+215)	1250 (1100+150)	1550 (and up to 1918)

Source: Federal Ministry for Health⁷⁷

Residential care

The long-term care insurance grants a lump-sum to individuals who can no longer be cared for at home (even when short-term stays or day care are provided) to cover a part of the costs of being institutionalized. In 2013, the lump-sum for residential care (in German “*vollstationäre Versorgung*”) amounted to € 1023, € 1279 and € 1918 per month for care levels I, II and III. The lump-sum aims at covering for maintenance costs, medical treatment and social care provided in the residential care institution. The lump-sum cannot exceed 75% of the total fees charged by the institution.

⁷⁸ The Statutory Health Insurance covers expenses relating to medical

treatment. Board and lodging costs and infrastructure investment are in charge of the dependent older person. For those not being able to cover these costs, social assistance can be provided.

3.3.1.5 Luxembourg

In Luxembourg, the main actors in the provision of long-term care are the long-term care insurance (“Assurance Dépendance”) and the statutory health insurance (“Caisse nationale de santé Maladie”). Health and long-term care provision are both organized by the statutory health insurance.²³ The Long-term care insurance does not cover expenses related to illness (such as medical treatment or technical nursing) but covers help and personal care which are not covered by the health insurance. All insured individuals and their families are entitled to long-term care either when living in the community or when living in a residential care institution.^{23, 57} Eligibility to benefits is accorded based on needs, with no conditions on income or age. Benefits are granted in kind and in cash, but in kind benefits are privileged over cash benefits.

Needs assessment

The Evaluation and Guidance Unit (“Cellule d’évaluation et d’orientation”) is in charge of evaluating requests for benefits granted by the long-term care insurance. Individuals are eligible to benefits when support is needed to carry out activities of daily living (ADL) for a minimum of 3.5 hours per week and persists for more than six months. If loss of autonomy is temporary (less than six months), the Statutory Health Insurance covers the cost of personal care along with technical nursing. Health professionals from the Evaluation and Guidance Unit proceed to evaluate the level of dependency as indicated in the request for benefits form by the patient physician and the need for support to carry out the activities of daily living. The Evaluation and Orientation Unit prepares an aid plan including benefits in kind and in cash according to the dependent person. The aid plan is mainly designed in function of the amount of time needed to provide necessary help with ADL (and to a certain extent the instrumental activities of daily living) by a third person.²³

**Home care**

The aid plan established by the Evaluation and Guidance Unit for a dependent individual living in the community can include a shared plan for the tasks performed by health care professionals and by informal caregivers. The final aid plan is then signed by the dependent older person, the informal caregivers and the care network coordinator. The long-term care insurance pays directly formal care providers, while the dependent person receives funds to eventually compensate the informal caregiver. Assistance to individuals living in the community can include personal care, domestic aid, counselling and support, technical aids, home adaptations as well as arranging short-term stays or day care in a semi-stationary institution.

Residential care

The long-term care insurance, the statutory health insurance and dependent older people share the cost of public residential institutions under the responsibility of the Services for the Elderly (in French “Services aux seniors (Servior)”) and of private residential institutions. The long-term care insurance provides funds to cover the cost for the support with the activities of daily living as established in the aid plan. The statutory health care insurance covers health care expenses, such as physician visits and technical nursing. Finally, dependent older people pay out-of-pocket the cost of board and lodging as well as any services or amenities not covered or only partially financed by the long-term care insurance or by the statutory health insurance. Dependent elderly whose income is insufficient to cover the entire board rates may be eligible to receive help from the National Solidarity Fund (“Fonds National de Solidarité”).^{23, 57}



Table 4 – Responsibilities in financing long-term care benefits (2013)

	Belgium	France	the Netherlands	Germany	Luxembourg
Residential care					
• Board and Lodging	Dependent elderly and descendants	Dependent elderly and their descendants	Dependent elderly Medical Expenses Act (AWBZ) covers a part of lodging costs. From 2015 onwards, the AWBZ will no longer cover lodging cost	Dependent elderly	Dependent elderly
• Personal care and support in residential care facilities¹	Statutory health insurance	Statutory health insurance Departments and National solidarity fund for dependency (CNSA) via financing of the cash-for-care allowance (APA)	Exceptional Medical Expenses Act (AWBZ).via severity-of-care packages	Long-term care insurance	Long-term care insurance
Home care					
• Rehabilitative nursing	Statutory health insurance	Statutory health insurance	Exceptional Medical Expenses Act (AWBZ). From 2015 onwards, in charge of Health care insurance (ZVW)	Statutory health insurance	Statutory Health insurance
• Technical nursing (specialized nurse care)	Statutory health insurance	Statutory health insurance	Exceptional Medical Expenses Act (AWBZ) From 2015 onwards, in charge of Health care insurance (ZVW)	Statutory health insurance	Statutory Health insurance
• Personal care	Statutory health insurance for hygienic nursing care ² Non-medical personal care is provided by family care services subsidised by local authorities ²	Departments and National solidarity fund for dependency (CNSA) via financing of the cash-for-care allowance (APA) In some case the statutory health care insurance	Exceptional Medical Expenses Act (AWBZ). ⁵ From 2015 onwards, in charge of the municipalities under the Social Support Act (WMO)	Long-term care insurance. The statutory health insurance may intervene when prescribed by a physician and when the person is not entitle to long-term care benefits	Long-term care insurance. The statutory health insurance may intervene when prescribed by a physician and when the person is not entitle to long-term care benefits
• Domestic help	Regions or local authorities subsidizing family care services ⁴	Departments and National solidarity fund for dependency (CNSA) via	Municipalities under the Social Support Act (WMO)	Long-term care insurance. The statutory health insurance may intervene	Long-term care insurance.



		financing of the cash-for-care allowance (APA)			when prescribed by a physician and when the person is not entitled to long-term care benefits	
• Support and counselling	Depending on who provides support and counselling	Depending on who provides support and counselling	Municipalities under the Social Support Act (WMO)	Long-term care insurance	Long-term care insurance	
Needs assessment						
• How?	Scales used vary according to the type of benefits granted	AGGIR scale	Specific assessment scale	Evaluation of ADL/IADL difficulties combined with the time spent to cover them	Evaluation of ADL/IADL difficulties combined with the time spent to cover them	
• Who?	Service provider	Medico-social team of the General Council and the coordinating physician	Centre for care Assessment (CIZ)	Medical Review Board	Evaluation and orientation unit	
• Is there an aid plan?	Only in certain cases (via coordination of services)	Yes	Yes	Yes	Yes	
• Does income limit access to benefits in the care plan?	Income related co-payment	Income related co-payment	Income related co-payment	No	No	

Source: Colombo et al. (2011)², Triantafilou et al. (2010)⁷, Lundsgaard (2005)⁵, Genet et al.^{1, 79} and Semueus et al.⁸⁰. Other sources used to update or to verify available information were: Belgium⁸⁰⁻⁸³- France⁶⁵ Chevreur, 2009 #155; Haut conseil pour l'avenir de l'assurance maladie, 2011 #156; Le Bihan, 2011 #164}, Germany^{72-74, 76, 78, 84}, Luxembourg^{57, 85}, The Netherlands^{67, 70, 71}. ¹Refers mostly to personal care and support. In all countries health care expenses relating to physician visits or specific use of pharmaceuticals are covered by the statutory health insurance. Dependent elderly may need to cover a part of expenses related to personal care that are not covered by the social security ²Personal hygiene or feeding needing special care must be provided by nurses and are financed by RIZIV – INAMI. ³Services can be financed and provided by regional authorities (regions) as well as by municipalities (in French "Commune" and in Dutch "gemeente"). A detail description can be found in the appendix (see appendix 2 in the report supplement for more information). ⁴Not to confound social care services subsidised by the regions with for-profit vouchers services (in French "Titres-Services" and in Dutch "Dienstencheques").



3.4 Overview on informal caregivers in selected countries

3.4.1 Care-receivers preferences on the provision of formal and informal care

According to the 2012 Ageing Report⁸⁶, in many Member States a high number of people do not turn to formal care services and rely exclusively on informal care. This choice seems to be influenced by psychosocial, cultural and economic factors as well as to the ability of services which appear to be somehow related. Whereas older people prefer to age and remain at home for their own well-being and comfort, rooted traditions encourage family members to take care of them and to perceive it as a family duty.

Table 5 provides selected results on preferences for formal and informal care based on the Eurobarometer survey from 2007. In the selected countries, individuals reported preferring long-term care to be provided at their own home, for themselves as well as for their parents. A larger proportion of individuals responded that they would prefer to be looked after in their own home using informal care than using formal care in Belgium, Germany and Luxembourg. However, it should be noted that particularly in Germany almost half of the respondents preferred to be cared at home by an informal caregiver than by formal care providers. In France and the Netherlands a different picture emerges: more respondents prefer being cared at home with the help of formal caregivers than with the help of informal caregivers.

Concerning the care provided to elderly parents, respondents expressed a preference for choosing formal care over informal care (ranging from 32 to 52%) in all countries, with the exception of Germany.^{87, 88}

Table 5 – Preferences for formal and informal care based on the Eurobarometer survey (2007)

	Belgium	France	The Netherlands	Germany	Luxembourg
Own Care					
• At home using formal care (%)	34	43	42	24	30
• At home using informal care (%)	40	23	33	48	35
Parents' care					
• At home using formal care (%)	38	46	52	27	32
• At home using informal care ^a	22	18	20	30	27
• In a nursing home (%)	19	12	18	8	15

Source: Eurobarometer 2007^{87, 88}. ^aChoice defined as: one of their children should regularly visit their home, in order to provide them with the necessary care

3.4.2 Who are the informal caregivers?

In this section, a comparative perspective on the numbers and characteristics of informal caregivers for the countries included in the international comparison is presented. Findings from Riedel et al.⁸⁹ and Colombo et al.² were taken into consideration. The authors' estimates are based on data from the second wave of the Survey of Health, Ageing and Retirement in Europe (SHARE).



Box 5 – Informal care on the Survey of Health, Ageing and Retirement in Europe (SHARE).

The SHARE survey is a “multidisciplinary and cross-national panel database” of micro data for adults aged 50 years or older which includes questions on family networks, health and socio-economic status. The SHARE survey provides the most recent comparable data covering most countries taken on board in the present study and it allows for a time perspective for some of the countries since 2004. The SHARE survey does not cover all EU28 Member States (it covers 20 countries, of which some do not belong to the EU), leaving Luxembourg out the current sampling.

The SHARE survey includes questions on whether informal care is provided **within or outside the household**, on the **type of care** provided (personal care, practical household help or help with legal paper work), the **reference period** (during the last 12 months, almost daily, almost every week, almost every month, less often), on the time spent caring (periodicity and total amount of hours) and on the **relationship** between the informal caregiver and the care-receiver (including detail listing of family members or friends and acquaintances). For members of the **same household**, question on tasks provided by informal caregivers cover only personal care.

Before the SHARE survey, the European Community Household Panel (ECHP) (1994-2001) was the most comparable source of information across European countries (included thirteen countries) on informal care activities. The ECHP covered adults aged 16 years or older allowing for estimates on informal care on the general population.

Table 5 depicts the proportion of informal caregivers aged 50 years and older providing “care on a daily basis”^k to individuals aged at least 65 years.⁸⁹ The Netherlands is the country that has the lowest percentage of informal caregivers providing personal care only (3.7%) and any type of

^k According to Riedel et al.⁸⁹, focusing on provision of care on a daily basis allows to make a clear distinction between usual and occasional help.

care (personal care or support 4.4%), while Belgium presents the highest percentage for both types of care (6.8% and 8.8%, respectively).

Colombo et al.² also provide estimates on the proportion of the population reporting to provide informal care both on a regular and occasional basis. Colombo et al. estimates cannot be directly compared to that of Riedel et al. as the former neither limit their analysis to care provided on a daily basis nor to adults aged 65 years or older. As expected, a higher proportion of individuals provide informal care when not limiting the analysis to regular care only. Colombo et al. also find that a higher proportion of individuals provide personal care in Belgium than in the other countries in our sample.

Table 6 – Proportion of informal caregivers on the population aged 50 years or older (SHARE data, 2006/2007)

	Type of care	Belgium	France	Germany	Luxembourg	The Netherlands
Regular care provided to adults aged at least 65^a	Personal care only (%)	6.8	6.0	5.8	N.A	3.7
	Personal care or help with housekeeping or paper work (%)	8.8	7.2	7.4	N.A	4.4
Occasional or regular care to individuals because of illness or disability^b	Personal care only (%)	12.1	10.7	11.0	N.A	11.4
	Personal care or help with housekeeping or paper work (%)	40.7	28.2	34.2	N.A	39.2

Source: ^aRiedel et al.(2011)⁸⁹, ^bColombo et al (2011)². N.A: not available



Table 7 – Proportion of informal caregivers on the population aged 50 years or older according to gender (SHARE data, 2006/2007)

		Belgium	France	Germany	Luxembourg	The Netherlands
Personal care only (%)	Women	7.2	6.7	5.8	N.A	3.7
	Men	6.3	5.1	5.8	N.A	3.8
Personal care or help with housekeeping or paper work (%)	Women	9.5	7.7	6.9	N.A	4.1
	Men	8.0	5.5	7.9	N.A	4.7

Source: ^aRiedel et al. (2011)⁸⁹. N.A: not available

According to the 2012 Ageing Report⁸⁶, informal caregivers are mainly spouses/partners, children or children-in-law. Riedel et al. (2011)⁸⁹ results are in line with these findings, showing that the partners are the principal care providers, in particular among informal caregivers aged 65 years or over.

Compared to individuals not providing informal care, informal caregivers are less likely to be employed as well as to work on a full-time basis. Colombo et al. have revealed that caregivers active in the labour market work, on average, two hours less per week when compared to non-caregivers and they appear also to be over-represented in part-time work. Carrera et al.⁸⁷ indicate that, in 2007, approximately 10% of the female citizens of each of the five countries considered in the present study have withdrawn (partially) from the labour market to take up caring responsibilities to close family members including older relatives.

Table 8 – Percentage of informal caregivers and non-caregivers by labour force status

Country	Provides informal care	Belgium	France	Germany	The Netherlands
Retired	Yes (%)	22.3	24.0	23.5	6.5
	No (%)	25.6	25.5	20.5	11.0
Employed	Yes (%)	39.0	51.6	48.2	52.4
	No (%)	42.7	52.7	53.8	5.1
Unemployed	Yes (%)	10.5	4.3	9.7	2.9
	No (%)	6.0	6.1	11.2	3.0
Homemaker	Yes (%)	16.5	13.8	11.9	27.0
	No (%)	13.0	9.3	8.9	17.6

Source: Colombo et al. (2011)²

Taking into account the high percentage of informal caregivers and the impact of performing these activities in their lives (at personal, social, professional and financial level), measures to support them have been put in place in the last decades. The policy measures available in each of the five selected countries are presented in the sections below.

Table 9 – Target population for long-term care

	Belgium	France	The Netherlands	Germany	Luxembourg
Share of the population aged 65 years or older (2012)^a	17.3	17.1	16.2	20.6	14.0
Share of the population aged 80 years or older (2012)^b	5.2	5.5	4.12	5.4	3.9
Individuals aged at least 65 years who receive informal care^b	31	21	28	N.A.	N.A.
Percentage of the population aged 50 years or older receiving home care^c	14.1	17.6	10.9	5.1	-
Dependent elderly according to benefits received					
At home (60+)	176 598 (2011) ^d	727 000 (2010) ^e	227 000 (2007) ^f	1 348 504 (2012) ^g	9853 (2011) ^h
In an institution	126 720 (2011) ^d	458 000 (2010) ^e	164 000 (2007) ^f	649 242 (2012) ^g	5962 (2011) ^h

Source: ^aEurostat(2013)⁹⁰, ^bRiedel et al (2010) ,^cColombo et al(2011)², ^dUsers of home nursing financed by the Statutory health insurance (INAMI – RIZIV)⁸², ^eNumber of individuals receiving the APA⁹¹. ^fMot et al. (2010)⁶⁹, ^gStatistisches Bundesamt (2013)⁹² and ^hMinistère des Affaires et de la Santé (2013)⁹³

3.4.3 Definition of maintenance obligation towards dependent individuals and definition of a status for caregivers

Despite the differences of long-term care policies, the position of the family remains essential when considering looking after a dependent older person and there are persisting social expectations that family members will continue to look after them. Yet, as pointed out by Triantafillou et al. (2011)⁷, there is no legal recognition of the need for policies to reconcile work and care responsibilities when looking after family members, except in the case of children. Long-term care policies rarely include specific support policies for informal caregivers. In addition, it is not straight forward to assess the extent of families' legal obligation towards dependent older people. Triantafillou et al. (2011)⁷ pointed out that three approaches exist when considering the legal provisions concerning responsibilities towards dependent older people: i) primary devolving on the immediate family (spouses and children); ii) designated to the national authorities (at different levels e.g. municipalities or the state and iii) through the protection of persons in need by a the long-term care insurance. The maintenance obligation is certainly a key aspect when considering the care responsibilities towards family members. In all countries included in the international comparison, the Civil Codes provide the general framework of the maintenance obligation towards family members. This obligation is clearly defined when considering the responsibilities from parents towards children, while the extent and form of obligations towards other family members and towards dependent individuals is not clearly outlined.⁹⁴ The maintenance obligation is neither defined in terms of which needs must be covered nor on the dependency level of the individual. Moreover, little information is available to appraise whether obligations towards dependent older people are enforced in each country. Lack of a definition on the care obligations towards dependent older people from families combined with multiple eligibility criteria to access health and social care sectors make it difficult to assess how much care needs are to be provided by families. Not surprisingly, seldom is informal caregivers' participation or place in the long-term care policies defined. The latter holds for two out of three countries where a long-term insurance system encompasses policies for frail-elderly people (The Netherlands and the Luxembourg) as well as for countries where the long-term care arrangements are not formally covered by a separate insurance system (France and Belgium). Only in Germany,



the legal framework for the long-term care insurance (in German “*Soziale Pflegeversicherung*”) includes a legal definition for “informal caregiver” (§19 *Begriff der Pflegepersonen*)⁹⁵ as well as the list of social benefits to which s/he is entitled (§ 44 bis 45: *Leistungen für Pflegepersonen*).⁹⁶ In Germany, a caregiver is a person who looks after one or more dependent individuals on a non-commercial basis for, at least, fourteen hours per week.⁹⁵ The dependent person must declare her/his caregiver when claiming benefits from the long-term insurance. Benefits for informal caregivers may include: social security benefits (health insurance, pension and unemployment contribution), support and respite care as well as benefits during leave periods. While in Luxembourg there is not a specific definition for an “informal caregiver”, the Dependency insurance framework makes a reference to a “third-person” providing non-professional care when defining the amount of benefits in cash that can be provided to the dependent older person (*Art 354: Assurance dependance. Livre V*). The following article 355 opens the possibility of the payment of pension contributions to this third-person (see section on pension contributions for more details).

The maintenance obligation or the existence of an informal caregiver status may depict how beliefs, preferences or social norms, deeply rooted in each nation, play a crucial role in determining how care responsibilities are distributed between the state, the market and the family. Table 10 depicts the legal obligation to support family members as well as whether the informal caregiver benefits from a specific statute in each country.

In Belgium, the notion of “informal caregiver” is included in several legislative documents of both the federal⁹⁷ and the regional governments (e.g. *Woonzorgdecreet* March 13, 2009⁹⁸; *Code Wallon de l’Action Sociale et de la Santé* September 29, 2011⁹⁹). Yet, there is no general definition granting entitlements to specific social benefits linked to the status of caregivers. At the time of writing this report, political discussions were ongoing to grant a legal status to the informal caregiver. In a bill of law, approved by the Council of Minister in March 2013, recognition of the informal caregiver by her/his sickness fund is foreseen as a first step.

Particular social rights or guarantees linked to the status of informal caregivers are to be elaborated in a next phase. Several recognition criteria are set: caregivers need to be adults or removed from guardianship, being a sibling or having an affective, confident, close or geographic relationship to the care-receiver. Moreover, the period of caregiving lasts for at least 6 months, during on average 20 hours/week. The caregiving for individuals with a severe care need needs to take place in a non-professional way, but the informal caregiver needs to collaborate with at least one professional care provider. Several social partners and stakeholders together with the Communities and the Regions were consulted and provided comments to the text.¹⁰⁰⁻¹⁰³ Concerns such as the risk for an interruption 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 of caregiver vary.



Table 10 – Legislation on family support for dependent family members

	Belgium	France	The Netherlands	Germany	Luxembourg
Terms used	Aidant proche, proche aidant, aidant naturel, mantelzorger	Aidant naturel, aidant proche	Mantelzorger	Pflegegeperson	Aidant informel/ private pflegeperson
Is there an obligation to provide support to family members?					
• Descendants?	Yes	Yes	Yes	Yes	Yes
• Ascendants?	Yes	Yes	No	Limited	Yes
• Siblings?	No	No	No	No	No
• Family in law?	Yes	Yes	Yes	Yes	No
Does the support obligation include in kind (e.g. goods in kind such as housing)	Yes	Yes	n.a.	Yes	n.a.
Legal status or definition for caregivers	Political discussions on draft bill regarding the recognition of caregivers ongoing. Different definitions in regional legislation, yet no entitlements to social benefits linked to this definition.	No	No	Yes, in the legal framework of the long-term care insurance	No

Source: Information was first retrieved Chiara et al.⁹⁴ and Triantafillou⁷. Other sources of information used to update or to verify available information were: Belgium^{81, 104, 105}, France¹⁰⁶⁻¹⁰⁸, The Netherlands⁶⁹, Luxembourg⁵⁷ and Germany⁹⁵



3.5 Measures aiming at avoiding or reducing loss of income, social security benefits or employment

3.5.1 Financial support for informal caregivers

Financial support to caregivers may aim at providing recognition or reducing income loss (via income support payments).^{3, 5} Caregiver allowance programs aim at giving some recognition to the caregiver and not to providing a direct remuneration for the care provided. In some cases, their objective is to cover out-of-pocket expenses that may arise (e.g. transport costs) when looking after sick or elderly dependent individuals. Income support payments for informal caregivers aim to partly cover the loss of income relating to providing care. Levels of entitlements vary, but are usually below the market value of the help from a formal caregiver. Cash-for-care benefits provided to the dependent individual may be used to compensate their caregiver. In some cases, a strict regulation of a labour contract is established within the scope of the program. The compensation level can be based on the wage rate of a market substitute (e.g. formal care provider) or based on a fixed lump-sum. When a labour contract is established, the informal caregiver is usually entitled to social security benefits (pension and health insurance), whereas social security contributions are in charge of the employee (dependent older people). Among the countries included in this international comparison, payments for informal caregivers come from a caregiver allowance or from arrangements via cash-for-care programs.

3.5.1.1 Caregiver's allowance

A caregiver allowance is available only in Flanders (Belgium) and the Netherlands. The *Mantelzorgpremie* is available at the level of several Flemish local authorities (provinces and municipalities). Each local authority sets its own eligibility requirements and the amount attributed to the caregiver. In the Netherlands, the *mantelzorgcompliment* is organized at a national level and is paid directly by the Social Insurance Bank (SVB) (in Dutch *Sociale Verzekeringsbank*). In both countries, the amount granted was reduced in order to be able to pay the allowance to an increasing number of caregivers. In Belgium, the average amount of the allowance decreased from €37 per month (€444 per year) to €30 per month (€360 per year), respectively in 2008 and 2012.¹⁰⁹ In the Netherlands, in 2012, the allowance was reduced from €250 to €200¹¹⁰, in order to respect the 65 million euro budget assigned to the policy¹¹¹.



Table 11 – Caregiver allowance

	Belgium	The Netherlands
Availability	Yes, available in most Flemish local authorities <ul style="list-style-type: none"> • <i>Mantelzorgpremie</i> 	Yes, national. <ul style="list-style-type: none"> • <i>Mantelzorgcompliment</i>
Level of provision	Flemish municipality or province	Sociale Verzekeringsbank, (SVB)
Eligibility criteria	Each municipality or province establishes their own eligibility criteria. Most common criteria <ul style="list-style-type: none"> • Residence of the caregiver, the dependent person or both Other criteria <ul style="list-style-type: none"> • Co-residence • Access to the care insurance • Care-receiver age, dependency level or living at home • Family link between caregiver and care-receiver • Means-tested or according to insurance statute • May be paid to the care-receiver 	<ul style="list-style-type: none"> • The dependent person must introduce the demand and cannot live in an residential facility • Only one informal caregiver is covered per year • Dependency Evaluated by the Centre for Care Assessment for 53 weeks (371 days) • No limited access based on co-residence and no impact on the cash-for-care allowance
Amount	In 2012, average amount of €30 per month (minimum €2 and maximum €100 per month)	In 2013, a non-taxable amount of €200 per year
Rate of use	In 2012, it was available in: <ul style="list-style-type: none"> • 252 (out of 308) Flemish municipalities • 3 (out of 5) Flemish province • Total number of beneficiaries in 2012: 30 242 	Total number of beneficiaries <ul style="list-style-type: none"> • 2010: 230 698 • 2011: 314 898 • 2012: 377 313

Source: Belgium¹⁰⁹. The Netherlands¹¹⁰ In 2010 mantelzorgcompliment system was modified, information on this table corresponds to the requirements of the systems as of July 2013¹¹². France, Luxembourg and Germany have no caregiver allowance and for the sake of clarity were not included in the table.



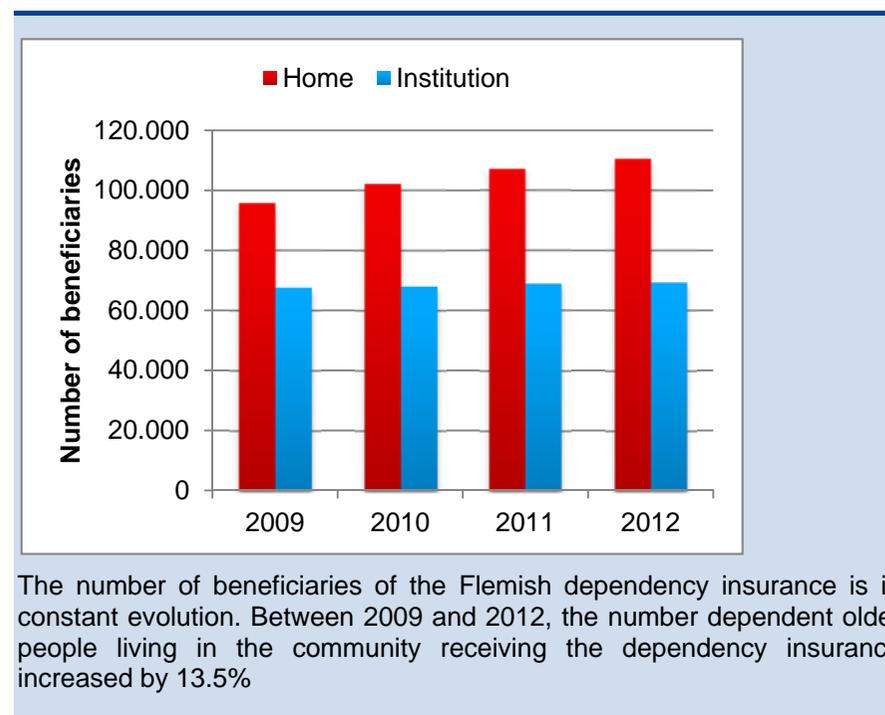
3.5.1.2 Cash-for-care allowances paid to the dependent older person

The extent in which cash-for-care benefits (also referred to as cash-for-care allowance) may be used to remunerate informal caregivers is highlighted in this section. It was systematically reviewed whether a formal contract can be established between the informal caregiver and the owner of the cash-for-care allowance. In addition, the person/institution in charge of paying social contributions for health, pension and unemployment was identified.

In Germany, if only informal care is provided, a specific amount (*Pflegegeld*) is paid to the dependent older person. The amount ranges from € 120 to € 700 per month (see section 3.3.1.4 on the long-term care insurance for more details). The dependent person can claim pension contribution for their caregivers (see section 3.5.2). In addition, all informal caregivers benefit from health care coverage and, in some cases, from unemployment benefits (details on the access to these advantages are presented in section 3.5.3). If the dependent older person uses a short-term stay facility or if the caregiver benefits from respite care (see section 3.6.1), half of the *Pflegegeld* is still paid. Caregivers not receiving any compensation can also claim a tax-credit of € 924¹ per year. The assessment of the informal caregiver capacity to provide care starts at the beginning of the process leading to claiming benefits. After granting benefits, the assessment of the care provided by informal caregivers is mandatory: three times a year for care level III and twice a year for the other care levels.⁷³ After an assessment, a modification on the care plan (understood as the benefits received by the dependent older person) may be proposed. A change may not only aim at insuring that appropriate care is provided but also at reducing the burden of the caregiver. For instance, it can be proposed to introduce formal care at home or day care in an institution.¹¹³ In 2011, 919 697 individuals aged 60 years or older received a cash-for-care allowance for informal care only.

In Belgium, the Flemish care insurance (in Dutch “*Vlaamse zorgverzekering*”) grants a monthly lump-sum of € 130 (in 2013) to cover non-medical needs or to compensate caregivers.⁸¹ In December 2012, 80,7% of the total number of individuals receiving the lump-sum were aged 65 years or older (corresponding to 69 393 and 110 551 individuals living in a residential facility and in the community, respectively).

Box 6 – Beneficiaries of the Flemish care insurance aged 65 years and older



The number of beneficiaries of the Flemish dependency insurance is in constant evolution. Between 2009 and 2012, the number dependent older people living in the community receiving the dependency insurance increased by 13.5%

Source: Flemish Agency of Care and health (in Dutch “*Vlaams Agentschap Zorg en Gezondheid*”)

¹ A tax-credit is an amount deducted from the income tax.



Currently, at the level of the Belgian federal authorities, the allowance for a dependent older person (in French “*allocation pour l’aide aux personnes âgées (APA)*” – and in Dutch “*tegemoetkoming voor hulp aan bejaarden – THAB*”) is attributed to all individuals aged 65 years or older who suffer from disability or from an age-related illness. In 2010, the number of beneficiaries¹¹⁴ amounted to 147 583 individuals, corresponding to 7.9% of the Belgian population aged 65 years or older.. A care contract within the scope of the Flemish dependency allowance or via the allowance for a dependent older person is currently not foreseen. In Belgium, a labour contract can only be established within the scope of the personal assistance budget for individuals aged less than 65 years old suffering from a handicap (in Dutch “*Persoonlijke-assistentiebudget*”). The discussion on this budget is beyond the scope of this report as it is not granted to elderly dependent individuals (aged 65 years or older).

In France, the owner of the cash-for-care allowance (in French “*Allocation personnalisée d’autonomie (APA)*”) can establish a labour contract with the informal caregiver, except if the caregiver is the spouse, the partner or the person with whom a civil partnership is established. The labour contract must comply with the collective agreements of the labour law for home employees and employers (in French “*Fédération des particuliers employeurs de France*”). Individuals receiving the allowance are exempted from paying social contributions and the amount paid to a home employee can lead to a tax-deduction or a tax-credit.⁶⁶ Employees under this type of contract are entitled to all of the social benefits (health, unemployment and pensions). The establishment of a labour contract with a health or care professional or with the informal caregiver is subjected to respecting the coverage of the care activities as established in the care plan.⁶³ However, the recruitment of a relative is not favoured by health and social care professionals who assess the level of dependency, the level of needs and determine the care plan.

Box 7 – Labour contract with the caregiver: different possibilities in different countries

According to Le Bihan and Da Roit, in Germany, the cash-for-care policies implicitly aim to encourage the provision of informal care without setting a formalized support for the caregivers. Opposite to this, in France and the Netherlands there is formalization in the support process, as the cash-for-care policies can be used to pay a wage to the informal caregiver.¹¹⁵

In Belgium and in Germany, a contract between the caregiver and the dependent older person is not directly foreseen in the context of the cash-for-care programs. In both countries, if a labour contract is set between the dependent older person and any other third-party (e.g. a relative), the dependent older person is in charge of the payment of all social contributions and of a minimum salary. In Germany, the establishment of a labour contract between the parties (dependent older person and informal caregiver) implies that benefits provided by the long-term care insurance to informal caregivers are no longer granted.

In France, the Netherlands and in Luxembourg, a labour contract can be set between the dependent older person and the informal caregiver. The payment of social contributions is not always in charge of the employer (dependent older person).



In the Netherlands, dependent people can receive a cash-for-care allowance to cover their care needs as assessed by the CIZ. The cash-for-care allowance can be used to remunerate informal caregivers under a care contract. The care contract (In Dutch “*zorgovereenkomst*”) can take two modalities: either a labour contract or a care agreement (in Dutch “*zorgovereenkomst met een freelancer*” or “*zorgovereenkomst met een partner of familielid*”).¹¹⁶ If a labour contract is signed between the parties, the dependent person must pay the minimum legal wage and may choose to pay social contributions. Social contributions not paid by the dependent older people are in charge of the informal caregivers. If a care arrangement is signed between the parties, the dependent person is neither obliged to pay the minimum wage nor social contributions. If social contributions are not paid by the dependent older person, they are in charge of the caregiver. In addition, when the dependent older person uses the cash-for-care allowance (*Persoongebonden budget*) to remunerate the informal caregiver, the care period may be taken into account when calculating unemployment benefits and in the career-length requirement for pensions via the *Mantelzorgforfait*.

Remuneration received by the informal caregivers via these contracts is subjected to the income tax.

In Luxembourg, the Evaluation and Orientation Unit (in French “*Cellule d'évaluation et d'orientation*”) can set up a shared care plan (in French “*plan de partage*”) between formal care providers and the informal caregiver. The dependency insurance pays directly formal care providers, while the dependent person can receive up to €262.50 per week (in 2013) in cash to compensate the informal caregiver. The shared care plan is not a formal contract but dependent older people may choose to sign a labour contract with the caregiver, except if the caregiver is the spouse. The dependent older person (the employer) pays social contributions for unemployment and health care, whereas the dependency insurance is in charge of the contribution for pension (see section 3.5.2).⁵⁷

Box 8 – Are tax relieves a way to incentive the work of informal caregivers or to reduce the cost of formal care services?

In all countries studied, when a salary is paid to informal caregivers using the cash-for-care allowances, the informal caregiver’s income is subjected to the income tax. When a labour contract is not signed between the parties, a financial compensation to the informal caregiver using the cash-for-care allowance is not subjected to taxes in Germany while it is subjected to the income tax in the Netherlands. For the other countries, we did not find a clear reference on whether a financial compensation outside the scope of a labour contract is subjected to taxes.

In this report, we did not look in detail to tax deductions (a reduction in taxable income) or tax credits (a direct reduction of the tax due) that aim to reduce the cost of formal care services (e.g. cost a home employee or adaptation of home services). These tax relieves (which include deductions and credits) for families may prove to be an indirect form of support² for informal caregivers, however their aim is to reduce the cost of formal care rather than to incentive, the informal caregiver’s work.

Tax relieves for families to cover care related cost or expenditures is a rather complex issue as they may depend on: the household’s composition (e.g. co-residence) and income, the family ties (spouses/partner, children, grandchildren, etc.), who covers care expenses (the dependent person, the informal caregiver), on the type of expenses (e.g. cost for formal employee, home adaptations) and on the handicap level. For instance, in Belgium, it is possible to obtain a tax deduction for the household when co-residing with certain family members (including people aged 65 years or older). The tax deduction is neither linked to a degree of dependency nor to provide informal care.


Table 12 – Informal caregivers’ role in the consumer-directed care programs

	Belgium	France	The Netherlands	Germany	Luxembourg
Type of program	<ul style="list-style-type: none"> Vlaamse zorgverzekering Allocation d'aide aux personnes –tegemeetkoming voor hulp aan bejaarden 	Allocation personnalisée d'autonomie	Persoongebonden budget	Pflegegeld	Assurance dependence
Is it possible to set a contract with the caregiver?	Possible. However, a care contract is not foreseeing (defined) in the context of the allowances.	Yes. A labour contract can be established with a family member with the exception of a partner	Yes. Labour contract or care agreement	Possible. However, a care contract is not foreseeing (defined) in the context of the allowances.	Yes A labour contract can be established with a family member with the exception of spouse
If a labour contract is signed, payment of social contributions by:					
<ul style="list-style-type: none"> Health 	Dependent elderly	Social security	Dependent elderly or caregiver	Dependent elderly*	Dependent elderly
<ul style="list-style-type: none"> Unemployment 	Dependent elderly	Social security	Dependent elderly, caregiver or social security (<i>mantelzorgforfait</i>)	Dependent elderly*	Dependent elderly
<ul style="list-style-type: none"> Pension 	Dependent elderly	Social security	Dependent elderly, caregiver or social security (<i>mantelzorgforfait</i>)	Dependent elderly*	Dependency Insurance
Percentage of users compensating caregivers	20%	16%	33%	n.a.	Since the establishment of the dependency insurance, the number of formal caregivers with a labour contract amounts to 496.
Payments to caregivers subjected to income tax?	Yes, under a labour contract	Yes, under a labour contract	Yes (both for a labour contract or care agreement)	Yes, under a labour contract	Yes, under a labour contract

Source: *If no labour contract is signed the long-term care insurance covers social contributions. All information on the table is related to the consumer-directed care programs in each country. Information was first retrieved from one of the following sources: Colombo et al.(2011)², Triantafilou et al. (2010)⁷, Lundsgaard (2005)⁵, Riedel et al.⁸⁹ and Gasior et al.(2012)¹¹⁷. Other sources used to update or to verify available information were: Belgium⁸¹, France^{66, 118, 119}, Germany^{77, 92, 113}, Luxembourg⁵⁷, The Netherlands¹¹⁶.n.a. not available.*



3.5.2 Pension benefits for caregivers

In Belgium, France and the Netherlands, informal caregivers may benefit from pension contributions if and only if the care provided is encompassed in a labour market program. The labour market program corresponds in Belgium to the access to a paid leave and in France and the Netherlands to establishing a labour contract between the dependent older person and the caregiver. In the Netherlands, employers are not obliged to pay social contributions within the scope of a care contract (see section 3.5.1.2). On the contrary, in Germany and in Luxembourg, pension contributions are primarily set up as a mechanism to compensate for periods of unpaid work during which the care provider makes limited or no pension contributions.

In Germany, the long-term care funds pay pension contribution for caregivers aged 15 years or older, who work less than 30 hours per week, provide care in the long-run (for more than two months) and whenever the dependent individual is covered by a home care plan (once home care is stopped, contributions are no longer paid).¹²⁰ If the caregiver is in paid employment for more than 30 hours per week, s/he may choose to pay the pension contribution corresponding to the hours of care. Caregivers not receiving a full-pension (e.g. disability pension) can increase their pension via these benefits. The total pension contribution depends on the hours of care provided per week and on the dependency level of the care-receiver.¹²⁰ As of 1 January 2013, when several caregivers provide care for more than 14 hours per week to one dependent individual, they are entitled to pro rata pension contributions for the hours of care (see section on minimum conditions to receive benefits (see section 3.4.3)). In 2011, 414 000 informal caregivers benefited from pension contributions. The pension contributions in Germany are only paid when no-formal labour contract is signed between the parties. If the dependent older person signs a labour contract with a third-party (relative or other individual), s/he is obliged to cover all social contributions. In Luxembourg, one caregiver per dependent older person is entitled to pension contributions based on the monthly social minimum wage for a full-time worker. If more than one caregiver looks after the dependent person, the yearly contributions are divided into equal periods among the different caregivers (e.g. for two caregivers, pension contributions are paid and cover six months). In 2010, from 1218 dependent individuals receiving cash benefits only, 20% claimed the payment of pension contributions for informal caregivers.⁵⁷

Since the establishment of the dependency insurance, 2545 caregivers have benefited from pension contributions (of which 496 benefited from a labour contract). On average, informal caregivers benefited from pension contributions with and without a labour contract for 31.8 months and 43.4, respectively.

Among the caregivers benefiting from pension contribution, women are the main beneficiaries amounting to 90.2% and 92%, respectively in Germany and in the Luxembourg. These data corroborate the finding that informal care is mainly provided by women.



Table 13 – Pension contribution for caregivers

	Belgium	France	The Netherlands	Germany	Luxembourg
Dependent person must claim the payment	No	No	No	Yes	Yes
Are pension contributions paid?	Limited, only under a paid leave program	Limited, only when a labour contract is established via the cash-for-care allowance	Limited, only when a labour contract is established via the cash-for-care allowance	Yes, under certain conditions	Yes, when the person does not have a pension right
How many caregivers are covered?	All caregivers who use a paid leave	All caregivers covered by a labour contract	All caregivers covered by a labour contract	All caregivers, pro-rata of the time spent caring	One caregiver per period
How are contributions calculated?	Based on a fictive income during the paid leave	Based on the salary paid	Based on the salary paid	Based on a fictive income and according to: <ul style="list-style-type: none"> • Hours of care per week • Dependency level • Area of residence of the dependent person 	Based on the minimum salary of a non-qualified worker.
Who pays contribution	-	Employer. Exemption of contribution payment is possible	May be paid by the employer. Otherwise in charge of the employee	Long-term care funds (Pflegekassen)	The Dependency Insurance
Number of beneficiaries	-	-	-	414 000, actively insured in 2011	2545, since the establishment of the measure

Source: Information was first retrieved from one of the following sources: Colombo et al.(2011)², Triantafilou et al. (2010)⁷, Lundgaard (2005)⁵, Riedel et al.⁸⁹ and Gasior et al.(2012)¹¹⁷. Other sources used to update or to verify available information were: Belgium¹²¹, France^{66, 119}, Germany¹²², Luxembourg⁵⁷, The Netherlands¹¹⁶.



3.5.3 Unemployment benefits for caregivers

One question is whether the informal caregiver may claim unemployment benefits when s/he decides to stop working in order to provide care. The access to unemployment benefits is not granted to employees terminating (unilaterally) their labour contract in order to provide informal care. However, unemployment benefits may be maintained under certain conditions if a person provides informal care either during an unemployment period or during an unpaid leave.

In Germany, since 1 February 2006, individuals may opt to voluntarily pay contributions for the unemployment insurance during care periods. In order to do so, the caregiver must have been insured for unemployment for, at least, 12 of the 24 months preceding the beginning of the care period. In addition, individuals must be recognized by the long-term insurance as an informal caregiver (providing more than 14 hours of care) and must contact the unemployment office. By providing voluntary contributions, caregivers are entitled to receive unemployment benefits during the care periods. Individuals looking out for a dependent person during an unpaid leave are also entitled to receive unemployment benefits. Unemployment contributions during the unpaid leave time are paid by the long-term care insurance. In Belgium and in the Netherlands, individuals receiving unemployment benefits may be exempted from the duty to look for employment for a fixed period (see Table 14). In Belgium, the exemption rules do not specify that the time is used to care for a dependent person but to deal with a difficult social or family situation. The National Employment Office (ONEM – RVA) decides whether to grant the exemption based on each dossier. In the Netherlands, care periods can be included in the calculation of the time necessary to collect unemployment benefits. However, individuals must be paid via the cash-for-care allowance and care activities should have prevented her/him from working for, at least, 52 days in a year.

In Luxembourg and in France, unemployment benefits are not extended or modified when providing informal care. In France, the only exemption is to combine the Aid to return to work benefits (in French *“aide de retour à l’emploi”*) with a paid activity. For instance, an informal caregiver signing up a labour contract with the care-receiver (via the cash-for-care allowance) may be able to keep her/his unemployment benefits if her/his salary is under a certain threshold.¹²³



Table 14 – Unemployment benefits for caregivers

	Belgium	France	The Netherlands	Germany	Luxembourg
Are there specific unemployment requirements/exemptions for informal caregivers?	Not directly. May apply for the exemption based on social and family difficulties.	No	Yes	Yes	No
Conditions	Being in a difficult family situation	–	Being a caregiver “Mantelzorgforfait” Not working for more than 52 days because of care responsibilities and being paid via the cash-for-care allowance	Providing care for at least 14 hours per week Having been insured for unemployment	–
Advantages	During a minimum of 3 consecutive months and up to 12 months: No duty to look for employment Can refuse a job offer Does not need to be inscribed as looking for employment	–	Being a caregiver: No duty to look for employment for 6 months. Renewable for 6 (+ eventually 1) “Mantelzorgforfait” counts as 6 months per year when not being in paid employment for at least 52 days	Unemployment benefits are granted when in unpaid leave or in certain conditions when providing informal care.	–
Number of beneficiaries	N.A.	-	N.A.	N.A.	

Source: Information was first retrieved from one of the following sources: Colombo et al. (2011)², Triantafyllou et al. (2010)⁷, Lundgaard (2005)⁵, Riedel et al.⁸⁹ and Gasior et al. (2012)¹¹⁷. Other sources used to update or to verify available information were: Belgium¹²¹, The Netherlands^{124, 125}, France¹²³, Germany¹²⁶ and Luxembourg¹²⁷. N.A.: not available Leave arrangements



3.5.4 Leaves for caregivers

According to a recent report², two-thirds of the OECD countries have implemented leave arrangements to care for dependent or ill individuals. The leave objective (e.g. caring for a person with long-term illness or for a palliative patient) and the array of benefits (e.g. whether receiving an income replacement or social insurance coverage) vary considerably between countries. In this section, we focus on leave arrangements that can be used to combine work and care responsibilities for individuals who are not terminally ill in the mid- and long-term. We systematically reviewed

whether, during the leave period, pension and health insurance rights were covered. Although not described hereafter, it is important to mention that short-term leaves (duration usually less than ten days) and leaves to care for terminally ill patients are available in most countries included in this international comparison.²

Table 15 illustrates whether employees are legally entitled to care leaves, thus leaves based on collective agreements (or firm specific policies) were also not included but are discussed in the text.

Table 15 – Summary of available mid- and long-term specific leaves to care for a dependent older people

	Belgium	France	The Netherlands	Germany	Luxembourg
Right¹ to paid work leave for caregivers of non-terminally ill individuals	Yes, according to employment sector	No	No	No	No
• Health insurance or Occupational accident insurance	No, but covered by the mandatory sickness insurance	–	–	–	–
• Pension	Yes, as long as he/she receives an income replacement	–	–	–	–
Right^a to unpaid care leave	No, but available via collective agreements ^b	Yes, private sector	No, but available via collective agreements	Yes	No, but available via collective agreements ²
• Health insurance or Occupational accident insurance	–	No, but covered by the mandatory health insurance	–	Yes	–
• Pension	–	Yes	–	Yes	–
Right ^a to flexible work-arrangements	Yes, through use of part-time leave	No	No, but available via collective agreements ²	No, but a legislative act regulates collective agreements ²	No, but available via collective agreements ²

Source: ^aRight refers to legal entitlement. ^bFlexible work arrangements exist under collective agreement. Information was first retrieved from one of the following sources: Colombo et al.(2011)², Triantafilou et al. (2010)⁷, Lundgaard (2005)⁵, Riedel et al.⁸⁹ and Gasior et al.(2012)¹¹⁷. Other sources used to update or to verify available information were: Belgium¹²¹, France¹²⁸, Germany¹²⁹, Luxembourg⁵⁷ and The Netherlands



Paid leave

Belgium is the only country in our sample where most employees have a legal right to a paid leave to care for a dependent individual. Employees in the private and public sectors have access to the medical assistance leave (in French *Congé pour assistance médicale* and in Dutch *verlof voor medische bijstand*) to care for a seriously ill family member up to the second degree. The leave can be used either on a full- or on a part-time basis, employees receive a taxable allowance (income replacement) and pension contributions are paid by the government. The full-time leave can be taken in periods of one to three cumulative months for up to a total of twelve months. Employees can also choose to reduce their working schedule to 50% of their regular hours if working at least 28.5 hours per week (75% of full-time equivalent) or by 20% if working on a full-time basis. In this case, the medical assistance leave can be taken during a maximum of 24 months. The number of people using the medical assistance leave increased from 5554 to 11 443 in the period from 2007 to 2012, respectively.

In Belgium, employees in the private sector can also take a time-credit aiming at looking out for a sick or dependent individual (in French *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* and in Dutch *Tijdskrediet met motief verlof voor medische bijstand: Bijstand of verzorging aan een zwaar ziek gezins- of familielid*). This time-credit can be used either on a full or on a part-time basis, employees receive a taxable allowance (income replacement) and pension contributions are paid by the government. This time credit can last to up to 36 months independently of whether the leave is taken on a full-time or part-time basis. The medical assistance leave and time-credit to provide care can be combined to extend the care periods. Colombo et al. ² pointed out that Belgium provides the longest leave within a selection of 23 countries.

Besides these leaves, employees from the private and the public sectors may claim respectively a time-credit without a motif and career-interruption (in French *“interruption de carrière ordinaire”* and in Dutch *“Loopbaanonderbreking”*). These arrangements may be used to temporarily exit the labour market but their main objective is not defined in terms of a care need.

Unpaid leave

Next to a paid leave, employee's right to unpaid leave is available in two countries, i.e. Germany and France. The Act for Care (*Pflegezeitgesetz*) in Germany provides up to six months of unpaid leave for employees^m when looking out for a close relative (2nd degree family member).⁷⁵ In Germany, the unpaid leave time qualifies for the calculation of pension period for individuals who are in paid employment for less than 30 hours per week.

In France, a renewable unpaid leave is available for up to three months. The total duration of the leave cannot exceed a maximum cumulated duration of one year in one's career. The Family Support Leave for the private sector (*Congé de soutien familial pour le secteur privé*) can be used to look after family members to up to a 4th degree. In France, the unpaid leave time may qualify for the calculation of pension period. However, social contributions are not paid for individuals whose family income is above a certain threshold.

Flexible work arrangements

In Belgium, the paid leave also offers caregivers an opportunity to set a flexible work timetable (see before). In 2012, a legislative act regulating flexible care leave conditions was introduced in Germany. The act sets a framework for flexible work arrangements but does not make them mandatory. Final decision relies on the employer. The leave sets a long-term credit balance between working hours and remuneration for both the employer and the employee. During the leave time, the employee receives a salary at a rate of 1.5 times the effective working time. If the working time is reduced from 100% to 50%, the corresponding income is 75% of the full-time salary ($50\% \times 1.5 = 75\%$). When the leave period comes to an end, the worker returns to a full-time work schedule receiving a reduced salary (at 75%). This arrangement will last for the same time as the leave period.¹²⁹ This leave period can last up to 2 years and the worker must work, at least, 15 hours per week. Pension rights are maintained via the regular payment of pension contributions by the employer or via the caregiver pension protection plan (see section 3.5.2). The employer subscribes a specific

^m Except for public officers who benefit from a special regimen. It concerns firms having 15 employees or more



insurance (*Familienpflegezeitversicherung*) to cover the risk of non-repayment during and after the leave.

In the Netherlands, the government, employers and employees are setting up projects allowing caregivers to manage their care and work responsibilities. Projects are based on collective agreements. Care time can amount to half of the effective number of hours of work, limited to a maximum of 12 weeks per year.

3.6 Availability of respite care, psychosocial support and information and communication technology (ICT)

3.6.1 Legal entitlement to respite care

Respite care is considered as one of the three main interventions (along with psychosocial support and information and communication technology) targeting informal caregivers of community dwelling elderly dependent individuals.¹³⁰ Respite care is usually defined as a **temporary break** from caregiving activities that aims at reducing caregivers' burden and enhancing their well-being.¹³¹ In terms of policy goals, respite care may aim not only at improving the caregivers' outcomes but also at allowing them to provide care in the long-run.⁷ Respite care interventions are difficult to identify because they may be conceived to simultaneously arrange formal care provision to the elderly dependent and a break to the caregiver. In this section, information on respite care was collected whenever: i) caregivers are legally entitled to respite care benefits, ii) "care plans" include respite care and iii) measures or programs creating a "mandatory" or minimum number of short-term care facilities (day and night care, short-term stays beds). This last point was added because respite care service provision is often linked to institutional care.^{2, 7, 89} When possible, information on availability and use of respite care was collected.

Table 16 – Respite care allowance as according to the long-term care insurance (2013)

		Care level			
		0	1	2	3
Respite care allowance up to (<i>Verhinderungspflege</i>)	Up to				
Close family member (up to second degree)	For dependent individuals ¹	-	235	440	700
	For persons with considerable care needs (e.g dementia)	120	305 (235+70)	525 (440+85)	700
By another person		1550	1550	1550	1550
Short-term residential care (<i>Kurzzeitpflege</i>)	Expenses up to	1550	1550	1550	1550

Source: Federal Ministry of Health⁷⁷

Shultz reports that a policy goal of the German long-term care system is to support informal caregivers "with provision of respite care, contributions towards the social security benefits of those not employed or working less than 30 hours a week, training courses or counselling".⁷³ According to Shultz, in 2007 0.24 billion euros were spent in respite care.⁷³ In 2012, 74 210 informal caregivers received the budget for respite care. Since 1 January 2013, in Germany, the New Care Guidance Act (*Pflege-Neuausrichtungsgesetz – PNG*) aims to improve and to facilitate the access to the respite care services (including facilitating the use of short-term residential facilities and rehabilitation centre) and the promotion of preventive measures to avoid caregiver burden. The new support for informal caregivers include, among other measures, to continue the



payment of the cash allowance (up to 50%) while the dependent older person is in a short-term care facility or if a close family member is looking out for them. The PNG extended the coverage of the “respite care allowance” (in German “*Verhinderungspflege*”) to caregivers of less dependent individuals (level 0) having provided informal care for, at least, six months. The respite care allowance covers a period of up to 28 calendar days and “respite time” can be taken for a couple of hours a day (e.g. to go to the movies) or for several days in a row (usually for short-term residential care). During respite time, the caregiver’s pension benefits are paid by the long-term care insurance. The allowance amount varies according to: i) dependency level and ii) the person or institution looking after the dependent individual during the caregiver’s respite time (see Table 16). Whenever the respite time is covered by a close family member (up to second degree), it is assumed that s/he does it as a part of the family solidarity. As a consequence, the payment to this family member corresponds to that provided when only informal care is used to cover the needs of the dependent individual (specific amount of the cash-for-care allowance). Any additional expenses incurred during the respite time can also be reimbursed (e.g. transport cost) by the long-term care insurance. The respite care allowance can amount to a maximum of €1500. Many caregivers facing an excessive care burden engage home-helpers to assist them in looking out for the dependent individual.

Table 17 – Respite care allowance as according to the long-term care insurance (2013)

	1995	2000	2005	2010	2011	2012
Total number of caregivers benefiting from respite care	10 464	6 313	14 263	45 491	56 322	74 210

Source: Federal Ministry of Health ¹³²

3.6.2 Respite care summing up multiple possibilities

Respite care can, to some extent, be included and financed through benefits provided by the long-term care insurance in Luxembourg ⁵⁷ and the Netherlands.⁶⁹ The Evaluation and Orientation Unit from the Luxembourg Dependency Insurance includes support activities in the care plan which specifically aim at: 1) allowing elderly dependent to stay at home and 2) providing respite care to the informal caregiver. Support activities cannot exceed 14 hours per week, are provided in kind and cannot be exchanged in cash as other benefits from the Dependency Insurance. Respite care can be provided at home, in a non-residential centre (*centre semi-stationaire* can include day- or night-care centre) or in a residential care institution.⁵⁷ According to the Dependency Insurance last evaluation report, the proportion of dependent individuals benefiting from support activities increased from 52% in 2001 to 79% in 2010.⁵⁷ As for all services provided by the Dependency Insurance, support activities are made available to cover a need of the dependent person. Therefore, the Dependency Insurance evaluation does not provide information on how many caregivers benefited from respite care through this mechanism. However, the evaluation points out that the number of hours of support activities (according to the dependent care needs) provided in non-residential centre doubled between 2005 and 2010. According to the same report, respite care is included more systematically as a part of the care plan of the dependent individual.

In the Netherlands, elderly dependent individuals (as established by the criteria under the *Algemene Wet Bijzondere Ziektekosten (AWBZ)*) can ask for the reimbursement of respite care for her/his caregiver. The caregiver must have provided care for, at least, three months and the reimbursement level depends on the care-receiver household taxable income. The AWBZ can cover the cost of respite care only for affiliated care providers. The dependent older person may also use her/his cash-for-care allowance to cover the cost of respite care for providers not having an agreement with the AWBZ. Finally, sickness funds may include in their insurance package the cost of respite care.¹³³



In France and Belgium, arrangements to cover the cost of respite care depend from specific reimbursements from health care authorities, the cost itself of respite care alternatives (e.g. provision via non-profit institutions) and of the criteria to access short-term facilities.^{106, 134} Since 2007, plans to extend day care to provide respite care to informal caregivers in France have been undertaken. The decision was to create approximately 2500 places per year in day care services and to provide 1100 beds for temporary stays.⁶⁵ However, use of day care and short-term stays accounts for less than 1% of the users of residential facilities.¹⁰⁶

In Belgium, on 1 January 2013, the number of beds for short-term stays in nursing homes and of places in day care amounted to 2498 and 2166, respectively (<http://www.inami.fgov.be/care/fr/residential-care/specific-information/stats.html>). Sickness funds also provide different types of respite care, including respite care at home. Data on use of these services was not available at the moment of the publication of this report.

3.6.3 Global policy for psychosocial support and information

Legal entitlement to psychosocial support and information for informal caregivers is granted by the long-term care insurance in Germany and in Luxembourg. As a result of the strong need for information, since 2008, in Germany, case management and counselling is provided via information centres free of charge (In German "Pflegestützpunkte"). Around 600 information centres were planned, and as of 2010, 250 were already operational.⁷⁴ Impact evaluation of the information centres in Germany is being carried out by different entities.^{135, 136}

In Luxembourg, informal caregivers can receive training and support via the Evaluation and Orientation service and from home care providers. In 2010, around 4% of individuals (corresponding to 318 out of 7836) entitled to benefits received from the long-term care insurance had access to psychological support.^{57, 85}

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 other countries, support and training is provided from local initiatives and different care providers. Currently, data on access to these initiatives is limited.

In France, several structured initiatives at the level of the departments and municipalities provide information as well as coordination of services. Coordination structures aim countering possible negative impacts relating to the highly fragmented system that currently exist in the elder care sector. The Local centre for information and coordination (in French "Centre Local d'Information et de Coordination – CLIC"), the SSIAD, the Houses for the autonomy and integration of Alzheimer patients (in French "Les maisons pour l'autonomie et l'intégration des malades d'Alzheimer, communément appelées (MAIA)") and the Centre of community social welfare (in French "Centre communal d'action sociale (CCAS)) can provide support and information to informal caregivers. The CLICs are financed by the state and local authorities and must provide advice and guidance to dependent older people and their families regarding the different types of assistance available to them.

Support for informal caregivers is fragmented between the regions and even between municipalities in the same region.^{56, 137} In Flanders and in the Flemish governed centres of the Brussels Capital region, the local and regional service centres give information and provide training and hobby activities for the elderly, but also for informal caregivers and volunteers. Furthermore, caregiver associations distribute information to dependent individuals and their caregivers, organise activities and represent the caregivers' interests. Currently, six non-profit associations (*Steunpunt Mantelzorg Liever Thuis LM Ziekenzorg van de Christelijke Mutualiteiten Ons Zorgnetwerk OKRA-ZORGRECHT van OKRA, trefpunt 55+ and S-Plus Mantelzorg*) active in Flanders and Brussels have been accredited. In Wallonia, the non-profit organization *Aidants proches*, created in 2005, is the sole caregiver's association. The association provides information to informal caregivers and has developed an inventory on the available initiatives providing support to informal caregivers and formal services for the dependent person.¹³⁸ Finally, sickness funds, the coordination services at the federal and regional level also regularly serve as information points.



Table 18 – Right to psychosocial support and information

	Belgium	France	The Netherlands	Germany	Luxembourg
Is there a legal entitlement to	No	No	Yes	Yes	Yes
• Training, education	No	No	Yes	Yes	Yes
• Collective support	No	No	Yes		No
Who provides training, information and/or education	Sickness funds and home care services, social services of the hospitals, OCMW/CPAS, local and regional service centers in Flanders, 'Integrated Home Care Services' (Geïntegreerde Diensten voor Thuisverzorging, or GDTs/Services Intégrés de Soins à Domicile, or SISDs). Primary Care Cooperation Initiatives (Samenwerkingsinitiatieven Eerstelijnszorg) in Flanders and Brussels (Dutch speaking), Coordination Centres for Home Care Services (Centres de Coördination de Soins et Services à Domicile) in Wallonia and Brussels (French speaking).	SSIAD, Local centre for information and coordination, houses for the autonomy and integration of Alzheimer patients, Centre of community social welfare	WMO	Pflegestützpunkte	Evaluation and Orientation service

Source: ¹Right refers to legal entitlement. ²Information was first retrieved from one of the following sources: Colombo et al.(2011)², Triantafilou et al. (2010)⁷, Lundgaard (2005)⁵, Riedel et al.⁸⁹ and Gasior et al.(2012)¹¹⁷.



3.7 Evaluation of measures for informal caregivers at a national level

In a perfect world, each policy measure or instruments should be evaluated according to its main objectives. In addition, secondary or unintended effects of a given policy should be identified and then evaluated. In the case of the impact of policies on caregivers, not only is it not straightforward to define which policy must be considered but also which outcome should be measured. Although costly, ideally all policies should be evaluated on outcomes on both the informal caregiver and the dependent older person.

Take for instance a policy aiming to delay institutionalisation by increasing the number of hours of formal care provided. It will certainly be suitable to evaluate if the dependent older person indeed stayed at home longer. However, a secondary effect could be that the burden on the informal caregiver is reduced in the beginning of the intervention (e.g., s/he provides less personal care) but increased in the long-term.

Hereafter, we provide an overview of existing results of assessments of national policies regarding their impact on informal caregivers. We focused on results on uptake and cost of policies. However, other outcomes referred in the literature were also mentioned (impact of support measures on informal caregiver's income, labour market participation or on health outcomes) Results are based on evidence of studies included in this international comparison (mostly based on a macro-level) and on evaluations conducted by governmental institutions responsible for implementing the existing policy measures. The results from the scoping review in OVID Medline and Econlit are also included.

Overall, there is little information on the uptake of support measures by informal caregivers and on their cost for the authorities. One possible explanation is that, in most cases, there is not a legal definition of the informal caregiver status. As a result, scenarios on the cost of long-term care services do not include the cost for informal caregivers.^{91, 139} Moreover, the procedures to obtain funding or support or even the groups entitle to benefits are sometimes unclear. In addition, the implications of policies on short-term and long-term care outcomes for caregivers are not easily evaluated, in part because of the lack of information concerning the use of policies, but also due to the fact that defining specific caregivers' outcomes proves to be a difficult issue. Although all countries have

implemented policies to support caregivers, very different pathways have been designed.

3.7.1 *Assessing the support measures to avoid loss of income, of social security benefits or of employment*

Caregiver's allowance

As described above (see section 3.5.1.1), caregiver's allowance are only available in one region in Belgium, i.e. Flanders, and in the Netherlands.

In 2008, an evaluation of the Dutch allowance was ordered by the Ministry of Health.¹¹¹ The evaluation focused on analysing the reasons explaining the low uptake, the quality of communications on the policy provided to informal caregivers, the experience and perception of informal caregivers with the policy, and scenarios to improve the attribution rules. Vijvinkel et al. (2008)¹¹¹ concluded that the uptake of this program was lower than expected because the process did not seem to be sufficiently clear to the officers and the users, and the cash allowance had not been amply advertised. In certain situations, the users have decided not to apply for this scheme because of the complexity of the process or because the financial compensation was not satisfactory to undergo such bureaucratic procedures. The caregivers who have requested this allowance considered this benefit an appreciation for their caregiving efforts and had a positive attitude towards the monetary compensation. On the other hand, the caregivers who invested their time and energy in applying and were not granted this benefit because of not fulfilling the requirements reported negative opinions towards it. In 2008, a total of 31,649 people received the allowance. As the programme became better known and eligibility requirements were softened, the caregiver's allowance became more popular. The budget allocated for the policy has remained unchanged and corresponds approximately to 65 million euros.

The caregiver allowances gained popularity in Flanders and in the Netherlands. As a consequence of this popularity, the amount granted was reduced in order to be able to award it to an increasing number of caregivers.^{109, 110} Studies focusing on the experience of caregivers enjoying this type of policy show that they appreciate this kind of recognition but that it is not a driver to be a caregiver.^{52, 111}



Cash-for-care allowances

One of the main characteristics of the cash-for-care programmes is to allow care-recipients and their families to set their preferred-care arrangements. Among preferred-care arrangements, families may choose between compensating the informal caregiver and purchasing formal care services. Among the countries studied in this international comparison, different rules are applied when compensating an informal caregiver.^{5, 63, 89, 115} The possibility of setting a formal payment is different across the countries studied. While in Germany and Flanders (Belgium), the policy takes the form of a non-formalised support measure for the caregiver with a limited possibility of setting a labour contract, in France, the Netherlands and Luxembourg a more formalised framework towards the monetisation of care exists.^{83, 115}

Information on the socioeconomic characteristics and on the number of informal caregivers who benefit from this compensation is limited. For Flanders, France, the Netherlands, and Luxembourg some estimates are available (see Table 12). Estimates come from surveys on the use of the cash-for-care programs; therefore, it is not possible to know whether these estimates are representative of all cash-for-care users. Only for France and Luxembourg could data be found about the caregivers' compensation via a labour contract. These data indicate that few informal caregivers have a labour contract with the dependent older person. In France, there is some evidence that mostly women benefit from this type of compensation.^{63, 140} Petite and Weber (2006)¹⁴⁰ also point out that the labour contract is most often established between the dependent older person and a child or a child-in-law.

When a labour contract can be signed between the informal caregiver and the dependent older person, this type of benefit does not seem to compensate for the volume of services delivered by informal caregivers.⁷ In France, there is some evidence that the involvement of the informal caregiver goes beyond what established in the care plan.^{63, 140} In Luxembourg, the evaluation conducted by the Luxembourgish Ministry of Social Security (2013) points out that it is not an explicit objective of the system to recognise the informal caregiver as a formal employee through the establishment of a labour contract.⁵⁷ The report clearly states that such a policy (i.e., making mandatory the recognition of the informal

caregiver as a formal employee) would increase the cost for the long-term care insurance.⁵⁷

In Germany, the cash-for-care scheme intends to provide “implicitly and non-formalised” support to informal caregivers.^{115, 135} In line with this, the cash-for-care allowance and its impact on informal care were reviewed in the context of an evaluation of the German system. Wingefeld et al. (2013) concluded that payments in cash to informal caregivers are not to be considered as remuneration for a service, but rather as means to promote care in the normal environment of the dependent person.¹³⁹

Colombo et al. (2010) warn of several risks that might occur due to establishing a labour contract between the dependent older person and the informal caregiver. For instance, these authors argue that these contracts can create a poverty-trap for the latter as it might be a low-paid job which might affect her/his 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 labour contract comes to an end, regardless of the circumstances (e.g. institutionalisation).^{115, 135}

Social security benefits for pension and unemployment

In Belgium, France, and the Netherlands, informal caregivers are entitled to pension benefits if they were enrolled in the labour market through a contract with the care-receiver. This may have economic consequences in terms of present salary and future pension income. Informal caregivers are usually not entitled to certain social rights and incomes when compared to other workers. As stressed by Colombo et al. (2011)², working-age caregivers experience a higher risk of poverty, and women seem to be the most vulnerable. The authors justify these findings by indicating that higher poverty may be related to lower employment rates and lower working hours for caregivers (which result in a reduced annual income) and differences in the composition of the household with fewer household members earning a salary.

Given that little or no evidence is available on the labour contacts for informal caregivers, information on the payment of pension contributions related to these contracts is also missing.



For Germany and Luxembourg, data on the uptake of the use of pension contributions was available from the long-term care insurance (see Table 13). In 2012, in Germany, a budget of 0.9 billion euros was devoted to paying contributions for pensions for informal caregivers.¹²² Information on the socioeconomic characteristics and on the number of informal caregivers who benefit from pension contributions is limited. The only information available for Germany and Luxembourg is that more than 90 per cent of the beneficiaries are women. Whether pension contributions benefit all informal caregivers entitled to this financial resource remains an open question.

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

Leave arrangements and flexible working arrangements

Belgium is the only country in our sample where most employees have a legal right to a paid leave to care for a dependent individual. Belgium's leave policies are seen as generous compared to those of other countries.² There are currently no available studies on how these leaves influence the provision of informal care. According to Casman et al. (2007)⁴⁰ in light of the difficulty of managing work and care responsibilities experienced by working caregivers, very few reported using the leaves available to them. In the report of Casman et al. (2007), caregivers reported using time-credit or the career-interruption leave in order to manage their work and care responsibilities.⁴⁰ Available data on leaves show that the uptake of the medical assistance leave has increased in recent years. While other leaves available in Belgium (i.e., time-credit and career-interruption leave) may also be used to provide care (Casman, 2007), the reasons behind their use cannot be retrieved from the National employment office database (NEO – ONEM – RVA).

In Germany and the Netherlands, caregivers report that short-term leaves (usually used for personal emergencies) are seen as a last resort when they can no longer cope with their care and work responsibilities.^{36, 136, 141} Before turning to these leaves, caregivers reported using first their free-time (i.e., non-working time) to provide care.^{141, 142} Kholer and Döhner (2011) suggested that in Germany very few caregivers are making use of available leaves as these are not paid.¹⁴²

While the discussion on the impact of care on employment and vice versa is ongoing, the impact of leave policies or flexible work arrangements is

seldom formally assessed in studies. One reason explaining the lack of evaluations is that databases used to assess the impact of care activities on labour market participation (and vice versa), such as the PSBH or SHARE, do not include information on these policies, making it therefore impossible to evaluate how they modify care and work patterns and caregivers' income.

3.7.2 Assessing respite care and psychosocial support

There is little information available about the uptake and expenditures for respite care services or for psychosocial support. Nonetheless, evidence could be found on the uptake of respite care and on psychosocial support in Germany and Luxembourg. The availability of this information could be related to the fact that in both countries there is a legal entitlement to provide these services.

In Germany, the uptake of respite care has constantly increased from 45,491 in 2005 to 74,210 users in 2012. However, uptake remains low. In 2011, 1,182,057 individuals of all ages were granted a cash-for-care allowance related to receiving informal care only.⁹² For the same year, the total number of individuals benefiting from respite care benefits amounted to 56,322. If all individuals having a budget for informal care need help from, at least, one informal caregiver, less than 5 per cent of all informal caregivers have benefited from respite care. In 2007, the budget allocated to respite care amounted to 0.24 billion euros. Since 2008, Germany implemented a global policy on psychosocial support and guidance via information centres ("Pflegestützpunkte"). An evaluation of this policy is currently being undertaken and will look at the supply side (i.e., from the providers' point of view) and on the use (i.e., from the patients' point of view) of services.

The first evaluation from centres in Hamburg provides interesting insights concerning the impact of this national policy.¹³⁶ The study points out that it is difficult to evaluate the proportion (the policy uptake) of the population in need of support who actually received it from the information centres. This is related to the difficulty of evaluating how many caregivers are in need of support (target population). Döhner et al. (2011) reported that higher educated people and people in paid employment compose the majority of those who ask for support and counselling.¹³⁶ The authors point out that more targeted strategies may be needed to attain people from less privileged backgrounds.



In Luxembourg, the evaluation report of dependency insurance stresses that the number of hours of support activities provided in non-residential centres doubled between 2005 and 2010. According to the report, this could be interpreted as an increase in use of respite care in day care centres. The report also mentions that only 4 per cent of individuals covered by dependency insurance received counselling sessions.⁵⁷

As mentioned above, information on the uptake of these types of policy measures for the other countries included in the international comparison is limited. Since 2007, in France, plans to extend day care to provide respite care to informal caregivers have been undertaken. Yet, there is some evidence that the funding available for respite care has not been used and that the uptake of respite care remains low. This is explained by the refusal of care-receivers to go to day care centres.^{38, 50} In Belgium, the number of places in day care centres and of short-term beds in nursing homes has increased in the last decade.⁸² However, no information was found on the occupancy rate or on the socioeconomic characteristics of the families and the users of this type of respite care in day care centres. In the Netherlands, van Excel et al. (2006, 2007, 2008)¹⁴³⁻¹⁴⁵ surveyed informal caregivers' attitudes towards respite care and the need and use of respite care in three subsequent and explorative studies. They concluded that a considerable proportion of caregivers needs support but does not readily ask for respite care or other type of support. The impact of respite care and psychosocial support on informal caregivers' health and well-being has been largely evaluated in the scientific literature.^{44, 130, 131, 146-148} Most studies included in the reviews concern non-European countries (mostly the United States, the United Kingdom, Canada, and Australia). Overall, all studies point out that support interventions tend to have small positive effects in caregivers' health outcomes. Yet, the limited evidence does not necessarily imply the lack of an effect. Family caregivers generally feel satisfaction and gratefulness about the professional support and feel less burdened or depressed in the short time follow-up.

Shaw et al. (2009) also identified in their review the barriers to uptake of respite care services.^{89, 131} Barriers identified included the personal backgrounds and beliefs of caregivers, 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. The supply services as well as the knowledge of their availability were reported as limiting the uptake of respite care. Concerns about the quality of care provided, the cost of services, and waiting lists were also cited among the reasons limiting the uptake of services.

In line with Shaw's findings, in Belgium, caregivers frequently express the need for more modalities of respite care and home care.⁴⁶ Yet, in practice, they rather feel reluctant to look for professional help, often request respite care in an ultimate stage or in a critical moment in the care situation, and experience a higher burden if they do use help.^{47, 51} Barriers to the use of professional help relate to psychological aspects and attitudes of care-receivers and caregivers as well as to the organisation of professional help.⁵³ Resistance of the care-receivers stems from the idea that care should be based on family solidarity, the feeling of loss of privacy and independency, the difficulty of acceptance, and feelings of shame.⁵³ Caregivers also experience feelings of guilt towards the care-receiver or feelings of not complying with social expectations. Organisational aspects hamper the use of professional help as well. The lack of knowledge or information on the services, the lack of a diagnosis, the financial accessibility, the eligibility procedures (e.g., the burden of the administrative procedures) and physical elements (e.g., no transportation to the day care centre) are mentioned as hindering factors. Input from third parties, such as professionals providing information on professional help or working in the elderly sector can help overcome the barriers.



4 POLICY MEASURES IN THE EYES OF CAREGIVERS: A CASE STUDY ANALYSIS

The objective of this chapter is to enrich the evidence that was made available in the previous chapters, in particular to provide empirical evidence on the effects and experiences regarding policy measures for informal caregivers. This chapter is divided into three sections. The methodology of the study is presented in the first section. The second section covers the results on national and regional policy measures at the level of each country or region (intra-analysis). The last section presents the comparison of findings of Belgium contrasted to the different regions abroad (inter-analysis).

4.1 Design: an embedded multiple case study

The case-study methodology presented in this section aims at providing a detailed answer to the following research questions:

1. Are informal caregivers aware of the existing support measures?
2. Do informal caregivers benefit from existing support measures and how?
3. What has been the impact/effect of these support measures on the informal caregivers' lives, on the continuity of care for the dependent older person and the possible impact on the institutionalization process?

4.1.1 Why a case study design?

To answer the research questions, an **embedded multiple case study design** was chosen as the most useful approach.¹⁴⁹ Case study research is a qualitative approach in which the investigator explores a bounded system (a case) or multiple bounded systems (cases) through detailed, in-depth data collection and aiming to interpret and make sense of the experiences of the participants and the world in which they live. A case study is a good approach when the inquirer has clearly identifiable cases with boundaries and seeks to provide an in-depth understanding of the cases or a comparison of several cases.¹⁴⁹

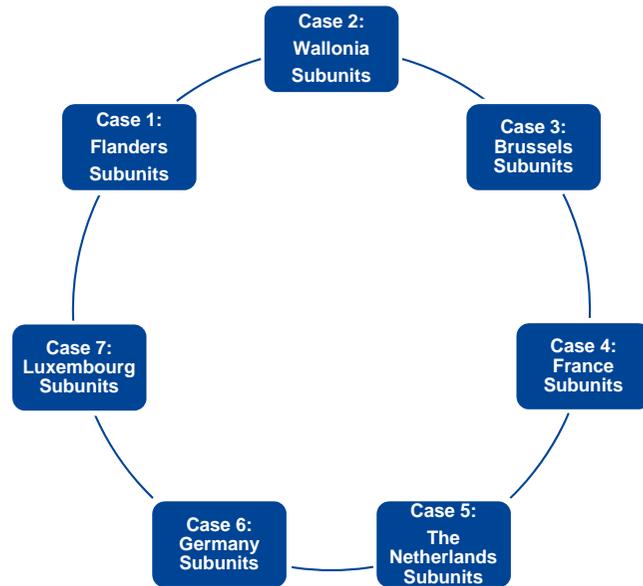
Multiple case studies allow for comparison, particular in diverse settings. In this regard, we will describe and compare the experiences and perceptions of informal caregivers in **seven cases within their realities and context**. The aim is not to make a systematic comparison but to understand and learn from abroad to improve the system in Belgium. The cases represent the different settings that will be studied: Belgium (with Flanders, Wallonia and Brussels considered as separate cases), Germany, France, the Netherlands and Luxembourg. Brussels case reflects the reality of non-Belgian informal caregivers. The focus on migrant and ethnic minority dyads aimed to disentangle the influences of some contextual living conditions on the use of existing policy measures and, eventually, to identify how they use these measures. Migrants and ethnic minorities groups tend to have a lower socio-economic status and live in deprived neighbourhoods with a lower supply of social and health services.¹⁵⁰ We did not include non-native informal caregivers from other cities in Belgium because of the time constraint, however this needs to be explored in further research.

Within each case, multiple "embedded" case studies have to be performed (Figure 1). For each dyad of the dependent older person (DEP) and their main informal caregiver (ICG), we have studied benefits for caregivers as identified in the second chapter (international comparison), barriers and facilitators for the uptake of benefits and informal caregivers' experiences and perceptions of these advantages. Informal caregivers' experiences and perceptions of formal care services provided to the dependent older person has also been analysed. Formal home care was assessed with respect to the continuity of care provided to the dependent older person as well as with respect to the relationship between health professionals and the informal caregivers.

The cases were not selected for their capacity to represent the whole population of ICGs and DEP in the different countries investigated, nor to be generalised beyond the setting in which results were generated. Representativeness and generalisation rely, here, on other conceptions than those of quantitative logic. Investigation of non-representative cases nevertheless, allow the researcher to test whether the first emerging explanations from one case are robust enough when applied to other cases, in order to construct an empirically based description of the issue investigated.



Figure 1 – Embedded multiple case design



4.1.2 Recruitment of dyads

Initially, recruitment was planned to be carried out only via general physicians (GPs). However, difficulties in recruitment via GPs in France, Luxembourg and Germany lead to extend the recruitment strategy via other health and care providers: local GPs, nursing services, elderly homes or social services. Health and social care professionals helping in the recruitment were asked to identify dyads in common care situations where they could identify the primary informal caregivers, i.e. people considered as being the most involved in the care provided to a dependent older person.

A blueprint was made to select cases in each case-study subunit.

4.1.2.1 General blueprint guidelines: the selection criteria

1. The case study subunit of this study is the “dyad”, composed of the dependent older person (DEP) and his/her main informal caregiver (ICG), within their living “context”.
2. A minimum of five dyads per region/country were to be interviewed.
3. The selected dyads have to reflect some various but “common” situations, defined as situations often met in practice, not the exceptions. “Common cases” should include dyads receiving a lot of formal services as well as little or no services at all, living in the community or in an institution (level of services refers to the situation before institutionalization).
4. The recruitment of the dyads has to be done by general practitioners or other health professionals, who are well placed to identify such “common situations. The contact person had to ask the dyad whether they were willing to participate in the study.
5. A necessary condition for inclusion of a dyad is having the ability to carry out the interviews separately with the DEP and the ICG in order to avoid the mutual influence of each other during the interviews.
6. Ideally, interviews of the complete dyads (ICG and DEP) were targeted, but in some situations we expected that the health condition of the DEP may not make it possible to be interviewed. For each case study, the objective was to interview at least three dyads.
7. When it was possible to interview the dyad, the first interview was conducted with the ICG, in order not to burden the DEP with too many questions (already covered with the ICG).



4.1.2.2 *Informal caregiver characteristics*

1. The caregiver has taken up her/his role for at least one year. Only people considered as being the most involved in the care provided to a dependent older person (as selected by the recruiters) were interviewed.
2. Different dyads should reflect also the diversity of relationships between the DEP and the ICG. A mix between partners, child caregivers and other ties (not necessarily family ties) will be defined by the sampling.
3. At least two caregivers still had to be in paid employment.
4. For each case, we ideally aim to interview at least one male caregiver.

4.1.2.3 *Dependent elderly characteristics*

1. the dependent older person needs to be 70 years or older and not being:
 - in palliative care.
 - hospitalized in the past four weeks
 - having an acute disease
2. Two out of the five DEPs should be recently institutionalized but less than four months.
3. Ideally, dependent older people with a variety of medical conditions are recruited. Two out of 5 DEP should suffer from dementia.
4. One older person with dementia should have been recently institutionalized and one should live in the community.

During the fieldwork, some of these selection criteria had to be more or less adapted to the situations investigated with regard to the principle of the diversity of selected situations (see limitations).

4.1.3 *Preparation of the fieldwork in each of the case studies*

4.1.3.1 *Development of template and interview guide: semi-structured interviews*

Based on the finding of the international comparison, a guide for semi-structured interviews was made in English. This first version of the interview guide was prepared by three experts (two sociologists and one economist). Three recent surveys identified in the scope review of the literature in Chapter 3, were used to ensure that all topics in relation with policy measures (e.g. basic questionnaire, definition of care tasks...) were appropriately used and addressed in the semi-structured interview guide.^{8, 151-153} This first version was then reviewed by the rest of the research team, this allowed to include modifications on content as well as on wording from experts from other fields (physicians, nurse).

Different semi-structured guides were used for DEP and their informal caregivers living in the community or in nursing home. A total of four different semi-structured interview guides were used (see the appendix 11 in the report supplement). Once these interview guides were adapted, they were then translated into the national language used in each case and back translated to ensure reliability.

A first pilot interview was performed with an ICG in the French speaking part of Belgium to assess the comprehensibility of questions and feasibility of the data collecting process. A second pilot, with ICG and DEP was performed in the Dutch speaking part of Belgium. Adaptations were made when necessary and the semi-structured guides were finalized. The final semi-structured guides were then send to the different research teams performing the fieldwork and the analysis.

4.1.3.2 *Template for all case studies.*

To gather field data related to each dyad (from interviews with the ICG and the DEP) and to prepare their analysis, a "coding framework", was made, based on the semi-structure questionnaires and by defining 7 different domains investigated. Following domains were used for both data collection and analysis. They are refined in collaboration with the KCE research team:

- Essentials about the dyad: baseline information about the ICG and the DEP (socio-demographics), including:



- gender of each other
- age
- education level
- number of children and grandchildren
- relationship between the ICG and the DEP
- living location of both
- current or past job occupation of the ICG
- ethnic origin (especially for Brussels dyads).
- Domain 1: About the role, experiences of the ICG and relationship with the DEP.
 - The circumstances he/she became caregiver
 - Motivation to take care of the DEP
 - Impact of being an ICG (on the relationship with the DEP, on work situation, on his/her life)
 - Positive /negative aspects of the ICG role
 - About the relation with the index patient
 - Facilitating / hindering elements to play this role (helpful information, financial aspects)
 - Recognition at formal / informal level
 - Health conditions of the ICG
- Domain 2: About the health conditions of the DEP in his/her context
 - Health conditions of the DEP
 - Past health situation
 - Recent evolution during the past 6 months
 - Reasons why the DEP was institutionalized, (if applicable)
 - About the life in nursing home
 - Why care receiver is successfully at living at home (if applicable)
 - Motivations
 - Home adaptations
- Domain 3: About the informal social support the ICG and the DEP receive (from family members, friends, neighbours...)
 - Family composition
 - Help the ICG receives from other family members
 - About the 'family system' (tensions between members...)
 - Other people who bring help (undeclared worker...)
 - Other family member or relative who need to be cared for
- Domain 4: About the tasks performed by the ICG since the DEP became dependent and before the DEP was institutionalized
 - Household activities and domestic aid (including food preparation, cleaning, washing, ironing, sewing clothes, taking care of and playing with children, shopping or maintenance work, odd jobs, gardening)
 - Personal care (dressing / undressing, washing, hair care, shaving, help to go to the toilet, assistance to eat and to drink)
 - Medical care (including arrange medication or medical support)
 - Practical support (mobility inside and outside the house, assistance with walking or wheelchair, visiting family or friends, seeing to health care contacts, organizing help, physical aid, house adaptation, taking care of financial matters, receiving formal caregivers)
 - Surveillance (only for the caregiver)
 - Other : availability for the DEP
 - Time spent per week to perform these care tasks
- Domain 5: About formal services the DEP receives at home, and about 'experience' with these services (interruptions, coordination, accessibility, information, administrative requirements and procedures...)
 - Use and help from personal care by a nurse
 - Use and help from a physiotherapist
 - Use and help from an occupational therapist
 - Use and help from domestic help service
 - Use and help from home attendant service



- Use and help from Granny-sitting service
- Use and help from family help service
- Use of meals-on-wheels
- Use of technical materials and assistance of tele applications (tele surveillance)
- Use of psychological help or group sessions
- About missing services mentioned by the ICG
- Use of formal services outside the home
- Domain 6 : About informal help / formal services the ICG uses or receives
 - Use and help from home care services for health conditions
 - Use and help for household activities
 - Use and help from respite care services at home (targeting the DEP but helping the ICG)
 - Missing services for the ICG
- Domain 7 : Financial support of the ICG
 - About the financial conditions of the ICG and of the DEP
 - Use of and help from special plans for their professional work of ICG (financial protection as workplace policies, social protection...)
 - Direct financial stimulus from local, regional and national authorities to ICG
 - Financial remuneration (caregiver allowance, cash-for-care allowance...)
 - Use of and help from tax reductions for ICG
 - Use of and help from relieve services for index patient to help ICG (respite care services)

The template allowed us to code all the verbatim in the native language from the interviews with the members of a same dyad when related to the same issue under a same (main or sub) code. Each coded verbatim was identified in order to specify from which interviewee the data came by using the following coding : 1) by the region/country where the interview was conducted (NL for Netherlands, WL for Wallonia, BXL for Brussels, FR for France, LU for Luxembourg, DE for Germany); 2) by the number of interview in the related region / country; 3) and by the category of the interviewee (1A : ICG who take care of DEP living in the community ; 2A : DEP living in the community; 1B : ICG for DEP recently institutionalized; 2B : DEP recently institutionalized). For instance, the verbatim from the first interview we made in Wallonia with the ICG who takes care of her mother in law was coded: (WL_1_1A).



4.2 Data collection and analysis: a coordinated approach

4.2.1 Organization of the data collection between researchers and coordination

Ethical approval was obtained from the University of Antwerpen.

The researchers met at one kick-off meeting before start of data collection and aligned the way of data collection (template for case studies). Final of reporting of each case was in English which is needed for further analysis. In order to have a single analysis framework, a grid for the analysis of the interviews was developed based on findings from the two pilots. An external expert reviewed results and improved the initial analysis grid. The grid was then sent to the four researchers carrying out the interviews. The first interview in each case-study subunit was then encoded to appraise the validity the analysis grid. A teleconference was organised with all team members after each first interview of a case was performed to debrief and to adjust the framework if necessary.

All interviews were initially analysed in the native language by a member of the research team. In a second phase, the quotes illustrating the findings were translated into English and checked by the original interviewer. The final reports were delivered in English. All researchers hold active knowledge of the native language and passive knowledge of the other languages and are able to report in English.

4.2.2 Intra-case analysis

Firstly, a descriptive country reports include the 7 research domains and are available in the appendix. Each case was analysed using the analysis grid developed for the project. The framework can evolve during the gathering of data and any changes are communicated between the researchers. To allow for comparison, the national researcher provides a report in English for the intra-case analysis. This allows a set of 7 reports in English. Based on the descriptive country reports, the three research question are addressed for each country in one section of this chapter.

4.2.3 Lessons learned from abroad: inter-case analysis

A first version of the inter-case analysis was led by two researchers. The inter-case analysis was based on the country reports as well as on the detailed descriptive reports included in the appendix 4 to 10 included in the report supplement. Their analysis was confronted and validated by the other researchers to check the interpretation and to make sure that the context was not misinterpreted. The inter-case analysis was performed in order to confront the findings from Belgium (Wallonia, Flanders and Brussels) with the findings from abroad and learn from them in how we can improve our system. Results are presented in section 4.4 of this report.

4.3 Results for the intra-case analysis

4.3.1 The ups and downs of the recruitment strategy

Initially, it was stated in the protocol that the DEP and ICGs would all be recruited through GPs, in order to make the process as uniform as possible in the different regions. However, this was not always possible due to time constraint. Some GPs in Germany, France and Luxembourg pointed out that they were interesting to participate in the project, but eventually did not because of the tight time schedule for the project. Recruitment was then performed with the help of different health and care professionals working in the field. In Flanders and the Netherlands, the dyads were recruited through the GP, while in Luxembourg recruitment was performed through a variety of health professionals. In Wallonia and Brussels, the dyads were mainly recruited by GPs working in Medical Centres (Maison médicale / wijkgezondheidscentra) who are working in group practices. Although the number of such medical centres is growing in Belgium, although more in Wallonia and Brussels than in Flanders, it is nevertheless important to point out that only a small minority of people are affiliated with them. This implies that DEPs and ICGs affiliated to such medical centers are over represented in our Wallonia sample. In France and Germany the dyads were recruited through a GP, through nurses or through the supervisor of a local hospital or care services.



In Germany, for patients suffering from dementia, recruitment went via an association for older people with dementia and their families. This should be kept in mind when interpreting the German results, since dyads identified in this way, are much more likely to be well informed and to receive more services than average. The ICGs being active in support groups also could be considered to be more pro-active than the average ICG.

In Wallonia, France and Luxembourg some problems were encountered to recruit people who were institutionalised recently. In France, this was due to the fact that institutionalization occurs at a late stage, in many cases due problems related with severe dementia. This created difficulties for recruitment in the sense that the DEP could no longer be interviewed and that ICGs, still very affected by the evolution in the situation of the DEP, were not keen to participate in a study. Also, in many cases, institutionalization occurred prior to the 4 months limit set for the sampling. In Wallonia, the difficulty to recruit people recently institutionalised can partly be explained by the fact that dyads were recruited through GPs, who mainly refer people who are living in the community.

In Wallonia, Brussels and in Luxembourg, the selection criteria regarding institutionalisation were not met, as only one person recently institutionalized was included.

Luxembourg did not include ICG of working age, therefore it was not possible to know whether people working have a different strategy in the use of formal services than people who are not active on the labour market.

4.3.2 *Sample description*

DEP demographics

According to the selection criteria, the dependent older person needs to be 70 years or older. Only in two dyads, (Brussels) the dependent older people were slightly younger (66 and 69 years old). The average age of all DEPs is 85 years.

In most countries, the majority of the DEPs are female, with the exception of Luxembourg, where three of the five DEPs are male and their wives are their ICGs.

All DEPs had family ties with the ICG, except in one case in France. Care was usually provided by the spouse or by a child(-in-law).

When the DEP was not institutionalized and married, they shared the house with the partner or wife/husband who was the main caregiver. In the Netherlands, Germany, Wallonia and France, a mix of co-residence status with child(-in-law) ICG was present. Only in Brussels, all daughters providing care also lived with the DEP.

In Brussels, we explicated looked for dyads of people of foreign descent. The non-native Belgians living in Brussels are either from Turkey, Morocco or Romania.

ICG demographics

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 active job occupation the sample is quite heterogeneous, except for Luxembourg where the sample is older and therefore all informal caregivers were retired. 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.



4.3.3 Flanders

4.3.3.1 Context of the DYADS

Dyad 1

The DEP is female and 79 years old. She has been ill all her life and has had a lot of health issues, both psychological and physical. She also had a lot of surgery. At the time of the interview, the health situation still is unstable. The caregiving became more intense after the DEP lost her partner and became a widow 2,5 months ago. It was a second marriage and the husband was a good stepfather to the ICG and the other children. It is visibly a very close family. The DEP has many social contacts, lives in the centre of the village and wants to keep on living here. She knows how to contact help and has a close contact with the social worker of the Public Center for Social Welfare. She is aware of the fact that she will need more help in the future. She is actively working to find a solution for her living arrangement. She wants to live in the centre of the village, in the service flats nearby. She uses as much formal help as she can afford (personal care, domestic aid, handyman service, diner at home, personal alarm, transport).

The ICG is the daughter (56 years old). She lives nearby. She worked as a hairdresser for a few years (self-employed) and now she is a housewife. The ICG is also a widow. She lost her husband at a young age. She was left with two children and has a new partner with whom she cohabits since the children were relatively young. She does not have to work because she receives a widows' pension. The ICG has three sisters. They all take care of their mother. Most common tasks are housekeeping, practical support and transportation (doctor, hospital, shop,...). The mother (DEP) has close contacts with the social worker and requests formal help if needed. The ICG most of the time gives practical support, such as transportation and doing groceries.

Dyad 2

The DEP is male and 84 years old. He has been ill since 1972. Since his retirement, his physical condition has been getting worse and he has developed cognitive disabilities in the last couple of years. The dementia process is at an advanced stage. The DEP is very dependent, he even needs surveillance care.

The ICG is 84 years old. The DEP is her husband. Both DEP and ICG are elderly. For a very long time they lived abroad. They moved back to Belgium when they retired. They are living in their own house. The relatives live at different places in the country. The ICG is still independent, but is aware of her age and the need for help in the future. Recently, she has been confronted with physical problems herself.

The ICG is still active as a volunteer in her own neighbourhood. She receives help from her daughter once a week, to do the shopping. Her brother and nieces live nearby. Her brother and sister-in-law bring small groceries when they visit. The nieces come to look after the DEP when the ICG has to go away.

She thinks it is very important to do as much as possible herself. She cannot drive a car, but she manages to use public transportation when needed (to go to the pharmacy, shop,...). It was difficult to interview the ICG as she Experienced difficulties in understanding the questions. She sees the care for her husband as a 'normal' part of their relationship, and not as a task.

Dyad 3

The DEP is female and 84 years old. She has been widowed for two years. She has recently been institutionalised (since October 2013) because of problems associated with dementia. Previously, she has been hospitalised several times. During the last four years, the situation has been getting worse, and especially over the past two years it worsened significantly. The only formal help she received, was nursing help.

The ICG is male and 55 years old. He is the son of the DEP and has been living together with his mother all his life. The ICG has one sister, who works nearby the parental house. The father and two other children are deceased. The ICG himself is on long-term sick leave (invalidity) and for a



long time was cared for at home by his mother. He is on long-term sick leave.

He considers taking care of his mother as self-evident. His mother became ill in a short period of time. Her health has deteriorated since the death of her husband. The son cared for her at home for as long as possible, until she was immobile, with late stage dementia, and it was no longer feasible for him to care for her in their present living environment. In the end the house needed adaptations, which were too expensive. There was no other formal help except for the nursing help.

Dyad 4

The DEP is female and 75 years old. She has recently been institutionalized because of Parkinson's disease (moderate cognitive impairment). She was admitted for a short stay in the nursing home until a permanent place was available. Before that, she was living alone a house in the city. She has been widowed for 17 years.

The DEP has a history of mental health problems. She was not a person who liked to socialise, and spent most of her time alone without making efforts to participate in voluntary associations. She had a difficult relationship with her family and they were not close. When psychological (due to Parkinson disease) as physical difficulties occurred, the DEP received a lot of formal help at home (nursing help/ personal care, domestic aid, physiotherapist at home, once a month a visit from the general practitioner, diner at home, personal alarm and transport). She even had help from her neighbours.

The most important ICG is the daughter-in-law. She is 53 years old. She is working full time as a teacher, and she was the only one with flexible working hours allowing her to provide support. Her partner is a nurse, and consequently has knowledge about the medical problems.

The ICG and her family recently went through a very difficult time. The ICG had to cope with breast cancer in the previous year. At the same time, the condition of her mother-in-law worsened significantly. The DEP not only has physical but also mental problems, which at times made the situation very difficult for the daughter-in-law. The son took time credit (1/5) for a few months to take care of his wife, the household and the DEP (his mother). More formal help was organised. The coordination of care was organised by the daughter-in-law (ICG).

Dyad 5

The DEP is female and 84 years old. She has been widowed for the past 16 years and lives in a service flat, an adapted apartment complex for older persons. For the last couple of years, she has been struggling with a lot of health problems, and she was admitted to hospital many times. Living alone in her home no longer was possible. At the moment, she is living alone in a service flat (without surveillance). Her children live nearby. She receives formal help for as much as possible and according to her wishes (nursing care, physiotherapist, domestic worker, personal alarm system) She does not wish to receive meals on wheels or help with transportation. She has always been engaged in the support of home caregivers and has been a volunteer herself. She has many social contacts with friends, family and neighbours. She knows where to gather information about help.

The ICG is the daughter-in-law. She is female and 55 years old. She works mornings as a housekeeper. She says she has time to support her mother-in-law. It is a caring family. The son is a volunteer at the transportation service of the Red Cross. The son and the daughter-in-law arrange for formal help and contact the formal home care services.

The ICG has experienced health problems herself because of an accident a few months ago. During this time, extra help for the DEP was requested and was received. Currently, she is still on sick leave.



4.3.3.2 *Are informal caregivers (ICG) aware of the existing policy measures?*

Awareness of existing measures targeting the DEP

In Flanders, not all ICGs were aware of existing support measures. They were also not actively looking for it.

The DEP receives help from the ICG with administration, filling in papers to request help, financial aspects. The ICG, most often, is the one who arranges help and he/she (ICG) searches for information, in order to support the DEP. The ICG (and DEP) need to look for information by themselves and this is not something that is self-evident or easy. Both the ICG and the DEP in most cases are unaware of the existing policy measures, with the exception of nursing help and domestic aid, which are also the most requested formal services requested by the DEP. Only in one single case, the DEP found the necessary information herself, with the help of a contact person from the Public Centre for Social Welfare. She was aware of the support measures that she could request (as DEP).

ICGs with a lower educational level seem to seek less information or help either due to financial restraints or because of their inability to identify the appropriate resources for information.

SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS FLANDERS PART 1-5-7

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 (VL_4_1B_time 40'19")

It's really researching and calling around, getting to know/ finding out. And then you see peers left and right who experience the same problems, the same situation and you work it out. It's really insisting, repeatedly filling out forms (VL_4_1B)

Ik denk dat de ene dienst over de andere, dat er dit en dat en. Via de dokter en... ja, want ik wist niet dat er zoveel diensten waren. Ik stond er echt van te kijken. Er zijn er echt veel. Het liep door elkaar heen. (VL_1_1A_time 24'38")

I think that one service after another, this and that. Through the GP and...I didn't know so many different services existed. I really was astounded. There are a lot of services. It all got blurred. (VL_1_1A)

De eigen kinderen hebben die diensten opgebeld (...) Ze hebben ook de papieren allemaal moeten invullen (VL_5_1A_time 23'28")

Her own children called the services (...) They have also had to fill out all the paperwork (VL_5_1A)

Mijn zoon en mijn schoondochter regelden de rekeningen, administratie, winkel voor kleding,... (VL_4_2B_time 9'33")

My son and my daughter-in-law managed the accounts, administration, clothes shopping,... (VL_4_2B)

Awareness of existing measures targeting the ICG

Regarding the policy measures available for the ICG, neither the ICG nor the DEP were appropriately aware of the existing policy measures for them (e.g. "mantelzorgpremie"), except in one case (where working and taking care had to be combined). Overall, information was hard to find.

If information was present, it was provided by someone else. This available information was given at discharge from the hospital (by social workers) and at moments when help was needed in urgent and critical situations. If the need for help increased due to hospitalisation and if the combination of working and caring no longer was possible, information about support measures was sought for by the ICG themselves, but this was not easy or straightforward.

It also seems that the ICG and the DEP do not make a distinction between the different allowances that they receive, "mantelzorgpremie" and "Vlaamse zorgverzekering". They see them as something similar. The following quotes illustrate the confusion.



SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS FLANDERS PART 3-5-7

Ik (ICG) trek een mantelzorgpremie, hey. Dat is 130 euro per maand. (...) De meeste mensen weten niet waar je van kan genieten, en zij (maatschappelijk werkster) zegt dat eigenlijk (VL_2_1A).

I (ICG) get a caregiver's allowance, hey. It is 130 euros per month. (...) Most people do not know you can benefit from these, and she (social worker) actually tells you (VL_2_1A).

Iedere maand van de mantelzorg krijg je een bedrag, dat wel. Dat heb ik van het begin af aan, op de ziekenkas gekregen. Daar heb je recht op zeiden ze, dat wel (VL_3_1B_time 46'48")

Every month you give care, you get a sum of money, sure. I got that from the onset on, via the care insurance . They told me I was entitled to that (VL_3_1B_time 46'48")

Er is maar een tegemoetkoming dat wij (ICG) gevonden hebben en dat is die van de mantelzorg zelf, dat is die 130 euro (VL_4_1B_time 40'49")

There is only one benefit we (ICG) found and that is that for the homecare itself, which is the 130 euros (VL_4_1B)

4.3.3.3 *Do the informal caregivers (ICG) benefit from existing policy measures and how?*

Policy measures targeting the ICG

The use of existing support measures and knowing them is helpful in keeping a balance, in particular when the ICG has a full-time career. Only one ICG combined work and care. Policy measures, such as leave arrangements (paid leave, flexible work arrangements) were sought for and used. Cash-for-care allowances ("Vlaamse zorgverzekering") were requested in a few cases. This allowance however was often too small to cover the costs for the ICG.

SEE REPORT INTRACASE ANALYSIS – DESCRIPTIVE RESULTS FLANDERS PART 2-7

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 (VL_4_1B_time 44'25")

It's a bit like a fixed schedule, but you could be flexible with it. They saw to it at work that I was able to switch shifts with colleagues. They are very nice colleagues, they have taken my situation into account (VL_4_1B)

Mijn man heeft wel eventjes tijdskrediet opgenomen, om 4/5de te gaan werken, een maand heb je dat gedaan. Dat was vooral omdat ik ziek was (VL_4_1B_time 42'57")

My husband has temporarily taken time off, "time credits", and worked 4 out of 5 days for one month he did that. That was mainly because I was ill (VL_4_1B)

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. Ik (DEP) vroeg, krijgen ze dan geen 15 euro voor een bosje bloemen. Ik vindt wij moeten die waarderen en vrijwilligerswerk wordt niet gewaardeerd; het is omdat je dat graag doet. Je moet daar eigenlijk niets voor hebben. (VL_5_2A_time 38'27")

The amount is not the same everywhere. In one place they get 50 euros, 20 euros at the other. That's a big difference. And here they get nothing. I (DEP) asked, can't they receive 15 euros for a bouquet of flowers? I think that we need to appreciate them and volunteering is not appreciated, it's because you're happy to do it. You do not really have to receive something in return. (VL_5_2A)

Again, only in the one instance where work and care were combined, respite care was used in the final stage of the care at home. The ICG herself was ill and unable to provide the necessary care. Institutionalisation of the DEP was pending.



Op een gegeven moment heb ik gezegd, X (familiehulp) kan je nu eens meegaan (naar de dokter) want voor mij is het efkes te veel. Ik kan geen ziekenhuis meer zien. Het is goed geweest, en dan heeft ze dat wel gedaan. Ze had ook controle over jullie moeder en ze zei Y nu ga je stappen (VL_4_1B_time 25'15'')

At one point in time I said, X (family help), can you accompany her (to the doctors) this time, because for me it's a bit too much at the moment. I can't stand another hospital. It went well, and she did it. She also could control your mother and she would say, now, Y you are going to walk (VL_4_1B)

Policy measures targeting the DEP

The ICGs are very concerned with the financial implications of needing more professional help. They want to avoid this for as long as possible, even it means that they have to look after the DEP 24/7. Only when the need for help increased due to hospitalisation, and when the combination of work and care no longer was feasible, information about support measures was sought for, but this was not easy or straightforward.

SEE REPORT INTRACASE ANALYSIS – DESCRIPTIVE RESULTS FLANDERS PART 2-7

Het is gestart via de sociale dienst van het ziekenhuis. Die hebben contact opgenomen met mij. Wij hadden ons adres opgegeven als contactpersoon. En die hadden dan gevraagd Wat gebeurt er als DEP thuis komt? (...) En dan is er verpleging gekomen. En dan is ze terug opgenomen geweest en dan heb ik direct aan de sociale dienst gevraagd wat kunnen we nog meer (VL_4_1B_time 1°11'58'')

It was started by the social service of the hospital. They contacted me. We had given them our contact data. And they asked, what happens if DEP comes back home? (...) And then nursing care at home was started. And then she was admitted again, so then I immediately asked the social services what else can we do? (VL_4_1B)

Familiehulp moeten we per uur betalen. Ik heb wel een tegemoetkoming voor hulp aan bejaarden, dat heb ik van april. Daar kan ik mijn hulp wel van betalen. En van de zorgkas. Ik heb 15 u hulp per maand, dat is 60 euro per maand, dat tikt wel door hoor. (VL_5_2A_time 31'13'')

Family care has to be paid by the hour. I have received an 'elderly assistance' allowance from April on. That helps to pay for the help I get. As well as the health care fund. I get 15 hrs of help per month, which is 60 euros per month, that is a substantial amount of money! (VL_5_2A)

Nee, je weet dat je overal hulp voor kunt krijgen, maar het moet ook betaald worden en dus alles wat je zelf kunt, en je had overdag toch tijd om iets te doen, zolang ik het zelf kan heb ik echt geen hulp nodig voor niets (VL_3_1B_time 45'10'')

No, you know that you can get help for everything, but it also has to be paid for, and so everything you can do yourself, and if you have the time during the day time to do something, as long as I can do it myself, I really don't require help for anything. (VL_3_1B)

4.3.3.4 *What has been the impact/effect of these policy measures on ICG lives, on the continuity of care for the dependent older person (DEP) and the possible impact on the institutionalization process?*

On the continuity of care for the DEP

The use of support measures (all kinds of formal help) towards the DEP is helpful in providing all the care the DEP needs. The ICG, together with the formal help that is available, tries to provide continuity of care.

Policy measures directed at the ICG (leave arrangements, flexible work arrangements) however are not well known and therefore seldom used. Only when the care situation is no longer sustainable, solutions are sought, but not easily found (except in one case)



SEE REPORT INTRACASE ANALYSIS – DESCRIPTIVE RESULTS FLANDERS PART 1-5-6-7

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 (VL_4_1B_time 24'49")

I had the advantage of being at home for a year (sickness). In that sense, it meant I could basically step up. I could also sometimes go along to the doctor. (VL_4_1B)

Als ik echt weg moet naar een begrafenis of zo heb ik nog twee nichtjes die komen oppassen. (VL_2_1A_time 7'12")

If I have to go to a funeral or so I have two nieces who come to watch. (VL_2_1A)

On the institutionalization process

In Flanders, the DEPs like to live at home for as long as possible, even if there are financial limitations. The ICG wants to take care of the DEP him- or herself for as long as possible, without much professional help.

More help implies higher costs for the ICG and for the DEP. ICG and DEP are aware of the fact that there are long waiting lists for nursing homes, service flats, and for respite care in nursing homes. The daily cost for staying in a nursing home is considered to be high.

The ICG often seems to be a full-time caregiver who helps his/her family and provides continuity of care without much professional assistance. When adaptation of the home is necessary, institutionalisation can often no longer be delayed.

SEE REPORT INTRACASE ANALYSIS – DESCRIPTIVE RESULTS FLANDERS PART 5-7

Ze betaalt het rusthuis met haar pensioen, daar komt ze om het rusthuis te betalen niet mee toe. Er zijn wel papieren ingevuld om te bekijken of ze het terugbetaald krijgt, maar dat zullen we moeten afwachten dan denk ik (VL_3_1B_time 44'22")

She pays for the nursing home with her pension, but it doesn't stretch far enough. Of course we have filled in forms to see whether or not it will be refunded, but I think we will have to wait and see (VL_3_1B)

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. (VL_4_1B_time 16'08")

Then the house was no longer adapted to her situation, the nurse said that showering was going to get difficult, to step into the shower every time. And then it was not in line with what the fire insurance required, it still had a gas stove, and the ventilation was not working properly. (VL_4_1B)

On the caregivers lives

The caregiver's allowance ("mantelzorgpremie") is not provided in all the cities/villages our respondents live in. The cash-for-care allowance ("Vlaamse zorgverzekering") is low and cannot cover all of the costs for informal care.

Existing support measures (leave arrangements; for example time credit and flexible work arrangements), if known, were helpful in keeping the balance between care, dealing with health problems and working.



SEE REPORT INTRACASE ANALYSIS – DESCRIPTIVE RESULTS FLANDERS PART 6-7

Het bedrag dat je krijgt van mantelzorg iedere maand, daar kan je boodschappen voor doen en dan is het ook op, van dat beetje kan je de financiële dingen niet doen. Als je overal hulp moet halen en alles moet bekostigen dan moet je een goede portemonnee hebben hoor (VL_3_1B_time 48'36'')

The amount that you get every month from the care allowance, you can use for groceries and then it's gone, with that small amount you cannot cover all financial things. If you need to look for help everywhere and everything has to be paid for, then you need to have some savings (VL_3_1B)

4.3.4 Wallonia

4.3.4.1 Context of the DYADS

In the situations investigated in Wallonia, the DEP can stay at home thanks to the overall support system. This system is a mix of some formal home services and sometimes other informal support, but coordinated by the ICG. In the different situations, the support system is at a relative equilibrium: without one of its components, the whole system may collapse, and maintaining the DEP at home would be compromised.

Dyad 1

The DEP (WL_1_2A), 78 years old, 80% disabled, finished an arduous cancer treatment. She lives in the house of her son and daughter-in-law since her release from the hospital, six years ago. At the moment, the situation of the DEP is stable. She is relatively independent, but only in the limited context of the family home as she can't walk anymore and has to move around with a wheelchair. With the exception of medical visits and some limited excursions, she hardly ever leaves the house. Since the ICG had a hip and shoulder surgery, she cannot push the DEP's wheelchair anymore. Therefore, The ICG's husband has to take leave from work when the DEP needs to leave the house.

The ICG (WL_1_1A) is her daughter-in-law (55 years old), who benefits herself from an allocation for disabled people. She takes care of the DEP with the help of her husband, who is working in a sheltered workplace. At the moment, she does not see the care in terms of burden, quite on the contrary. As she doesn't work, she now has company in the house and it doesn't take her more than a quarter of an hour a day to take care of the DEP. Six years ago, the situation was different, as they had to take the DEP into their house after a hospitalization. The home had to be adapted given the condition of the DEP, and she then needed more care. According to the ICG, caring for the DEP is the natural thing to do: it was the DEP's turn to be cared of, as she had taken care of her husband when he suffered from Alzheimer's disease.

The other five children of the DEP are not directly involved in her care. Nevertheless, the main caregiver can count on the occasional help from some other family members when there's a problem. The caregiver's daughter comes to the house once every two weeks to help her with housekeeping.

The DEP, the ICG and her husband are affiliated to the same medical house and have the same GP, who is their main link with the health insurance system. Formal home care services for the DEP include a daily visit from a physiotherapist from the medical center. Otherwise, the couple says they do not need anyone, as they can manage the situation on their own. The ICG said that she doesn't know where and how they could ask for more formal support. They don't know where to ask for an electric wheelchair, for example, which should allow them to go outside with the DEP more easily.



Dyad 2

The DEP (WL_2_2A), aged 82, is hemiplegic after suffering from two consecutive strokes. She lives alone at home and benefits from a variety of professional home care services organized by her son. After her hospital stay, the social service of the rehabilitation centre proposed that the DEP returned home, supported by a series of home services. Currently, she receives help with meals, personal care and housekeeping help. From Monday up till Saturday, a home help (in French "aide familial") comes in every lunch time to prepare a meal. A nurse from the medical house comes twice a week for a bath and for the preparation of medication. Three times a week, a physiotherapist from the medical centre comes to the DEP's house. Finally, a housekeeper comes every two weeks to clean the house. Up till now, the caregiver coordinates all the services needed by his mother.

The IGC (son of the DEP - WL_2_1A) is still professionally active. He works in public administration, which helps him to be well informed on the different forms of formal support that his mother can benefit from both the federal (financial or income replacement) and at the local (home care services) governmental level. He has taken all the necessary administrative steps in order to have access to as much formal support as possible. He also takes care of all other administrative tasks related to the payment of the costs of the local support system. He can easily adjust his working hours to visit his mother weekly or to go with her to the doctor.

According to him, the situation is currently manageable, even if he does not see any positive elements in this situation (as he says, he did not choose the situation). Nevertheless, he finds it 'normal' to play this role. He lives within an hour drive from his mother's house and his weekly visits take half day. However, in his view, staying at home is the best solution for his mother as she doesn't want to go to a nursing home.

In case of problems, in addition to professional services, the caregiver can also count on a series of people living in the immediate environment of his mother: a neighbour who is the first person contacted by the remote monitoring and alarm service in case of a new fall, a niece who comes to visit the DEP once a week, a friend, etc. These people do not perform specific tasks, but are available if needed. Nevertheless, the current situation largely rests on the caregiver's shoulders, without whom his mother could no longer stay at home.

Dyad 3

The DEP (WL_3_2A), aged 90 is highly dependent (she benefits from nursing "forfait C"): she cannot walk anymore and suffers from a rare form of dementia. She now lives in an apartment attached to the home of her youngest daughter, who is the main caregiver (WL_3_1A). Together with her 4 brothers and sisters, she has set up a shared monitoring and support system for their mother. Through an informal organization and with the use of a "road book" (coordination and communication tool) they divide the time needed to be present between the 5 children. The DEP benefits from the presence of one of her children day and night, 24 hours a day. The main caregiver ensures nights, while the other children ensure presence during daytime. When one child make it to ensure her/his permanence time, s/he relies on a home attendant of the complementary health insurance whom they have to pay for. Due to the health conditions of the DEP however, they pay a lower price (5 euros per hour instead of 8 or 35 euros a night instead of 56).

According to the main ICG, the system "holds" under the following conditions: she has to put her own life on hold, she needs to have a supportive husband, to have the regular support of her brothers and sisters, to be able to call a service (home attendant) in case of unavailability of one of the children, and the costs not covered by insurances need to be shared by all of them.

Every day a nurse from the medical centre comes in the morning to wash the DEP, and at lunch time to help the DEP with cooking and eating. In the early evening, an independently employed nurse comes to assist the caregiver with putting the DEP to bed. Three times a week, the ICG sleeps in her own house and a home attendant is paid to stay overnight in the apartment of the DEP.

But if the support system in place "holds", it is also very expensive for the caregivers. Indeed, neither the pension of the DEP (1040 euros per month), nor the various measures the DEP benefits from are substantial enough to cover all the costs.

**Dyad 4**

The caregiver (WL_4_1A) is the only child of the DEP (WL_4_2A), a 90 year old man suffering from Alzheimer's disease, mental health disorders and heart problems. Since the death of his wife, the DEP lives alone in his home. The ICG has a 12 year old son, but he does not live with him. Since the DEP showed signs of physical and mental frailty (for about two years), the ICG has to stay overnight in the house of his father. Given that the DEP owns his house and receives a retirement pension, he is not eligible for any financial assistance. The ICG decided to be fully in charge of the situation as they have to cover all the cost of formal services available and because he was not satisfied with the timing and the deliverance of services which were provided by the municipality (CPAS/OCMW).

The current situation is perceived by the caregiver as very "heavy", although still "manageable" because his father is not incontinent, can still get up and move around without assistance, and also because they have a good relationship. The caregiver has been looking for a nursing home for his father, but he could not find a place available. While waiting to find an appropriate place, he provides all the services that his father could benefit from in a nursing home. From the perspective of the caregiver, the "ideal situation" would be that his father could benefit from permanent assistance at home at the same daily cost of the nursing home (about 40 euros per day). But, according to him, this is not possible today in Wallonia.

Dyad 5

The DEP (WL_5_2A), 92 years old, suffers from medium to severe dementia.

The ICG (WL_5_1A) is the cousin of the DEP. She does not consider the situation as particularly difficult, even if she feels her life is "on hold", i.e. she can no longer leave the DEP at home by herself too often or too long.

The caregiver has been take care of her aunt for over ten years now, since the death of her sister, who lived with the DEP.

With the help of a neighbour, the caregiver performs all the needed tasks allowing the DEP to stay at home. This mainly consists of homework and surveillance. The neighbour is paid by the caregiver as an undeclared worker with the pension of the DEP. Without this informal help, the caregiver would have to take the DEP into her own home, as she has done for several other relatives before.

With the exception of the nurse from the medical centre who comes in every morning, the DEP does not use any other professional services.

Dyad 6

The DEP (WL_6_2B), 79 years old, has been suffering from deep depression for years, and was "placed" in a nursing home close to his home, four months ago. He is now nearly completely paralyzed, but his mental health problems have almost completely disappeared after stopping the use of all medication.

His wife, the ICG, had to undergo several surgeries and has been treated for cancer. She could no longer take care of him when he fell or when he was delirious. She emotionally suffers because of the current situation, feeling guilty her husband had to be institutionalised. She would take him back home if she could find a service that would come several times a day to the home in order to move him from his bed to his chair and vice versa.

Every day she spent several hours with him, brings him breakfast and evening meals, and washes him. Due to the lack of care received by her husband in the nursing home, caused by a lack of staff, she pays for the services of a physical therapist and a speech therapist for her husband. She also pays a young cook of the nursing home who therefore regularly helps the DEP to walk.



4.3.4.2 Are informal caregivers (ICG) aware of the existing policy measures?

Awareness of existing measures targeting the ICG

In Wallonia, none of the interviewed persons mentioned the policy measures targeting the ICG, as identified in the international comparison. This is probably because they are not eligible or because these measures do not respond to their needs.

SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS WALLONIA (PART 7)

“Je ne crois même pas que cela existe, je le saurais...” (WL_2_1A_M)

“Non, rien. Il y en a qui touchent de tous les côtés, nous on ne reçoit rien ” (WL_5_1A)

They are mostly informed about the existence of respite care services (day care centres, home attendant or others), but the cost and the structure of the services diminish their accessibility.

SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS WALLONIA (PART 7)

“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 ? ” (WL_4_1A)

“Je sais qu'il y a des services où on pourrait la déposer et venir la reprendre, mais cela ne lui plairait pas... et je ne voudrais pas lui mettre des étrangers dans sa maison...” (WL_5_1A)

Nevertheless, they indirectly benefit from various measures that support the DEP.

Awareness of existing measures targeting the DEP

The ICGs are unequally informed about the measures and services targeting the DEP that can either reduce the cost of home care services or the care tasks performed for the DEP. Lack of a centralized information source hinders the accessibility of home care services.

Access to home care services seems directly related to the ICG's (and/or to the DEP's) ability to look for the information which in return depends on their background (e.g. education level), on their needs and on whether they have a proactive attitude towards the search for help.

SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS WALLONIA (PART 7)

“On n'a jamais rien demandé, mais on ne nous a jamais proposé non plus. On ne sait même pas à qui se renseigner. Il paraît qu'il faut écrire à Bruxelles, mais où ? On n'a jamais eu l'adresse...” (WL_1_husband of the ICG)

“ Pour tout ce qui est je dirais administratif : belgacom, electrabel, la carte handicapé, les services qu'on peut avoir ici, notamment le service social de la Vierge noire, ça je connaissais déjà avant grâce à quelqu'un qui travaillait là et qui m'a un petit peu aidé. C'est moi qui ai rentré le dossier... Ça c'est le CPAS que j'ai été trouvé, qui m'a dit qu'on pouvait avoir droit à une petite indemnité. Donc j'ai rentré le dossier via le Dr B” (WL_2_1A)

The DEP and the ICG get information little by little. They get it, for example, from social workers at discharge from the hospital. The GP can also play a central role in the access to the information.

**SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS WALLONIA (PART 7)**

“Je savais qu’un service de kiné et d’infirmiers existaient à la maison médicale parce que quand maman avait des problèmes de santé elle appelait un kiné et c’est le Dr B. qui venait voir ce qu’il fallait à ce moment-là. Pour le reste, c’est surtout le service social du centre de revalidation. Au niveau de l’aide familiale, j’ai été mis en contact via les aides sociales du centre de revalidation, qui vous donnent les informations nécessaires” (WL_2_1A)

4.3.4.3 Do the informal caregivers (ICG) benefit from existing policy measures and how?**Policy measures targeting the DEP**

Available measures for the DEP benefit the ICG in two ways: either by reducing their care responsibilities, or because the overall cost of maintaining the DEP at home is reduced.

SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS WALLONIA (PART 6)

“Ce qu’elle a, c’est un forfait pour le téléphone, des petites choses comme ça... ça c’est un petit peu ma sœur qui s’est occupée de ça...” (WL_3_1A)

“Pour les aides familiales, qui viennent une fois par semaine trois heures, comme elle est handicapée, elle peut payer 5 euros au lieu de 8, c’est par la mutuelle...”

“Depuis son AVC, elle a une indemnité de personne handicapée. Cela lui couvre certainement ses frais d’aide-ménagère. Cela tourne autour de 240 euros par mois” (WL_2_1A)

Measures mentioned by the ICG and to which they have no access because they don’t meet all requirements (either the DEP or the ICG) include a tax reduction and access to a disability allowance.

SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS WALLONIA (PART 8)

“En termes d’aménagement fiscal, il n’y a rien. Il y a juste un aménagement fiscal au niveau du revenu cadastral, mais elle n’entre pas dans les conditions, c’est une question d’âge, il faut faire la demande à partir d’un certain âge. J’ai fait la demande par acquis de conscience parce que je suis dans la maison (SPF finances), mais elle n’en a pas eu droit...” (WL_2_1A).

“Il ne peut pas bénéficier d’une pension de personne handicapée parce qu’il est propriétaire de sa maison, ça veut dire qu’il peut couvrir ses frais...” (WL_4_1A)

The main impact of such “measures” is thus a reduction of the costs engaged by the “informal support system” set up around the DEP.

Although the different professional services are considered to be central pieces needed to maintain the DEP at home, the ICG are often critical about the way professionals deliver care. In a certain way, some of these services are perceived as inadequate or as too expensive (domestic help, home attendant...).

SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS WALLONIA (PART 5)

“Sauf que pour les repas, la dame vient parfois à 11 heures, c’est trop tôt, c’est midi, je préférerais à midi, mais c’est comme ça les arrange...” (WL_2_2A)

“Je ne veux pas incriminer, mais j’ai vu comment cela se passe... alors quand j’ai vu les factures que je recevais... ça ne me convient pas, ça ne me satisfait pas... Pour le ménage, ils te comptent deux heures, déplacement y compris...” (WL_4_1A)

“Avant, il y avait une femme de ménage des titres services, mais elle ne faisait pas à ma manière...” (WL_5_1A)



Related to the criticism directed toward formal services, ICG also mention “missing” services that they have been looking for for several years, and services that are more adapted to their own situations that do not exist in the local support system.

SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS WALLONIA (PART 5)

“ Si j’avais ne fût-ce qu’un service, ou une association de bénévolat, qui viendrait même deux heures par semaine, avec qui ma maman pourrait parler de temps en temps, ce serait déjà super..... j’aurais déjà quelqu’un quelques heures par semaine, je ne dis pas gratuitement, mais on vous demande jusqu’à 10, 15, 20 euros par heure... Pour un nouvel an, on vous demande 75 euros... et ils ne font rien hein... il n’y a rien vous savez... ” (WL_3_1A)

“ Je pense que le problème, c’est le manque de compagnie. Je pense que ce qui ce qui le fait le plus souffrir. S’il pouvait y avoir des gens qui éventuellement pouvaient lui rendre visite, je pense que cela lui serait très agréable. Je pense que le fait de rester seul en permanence lui est très lourd à supporter. Je suis allé au CPAS, on ne m’a jamais proposé, non, je n’ai jamais vu dans la documentation ce genre de chose... ” (WL_4_1A)

“ Cela fait maintenant deux ans que j’essaie de trouver deux personnes qui viendraient au moins quatre fois par jour pour le déplacer, parce qu’il ne peut pas rester au lit toute la journée... Parce que vous savez, il est dur comme du bois, et il faut toujours être à deux pour le soulever, pour le mettre au lit, du lit au fauteuil, du fauteuil au lit... On m’avait donné des adresses à Bruxelles, partout... J’en ai fait venir pas mal, mais toujours seuls, mais seul, ce n’est pas possible, parce qu’il est trop lourd, il ne peut pas vous aider, c’est un poids mort... Si un tel service existait, je le ferais, je le reprendrais ici... Ma maison est suffisamment grande, je le garderais en bas... Parce qu’ici il y a quand même beaucoup d’infirmières indépendantes, mais elles ne viennent jamais à deux...” (WL_6_1A)

4.3.4.4 What has been the impact/effect of these policy measures on ICG lives, on the continuity of care for the dependent older person (DEP) and the possible impact on the institutionalization process?

On the continuity of care for the DEP

In the five situations investigated in Wallonia, the support system set up around the DEP does not allow for avoiding interruption of care, often because leaves or absences of care professionals are insufficiently or not covered by the home care services. The ICG him/herself has to provide continuity of care through her/his own support system (family, neighbours,...).

SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS WALLONIA (PART 9)

“Depuis six ans, la kiné vient deux fois par semaine... sinon ils ne viennent pas quand ils sont en congé” (WL_1_1A)

“ 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... ” (WL_3_1A)

On the institutionalization process

In Wallonia, as in other regions, the DEP wants to stay at home for as long as possible and, when it is possible, the ICG also prefers to keep looking after the DEP themselves, at least those ICG who are no longer professionally active. The bad reputation of the nursing homes also plays a role in the choice to try to maintain the DEP for as long as possible at home.

**SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS WALLONIA (PART 9)**

“ Ma grand-mère était dans un home, ils étaient soit dans une pièce avec une TV, ils sont assis, ils ne discutent pas, dans une autre petite pièce on fumait (...), j'étais déjà dégoutée ... Voilà le problème. Il y en a peut-être des bons, mais jusqu'à présent, on a vus tous les mauvais... donc sans savoir dans lequel elle (l'aidée) va tomber... les personnes qui sont là-bas, sont un peu délaissée, ici, elle est 24heures sur 24, elle a tout ce qu'elle a besoin... Ici elle a tout ce qu'elle a besoin... ” (WL_1_husband of the ICG)

“ Je trouve que le matin et le soir ils ont peu à manger, je regrette de le dire, mais au home, les tartines sont petites... Et, comme dans tous les homes, il paraît qu'il y a restriction du personnel. Ce n'est pas de leur faute... Je ne peux pas revenir avant qu'il soit couché, parce que je dois être sûr qu'on l'a bien couché, est-ce qu'on lui a donné à boire, etc., parce que, comme je vois sa chambre d'ici, j'ai quand même dû aller plusieurs fois au milieu de la nuit parce qu'on avait oublié de le coucher, il était toujours dans son fauteuil, ou bien on oublie de le lever le matin, et quand j'arrive à 11h, il est toujours au lit, depuis la veille au soir... Ce sont des choses qui ne doivent pas arriver... ” (WL_6_1B)

On the caregivers lives

The caregivers interviewed in Wallonia see their caregiver's role in the area of the “natural” relationships between parents, between the members of the same family. Being paid for that role is therefore not an item, because of underlying values and because of how they were brought up.

SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS WALLONIA (PART 9)

“Je n'y ai jamais pensé... À partir du moment où cela se fait dans le système familial, non, pour moi cela va de soi que j'aide ma mère, sans que je me dise que cela me coûte du temps, de l'argent... cela va de soi. Maintenant, tout dépend de la famille... c'est naturel, cela me semble une relation naturelle entre parents et enfants, même si personne ne demande cela, cela se fait tout seul... ” (WL_2_1A)

“ Cela m'aiderait, mais cela ne changerait rien à notre relation, c'est mon père... Je pense que c'est le devoir de chaque enfant... ” (WL_4_1A)

“ On a aussi appris que quand je la prends par exemple pour aller à l'hôpital, que je pourrais me faire rembourser mes kilomètres... Mais c'est ma mère, je ne vais pas commencer à calculer : aujourd'hui je l'ai prise deux kilomètres pour aller là-bas, etc. On préfère se débrouiller tout seul, on est plus tranquilles... ” (WL_1_husband of the ICG)

This may explain why the caregivers do not ask to receive financial support. For them, it is not necessary to be paid for the tasks they perform as a caregiver. Although in some cases, they have to pay for services out of their own pocket.



4.3.5 Brussels

4.3.5.1 Context of the DYADS

Dyad 1

The ICG and the DEP are both of Moroccan origin. The ICG, born in 1936, is 78 years old. She arrived in Belgium in the 1980s and was an illegal citizen for several years. Her situation was regularized in 1986, when she married the DEP. She worked some years as a housekeeper and is now retired. She lives with her husband in social housing (an apartment). The ICG has two daughters, from a first marriage, who still live in Algeria. Her sister, who has nine children, lives in Brussels. The ICG can rely on her and her children for help when she needs it.

The DEP, 79 years old, is mentally disabled. All the members of his family live in Morocco. Nobody knows how and when he arrived in Belgium. He worked for 17 years in a sheltered workplace. After several stays in a psychiatric hospital because of his violent behaviour, he has now been living at home for 5 years, using heavy medication. He spends most of the day in bed, and does not require 24h/24 surveillance, which allows the ICG to leave the house during the day.

The ICG considers the current situation to be quite manageable, without any formal service at home, and for as long as the DEP is not incontinent. In fact, the GP is the only professional who regularly comes at home and is the only intermediary between the dyad and the local health and social system.

Dyad 2

The ICG, 51 years old, is the youngest daughter of the DEP, 85 years old. They are part of a Turkish family with 5 children. Four years ago, the ICG started to take care of her mother. For her, it was a moral obligation from which she could not escape. After her marriage, the ICG joined the family of her husband, but stayed very close to her mother, who never spoke French, unlike the ICG who quickly learned it at school. So, just after their arrival in Belgium, the DEP was dependent on the ICG for all administration and for contacts with organizations.

For several years the DEP lived in the same house as the ICG, till tension appeared between the husband, the ICG and the DEP. The husband

blamed his wife for spending too much time with her mother at the expense of their relationship. He required her mother to leave their house and forced the ICG to choose between them.

The ICG has tried to implement a system of shared support (see dyads 6 and 5) between the four daughters of the DEP, but they didn't agree. The ICG also considered leaving her husband and renting an apartment to share with her mother. But as this was not possible, the ICG looked for admission of her mother in a nursing home, close to her home. This 'solution' was experienced by both the DEP and the ICG as a profound disruption of their situation, and was very painful for both of them. Today, the ICG continues to visit the DEP every day and to bring her food.

Since the DEP has been institutionalized, the caregiver's life has changed a lot: she felt relieved of a great burden, and her husband is also satisfied. According to the ICG, the DEP is better supported in the nursing home than was possible at home.

Dyad 3

The main informal caregiver, 60 years old, is the spouse of the DEP, 66 years old and suffering from Alzheimer's disease. Both arrived in Belgium in 1973. The couple has five children: two daughters and three sons, all born in Belgium. They live on the second floor of a house together with one of their sons. Other children live nearby and take turns to relieve the caregiver in the evenings and during weekends.

For almost two years now, the DEP has become totally dependent on his wife. After an initial period during which the DEP manifested verbal and physical violence against her, his condition is now relatively stable, but his wife had to do more and more things for him. For the ICG, it is a full-time job, according to one of her daughters, who is a secondary caregiver. Sometimes she says she cannot cope anymore, but on the other hand, she refused help from home care services. According to the secondary informal caregiver, the situation at the moment is manageable.

Once a week, a nurse from the medical centre comes to the home to prepare the medication of the DEP. The medical centre also proposed that a nurse could come around to help the DEP for taking a bath, but the ICG refused because she considers this to be humiliating for her husband. She also feels this is her task. Two days a week, the DEP spends his day in a



day care centre, where he benefits from different services, and this allows the caregiver to rest a little and to take her mind of things.

Each year, the DEP and his spouse go back to Turkey to their family in the countryside for five months per year. Each of the children joins them in turn, to help their mother and to supply her with medication for the DEP from Belgium.

Dyad 4

The informal caregiver, of Romanian origin, takes care of her father in law, 69 years old, suffering from multiple and complex health problems (renal failure, diabetes, memory loss...). She also takes care of her mother in law, who is less dependent than her husband. The ICG has done this since she arrived in Belgium in 2005. She quickly learned French which allows her to communicate with the different hospital professionals she has met. She has gradually become both the interpreter and the reference person between the hospital and the family members. Her husband, who cannot speak or read French, cannot play this role.

The ICG performs a large part of the care tasks needed by the DEP. Several of his own children live in Brussels or elsewhere in Belgium, but none of them takes care of their father. The ICG explains that this situation is a 'Romanian custom': with Romanians, she said, the custom is that the younger son must take care of his parents until their death. As her husband can only play this role in a limited way since he is also dependent and does not speak the language, this role rests on the shoulders of his wife.

The whole family (four adults and three children) lives in the same apartment in Brussels. Since her arrival in Belgium, the ICG has had three children, two boys and a girl. Last year, one of her boys made a serious fall and had to be hospitalized for several weeks. During this period, the ICG has somewhat neglected her parents in law in order to spend more time with her son. Thankfully, during this period nothing happened to the DEP.

Being in the country illegally, the ICG works as an undeclared worker a few days per week, which allows her to be often available to take care of her father in law and to accompany him throughout the many medical and administrative steps they have to take. The situation will change when the ICG will be regularized because she'll probably have to find a full time job. Because of her illegal situation, of course, the ICG does not receive any

income or allowance (family allowance) from the public authorities. The only source of income for the couple is what they both earn as undeclared workers. According to the ICG, the costs of health care for the family members, however, are relatively low, because her parents in law benefit from a low-income status (BIM or 'vipo') and both have a health insurance.

The situation is perceived as relatively 'heavy' through the eyes of the ICG, who says that she is always on the road, her mind is always full of things she needs to do for the DEP, and she cannot rest or take a little time for herself. She can only relax when the DEP is hospitalized. But what is especially heavy, from her point of view, is the lack of recognition she receives from her parents in law. If they could be more grateful, she said, it would give her, a little more strength to run around for them...

Dyad 5

The caregiver, of Turkish origin, arrived in Belgium in 2000 together with her grandmother (DEP) when her father married a Belgian woman living in Wallonia, yet he is now divorced. Since a year, the DEP, 72 years old, can no longer stay alone at home, because her physical and mental health deteriorated. After two stays of several weeks in the hospital, she returned home, but she requires 24h/24 surveillance.

The DEP is thus the grandmother of the ICG. The DEP has always been like a mother to the ICG who came to live with her father, in order to take care of her grandmother. So the whole family lives in the same house, which allows the sharing of the DEP's surveillance that is provided in turn by the father of the caregiver (during the day), the caregiver (evenings and weekends) and the brother of the caregiver (evenings and weekends too). This organization is made possible because the father of the caregiver does not work, and because all three are currently single.

Every week, a nurse comes at home to prepare the medication. When it is not possible for the nurse to come by, the caregiver does it herself. The only professional service they use (apart from the nurse) is a transportation service that helps them when the DEP has to go to the hospital.

In the current situation, the caregiver does not encounter any real problem0073. When the day comes they can no longer can take good care of the DEP, they will consider her entry into a nursing home.



Dyad 6

The DEP is born in Turkey, in 1937. She arrived in Belgium in 1974, together with her husband and their five children (4 daughters and 1 son), who were all born in Turkey. The youngest daughter was 3 years old when they arrived. The DEP lived alone in her apartment, with the help of a family help who came to cook for her, until her husband died. The four daughters then decided together to take care of their mother, so the DEP moves between the houses of her daughters every couple of months.

Since the DEP was bedridden, she shows signs of mild dementia. She barely speaks, she cannot walk by herself anymore and she is incontinent. She also suffers from diabetes and is nourished with an abdominal probe.

Her four daughters, living all close to each other, are sharing the care for their mother by looking after her in turn, what makes the situation easier to support. None of the ICG are working, which facilitates the care organization.

The tasks that the daughters have to do for her are limited to her daily toilet, changing diapers three to four times a day, to give her medication, to care for her bedsores, to give her a daily injection, to control her insulin intake and to feed her.

Once a week, a nurse comes at home to prepare her medication and to change the bandage of her abdominal probe. Previously, the nurse also washed her, but in the absence of a "special" bed, she has refused to do so, at the expense of the daughters/caregivers. So there is no nursing support anymore. This is the main weakness of the support system they have put in place. Given that the DEP "circulates" between the homes of her four daughters, they cannot afford to pay for such a bed in each house. Her daughters/caregivers have also asked a physiotherapist to come at least once a week, but the GP considered this not to be necessary.

4.3.5.2 *Are informal caregivers (ICG) aware of the existing policy measures?*

The data collected during the interviews with non-native dyads gives an overall picture of scattered information. The DEP and ICG receive information unequally from the different professionals (social workers, GP, physiotherapist...) with whom they are in contact, depending on the circumstances. They are not automatically informed about existing measures, but only when they directly ask. Furthermore, the health

professionals are themselves unequally informed or up to date about existing services or measures outside of the health field, like the day care centre or like the allowance for elderly people.

Awareness of existing measures targeting the ICG

In the different situations investigated, the social workers and the GP played a central role in informing the ICG about the existing measures and services, although the level of information varies from one situation to another. While some ICG think they are well informed, like in dyad 5, others feel they have to gather the information about the existing measures by themselves. For illustration, the ICG of dyad 5 is well informed about the measures, which allows her to reduce her working time, and about existence of transportation services she can use when her grandmother has to go to hospital, etc.

SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS BRUSSELS (PART 6)

“ Si elle ne va pas bien, si elle doit rester dans son lit, à ce moment-là je vais demander... parce qu'ils m'ont posé la question, l'assistante sociale m'a dit que je peux demander pour aménager mon temps de travail. Pour l'instant, elle est bien, mais pourquoi pas, pour plus tard, si elle n'est vraiment pas bien, mais autrement, ça va. J'ai pris un congé un jour, lorsqu'elle est sortie de l'hôpital. J'essaie de m'arranger avec mon père... ”
(BXL_5_1A)

“ Oui, ça existe, mais par la mutuelle, on a demandé, et aujourd'hui on a fait appel, aujourd'hui ils vont venir, service transport avec une personne. Je me suis renseigné. C'est l'assistance sociale de la maison médicale qui m'a donné le numéro et qui m'a dit que je pouvais appeler ici... ”
(BXL_5_1A)



Awareness of existing measures targeting the DEP

The more the ICGs are in contact with the different social and health professionals, the more they are informed about the existing measures for themselves, but also for the DEP. As a consequence, the ICG who has few social relations and very few contacts with the social and health care system, like the ICG of dyad 1, completely depends on the information she gets from the GP.

SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS BRUSSELS (PART 6)

“ Si j’ai besoin de quelque chose, je téléphone au Dr V. Jamais j’ai été à la commune ou au CPAS, parce que c’est lui qui connaît sa maladie et tout ça..., je téléphone au Dr V. et il vient. (...) l’année passée, le Dr V. m’a aidée. (...) J’ai demandé au DR V. pour qu’un infirmier vienne le laver. L’année passée j’ai été, le Dr V. m’a aidée à le faire rentrer à la résidence...” (BXL_1_1A)

The social workers and the GPs play a key role in giving the ICG information about the existing measures and services targeting the DEP.

SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS BRUSSELS (PART 6)

“ Il y a une fois où un assistant social est venu ici, il m’a demandé si je voulais quelque chose, pour le ménage ou quoi, mais j’ai dit non merci...” (BXL_1_1A)

“ D’abord c’est celle (assistante sociale) de la maison médicale, c’est elle qui m’a le plus renseignée, parce que si elle ne m’avait pas donné tous les numéros... Oui, on peut trouver, mais c’est beaucoup plus facile si elle me les donne... elle est déjà passée à domicile, mais sinon, je téléphone, je laisse un petit mot et elle me rappelle ou c’est moi qui rappelle. Cela se passe très bien. C’est aussi elle qui me renseigne sur ce que je peux demander comme matériel à la mutuelle. Par exemple, on a demandé une chaise percée, une tribune, mais elle ne veut pas.” (BXL_5_1A)

“Il y a beaucoup de choses que nous on ne connaît pas, alors on demande au Dr V...” (BXL_6_1A)

The GP and the social worker also play a key role as an intermediary in the access of the dyads to the local support system.

SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS BRUSSELS (PART 6)

“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.” (BXL_3_1A)

“ Cela se passe bien, on fait tout ici (au centre médical). Cela m’aide bien, quand j’ai besoin d’un conseil ou de quelque chose, je viens ici...” (BXL_4_1A)

But if social workers and GP play a central role between the dyads and the local support system, these professionals are not equally informed or up to date about some services or measures outside of the health field, like the day care centre or the allowance for elderly people. Some ICG thus are under the impression that the needed information is scattered between the different professionals working in the different sectors (social, health...).

SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS BRUSSELS (PART 6)

“La maison médicale nous aide à nous diriger vers les spécialistes, on va dire, vers tout ce qui est médical... (Mais) on ne sait pas vraiment où aller, dans quel service aller pour demander de l’aide, on est pas assez bien renseignés, on ne sait pas ce dont on a droit, ce dont on n’a pas droit, il faut vraiment chercher soi-même, c’est vraiment par le bouche à oreilles, il faut faire une enquête soi-même, c’est malheureux.” (BXL_3_1A)

“On a introduit une demande auprès de l’APA, aide pour personnes âgées... Mais même ça, ce n’est pas à l’hôpital, ou un médecin, ou une



assistante sociale qui nous en a parlé, on l'a su bêtement, on ne savait même pas que l'APA existait, c'est une copine de mon frère qui en a parlé à mon frère parce que sa maman touchait une allocation de l'APA et j'ai été me renseigner, 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... C'est vraiment le bouche-à-oreilles et le on dit, qu'il faut un peu plus gratter, pour voir si c'est exact. 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." (BXL_3_1A)

4.3.5.3 *Do the informal caregivers (ICG) benefit from existing policy measures and how?*

In the six situations we investigated, the ICGs do nearly everything for the DEP they can by themselves. The few services the DEP receives at home are mainly related to medication issues that the ICG cannot manage. The existing financial measures (allowance for disabled people, allowance for elderly...) they use, do help them, by providing an additional income or in reducing the costs of the day care centre or of the care material the DEP needs.

Policy measures targeting the ICG

The offers for respite care services *at home* were mainly declined by the ICG who prefer to do the surveillance of the DEP by themselves, because they don't want professionals coming into their home to do tasks that they can do themselves.

SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS BRUSSELS (PART 5)

" Pour les vacances, il (l'assistant social) m'a dit tu peux partir, lui il reste ici et on va lui apporter à manger, mais j'ai dit non, je ne peux pas le laisser ici tout seul..." (BXL_1_1A)

" On m'a demandé si j'avais besoin, quand j'ai envie de sortir, on vous envoie quelqu'un pour une heure ou deux, comme ça vous pouvez sortir, mais j'ai dit non, ça va, on se débrouille " (BXL_5_15)

Short stays in day care centers (not at home) are more easily used by ICG to allow them to rest.

SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS BRUSSELS (PART 5)

"Il est resté là-bas vingt jours, à la résidence, c'est comme une maison de repos..." (BXL_1_1A)

"Il va dans un centre de jour, deux fois par semaine. (...) Pendant ces deux journées, elle récupère un peu, elle essaie de récupérer de sa semaine..." (BXL_3_1A)

Policy measures targeting the DEP

The access to existing measures is often linked with some administrative steps to be taken with the local authorities. But as most of the DEP do not speak French or Dutch, the ICG thus also has to make sure that the DEP receives the services he/she has the right to. The non-native DEP are not only "dependent" in their daily life because of their health conditions, but more broadly because they need help from other persons for administrative, legal, political, and educational matters.

SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS BRUSSELS (INTRODUCTION)

" Normalement, il peut toucher une allocation d'handicapé, mais ça fait dix ans que je cours à gauche et à droite. (...) Le Dr V., a dit qu'il a le droit, mais moi je suis fatiguée, et j'ai laissé le papier, la date est passée. Le Dr V. m'a demandé si je voulais encore un papier, mais je lui ai dit que non, que je veux pas courir à gauche et à droite, je comprends pas bien le français, je parle pas bien, alors j'ai dit non, je suis fatiguée..." (BXL_1_1A)



This 'linguistic' dependence explain why the youngest daughter or daughter in law has to help the DEP with all administration around care: the ICG is also often the only one of the children who has learned to read and to speak French and thus the only one who can help the DEP in these matters.

SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS BRUSSELS (INTRODUCTION)

“ 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. ” (BXL_2_1A)

“ Quand je suis arrivée ici je ne savais pas parler français, seulement anglais. J'ai été obligée d'apprendre à parler, parce que j'étais en contact avec des personnes qui ne parlaient que le français. Malheureusement, mon mari ne sait pas lire et écrire. C'est ça la difficulté. Il ne sait donc pas donner les médicaments, même si le pharmacien écrit sur la boîte combien de fois il doit prendre par jour... C'est ça la plus grande raison qui l'empêche de s'occuper de ses parents...” (BXL_4_1A)

The main financial supports for the DEP mentioned are reimbursement of the care costs by the health insurance or by the PMSSD, allowance for disabled people and allowance for elderly people (APA).

SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS BRUSSELS (PART 6)

“ Elle bénéficie d'une allocation pour personnes âgées (APA). Elle reçoit quatre cent et quelques, je ne sais plus... Et c'est ce qu'elle m'a dit aussi l'assistante sociale, elle m'a dit qu'on pouvait faire une demande, parce que c'est une personne âgée, il faut remplir le formulaire, elle a fait une démarche pour ça aussi, elle avait juste besoin de sa carte d'identité, elle passe chez nous, il n'y a pas de problème. ” (BXL_5_1A)

“ Ils ont une carte médicale de la mutuelle, donc c'est remboursé. Il y a des médicaments qui ne sont pas remboursés, mais la majorité, 95 % sont remboursés, merci à Dieu... Quand mon beau-père est à l'hôpital, c'est

remboursé par le CPAS. Par exemple, hier, il a une carte médicale mais il ne peut être hospitalisé qu'à l'hôpital du CPAS. L'infirmière m'a dit que je devais bien avoir sa carte médicale pour voir si tout est en ordre et qui est son assistante sociale. J'ai été voir si tout était en ordre. ” (BXL_4_1A)

“ Pour la nourriture, on paie une histoire de trois à quatre cent euros, plus environ 50 euros pour la machine et tout, plus ses langes,... Nous on paie nous-même. Juste pour sa nourriture, la mutuelle rembourse un petit quelque chose... Je crois que une fois par an on reçoit de l'argent pour ses langes ” (BXL_6_1A)

These existing financial measures help the DEP in the same way that these measures help anybody else: by providing an additional income or in reducing the costs of the day care centre or in reducing the cost of care material the DEP needs.

But as the income of the DEP generally is barely sufficient for the general living costs, it does not allow them to use these services frequently because of the cost.

SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS BRUSSELS (PART 7)

“ 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... ” (BXL_3_1A)

The non-native DEP, as well as the ICG use very few formal services at home. The reasons for this seem to be linked with some cultural/religious factors. First, some tasks are considered to be intimate and thus should be performed by an informal carer because they can affect the 'honour' of the DEP. Second, the formal services coming at home are also perceived as invasive. Finally, as in most of the professional services, it is impossible to choose the gender of the professional who will come at home, what can hinder the use of such services linked with this intimacy/gender issue.



SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS BRUSSELS (PART 5)

“ Je ne vais pas dire que c’est la faute à ma maman, mais au départ, l’infirmier, il était prévu et pour son pilulier et pour lui faire prendre son bain, mais elle n’a pas voulu, elle a dit qu’elle préférerait garder cette tâche pour elle parce que comme mon papa était quand même plus lucide l’année passée, pour elle c’était une humiliation par rapport à mon papa, que quelqu’un d’autre vienne lui donner son bain “ (BXL_3_1A)

“ Ici, au centre médical, ils m’ont demandé si j’avais besoin de quelqu’un pour les médicaments et tout ça, j’ai dit que non ça va, je peux le faire. Le ménage c’est moi aussi qui le fais. Je préfère le faire moi-même dans ma maison. Cela ne me plairait pas “ (BXL_4_1A)

“ Non, il n’y a rien. Il y a juste l’infirmier passe une fois par semaine, pour préparer ses médicaments, et c’est tout. Surtout qu’elle ne veut pas un homme infirmier...” (BXL_5_1A)

Home nursing is the most used formal services, but the nurse often only prepares medication. In only one situation the nurse washed the DEP, but she decided to stop doing this because of the absence of an adapted bed.

SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS BRUSSELS (PART 5)

“ Ils m’ont proposé, mais j’ai dit que ça va. Il y a juste l’infirmier qui passe une fois par semaine, pour préparer ses médicaments, et c’est tout... C’est nous qui faisons tout, mais on demande des renseignements. Par exemple pour la salle de bains, on a regardé avec l’infirmière et on nous a dit que pour l’instant elle a seulement besoin d’une poignée, c’est tout “ (BXL_5_1A)

“ Au début, il y a une infirmière qui venait, qui la lavait tous les jours... Comme elle avait une escarre à son pied, tous les jours elle venait la soigner et la laver. Et je ne sais pas pourquoi, par après, l’infirmier a décidé de ne plus faire les soins. Elle avait dit que si ma sœur ne prenait pas un lit spécial, qu’elle ne pouvait plus la laver. On lui a dit que si ma mère habitait la même maison, on prendrait un lit, mais comme elle voyage, ce n’est pas possible. ” (BXL_6_1A)

In two situations, a physiotherapist at home had been asked by the ICG but surprisingly, the GP considered that it was not or no longer useful for the DEP.

SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS BRUSSELS (PART 5)

“ J’ai demandé un kiné ces derniers temps comme elle ne bouge pas, et parce que quand elle se baisse, ses genoux craquent, mais le Dr P. m’a dit que ce n’était pas nécessaire pour l’instant. “ (BXL_5_1A)

“ La kiné, en fait, d’après le Dr V., elle n’en a pas besoin, mais moi j’ai demandé car elle en a besoin, parce que quand elle était à l’hôpital elle avait de la kiné tous les jours, et si elle n’en a pas, elle devient de plus en plus raide, et pour la lever, c’est plus dur pour nous. Il y a la kiné qui venait deux fois par semaine, mais quand le Dr V. s’est absenté.... Je vais demander que le kiné vienne. On a la droit quand même, on a notre mutuelle et tout... “ (BXL_6_1A)

In only one situation (dyad 2), a home cleaning service was asked, just before the DEP was institutionalized. This was viewed by the ICG as useful because it relieved her of this task and because it was also some form of surveillance for the DEP.



4.3.5.4 *What has been the impact/effect of these policy measures on ICG lives, on the continuity of care for the dependent older person (DEP) and the possible impact on the institutionalization process?*

On the continuity of care for the DEP

Two different causes of interruption of care services are mentioned by the interviewees. The first one is related to some occasional interruptions in the home visits of the professionals, which in fact are due to communication problems between home professionals and family members. These interruptions are sometimes a consequence of the way the support system is set up by the ICG, as in the case of dyad 6, where the DEP 'circulates' between the houses of her four daughters. When the caregiving is shared between several ICG and thus between several places, it may be difficult to organize professional services.

SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS BRUSSELS (PART 9)

“ L’infirmier nous a oublié la semaine passée, mais je crois qu’il est trop occupé. J’ai appelé la maison médicale, et on m’a dit qu’il était en formation... Il avait oublié de le dire. Alors j’ai préparé les médicaments comme la semaine passée, c’est pas difficile, parce qu’avec le s**, j’avais peur, mais maintenant c’est tout à fait facile... ” (BXL_5_1A)

A second but ‘specific’ (related to the relations migrants keep with their country or origin) cause of interruption of care is the regular stays of migrants in their country of origin.

SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS BRUSSELS (PART 9)

“ Mon papa part durant cinq mois en vacances par an, en Turquie, encore maintenant. (Là-bas, il n’y a) rien du tout, absolument rien. Il n’y a même pas un infirmier qui vient. C’est moi qui dois préparer tout un plan avec les médicaments qu’il doit prendre, mais maintenant elle (l’aidante principale) les connaît par cœur, à force de les donner, donc elle arrive à préparer le pilulier là-bas elle-même ” (BXL_3_1A)

The existing support measures cannot have an influence on these two causes of disruptions in care. However, on the issues of continuity of care and institutionalization of the DEP, the data collected suggest that when the ICG is alone to take care of the DEP at home and when the ICG is working, the home situation may not be the best place to guarantee continuity of care, as illustrated by dyad 2.

SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS BRUSSELS (PART 9)

“ Elle est encore mieux, parce que là ils contrôlent tous les jours son diabète, ce que nous on ne faisait pas ici... Elle a tous les jours ses médicaments, trois fois par jour... Elle est sous contrôle là-bas, pas à la maison. Moi je faisais ça le matin mais l’après-midi je ne contrôlais plus rien. Quand je revenais le soir, j’étais parfois tellement fatiguée que je ne montais pas. Donc, d’un côté, c’est très bien qu’elle est sous contrôle... C’est ce que j’ai essayé de lui expliquer... ” (BXL_2_1A)



On the institutionalization process

For all the non-native ICG interviewed, the institutionalization of the DEP is the last option. They take the decision to institutionalize the DEP only if there are no other solutions available to them.

The context in which the dyads live, however, conflicts with the cultural model that prescribes that the youngest child of the family should take care of the elderly parents. For example, in the host country, women have to work rather than to stay at home and take care of the older parents. This makes it harder to keep the DEP at home. As illustrated in dyad 2, tensions may occur between the DEP and his/her children and children in law and institutionalization of the DEP may be the only way to get out of the crisis.

SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS BRUSSELS (PART 9)

“ Mon mari était fâché à cause de ça, parce qu’il disait tu travailles, tu travailles à la maison, tu t’occupes d’elle, mais on n’a plus rien ensemble... Il avait raison, on ne savait pas aller à un mariage, on ne pouvait pas partir un week-end à nous deux parce qu’il fallait toujours être là... il y avait beaucoup de tensions... C’était un conflit en permanence, je ne voulais rien cacher à l’un ou à l’autre, mais c’était devenu un vrai problème. Cela ne pouvait plus continuer, on en était venu à un stade où mon mari ne me parlait plus, mon mari et ma maman de ne se parlaient plus... Il a dit c’est moi ou c’est elle, il faut choisir... ” (BXL_2_1A)

When institutionalization of the DEP occurs, it inevitably raises conflict and tensions between those who are living ‘there’ and those who are living ‘here’ and who have to make the decision, because two visions on care for older parents are conflicting.

SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS BRUSSELS (PART 9)

“ Pour nous, il est tout à fait normal que quand ça ne va plus, que la personne va dans un home, pour moi c’est très facile d’accepter ça. (...) Parce que pour des personnes comme moi, qui sont depuis 40 ans en Belgique, c’est sûr qu’on ne va plus retourner en Turquie. On va rester ici. Maintenant, on commence à accepter qu’il n’y a pas d’autre solution, on en parle, on se dit qu’on est prêtes, le jour où ça ne va plus, on rentre, on ne dit pas que ce sont nos enfants qui vont s’occuper de nous... ” (BXL_2_1A)

“ Normalement, chez nous, c’est toujours le garçon qui doit s’occuper des parents, parce que la fille quitte la maison quand elle se marie, c’est toujours au garçon de s’occuper des parents.” (BXL_2_1A)

“...On habite le village, et ce sont toutes des personnes, des cousins, tout le monde est dans le même village. Mes sœurs sont mariées avec des garçons du village. Mes frères sont mariés avec des filles du village, donc on se retrouve tous quand on va en vacances, c’est tous des cousins, et de la famille, de Hollande ou de France qui reviennent au village et là tout le monde se retrouve. Et là, tout de suite, le sujet revient à maman. Est-ce qu’elle aurait pu encore venir en vacances, pourquoi est-ce que vous l’avez enfermée ? Elle aurait pu rester avec l’une des autres filles, avec l’un des garçons, est-ce que c’était vraiment utile de l’enfermer ?... elle a une sœur, ma maman, en Turquie, elle a dit qu’il fallait absolument que vous l’ameniez, pourquoi est-ce que vous l’avez enfermée ? Personne n’a dit mais vous avez bien fait. Personne ne m’a dit ça. Tout le monde nous a dit que c’est moi qui l’ai enfermée. ” (BXL_2_1A)

“ La tradition, ou les coutumes jouent beaucoup aussi... rien que nous, entre filles et garçons, on a accepté qu’elle entre dans une maison de repos, mais autour de nous ce n’est pas le cas, parce que mes beaux-parents vivent en Turquie... ” (BXL_2_1A)

“ Chez les Roumains, c’est le plus petit qui doit garder ses parents, c’est la coutume. ” (BXL_4_1A)



In some complex situations, where the care giving is not shared between several ICGs, but rest entirely on the shoulders of the youngest daughter, institutionalization occurs especially because the ICG cannot find a good equilibrium between the different social roles she plays as caregiver, worker, spouse, mother...

SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS BRUSSELS (PART 9)

“ Eux (frères et soeurs) ne travaillent plus, ils sont chez eux à la maison. Il y en a deux pensionnés et une encore au chômage, mais moi je travaille encore, ça change beaucoup... Mon mari a dit que les autres enfants prennent aussi un peu en charge... mais mes sœurs ne voulaient pas... tout le monde avait une excuse... J'ai dit à ma maman qu'il n'y avait pas d'autre solution... Il aurait fallu que l'une d'entre elles la prenne un an à la maison pour qu'elles comprennent ce que moi j'ai vécu ici... ” (BXL_2_1A)

“ Je travaille un peu en noir, c'est pour cela que j'ai du temps pour l'instant... Comme je vous l'ai dit, j'ai fait une démarche de régularisation, je dois alors travailler avec un contrat de travail, à partir du mois de janvier, 34 heures par semaine. Je vais être plus souvent partie, je ne serai plus toute la journée à côté de lui. ” (BXL_4_1A)

“ À un moment donné j'ai eu des soucis avec l'un de mes fils qui prenait de la drogue. Je m'en suis voulu, parce que je m'occupais tellement de ma maman que je ne m'occupais pas de mes garçons. Je m'en suis voulu parce que je n'avais pas remarqué, je n'ai pas fait ce qu'il fallait pour mon fils et quand j'ai appris ça, j'ai un peu délaissé ma maman, parce que c'était d'abord mon fils. (...) ” (BXL_2_1A)

Institutionalisation thus is not a consequence of the health or mental health conditions of the DEP, but happens because the combination of the social roles they have to play hinder the children to play this role.

On the caregivers lives

The 6 non-native ICGs interviewed mention at least one major impact of their ICG role on their own life. Since they took up care, their life has changed. They feel 'stuck' at home, because the DEP needs 24 h/ 24 surveillance. Therefore, they feel that they no longer have any time for themselves.

SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS BRUSSELS (PART 2)

“Maman est une femme qui était très indépendante. Tous les jours elle était en vadrouille, que ce soit avec mon papa ou sans mon papa.. Maintenant, tout a changé, elle a tout sur les épaules, elle ne sait plus sortir quand elle veut, il faut une surveillance non-stop à la maison, elle ne peut pas l'enfermer à la maison et sortir... ” (BXL_3_1A)

“Je suis toujours en route. Il y a des fois que j'oublie certaines choses, ma mémoire est toujours occupée, où je dois aller, quoi je dois faire, je dois amener le papa là... Chaque fois que je viens à (centre médical), c'est pour lui ou pour elle, ou pour mes enfants, on me dit de laisser un peu de temps pour moi, mais je n'ai pas le temps... il a besoin de quelqu'un toute la journée pour rester avec lui. ” (BXL_4_1A)

For this reason, the day care centres are used by the ICG as a respite service allowing them to rest a little bit, to take a break or to be able to go on holiday.

SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS BRUSSELS (PART 5)

“cela fait dix ans que j'ai pas voyagé à cause de lui... parce que j'ai besoin de souffler un petit peu, mais ça coûte cher... L'année passée j'ai été, le Dr V. m'a aidée à le faire rentrer à la résidence, c'est comme ça je crois, c'est comme une maison de repos, à Schaerbeek, il est resté là-bas vingt jours.” (BXL_1_1A)



“ Depuis un mois il va dans un centre de jour deux fois par semaine, le mardi et le jeudi. Au départ il avait du mal à s'habituer, c'était nouveau, il ne voulait pas manger, pas participer aux activités, mais au bout de trois semaines il a tout doucement commencé à s'y faire. (...) Ils ont quasiment toutes les disciplines, il y a aussi de l'ergothérapie, de la kiné, il a des activités de groupe... c'est assez complet comme centre. (...) Pendant ces deux journées, elle (l'aidante principale) récupère un peu, elle ne sort pas constamment les deux jours. Il y a une journée qu'elle passe avec moi ou avec ma sœur, on va manger un bout, on va faire un peu de shopping, pour la distraire un peu, ou bien elle va voir ses copines, mais autrement elle essaie aussi de récupérer un peu de toute sa semaine. ” (BXL_3_1A)

4.3.6 France

4.3.6.1 Context of the dyads

Dyad 1

The DEP is a 95 year old woman. She became a widow at an early age and used to have a bookshop. When she entered her 80s, she progressively lost her autonomy. The caregiving relationship started in this context, involving a couple of former neighbours. The ICG also used to work for the DEP as a bookshop employee, and eventually bought the store from the DEP when she retired, by means of a life annuity. The son of the DEP lives in another city and is consulted for all major decisions taken by the ICG, only irregularly visits his mother, and does not provide assistance on a daily basis. The DEP has no social contact outside the team of formal and informal caregivers, as she lost most of her friends and relatives. The care relationship evolved in 2007, after the DEP's condition worsened, the role of the ICG(s) increased and the ICG(s) started to coordinate the dozen or so formal care and health professionals who look after the DEP at home. Although the professional status of the DEP as a private entrepreneur was not especially favourable in terms of social and medical insurance, she nevertheless benefits from the “Aide Personnalisée d'Autonomie” (APA) (cash-for-care allowance). As the ICG is very much informed about all services available, the DEP also benefits from local plans and financial/tax incentives such as vouchers (“chèque emploi service universel”) to cover additional costs related to domestic aid.

The ICG is a 64 years old woman. Although she retired a few years ago, she remains very active through voluntary work in a variety of local associations, and provides care on a more occasional basis to other relatives and neighbours. The caregiving relationship is shared with her husband, who is also retired and recently suffered from health problems. The ICG provides assistance to the DEP for administrative issues and the preparation of meals which are brought to the domestic aids and the DEP every day by the ICG's husband. However, their role mainly consists in coordinating the formal caregivers, collecting information on available services, making decisions with the son of the DEP to adapt the support system established when needed. The ICG started to provide care mainly for moral/ethical reasons, and reflects quite a lot on the sense, complexity and the social cost of this relationship, and of the French care system in general. She considers the economic and social cost of this system to be high, due to the lack of control of the (actual) activities of formal caregivers, but also due to the fact that it largely relies upon predominantly female, low qualified, domestic aids.

Dyad 2

The dyad comprises two spouses, both aged 86, living in the heart of a village where they both worked as bakers for decades, thus building a strong social network. They have three children, only one lives nearby and may provide some assistance. In 2011, the DEP (wife), fell down while visiting her husband at the hospital and broke her leg. After a long stay at the hospital and in a recovering house, the dyad came back home, where the ICG assists his wife. Currently, the autonomy of the DEP is very limited (she moves only with difficulty), which necessitated continuous attention and care, but her health condition otherwise is relatively good. Both the DEP and the ICG benefit from the APA, although at different degrees: while the DEP is credited of approx. 55 hours of services/month, her husband benefits from approx. 25 hours, because of his own disabilities, but also because of his role as an ICG. As part of the care system structured via the APA, about ten formal caregivers (nurses, domestic aids, physiotherapists) intervene on a daily or weekly basis, at very limited costs. The DEP emphasized that home helps, who operate locally, already belonged to the social circle of the couple, thus making formal care less “formal”.



This situation is depicted by the dyad as close to an optimum, due to strong family and social networks, to the fact that services are delivered locally by people they both know since their childhood, and to the willingness of the ICG to maintain a true marital relationship with his wife, that goes far beyond care. Mandatory hours for service delivery (especially at night) have thus been negotiated in order to secure privacy and shared activities. The role of the ICG is framed by this. He not only fills in “holes” left by formal care, but also prepares meals, ensures continuous surveillance and brings the DEP to bed. Both the ICG and the DEP emphasise that they feel “privileged”, both in terms of financial and of care support, despite their lack of autonomy.

Dyad 3

The dyad is living in very poor conditions in an isolated farmhouse. Access to the house is relatively difficult in winter and after heavy rains. The house lacks modern comfort, especially around heating and isolation. It barely changed since the 1960s. The DEP is an 87 year old woman, suffering from fast-evolving Parkinson’s disease. In 2004, she broke her femur and never fully regained her mobility. Moreover, her autonomy further worsened due to limited control over her hands, thus increasing the need for permanent care. She has a daughter (ICG) and a son, both in their 40-50s.

The ICG is her daughter. She is 47 years old, single and has no children. She seemingly always co-habited with the DEP. Formerly working full time, she reduced her work schedule to 80% and later 60% to cope with her role as an ICG. This role started after the death of her father and considerably evolved, in terms of dedication and complexity, after the DEPs accident in 2004, and more recently when she was diagnosed with fast-evolving Parkinson’s disease. The daughter is the only ICG, as her brother does not take an active part in daily care and lives about 40kms away.

Although both the DEP and the ICG (much more recently) benefit from the APA (Aide Personnalisee d’Autonomie), and are being assisted by nurses, domestic aid and a physiotherapist, are under the close supervision of the local GP, the ICG is strongly affected and hardly copes with the situation. Her mental and physical health have been impacted heavily, leading to an almost non-viable situation. The drop of her income – following the decision to opt for a 60% part-time, is not fully compensated by the benefit from the APA, thus worsening an already precarious situation. While the

health situation of the DEP evolves negatively, the psychological and health situation of the ICG also appears to be on the verge of becoming dramatic. Nonetheless, institutionalization does not seem to be considered as an option by the ICG.

Dyad 4

The DEP is an 87 year old woman. Her husband died about two years ago, and this event triggered a negative evolution in terms of psychological health and autonomy. Living in relative isolation, the DEP’s house was sold and she eventually moved to the village where her daughter currently lives. The DEP lived in a semi-independent house, maintaining some degree of autonomy without building social relationships other than with her daughter and the family of the latter. After a domestic accident, she broke her femur and was institutionalized after discharge from a rehabilitation centre. While she does not blame her daughter for this decision, she feels she has become “useless” and socialises hardly within the institution.

The ICG is a 56 year old woman and the single child of the DEP. She is married and has two children. The ICG works full time. Recently, however, she left on sick leave due to mental health problems. Mental health decline is related to depression and to experiencing difficulties in coping with the decision to institutionalize the DEP.

No service (domestic aid nor medical support) was used prior to the institutionalization. In this case, (heavy) dependence occurred quite suddenly, and no formal services were delivered at home to the DEP. The decision to place the DEP in an institution nearby came quite straightforward and no other option was seriously considered, following the recommendations of health professionals.



Dyad 5

The DEP is an 87 year old woman, formerly a physiotherapist. The loss of her husband had a direct impact on her health condition and autonomy. The health condition of the DEP worsened progressively, starting with difficulties in mobility and a lack of autonomy in dealing with daily tasks and administrative issues, thus necessitating the assistance of her relatives. Neurological problems progressively appeared, hardly noticed by the main ICG (the daughter), which made it necessary to require assistance from locally delivered health and home care services. Due to her relatively good financial situation (and the one of the ICGs), the DEP was not entitled to benefit from the APA. Yet, while health services (nurses, GP) were covered at 100% by her health insurance, domestic aid was financed up to 35%. Due to budget cuts in the expenses of local authorities, this financial support was nonetheless cut in 2013 and the ICGs now have to pay for it themselves.

The main ICG (daughter) assumed this role jointly with her husband since the death of her father. ICGs mainly assisted the DEP through daily presence, dealing with administrative issues and grocery shopping, while the DEP was visited by nurses and home help on a daily basis, during two years. Very recent institutionalization was due to a Cerebral Vascular Accident (CVA) and to the sudden worsening of DEP's neurological condition. Whereas ICGs pointed out the quality of the formal services delivered to the DEP, they also emphasized the initial lack of information for informal caregivers. ICGs referred to a general fatigue provoked by the stress and responsibilities that came with the care relationship, which progressively led to more mental health problems.

4.3.6.2 *Are informal caregivers (ICG) aware of the existing policy measures?*

Awareness of existing measures targeting the DEP

In France, all ICGs but one (dyad 4) were aware of existing support measures and available services, and actually used these. Nevertheless, awareness about support measures primarily concerns those for the DEP, which strongly affects the burden of responsibilities and tasks to be taken up by the ICG. Information about these policy measures – in particular about the “Aide Personnalisée d’Autonomie”, but also medical services provided locally by public structures, tax benefits attached to the use of the “Chèque emploi universel”, and access to home help through authorized associations (ADMR...) is widely accessible in France and is jointly delivered by GPs, private nurses, social workers (notably those working in municipal social centres: CCAS).

However, differences in social backgrounds between the dyads result in different degrees of information/awareness, with better informed caregivers being those who have a direct contact person working in the health or social care system. For instance, in dyad 2, the fact that one of the daughters of the DEP works for the regional health insurance service (CPAM) provided the dyad with first-hand, fully updated information about policy measures, thus resulting in a close-to-optimum situation in which the main caregiver only “fills in blanks” left by formal services, as he mentioned. To a lesser extent, in dyad 3, the ICG also benefited from good information about available services, as she works in a local hospital as a cook. In this case, the access to policy measures also revealed to be high both for the DEP and the ICG. Nevertheless, this did not result in an optimal situation due to the personal psychological and health problems of the ICG, the lack of financial resources and bad living conditions.

In contrast, the DEP who is not entitled to the APA because of having a higher income, also seems to have less access to information. The ICG(s) finally had access to most available services and resources, notably thanks to the added information provided by a social worker belonging to their inner family circle, and the support of the local GP. Yet, in dyad 4, the ICG seems to have had only limited access to information, and the decision to institutionalize the DEP was taken mainly drawing upon the information provided by health professionals.

**SEE DESCRIPTIVE COUNTRY REPORT, FRANCE PART 5-6*****Dyad 2***

“ C’est surtout par ma fille. Celle qui vit à Marseille est assez au courant puisqu’elle travaille à la Caisse Régionale d’Assurance Maladie depuis 36 ans. C’est une information qu’on a eu et dont on s’est servi pratiquement tout de suite. On a dû être pratiquement les premiers à en bénéficier à St Michel, parce qu’on avait un dossier, on peut dire en béton.” (FR_02_1A_M)

“ Il y aussi une infirmière qui est venue deux fois (pour (...)). Le responsable CASIC aussi, est venu pour se rendre compte si tout va bien.” (FR_02_1A_M)

Dyad 5

“ Dans un premier temps, une assistante sociale à l’Hôpital de Banon (...) nous a dit : “ vous avez droit à ça “, ensuite une cousine (...) qui a été assistante sociale et à qui nous avons téléphoné, nous a dit : vous avez droit à ça. Ensuite il faut aller voir l’ADMR. On se rend compte que l’ADMR des Alpes-de-Haute Provence ne fonctionne pas (in this isolated village on the edge of another district). Alors il faut découvrir l’ADMR (du Vaucluse). Il faut prendre connaissance, un contrat. On apprend qu’une partie des aides peut être prise en charge par l’état : il y a une assistance sociale qui vient d’Apt, une autre d’Avignon qui viennent voir que tout marche (...), pour vérifier l’état de ma belle-mère “. (FR_5_1B_M)

Awareness of existing measures targeting the ICG

The APA was used also by the ICG in dyads 2 and 3. In dyad 2, the ICG (Male, 86) benefited from the APA both due to his own lack of autonomy and his role as an ICG. In dyad 3, the ICG benefited from nearly the maximum monthly APA hours because of her role as an ICG. It is also worth mentioning that, except for dyad 1, awareness about respite care was quite limited. Respite care, although available in the form of day-care centres and short-stay institutionalization, was not used by ICGs of our sample, mainly for psychological reasons and because of the emotional nature of the care relationship. Yet, the ICG in dyad 3 used a leave arrangement (Congé de solidarité familiale), in the form of a 60% part-time awarded for 3 months (renewable), without compensation for the drop of income, but indirectly compensated by the benefit of the APA (see: above).

SEE DESCRIPTIVE COUNTRY REPORT, FRANCE PART 5-6***Dyad 1***

L’autre jour, je discutais avec une jeune fille dans le bus, qui faisait son mémoire sur l’aide ponctuelle aux aidants (...) Elle me disait que les maisons de retraites mettent en place des systèmes de garde pour un court laps de temps. Alors elle m’encourageait à ça, elle voulait me démontrer le bien-fondé de la chose. Alors j’ai réfléchi à ça et je pense que dans ce cas, la perturbation qu’on induit (pour la personne dépendante) peut la faire mourir. Ça serait catastrophique. C’est là qu’il y a une ambiguïté, parce que des fois, mon mari et moi, on en a marre, c’est vrai, mais on continue parce qu’on se dit que le moindre grain de sable va avoir une connaissance immédiate. (FR_01_1A_F)

Dyad 2

C’est surtout par ma fille. Celle qui vit à Marseille est assez au courant puisqu’elle travaille à la Caisse Régionale d’Assurance Maladie depuis 36 ans. C’est une information qu’on a eu et dont on s’est servi pratiquement tout de suite. On a dû être pratiquement les premiers à en bénéficier à St Michel, parce qu’on avait un dossier, on peut dire en béton. (FR_02_1A_M)



Dyad 3

Je suis pas au courant (de services susceptibles de lui offrir un répit) (...) L'astuce, d'abord, c'est qu'il faut trouver les bons intervenants. L'année dernière, j'ai eu de grosses difficultés avec une aide-ménagère. Parce qu'il faut faire confiance, et c'est pas évident. Je peux pas dire demain à Paul, Pierre ou Jacques de venir...(FR_3_1A_F)

4.3.6.3 Do the informal caregivers (ICG) benefit from existing policy measures and how?

Policy measures targeting the DEP

ICGs directly benefited from policy measures to which DEPs were entitled, i.e. the APA in the first place. Two ICGs were themselves entitled to the APA, either because they had disabilities themselves or because of their role as a carer or both. Even without access to the cash-for-care allowance (e.g. because of having a high income), available services and existing support measures for the DEP were used, thus turning ICGs into care managers of a support system involving a number of formal services delivered by professionals (including domestic aids (up to 3X/day), nurses operating on a private status or through local public hospitals (up to 3X/day), GPs (up to 1X/week), and physiotherapists (up to 3X/week)).

Only in dyad 4, it appears that the ICG was not properly informed about available services and measures. This is due to a specific situation in which the loss of autonomy appeared quite suddenly, thus resulting in the intervention of health professionals operating at the hospital, rather than from local GPs or social services having a more refined picture of the living conditions and personal situation of the DEP.

As it mentioned before, accessibility to existing policy measures is related to different variables (personal networks, information provided by local social services and GPs, personal financial situation of the DEP, which conditions access to the APA, and to a lesser extent, to other local support plans, physical status of the DEP (usually assessed by GPs and practitioners delegated by the local authorities managing the APA, professional situation, psychological and health condition of the ICG).

SEE DESCRIPTIVE COUNTRY REPORT, FRANCE PART 5-6

Dyad 1

Mme... (bénéficie de) 3 heures ADMR + 1h1/2 CESU tous les jours, sans compter l'aide bénévole. Si on comptait 2h bénévoles par jour, je ne sais pas à quoi ce serait évalué. (FR_01_1A_F)

Dyad 2

Ces heures (APA : Aide Personnalisée d'Autonomie) sont pour moi. Souvent, lorsque ma femme à 2 heures, moi j'en ai 1. L'autre jour j'avais un dépassement horaire, et ils m'ont appelé pour me demander ce que je préférais supprimer, pour récupérer le dépassement du mois d'avant. (FR_2_1A_M)

Ces heures se transforment en aide financière. Je ne reçois pas d'argent, c'est directement versé (aux prestataires). Dans le contrat (APA), je suis (inscrit) avec mon épouse. (FR_2_1A_M)

Dyad 3

Au mois d'avril, il a fallu réévaluer son dossier. Même en 2011, il a fallu réévaluer sa situation. Bon, sa situation a changé brutalement deux mois après. Donc cette année, on a encore réévalué, parce que moi quand même je voulais me faire aider. Parce qu'à 80%, j'ai perdu de mon salaire et à 60%, c'est la fin des carottes, quoi. Donc ils m'ont octroyé des heures à moi. Si vous voulez, c'est comme si ma mère m'employait avec des chèques emploi service. En gros, c'est ça. J'ai commencé à en faire la démarche au mois de janvier et on a eu le résultat au mois de mai. (FR_3_1A_F)



Policy measures targeting the IGC

Besides receiving the Allocation Personnalisée d'Autonomie (2 ICGs), ICGs did not refer to other services for themselves such as the use of respite care or unpaid leaves. The ICG in dyad 3 nonetheless used a leave arrangement (Congé de solidarité familiale), in the form of a 60% part-time awarded for 3 months (renewable), without compensation for the drop of income, but indirectly compensated by the benefit of the APA (see: above).

SEE DESCRIPTIVE COUNTRY REPORT, FRANCE PART 5-6-7

Dyad 1

“ Alors j'ai réfléchi à ça et je pense que dans ce cas, la perturbation qu'on induit (pour la personne dépendante) peut la faire mourir. Ça serait catastrophique. C'est là qu'il y a une ambiguïté, parce que des fois, mon mari et moi, on en a marre, c'est vrai, mais on continue parce qu'on se dit que le moindre grain de sable va avoir une connaissance immédiate.“ (FR_01_1A_F)

“ Nous sommes partis nous occuper du père de mon mari. Nous avions prévu de partir 8 jours. Cela m'a demandé deux jours de préparation pour qu'il y ait absolument tout, prévenir tout le monde. Mon mari a décidé de rester un peu plus auprès de son père, et moi je suis rentrée pour reprendre le relais auprès de Mme... Je ne pouvais pas partir 8 jours, car je n'avais pas prévu pour. Là nous sommes repartis 8 jours, c'était assez exceptionnel, mais j'y retourne “. (FR_01_1A_F)

Dyad 2

“ La question ne s'est jamais posée. Je ne pense pas, moi, à laisser mon épouse, parce que je n'ai pas non plus une mobilité (...) mes jambes, tout ça. Donc j'ai pas l'ambition de confier mon épouse. Je pourrais, parce qu'il y a des gens disponibles “. (FR_02_1A_M)

“ Si c'était une question d'argent, je pourrais me prendre huit jours de congés “. (FR_02_1A_M)

Dyad 3

“ J'ai demandé à passer à 60%. C'est un congé de solidarité familiale. J'y ai droit 3 mois, renouvelables. Mais bon, je vais continuer à 60%, de toutes façons, je ne peux pas faire autrement. D'abord, je ne me sentirais pas ni physiquement ni moralement “. (FR_3_1A_F)

“ Cet été, j'ai été coincée. (...) La personne qui vient, L..., était en congé, et l'autre personne aussi. Je n'avais personne. J'ai dû poser des congés. (FR_3_1A_F)

Des fois, j'en ai besoin, parce que je pète les plombs. (...) Mais moi, il faut que je sois là 7 jours sur 7 “. (FR_3_1A_F)

Dyad 5

“ Quand je dois partir, je préviens le fils de Mme.: je serais absente 8 jours, j'ai tout préparé. Je préviens l'ADMR, les infirmières, après c'est à Dieu-va “. (FR_5_1B_F)



4.3.6.4 *What has been the impact/effect of these policy measures on ICG lives, on the continuity of care for the dependent older person (DEP) and the possible impact on the institutionalization process?*

In France, the access to policy measures summarized above, had a direct and huge impact on ICGs' living conditions, the continuity of the care delivered to the DEPs and the (non)institutionalization process.

On the caregivers lives

The wide availability of policy (mainly financial but also in terms of coordination via social and health professionals) measures and formal care services to the DEPs directly benefits to the ICGs. As the (high) degree of intervention and frequency of formal care services does not much vary among dyads, the roles the ICGs take up, are mainly influenced by the following variables:

- Their own personal (psychological, professional, health) situation, which makes them more or less ready to cope with the care relationship;
- Their affective or emotional relationship to the DEP, which also determines what ICGs consider to be their own contribution/duty as part of the support system.

SEE DESCRIPTIVE COUNTRY REPORT, FRANCE PART 5-6-7

Dyad 2

“ (Le plus indispensable) ce sont les infirmières, parce qu’elles sont là pour la lever le matin et ce sont elles qui lui font la toilette. Une fois par semaine, il y a la grande de douche (...). Le soir, on lui met une couche de nuit, et je ne sais pas la mettre ”. (FR_02_1A_M)

Dyad 3

“ Il intervient les aides-soignantes, le matin (...).Elles arrivent pour faire la toilette, pour la lever. Elles arrivent vers 9h. La toilette jusqu’à 9h30. Ensuite on doit la faire déjeuner. Dans le meilleur des cas, elle finit vers 10h10. A 12h, il faut la faire manger, donc il y a un tout petit deux heures entre les deux ”. (FR_3_1A_F)

(Domestic aids) : “ Elles m’aident pour lui donner ses repas, pour le ménage. C’est sûr que ça me soulage, sans ça je pourrais pas fonctionner (FR_3_1A_F)

Dyad 5

“ (service indispensable :) L’infirmière qui passait le matin et le soir pour les médicaments ” (FR_5_1B_F)

On the continuity of care for the DEP

None of the dyads included in our sample experience disruption in the provision of formal services. The APA beneficiaries benefit from provision of formal care services according to the care plan. For the dyad without access to the APA (those with higher incomes), services seem to available in a less structured way, but via similar authorized formal care providers. In our dyads, GPs, local social services and hospitals, and the AMDR (providing authorized domestic aid) play a key role in ensuring the continuity and quality of formal services. It is worth stressing that almost no informal help was used (with the relative exception of dyads 3 and 5, with the intervention of neighbours or informal domestic aid, respectively at no cost – dyad 3 and a limited cost, dyad 5).

SEE DESCRIPTIVE COUNTRY REPORT, FRANCE PART 5-6-7

Dyad 1

“ Dans la soirée, vient l’équipe infirmière du soir, ce ne sont pas les mêmes. Ils la toilettent, la changent ” (FR_01_1A_F)

“ A 7h-7h30, une dame vient ouvrir les volets de la chambre et donner le petit déjeuner de Mme... Elles restent 1/4h environ “. (FR_01_1A_F)

“ L’aide-ménagère (ADMR) va arriver vers 10h45-11h00 (...). Mme... va déjeuner avec le repas que j’ai préparé, les filles vont laver l’assiette, faire son lit et vider la chaise percée dans sa chambre, ce qui est toujours un énorme problème “. (FR_01_1A_F)



“ Une dame du soir vient pour la faire manger et la coucher, et elle referme la porte “. (FR_01_1A_F)

Dyad 3

“ Les aides-soignantes interviennent de cette façon 7 jours sur 7, férié, pas férié, qu’il neige où qu’il vente “. (FR_3_1A_F)

Dyad 5

“ On a eu la chance d’avoir l’aide à domicile, l’ADMR, qui était très efficace, donc on était aidés “. (FR_5_1B_F)

“ La personne qui tous les jours, allait chercher les repas (à l’hôpital local). Des repas complets, diététiques, qui ne coûtaient trois fois rien : 3,50 euros, on était surpris (...). Et ça a duré tout le temps, jusque les derniers temps “. (FR_5_1B_M)

It is also worth stressing that this system also relies upon very institutionalized and professionalized home care services, as the ADMR, which expanded its activities from rural to urban areas. The growth of these services mainly depends upon an extremely flexible (scattered hours), ill-paid and occasionally low-motivated or qualified – almost exclusively female, group of staff. It thus contributes to maintain the gendered dimension of care.

On the institutionalization process

Altogether, these elements contribute to explain that institutionalization seems to intervene only in the last stages or in case of an emergency, as the last and least preferable, solution. Institutionalization is usually caused by a sudden worsening in the DEP health condition making it impossible to maintain the DEP at home. This situation was confirmed by the information provided by the director of a local hospital also serving as a geriatric institution (which is almost always the case) and local GPs contacted for the purpose of this study, who depicted public institutions as mainly receiving heavily dependent people.

SEE DESCRIPTIVE COUNTRY REPORT, FRANCE PART 5-6-7

Dyad 1

Les infirmiers, le kiné, le médecin sont pris à charge à 100% par la sécurité sociale. Mme ... était commerçante, inscrite au RSI (Régime Social des Indépendant), et est prise en charge. La carte vitale de Mme... est le bien le plus précieux de la maison, et les professionnels l'utilisent pour déclarer leurs actes. La sécurité sociale prend en charge également le lit médicalisé. (FR_01_1A_F)

Dyad 2

Ma femme bénéficie de 53 ou 55 heures par semaine et moi de 25 heures environ (APA : Aide Personnalisée d'Autonomie). Et ce pour une somme dérisoire. L'autre jour, je devais trois mois de prestations au CASIC, alors je leur ai fait un chèque de 5 euros pour tous les deux, pour trois mois. C'est pour ça, même si on est pas des nantis – parce que si on reçoit une aide, c'est parce que mes revenus ne sont pas suffisants (FR_02_1A_M)

(Le plus indispensable) ce sont les infirmières, parce qu'elles sont là pour la lever le matin et ce sont elles qui lui font la toilette. Une fois par semaine, il y a la grande de douche (...). Le soir, on lui met une couche de nuit, et je ne sais pas la mettre. (FR_02_1A_M)

Dyad 5

L'APA (Aide personnalisée d'Autonomie), elle n'y avait pas droit, pour des raisons financières. Mais par contre elle avait droit à je crois 35% d'aide jusqu'à cette année, pour payer la personne qui venait au titre de l'ADMR. Mais avec les restrictions budgétaires, on a supprimé cette aide cette année. (FR_5_1B_M)

Elle bénéficiait de ce qu'on appelle le 100% médical, ce qui fait que les infirmières qui venaient ne lui coutaient rien, ni à nous non plus. (FR_5_1B_M)



4.3.7 The Netherlands

4.3.7.1 Context of the DYADS

Dyad 1

The DEP is female and 84 years old. She is recently widowed (5.5 months). The DEP's health situation has deteriorated since the death of her husband, and she developed cognitive problems. The DEP is in the early stages of dementia.

The ICG is the 59 years old son. He is single. A combination of circumstances (divorce, burnout (illness), death of father and mother's health decline) made him move in with his mother. He moved from the city to the country to take care of his mother (since the death of his father). He is on long-term sick leave. His father was very ill before he died and his mother took care of him at home. She only had nursing help. All the other tasks she did by herself during her husband's illness.

The ICG receives no caregiver's allowance ("*mantelzorgcompliment*"). Formal home care services are paid by the health insurance and are included in the care package of the DEP. They do not receive a lot of formal help, only home nursing. The son is doing the household, gives practical support and does surveillance.

The son is the only person the DEP can rely on. The family is very private. They have very limited contacts with the social environment. The only family nearby is the family of the daughter and son-in-law, who both still are working and are not always able to offer immediate assistance.

Dyad 2

The DEP is male and 86 years old. His wife died 2 years ago. Since then his health situation has deteriorated (especially cognitively). He is living together with his son. Recently, he started to receive nursing help every day, especially to assist with the medication intake and for his personal care. He also receives home help once a week. Diner is brought to the home daily, for him as well as for his son.

The ICG is the 58 year old son of the DEP. He is a farmer (self-employed) and single. He owns his own home, but lives together with his father on the farm. He has been taking care of his father for one month at the time of the interview. Before he moved in, his sister visited their father daily. Because

of breast cancer, she no longer could look after her father. The ICG is giving practical support and doing administration. The home organization coordinates nursing care and home help. Except for the DEP's participation in the cost of care, payments for formal help are included in the care package. The ICG does not receive the caregiver's allowance ("*mantelzorgcompliment*"), and is not financially compensated by the DEP for caregiving.

Dyad 3

The DEP is female and 84 years old. She has been widowed for 14 years. Since October 2013, she has been institutionalized in a service flat with surveillance support and practical support. She was a very lonely person before she moved out of her house. Now (in the service flat) she receives a lot of formal help: nursing help, home help, a personal alarm system, and having dinner once in a while in the public area of the service apartment. She thinks it is normal that her daughter takes care of her.

The ICG is female and 54 years old. She is the only daughter of the DEP. She has three brothers, but only one of them offers help in giving care for the DEP. She works part time (50%) at the town hall in her own town, but she has been on sick leave for the past three months. She has a lot of social contacts. While she is on sick leave, she visits her mother every day, but once she gets back to work, she will no longer be able to do that. She arranges practical support, administration, transportation, etc. She receives the caregiver's allowance for giving informal care and she also can take unpaid sick leave for a maximum 12 days per year to take care of her mother.

**Dyad 4**

The DEP is female and 80 years old. She has been a widow for 18.5 years. She lived in an apartment in the city for several years. A few months ago, she moved to a service flat in the country side to live closer to her children. She has no need to use the care facilities offered by the service flat, such as surveillance, or having meals delivered at home. The only help she receives, is a nurse coming to the home twice a day, and home help once a week. Formal services are paid for by the health insurance. She pays a fixed amount a year and all available services are included. In the city more services were available than where she lives now.

The ICG is her 47 year old daughter. She works full time (100%) and is single. She visits her mother every day. She has diner with her mother, does the administration and gives practical support. She is unable to take up time credit or unpaid leave to take care of her mother because of her financial situation. She receives the caregiver's allowance since this year. Her sister helped her to request the cash allowance.

Dyad 5

The DEP is female and 96 years old. She has always been single. Since May 2013 she has been institutionalized, first in a short-stay residential facility and then, when a room was available, in the nursing home of her home town. The DEP has always been a happy person. At the moment, she is in an advanced stage of dementia. She made arrangements before she became ill. Practical support and care tasks were divided between her four nieces in agreement with the DEP.

The DEP receives all the formal services that are included in the care package (day care, transport, personal alarm, diner at home, home help, personal care and general practitioner) or extra's which she can afford financially (hairdresser, pedicure).

The ICG is female and 59 years old. She works full time (100%) as a team leader (management). The DEP is her unmarried aunt. The DEP was as a second mother for the ICG and the other nieces. Together with her and three other nieces she divided the practical help and the care tasks. Coordination of care happened in agreement with the DEP. The ICG does not receive a "mantelzorgcompliment". She was not able to take a leave from work. The DEP is not her mother, so care leave cannot be requested.

They rely on professional care for as much as possible. The family is financially well off.

4.3.7.2 Are informal caregivers (ICG) aware of the existing policy measures?**Awareness of existing measures targeting the DEP and the ICG**

The ICG is often aware of existing support measures (e.g. respite care, "mantelzorgcompliment"). Information about these policy measures is accessible through the internet, experts, the health insurance, the town, etc.

Also the DEP (when his or her mental condition is good enough) is aware of the existing policy measures (respite care, WMO contribution). From the town, the DEP receives a WMO contribution, a financial contribution for dependent older people. Often things are being arranged by home care services. The most requested formal care is nursing care, family help, meals delivered to the home, personal alarm, transportation and services outside of the home. The frequency of these services, depends on the autonomy and the health situation of the DEP or if there has been an hospitalization.

DEP and ICG are not fully aware of the measures that are available. If ICG and DEP need more information, they can request it. DEP and ICG can receive information through a central contact person from the health insurance (in the town DEP lives). S/he can offer information or coordinate formal help. Therefore, he does not need to be proactive in the search of information as this is provided by health and care professionals. Care is offered in a care package by health insurance or by the municipality.



SEE REPORT INTRACASE ANALYSIS – DESCRIPTIVE RESULTS NETHERLANDS PART 2-5-6

Er zijn hier wel eens van de speciale middagen voor de mantelzorgers. Maar dat is altijd door de week en dan moet ze werken. En ze moet ervoor naar Breda, want ik heb het hier in de buurt nooit gehoord. (NL_4_2A_time 50'57")

Now and then, they organize special afternoons for informal caregivers. But that is always on weekdays and they have to work then. And they would need to go to Breda, because I have never heard of it in this neighbourhood. (NL_4_2A_time 50'57")

Dat heb ik allemaal zelf uitgezocht. Ik ben naar het gemeentehuis geweest en ik heb (stilte) op internet aan het kijken geweest. En van de verhuurder, van xx, die hebben ook best veel informatie gegeven waar ik naartoe kon gaan. (NL_3_1B_time_a 7'11")

I figured it all out for myself. I went to the town hall and had (silence) a look online. And the landlord, of xx; they also gave me quite a lot of information about where I could go. (NL_3_1B_time_a 7'11")

Ik heb zelf niet veel informatie gezocht of gehaald. Het loopt, ik haar daar nog geen behoefte aan gehad; ik probeer het wel bij de houden in de krant of op de televisie. Maar er is wel snel verandering, de zorg en zo. (NL_1_1A_time 37'25")

Personally, I haven't looked into it much. As everything is working right now, I haven't felt the need to do so. I do try to keep track of what is in the newspapers or on television. But things change rapidly in care et cetera. (NL_1_1A)

4.3.7.3 Do the informal caregivers (ICG) benefit from existing policy measures and how?

Policy measures targeting the DEP

Not all dyads benefit from the policy measures available for the ICG (care leave, "mantelzorgcompliment"), for different reasons. Accessibility of information and having adequate financial means, make it easier to give informal care. Formal care is offered in a care package. If there is need for more information, this information is very accessible. The DEP and the ICG have no problems in requesting care. Formal care is accessible through several care services. Increasing formal help implicates no increase in financial costs.

SEE REPORT INTRACASE ANALYSIS – DESCRIPTIVE RESULTS NETHERLANDS PART 7

Deze zorgen (verpleegkundige) krijgen we allemaal gratis. De poetshulp is ook gratis. Het eten moet je betalen. Misschien dat de poetshulp een kleine bijdrage is. Het wordt betaald vanuit de overheid. Dit is gratis. (NL_2_1A_time 8'16")

These things (nurse), we all get for free. The cleaning help is also for free. The food you have to pay for. Maybe for the cleaning help, a small contribution is paid by the government. This is free. (NL_2_1A_time 8'16")

Het is echt hulp van de stichting (poetshulp), omdat je bejaard bent. Je wordt gekort. De verpleegkundige moet ik niet betalen, dat zal wel in het budget zitten, daar krijg ik nooit de rekening van, wel van de poets. Ik denk dat het hier het ABWZ is, dat is de gemeente waarbij je verzekerd bent. (NL4_1B_time7'30")

It's really help from the foundation (cleaning help), because you're elderly. You're given a reduction. I don't have to pay for the nurse, that'll be in the budget, I never get a bill for that, only for the cleaning. I think it's the ABWZ here, which is the municipality where you're insured at. (NL4_1B_time7'30")



De verpleegkundige zit in je basisverzekering. En het poetsen, dat is afhankelijk van je inkomen en daar betaal je een bijdrage per maand voor. En de rest wordt betaald door de gemeente (ABWZ). Daar moet ze in ieder geval een eigen bijdrage voor betalen. (NL_4_1A_time 17'09")
The nursing help is part of your insurance package. And the cleaning, that depends on your income and you pay a monthly contribution. And the rest is paid by the council (ACTD). You must at least pay a contribution. (NL_4_1A_time 17'09")

Policy measures targeting the ICG

Finding a balance between informal caregiving and working is difficult for every working ICG. The ICGs notice that the experience of being on sick leave is helpful in giving informal care. When the combination of working and giving care is unavoidable, support measures are sought for, but using these support measures is not always possible.

Care leave is unpaid. Not all ICG have the possibility to take unpaid care leave because of the financial implications. Care leave is only available if the DEP is a parent.

SEE REPORT INTRACASE ANALYSIS – DESCRIPTIVE RESULTS NETHERLANDS PART 7

Als ons moeder naar het ziekenhuis moet, dan kan ik op het werk wel vrij vragen. Dat heet zorgverlof. Ik heb daar 12 dagen per jaar recht op. (NL_3_1Bb)

If mother has to go to hospital, then I can easily ask for time off at work. It's called 'care leave'. I have the right to it for 12 days per year. (NL_3_1Bb)

Op het werk hebben ze er begrip voor. We kunnen zorgverlof nemen als we dit nodig hebben. (NL_3_1Bb)

At my work, they understand what the situation is. If we need to, we can take time off for care. (NL_3_1Bb)

Zorgverlof kan met een ziek kind of zo, en maximum 3 maanden. Maar het is niet vergoed. En het geldt niet voor de zorg aan een zieke tante. Het is enkel binnen je eigen gezinssituatie. (NL_5_1B_time 9'54")

Care leave is possible for a sick child and so forth; for a maximum of three months. It's not compensated, however. And it's not valid regarding the care for a sick aunt. Only for your immediate family. (NL_5_1B)

Tja daar kan ik niet op antwoorden. Wat zal ik zeggen. Ik ga er elke dag naartoe. Als ik terug ga werken (momenteel ziekteverlof) bouw ik dit af naar 4 x per week. Neem dat ik er een uur per dag zit. Als er iets moet gebeuren is dat meer. (NL_3_1Bb)

Well, I can't answer that. What can I say? I go there every day. If I have to go back to work (at the moment sick leave) I'll reduce it to four times a week. I'm there roughly one hour a day, more if something happens. (NL_3_1Bb)

Ik weet wel dat er een regeling is geweest voor mantelzorgers. Maar dat heb ik verder niet uitgezocht. Dat speelde zo niet. We hebben wel steun gezocht voor materiaal, dat soort dingen daar ga je achteraan. (NL_5_1B_time 33'38")

I know that there is new arrangement for informal caregivers. But I haven't looked any further into it. It's not of much importance. We did look for support with devices, that sort of thing you follow up. (NL_5_1B)

Remuneration is not always asked for, and has no influence on whether or not to give care. They did know about the caregiver's allowance, but did not always request the allowance because of feelings of reciprocity towards the DEP, and also because of the complexity of administration in order to obtain the small amount of money. They didn't think it was worth the effort.



Zo een mantelzorgpremie, 200 euro per jaar, hebben we pas nog gekregen. Daar zijn we met zijn 4 van gaan eten, mijn broer en zijn vrouw en wij 2. Want zij helpen ons moeder ook he. (NL_3_1Bb)

Well, an informal care allowance, two hundred euros per year, we just received that. We went out for dinner with the four of us with that money; my brother, his wife and us two. Because they also help our mother. (NL_3_1Bb)

Ik krijg geen bijkomend bedrag. Mijn moeder heeft het toen gehad voor mijn vader, 250 euro. En dit jaar is dat afgeschaft. En ik heb het nog niet aangevraagd; Dit jaar kan ik het nog aanvragen, dat is het laatste jaar. (NL_1_1A_time 55'25")

I don't receive an additional cash allowance. My mother did, for my father – 250 euros. But it was abolished this year. And I still haven't requested it. This year is the last year I can request it. (NL_1_1A)

Ik vind het belangrijk dat je mantelzorg doet. En daar moet je niet voor betaald worden. Maar ik kan begrijpen als je niet werkt of geen werk hebt omdat je mantelzorg doet, dan is het iets anders. (NL_5_1B_time 37'20")

I think it is important to give informal care. And you should not be paid for that. But I can understand that, if you do not work or do not have work because you give informal care, then it's another matter. (NL_5_1B_time 37'20")

Respite care is not frequently used. ICG first try to solve their absence with the existing formal or informal help. Both DEP and ICG like to have someone trusting nearby. A trusting relationship with the carer is essential and is a barrier in using respite care. Respite care/ short stay in one case was used to bridge a period of time and to prevent institutionalization.

SEE REPORT INTRACASE ANALYSIS – DESCRIPTIVE RESULTS NETHERLANDS PART 6

En de dagopvang. Het heeft wel wat voeten in de aarde gehad voordat ze (Dementerende DEP) iets oppakte. Maar de dagopvang daar ging ze twee keer per week naartoe. Dat wilde ze ook niet, maar eenmaal als ze daar was, dan was het goed. (NL_5_1B_time 22'32")

And the daycare? It wasn't self-evident for her and it did take time before she (Dementing DEP) accepted it but then she went twice a week to the day care center. She did not want to go, but once when she was there, it was fine. (NL_5_1B_time 22'32")

Ik zeg dan aan mijn broers, gaan jullie een keer extra bij mijn moeder kijken, want wij gaan op vakantie. En dat is geen probleem. (NL_3_1Bb) So I told my brothers, you have to go and check on mother one or two extra times, as we're going on holiday. And that's no problem. (NL_3_1Bb)

4.3.7.4 *What has been the impact/effect of these policy measures on ICG lives, on the continuity of care for the dependent older person (DEP) and the possible impact on the institutionalization process?*

On the continuity of care for the DEP

Having access to information and favourable financial conditions make informal care giving easier. In the Netherlands, care is offered in a care package. DEP and ICG, in most dyads, have no financial worries about the possibility to request care. Beside the amount that is to be paid (a month/ a year) to the health insurance, they can get all the help they need, if this help is included in the care package. If extra help is necessary, the ICG has to find out whether this help is included in the package. Depending on the financial situation of the DEP and the ICG, supplementary help on top of basic/standard help, can be requested. During holidays, continuity of formal home care services was ensured as much as possible for nursing care and to a lesser extent for home help.



SEE REPORT INTRACASE ANALYSIS – DESCRIPTIVE RESULTS NETHERLANDS PART 5

Aanpassingen aan huis doen we afhankelijk van de mogelijkheden en de kosten. We hebben al wat aanpassingen gedaan bij mijn vader, zoals de lift. (NL_1_1A_time 48'57")

Modifications to the house we do ourselves, depending on our capabilities and on costs. We already had some modifications done for my father, such as the elevator. (NL_1_1A)

Als er meer hulp nodig is, zou dat financiële problemen kunnen geven. Maar dan ga ik ervan uit dat er ergens wel een potje voor is. Het is niet mijn moeder heeft ook maar gewoon een klein pensioentje. Ze heeft ook niet zo een breed inkomen. Het is niet erg als je er een bijdrage voor moet leveren, maar dan net als bij gezinshulp op je inkomen. (NL_4_1A_time 22'30")

If more help was needed, that could possibly cause financial problems. But then I'm assuming that there always is some fund stashed somewhere. My mother receives a normal, small pension. She also does not have a huge income. It's okay if you have to make a contribution, but as is the case with the home help, it should depend on your income. (NL_4_1A_time 22'30")

Je moet een bijdrage betalen voor alle hulp. Naarmate de bijdrage, zorg aan huis en andere zorgen. (NL_5_1B_time 29'47")

You have to pay a fee for any help. According to your contribution, you receive home care and other services. (NL_5_1B_time 29'47")

Zij kreeg al deze zorgen na een kleine bijdrage te betalen. Ze had geen financiële zorgen. Er zijn geen zorgen wegvallen omdat het niet betaald kon worden. (NL_5_1B_time 30'00")

She got all these services for a small contribution. She had no financial worries. There were no worries due to not being able to pay. (NL_5_1B_time 30'00").

In de vakantie liepen de professionele diensten door. In de zorg die hadden wel vakantie, maar we hadden duidelijk gezegd, ze kan niet zonder, dus daar was wel vervanging. (NL_5_1B_time 24'00")

In the holidays, there was a continuity of the professional services; they also had holidays in the health service, but we made it clear she couldn't do without, so there were replacements. (NL_5_1B)

On the institutionalization process

Living situations can be adapted until institutionalization is unavoidable. Institutionalization occurs when living at home is no longer possible and/ or adaptations at home need to occur. Home adaptations are possible when the family (IGC, DEP or both) can financially afford to put them in place. Often moving to any kind of residential home happens gradually. They move from their own house to a service flat, in a first stage without surveillance, later with surveillance, and later they finally move to a nursing home.

SEE REPORT INTRACASE ANALYSIS – DESCRIPTIVE RESULTS NETHERLANDS PART 2

Vlak voor haar opname is het heel snel gegaan. Toen ging het proces ook heel snel. Toen hebben we echt een paar keer bij elkaar gezeten en bekeken hoe gaan we dat doen. want het is natuurlijk altijd aangrijpend, zo een opname op een gesloten afdeling. (NL_11'25")

Just before her admission, everything happened very fast. The process also went very fast then. We sat together a couple of times to look at what we were going to do, as it's always very emotional, of course; to have her admitted to a closed ward, to give her up.

Ze woont nu bijna 4 maanden in deze flat. Ze woonde van te voren in Breda, ook wel gewoon in een flat. Maar het is wel fijn dat ze nu dichterbij de buurt woont en op zich dat er hier ook, als het nodig is zorg is. Ze kan bij wijze van spreken een deur verder verhuizen als het nodig is (een verpleeg of bejaardentehuis). (NL_4_1A_time 5'27")



She's now lived for almost 4 months in this apartment. She previously lived in Breda, also in a flat. But it is nice that she lives closer by - for her too - as she needs care. She can, so to speak, move on further if it is necessary (a nursing or retirement home). (NL_4_1A_time 5'27").

On the ICG lives

The ICGs in the dyads have family ties with the DEP. Reciprocity (the mutual obligation within a relationship to respond with a counter-gift, or family looks after each other) was strongly present within these dyads. Care coordination in agreement with the DEP was a strong motivator to give informal care.

The caregiver's allowance for the ICG is small and has no impact. Informal care costs could not sufficiently be covered with this allowance. In a few dyads, the DEP pays the ICG for made costs.

SEE REPORT INTRACASE ANALYSIS – DESCRIPTIVE RESULTS NETHERLANDS PART 5-7

Mantelzorg geven ging in goede harmonie met haar. Ze (DEP) kon goed aangeven wat ze van ons wel of niet kon verwachten. Bijvoorbeeld in bad of douche doen is voor een professionele zorgverlener. Die regie hebben we samen met haar gedaan (NL_5_1B_time 15'35")

Giving home care worked in good harmony with her. She (DEP) was able to indicate to us clearly what she expected from us and what she didn't. For example, bathing in the shower or bath was left to a professional carer. The choices were made together with her. (NL_5_1B)

4.3.8 Germany

4.3.8.1 Context of the DYADS

Five dyads (five ICG and two DEP) living in Germany were interviewed during January 2014. Three other DEP were either already institutionalized and, therefore, not present during the interview, or could not express themselves because of their health conditions. The recruitment of the dyads was done according to the selection criteria. Dyads were contacted through a mobile nursing service and a support group for Alzheimer/Dementia and through personal contacts of the interviewer.

In this section, we briefly describe the five situations we have explored by interviewing the ICG and, when possible, the DEP. These five situations are quite heterogeneous as far as educational level and socio-economic situation, relationship between ICG and DEP and age are concerned. However, since recruitment was done with the help of a mobile nursing service and a support group for dementia/Alzheimer, all the dyads received some kind of external help.

Dyad 1

The DEP, 77 years old and female, has become disabled after a stroke in 1998. Her disabilities are mainly physical (her left side is partially paralysed), but her mental capacities have, to some extent, been affected as well. Since 2004, her husband, the ICG (79), takes care of her. The couple is married for over 50 years now and is relatively wealthy. After having sold their house, the couple lived in a nursing home together for some time, and later bought their own apartment and made it barrier-free. Both the ICG and the DEP are very optimistic and have a positive attitude towards life. The DEP's situation has, –according to the ICG, improved a lot during recent years. After being confined to her bed right after the stroke, physiotherapy and intensive care have enabled her to get back into a wheelchair and then even to walk with her walker-rollator to a certain extent. She is relatively limited to the context of the apartment and leaves the house only rarely for medical visits. The couple uses professional external help of a mobile nursing service (*Pflegedienst*) on a daily basis, which is partly financed by the long-term care insurance. The DEP is classified in care category 1 (Pflegestufe 1). The physiotherapist visits the DEP frequently. The caregiver takes his role very seriously and does not consider it to be a heavy burden or a duty.



Dyad 2

The DEP, aged 75 and male, has become severely disabled (100%) after a stroke in 2012. His disability has also been aggravated by kidney failures and subsequent coma triggered by diabetes. Unlike the first dyad, the DEP has a rather pessimistic view towards his own situation and does not fully identify with the changed situation and his dependency on others. The DEP is being taken care of by his wife (73) who lives with him in their rented, small apartment. He complains and feels guilty because of the burden he puts on his wife. They constitute a classical working-class couple with an income which is probably below average. The couple has 8 children, 11 grandchildren and 2 great-grandchildren, with most of them living close by. The ICG is supported by a mobile nursing service 5 days a week, a physiotherapist and an occupational therapist. However, the DEP is rather sceptical about the external help and prefers to be assisted by the ICG. The ICG has a general knowledge about the accessibility of support measures, but she relies on intermediaries, such as her doctor, to receive advice and is sometimes unsure about who pays what and what rights she has exactly. Although the DEP and the ICG have sufficient financial means, they are favouring monetary support over better support infrastructures. The DEP has applied twice to be considered in the higher care category (Pflegestufe 1) but both requests have been rejected.

Dyad 3

The DEP, a 80 year-old female, suffers from dementia since 2009. After being taken care of by her daughter for almost 4 years, she was institutionalized at the end of 2013. The dyad comes from the upper middle-class and they lived together in one house. The ICG (56) quit her job and became self-employed to have more flexible working hours and to take better care of the DEP. The ICG had the sole responsibility for the DEP after her father (the DEP's husband) died. The ICG has limited family support as she has no children and her sisters live in Southern Germany. The ICG claims to be no "care-person", meaning that, before her mother was institutionalised, she considered the care a psychological and physical burden due to the fact that her mother was not easy to deal with and did not accept external help. Even though there are no close family members present, before the institutionalisation took place, the ICG tried to establish a personal network with neighbours to look after the DEP. Until the time of institutionalization, the ICG used an external mobile nursing

service but is critical about it. Now, with the DEP being institutionalized, the ICG still visits her on a daily basis and considers this a burden (however to a limited extent). According to the ICG, the missing flexibility and the unrealistic assumptions public support programs are based upon have eventually led to the institutionalization (rather than the financial aspect).

Dyad 4

The DEP is an 80 year old woman suffering from dementia, rheumatism and hip problems since 2005. She was being cared for by her 56-year-old daughter, who shared the responsibility on equal terms with her twin sister. The DEP has 5 grandchildren who partly supported the ICG. Both the DEP and the ICG lived in a rural area. The DEP lived in her own house until the moment of institutionalization in late 2013. The ICG claims to be a "care-person", meaning that she has a professional background by working in a nursing home (on a 400 Euro-Basis) and past experiences with the care of her father-in-law (from 1994 to 1996). Unlike the previous case, the ICG "likes to care" and considers it to be personally enriching and fulfilling. Before the institutionalization, the ICG firstly took an unpaid leave with the long-term care insurance paying her pension contributions for 6 months, and then quit her job because she felt bad about not being there for her mother. As the ICG could not guarantee a 24h surveillance, she opted for institutionalizing her mother. The ICG has occasionally used external services, such as a mobile nursing service, when she was on holidays (Verhinderungspflege) and was relatively well-informed about other support possibilities. Since the ICG had a limited income and her husband is not liable for the DEP, the costs for the stationary care are now completely covered by the DEP's widow pension and public money.

Dyad 5

The DEP is a 91 year old man, who is partly paralysed from the lumbar vertebra downwards since 1939 following a sports accident (high jump). The caregiver is his wife (81), who is married to him since 1959. The DEP was able to move with a cane and work until 1977. The couple has no children, but some distant relatives live close-by. The DEP was an administrator and receives a relatively good pension. The ICG had no paid-job but was very active in charity organizations before she gave up her position at the end of the 1980s due to increasing care necessities of the DEP. They live in their own house in a rural area. The DEP is in good



mental health but confined to his bed. The ICG considers the care to be her life task and was well-aware of it when she got married. The ICG uses undeclared workers for cleaning and garden services and a mobile nursing service when the ICG fell ill herself and for changing the DEP's catheter. The money the ICG receives through the long-term insurance (Pflegegeld, 440 Euro per month) is a crucial factor for the ICG who is afraid of financial burdens when the DEP will die. Main sources for information regarding support measures are the family physician and the insurance company. The ICG has negative experiences with the MDK (Medizinischer Dienst der Krankenkassen) who assessed the DEP's care situation.

4.3.8.2 *Are informal caregivers (ICG) aware of the existing policy measures?*

Awareness of existing measures targeting the DEP and the ICG

In Germany, all the ICGs interviewed were aware of existing support measures for the DEP and for the ICG and used them more or less extensively. Sources of information vary: most respondents had been informed through their GP, the health insurance, care homes, mouth-to-mouth propaganda or local support groups. According to the ICGs contacted for this study, there are enough sources of information, but the ICGs had to pro-actively look for them. None of the interviewees mentioned the legal entitlement to psychosocial support and information. One of the pro-active ICGs was very satisfied with the information from a patient association.

"There are local information services from the city, where you can get advice. But we never used that. A lot works through mouth-to-mouth propaganda." (DE_1_1A time 35'03")

"You can also ask the insurance company if you have questions in the medical area or for the nursing service." (DE_1_1A time 35_21")

"The nurse from our GP helped me with some paperwork, where I did not know what to do. She was very nice, also in the communication with the insurance, before the MDK (medical service of the insurance that assesses care needs and grants financial help). " (DE_2_1A time 24'45")

"My husband gets care level 1, I get 235 Euro. The people from the nursing service took care of that for me. Mrs. S. (owner of the care service)

somehow managed that with the insurance. But I don't know exactly what all she did." (DE_2_1A time 18'40")

"Because I had a lot of time, I looked for information on the internet. When the situation got acute, I had all the documents in my desk." (DE_3_1B time 33'45")

"In the beginning I also used information services offered by Caritas (Catholic relief service). They had an exchange circle for people who take care of others. But most of the stuff they told, I already knew through working in the nursing home." (DE_4_1B)

"We have personal ties with the people who own the mobile nursing service. You know each other here in the village." (DE_4_1B)

"That there was support, that was clear for me. Maybe not every detail, but we had information coming from the GP, talks with people we knew, health insurance and so on". (DE_5_1A_F)

4.3.8.3 *Do the informal caregivers (ICG) benefit from existing policy measures and how?*

Policy measures targeting the DEP

All DEPs received in-cash or in-kind support (Pflegegeld/Pflegedienst). The in-cash services then indirectly were received by the ICG. The income level of the dyads seems to influence their perception of support measures, as well as the choice among them. Whereas the ICG without financial constraints sees the payments more or less as a "nice to have" budget, the others depend on these payments to keep their living standards. Dyads with less financial means seem to favour in cash payments over in-kind support. The fact that there are no direct payments to the ICG, but only indirectly through the DEP, does not seem to be a relevant issue in all five cases. Either the couples have joint bank accounts (if married) or the ICG has general power of authority to manage the DEP's financial matters (as in the two dementia cases). However, some are in favour of direct payments because they consider that it is actually the ICG who should be paid.



“I should get the money. I care for my husband and nobody else.” (DE_2_1A_F)

“It always was manageable. My mother has a small pension, which of course is used for the home place. But she was never a financial burden (...). The care time was paid for by the insurance. There were no financial problems. Because my husband works full-time, the money is sufficient. The home place is partly paid for by the insurance, the other part is taken over by the public authorities, because my mother's pension is not high enough.” (DE_4_1B_F)

“If the care service was coming regularly, I would have 440 EUR less because then it would be the service payed and not me. I don't know if I could keep the house longer when the money is gone, also if my husband would die. My widow pension would be less.” (DE_5_1A)

The in-kind services were mainly offered through a mobile nursing service responsible for basic hygiene, dressing and basic medical services such as blood sugar measurements. In one case, in-kind and in-cash support was used for architectural changes in the apartment to make it barrier-free. Other external services comprise physiotherapists or occupational therapists.

“When there are wounds, I do everything what I think is responsible, band aids and such. Everything else has to be done by professionals; my wife is a marcumar-patient.” (DE_1_1A time 29'53")

“For the renovations to make the apartment barrier-free, there is an information point from the city, they send an architect to do the assessment, which is for free. (...) After we sold our house, we bought this apartment to make it suitable for handicapped. We got 2400 EUR from the insurance for the renovations. Since the apartment was new, I could integrate my wife into the planning process, which gave her a task. The renovations cost more than 44.000 EUR. We could only do it because we had the money. People who cannot afford it, stay in a home, 99% of the cases.” (DE_1_1A time 10'04")

“It is too much, every time a different nurse taking care of my husband. I got used to doing the blood pressure measurements myself and the blood

sugar. Saturdays and Sundays I don't want anybody in my house, I want to sleep long (...). The nursing service usually comes to do the blood sugar and the injections. One time in the morning and at noon.” (DE_2_1A time 12'40")

“I only used the nurse service in emergencies, e.g. when I was sick. Or for the changing of the catheter, when there were medical things and I thought I wasn't competent enough.” (DE_5_1A)

As for the mobile care service, criticism was made concerning punctuality and reliability.

“The mobile nursing service comes each day during weekdays. On the weekends I do everything alone.” (DE_1_1A time 14'23")

“But then changing clothes and putting my mother to bed did not go well. From then on, I had the service also in the evening. That did not work and still does not work. They don't come on time. I had a lot of anger on the weekends. If my husband and I wanted to take an evening off on Saturday, we were depending on punctuality and have been disappointed a lot of times. In the end, I did the things myself and sent the service away, when they arrived with a 2 hour delay.” (DE_3_1B time 7'53")

Policy measures targeting the ICG

Several ICGs used respite care. This is used mainly in emergency situations when they were ill themselves and could not deliver care services. Respite care is also used to get some relaxation and relief.

“We had respite care, when I was in the hospital last year. We were very happy with that.” (DE_1_1A time 45'05")

“We used the mobile nursing service when I was on holidays in B. But I always had a bad conscience.” (DE_4_1B).

“I told the doctor that my husband should go to a day clinic for rehabilitation. They picked him up and he would see somebody else than always me. Then I can do other things and have some relief. I will get a piece of paper and then it will be possible.” (DE_2_1A time 16'09")



“You have a certain right for respite care, to make it possible for caregivers to have holidays. But the places in M. had to be applied for 9 months ahead of time. So going on holidays spontaneously was not possible.” (DE_3_1B time 47’12”)

One ICG took an unpaid leave with publicly financed pension contributions for six months, but eventually quit her job. Another ICG gave up her old job due to the “in her view” inflexible and unrealistic assumptions about flexible work arrangements.

None of the ICGs complained about difficult accessibility to policy measures. According to the information collected in the interviews, no obvious relation could be established between socio-economic status or education and accessibility to information. However, the ICG who are older and less educated seem to be more reliant on intermediaries such as the GP.

“I told the doctor that my husband should go to a day clinic for rehabilitation. They pick him up and he would see something else than always me. Then I can do other things and have some relief. I will get a piece of paper and then it will be possible.” (DE_2_1A time 16’09”)

“You have a certain right for respite care, to make possible for caregivers to have holidays. But the places in M. had to be applied for 9 months ahead of time. So going on holidays spontaneously was not possible.” (DE_3_1B time 47’12”)

“The “Family care time” (Familienpflegezeit, flexible work arrangements) doesn't work either. What the government has come up with is nonsense. You can't do only 2 years of flexible work hours. Dementia usually lasts 10 to 12 years, so reducing work to 15 hours for only 2 years does not help. With dementia patients you have good days and you have bad days. And everything is on a voluntary basis with the employer. It would of course be better if caregivers had a real right which they could count on.” (DE_3_1B time 45’15”)

“When I cared for my father-in-law and afterwards when I cared for my own mother, they paid pension contributions. That was great.” (DE_4_1B)

4.3.8.4 *What has been the impact/effect of these policy measures on ICG lives, on the continuity of care for the dependent older person (DEP) and the possible impact on the institutionalization process?*

Impact on the continuity of care for the DEP

Existing policy measures, especially the mobile nursing service, definitely have a supportive effect on the ICG and seem to have a prolonging effect on the continuity of care.

Negative criticism about the mobile services offered was made, especially concerning reliability and punctuality.

The existing policy measures take away pressure from family networks or neighbours who would otherwise hold more responsibilities. Both the ICGs and the DEPs want to stay at home. Several reasons support this intention/wish:

- They consider the care provided at home is better;
- They want to stay active and autonomous;
- They do not want to take the “home feeling” away from the DEP.

The in-cash services for the DEP seem to have a larger effect on the continuity of care for those dyads who are financially dependent. They consider it to be crucial, whereas others consider it to be a “nice-to-have”.

“My father and my mother always wanted to get things done on their own, they did not want to bother other people. They resented external care for a long time and did not want to move into a nursing home. So we tried to do it at home. My parents and I lived together in the same house, which made things much easier. But still, I was the only daughter living close-by.” (DE_3_1B_F time 2’01”)

“My mother always felt home at her house, I did not want to take that feeling away from my mother, as long as it was possible. (...) We live in the countryside. Caring at home was still a natural thing here, more than in the cities (...) But at a certain point she became a danger to herself and others. But I could share the responsibility with my sister.” (DE_4_1B_F)



“Two years ago my husband had a stroke. He has so much, I can't even tell you what all it is (...) Rheumatism, Diabetes, kidney failures (...). Then, he was in a clinic for half a year. Then he came home. (...) He only wants to be cared for by me, the others don't do it good enough for him. That's why we opted for care at home.” (DE_2_1A time 1'42")

Impact on the institutionalization process

Institutionalisation is postponed as much as possible; the main factor affecting institutionalisation is the ability of the ICG to cope with the care. Support measures in the form of care to the DEP and respite care for the ICG seem to have an impact. Financial support de facto rewarding the care by the ICG has an impact on the less affluent, but could have an adverse effect as this puts (additional) responsibility and pressure on the ICG.

“I simply could not guarantee my mother's safety any longer, she fell too often (...). I never knew whether she would turn on the cooking plates and forget them. That would have been a danger for other people as well (...). We got very quickly a place in the home.” (DE_4_1B)

“When I cannot do the work anymore, no mobile nursing service would help much. Then we both would have to go to a home”. (DE_5_1A)

“Delaying the moment of institutionalising is not possible by giving more cash to people, only if you improve the mobile nursing services. Giving more cash would be throwing money out of the window, if you ask me.” (DE_1_1A)

Impact on the ICG lives

As mentioned, the mobile nursing services and respite care measures were appreciated and criticized at the same time. Even though ICGs generally found it supportive, they criticized waiting lists for respite care measures or unreliable nursing services.

The costs of care were only criticised by one or two ICGs, especially because in one case the ICG was liable to pay for the DEP's institutionalisation.

Flexible work arrangements offered legally did not keep the two ICGs still in working age from giving up their jobs. Inflexibility and unrealistic assumptions about the care that a dementia patient requires, are being harshly criticised.

Remuneration for ICGs is only provided indirectly through the DEP and among the dyads access to in-cash payments was never a problem.

“There is the legal guaranteed time (unpaid leave), but it is only legally binding for companies which have more than 15 people, everything else happens on a voluntary basis. We had a small company with 4 people in the office. I don't know anybody of my friends who used this support scheme. It is not widely known among caregivers and is difficult to organise in the companies. The “Familycaretime” (Familienpflegezeit, flexible work arrangements) doesn't work either. What the government has come up with is nonsense. You can't do only 2 years of flexible work hours.” (DE_3_1B time 45'15")

“My boss had experiences with his demented mother and was very understanding concerning my situation. We had an informal deal for me to have as much flexibility as possible. (...). Flexibility is everything when caring for a dementia patient.” (DE_3_1B_F)

“I always had early working hours. So I was working and thought: Now your mother does not have her breakfast, actually you should be home.” (DE_4_1A)

“You have a certain right for respite care, to make holidays possible for caregivers. But the places in M. have to be booked 9 months ahead of time. Spontaneous holidays are nearly impossible.” (DE_2_1B)



4.3.9 Luxembourg

4.3.9.1 Context of the DYADS

Dyad 1

The DEP, 82 years old, lives in a nursing home. Dependency was the consequence of Parkinson and started due to problems of balance and regular falls. This was a slow progress. The ICG is his wife, who is younger (73) and who took the care role up naturally. The trigger for institutionalisation was the diagnosis of colon cancer for the ICG. The DEP asked for institutionalization fearing the consequences in case his wife could not take care of him anymore.

The care provided by the ICG covered all aspects linked to the household, the medication and the permanent attention. This last aspect was a high burden, which she realized fully only after institutionalization. Respite care was proposed and known, but refused by the DEP.

Formal care consisted mainly of personal care by nurses and of medical related acts. Personal care included daily and regular assistance (dressing, compressions, and personal care three times per week), medical interventions were linked to regular injections and blood samples. The only non-medical assistance was a meals-on-wheels service.

Information was available on care possibilities. There were no financial issues as the long-term care insurance took care of most of the costs.

Dyad 2

The DEP, a man aged 89, has various health problems. He cannot walk since last summer. He lives alone at home with his wife, who is not much younger (86) and takes care of him as much as possible. Home care services come four times a day for various care tasks, mainly medical. Many of the care tasks are still taken up by the ICG (washing, helping to go to the toilet, preparing meals, feeding, etc.) including some medical related tasks (like changing a catheter). The household has a housekeeper who comes twice a week, not part of the care plan. Emergency nursing services of the home care organization are used for exceptional situations (mainly events at night). The ICG has children who are not involved in the care. One niece of the DEP living nearby plays the role of "taxi" to drive the ICG to do shopping or go herself to the doctor.

She recently started to use a granny-sitting service from the home care organization when she goes out of the house. This helps to reduce her stress levels when she goes out of the house. She receives 500 euro per month as a cash allowance from the "assurance dependance", and most acts are being reimbursed through the health insurance. There is a hospital bed installed and an elevator is planned to be installed, all paid by the "assurance-dépendance". The trigger to institutionalisation would be the health status of the ICG. She suffers from osteoporosis and is concerned that if something happens to her, he would go to an institution. She has put him on a waiting list to be prepared.

Dyad 3

The DEP, a man aged 81, suffers from Parkinson's disease. He has periods of regular falls and of hallucinations. His health condition has recently improved following a new treatment. He lives at home and the ICG is his wife (75). The couple has three daughters who do live in Luxembourg, but in other towns. They provide little direct support even if they are regularly visiting. The ICG is only in charge of personal care during holidays. Homecare services visit daily for personal care. Formal care also gives the injections. ICG acts as care coordinator including on medication. Blood samples are taken twice a week and ICG keeps track and tells the formal caregiver which dose to use.

DEP and ICG do get out of the house on a regular basis, with assistance from the Parkinson's association (once a week and during the holiday), from the home care organization (twice a week) and with the help of mobility service for persons with reduced mobility to make this feasible. They use tele-alarm (the ICG pushes the button), have (received) a hospital bed, home help and the ICG receives a cash allowance of 780 Euro (reduced from 980 Euro after they started to use the cleaning service). All services mentioned are covered by the long-term care insurance. Respite care is not really used, as the ICG accompanies the DEP to most out of home activities. The system seems to be stable as long as the ICG's health condition remains sufficiently good.



Dyad 4

The DEP is a lady of 75 years who suffers from physical and mental health problems. The ICG is her husband who suffers from diabetes himself. They both live together at home. The couple has one daughter who works in Luxembourg, but lives across the border. She provides occasional support. The ICG has a driving license and brings the DEP two days a week to a day-care centre.

The ICG takes care of most domestic tasks (took over from his wife without any prior experience), with the exception of ironing and cooking. For the ironing, the solution has been to request cleaning services to a homecare service, but the cleaning person irons instead of cleaning and the ICG does the cleaning. To solve the cooking problem, a meals-on-wheels service is being used. Personal care is mostly done by the ICG, although homecare professionals do it also once a week and the DEP moreover takes a shower once a week at the day-care centre. The ICG acts as care coordinator for medication and receives a cash allowance amounting to 220 Euro/month. The triggers to get the system out of balance would be an evolution towards more severe dementia (ICG says he could not cope) and the health of the ICG deteriorating.

Dyad 5

The caregiver is the daughter of the DEP. The DEP is 90 years old woman and still lives alone at home. She has no specific illness diagnosed, but is becoming gradually more dependent and shows signs of dementia. She has a pacemaker. The daughter is 65 years old herself, lives at 5 km from her mother and is married. She took over the full household management and acts as a care coordinator. Personal care is done by her as well, but DEP is not (yet) completely dependent. She can still dress and go to the toilet autonomously. She lives in her environment but does not take care of this environment herself anymore (garden, chickens, etc.).

Formal homecare service comes twice a week for blood samples and twice a day when the ICG goes on holidays. The ICG is in contact with the GP and sporadically with homecare organizations linked to the municipality, mainly for organizational matters when she leaves for holidays. She minimizes external help and delays the use of external services.

She is considering having formal homecare visits daily. This would mean a relief for her, but she would still have to be present at least twice a day.

Tele-alarm button is necessary (because of the risk of falling) but not a solution as the DEP might push it by accident, will not hear the phone ringing, and will then get an ambulance at her door. She does not receive any financial help and considers this unnecessary, as it is not for money that she takes care of her mother. The system is in balance and the risks to the system are mainly the ICG's health status and potential pressures from her environment to reduce the time invested. The fear of the ICG is that her mother will die fast when she goes in an institution.

4.3.9.2 *Are informal caregivers (ICG) aware of the existing policy measures?*

Awareness of existing measures targeting the DEP and the ICG

Informal caregivers are well-aware of the measures to support the DEP and to support them. The main source of information is either the GP (family doctor) or the social service at the hospital.

During hospitalisation, the need for care is identified and when the patient goes back home, there is a smooth transition. A person comes by to assess the needs, and this needs assessment is updated at regular intervals. The homecare organisation, which gets paid by the long-term insurance, is in charge and takes as a matter of fact also the initiative to assess the needs.

SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS LUXEMBOURG PART 1-5-7

The social assistant in hospital explained me everything and established the first contact. Then the team of (organisation's name) made all the paper work and took care of all administrative steps. (L_2)

All information was provided by the hospital's social assistant (L_1)



4.3.9.3 *Do the informal caregivers (ICG) benefit from existing policy measures and how?*

Policy measures targeting the ICG

The dyads of this sample are benefiting from existing policy measures to supporting informal caregiving. The accessibility to the available policy measures has been made quite smoothly through formal channels (e.g. hospital's social assistant, family doctor). It seems that the way the system is organised is enabling the enjoyment of the existing policy measures. The dyads report that the whole process has been mediated by health and social care professionals.

In Luxembourg, there is a policy to provide cash allowances, the height of which is based on need for care and actual use of formal care. If care is provided by informal care rather than formal care, the cash allowance will be higher. This cash allowance is for the DEP and meant to be used to reward informal caregivers, even if not explicitly paid or targeted to the ICG. A consequence is, as it has been mentioned by respondents, that at the moment that a certain service has been added, the amount of the cash allowance has decreased.

Respite care is used in this case mainly through the use of day centres. This is a way for the ICG to have a day off. The actual use of this possibility is very dependent on the DEP attitude and not related to the cost (see below). Granny-sitting is also offered through formal care services in Luxembourg and can be considered as a form of respite care, very appreciated when used.

SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS LUXEMBOURG PART 5-7

The social assistant in hospital explained me everything and established the first contact. Then the team of the Home care service filled out all paper work and took care of all administrative steps. (L_2)

All information was provided by the hospital's social assistant. (L_1)

It all went extremely fast, there was a man from Assurance Dependence that came to assess the situation and the degree of burden, then the ICG only had to sign. The next month the money was there. (L_3)

At first they got 980€ per month but after having taken the cleaning lady they receive 780€. (L_3)

The “Assurance Dépendance” gave us about 1000€ a month because I was taking care of him, that was when (organisation name) came twice a day. Since he is partly paralysed they come 4 times a day, and we still get about 500€ each month. (L_2)

Formal home care

The need is of the DEP and the ICG is assessed as described above. The DEP is categorised. The tasks taken up by informal care and formal care will define the cash allowance that is provided. This is provided to everybody who is assessed to need more than 12 hours of care a week. Based on the information of the interviews, this is irrespective of income.

Accessibility is high, as the ICG does not need to take much initiative. It all arrives quite naturally without much effort on the part of the ICG.

SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS LUXEMBOURG PART 2-7

It's a very good system, there is someone that comes evaluation your situation and calculated how many hours and minutes you need assistance, it goes really fast, there isn't a lot of paperwork. (L_4)

The Social Assistant from Assurance Dependence comes at home analysing the situations and the requirement. It goes really fast. (L_2)

4.3.9.4 *What has been the impact/effect of these policy measures on ICG lives, on the continuity of care for the dependent older person (DEP) and the possible impact on the institutionalization process?*

On the continuity of care for the DEP

The impact is high in terms of allowing the ICG to cope and be able to provide the informal care. The balance that is found between informal and formal care is at the basis of the feasibility for the ICG. The regular



assessment allows reorganising the balance in case the ICG cannot cope with some tasks anymore.

The impact of the cash allowance, which is defined based on the balance between informal and formal care, is however low. There is no “addition”; as the ICG describes this as “nice to have”, and based on results of the analysis, one can interpret that the cash allowance received does not make a difference for the ICG. They would provide the care anyway and their own resources and pensions seem sufficient to cover their financial needs even if none of the dyads should be considered as part of “upper” classes (rather mid – low).

SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS LUXEMBOURG PART 7

We were quite astonished, are glad to receive the money but they would keep him at home anyway. (L_3)

It's nice but to us it wouldn't change anything if they didn't give it to us. (L_2)

On the institutionalization process

With the exception of one DEP, the remaining DEPs have not been institutionalised so far. What triggered the institutionalisation of this single DEP, was the health condition of the ICG and not the unavailability/inaccessibility of policy measures to support her role as caregiver or the unavailability of home care.

Both the easy access to information and the smooth accessibility of actually receiving the benefits (support of home care, mainly formal home care) might have an influence on delaying the institutionalisation process. The dyads of this sample are entitled to a number of heavily subsidised services (e.g. domestic aids, meals delivery, tele-alarm) and products (e.g. hospital beds) that allow them continuing living at home and, thus, delaying institutionalisation.

SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS LUXEMBOURG PART 1-5

There was no motivation, it wasn't really a question of choice, I was there like I always was, he started to fall, to be less independent, more fragile, what should I have done. (L_1)

“Meals on wheels”, service delivering meals to elderly or ill persons, provided and managed by the municipality they live in. This service was ordered as the ICG was in treatment for colon cancer and couldn't cook anymore. (L_1)

On the caregivers lives

The policy measures do not have a financial impact on the caregivers' lives as none of the dyads has financial problems (one of the dyads even did not request the cash allowance). On the other hand, the services they use seem to assist them in the provision of care and allow them to cope better with their role.

The use of respite care very much depends on the attitude of the DEP. Some refuse, others accept. The ICG is not putting pressure on the DEP. Respite care in this case study was only in the form of visits to day-care centres or similar.

SEE REPORT INTRA CASE ANALYSIS – DESCRIPTIVE RESULTS LUXEMBOURG PART 5

Well, we recently started to use the “granny-sitting” service of Home care service. Every time I have to go shopping or have to go to the doctors, etc, there is a person that comes and remains with him. It's more of a company. She sits with him and they talk. It allows me to be less stressed when leaving the house; I have a much better conscience. (L_2)

When I go on vacation, I ask for HELP to come twice a day to check medication intake and if she didn't fall. (L_5)

There could be day care centres and activities but he doesn't want to go or more accurately he cannot go. (L_2)



DEP goes to a day care centre twice a week. They do handicraft, crosswords, cooking (like cookies for Christmas). DEP stays there from 9h30 to 17h00. ICG drives DEP to the centre, there is also a bus but it never was punctual. (L_4)

4.4 Results of the Inter-case analysis

The section hereafter results from the comparison of findings from the case-studies in Belgium (Wallonia, Flanders, and Belgium) with the findings from abroad. From this empirical qualitative analysis, we can learn how we can improve our system. Details per case study, can be found in the country reports dedicated to the research questions as well as to the descriptive country reports, which included all the topics of the interview guidelines.

4.4.1 *So many nationalities and cultural backgrounds, the same reasons to care...*

Reciprocity

In all our dyads, the informal caregivers (ICG)s showed a high degree of resilience towards being an ICG, which was grounded in their belief that it is their duty to care for their family. The family relationship and the reciprocity principle (i.e., the mutual obligation of the members from a same family to look after each other at different moments in life) are often mentioned by the ICGs. They naturally play this role, especially when the caregiver is a child of the dependent older person (DEP). The ICGs just do the things they need to do; they do not reflect on or worry too much about giving informal care.

To take care of a parent, nevertheless, can be perceived as ambiguous by caregivers. Next to the natural role of being an ICG, taking care of a dependent older person is a stressful role that can only be played under some key conditions. Neighbours are rarely involved in informal care giving in our sample. Usually, other family members play an important support role, but it is not a hands-on activity. When care tasks are divided among different informal caregivers, seldom is there an equal share of care distributed among them.

What they do

ICGs have a variety of tasks ranging from daily household activities, administration, and surveillance. All ICGs tried to do as much as possible by themselves. Compared with spouse-caregivers, non-spouse caregivers are not very keen on providing personal care, which is transferred to health and social professionals. However, in our sample, the non-native ICGs living in Brussels felt that personal care should be provided to a maximum extent by themselves. This was related to refusal from the DEP to receive this type of care by a health professional. Involvement with medical care related tasks are more exceptional for informal caregivers; although, there are some examples in the dyads. Informal caregivers often do play a significant role in the case management of the dependent person. They coordinate, at least to some extent, the care, both medical and non-medical, pass on information from one caregiver to the other, and make sure the dependent person complies with medication.

4.4.2 *Are informal caregivers aware of the existing support measures?*

What do they know?

In our sample, in Belgium (Flanders, Wallonia, and Brussels), when ICG respondents in this study were aware of policy measures, they concerned formal care services for the DEP. Even then, the knowledge level and therefore the access to services was highly heterogeneous and dependent on the ICG's socioeconomic characteristics. The ICGs do not actively look for information about these issues because they worry about the financial implications, except when they still participate in the labour market. ICGs seem to look for help for themselves as a last resource when the formal support system for the DEP is no longer sufficient. Not surprisingly, they are seldom aware that respite care may be available.

For the dyads living in the other countries (i.e., France, Luxembourg, the Netherlands, and Germany), ICGs are also well-informed about support measures for the DEP. Compared to the ICGs living in Belgium, ICGs living in the other countries seem to be more aware about 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.

Who provides information?



In Belgium, in the cases where the respondents received information, it was provided at discharge from the hospital by social workers and at moments where help was needed in urgent and critical situations. In Wallonia and Brussels, the general practitioner (GP) is mentioned as playing a central role in the access to the information process.

Information sources in other countries in our sample are similar to that mentioned by ICGs 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. For instance, in France, detailed information about available services is communicated through local social services operating at the level of the municipality and the departments. In France, information is also delivered to the family by nurses intervening at home. In Germany, Luxembourg, and the Netherlands, workers from the long-term care insurance are also in charge of providing information to the ICG and the DEP about available benefits. In Luxembourg, when dependency is identified by one health care professional or institution, the DEPs and the ICGs are referred to homecare services organisations who are paid by long-term care insurance. These organisations are proactive, look for new customers, and aim at facilitating the whole process for their customer.

Information provided is not limited to benefits for the DEP but also to support measures for the ICG. For instance, in the Netherlands, the ICGs are well aware of existing measures (i.e., *mantelzorgcompliment*, unpaid leaves, and respite care) to support them.

As pointed out by dyads 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.

4.4.3 *Is the access to support measures related to informal caregivers' characteristics? Do informal caregivers benefit from existing support measures and how?*

The largest support comes from the measures for the DEP

From our data, it seems that the ICGs in all the cases do as much as possible without professional help. Yet, we can see a difference in perspectives depending on the financial situation and whether the ICG is still in the labour force. In those cases in which they are still working, they do look for more professional help. In Belgium, the formal services for the DEP are in most dyads the only source of support for informal caregivers. Informal caregivers expressed that access to formal care services or to cash-allowances for the DEP is hindered by the difficulty of finding a way in the system as well as by the cost of services. However, all of the DEPs 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, having access to formal services for the DEP seem even more difficult. The language barrier of non-native DEPs living in Brussels adds an additional difficulty level for the ICGs as they need to cope with all the administrative issues surrounding access to formal care.

Informal caregivers in our sample in France, Luxembourg, and the Netherlands did not explicitly mention that the cost of formal care limited access to services for the DEP. In Germany, some ICGs criticised the cost of formal care, especially because in one of the cases, the ICG was liable to pay for the DEP's institutionalisation. In Germany, dyads with less financial means seem to favour the cash-for-care allowance vs. formal care services. The allowance allow as them to cover the household expenses and to maintain their living standards. From our sample in France, the GP or the nurses intervening at home inform the DEP and the ICG that a social worker can provide more information about formal care services and the cash-for-care allowance. For people who are not eligible for the APA due to incomes 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 makes it possible to pay for domestic aids. In the Netherlands, care is also offered in a care package by health insurance.



More needs, more search for help

In Belgium, when the DEP needs more care and is more dependent, the ICG will look for more information about services. In particular, the ICGs who are working look for more formal services: domestic aid, home care, telesurveillance, meals on wheels, and nursing help. ICGs in Belgium reported being worried about the financial implications of using more formal help and tried to postpone it as long as possible.

In the Netherlands, France, and Germany, if care needs increase, more formal help is included in the care package. The ICGs did not mention that access to more formal care would have financial implications. If there is need for information or more formal help, this is accessible through several care services. The DEP is willing to move to an adapted home and have more help. All of these measures are coordinated by long-term care insurance. In Luxembourg, when the need for significant long-term care is identified, the DEP and the ICG were immediately put into contact with homecare services. If care needs changes, new arrangements are organised.

Measures targeting caregivers' income

Caregiver's allowance

In Flanders, the ICG and the DEP do not make a distinction between the *mantelzorgpremie* and the *vlaamse zorgverzekering*. In our dyads in Flanders, the caregiver's allowance was not provided in the city/village of most of our respondents. In the Netherlands where the caregiver's allowance is considered a nice to have, but it does not make a difference in whether their caregiver role is recognised and appreciated or in covering the ICG's expenses. Caregivers' allowances are not available in the other countries.

Flexible work arrangements, leaves, and pensions

In Belgium, working caregivers use as much formal care as possible for the DEP in order to keep on working. 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, ICGs mentioned that having a flexible work schedule was enough to cover care needs; therefore, they did not need to use available leaves. In other countries, access to leaves is limited (e.g., short-time leaves, unpaid leaves) or non-existent; therefore, the ICG used the short-term leaves only

in emergencies to cover unexpected care demands. When the balance between working and providing care is lost, due to a combination of circumstances, the ICG looks for solutions that are available. In Flanders, part-time work using time-credit leave (1/5), flexible work hours, and sick leave were used in one case to bridge a difficult period. In France, one caregiver used a complex arrangement to reduce the work schedule: an unpaid leave was combined with partial financial compensation from the French cash-for-care allowance. The drawback from this arrangement was that the financial compensation did not cover the income loss; therefore, the ICG faced a difficult financial situation. In Germany, two ICGs were still working when care began. The first one took an unpaid leave but eventually 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 unrealistic and unhelpful.

Cash-for-care used to compensate the informal caregiver

In the interviews carried out in Belgium, no reference was made to the *vlaamse zorgverzekering* or *Allocation d'aide aux personnes – Tegemoetkoming voor hulp aan bejaarden* as a means to compensate the caregiver. ICGs mentioned that the *vlaamse zorgverzekering* is small and her/his own out-of-pocket expenses or the costs of requiring more formal help. For some caregivers, the financial compensation was not satisfactory compared to the level of bureaucratic procedures to undergo to. In the other countries (Luxembourg, France, the Netherlands, and Germany), there was no mention of a labour contract between the ICG and the DEP. However, in France, one caregiver partially benefited from financial compensation via the cash-for-care allowance as she reduced the number of working hours to look after the DEP. Also in France, thanks to his caregiver role, one ICG who also received the APA and who cared for a very dependent spouse, had access to additional benefits. In Luxembourg, when additional services were provided, the cash amount received by the DEP was decreased. When discussing cash-for-care benefits provided to the dependent older person, such benefits are usually perceived by the ICG (in the different countries) as a means to cover household expenses. The importance of the allowances in the eyes of the ICG depended on their financial situation. Dyads without financial problems (in Luxembourg, in Germany and Belgium) saw it as "a nice to have" while other relied on this payment to keep their living standards covering some household



expenses (a dyad in Germany) and in some cases formal care services (Belgium).

Measures on respite care and psychosocial support

In Belgium, ICGs reported that when respite care alternatives were available, they were seldom adapted to the ICG and/or the DEP needs or preferences. For other ICGs and DEPs, in their views, it is not acceptable to use these types of services. Hesitancy appears to be due to lack of trust and to the strong relationship between the ICG and the DEP. ICGs do not like to entrust the care of their family to nonfamily members for their personal benefit. Use of respite care use 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 respite care is needed, the other informal caregivers are the first resource to be contacted. Some caregivers willing to use respite care in Belgium (in particular amongst ICGs living in Wallonia and among non-native informal caregivers) reported that the cost of services limited their access.

The ambiguous perception of ICGs of respite care is also present among the ICGs from the other countries. Contrasting feelings on whether it is an appropriate option for the DEP are always present. In France, for instance, it is either perceived as illegitimate or even burdensome because it interrupts the continuity of care services and the care relationship. For example, using a day care or short stay institution may entail more complications and is thought to threaten the fragile equilibrium reached for the DEP.

However, when respite care seems to be adapted to the DEP's and ICG's needs, it is welcomed and does provide solutions. In Luxembourg, a service in which someone comes to the DEP's house to look after the DEP for some time was mentioned as a valid alternative to respite care facility. In Germany, respite care was only used in emergencies, for example, when the ICG fell ill. Respite care as a simple way to relieve the ICG from a burden was used only in some cases because most ICGs did not see their caregiving role as a burden and therefore saw no need to have holidays from caregiving. In Germany, long waiting lists hindered access to respite care services.

In contrast to Belgium, in the other countries, informal caregivers who were willing to use respite care did not cite that financial constraints were a limitation to their access. None of the interviewed caregivers made a reference to the policies about psychosocial support. It was even mentioned by two French ICGs that these services were missing altogether.

4.4.4 What has been the impact/effect of these support measures on the continuity of care for the dependent older person and the subsequent impact on the institutionalization process?

Continuity of care

Without a doubt, the ICGs interviewed play an essential role in arranging and managing the continuity of care for dependent older people. When they can no longer fulfil this role, other family members, friends, and neighbours are called to ensure the continuity of care.

In Belgium, formal home care is available and is used to some extent by the DEP in our sample. However, the care is often fragmented between different services, and those services do not seem to communicate with each other. This lack of communication adds to the burden of the ICG. In fact, overseeing all the activities and providing continuity of care together with his/her informal support network seem to become a burden. In our sample in France, the main coordination role belongs to the ICG, as social services only intervene to make decisions about the rescaling of the care plan. This role is especially significant, as the number of intervening care professionals is usually high. Interestingly, people who do not qualify for the care package in France because their income is above a maximum threshold can find it more difficult to access the system. In Luxembourg, the homecare organisation paid by the long-term care insurance ensures a smooth passage to the community after a hospitalisation. In our sample in Germany, continuity of care seemed manageable for all ICGs; however, they are aware of the delicate balance and rely on personal networks in emergency situations.

To some extent in all case studies, the ICGs mentioned that turnover from health and care professionals was a reason for a disruption in the continuity of care. However, in the Netherlands and in France, dyads mentioned that care providers try to ensure continuity of care as much as possible during the holidays and in the night if needed.



For working 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, ICGs on sick leave reported that this time-out from work allowed them to care for the dependent older person.

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

Institutionalisation

In all our dyads, the ICG and the DEP prefer at-home care rather than in an institution. Living at home granted a larger level of autonomy to the DEP and allowed the DEP to maintain the home feeling and social environment. Concerns about the care provided in institutions were also cited by some ICGs in Wallonia and in Brussels as a reason to try to avoid institutionalisation. In Belgium, the ICG and DEP are aware that there are enormous waiting lists for institutionalisation. Also, the cost for putting a DEP in a nursing home is high; therefore, ICGs want to avoid this situation as long as possible. In our sample from Brussels, institutionalisation may occur when the ICG cannot find a good equilibrium between the different social roles played as caregiver, worker, spouse, parent, etc. In Germany, the support received, especially from mobile nursing services, seems to have a delaying effect on institutionalisation to a certain degree. The ICG looking out for the two dependent older people that had already been institutionalised did not complain about long waiting lists. As for the costs, it depended on whether the ICG was made liable for the expenses or not. In the Netherlands, living situations can be adapted until institutionalisation is unavoidable and people are made aware of the possibilities of adaptations. Therefore, moving out the home happens gradually: it is a stepwise process. Yet, in France, institutionalisation seems only to happen at an ultimate stage relating to the worsening health conditions of the DEP.

The strong preference expressed both by DEPs and ICGs for avoiding institutionalisation, relates not only to the financial cost of institutionalisation, but also to the quality and accessibility of formal care services delivered at home. In our Luxembourg sample, persons entitled to the long-term care insurance have access to heavily subsidised services (e.g., domestic aid, meals delivery, tele-alarm) and products (e.g., hospital beds, adaptations to the house) that allow them to continue living at home, and thus delaying institutionalisation. In all countries, institutionalisation seems unavoidable at some point, either when surveillance becomes unmanageable (Germany), when the health of the ICG is at stake, or when the ICG can no longer care for the DEP (Luxembourg).

In the Netherlands, moving out the home happens gradually for the dyads in our sample, it is a step wise process. Yet, in France, institutionalization seems only to happen at an ultimate stage relating to the worsening health conditions of the DEP. The strong preference expressed both by DEPs and ICGs for avoiding institutionalization, relates to the financial cost of institutionalization, but also to the quality and accessibility of formal care services delivered at home. In Luxembourg, persons entitled to the assurance dependence have access to heavily subsidised services (e.g. domestic aid, meals delivery, tele-alarm) and products (e.g. hospital beds, adaptations to the house) that allow them to continue living at home, and thus delaying institutionalisation. In all countries, institutionalization seems unavoidable at some point, either when surveillance becomes unmanageable (Germany) or when the health of the ICG is at stake or he can no longer care for the DEP (Luxembourg).



5 CONCLUSION AND DISCUSSION

The discussion and conclusion can be found at the end of the Synthesis of this study, which is published as a separate document on our web site. It can be accessed from the same referral page as the current document.



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