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Federaal Kenniscentrum voor de Gezondheidszorg
Centre Fédéral d'Expertise des Soins de Santé
Belgian Health Care Knowledge Centre

SUPPORT FOR INFORMAL CAREGIVERS – AN EXPLORATORY ANALYSIS

APPENDIX

2014
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KCE REPORT 223S
HEALTH SERVICES RESEARCH

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APPENDIX

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2014 www.kce.fgov.be

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Acknowledgements:	Informal caregivers and dependent older persons who agreed to be interviewed, health and care professionals who helped in the recruitment, Hilde Bastiaens (Universiteit Antwerpen), Jean-Luc Ludewig (Quest), Johannes Böhmer (Zenit), Caroline Ducenne (Aidants-Proches ASBL), Céline Feuillat (Aidants-Proches ASBL), Hugo Vandenhouwe (OKRA-ZORGRECHT van OKRA, trefpunt 55+), Johan Tourné (Ziekenzorg, Christelijke Mutualiteit), Sophie Delcours (Liever Thuis, Liberale Mutualiteit), Erna Scheers (Vlaams Agentschap Zorg en Gezondheid), Mélanie Bérardier (Ministère des Affaires sociales et de la Santé – France), Ross Blommaert (Sociale Verzekeringsbank – Nederland), Maite Loraine (Ministerie van Volksgezondheid, Welzijn en Sport – Nederland), Erika Shulz (Deutsches Institut für Wirtschaftsforschung –Deutschland), Andrée Kerger (Ministère de la Sécurité Sociale du Grand-Duché de Luxembourg), Norbert Lindenlaub (Ministère de la Sécurité Sociale du Grand-Duché de Luxembourg)
Other reported interests:	Membership of a stakeholder group on which the results of this report could have an impact.: Véronique Tellier, Roy Remmen Participation in scientific or experimental research as an initiator, principal investigator or researcher: Kurt Debaere, Blanche Le Bihan Grants, fees or funds for a member of staff or another form of compensation for the execution of research: Blanche Le Bihan, Roy Remmen, Evi Willemse, Anja Declercq Consultancy or employment for a company, an association or an organisation that may gain or lose financially due to the results of this report: Véronique Tellier

	Payments to speak, training remuneration, subsidised travel or payment for participation at a conference: Jurn Verschraegen Presidency or accountable function within an institution, association, department or other entity on which the results of this report could have an impact: Karin Cormann, Roy Remmen
Layout:	Ine Verhulst
Disclaimer:	• **The external experts were consulted about a (preliminary) version of the scientific report. Their comments were discussed during meetings. They did not co-author the scientific report and did not necessarily agree with its content.** • **Subsequently, a (final) version was submitted to the validators. The validation of the report results from a consensus or a voting process between the validators. The validators did not co-author the scientific report and did not necessarily all three agree with its content.** • **Finally, this report has been approved by common assent by the Executive Board.** • **Only the KCE is responsible for errors or omissions that could persist. The policy recommendations are also under the full responsibility of the KCE.**
Publication date:	03 June 2014
Domain:	Health Services Research (HSR)
MeSH:	Caregivers, public policy, financial support, respite care
NLM Classification:	WY200
Language:	English
Format:	Adobe® PDF™ (A4)
Legal depot:	D/2014/10.273/41
Copyright:	KCE reports are published under a “by/nc/nd” Creative Commons Licence http://kce.fgov.be/content/about-copyrights-for-kce-reports.
How to refer to this document?	Anthierens S, Willemse E, Remmen R, Schmitz O, Macq J, Declercq A, Arnaut C, Forest M, Denis A, Vinck I, Defourny N, Farfan-Portet MI. Support for informal caregivers – an exploratory analysis – Appendix. Health Services Research (HSR) Brussels: Belgian Health Care Knowledge Centre (KCE). 2014. KCE Reports 223. D/2014/10.273/41. This document is available on the website of the Belgian Health Care Knowledge Centre.

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APPENDIX 1. STUDIES ON BELGIAN INFORMAL CAREGIVERS

Table 1 – Studies reviewed

Reference	Included in the review	Reason for exclusion	Survey data use (source)
1	Yes	6 references are included in one book	Two surveys: Care in Flanders and Mantelzorg in Flanders
2, 3	Yes		LOVO_1
4	Yes		Qualidem project
5	Yes		NADES
6	No	Information on preferences for formal care only	-
7	Yes		PSBH
8	Yes		Lovo_1
9	No	Theoretical modelling, no information on prevalence	-
10	No	Not available	
11	Yes		
12	Yes		Survey on Wallonia caregivers
13	Yes		Qualitative research
14	No	Theoretical framework of the long-term care insurance	-
15	Yes	Context	Caregivers from Kruibeke/Flanders (qualitative analysis)
16	Yes		Two surveys: Care in Flanders and Mantelzorg in Flanders
17	Yes		Context of policies and place of the caregiver in the long-term care system
18	Yes		Care in Flanders
19	Yes		Qualitative research

20	Yes		Literature review and qualitative research
21	No	Caregivers of institutionalised individuals	
22	No	Guide from Ziekenzorg CM	-
23	Yes		SEE 2001
24	Yes		LOVO_1
25	No	Theory of care	-
26	No	Theory of long-term care	
27	Yes		LOVO_1
28	Yes		SEE 2001
29	Yes		SEE 2001
30	Yes		-
31	Yes		SHARE
32	Yes		SHARE
33	No	Caregivers form different European countries	-
34	No	Not available, contacted authors and a publication is being screened	-
35	No	Information on formal care use only	-
36	Yes, published before 2005 but containing interesting policy information		Informal care in Flanders
37	Yes		National registry and SEE 2001
38	No	Detail estimates for Belgium are not available	PSBH
39	Yes		Discussion on policies for ICG in Belgium
40	Yes		Survey on sample of (future) users of the “zorgverzekering”
41	Yes		-
42	No	Caregivers of institutionalised	-

		individuals	
43	yes		Belgian Sentinel Network of GPs
44	yes		Qualidem
45	No	Systematic literature review	Systematic literature review
46	yes		Qualidem
47	No	Systematic literature review	Systematic literature review
48	No	Systematic literature review	Systematic literature review
49	No	No specific estimates for Belgium	-
50	Yes		Qualitative and quantitative research
51	No	Caregivers of institutionalised individuals	-
52	No	Discussion of the policy context for dementia patients	/
53	No	Systematic review of tools used to measure caregiver burden	-
54	Yes		SCV (2008)
55	Yes		SCV (2011)
56	Yes		VOZS
57	Yes		VOZS
58	No	Disabled individuals only	-
59	Yes		VOZS
60	Yes		Long-term care system
61	No	Theoretical concepts on coping strategies	/
5	Yes		NADES
62	Yes		Qualitative research
19	Yes		Qualitative research

Table 2 – Belgian studies identified in tertiary education institutions (2005- October/2013)

Institution	Search engine by university	Word	Number of results	Selected for abstract and review
VUB (Project Research)	http://www.vub.ac.be/infovoor/onderzoekers/research/onderzoeksprojecten.html	Informal care	4	1
		Care	246	1
		mantelzorg	0	
		zorg	0	
UA (Academische bibliografie Expertise research)	http://anet.ua.ac.be/acadbib/ua/	informal care	5	2
		care	381	7
		mantelzorg	14	13
KUL (via liras)	https://lirias.kuleuven.be/ excluded conference proceedings, dissertations or text ressources	Informal care	13	2
		caregiver	30	11
UCL	http://rch2011.adre.ucl.ac.be/home/fr	informal care	7	4
	http://dial.academielouvain.be/vital/ excluded communications	caregiver or informal care or aidant	320	7
Liege	http://orbi.ulg.ac.be/simple-search?query=caregiver	caregiver	29	3
		informal care	0	0
		aidant	36	1
Hand search	Roi Baudouin Foundation			2
	Studiedienst van de Vlaamse Regering http://www4.vlaanderen.be/sites/svr/Pages/default.aspx			3
	Other (including expert suggestions)			20

Table 3 – Summary of results on the prevalence of caregiving reported in the Belgian literature.

	Deboosere et al. (2006)[23] (SEE)[a]	Vanderleyden (2006)[3] (LOVO_1)[b]	Vanbrabant and Craeynest[63] (CBGS)[c]		Vanderleyden and Moons (2010)[54] (SCV)[d,f,g]		Vanderleyden and Moons (2012) (SCV)[e]
Survey characteristics							
Age of caregivers	15 years or older	55-90 years	25-64 years		18-84 years		18 years or older
Intensity of care[i]	Care provided on a regular basis	Care provided on a regular basis	Highly involved caregivers	All caregivers (less and highly involved caregivers)	Care provided on a regular basis	Care provided on a regular and occasional basis	Care provided on a regular and/or occasional basis
Prevalence estimates							
• **Belgium**	9.4%(n=719 686)	-					
• **Flanders**	8.8%(n=454 385)	27% (n=641)	19% (n= 515)	64% (n=1717)	18.0% (n=263)[f]	53.2% (n=779)[f]	23.4% (n=564)[f, h]
• **Wallonia**	10.4%(n=256 680)	-	-		-	-	-
• **Brussels**	9.6% (n=64 207) ,	-	-	-	-	-	-
Gender							
• **Women**	12.6% (n=273.144)	28% (n=360)	22% (n=309)	66% (n=927)	21.2%(n=159)	53.6% (n=401)	20.9% (n=n.a)
• **Men**	8.0% (n=176.048)	26% (n=283)	16% (n=204)	62% (n=792)	14.7% (n=105)	52.9% (n=378)	25.7% (n=n.a)
Age groups		-	-	-		-	-
• **15-24**	4.25% (n=73 991)				-		
• **25-44**	7.39% (n=480 177)	-	17% (n=245)	45% (n=641)	12.3% (n=80)[g]	56.4% (n=365)[g]	37.2% (n=n.a)[g,h]
• **45-54**	13.95% (n=319.765)	-	20% (n=148)	46% (n=641)	24.5% (n=68)	60.6% (n=168)	42.6% (n=n.a.)[h]
• **55-64**		36%(n=345)	23% (n=536)	45% (n=641)	28.2%(n=64)	52.9% (n=120)	50.2% (n=n.a.)[h]
• **65-74**	12.39% (n=104 730)	25%(n=216)	-		20.8% (n=37)	46.1% (n=82)	28.9% (n=n.a)[h]
• **75 and over**[i]	9.4%(n=61.668)	16%(n=88)	-		11.3% (n=15)	33.1% (n=44)	25% (n=n.a)[h]

Source: [a]Based in Deboosere et al.(2006)[23], page 93. Please note that the sum of the number of informal caregivers per region slightly differs from the data reported for Belgium (in 435 caregivers). This difference can be attributed to our own rounding error. [b]Based in Vanderleyden(2006)[3], page 257. [c]Based in Vanbrabant and Craynest (2004),page 264. Result from Heyden and Mortelmans (2007)[64]are not presented in this table as they are also based on the CBGS data. [d]Based in Vanderleyden and Moons(2010) [54,] page 10. [d]Based in Vanderleyden and Moons(2012[)54, 55], page 23. [f]Covers also Dutch speaking people living in Brussels.[g]The age catergory refers to the 18 to 44.[h]The authorsused different definitions for informal care in the article, therefore the total with Flanders cannot be compared with the reported value according to the age groups. [i]Depending on the survey the oldest age group may be limit to a specific age, see previous table for details.[i]Each survey uses a specific definition for care intensity, shee previous table for details. SEE: General socio-economic survey. LOVO_1: Living conditions of Flemish elderly. CBGS: Centrum voor Bevolkings- en Gezinsstudie, survey Care in Flanders. SCV: Socio-cultural changes in Flanders survey

APPENDIX 2. OVERVIEW OF THE BELGIAN HOME CARE SYSTEM

Formal services interact with the pivotal work of caregivers as complements and sometimes as substitutes.{Declercq, 2009 #96;Demaerschalk, 2013 #99;Geerts, 2012 #105;Declercq, 2009 #96} Therefore we cannot talk about the caregivers' role without discussing these services. The Belgian long-term care (LTC) system for elderly offers different home services, residential care facilities and supporting facilities for elderly according to their dependency and ability to stay at home. In the following sections the currently existing long term care services for elderly will be described. The overview of the long-term care system is based on a report of Van den Bosch et al. (2010).[65] As for this report we focus on elderly with caregivers in the home situation, we do not zoom in to the (permanent) residential care facilities but rather in the provision of home care services.

Appendix 2.1. The organisation of home care services: a fragmented picture

The organisation and financing of the formal care services can be situated at different governmental levels. While the organisation of the social security system (of which public health insurance is part) is a federal responsibility, the Flemish-, French[a]- and German speaking[b] communities are responsible for 'person-related matters', including some that affect health and LTC. In Brussels-capital region, the regulatory bodies of the Flemish and the French speaking communities, the Flemish Community Commission (FCC)[c], the French Community Commission (COCOF)[d] and the Common Community Commission (CCC)[e] are competent for these matters.[f] LTC services provided through the health insurance system only cover (home) nursing care (as well as paramedical and rehabilitation care) and part of personal care to dependent elderly. A range of other non medical aspects of care and services for elderly is organized and provided at the regional and local level. The regional[g] governments have issued decrees that regulate a wide range of issues related to LTC services: organisation and certification of organisations for domestic aid, facilities such as day and short care centres, integration and coordination of services at the local level and so on.

The multitude of competent governments and their different governance of organisations and services for home care render the organisation of home care services very complex, fragmented and sometimes overlapping. Furthermore, not all organisations operate as accredited bodies by a competent government (e.g. associations operating with service cheques,..).

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[a] http://socialsante.wallonie.be/?q=aines

[b] http://www.dglive.be/fr

[c] http://www.zorg-en-gezondheid.be/v2_home.aspx?id=22794

[d] http://www.cocof.irisnet.be/nos-competences/affaires-sociales/maisons-de-repos

[e] http://www.ccc-ggc.irisnet.be/fr

[f] As for the services in Brussels that fall under the competence of the Flemish Community, the Flemish Community is the legislative body, we refer to the situation in Flanders for these services

[g] we will use the generic term 'regional' in the rest of the text to designate the sub-national level of authority. The Flemish and German-speaking communities assume their responsibilities themselves, while the French-speaking community has devolved its responsibility to the Walloon region for matters relevant to the Walloon territory. For an overview of the legal framework

Table 4 – Home care services in Belgium (2013)

	Flanders	Wallonia	Brussels	German-speaking community
Nursing care				
Who provides	Nurses employed by private organisations public, centers for social welfare and sickness funds or by self employed nurses			
Public financing	**Basic nursing care:** Lump sum/diem based on care profile paid by RIZIV/INAMI Additional lumps sums for palliative and intensive hygienic care. **Technical nursing care:** Fee for service Day limit			
Patient co-payments	Generally, the level co-payments of the patient for home nursing is (approximately) 25% of the tariff but often not asked Patients with increased reimbursement pay 0.24 euro/day for basic nursing care			
Needs assessment	In the scope of financing By the treating nurse 4 categories of care profile based on the Katz Scale.			
Aid plan	Minimum content regards planned nursing activities, frequency and timing			
Personal care and domestic aid				
Who provides	Private organisations, public centers for social welfare and sickness funds offer facilities for personal care and domestic aid. In Flanders specific services offering logistic help, complementary to the services for personal care and domestic aid are foreseen.			
Public financing		Regional/Local		
Patient co-payments	Family help: Fee/hour, fixed by Flemish	Fee/hour fixed by Walloon government in relation to the	Fee/hour fixed by COCOF in relation to the means	Fee/hour in relation to the means of the

	government calculated based on the means and the composition of the family. Reduction of the tariff possible if high BEL score[h] (>35). Additional domestic aid: fee/hour set by association. The income and composition of the family need to be taken into account. Acute family care: fixed amount: 7,5 euro/hour, 4,5 euro/hour for WIGWE/OMNIO or increased reimbursement Logistic help: fee/hour set by association. The modalities of calculation are not legally set, but income and composition of the family need to be taken into account.	means and composition of the family.[i]	and composition of the family[j]. CCC: Fee/hour in relation to the means and the composition of the family FCC: see Flanders	family, maximum tariffs set by the government

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[h] Art. 1 N 2 Ministerieel besluit van 26 juli 2001 tot vaststelling van het bijdragesysteem voor de gebruiker van gezinszorg, *B.S.* 12 december 2002; http://www.zorg-en-gezondheid.be/v2_default.aspx?id=23550&servnav=true&terms=sociaal+onderzoek#Sociaal onderzoek bij de gebruiker

[i] Art. 240 Waals Wetboek van 29 september 2011 Sociale Actie en Gezondheid, *B.S.* 21 december 2011

[jj] **Art.** N2. Bijlage II. Besluit 2009/520 van 14 mei 2009 van het College van de Franse Gemeenschapscommissie tot vaststelling van het barema van de begunstigden en het statuut van de gezins-, bejaarden- en huishoudhelpers in de diensten voor thuishulp, *B.S.* 9 juli 2009

Needs assessment	Social examination Social assistant, qualified personnel of the respective service	Social examination Social assistant, social nurse specialized in community or public health decides on the provision of care	Social examination	A case manager defines the needs together with the elder and his/her family.
Coordination of services				
Who provides services?				
Federal	Geïntegreerde dienst voor Thuisverzorging: (GDT/SISD)	Services intégrés de soins à domicile (SISD)	Geïntegreerde dienst voor thuisverzorging/Service intégrés de soins à domicile	Services intégrés de soins à domicile (SISD)
Regional	Samenwerkingsinitiatieven Eerstelijnszorg (SEL)	Centres de Coordination de Soins et Services à Domicile (CCSSD)	Samenwerkingsinitiatieven Eerstelijnszorg Centres de Coordination de Soins et Services à Domicile	Centres de Coordination de Soins et Services à Domicile Bureau de Consultation
Care plan?	GDT/SISD: a care plan is set up during multidisciplinary consult			
Is there public financing?	GDT/SISD: Health care system (RIZIV – INAMI) - € 0,1964/habitant. Multidisciplinary consult at the patient’s home: € 46,69 Multidisciplinair consult elsewhere: € 35,02 Registration: € 14,60			
	SEL: Flemish government 60.000/year + 0.20 euro/habitant of region	CCSSD: Walloon government for personnel costs, operational costs, cost for training personnel		
Support and	Sickness funds, caregiver associations, social services of the hospital, OCMW-CPAS			

counselling	Flanders: Regional and Local Service Centers			
Is there public financing?	Financing and subsidies from the respective competent governments			
Respite care				
Short stay				
Who provides services?	Home care centers (Woonzorgcentra), rest and nursing home or revalidation center. Maximum length of stay: 60 succeeding days or 90 days/year.	Rest home or rest and nursing home. Maximum length of stay of 3 months or 90 days/year	FCC: see Flanders CCC: rest home or rest and nursing home. Maximum length of stay of 3 months or 90 days/year COCOF: Rest and nursing home. Max. Length of stay 90 days/year	Rest home or rest and nursing home. Maximum length of stay of 3 months/year
Are there out-of-pocket payments?	Day price	Day price	Day price	Day price
Day (care) center				
Who provides services?	• Day care centers that are operated by accredited centers for family care and additional home care or other centers. • Day (care) centers that are linked to a rest home or a rest and nursing home. .	• Day (care) centers linked to rest homes or rest and nursing homes	FCC: see Flanders CCC: Day (care) center: part of or connected with rest home COCOF: Day center: linked to service for domestic aid or coordination center for home care.	Day (care) centers: not defined in law whether they need to be part of rest home or rest and nursing home
Are there out-of-pocket payments?	• Tariff/hour for centers operated by accredited centers for	Day price	Day price	Day price

	family care and additional home care - Day price for others			
Hosting				
Who provides services?	Hosting facilities coordinate and organise care and accommodation in hosting families	Hosting is managed by a local, inter-communal or provincial social service, a public center for social action or an association without lucrative purpose recognised by the minister,	CCC: / COCOF: / FCC: See Flanders	/
Are there out-of-pocket payments?	2,6 euro/hour 25 euro/night 30,22 euro for 24 hour period	26 euro/ for 24 hours	FCC: See Flanders	/
Sitting services				
Who provides services?	- Professionals employed by facilities for home help and additional home care. - Accredited sitting services work with volunteers	Professional house sitters holding a degree or certificate that allows to provided family- or geriatric helper employed by accredited services for domestic aid and personal care	FCC: see Flanders CCC: integrated in services provided by facilities for home help and additional home care COCOF: integrated in services provided by facilities for home help and additional home care	Occasionally organised by volunteer services
Are there out-of-pocket payments?	Max. 2,71/hour	Tariff set by the organisation	FCC: see Flanders CCC and COCOF: fee/hour	/

Home nursing care

Home nursing in Belgium is organised via employee-nurses and via self-employed nurses. Most of the employee-nurses in home care are employed by private organisations with a specific focus on home nursing[k]. A small proportion of employee nurses are employed by the local public centres for social welfare and by self-employed nurses. For most self-employed nurses, delivering nursing care at the patient's home is their main and sole professional activity. Other self-employed nurses are working under a mixed professional statutory: on the one hand they are employee-nurses in a hospital, a nursing home or a medical practice (a general practice or a medical specialist's practice) and on the other hand, beyond their working hours, they may develop self-employed professional activity in delivering nursing care at home.[66]. From 1 April 2014 onwards an integration between activities performed by nurses and by aid-nurses, working under the supervision of nurses is foreseen.[l]

Home nursing care is available for persons with low to severe activities of daily living (ADL) and/or cognitive limitations, irrespective of their age. Care provided by home nurses includes technical nursing interventions (for example wound dressing and administering medication) and basic nursing care (mainly hygienic care in patients with ADL dysfunction). 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.[m] 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.[n] 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.

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 home 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. Patients only pay user charges.[o] Generally, the level 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.

On the home nursing organisation level, specific costs for organisation, coordination, programming, continuity, quality and evaluation are also financed[p]. Furthermore a subsidy for the costs related to computerization was introduced since 2006.

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[k] a list of accredited organisation for home nursing Vlaams Agentschap zorg en Gezondheid http://www.zorg-en-gezondheid.be/adressen_diensten_voor_thuisverpleging/#Waar vindt u een erkende dienst voor thuisverpleging?

[l] http://www.inami.fgov.be/care/nl/other/infirmiers/information-topic/auxiliary-nurses/index-integration.htm#1

[m] http://www.riziv.be/care/nl/other/infirmiers/general-information/circulars/2012/pdf/201201annexe3.pdf

[n] See circular regarding the contents of the care plan: http://www.riziv.be/care/nl/other/infirmiers/general-information/circulars/2012/pdf/201201annexe1.pdf

[o] See for the tariffs http://www.riziv.be/insurer/nl/rate/pdf/last/other/infir20130101corr2nl.pdf

[p] Koninklijk besluit van 16 april 2002 tot vaststelling van de forfaitaire tegemoetkoming van de verplichte verzekering voor geneeskundige verzorging en uitkeringen voor de specifieke kosten van de diensten thuisverpleging en van de voorwaarden voor het toekennen van die tegemoetkoming*, B.S.* 9 mei 2002

Domestic aid and personal care services

Services for domestic aid and personal care are organized, financed and provided at the regional and local level. Both private providers and Public Centres for Social Welfare offer subsidized home care services. The offered services include personal care services such as personal hygiene services (washing, clothing, nursing, etc.), psycho-social and pedagogical support and assistance (company, contact point, referral to other care providers, etc) as well as domestic aid such as household help (cooking, washing and ironing, etc) or cleaning services. Several services also offer equipment or systems enabling the autonomous stay at home, such as for instance alarm systems. The type of activities and services offered by the home care services aid are quite similar in all regions[q]. The volume of domestic aid and personal care services subsidised by the regional governments is limited by yearly quota of subsidized care hours that accredited organizations can provide. The quotum of subsidised hours per service differs per region according to the competent government. The Flemish government refers to population projections to base its calculation on, whereas the other governments multiply the hours/service of the preceding year with a fixed coefficient. Users of domestic aid and personal care services 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. Maximum tariffs are set by the respective governments, except for additional domestic aid and logistic aid in the respective services in Flanders and the Dutch speaking one in Brussels Capital region, where tariffs are set by the services themselves. The needs assessment for the eligibility for home care also differs in the Communities. In Flanders, the care need of a dependent elder is determined via a social examination by an employee of the respective facility providing family care. The need assessment is performed based on the BEL score, a tool including 27 items divided over 4 types of care need: domestic, physical, social and psychological. In Wallonia, instruments as SMAF (Système de mesure de l'autonomie fonctionnelle) or photogramme are used. Currently BELRAI, the Belgian version of the Resident Assessment Instrument (RAI), a web based system for needs assessment is tested for implementation for all actors in home and residential care in Flanders.[r] Wallonia signed the eHealth agreement protocol, which also contains the implementation of the BELRAI. In the German speaking community, the use of a scale for needs assessment is foreseen for the near future. Currently needs assessment is done by a case manager.

Information and other support services

Overall, different regional and local organisations and institutions (services social work of the sickness funds, caregiver associations, social services of the hospitals, OCMW/CPAS,…) provide information on long term care for elderly and caregivers. Furthermore, other supporting services enabling the autonomous stay at home for the elderly (e.g. personal alarm systems, technical adaptations in the house, ...) are provided by some of these organisations and institutions. In Flanders and in the Flemish governed centres of Brussels Capital region, regional service centres give information and training through group activities for elderly, informal caregivers and volunteers. They also offer services as hairdressing, hygienic help and warm meals, assistance in shopping or transport. Information and advice on all kinds of material and immaterial aids (including support technology, house adaptations, personal alarm systems, occupational therapy …) is provided as well. The centres also organise multidisciplinary consult (such as GP, physiotherapist, home nurse, etc) for an individual patient. Local services centres provide information and services that overlap to a large extent with those offered by the regional service centers. Yet, they primarily focus at the local population.

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[q] See for legislation on the services, mainly in Woonzorgdecreet van 13 maart 2009, *B.S.* 14 mei 2009 and its executor decrees for Flanders and Code wallon du 29 septembe 2011 de l'action sociale et de la santé, *M.B*. 21 décembre 2011 for Wallonia

[r] http://docs.vlaamsparlement.be/docs/stukken/2013-2014/g2215-1.pdf

Respite care

Several respite care facilities are organised in and out of the elderly's home. Depending on the need, respite care can be a once only, an occasional option or a recurring event, with a fixed or varying length of stay. The minimum age to benefit from respite care in residential facilities is 60 in Wallonia, Brussels and in the German speaking Community, 65 in Flanders. Deviations from the minimum age criterion are possible when motivated.

Day care centres and short stay centres provide nursing and personal care services for older persons with moderate to severe ADL or cognitive limitations who 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 days a week, but they spend the night at home. Some centers also offer overnight stay for the elderly. According to the competent government, the maximum capacity of the centers differs. Day (care) centres and night centers in Flanders, Wallonia and Brussels are linked to a rest home or rest and nursing home and are co financed by the NIHDI and the respective Community governments.[s] In the German speaking Community, it is not defined in law whether these centers need to be linked to a rest or nursing home.[t] In Flanders, additional day care centers managed by accredited centers for family care and additional home care or other centers are created to increase the capacity; they are solely subsidised by the Flemish government. The patient contribution paid in day (care)- and night centers consists of a "day price". The minimal services and elements that must be included in the day price are set in law. Day care provided in centers operated by accredited centers for family care and additional home care in Flanders charge a price per hour.

Short-stay centres provide residential services to older persons for a limited time period to temporarily alleviate the burden of informal caregivers. Short stay during the day and/or night with a maximum period[u] set in law, is provided in rest homes and rest- and nursing homes. A day price covering at least the minimum elements defined in law is to be paid by the patient. The price for short stay corresponds to the tariff charged to permanent residents. Overall, the cost of stay is paid by the occupant while medical costs and the cost of care are taken by the compulsory health insurance scheme.

No or low-care older people can stay in 'service flats' and similar accommodation which combine individual living arrangements with collective facilities (meals-on-wheals, home help, …)., Sickness funds also provide different types of respite care, including respite care at home such as sitting services. Sickness funds also often manage recovery centres focus at providing revalidation care and/or stay for individuals recovering from an operation, hospital stay or interruption of activity due to severe health problems. These centres are open to everyone and do not specifically target the elderly. Stay can also be foreseen for the caregiver. The Flemish government additionally recognised recovery centres. A maximum stay of 60 days is foreseen.

Several services focus at the integration of care for elderly in a more domestic environment. Hosting is organised in a host family's home where the elderly is taken care of on a voluntary basis during the day, at night or for several days. Hosting services are currently available in Flanders and in Wallonia. The user contribution is legally set in Flanders at 2,5 euro/hour during the day and 25 euro/night. At the time of writing the report the modalities of hosting are discussed in Wallonia. The user contribution is 26 euro/day. Sitting services in the elder's house are integrated in the services for domestic aid and personal care organised by the different governments.

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[s] Ordonnantie van 24 april 2008 betreffende de voorzieningen voor opvang of huisvesting van bejaarden, *B.S*. 16 mei 2008; Decreet van 22 maart 2007 betreffende het te voeren beleid inzake de huisvesting en het onthaal van bejaarden, *B.S.* 24 januari 2008

[t] Décret du 4 Juin 2007 relatif aux structures d'hébergement, d'accompagnement et de soins pour personnes âgées, aux résidences pour seniors et aux maisons de soins psychiatriques, *B.S*. 11/09/2007

[u] 90 days/year and 60 (Flanders) or 90 (Wallonia and Brussels) succeeding days. German Community: 3 months.

These attributed subsidised hours seem not to respond to the demand, however. Consequently, many private, non controlled nor subsidised initiatives and non declared workers do this work[v]. In Flanders additional sitting services working with volunteers have been set up to create extra capacity.

Co-ordination and integration of Long term care

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.

At the federal level, 'Integrated Home Care Services' (Geïntegreerde Diensten voor Thuisverzorging, or GDTs/Services Intégrés de Soins à Domicile, or SISDs) coordinate the provision of care in rather broadly defined geographical areas and receive financing of the NIHDI (0,1964 euro/habitant for 2013).[w] 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 consult that will serve to draft a care plan aligning the different care interventions. The care plan includes the planned care, the status of the functioning in daily life, a description of the formal and informal care network and the tasks of the different caregivers and health care professionals.[x] The care providers participating to the multidisciplinary consult are reimbursed by the NIHDI if at least 3 health care professionals, of which one is the general practitioner participate, the patient is residing at home and consent to a consult and if during the consult the level of dependency is evaluated, a care plan is drafted and followed up and an allocation of tasks takes place.

In **Flanders**, home care is further coordinated by 'Primary Care Cooperation Initiatives' (Samenwerkingsinitiatieven Eerstelijnszorg, or SELs.[y] SELs aim at cooperation between services and health care providers involved in the care for the dependent elderly. Other care providers, informal caregiver associations and volunteer associations, active in the region of the SEL are invited to be member of the SEL. SELs also offer training for care providers and provide information (Agentschap zorg en gezondheid, 2013). SELs can be accredited and subsidised for 1 region. SELs are entitled to 60.000 euro/year + 0.20 euro/habitant of the region where the SEL is active. In Flanders and Brussels, 15 SELs can be accredited. The SELs cover the same region as the GDTs. In Flanders all SELs are accredited as GDTs.

In **Wallonia**, 'Coordination Centres for Home Care Services' (Centres de Coordination de Soins et Services à Domicile, or CSSDs) operate in the same region or in part of the region of the SISDs. Their main tasks consist in informing and assisting the elder with regard to the home care situation or decisions on the institutionalisation, contributing to training programs for services and health care professionals offering home care, providing different services for home care or via convention and establishing functional links with the respite care and residential sector.

In **Brussels**, 5 Coordination Centers for Home Care Services have been accredited by the COCOF.[z] 1 SEL is accredited for Brussels.

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. An example is the care programme for geriatric patients who are discharged from hospital. The programme targets 'in-depth interaction between the hospital and aid and care services at home and the general practitioner, particularly via an external liaison function developed within hospitals, in order to provide a 'care continuum'' (Federale Overheidsdienst Sociale Zekerheid, 2009).

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[v] Personal communication Département des Aînés et de la Famille Wallonie

[w] Royal Decree of 8 July 2002, *B.S.* 05/10/2002

[x] Koninklijk besluit van 14 mei 2003 tot vaststelling van de verstrekkingen omschreven in art. 34, eerste lid, 13°, van de wet betreffende de verplichte verzekering voor Geneeskundige verzorging en uitkeringen, gecoördineerd op 14 juli 1994, *B.S.* 23 mei 2003

[y] Order of the Flemish Government of 19 December 2008, *B.S.* 31/03/2009

[z] Décret du 5 mars 2009 relatif à l'offre de services ambulatoires dans les domaines de l'action sociale, de la famille et de la santé, M.B./*B.S.* 08/05/2009

Appendix 2.2. Policies and services particularly targeting/supporting caregivers

The services listed in the previous chapter provide primarily help, support or assistance to the dependent elderly. Indirectly, however, they also affect the informal caregiver as the services provided will often complement, alleviate or (temporarily) substitute their task. In the next chapter the services or initiatives specifically targeting informal caregivers will be discussed.

Informal caregivers associations

Since 1998 caregiver associations in Flanders (or Dutch speaking in Brussels Capital Region) have the possibility to get accreditation and subsidies from the Vlaams Agentschap Zorg en Gezondheid. Currently, six non-profit associations active in Flanders and Brussels have been accredited. Their main task consist of regularly actively discussing with the members, providing information to persons in need of care and care givers, organising activities enhancing contact between people in need of care and care givers, collecting problems reported by the users and the care givers, reporting problematic situations to the government and representing the interest of the users and care givers. In Wallonia, the non-profit organization "Aidants proches"[aa] was created in 2005 by the Foundation King Baudouin. The mission is to gather and distribute information for caregivers and to represent their interests. The association gets subsidies from Le Ministère des Affaires Sociales, de la Santé et de l'Egalité des chances, La province du Brabant Wallon, Le SPF sécurité sociale, La Cocof, La Cocom, La Ville de Namur. Furthermore funding comes from sponsors and private gifts.

A legal status for caregivers

Today care givers have no legal status, guaranteeing access to specific social rights. There are several protective measures stemming from social security or labour law. In some sectors, there are legal options to combine care and work such as for instance. Yet, these measures are not linked to the status of caregivers. . In the past, several bills of law on the creation of a legal status for informal caregivers have been introduced[bb]. The study from the University of Namur was used as baseline for the discussion with different partners to create a legal status with the objective to set guarantees ensuring the accessibility of social rights for informal caregivers.[30] The request for a (national) legal status for informal caregivers primarily stems from Wallonia. Caregiver associations in Flanders, are rather exercising restraint since they fear that contributions by the municipalities (cfr. Infra) would disappear, once a legal status would be set by the federal government.

The most recent draft bill of law has been approved by the Council of minister in March 2013. The text defines the notion of caregiver but does not specify any particular rights or guarantees. According to the secretary of State who submitted the text, the recognition is a first primordial step in the process. The definition of the access to social rights for caregivers should be the next step. According to the draft bill, the sickness fund of the caregiver is competent to grant the recognition. In order to be recognised as a caregiver, one needs to be major or removed from guardianship, being a sibling or having an affective, confident, close or geographic relationship to the care receiver. The period of caregiving lasts for at least

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[aa] www.aidants–proches.be

[bb] wetsvoorstel betreffende de sociale erkenning van mantelzorgers, van 10 februari 2011, ingediend door J. Fernandez Fernandez c.s. (Doc 53 1192/001); wetsvoorstel tot wettelijke erkenning van de mantelzorgers en tot behoud van hun sociale rechten, van 27 april 2011, ingediend door M. Gerkens en M. Almaci (Doc 53 1399/001); wetsvoorstel tot erkenning van de mantelzorgers, van 3 oktober 2011, in-gediend door C. Fonck (Doc 53 1768/001); wetsvoorstel tot wettelijke erkenning van de mantelzorgers en tot behoud van hun sociale rechten, van 14 juli 2011, ingediend door Cécile Thibaut en Mieke Vogels (Doc Senaat 5-1172/1); Wetsvoorstel van 11 januari 2012 betreffende de erkenning van de mantelzorger, Parl. St. Kamer 2011-12, 53 1988/1

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. The care need is determined by the scales of the Direction-General Persons with a disability and criteria regarding the ability to live independently. The Council of equal chances for men and women, the Federal Advice Council for elderly, the social partners and the National Superior Council for disabled persons and the National Labour Council adviced on the text. The Communities and the Regions were consulted on the issue and the text is at the time of writing this report pending for an advice of the Council of State. Base on these advices a procedure and executory dispositions will be elaborated. Afterwards the parliamentary process can start. In several preliminary discussions it was raised whether the recognition of care givers falls within the competence of the federal legislator, given the competence of the communities regarding aid to persons. Other concerns such as the risk for a stop in the investment in services for domestic aid, competition between professional care providers and informal caregivers, inequality between recognised and non-recognised caregivers, etc.. were ventilated by the advising bodies. It should also be noted that regional legislation and the current draft bill are not aligned. For instance several definitions of the notion care giver exist and the scales used for the needs assessment are differing.

Appendix 2.3. Financial contribution for care givers

At the federal level, there is no formal financial rewarding for informal caregivers. Caregivers can indirectly benefit from the Flemish care insurance (Zorgverzekering) (cfr. infra), but only if the care receiver decides to give the amount (or part of it) to the informal caregiver.

Several municipalities, however, provide a local allowance for caregivers (Mantelzorgpremie). This is a voluntary initiative and the amount as well as the modalities (age, ability to be independent, domiciliation as a condition for eligibility, …) differ between municipalities. In 2012, 82 % of the 308 municipalities in Flanders provided a contribution. 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. [67] Several municipalities set different indicators such as

Appendix 2.4. Financial contribution to dependent elderly for non-medical costs: “Zorgverzekering”

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. [68] The amount is granted to individuals living in the community or in a residential facility and from 1 June 2013 it is automatically paid to severely dependent individuals who receive home care services from recognized services for family and complimentary care (in Dutch “erkende dienst voor gezinszorg of aanvullende thuiszorg”) or from recognized services for logistic help (in Dutch “erkend erkende dienst voor logistieke hulp). 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). At the moment of the creation, the Flemish care insurance was also considered as a tool to support informal caregivers. [31, 69]. According to a study of the Hoger Instituut voor de Arbeid, only 20% of the persons benefiting from the contribution pay the principal caregiver.[40]

APPENDIX 3. INTERNATIONAL COMPARISON

Appendix 3.1. European projects on informal care

This appendix provides a snap-shot of the international reports selected in the first step of our the literature review.

Multilinks[70]

The Multilink project aims at analyzing how demographic changes have modified or influenced family solidarity, well-being and integration. The intergeneration family obligations are analyzed. The project provides the first overview of the institutional framework surrounding the responsibilities towards frail elderly individuals. The study points out the difficulty to have up-to-date information concerning home care and residential services in European countries (the study refers to data available on the 2005 OECD report on Long-term care). A first description of the legal framework determining the maintenance obligation of children towards parents (ascendants) was included for twenty-two countries (Austria, Belgium, Czech Republic, Finland, France, Germany, Greece, Ireland, Italy, Latvia, Lithuania, Luxembourg, Malta, Netherlands, Poland, Portugal, Romania, Slovenia, Slovakia, Spain, Sweden and the United Kingdom).

Long-term care policies for older people: How Can it Help Improve Care Outcomes, Employment and Fiscal Sustainability[71] and Long-term care for older people[72]

Lungaard reviews the major long-term care programmes relating to home care (including the role of informal caregivers) in twelve European Countries (Australia, Austria, Canada, Germany, Ireland, Japan, Luxembourg, Netherlands, Norway, Sweden, the United Kingdom and the United States). The OCDE report of 2005 reviews long-term care arrangements (including residential care) for nineteen countries (Australia, Austria, Canada, Germany, Hungary, Ireland, Japan, Korea, Luxembourg, the Netherlands, New Zealand, Norway, Mexico, Poland, Spain, Sweden, Switzerland, the United Kingdom, and the United States). Description of direct income support as well as on other resources (e.g. personal budget) that can be used *to pay* for informal care are provided in both reports.

Help-wanted? : Providing and Paying for Long-term Care[73]

Within an analysis of the need for long-term care from an elderly population, two chapters of this report analyze 1) the role of caregivers, 2) the impact of caring on caregivers mental health, poverty and labour market participation and 3) as policies to support informal caregivers.

Interlinks project (2008-2011)[74]

The Interlink project reunited 15 partners around thirteen 13 countries (Austria, Denmark, Finland, France, Germany, Greece, Italy, Netherlands, Slovakia, Spain, Sweden and the United Kingdom and Switzerland) in order to construct and validate a general model to describe and analyze long-term care provision for elderly individuals. The role of informal caregivers was extensively reviewed in this project for seven countries (France, Germany, Greece, Spain, Italy, Slovakia and Sweden). The project includes an analytical framework to describe and classify caregiver support measures.

Typology (2010, Triantafillou)

- Non-specific and indirect (home based professional formula services, home support devices and home adaptation, monitoring technologies
- Non-specific and direct (all type of respite care)
- In-kind specific support (information advice/counselling, training/education, self-help and peer support groups, advocacy groups and informal carers' associations, employment support).

Carers@work[75]

The project assesses individuals experience when combining care and work responsibilities in four European countries: Germany, Italy, United Kingdom England and Poland. The project gathers evidence on specific conflicts and strategies of informal caregivers within the scope of each national reality. In other words, on how individual responses to the care-work conflict are adapted according to available support measures. The project is organized around three main parts: 1) a literature review and analysis of secondary databases (SHARE/ELSA and EUROFAMCARE), 2) analysis of the care-work situation at the level of the firm and 3) qualitative interview of informal caregivers.

ANCIEN (Assessing Needs of Care in European Nations study) (1 January 2009 -31 October 2012)(http://www.ancien-longtermcare.eu/).

The ANCIEN project aims at analyzing 1) how will the 1) need, demand, supply and use of LTC develop and 2) How do different systems of LTC perform? Among the work packages of the project the provision and determinants of formal and informal care across European long-term care systems. The Belgian Federal Planning Bureau (FPB) and the Netherlands Bureau for Economic Policy Analysis (CPB) were responsible for scientific coordination. The Eurobarometer 67. Included question on provision of informal care

MA:IMI project (Mainstreaming Ageing: Indicators to Monitor Implementation)[76]

The publications aims at providing information the development of ageing policies in an international comparative perspective. The data covers countries in Europe and North America.

Home care across Europe [77]

The report probes a wide range of topics including the links between social services and health-care systems, the prevailing funding mechanisms, how service providers are paid, the impact of governmental regulation, and the complex roles played by informal caregivers. Drawing on a set of Europe-wide case studies (available in a second, online volume), the study provides comparable descriptive information on many aspects of the organization, financing and provision of home care across the continent. It is a text that will help frame the coming debate about how best to serve elderly citizens as European populations age.

Table 5 – Overview of available information from different projects on informal care and long-term care

Project	Belgium	France	The Netherlands	Germany	Luxembourg
ANCIEN					
• **Report on long-term care**	Yes	Yes	Yes	Yes	No
• **LTC typology based on system characteristics**	1	1	1	1	n.a
• **LTC typology based on use and financing**	1	3	2	1	n.a.
Interlinks	No	Yes	Yes	Yes	No
• **Informal care report**	n.a.	Yes	No	Yes	n.a.

Appendix 3.2. Scoping review of the literature

A scoping review of the literature was performed in MedLine OVID and Econlit including the terms presented in the two table hereafter. The scoping review was done for two reasons. First, policy measures to support caregivers were heterogeneous and evaluation of policies were included in very different fields. Second, a more qualitative synthesis of the results allowed to find gaps in the literature. To avoid missing important information, two researchers performed a quality appraisal of the scope review.

After discarding duplicates, 609 references remained. Based on titles and abstracts, articles having information on uptake, cost or information of impact of policy measures were selected. Impact of policies measures among non-elderly population were excluded (e.g. children, people with disabilities, cancer patients..). Only studies concerning Belgium, France, the Netherlands, Germany and Luxembourg UK were selected. After applying inclusion criteria, nineteen articles and two books remained. Full texts were then searched and inclusion/exclusion criteria were applied on full texts. Four articles were excluded because they were opinion letters. Five studies were excluded because they were not related to the research (out-of-scope). Four articles and two books covered different points of the institutional system.[73, 78-82] The six remaining articles discussed support measure such as respite care or psychosocial support.[46, 83-87]

Table 6 – Search strategy Ovid MEDLINE

	January, 2014
Database	Ovid MEDLINE(R)
Date covered	1946 to January 2014
Search strategy	1 Caregivers/ (20343) 2 (informal adj care$).tw. (2156) 3 (frail adj elderly).tw. (1849) 4 (family adj care$).tw. (4812) 5 exp Policy/ (119405) 6 allowance$.tw. (6009) 7 (respite adj care).tw. (499) 8 leave$.tw. (71389) 9 (support adj intervention$).tw. (906) 10 1 or 2 or 3 or 4 (24418) 11 5 or 6 or 7 or 8 or 9 (196822) 12 10 and 11 (949) 13 limit 12 to yr="2005 - Current" (492)

Table 7 – Search strategy Econlit

	January, 2014
Database	Econlit
Date covered	Database: Econlit <1886 to January 2014>
Search strategy	1 Caregivers.mp. [mp=heading words, abstract, title, country as subject] (231) 2 (informal adj care$).tw. (204) 3 (frail adj elderly).tw. (34) 4 (family adj care$).tw. (94) 5 Policy.mp. [mp=heading words, abstract, title, country as subject] (337563) 6 allowance$.tw. (1911) 7 (respite adj care).tw. (2) 8 leave$.tw. (4666) 9 (support adj intervention$).tw. (12) 10 1 or 2 or 3 or 4 (451) 11 5 or 6 or 7 or 8 (341711) 12 10 and 11 (186) 13 limit 12 to yr="2005 - Current" (125)

Appendix 3.3. National validators

Table 8 – Overview national validators

	France	The Netherlands	Germany	Luxembourg
General content of per country	A. Goualard (Service-public.fr)	Blommaert, Roos (Sociale Verzekeringsbank - Servicecentrum PGB)	Thomas Gaiessmer (AOK Die Gesunheitskasse)	Norbert Lindenlaub (Ministère de la Sécurité sociale)
Information on policy evaluation relating to measures for informal caregivers	Mélanie Bérardier (DREES – Ministère des Affaires sociales et de la Santé)	Blommaert, Roos (Sociale Verzekeringsbank - Servicecentrum PGB) Maite Loraine(Ministerie van Volksgezondheid, Welzijn en Sport)	Erika Shulz (DIW-Berlin)	Andrée Kerger and Norbert Lindenlaub (Ministère de la Sécurité sociale)

Table 9 – National autorithies websites screened for information

Non-specifc country reports	France	The Netherlands	Germany	Luxembourg
• www.oecd.be • http://www.healthservicesresearch.eu/hsr_database • http://www.euro.centre.org/	• http://www.drees.sante.gouv.fr/ • www.irdes.fr • http://vosdroits.service-public.fr/F16920.xhtml	• http://www.rijksoverheid.nl/onderwerpen • http://www.scp.nl/ • http://www.respijtwijzer.nl/over-respijtzorg	• http://www.bmg.bund.de/pflege.html http://www.familien-pflege-zeit.de/ http://www.deutsche-rentenversicherung.de/ • https://www.destatis.de/ • http://www.gbe-bund.de	• http://www.mss.public.lu/dependance/index.html

APPENDIX 4. FLANDERS

To answer the research question: ”What are the effects from the informal caregivers´ point of view regarding policy measures to assist them”? an embedded multiple case study design is chosen. We describe and compare the experiences and perceptions of informal caregivers in seven cases with specific benefits for this group. In this part, the descriptive results of the interview data of the Flanders case will be presented. Each case consists of dyads of dependent frail elderly (DEP) and the main informal care giver (ICG).

The dyads in the Flanders case were recruited by GPs (see table demographics). We kept a mix between spouse and child caregivers. Two DEPs were institutionalized but less then four months (at least 1 people with dementia), three were living in the community (at least 1 people with dementia), two caregivers are in paid employment and at least one male caregiver was selected.

An analysis grid was composed to code the interviews (see chapter 3 methods). This analysis grid is used to describe the analysis of the interviews for each case. During the analysis we focussed on the awareness of the ICG of existing policy measures and on their perception of benefits from them. Thereafter, we described whether these policy measures have made an impact/effect on the lives of the ICG, on the continuity of care for the dependent elderly and the subsequent impact on delaying the institutionalization process.

Table 10 –Demographics of informa caregivers demographics Belgium Flanders

Belgium Flanders	ICG 1	ICG 2	ICG 3	ICG 4	ICG 5
ICG demographics					
Gender	Female	Female	Male	Female	Female
Age	56	82	55	53	55
Education level	Secondary education	Primary education	Secondary education	Higher education	Primary Education
Marital status	Widowed/Co-habiting	Married	Single	Married	Married
Number of children	2	2	0	2	2
Number of grandchildren	4	2	0	0	1
Relationship with DEP	Daughter	Partner: Husband	Son	Daughter-in-law	Daughter-in-law
Living with DEP	No	Yes	Yes: Before institutionalisation	No	No
If ICG co-resides with DEP: other persons living together with ICG	/	None	None	/	/
If ICG does not co-resides with DEP: other persons living together with the ICG	Partner	/	/	Husband and children	Partner (husband) and children
Current or past job occupation	Housewife (widow contribution) Past: Haircutter	Housewife	Economically inactive(disable- sick leave)	Employed teacher in secondary school	Employed: cleaning with PWA
If employed % working	/	/	/	100%	42%
Type of work	Past: self-employed	House wife	Sick leave Before: carpenter	Employee	Manual worker

Table 11 – Demographics of dependent elderly in Belgium Flanders

Belgium Flanders	DEP 1	DEP2	DEP3	DEP4	DEP 5
DEP demographics					
Gender	Female	Male	Female	Female	Female
Age	79	84	84	79	84
Education level	Primary education	Primary education	Primary education	Primary education	Primary education
Marital status	Widowed since 2.5months 31/8/2013	Married	Widowed since 2 years	Widowed since 17 years	Widowed since 16 years
Number of children	4	2	4 (2 alive)	3	3
Number of grandchildren	?	2	0	4	7
Relationship with ICG	Partner: Wife	Parent: Mother	Mother-in-law	Mother-in-law	Partner: Wife
Living location	At home	At home	Institutionalised since October 2013	Institutionalised since 21/07/2013 in short stay, later in nursing home	At home
Dementia	No	Yes	Yes	No (Parkinson)	No

Appendix 4.1. Introduction

For Flanders, 5 dyads were interviewed.

Within these five dyads, 4 female ICGs were interviewed, and one male ICG. The ICGs all had family ties with the DEP. Differences in living situation, education, working situation and socio-economical status was present and heterogeneity between dyads is achieved according to the sampling frame (see table demographics in annex).

Two ICGs were living together with the DEP. From out of the 5 ICG's, one ICG is working (100%), two were on sick leave (one long term sick leave, the second short term cause of an accident) and two ICGs received a pension contribution.

Three DEPs were interviewed. The interviews with the DEPs were difficult and there was insufficient added value on top of the ICG interview. Data from the ICG interviews was confirmed by the ICGs. Other aspects related to the individual characteristics of the DEP such as Parkinsons disease, recently widowed, physical and psychical problems and age impeded answering to interview questions of the DEP.

Appendix 4.2. Part 1 – Coding of data related to the role, experiences of the ICG and relation with the DEP

In our dyads, there is an increasing need of help for the DEP after frequent hospitalisations. Physical disabilities, multimorbidity and cognitive disorders occur, with a growing need of help after every hospitalisation. When DEP loses his/ her partner the situation is rapidly changing and more help is needed.

> *Vanaf'72 heeft hij nog gewerkt, dan was hij op vervroegd pensioen, maar is hij moeten stoppen met een niercrisis. Vanaf '72 is hij op de sukkel, hij heeft nog goede dagen gehad, maar na hartoperatie, slokdarm,…heeft hij veel hulp nodig gehad. (VL_2_1A_time3'04'')*
>
> *From '72 he was still working, then he was on early retirement, but he had to stop because of a renal crisis. Since '72 he has suffered ill health, he has had good days, but since his heart surgery, oesophagus,… he has needed a lot of help. (VL_2_1A)*
>
> *Toen mijn stiefvader nog leefde, toen hadden we ook geregeld …maar toen deden hun der eigen dingen, toen waren we niet zo intens bezig met hun. Maar nu mijn moeder alleen is komen te staan, is het anders. Ik heb ze altijd op sleeptouw. Ik neem ze overal mee naartoe (VL-1_1A_time4'58 '')*
>
> *When my stepfather was still alive, we had … but then my parents did their one things, the intensity of being with them was lower. But now, my mother is alone, it is different. I have her always with me. I take her everywhere (VL-1_1A)*
>
> *Ik ben al 2 x gevallen in de hof, 1 x dat ik naar het ziekenhuis moest en de tweede keer dat ik niet meer recht geraakte, dan heb ik de buren geroepen, die zaten binnen. (VL_1_2A_time3'35")*
>
> *I fell down for two times in the garden. One time I had to go to the hospital, the second time I wasn't able to stand up and I shouted for the Neighbours. They were inside (VL_1_2A)*

Having family ties and living nearby are important factors in giving informal care. In all the dyads the most important ICG is the one who lives nearby. ICG all had family ties with the DEP. All ICGs were sons, daughters or in laws.

In all cases they live close to the DEP. Two ICGs live or had lived together with the DEP.

> *Ze woont niet super ver weg, een kilometer of twee, drie (VL_4_1B_time 19'41'')*
>
> *She (DEP) does not live far, a kilometer or two, three (VL_4_1B)*
>
> *Ik woon hier als enige in B., de rest van de kinderen wonen buiten B. wij zijn de enige van de kinderen die hier wonen is er iets dan wordt er naar ons gebeld (VL_5_1A_time 1'19'')*
>
> *I am the only one living in B, the rest of the children live outside B. We are the only one of the children who live here, if something happens they call us (VL_5_1A)*

Motivations to take care of the DEP are different between cases and depends on the relation between family members. Reciprocity (the mutual obligation within a relationship to respond with a counter-gift, a gift thus where family looks after each other) was strongly present in the dyads in the Flanders case study. Especially when the ICG was a son or a daughter. If dyads live together, it was either the partner, or a single child who has been living with the DEP his/her whole life. The ICGs and the DEPs in other dyads did not prefer to live together.

> *Mijn dochter zegt altijd doe het zolang je ons oma kan verzorgen, voordat het gedaan is (VL_5_1A_time 38'00'')*
>
> *My daughter always says do it as long as you can care for our grandmother, before it's over (VL_5_1A)*
>
> *Toen heb ik gezegd tegen mijn moeder, maak je geen zorgen, ik regel alles. Je hoeft niets meer te doen. jij hebt altijd voor mij gezorgd. Je hoeft je nergens niet van aan te trekken, dat zal ik wel oplossen (VL_3_1B_time 13'31'')*
>
> *So I told my mother, do not worry, I'll take care of everything. You no longer have to do anything. You've always taken care of me. You don't have to organize anything. I will solve this (VL_3_1B)*
>
> *We hebben de korte ervaring gehad met het overlijden van mijn vader in 1997. We hebben geprobeerd haar in huis te nemen. Maar dat was het niet. Het was een totaal andere waarheid dan dat je jezelf had voorgesteld. Vooral hoe zij zichzelf in haar leven beweegt ten opzichte van. Ze had geen respect voor ons eigen bestaan en dan gaat dat niet (VL_4_1B_time 1°14'18'')*
>
> *We had a short experience with the death of my father in 1997. We tried to take her in. But it was not to be. It was a totally different reality to what you imagine yourself. Especially with regards to how she behaved in comparison. She had no respect for our own existence and that was not nice. (VL_4_1B)*
>
> *Als ze echt lichamelijke hulp nodig heeft, zal er toch iets moeten gebeuren. Als ze niet meer alleen kan zijn, moet er iets gebeuren je kan er geen hele dagen bij en ik neem ze ook niet in huis.. zo ver ben ik niet, …, niemand wil dat, dat wil ze zelf ook niet (VL_1_1A_time41'00")*
>
> *If she really needs help for mobilization, we must rethink living alone. If she is not able to live alone, than there should happen something. It is not possible to stay with here whole days and I'm not taking here in my home. I'm not able, nobody want's that, she neither (VL_1_1A)*

The impact of being an ICG is influenced by the relationship with the DEP, whether there is help from family members and whether daily life has changed since giving informal care. Taking care of a parent or partner is a personal commitment. It is seen as a duty to take care of the family you love. Taking care of someone else gives a good feeling. Having a good relationship with the DEP and the personal commitment to take care of the DEP makes informal care giving easier .

> *Ik voel me goed als ik iets voor een ander gedaan heb, dan denk ik, ik heb mijn steentje weer bijgedragen. Ik ben een zorger. (VL_1_1A_time14 '05 '' Q9)*
>
> *I feel good when I do something for someone else. Then I think I did my part, I'm a caring person. (VL_1_1A)*
>
> *Als je bij haar bent is alles in orde, die vindt dat geweldig (…) ze leeft in een vacuüm, ze kan dat geweldig, een tasje koffie, dan is de tijd niet belangrijk. Niets is dan belangrijk voor haar maar je moet zelf wel kijken, is dat in orde en is dat in orde (VL_4_1B_time 36'48'')*
>
> *If you are together with her, everything seems ok (…) she lives in a bubble, she is very good in distract help, drinking coffee, time isn't important they. Nothing is more important for here, but you do have to look if everything is ok (VL4_1B)*

The professional working situation of the ICG had an impact on knowing policy measures and the use of them. ICGs who were not working and thus at home (sick leave, pension) did not have the need to look for policy measures (respite care – time credit – care leave…) to find balance between work and giving informal care. They filled out requests for cash allowance, if the social worker offered it to them. If the social worker or any other person, didn't introduce it to them, they wouldn't ask for the cash allowance or they wouldn't know about it.

> *Ik heb het voordeel gehad van een jaar thuis te zijn (ziekte). 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 in. I could also sometimes go to the doctor. (VL_4_1B)*

> *Nee dat valt wel mee. Ik vind dat dat goed gaat. Als je nu alle dagen moet werken is het anders en drukker. Maar nu kan ik het goed combineren (VL_5_1A_time 9'21'')*

> *No, not really. I think it works out well. If you have to work every day that's something different, more hectic. But now I'm able to combine everything well (VL_5_1A)*

ICGs who combined working with giving informal care were in more need for information and more help. Especially younger ICGs who combined a full time job with giving informal care. Surveillance and being there for the DEP is not always possible during the day. Continuity of formal care is necessary in this situation. Seeking information is not easy. Fill in papers to request help, doing a lot of telephone calls and being referred at every phone call occured during this search, you need perseverance to get there in the end.

> *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 with the same problems, the same situation and you work it out. It's really insisting , repeatedly filling out forms (VL_4_1B)*

Recognition as an ICG at formal level but especially at informal level, is important and influences hindering and facilitating elements. Most of the time the ICGs are not aware of being one. But once you become recognized as the most important ICG, there is no way back. The ICG in this situation just does the things family and surroundings expect them to do for the DEP. Even if the situation is getting difficult and the combination working and giving care has become difficult.

> *Ik heb mezelf nooit als mantelzorger gezien hoor. Daar heb ik nooit bij stilgestaan. Toen belde ze daar voor. Doe jij mantelzorg? Ergens ben je dat wel, ik heb er nooit niet bij stilgestaan (VL_1_1A_time37'56")*

> *I have never defined myself as Informal caregiver. I did not thought about is. Then I got a telephone call, are you informal caregiver ? someplace you are, but I never thought about it.(VL-1_1A)*

> *Ja kan dat wel zeggen (dat het moeilijk is), maar dat is een muur he. Dat is ook iets van mantelzorg. Ah ja ik zie dat u het moeilijk heeft. Dat u ook onder behandeling bent, maar uw moeder kan niet opgenomen worden zei dan de geriater (VL_4_1B_time 51'52'')*

> *Yes you could say that (it's hard), but you hit a brick wall, eh. That is also the thing about homecare. Ah yes, I see that you have it hard, that you are also undergoing treatment, but then the geriatrician tells you your mother cannot be taken into care (VL_4_1B)*

Hindering elements

> *En dan oh, ik heb geen eten en ik heb zo'n goesting in paardenvlees. En ik heb graag dat paardenvlees van daar komt, en vorige keer had ik paardenvlees van daar, en dat was niet lekker. Als ik bij haar was ging dat, maar als ik buiten was kwam de stoom uit mijn oren. Maar dat mens heeft geen realiteitsbesef meer, totaal niet (VL_4_1B_time 50'50'')*

> *And oh, I have no food and I have such a penchant for horse meat. And I want horse meat from such a place, and last time I had horse meat from there, and it was not good. If I was with her it was OK, but if I was out, then steam would be coming out of my ears. But that person has no sense of reality anymore, absolutely (VL_4_1B)*

Facilitating elements

> *Ik denk dat ze dat allemaal wel, hoe noem je dat dat ze dat wel netjes vinden… de omgeving (VL_1_1A_time38'59")*
>
> *I think they all, how do you call, the all find it net/ respectful, the surrounding (VL_1_1A)*

> *Ze helpen me als ze kunnen, ze helpen me zo dat het enorm is (dochters) (VL_1_2A_time7'25'')*
>
> *They help me if the are able to, the help me so much (VL_1_2A)*

> *Jawel, ons moeder is heel dankbaar naar ons toe, dat wel (VL_1_1A_time38'30")*
>
> *Yes, our mother is very thankful to us, yes she does (VL_1_1A)*

The ICGs just do the things they need to do, they do not reflect or worry too much about it. As long as there is help available at home and the ICG is able to take time for themselves, the DEP can stay at home and depend on his/ her ICGs for help/assistance.

> *Af en toe denk ik nou is het wel genoeg. Binnenkort gaan we 4 dagen weg en dan moet ik lekker aan niets denken, niet van ik moet dit nog doen, dat nog doen, lekker leeg, we hoeven niets (VL_1_1A_time 14'10 '')*

> *Once in a while, It is enough. Shortly we go on a trip for four days and than I don't need to think, don think of this and doing that, we don't have to do anything (VL_1_1A)*

> *Zo lang als ik mijn huishouden kan doen en ik heb hulp dan gaat dat (VL_2_1A_time8'30'')*

> *As long as I can do my household tasks and I have help then it's OK (VL_2_1A)*

> *Je kan zoveel niet meer doen he. Naar de parochiezaal enzo. Ik neem hem mee, maar je kan zo lang niet blijven (VL_2_1A_time8'17'')*

> *You can no longer do much huh. Go to the parish hall and stuff. I take him, but you cannot stay so long (VL_2_1A)*

Appendix 4.3. Part 2 – Coding of data related to the health status and occupation of the DEP (2 A or B)

Recent and repeated hospital admission increases the need for informal and formal care. Often more formal services are needed because of decreased mobility and loss of cognitive functionalities.

> *Drie jaar geleden, toen bij haar blaaskanker is vastgesteld. Dan heeft een heel zware operatie gehad, dan is ze teruggekomen en is de verpleging opgestart. Dit is via de sociale dienst van het ziekenhuis gegaan (VL_4_1A_time 5'31'')*

> *Three years ago, when she was diagnosed with bladder cancer. She underwent a very serious operation, then she came back home and the nursing began. This was through the social services at the hospital (VL_4_1A)*

> *En terug van het ziekenhuis, een paar weken in bed gelegen, De fysio therapie gegeven, toen kon ze niet meer gaan, van te voren kon ze nog wel gaan. Ze moest overal voort in bed gehoffen worden, in de stoel, op de wc. Dan heeft ze een week of vier, vijf gelegen en toen zeiden ze ook, nu moet je ze echt naar een verzorgingstehuis doen, want dit kan echt niet meer, want ze wordt echt niet meer beter. (VL_3_1B_time 23'19'')*

> *Dat is nog niet zolang (extra hulp) het ging een tijd goed, maar toen heeft ze een paar keer in het ziekenhuis gelegen. Een paar zware operaties gehad. want we dachten na de laatste operatie dat ze niet meer naar huis kon komen, naar een verzorgingstehuis. Maar dan is dat toch weer goed gekomen (VL_5_1A_time 6'44'')*

> *That's not been going too long (extra help) it was good for a time, just while she was in hospital a few times. Had a couple of serious operations, because we thought after the last operation, she would not be able to come home, she would have to go into a nursing home. But then yet again it worked out okay (VL_5_1A)*

> *En terug van het ziekenhuis, een paar weken in bed gelegen, De fysio therapie gegeven, toen kon ze niet meer gaan, van te voren kon ze nog wel gaan. Ze moest overal voort in bed gehoffen worden, in de stoel, op de wc. Dan heeft ze een week of vier, vijf gelegen en toen*

> *zeiden ze ook, nu moet je ze echt naar een verzorgingstehuis doen, want dit kan echt niet meer, want ze wordt echt niet meer beter. (VL_3_1B_time 23'19'')*

> *And back from the hospital, a few weeks in bed, the physiotherapy completed, then she could no longer go whereas previously she had been able to. She had to be lifted everywhere - into bed, into the chair, onto the toilet. Then she has a week or four, five like this and then they were saying now you should really take her to a nursing (VL_3_1B_time 23'19'')*

The DEP wants to stay at home as long as possible. Being at home is very important for the DEP. Not only for the social contacts and the neighbourhood, but also financial issues are an important reason to stay at home.

> *We spreken er wel eens over. Daar hebben we het wel eens over gehad. Ze zit nu goedkoper dan dat ze naar een bejaardentehuis gaat, ze staat wel ingeschreven. Ze heeft de buurt, de sociale contacten nodig (VL_1_1A_time41'53")*

> *We talk about it. We have spoken about it. She now lives cheaper than that she is going to a nursing home. She is registered for that. She needs the neighbourhood and the social contacts (VL_1_2A)*

Therefore giving informal care is necessary as long as possible when the DEP cannot look after him/herself anymore. Formal services and informal care in combination with adaptations to the home are acquired. Institutionalisation can occur if adaptations are no longer possible cause of technical issues,or the DEP is not a house owner or financial limitations.

> *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 appropriate, the nurse said that showering is going to get difficult, to step into the cubicle every time. And then it was not in line with the fire insurance, it still had a gas stove, and the ventilation was not working properly. (VL_4_1B)*

> *De wc is te klein, daar kan je niet draaien met zo'n ding, dan moet je dat allemaal aan gaan passen en dit is ook maar een huurhuis. (VL_3_1B_time 32'31'')*

> *The toilet is too small, you can't move in there with such a thing so then you would have to have everything fitted and this is only a rented house (VL_3_1B)*

When the situation is getting worse, increasing need for help is presenting with an influence on the life of the ICG, then institutionalisation is unavoidable.

> *Ze heeft nooit niet doorgehad wat een organisatie het geweest is. Naar dankbaarheid toe is dat soms heel pijnlijk en heel wrang, want je wordt niet bedankt. Nu durft ze al eens te zeggen, ferm dat jullie dat doen. We hebben het eerst naar ons hoofd geslingerd gekregen (…) dat je in haar privé dingen intreedt, dat is een heel verhaal van hoe zij zelf is, mensen willen daarin de waarheid niet zien (VL_4_1B_time 29'53'')*

> *She never realized what a lot of organization it took. In terms of gratitude it is sometimes very painful and very bitter, because you are not thanked. Now she dares sometimes to say, it's good of you to do that. At first she bit our heads off (...) how you're encroaching on her privacy, that's the whole story about how she really is, people do not want to hear the truth (VL_4_1B)*

> *Thuisgekomen in het ziekenhuis, en een bed in de kamer gezet. Ik zeg je hoeft niet meer naar boven. In het begin ging dit allemaal goed. Maar toen begon ze s nachts rond te lopen, iedere dag voort (VL_3_1B_time 14'24'')*

> *Having come home from the hospital, and put a bed in the room. I say you mustn't go upstairs any more. In the beginning it was all good. But when she started to walk around at night, it would happen every day (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 appropriate, the nurse said that showering is going to get difficult, to step into the cubicle every time. And then it was not in line with the fire insurance, it still had a gas stove, and the ventilation was not working properly. (VL_4_1B)*

Appendix 4.4. Part 3 – Coding of data related to support from non-professional individuals (from family members, friends…) that the ICG and the DEP receive

One ICG can't give informal care on his own. If work and care needs to be combined, dividing tasks between informal care givers is necessary.

In most situations informal care tasks are divided between family members. Most of the time children offer informal care. Neighbours are not regularly seen as informal caregivers but can be used by the ICG as a sort of 'control mechanism', to watch out and communicate with the ICG when issues or irregularities occur.

> *2 dochters, die komen meestal in het weekend. De enige zaterdags, de andere 's zondags. Als ze tijd hebben springen ze ook wel eens in de week binnen. De ene dochter zit thuis met haar man, en die doet ook wel eens in de week binnenspringen. De andere heeft een zaak in Holland, en die komt wel eens in de weekends binnenspringen.(…) Of ze bellen elkaar (VL_5_1A_time 12'00'')*

> *Two daughters, who usually come on weekends. One on Saturday, the other Sunday. If they have time they come sometimes in the week. One daughter is at home with her husband, and she does actually pop over in the week sometimes. The other has a business in Holland, and she sometimes pops over at weekends. (...) Or they call each other (VL_5_1A)*

> *DEP werd geweldig door haar buurt ondersteund, het is echt een schitterende buurt. Die buren komen 's morgens kijken bij haar, die komen vragen heb j 's morgens brood nodig. Die konden ook al eens bellen en zeggen het gaat niet goed met stappen en zo van die dingen. (VL_4_1B_time 3'15")*

> *DEP was greatly supported by her neighbours, it really is a fantastic neighbourhood. Neighbors who come in the morning to check on her, who come to ask if we needed bread in the morning. They even knew to make a phone call and say it's not going so well with the walking and this type of thing (VL_4_1B)*

Appendix 4.5. Part 4 – Coding of data related to tasks performed by the ICG

Giving informal care is a daily task.

> *Hmmm, oei oei daar zou je van verschieten. Elke dag ben je daar mee bezig. Pak dat dat elke dag minstens een half uur is. Ik denk meer (zoon) Dan is dat van papieren invullen tot telefoneren. Ik heb echt soms de hele voormiddag dat ik bezig was om alles op een rijtje te zetten, telefoneren, afspraken maken, verpleging, dokters, euh, ja (VL_4_1B_time 48'15'')*

> *Hmmm, heavens, you would faint from it. Every day you're busy with it. Take it that it's every day for at least half an hour. I think more (son) Everything from paperwork to making calls. To put it in a nutshell, I sometimes spent the whole morning, phone calls, making appointments, nursing, doctors, uh, yeah (VL_4_1B)*

> *(stilte) tja, een dag denk ik, ja dat weet je niet. Als je een dag naar het ziekenhuis moet ben je al een dag kwijt, maar dat doe je ook niet elke week. En je doet om de beurt. Ik kom er iedere dag, al is het maar een tas koffie drinken. (VL_1_1A_time 14'45'' Q11)*

> *(silence) one day I, you don't know. If you have to go to the hospital for one day, you already lose the whole day. But you don't do it every week. And you do that in turn. I come every day, often only for a bag of coffee. (VL_1_1A)Informal care givers perform a variety of tasks (VL_1_1A_time 14'45'' Q11).*

Household activities (doing groceries, making diner, doing laundry) and practical support (administration, transportations) are the most common tasks.

Personal and medical care is outsourced to formal services.
Surveillance happens with the support of a personal alarm. If the
neighbourhood is very close, they also alert if things happen.

> *DEP werd geweldig door haar buurt ondersteund, het is echt een schitterende buurt. Die buren komen 's morgens kijken bij haar, die komen vragen heb j 's morgens brood nodig. Die konden ook al eens bellen en zeggen het gaat niet goed met stappen en zo van die dingen. (VL_4_1B_time 3'15")*

> *DEP was greatly supported by her neighbours, it really is a fantastic neighbourhood. Neighbors who come in the morning to check on her, who come to ask if we needed bread in the morning. They even knew to make a phone call and say it's not going so well with the walking and this type of thing (VL_4_1B)*

Appendix 4.6. Part 5 – Coding of data related to formal services received at home and outside the home for the DEP.

If the need for help increases, formal services (nurse help and family help) are the primary steps that are taken. As the need of help increases, formal

services are used more often. Information about these services is achieved during hospital discharge, through the social assistant. After hospital admission

the DEP needs to return home and help is sought and advise and information is giving through the social services of the hospital.

> *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 at the hospital, who contacted me. We had given our address as the contact. And they asked, was happens if DEP comes home? (...) And then the medical supplies came. And then she was admitted again so then I immediately asked the social services what else can we do? (VL_4_1B)*

ICG receives request papers form the health insurance, from the social assistant of the hospital or they have followed these procedures from experience from previous situations.

> *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 Paula 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 at the hospital, who contacted me. We had given our address as the contact. And they asked, was happens if Paula comes home? (...) And then the medical supplies came. And then she was admitted again so then I immediately asked the social services what else can we do? (VL_4_1B)*

Often the past experience of giving informal care and the search that was made for requesting formal services makes ICG aware of the existing measures.

> *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_time24'38"")*

> *I think that one service over an other, this and that. By GP and…I didn't know their existed so much services. I really was astounded. Their a lot of services. They are intertwined (VL_1_1A)*

> *Ik heb dat nooit geweten en daar nooit niets iets van gedeerd (VL_5_1A_time 29'30'')*

> *I've never known that and never been bothered about it (VL_5_1A)*

In this Flemish case study, a lower education level seems related to social economical status. Less information is obtained or less help is requested due to financial limitations or worry about the financial implications of help but may also be related to not knowing the right contact persons.

> *Ik heb 1 keer een telefoontje gehad van XX, van het OCMW, of weet ik van wat, dat ze eens een keer kon langskomen om te bespreken hoe het thuis moet. Ik zeg, ik heb dat niet nodig, ik kan alles zelf en heb geen hulp nodig (VL_3_1B_time 39'35'')*
>
> *I once had a phone call from XX, from the OCMW (social welfare), or I don't know what, saying they would come by one day to discuss how it should be at home. I told them, I don't need that, I can do everything myself and I don't need any help. (VL_3_1B)*
>
> *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 that you can do yourself, and you had time each day to do something, as long as I could do it myself, I really don't require help for anything. (VL_3_1B)*

Appendix 4.7. Part 6 – Coding of data related to formal services used to relieve support the ICG

Respite care (example short stay) is used when the DEP is not able to live alone anymore. Short stay is then used to bridge a period of time and to prevent institutionalisation. When the ICG goes on holiday, informal care is continued by other family members. If the social network is small and family members are not available, then the ICG is less able to leave the house or to go on holiday.

> *Wij hebben een caravan in X, en daar gaan we van Pasen tot september gaan we daar elk weekend naartoe. En dan blijven we ook niet voor ons oma thuis. Want als er iets is dan bellen ze wel en dan zijn we er zo (VL_5_1A_time 18'01'')*
>
> *We have a caravan home in X, and we go there every weekend from Easter to September. Then we're not at home for Grandmother. Because if there's anything they'll call and we'll be there. (VL_5_1A)*
>
> *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)*
>
> *Als ik ergens heel wil gaan, moeder lag in bed, doe ik gewoon de deur op slot je gaat geen uur van huis, dat gaat niet, je weet van tevoren waar je aan begint. Dat wist je, je kan wel eens van huis maar niet de hele dag (VL_3_1B_time 40'35'')*
>
> *If I really want to go somewhere, mother lying in bed, I just lock the door you don't leave the house for a whole hour, that's not OK. You knew that in advance what you're getting in to. They/ she knew it, you can sometimes leave the house but not for the whole day (VL_3_1B)*

Respite care (care that allows the ICG to rest) is not frequently used and they are not aware of it. ICG first try to solve their absence with the existing formal or informal help. Both DEP and ICG like to have someone trusting nearby.

> *Een beetje door de vingers kijken, dat is heel lastig geweest, maar ik ben daar nu weer door, dat is denk ik voor heel veel mensen heel lastig, een beetje afhangen van andere mensen. Wat ik zelf kan doen probeer ik te doen (VL_2_1A_time9'20'')*
>
> *A little look through the fingers, that has been very difficult, but I am now back again, I think that is very difficult for many people, to be somewhat dependent on other people. What I can do myself, I try to do (VL_2_1A)*
>
> *(bij vakantie) We hadden dat zelf afgesproken met S. De mensen op de hoogte brengen, de geburen, L. mijn nichtje (VL_4_1B_time 1°21'15'')*
>
> *(on holidays) We had even agreed that with S. To keep people informed, the neighbours, my niece L. (VL_4_1B)*

They also feel that it is their duty to take care of the DEP. None of the dyads spoke about existing services for respite care or the use of other informal services.

> *Ik ben aangesloten bij het OCMW. Ik zeg al tegen de meisjes, dan kan ik wel eens zorgen dat ze rijden. Maar dat willen ze niet. (VL_1_2A_time35'55'')*
>
> *I'm connected with OCMW. I tell the girls, I can ask if someone from service rides with me, but they don't want it (VL_1_2A)*
>
> *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 X nu ga je stappen (VL_4_1B_time 25'15'')*
>
> *At one point I said, X (family help) can you sometimes accompany her (to the doctors) because for me it's a little too much. I can't look at another hospital. It went well, and she did it. She also had control over your mother and she would say, now X you are going to walk (VL_4_1B)*

Appendix 4.8. Part 7 – Coding of data related to the financial support of the ICG

Differences between education level, socioeconomically status and living situation has an influence on the care that the ICG requested for him/herself. In our dyads we could see a difference in support measures used by the ICG depending on the socio economic status. ICG with a low education level (in the Flanders case) didn't work (unemployed or sick leave) or worked partially. Free time (not working time) was used to care for the DEP. Being at home decreases the use of formal services.

> *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 a case of researching and calling around and getting to know/ finding out. And then seeing peers left and right with the same problems, the same situation and you work it out. It is really insisting, repeatedly filling out forms (VL_4_1B)*
>
> *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 schedule, but you could be flexible with it. They saw to it at my work that I was able to switch with colleagues. They are very dear workmates, they have taken me into account (VL_4_1B)*

An ICG with a higher education level worked 100% and requested all the care that was possible in order to be able to work and to look after the DEP at home. They searched for information by themselves, on the internet, local authorities, peers or at the hospital. They ware aware of flexible work hours, time credit opportunities,.. . When the ICG became sick, in one dyad, the husband used time credit during one month. Is was a grateful help to continue informal care. Flexible work hours as well helped ICG and the partner to keep the balance between the own sickness, giving informal care and working.

> *De RvA (rijksdienst voor arbeidsvoorziening - In het Belgische socialezekerheidsstelsel is de RVA belast met de organisatie van de werkloosheidsverzekering). was eventjes lastig met papieren invullen, naar Brussel en dan was dat teruggekomen, iets vergeten, dan zat ik weer op een verkeerde dienst, een andere dienst (VL_4_1B_time 43'46'')*
>
> *The RVA were difficult in filling in papers, to Brussels, and then papers came back, forgot something, then I were on the wrong place/service, an other service (VL_4_1B)*

Despite the difficult procedure to request these policy measures, ICG believe it helped them to bridge this difficult period.

Living situation and the presence of a computer and internet influence the amount of social contacts and the willingness the make use of formal services. The social environment of DEP and ICG influences the willingness to accept formal help. Also the possibility and capability to communicate with different professionals makes accepting help easier.

> *Ik heb 1 keer een telefoontje gehad van XX, van het OCMW, of weet ik van wat, dat ze eens een keer kon langskomen om te bespreken hoe het thuis moet. Ik zeg, ik heb dat niet nodig, ik kan alles zelf en heb geen hulp nodig (VL_3_1B_time 39'35'')*
>
> *I once had a phone call from XX, from the OCMW (social welfare), or I don't know what, saying they would come by one day to discuss how it should be at home. I told them, I don't need that, I can do everything myself and I don't need any help. (VL_3_1B)*
>
> *Zolang ik zelf baas ben heb ik geen hulp nodig. Dan krijg je die over de vloer, dan die. En het zijn toch nooit dezelfde. Als ik nu ergens heen wil gaan doen ik gewoon de deur op slot. (VL_3_1B_time 40'05'')*
>
> *As long as I am in charge, I need help. Then you have people coming over all the time, but never the same ones. If I want to go out somewhere now, I just lock the door. (VL_3_1B)*
>
> *Bij de mutualiteiten, internet, via google, mantelzorg, wat valt daaronder, wat moeten wij daaronder verstaan, wat zijn de mogelijkheden? De dokter gebeld, ook wel eens gevraagd wat kan. De mutualiteiten, de sociale mensen van de mutualiteiten die hebben ons ook wel geholpen. Het ergste is op de juiste dienst zitten he. Niet te schatten. Dus dat is het OCMW, dat ben ik niet, dat is iemand anders, dan wordt je doorverzonden, die zijn er niet. Later terug bellen, nadien terug bellen. Dan moet je echt stapsgewijs proberen om alles gedaan te krijgen (VL_4_1B_time 39'37'')*
>
> *From the health insurance, internet, via google, caregiving, whatever comes under that, what we must understand from it, what are the options? Calling the doctor, also sometimes asking what's possible. The health services, social workers from the health insurance, they also helped us a lot. The hardest part is finding the right service, eh? Not guessing. So that's the OCMW, that's not the one, that's someone else, then you will be transferred to someone who is not there. Later call back, again call back later. Then you have to really try and get everything done in stages (VL_4_1B_time 39'37 '')*

When the DEP lives in his/her own house, adaptations can be made for living at home for as long as possible . Making adaptations to the house are not possible when the DEP is renting a house from social authorities. When the DEP had a low social income, and had help from the OCMW, they received all the services they can use, even financial advantages, in term of discount.

> *En zelf doet ze ook, ze schokt de hele tijd naar het OCMW, dat doet ze zelf, ze zit er ook zelf wel achter. (VL_1_1A_time24' Q15)*
>
> *And she does that herself, she goes to the OCMW all the time. That, she does herself, she askes frequently on the social assistant (VL_1_1A)*

The ICG were not aware of a cash allowance for ICGs. These remuneration is not provided in all cities/regions.

If the allowance is provided, papers need to be filled in to request for it. The amount is small, and not all costs made by giving informal care are covered. This has an influence on the formal help that is requested.

> *Euhm, het is wel zo, wij klagen niet, wij hebben een goei loon. Maar als je ziet, de kosten, als je alles begint op te tellen, de tijd van fietsen, telefoon, ja vervoer, alle kleine dingen. Als je dat begint op te tellen kom je aan een serieus bedrag. Doet dat nu een persoon met die 130 euro, dat is een tegemoetkoming. Ga je daarmee toekomen? Nee (VL_4_1B_time 1°18'51'')*
>
> *Uh, it's true, we do not complain, we have a good income. But when you look at the cost, if you start adding it all up, the days of cycling, telephoning, driving, all the little things yes. If you start to count, it adds up to a serious amount. Does a person do all that on 130 euros now? This is an allowance. Are you going to continue? No (VL_4_1B)*

Low socio-economically dyads did not request for extra help. This is related to the high costs generated by the frequency in which formal help is coming.

> *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, you can use on shopping for there and then it's also used up on the little you need for the financial things. if you need to get help everywhere and everything has to be paid for then you need to have a nice wallet, y'know (VL_3_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 help, we have to pay per hour. I have received an 'elderly assistance' allowance since April. I can thus pay for my help. As well as the health care fund. I can get 15 hrs' help per month, which is 60 euros per month, that goes very quickly! (VL_5_2A)*
>
> *Ik denk dat dat al voor hun omdat zij invalide is, op goedkope basis is, maar dat moet ze zelf betalen. Zij heeft al een tegemoetkoming, als je van het OCMW korting krijgt. Ik denk niet dat ze teveel betaald. (VL_1_1A_28'00")*
>
> *I think it is cheaper, because she is invalid. But she has to pay herself. She already has an allowance If you receive discount from the OCMW. I don't think she pays to much(VL_1_1A)*

Key points of this case analysis

- **In Flanders not all the ICGs were aware of existing support measures and do not actively look for it. The ICGs are also very wary of the fact that if they would need more professional help it might have financial implications. They want to avoid this, even it means that they have to look after the DEP 24 hours. Only if the need for help increased due to hospitalisation and the combination working and caring was not possible anymore, information about supporting measures was sought or offered to them through the social service of the hospital but this was not easy or straightforward. Financial support measures that were used, where too small, even sosmall that extra help could not be requested.**
- **Existing support measures, for example time credit and flexible work hours, were helpful in keep the balance between giving informal care,and overcoming the own illness and working.**
- **Accessibility to the different existing support measures showed difficult to obtain. ICGs and DEPs need to look for it by themselves. If information was provided, it happened at discharge form hospital (by social workers) and at moments help was needed in urgent and critical situations.**
- **Remuneration for ICG is not provided in the city/village of our respondents. The cash allowance for the ICG is small, the informal care costs were not sufficiently covered.**
- **The DEPs in this study like to live at home as long as possible, even if financial limitations are present. They are aware that waiting lists for institutionalisation, in service flats, short stay and in nursing homes are enormous. The price for institutionalisation in a nursing home is high. The ICG often seem to be a full time carer who gives help on his/her family.**

APPENDIX 5. WALLONIA

We conducted an embedded multiple case study (Yin, 2008) to illustrate, describe and compare experiences and perceptions of informal caregivers (ICG) regarding the policy measures to assist them. The interviews were coded using an analytical grid used to analyze the data of all cases.

Appendix 5.1. Introduction

Six dyads living in Wallonia were interviewed during the month of November 2013. The ICG were interviewed sometimes in the presence of the dependent elderly they care for. In only one case, the dependent elderly person (DEP) answered to our questions. The others were not able to do it. Furthermore, one DEP, living alone, was interviewed at home.

5 dyads were recruited by GPs, most of them working in medical centers, the last one (dyad 6) by the way of our relational network. Because of our recruitment strategy, the majority of DEP were affiliated to a medical center.

All the selected dyads met the selection criteria, with one exception: only one DEP was institutionalized[cc]. These six situations can be considered as “ordinary or common cases”.

In this appendix chapter, we present the descriptive results from the interviews conducted in Wallonia.

The data presentation follows the logic of the interview guide, divided into seven parts. In a last section, we summarize the information to respond to the main research question.

We limit the description of the situation to the different elements that are part of the “support system”: relationship between the ICG and the DEP, the health condition of both, the tasks performed by the ICG, and the formal/informal services they use at home or outside.

Through the data, we can see here how the concept of a “support system” is in place for each DEP. Each “system” is thus the combination of activities done by the ICG and those performed by the professionals at home. The proportion of activities performed by the ICG is directly linked to the proportion performed by professional services. In this sense, the different situations (dyads) explore and illustrate different kind of combinations: at one end, we have situations where the ICG “does nearly all” (Dyads 1 and 4), and at the other end we have dyads where the great majority of care tasks are performed by professionals (Dyad 2).

Descriptive data related to the dyads

The six dyads illustrate a mix of different “ordinary” but nevertheless diverse situations, at least from the GP’s point of view by whom they were recruited.

As illustrated in the table demographics below, we kept a mix between child, child-in-law, spouse and cousin caregivers.

[cc] Despite our steps with more than forty nursing homes located in Wallonia, we were not able to recruit more than one dyad with the DEP recently institutionalized.

Table 12 –Demographics of the informal caregivers interviewed in Wallonia

	IXT 1	IXT 2	IXT 3	IXT 4	IXT 5	IXT 6
ICG demographics						
Gender	Female	Male	Female	Male	Female	Female
Age	55	51	57	65	72	78
Education level	Primary	Superior	Secundary	Superior	Secundary	Secundary
Marital status	Married	Married	Married	Married	Married	Married
Number of children	1	1	2	1	2	2
Number of grandchildren	2		1	0	2	
Relationship with DEP	Daughter–in-law	Son	Daughter	Son	Cousin	Spouse
Living with DEP	Yes	No	No, but very close	Yes, partly	No	No (institutionalized)
Other persons living together with ICG	Her husband	-	Her husband and one son	His wife	-	-
Current or past job occupation	Disability allocation	Officer	Shopkeeper	Employee, currently retired	Employee, currently retired	Medical chiropodist
If employed % working	-	100	100	100	100	100
Type of work	Economically inactive	(SPF)	Self-employee	Employee (BMW)	Employee	Self-employee

Within these six dyads, 4 ICG were women and 2 were men.
All of them have children and the most have grandchildren.
Three of them are living in the same house as the DEP they care for, what has an important impact on the number of activities they perform themselves (dyads 1, 3 and 4).
Only two ICG are currently professionally active, the others are either retired or have never worked.
Some have been caregivers for years; others have become an ICG more recently.

Table 13 – Demographics of the dependant elderly persons

Wallonia	DEP 1	DEP 2	DEP 3	DEP 4	DEP 5	DEP 6
DEP demegraphics						
Gender	Female	Female	Female	Male	female	Male
Age	78	83	90	90	92	
o Marital status	widowed	widowed	widowed	widowed	widowed	Married
Number of children	7	2 (but one is dead)	5	1	0	2
Relationship with ICG	Mother in law	Mother	Mother	Father	cousin	Husband
Living location	In one of her son’s home	At home	At home	At home	At home	In nursing home
Dementia or not	No	No	Yes	Alzheimer	Lightly	Lightly

Regarding the DEP, four are woman and 2 were Men.
Four DEP suffer from dementia.
Five on six were widowed.

Appendix 5.2. Part 1 – Coding of data related to the health conditions of the DEP

The DEP need to receive care from the ICG because their health and mental health conditions imply that they are no more able to cover their primary needs themselves or because they need assistance in some practical tasks. In this section, we synthesized the data related to the health conditions of the DEP:

> *"Maman a eu un cancer il y a six ans. Elle a été en réanimation trois mois et demi. On lui a dit qu'elle n'avait plus que trois mois à vivre. Quand elle est sortie de l'hôpital, elle avait à peine trente kilos, elle ne pouvait plus rentrer chez elle. C'est l'hôpital qui a proposé qu'elle habite soit dans un home, soit chez moi" (WL_1_1A)*

> *« Elle a eu un AVC en décembre 2012. Elle est rentrée en clinique en décembre, elle en est sortie en février pour aller en revalidation pendant deux ou trois mois. Le médecin m'avait dit que je pouvais chercher un home, parce qu'elle ne pourrait jamais rentrer chez elle… Après quinze jours en revalidation on m'a dit qu'on pouvait envisager un retour à la maison. Donc on ne m'a pas vraiment laissé le choix… et comme elle ne voulait absolument pas rentrer dans un home mais rester chez elle… Bon, j'ai dit que je prenais ça à ma charge » (WL_2_1A)*

> *« Il y a sept ans, elle est tombée en clinique. Il fallait qu'elle passe des examens, elle est tombée de son lit. On n'a jamais su ce qui s'est passé. Elle en avait pour trois à quatre jours, au bout du compte elle est restée neuf mois à l'hôpital parce qu'il a fallu l'opérer. On a préféré la reprendre pour qu'elle meure chez nous plutôt qu'à l'hôpital, et cela fait sept ans qu'elle est là…» (WL_3_1A)*

> *« Je me suis aperçu qu'il était nécessaire qu'il y ait quelqu'un en permanence, comme ses moyens diminuaient de plus en plus, j'ai décidé de venir loger ici toutes les nuits, parce qu'il est pris d'une insécurité dans son esprit, il a des genres d'hallucinations… La solution la plus simple aurait été de le placer, mais c'est bouché partout… » (WL_4_1A)*

> *« Il y a vingt-trois ans, la sœur de Georgette est venue habiter avec elle, et comme elle avait des problèmes de santé, je me suis occupée d'elle jusqu'à ce qu'elle meure, en 200. Alors Georgette s'est retrouvée toute seule, et c'est alors que sa santé a commencé à se dégrader, elle commençait à perdre la mémoire… Elle ne voudrait pas rentrer dans un home, et moi je ne veux pas la mettre… (WL_5_1A)*

> *« Tout a découlé d'une dépression (en 2003). Mon mari a toujours été dépressif depuis que je l'ai connu, il y a 55 ans. Et alors on l'a soigné pour une très forte dépression, qui a pris de l'ampleur, que pour finir j'ai dû le placer. On le soignait avec des médicaments, avec des doses de plus en plus fortes. Il était comme un zombie… Aujourd'hui, il est complétement paralysé, parce qu'on ne l'a jamais bougé, et moi je n'avais pas la force de le lever… » (WL_6_1A)*

As we can see, some of the DEP became dependent after an episode (fall, cancer) although others progressively.

Appendix 5.3. Part 2 – Coding of data related to the role, experiences of the ICG and relation with the DEP

In this section, we present the data related to the role of ICG, as perceived and experienced by the ICG themselves, in relation with the circumstances they were faced with.

The reasons why the interviewees became the ICG of the DEP

First, it is important to make a distinction between caregivers who say to have chosen to care for the DEP, in order to avoid the institutionalization of the DEP, and those who say they didn't had the choice; either because the DEP does not want to go to a nursing home, or either because of the lack of places in a nursing home. As we'll see below, those who have not chosen are also those who don't see positive aspects of their role as caregiver.

The family ties and the relational proximity between the ICG and the DEP are, of course, important factors explaining why the first one take care for the second one. All the ICG were in fact the daughter, the son, daughter in law or spouse of the DEP:

> *" (Comme) c'était déjà moi qui allait le plus souvent à l'hôpital, plus moi que les autres parce que les autres travaillent… et comme on l'aime bien, elle est chouchoutée depuis six ans" (WL_1_1A)*

> *« C'est ma mère, cela s'est fait tout seul, c'est par le lien, c'est parce que c'est ma mère. Quand on a appris que maman allait rentrer à la maison et pas dans un home on en a quand même parlé avec ma cousine, pour que je sois sûr que s'il m'arrive un problème, que je puisse compter sur elle… » (WL_2_1A)*

> *« Je suis la cadette de la fratrie. Cela s'est fait automatiquement que ce soit moi qui m'occupe de ma maman parce que ma sœur aînée est très malade, mon frère aîné a eu des pontages, je n'avais pas le choix de toute façon. Je trouvais a normal, ça coulait de source… Étant la plus jeune et étant celle qui s'occupait le plus de maman, il était évident qu'elle vienne habiter à côté de chez moi. Au début, je ne voyais pas pourquoi quelqu'un d'autre se serait occupé de maman… J'ai quand même partagé beaucoup de choses que ma sœur n'a pas vécues avec maman… » (WL_3_1A)*

> *« C'est quand même mon père, je m'en occupe, tant que c'est gérable, je pense que tout le monde a le devoir de s'occuper de son papa… d'autant plus qu'il y sûrement plus contraignant… » (WL_4_1A)*

> *« Je ne pourrais pas faire autrement, je ne peux pas laisser les miens comme ça… Maintenant, j'ai vu maman le faire, aider ma grand-mère, qui était impotente, comme on disait alors. C'est un rôle que je tiens un peu de ma maman… moi c'est ma vie, ça a toujours été comme ça… » (WL_5_1A)*

The reciprocity principle (the mutual obligation of the members from a same family to look after each other at different moments in life) is often mentioned by the ICG to explain why they « naturally » play this role, especially when the caregiver is a child of the DEP:

> *« …Et puis il y a eu avant, le père (le mari de l'aidée), il a eu la maladie d'Alzheimer, alors elle a dû s'occuper de son mari… il est décédé depuis 2001. C'est pour ça que maintenant… elle a fait son boulot comme on dit, et maintenant, c'est nous qui nous occupons d'elle… » (WL_1_1A).*

> *« Elle me rendait des services aussi, il ne faut pas l'oublier, elle a gardé mes enfants pendant des années aussi… » (WL_3_1A)*

The positive/negative aspects of the care giving

To take care of a parent is nevertheless perceived by the ICG as ambivalent: even though negative aspects are most cited, some of them see also positive relational aspects in their role. Taking care of a parent can be, for example, a mean to break the loneliness of some caregivers. Some caregivers say also that taking care of someone can also be a source of self-satisfaction.

> *« Je ne suis pas toute seule, et elle n'est pas toute seule" (WL_1_1A)*

> *« C'est valorisant, je me sens bien dans mon cœur » (WL_3_1A)*

But the care giving is mostly seen as a source of troubles, stress and anxiety. More than all, taking care of a parent is time consuming and is seen as a constraint:

> *« Parfois elle grogne… on se dispute de temps en temps, des fois elle ne comprend pas ce qu'elle doit faire… » (WL_1_1A)*

> *« Pour moi, il n'y a rien de positif, c'est plutôt des tracas, des cheveux blancs, très certainement, on n'est jamais tranquilles. En soi, ce n'est pas lourd, je ne suis pas encore coincé à un point où je ne peux plus partir en vacances, mais c'est dans le temps, dans la durée… » (WL_2_1A)*

> *« Moi j'ai tout le temps mon GSM près de moi, parce que s'il y a un accident… Et vous vivez toujours avec cette crainte. Bien sûr, avec le temps on s'habitue un peu, mais c'est une préoccupation constante.. » (WL_3_1A)*

> *« De positif, ben non, je suis bloqué, je n'ai plus de temps, ça perturbe tout à fait ma vie, c'est contraignant de s'occuper à temps plein d'une personne comme ça, c'est une situation pas facile… » (WL_4_1A)*

> *« Avant, j'aimais bien aller en ville avec les petits, mais maintenant, je suis tenue, je ne peux plus faire ça, parce que je n'oserais pas la laisser, je suis coincée ici… J'allais très souvent en vacances, maintenant je ne pourrais plus y aller… Mais il n'y a pas que cela, c'est aussi l'âge et tout… » (WL_5_1A)*

Facilitating elements to play this role

To take care of a DEP is a stressful role that can only be played under some key conditions. In this section, we illustrate these key conditions as they were expressed by the ICG themselves.

Amongst the six caregivers interviewed, two are professionally active, but can easily adapt their work time when needed. Both underline their flexible work conditions as a first condition allowing them to adapt to the DEP's needs, and without which it should be difficult to play their role as caregiver:

> *« Je travaille au SPF Finances depuis 5 ans, où je n'ai pas d'horaire fixe. J'ai un boulot qui me permet d'arranger mon horaire, mes rendez-vous, mon travail. Je peux travailler à la maison aussi, donc il y a moyen de goupiller. Il est vrai que si j'avais un horaire fixe, je serais limité à mes samedis pour aller faire ses courses (de l'aidé), mais il n'y a pas que les courses, il faut aller chez le médecin parfois… Si je n'avais pas cette possibilité-là, il faudrait que je prenne un jour de congé, ça jouerait certainement sur mon temps libre… » (WL_2_1A)*

> *« Quand maman a besoin de moi, je dois fermer la boutique, je ne pourrais pas faire autrement… Quand par exemple maman a un petit problème d'incontinence ou autre, mon frère m'appelle, je dois fermer le magasin… C'est sûr que si j'étais employée, ce ne serait pas possible, il aurait fallu la mettre quelque part… » (WL_3_1A)*

> *« Quand j'en ai absolument besoin, j'appelle mon patron et je lui dis que je ne sais pas venir, et s'il faut, j'appelle le Dr. Et il me fait un papier pour prouver, parce que sinon… Comme tous les patrons, une fois ça passe, deux fois, mais au bout de la troisième fois, ils disent que maman elle a bon dos… Je le fais de moi-même, je vais chez le Dr. Et je lui dis que j'ai besoin de trois jours, pour maman parce qu'il sait quoi, il me fait un papier, je donne ça à mon employeur, je suis pas obligé, mais quand même… Quand maman était à l'hôpital, je lui ai demandé (à mon patron) pour pouvoir travailler le matin, parce que sinon je fais les pauses, ben il n'y a pas eu de soucis, j'ai fait mes matins, comme ça à deux heures.. Ils sont larges d'esprit, heureusement… » (WL_1_1A's husband)*

Second, because of our recruitment strategy (see introduction), a majority of the DEP who are cared by the ICG interviewed are affiliated to a medical center and beneficiates from the fee system that seems to help them in facilitating some organizational aspects of the support system put in place:

> *« J'ai fait les démarches pour demander un lit à la mutuelle, pour trouver un kiné et une infirmière, mais comme elle dépendait d'une maison médicale, cela aide beaucoup… » (WL_2_1A)*

> *« D'être dans une maison médicale, ça je dois dire que c'est génial. Parce qu'au début, le Dr J., il était là presque tous les jours, c'est génial… » (WL_3_1A)*

Some caregivers also mention the moral support from the other family members as a key element that help them to play this role:

> *« J'ai la grande chance d'avoir un mari conciliant, qui adore ma maman, parce que sinon c'est impossible, ça ne pourrait pas marcher, je me serais séparée. S'il n'y avait pas ça, ce serait impossible… » (WL_3_1A)*

Recognition, is also a key element from the ICG's point of view that echoes to the issue of self-satisfaction mentioned above, although it seems not to have the same importance than previous elements because ICG should they play this role even they don't receive the expected recognition:

> *« Maintenant, de son point de vue, d'après des remarques que j'ai eues, je passe trop vite, je n'ai pas assez de temps à lui consacrer… » (WL_2_1A).*

> *« Moi je ne fais pas ça du tout pour qu'on me dise que c'est bien ce que je fais, pas du tout, mais quand on vous le dit, ça fait plaisir… Je n'ai pas besoin de reconnaissance de la part de ceux qui ne font rien… » (WL_3_1A)*

> *« On n'est pas reconnu du tout.. » (WL_4_1A)*

> *« Vous savez quoi, les gens disent que je fais cela pour l'argent, on me le répète. Ben qu'ils le fassent, ils verront ce que c'est… Quand je ne suis pas bien, il faut quand même y aller, et cela ne me rapporte rien, je n'ai jamais fait payer à qui que ce soit la nourriture que je lui fais… J'ai jamais eu de merci… » (WL_5_1A)*

Hindering elements to play this role

Conversely, some elements are perceived as playing a hindering role, as the lack of support in administrative steps or some accessibility conditions to obtain material help :

> *" On a demandé d'avoir un emplacement pour personne handicapée, pour mettre ma voiture pour quand je dois prendre maman, il faut aller à cent mètres plus loin, cela nous aiderait un petit peu… on a tous les trois une carte de personne handicapée, mais l'emplacement, on ne peut pas, ça fait deux ans qu'on a fait les démarches, mais toujours rien, c'est la police de J. qui doit venir…" (WL_1_1A)*

> *« Ce qui m'aiderait, c'est une chaise roulante électrique, parce que c'est dur à pousser dans les côtes.. Parce que cela ne me dérangerait pas de sortir un peu plus souvent, mais comme ça, non, parce qu'il faut que je la pousse… Mais comme ils le disent, c'est un luxe… » (WL_1_1A)*

The health conditions of the ICG themselves plays another key role:

> *« J'ai été opérée de l'épaule (prothèse), je vais à la maison médicale pour faire mes soins et pour avoir mes médicaments évidemment. J'y vais maintenant pour le kiné trois fois par semaine » (WL_1_1A)*

> *« J'ai été opérée de la hanche l'année dernière, on a dû me poser une prothèse je ne savais plus marcher, ça a été une période très difficile, je ne pouvais plus me lever… Mais je n'ai jamais été faire ma kiné, c'était compliqué, je ne l'ai pas faite… » (WL_3_1A)*

> *« J'ai été opéré du cœur, mais maintenant ça va, je suis en pleine forme, je fais du jogging, etc. » (WL_4_1A)*

> *« J'ai été opérée de partout. J'ai une prothèse de hanche, une prothèse de genoux, on m'a opéré plein de fois, j'ai été opérée pour une hernie discale, j'ai de l'arthrose, j'ai aussi des mini-thromboses… Si vous saviez la série de médicaments que je dois prendre tous les jours sinon je ne pourrais plus marcher… » (WL_5_1A).*

Institutionalization occurs when these health conditions of the ICG are too bad :

> *« Je ne pouvais plus le garder ici parce qu'il tombait beaucoup la nuit et je devais appeler les pompiers parce que je ne pouvais plus le mettre debout, il faisait 104 kilos. Il y avait parfois deux-trois pompiers… J'avais déjà eu deux fois le Guillain-Barré, c'est une maladie orpheline qui se met dans les muscles. Et puis j'ai enchaîné en 2006 avec un cancer très très avancé à l'ovaire gauche. J'ai eu de la chimio pendant six mois, et puis maintenant je viens à nouveau d'être réopérée, parce que j'ai levé beaucoup de fois mon mari et j'ai attrapé une éventration, on a dû me mettre une plaque dans le ventre… J'ai eu la toute grosse chimio, parce que quand on a découvert que j'avais un cancer… J'étais alors très fatiguée parce qu'il ne me laissait plus dormir du tout… il était complétement déphasé : il se réveillait, il tombait, il sortait tout des armoires, il divaguait, il n'était plus présent… il y avait des nuits où je le retrouvais couché sur moi... » (WL_6_1B)*

The impact of the ICG role on the ICG life

The DEP's needs, amongst them surveillance, have different impact on the ICG's live. It mainly introduce some limitations which affect the other social roles of the ICG who can no more work, no more have holidays, no more leave his/her home, etc.:

> *« Pour l'instant je ne peux pas travailler, c'est impossible… C'est contraignant de s'occuper à temps plein d'une personne comme ça J'ai reçu les résultats de sa prise de sang, tous ses paramètres sont dans le rouge… parce que je vois qu'il n'a rien mangé du repas qu'on lui a préparé. Par contre, je vois qu'il a mangé plein de biscuits et du chocolat. Hier, je me lève, je constate que la boîte de sucres en morceaux est vide, alors qu'il restait plus de la moitié… mais je ne peux pas rester en permanence à côté de lui… » (WL_4_1A)*

> *« Avant, j'aimais bien aller en ville avec les petits, mais maintenant, je suis tenue, je ne peux plus faire ça… » (WL_5_1A)*

Appendix 5.4. Part 3 – Coding of data related to support from non-professional individuals (from family members, friends…)

About the help the dyad receive from the family

In the Wallonia's dyads, there is only one situation (dyad 3) where the care tasks are divided between the different children of the DEP:

> *« Quand on prend l'engagement de s'occuper d'une personne qui est malade, alitée, et qui ne sait plus manger toute seule, boire toute seule, se lever, être autonome, et que vous travaillez, vous ne savez pas le faire toute seule, c'est impossible. J'ai la grande chance d'avoir quatre frères et sœurs, comme mes frères sont prépensionnés, ils viennent en journée… Au début, tout le monde va venir, les tantes, les sœurs de maman, qui sont vieilles aussi mais qui sont encore bien… et vous, vous comptez là-dessus… Mais aujourd'hui, il n'y a plus personne, que nous autres, on ne voit plus personne… » (WL_3_1A)*

In other cases the ICG is the only caregiver and no other people take part of the care giving. In these cases, it seems not necessary to share the care giving tasks, because the support system put in place works good. Family members are occasionally asked to help, but not regularly:

> *« Il y a ma fille, qui vient de temps en temps pour m'aider, mais c'est rare, comme elle travaille, mais quand il y a un problème, je téléphone et elle vient… » (WL_1_1A)*

> *« Il n'y a personne d'autre que moi, mais parce que je ne le demande à personne. » (WL_2_1A)*

> *« Non, je suis le seul… » (WL_4_1A)*

> *« Du côté de Georgette, il n'y a personne qui vient. Elle a un neveu, qui est marié à une Yougoslave, mais ils passent tous les six mois, c'est malheureux hein, il pourrait venir de temps en temps… » (WL_5_1A)*

About the help from other people outside the family circle

Neighbours are rarely involved in the care giving. When it's the case, their role is very limited (alert mechanism) or they are paid as undeclared worker.

> *« Quand je suis partie en vacances, c'était l'une de mes nièces qui était là au cas où… Mais elle n'a pas dû venir, parce que ce qui est en place suffit, il y a pas mal de gens qui passent… La voisine s'est portée volontaire pour… Maman a un appareil de télévigilance au cou, elle est la première personne qui est contactée en cas de problème. La deuxième personne c'est ma cousine, puis c'est moi. La voisine s'est portée volontaire pour… Maman a un appareil de télévigilance au cou, elle est la première personne qui est contactée en cas de problème » (WL_2_1A)*

> *« Il y a la petite voisine qui passe chez elle tous les matins pour l'aider à se lever et pour s'habiller, qui lui apporte de la soupe à midi, et tous les soirs, elle est chez Georgette de 19 à 21h. Elle vient aussi une fois par semaine nettoyer chez elle. En été, elle fait le jardin et tout ça… » (WL_5_1A)*

Appendix 5.5. Part 4 – Coding of data related to tasks performed by the ICG

The amount of tasks performed by the ICG varies in regards with the tasks performed by professional services the DEP receives at home. In the following section, we listed by category the care tasks the ICG say they are doing for the DEP.

Household activities and personal care

By 'household activities, we mean food preparation, cleaning, washing, ironing, sewing, taking care of and playing with children, shopping or maintenance work, odd jobs, gardening, etc.

> *« Je fais son lit. Elle arrive à le faire de temps en temps, mais je le fais… Le ménage, c'est aussi moi qui le fais, sauf quand je crie sur mon mari pour le faire, alors c'est lui qui le fait… Couper ses ongles des pieds… » (WL_1_1A)*

> *« Les courses, c'est surtout les courses… » (WL_2_1A)*

> *« Tous les jours, je prends le linge la lessive, les repas… tous les matins pour la toilette et tous les soirs pour la mise au lit, il faut que je sois là avec l'infirmière, parce qu'elle ne sait pas soulever maman toute seule… À midi, je fais à dîner, j'apporte à dîner à mon frère et à ma maman. (…) Donc tous les jours je dois prévoir à dîner pour entre 7 et 9 personnes. Tous les jours, les courses et l'intendance, l'eau… » (WL_3_1A)*

> *« Ce qu'il faut que vous sachiez, c'est qu'il ne fait plus rien. L'habiller, le laver, je lui fais prendre son bain, tout, c'est moi, je fais du ménage, je passe l'aspirateur tous les jours, je nettoie en partie avec du javel, parce qu'il est incontinent, donc le WC et tout ça, un petit peu de gestion.. Je regroupe à moi tout seul les types de services qu'il pourrait avoir dans une maison de repos où il y a des infirmières, un service d'entretien, enfin, tout… Je lui apporte le repas tous les jours. Le matin, je lui fais son petit-déjeuner, le midi, je lui apporte le repas que mon épouse fait pour nous, parce qu'il ne sait plus beurrer, je reste avec lui sinon il ne s'alimenterait pas… Les courses, c'est moi aussi… » (WL_4_1A)*

> *« À midi, je lui fais un repas chaud. Elle a un petit dessert, son petit verre de vin. Parfois, vers cinq heures, je descends avec un petit gâteau… Elle sait encore se laver toute seule, mais en général, c'est moi qui lui fais prendre son bain, comme ça je sais que c'est bien fait… Sinon, je m'occupe de tout… Parfois, elle m'appelle et elle pleure, alors je prends la voiture, je ne sais pas faire autrement… » (WL_5_1A)*

> *« Je lui porte le repas depuis qu'il est en MRS. Avant, je portais le petit déjeuner, le dîner, et le souper. Maintenant, je vais de 11 h 30 jusque 13 h 30 pour le dîner, le déjeuner de midi, et le soir je vais de 16 h 30 à 19 h 30. Je le fais parce que j'aime bien, et parce que, disons je trouve que le matin et le soir ils ont peu à manger, et mon mari mange très bien. Il mange deux grandes tartines le matin et le soir, tandis que, je regrette de le dire, mais au home, les tartines sont petites… Et il faut surtout lui donner à manger, parce qu'il est paralysé. Il ne sait même pas prendre un verre s'il a soif. » (WL_6_1A)*

Medical care

The 'cleaning activities' include arrange medication or medical support performed by the ICG as for example cleaning a wound:

> *« Il y a sa poche, c'est moi qui dois la faire tous les jours… Il y a des médicaments que je dois lui donner tous les jours… Quand elle est malade, je vais chez le pharmacien, qui regarde ce qu'elle prend, et il me dit ce qu'il faut faire. Elle doit faire de l'aérosol, parce qu'elle a dur à respirer. Après, dans la semaine, je téléphone au DR J. et je lui explique ce qui est arrivé » (WL_1_1A)*

> *« Les médicaments, tous les jours, c'est moi qui les mets dans une boîte, j'ai un semainier… » (WL_3_1A)*

> *« Il doit prendre des médicaments que je dois lui préparer, sinon il ne les prendrait pas. Il y a trois quatre médicaments sur la journée… » (WL_4_1A)*

Practical support

The tasks considered as 'practical support' include mobility support outside the house like assistance with walking or wheelchair, visiting family or friends, seeing to health care contacts, organizing help, physical aids or house adaptations and taking care of financial matters, receiving formal caregivers, etc:

> *« Parfois il faut la tenir pour monter les marches, parce que c'est un peu dur… Quand elle doit aller chez le médecin, alors je demande à mon mari de prendre congé, alors on va la conduire, sinon je dois la pousser, et c'est dur… Quand on part une journée, c'est mon mari qui pousse » (WL_1_1A)*

> *« Il faut aller chez le médecin, parfois, cela arrive que je doive passer chez elle pour un rendez-vous médical… » (WL_2_1A)*

Surveillance

Amongst the tasks that are mainly performed by the caregivers, surveillance is one of which consume more time, and, by consequences, that is also one of the most expensive when the caregivers have to paid somebody else. The use of home attendant, for example, is viewed as very expensive by the caregivers.

> *« Je fais quatre nuits par semaine auprès de ma maman, je dors dans le fauteuil… Les quatre autres nuits étaient réparties entre ma sœur et moi, mais comme ma sœur est tombée malade, c'est moi qui fais souvent trois nuits et elle vient une nuit… » (WL_3_1A)*

> *« Dans notre système, c'est celui qui doit s'absenter qui paie les gardes-malade. Moi je prends des gardes-malade de la mutuelle trois fois par semaine, et qui connaissent bien ma maman, parce que quand c'est chaque fois quelqu'un d'autre, avec maman qui perd déjà un peu la tête, ça ne va pas non plus… parce que je dois chaque fois expliquer où se trouvent les choses, mais vous savez qu'une nuit, c'est 50 euros… Donc, d'après le salaire de ma maman, ça revient à 35 euros par nuit… trois nuits par semaine, faites le compte… » (WL_3_1A)*

> *« Donc j'ai décidé de tout reprendre… Cela fait un an et demi maintenant. Au tout début, ce n'était pas encore nécessaire, jusqu'à ce que je me suis apperçu que c'était nécessaire qu'il y ait quelqu'un en permanence. Or, pour trouver quelqu'un qui vienne la nuit, ça coûte une fortune… » (WL_4_1A)*

Other tasks

We gather here the other "tasks" mentioned by the caregivers as administrative tasks, etc.

> *« Les aspects administratifs… » (WL_2_1A)*

> *« C'est aussi moi qui m'occupe avec mon petit-fils du cimetière, c'est moi qui dois m'occuper de ses morts... » (WL_5_1A)*

> *« Du jour au lendemain, je me suis retrouvé, mon mari étant quand même bohème, je me suis retrouvé devant des papiers, que je ne savais pas où ils étaient, tout étant mélangé… » (WL_6_1A)*

Table below provide an overall view of the tasks listed by the ICG during interviews. It appears that household activities are cited by nearly all the ICG (except in dyad 6 where the DEP is institutionalized). Personal care is only cited when the DEP and the ICG are both women or when the DEP is the husband of the ICG. Medical care tasks are limited to drug arrangements.

Table 14 – Tasks performed by the ICG

Tasks	ICG1	ICG2	ICG3	ICG4	ICG5	ICG6
Household activities (including food preparation, cleaning, washing, ironing, sewing, shopping and maintenance work…)	Partly, because the DEP can always do Some tasks like cleaning, washing, prepare food…	Only Shopping (weekly)	Yes (daily)	Yes	Only food preparation and shaving (daily)	Food preparation
Personal care	Nails care Hair care		Shaving (with the home nurse)			Daily shaving
Medical care	To change the colostomy bag (daily); To prepare and give the medications (daily); To prepare the aerosol;	No	To prepare the medications and to give them	To prepare the medications and to give them		
Practical support	Physical help in stairs; Transportation and mobility outside the home;	Transportation to the hospital or to the doctor (GP) or to the family members	To put the DEP to bed (with the home nurse)			Help for fooding or drinking
Surveillance and 'presence'			During four nights a week minimum	During the night (daily)	Daily visits (3-4 h by day, but not all days)	
Administrative	Yes	Financial administration (payment of services…)				Financial issues related to the house furniture…

Time spent to perform these care tasks

The ICG seems to have difficulties to estimate the time they spend daily to care for the DEP, because this time is often diluted in the time they spend to perform care tasks also to look after other family members, so it is not strictly divided.

> *« Le temps que je passe à faire sa lessive ou à préparer ses repas, je ne le compte pas, parce que je fais à manger pour nous aussi en même temps, ça ça ne compte pas.. » (WL_5_1A).*

The estimated time the ICG spent to take care of the DEP varies between a quarter of an hour per day (WL_1_1A) and four hours per day :

> *« Un quart d'heure par jour, environ ... » (WL_1_1A)*

> *« Avec les trajets, je dirais quatre heures par semaine » (WL_2_1A)*

> *« Trois heures par jour maximum " (WL_4_1A)*

> *« Quand je vais jusque-là, je reste entre trois et quatre heures, mais je n'y vais pas tous les jours » (WL_5_1A).*

Appendix 5.6. Part 5 – Coding of data related to formal services received by the DEP.

In this section, we present the data related to the professional services the DEP receive at home, as well as elements of perceptions of these services by the ICG.

Nurse home visits

The nurse services are obviously the most often present in the situations investigated, but used at different frequency, depending on the health conditions and the DEP's needs:

> *« Il y a des infirmières qui viennent deux fois par semaine pour une toilette complète et pour ses médicaments. Au début elles venaient tous les jours, ensuite elles se sont arrangées avec maman… » (WL_2_1A)*

> *« Ma maman est en forfait C. Il y a des infirmières qui viennent tous les jours pour faire sa toilette, matin, midi et soir… Mais l'infirmière qui vient pour la mettre au lit ne peut venir qu'à 16h maximum. Alors j'ai demandé à une copine infirmière (indépendante) de venir tous les jours. Donc l'infirmière de la MM vient le matin on la lave (elle a déjeuné avant), vient le midi pour la sortir du lit, on met maman sur le pot, on change son lange et on la remet sur le fauteuil, parce que on essaie de ne pas la laisser dans son lit, et elle dîne dans un fauteuil roulant… » (WL_3_1A)*

> *« Tous les jours, il y a une infirmière de la maison médicale qui passe pour soigner ses ulcères et lui mettre des bandages » (WL_5_1A)*

The nurses visits at home are perceived as very useful by the ICG, although some of them should like nurses come more frequently and later in the day :

> *« Je pense qu'une toilette tous les jours serait utile. Maintenant, est-ce que c'est faisable, est-ce qu'on peut demander, je pense que les infirmières sont aussi débordées, ce n'est pas la seule patiente" (WL_2_1A)*

When the DEP is affiliated to a medical center, nurses can not come at home later than 4 P.M. to put the DEP to bed, what oblige the ICG to asks an independant nurse to come at home to put the DEP to bed.

> *"Ça c'est la seule lacune de la maison médicale. On a dû mettre tout en place, mais l'infirmière qui vient pour la mettre au lit ne peut venir qu'à 16h maximum. Alors là c'est un gros problème, je ne vais pas mettre ma maman à 4h de l'après-midi dans son lit… Parce qu'à minuit elle va se réveiller. Donc, qu'est-ce que j'ai fait, j'ai demandé à une copine infirmière (indépendante) de venir tous les jours…" (WL_3_1A)*

Physiotherapist at home

The physiotherapist is the second professional services mainly cited:

> *« Depuis six ans, la kiné vient pour elle deux fois par semaine, pour la faire marcher ou pour la faire cracher, parce qu'au début, elle ne savait même pas marcher… » (WL_1_1A)*
>
> *« Le kiné a fait aussi beaucoup de travail pour qu'elle puisse se lever quand elle tombe » (WL_2_1A)*
>
> *« Alors j'ai aussi trouvé un petit kiné qui vient deux fois par semaine… mais je n'ai pas droit à un papier du médecin car il est dans une MRS… » (WL_6_1A)*

Domestic help

> *« Il y a une femme d'ouvrage qui vient toutes les deux semaines nettoyer la maison, et qui est payée par titres services » (WL_2_1A).*
>
> *"J'ai demandé de l'assistance au CPAS, et alors il y a une dame qui est venue tous les jours mais c'était très irrégulier. Elles venaient pour le laver, mais superficiellement. Je ne sais pas si c'est nécessaire, mais lui il préfère dans le bain. Et puis, après, elles font un peu de nettoyage. Mais vous savez, quand c'est à chaque fois une personne différente, c'est embêtant, dans la mesure où chaque fois, je suis obligé de lui dire voilà, il y a ça, ça… et puis il y a une conversation qui s'engage, sur les deux heures, il n'en reste plus qu'une. Pff. 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)*

Family help

> *« Il y a une aide familiale qui vient tous les jours, du lundi au samedi. Elle vient faire ses repas de midi. C'est un service qui dépend du CPAS. Mais pour ma mère, c'est une dame qui vient faire à manger… Mais ce n'est pas une cuisinière, c'est une aide familiale, pour faire à manger, pour faire des courses si nécessaire, aller au pharmacien si nécessaire… à part pour faire à manger, maman ne leur demande rien, elle n'utilise pas le système à plein. Elle part du principe que l'aide familiale n'est là que pour une heure, et qu'elle n'a pas le temps, ça la chipote, elle n'aime pas trop… » (WL_2_1A)*
>
> *« Pour les repas, il y a une aide ménagère qui vient une heure tous les jours. Je n'ai jamais deux fois la même. A midi, à midi moins le quart, ça dépend. Elle le fait avec ce que je lui dis de faire. C'est bien, ça m'aide à m'alimenter. Je trouve que ça va, je suis assez bien soignée… 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)*

ICT Support

When the caregivers are not living with the DEP, a distant surveillance disposal service is automatically there.

> *« Maman a un appareil de télévigilance au cou, et elle ne le quitte pas, il a déjà bien servi…. » (WL_2_1A)*
>
> *« Elle (Georgette), a un appareil à son cou, avec lequel elle peut m'appeler, parce qu'elle aime bien entendre ma voix. Elle m'appelle souvent quand elle est triste, alors elle pleure, et elle me dit qu'elle est encore une fois toute seule… Mais à cause de ça, je ne dors presque plus, elle m'appelle parfois à minuit… » (WL_5_1A)*
>
> *« J'habite juste à côté, mais je dors ici toutes les nuits, parce qu'il a changé le jour conte la nuit.. Le jour, il dort… et je l'entends, parce que j'ai posé un petit appareil (babyphone) et je l'entends jusque chez moi » (WL_4_1A)*

Table 15 –Formal services received by the DEP

DEP 1	DEP 2	DEP 3	DEP 4	DEP 5	DEP 6
• Physiotherapist at home two times per week	• Nursing home service: two times a week • Family help: one hour at lunch time, from Monday to Saturday • Physiotherapist at home: three times a week • Domestic help: every two weeks	• Nursing home service : two times a day • Independent nurse : once a day • Home nurse: three nights per week minimum		• Nursing home service: once a day	• Speech therapist one a week • Physiotherapist two times a week

Although these different professional services are considered as central to maintain the DEP at home, the ICG are often critical towards the way professionals deliver them. In a certain way, some of these services are perceived as not adequate to the different situations or too expensive (domestic help).

> *« 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)*

Missing services

Related to these critics addressed to formal services, ICG also mention "missing" services they look for since years or they think more adapted to their own situations but which, from their point of view, are not existing in the local support system:

> *« 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)*

> *« Si j'avais une aide de temps en temps, 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… vous en avez, si vous payez… S'il pouvait y avoir un service non payant qui pourrait venir 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)*

> *« 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…*

Appendix 5.7. Part 6 – Coding of data related to the financial support of the ICG

The financial support of the ICG and the DEP is an important issue. Except for dyad 3, the cost of the maintain of the DEP at home, is mainly covered by the retirement pension of the DEP, sometimes completed by a special allowance.

For example, in dyads 1 and 5, ICG says the pension of the DEP covers all the costs of the maintain of the DEP at home:

> *« On utilise sa pension pour payer les histoires de sa maison mais c'est tout. Sa pension suffit à payer tous ses frais, ça oui… On paie le cadastre, on paie son électricité et son eau, parce qu'elle va nettoyer aussi par là, elle va s'occuper de la maison quand même… et nous, bien sûr, on se débrouille avec ce qu'on a… » (WL_1_1A)*

> *« Elle a une bonne pension, meilleure que la mienne, son mari travaillait à la commune, et elle a en plus une pension de 200 euros environ qui vient de Bruxelles… mais elle couvre à peine ses frais… pourtant, elle n'a plus de frais pour la maison. (…) La petite voisine, c'est moi qui la paie (avec la pension de Georgette). Je lui donne à peu près 250 euros par mois, et souvent une petite dringuelle, quand je lui demande d'autres choses. Mais ça c'est du noir, hein… » (WL_5_1A)*

Unlike, in the dyad 3, where the 24/24h monitoring system is shared between the five children of the DEP who sometimes use home attendant, her income is not sufficient to cover it. The ICG add personal money to cover for the extra costs:

> *« Elle a une pension de 1040 euros par mois, donc si tout le monde ne met pas une partie… et l'argent, ça fait beaucoup d'histoires dans la famille, même s'ils sont gentils et tout ça, il ne faut pas oublier qu'il y a des belles-filles… parce que nous on est fort unis, sinon c'est impossible… s'il n'y avait pas ça, c'est impossible. Et il y a déjà eu des heurts… Si j'avais 2000 euros, ce serait magnifique, je pourrais payer tous ces gens sans devoir mettre de ma poche…ça permettrait… mais c'est le double… » (WL_3_1A)*

In other situations, the cost of home services hinders their use for the DEP who receives no home services because of their cost:

> *" Il a une pension de 1500 euros par mois (…) Et 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)*

In terms of financial support, the two measures the most frequently cited are:

1. A reduction in heating, electricity and telephone cost or in expenses incurred by the needed services to maintain the DEP at home;

> *« En raison de son handicap, elle a droit à une petite ristourne au niveau de l'aide familiale, je crois que cela apparaît sur la facture, mais je ne pourrais pas vous en dire plus… » (WL_2_1A).*

> *« 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)*

> *« Les langes, par exemple : 25 euros un paquet de langes… Moi je pense qu'on devrait avoir un subside… J'ai un forait, je reçois 450 euros par an, forfait incontinence par la mutuelle, ce sont les infirmières de la MM qui font la demande, mais qu'est-ce que c'est*

> *450 euros sur l'année parce que si vous prenez des langes de cacaille, tout passe sur le côté… C'est comme les médicaments… » (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… » (WL_3_1A)*

2. An allocation for disabled person (WL_1, 2 and 3_2A).

> *« 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)*

The impact of such "measures" is thus a reduction in costs of services comprising the "support system" set up around the DEP. But otherwise, it is striking that some caregivers, do not seem particularly inclined to seek information or intend to make steps to benefit from any financial measures.

> *« Non, rien, on n'a jamais rien demandé, mais on ne nous a jamais proposé non plus… (…) On a su qu'on aurait pu avoir une aide du cpas quand tout était fini.. 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_1A)*

Appendix 5.8. Part 7 – Coding of data related to awareness of the existing policy measures

Awareness of existing measures targeting the ICG

In Wallonia, the ICGs interviewed did not mention the four measures targeting the ICG as identified in the international comparison, probably because no one is in the condition to benefit from such measures. First, because we don't have unemployed people in our sample who could benefit from favourable conditions from the National Office of Employment (NEO). Secondly, the ICGs who are still active did not have to ask leaves or adapting working conditions because of their flexible work schedule, or because they are an independent worker (self employed) and can adapt their working time when needed.

They seem rather aware that no support measures for the ICG exist in Wallonia.

> *"Je ne crois même pas que cela existe, je le saurais…" (WL_2_1A) ;*

> *"Rien du tout…" (WL_3_1A) ;*

> *"Il y a beaucoup de choses qui n'existent pas en Belgique" (WL_4_1A).*

> *"Non, rien. Il y en a qui touchent de tous les côtés, nous on ne reçoit rien » (WL_5_1A)*

Respite care services

Different forms of respite care (short stays, day care centers…) were mentioned during the interviews but this service is part of those that are often viewed as not appropriate or too invasive by the ICG:

> *« Non, jamais elle n'accepterait (à propos de la formule de « court séjour) » (WL_2_1A)*

> *« Il est allé quelques fois au centre de jour au C. 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)*

> *« J'ai pris des vacances avec Jordan au mois d'août, j'ai dû le placer en court séjour, mais c'est une fortune hein … Je l'ai mis trois fois au centre de jour, mais à chaque fois ils appellent le médecin, c'est ça qui est lourd, alors que je leur prépare tout… A chaque fois que quelqu'un de nouveau arrive au centre, ils appellent le médecin pour faire un bilan, mais en même temps les médicaments nécessaires. Et à chaque fois, ils appellent le médecin, qui lui donne à chaque fois tous les médicaments que je leur avais donnés. Alors là moi j'ai dit stop hein… ils m'ont compté 150 euros de lessive, alors qu son linge était*

> *là. Au lieu d’avoir une facture de 300 euros, j’en ai reçu une de 450, je suis un peu refroidi hein… » (WL_4_1A)*

> *« Je sais qu’il y a des services où on pourrait la déposer et venir la reprendre (centres de jour) mais cela ne lui plairait pas. Pourtant, elle aime bien bavarder, mais cela ne lui plairait pas… » (WL_5_1A)*

> *« A pâques, je suis quand même partie une semaine avec les petits, mais alors la petite voisine et mon mari se sont occupés d’elle. Il allait voir tous les jours, il faisait les courses… Pour ça, je peux compter sur mes proches, et sur cette petite voisine, là… Je ne veux pas non plus que toute une série de personnes viennent chez elle… je ne veux pas lui mettre des étrangers dans sa maison.. » (WL_5_1A)*

The ICG are well informed of the availability of respite services, but the cost and the design of such services hinder them somewhat. One interviewee says to have used it, but in a limited way because of the cost of such a service, but also for practical reasons. In other situations, this kind of service is viewed as non adequate, because the caregiver does not want that "strangers" come in her home, for example, or because the DEP does not want to leave his home to go to the day center:

> *« 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 attributed to the DEP because of their health conditions and level of dependence.

Awareness of existing measures targeting the DEP

The ICG interviewed are not equally informed about the measures and services targeting the DEP but supporting them in reducing the cost to maintain the DEP at home or in reducing the care tasks that they have to perform for the DEP. However, the five situations explored illustrate clearly that no professional or no service currently plays the role of information provider. No professional or no service provide coordinated information to the ICG not to the DEP. By consequence, the search for the necessary information is sometimes, for the caregivers, a real ‘obstacle course’. The ICG interviewed mention with great resentment the lack of knowledge of the professionals to whom they addressed to be informed about what they could benefit:

> *« Quand maman a commencé à avoir des problèmes, j’ai fait appel à l’assistante sociale et je lui ai demandé ce que je pouvais avoir sans payer… Donc moi je voulais qu’elle me guide, parce que je ne connaissais rien des forfaits A, B et C… Donc moi je pensais pouvoir avoir une aide dans les démarches à faire… pour finir, je n’avais droit à rien du tout, je n’ai rien eu… C’est moi qui ai vu la chaise d’une dame dans la maison de repos où elle a été et je me suis dit que ce serait beaucoup plus facile pour maintenir maman à table… La dame du home me dit que j’avais droit à cette chaise… Et alors j’ai fait la demande auprès de la mutuelle, il y a quelqu’un qui est venu quand elle est sortie du home, et j’ai eu le fauteuil après 7 ans…» (WL_3_1A)*

Because of the absence of a function like a case manager who should play this role instead of the ICE or DEP themselves, the ICG and the DEP have to look for the information by themselves. By consequence, their level of information about these measures/services depends on their level of pro-activity.

The caregivers who are still active are also more pro-active in the searching of information about the existing policy measures and available services in Wallonia than the others. ICG who are not or no more working are not looking for the information about these measures to limit or to reduce their involvement in the care giving of the DEP.

> *« 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_1A's husband)*

> *« Je n'ai jamais rien demandé, mais je sais que je peux demander au Dr C., qui me renverrait à sa secrétaire » (WL_5_1A)*

> *« 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 trouver, 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)*

> *« Depuis que je suis rentrée de l'hôpital, j'ai une pension d'handicapée de la Vierge noire, c'est mon fils qui a fait les démarches… » (WL_2_2A)*

Obviously, the DEP and the ICG get the information through a 'drop by drop' process, which implies that information is sometimes received too late:

> *« On a su qu'on aurait pu avoir une aide du CPAS quand tout était fini » (WL_1_1A's husband)*

The discharge from hospital is part of these moments where crucial information is provided, mainly by the social assistants:

> *« 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)*

Appendix 5.9. Part 8 – Coding of data related to the way the DEP/ICG benefit from existing financial measures

Available measures for the DEP benefit in two ways to the ICG: either in freeing up time he can use for him, either in reducing the overall cost of maintaining the DEP at home, whose income does not always enough to cover these costs (see part 7).

The accessibility of policy measures

The measures mentioned by the ICG and for which the access is related to a specific measure are:

1. a limitation to be recognized as disabled person (and thus to benefits from an allocation) beyond the age of 65 :

   > *« J'ai essayé de le faire reconnaître comme personne handicapée auprès de la Vierge noire, on me l'a conseillé, mais on m'a répondu que comme son handicap s'est déclaré après 65 ans, qu'il n'y avait pas droit… il faut, pour être reconnu handicapé, que le handicap soit reconnu avant 65 ans… J'ai aussi téléphoné à l'Awiph, mais ils m'ont dit qu'il n'y avait rien, qu'il était trop âgé… parce que parfois, on en arrive à plus de 2000 euros (de frais de séjour en MRS) »*

2. a reduced taxation of habitation income, related to an age condition :

   > *« 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).*

3. a restriction to the house owners to obtain an replacement income as disabled people :

   > *« 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)*

Appendix 5.10. Part 9 – Coding of data related to the impact/effect of these policy measures

On the continuity of care

The continuity of formal care is an important issue because when the care is interrupted, the informal caregivers have often to find a solution for overcoming the lack of care that can have an impact on the DEP's conditions but also a financial one.

> *"(à propos des kinés)… Quand la femme est en congé, alors c'est Mr Jean, mais quand il y a vraiment un problème, sinon ils ne viennent pas quand ils sont en congé. Cette semaine ils ne sont pas venus, parce que Mme M. est en congé » (WL_1_1A)*

> *« Par exemple 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… Heureusement que j'avais la fille de ma belle-sœur qui était en congé et qui avait besoin, qui m'a dit tantine, repose-toi, je vais assurer les nuits à ta place… parce que même elle je dois la rémunérer, sinon vous n'avez personne… » (WL_3_1A)*

> *« En théorie, il devrait y avoir une ergothérapeute. On en a eu une deux jours. Elle n'est plus venue. Il doit avoir de la kiné tous les jours, il n'en a pas… Il y a une, mais qui s'est fait mal au dos, elle a une hernie, et donc elle s'occupe plutôt des papiers et tout ça… Parce que mon mari n'est pas le seul à être comme ça, il y en a d'autres, mais dont la famille n'est pas aussi présente… Alors j'ai aussi trouvé un petit kiné qui vient deux fois par semaine… mais je n'ai pas droit à un papier du médecin car il est dans une MRS… » (WL_6_1B)*

In the five situations investigated in Wallonia, the support system set up around the DEP don't allow to avoid some interruption of care, but without too many great consequences for the DEP.

> *"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 institutionalization process

In Wallonia, as in other regions, the DEP want to stay at home as long as possible.

> *" Ce n'est qu'après quinze jours en revalidation que l'on m'a dit qu'on pouvait envisage un retour à la maison. Elle ne voulait absolument pas rentrer dans un home mais rester chez elle. Aujourd'hui,on ne regrette vraiment pas" (WL_2_1A)*

When it is possible, the ICG also prefers to look after the DEP themselves, at least those who are no more professionally active. The reasons why the ICG say it is a better solution for the DEP are varying, but the lack of care people receives in nursing homes because of the limitation in human resources appears as a key element.

> *« 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, maintenant on peut plus, et il y avait le réfectoire… Mais là j'étais déjà dégoutée avant que maman était malade, alors là j'ai dit non, stop… 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_1A's husband)*

> *« Les maisons de repos : beaucoup d'arnaques… Tu es déjà allé au 34 en face de l'hôpital de B.? C'est glauque hein… Ils sont très gentils, mais moi je n'ai pas envie de mettre mon père là-dedans.*

> *C'est vétuste, c'est vraiment vétuste. C'est une petite chambre… Il y a des maisons qui sont très honorables, mais c'est entre 2000 et 2500 euros par mois… » (WL_4_1A)*

> *« 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)*

The caregivers interviewed in Wallonia express an ambiguous attitude towards an eventual financial remuneration for the caregiver. They see their caregiver's role in the area of the "natural" relationships between parents, between the members of the same family. In their view, it seems to be a differentiation criteria, based on some values, education… :

> *"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_1A's husband)*

This also explains why the caregivers do not ask to receive some financial advantages. For them, it is not necessary to be paid for the tasks they perform as caregiver.

In the five situations investigated in Wallonia to maintain the DEP at home is possible because of the support system put into place including some home services and sometimes other informal people, but coordinated by the ICG. In the different situations, the support system can be seen as more or less in an unstable equilibrium, in the sense that without one of its components, playing a central role, all the system collapses, the caregiver could no longer play her role, and the maintain of the DEP at home would be compromised.

Key points of these case analysis :

- **The main reasons why the ICG take care of the DEP are family ties and relational proximity between them. The reciprocity principle is often explicitely mentioned by the ICG to explain why they « naturally » play this role.**
- **Even if some ICG see positive relational aspects in playing their role, most of the ICG view it as a source of troubles, constraints, stress and anxiety.**
- **Flexible work conditions, affiliation to a medical center are seen as facilitating factors for the organisational aspects of the caregiving. Moral support, recognition are also seen as supporting the ICG to play this role in the time.**
- **The lack of support in administrative steps, the access conditions to obtain some material help, bad health conditions of the ICG are, conversely, seen as factors playing a hindering role.**
- **In most of the dyads, the care giving rest on only one ICG, who eventually can count on the occasionally help from a family member.**
- **Neighbours and friends are rarely (in only one dyad) involved in the care giving of the DEP, which is mainly kept in the family circle.**

- **The ICG seem to have difficulties to estimate the time they spend to care for the DEP because these tasks are often diluted in the other tasks they perform for them and for other family members.**
- **The time they estimate they spent to take care of the DEP varies between a quarter of an hour per day and four hours per day.**
- **Although the different formal services are considered as central pieces of the support system to maintainin the DEP at home, the ICG are often very critical towards the way professionals deliver them. These services appeared frequently as not adapted to each specific situations, either for availability reasons (nurse services not available after 4PM), either as too expensive (domestic help, home attendant…).**
- **Because of the absence of a function like a case manager who should play this role instead of the ICG themselves, the ICG have often to look for the information by themselves. By consequence, their level of information about these measures/services depends on their level of pro-activity.**
- **The caregivers who are still professionally active are also more pro-active in the searching of information about the existing policy measures and available services in Wallonia than the others.**

APPENDIX 6. BRUSSELS

Appendix 6.1. Introduction

In Belgium, as in other European countries, the life conditions of older people coming from immigration are the subject of increased attention from public authorities. Although it is known that very few ‘migrants’ are institutionalized in nursing home, it is difficult for the professionals of the social sector to know where and how the older migrants live (beside the fact that they live within their “community”). In fact, it is not easy to get into contact with them via the local health or social care services. .

We conducted interviews with 6 dyads living in the region of Brussels in order to shed light on the potential effects of supporting policy measures as perceived by ‘non-native’ informal caregivers. By ‘non-native’ we mean DEP and ICG coming from other countries than Belgium, mainly described as ‘migrant’ people, even when they have acquired the Belgian nationality. Our sample is composed by people who are originally coming from Turkey, Morocco and Romania. All are Belgian citizens, except the ICG in dyad 4 who didn’t take the necessary steps to be regularized.

We focused on the specific characteristics of this population that can play a role in their contacts with the social and health institutions in Belgium and in their use of services provided by these institutions. This include, among other, some elements linked to their living conditions.

The dyads were interviewed during the month of December 2013. The informal caregivers were mainly interviewed in the presence of the DEP they care for. But as unlike the ICG, none of the DEP spoke French. As a consequence, they didn’t really participate in the interviews. All dyads were recruited through GPs working in Medical centers to which the DEP were affiliated. They were selected according to the agreed criteria, although only one DEP was institutionalized (dyad 2). The others DEP were living in the house or apartment of the ICG.

Descriptive data related to the dyads

The way ‘non-natives’ DEP and ICG use services at their disposal depends on a series of specific variables such as: the time of arrival in Belgium, their ‘political / legal ’ status, etc. In this sense, it is important to note that the migrant dyads were from mixed socio-economic conditions: although having mainly a lower income than natives no one of them live in precarious conditions.

In our sample, date of arrival is variable. Some of the dyads arrived in Belgium more than forty years ago while others arrived more recently:

> *« Je dis pas les années que j’avais pas de papiers, mais c’est en 1986 ou 87 que l’on s’est marié à la commune… » (BXL_1_1A)*
>
> *« J’avais six ans quand on est venu en Belgique, c’était en 1968… » (BXL_2_1A)*
>
> *« Mon papa est ici depuis 1973, il est arrivé avec ma maman. Moi je suis née ici. On est à cinq enfants… » (BXL_3_1A)*
>
> *« Moi je suis arrivé en Belgique depuis 2005. Mon mari est venu ici avec ses parents en 2001 … » (BXL_4_1A)*
>
> *« On est arrivé en 2000, avec mon père, qui s’est marié avec une femme Belge, mais maintenant il est divorcé… On a déménagé ici à Bruxelles en 2001. » (BXL_5_1A)*
>
> *« Quand on est arrivé en Belgique avec toute ma famille, j’avais trois ans… en 1974… » (BXL_6_1A)*

Another important element, that can create some divergences between the DEP and the ICG of our sample, is the fact that most of the DEP arrived in Belgium when they were an adult and continue the ways of living and thinking from their origin country. In this way, they continue to mentally live in their origin country, unlike their children.

Table 16 – Demographic characteristics of the informal caregivers interviewed in Brussels

Brussels	ICG 1	ICG 2	ICG 3	ICG 4	ICG 5	ICG6
ICG demographics						
Gender	Female	Female	Female	Female	Female	Female
Age	78	51	60	24	28	43
Nationality origin	Moroccan	Turkish	Turkish	Romanian	Turkish	Turkish
Education level	Unknown	Until 14 years old	Unknown	Secondary	Secondary	Unknown
Marital status	Married (with the DEP)	Married	Married (with the DEP)	Married with the son of the DEP	Single	Married
Number of children	2 daughters	3 sons	5 children (2 daughter, 3 sons)	3 (2 sons and a daughter)	-	3 sons
Number of grandchildren	8	2		-	-	
Relationship with DEP	Her spouse	Her daughter	Her spouse	Her daughter in law	Her grand daughter	Her younger daughter
Living with DEP	Yes, they share the same apartment	No more	Yes, in the same house	Yes, in the same apartment	Yes, in the same apartment	Some months per year
Other persons living together with ICG	No	The whole family	A son is living in the same house	The spouse of the DEP, her husband and children	The father of the ICG and son of the DEP	The husband and their 3 children
Current or past job occupation	unemployed	Employee in a cleaning society	unemployed	Undeclared worker (as housekeeper)	Employee in a cleaning society	Unemployed
If employed % working	-	6 hours per day	-	2 or 3 days a week	100 %	-

Secondly, all the ICG interviewed are women. They are aged from 24 to 78 years and have generally a low level of education:

> *« Je n'ai pas été beaucoup à l'école, j'y suis allée jusque 14 ans. Je n'ai jamais terminé ma scolarité parce qu'avant on habitait à Gand deux ans et deux ans à Zele et c'était à l'école flamande que j'ai été quatre ans… » (BXL_2_1A)*

> *« J'ai fait que les 5 ans des premiers secondaires. J'ai été trois ans à l'école ici pour faire coiffeuse, mais j'ai arrêté, comme tous les Turcs... » (BXL_5_1A)*

Unlike the dyads interviewed in Wallonia, for example, the non-native ICG are parts of large, often recomposed families, whose members are often dispersed between several countries:

> *« Mon père il est mort quand j'avais 10 ans et ma mère s'est remariée en Roumanie, quatre ans après le décès de mon père. Donc, je suis seule ici, pas de frères, pas de sœur. J'ai un frère qui habite en Espagne et une autre sœur en Italie. Cela fait des années que je ne les vois pas… Mon beau-père a ici toute sa famille. Il a encore quatre garçons et une fille, ici en Belgique. Il y en a trois qui habitent le même bâtiment, une fille qui habite à Schaerbeek » (BXL_4_1A)*

> *« Elle (l'aidée) a deux fils en Allemagne, qui ne viennent plus jamais la voir et au fond du cœur, elle est toujours fâchée sur eux, elle dit : je les ai élevés et eux ne viennent jamais me dire bonjour. Ses deux filles sont en Turquie… » (BXL_5_1A)*

Half of the ICG are not professionally active; the others are either cleaners, or perform undeclared work (dyad 4). Their working time conditions (evening hours) are sometimes difficult to combine with their caregiver role, but most of them say they can arrange their work or their work is flexible enough to care for the DEP. When the DEP needs more help because of his/her health condition or because of unavailability of ICG, another informal caregiver will take care of the DEP, except in dyad 1, in which the DEP was institutionalized:

> *« À quatorze ans, j'étais déjà au travail, et depuis toujours, je continue à travailler dans le nettoyage… Pour le moment, je suis chef d'équipe chez … et je m'occupe de 12 personnes. Je travaille six heures par jour, ce n'est pas tout à fait un temps plein… mais donc j'ai toujours fini après huit heures. » (BXL_2_1A)*

> *« Je travaille un peu en noir, pas déclaré, c'est pour cela que j'ai du temps, trois à quatre jours par semaine, et c'est pour ça que j'ai le temps pour l'instant… » (BXL_4_1A)*

> *« Je travaille dans une société de nettoyage. Avant, je faisais le service coupé. Maintenant j'ai commencé un temps plein de midi à 20h30. C'est pour ça que parfois, la nuit, c'est difficile... Ce qu'il y a, c'est que souvent la nuit elle est difficile, elle ne dort pas, elle pleure ou elle se plaint qu'elle a mal… et comme elle dort dans la même chambre que moi, des fois, c'est vrai, je rentre tard, j'ai besoin de dormir… » (BXL_5_1A)*

> *« Je ne travaille pas pour l'instant, mes sœurs non plus, sinon ce ne serait pas possible (d'accueillir successivement l'aidée chez elles), on devrait s'organiser autrement… » (BXL_6_1A)*

Table 17 – Demographic characteristics of the dependent elderly persons from dyads in Brussels

Brussels	DEP 1	DEP 2	DEP 3	DEP 4	DEP 5	DEP 6
DEP demographic						
Gender	Male	Female	Male	Male	Female	Female
Age	79	85	66	69	72	77
Nationality Origin	Moroccan	Turkish	Turkish	Romanian	Turkish	Turkish
Education level	-	Unknown	Unknown	Unknown	Unknown	Unknown
Marital status	Married	Widowed	Married (with the ICG)	Married	Widowed	Widowed
Number of children	-	6 : 3 daughters and 3 sons (1 deceased)	5 children (2 daughter, 3 sons)	6 (5 sons and a daughter)	5 (3 sons, 2 daughters)	5 (4 daughters and a son
Number of grandchildren	-	At least 2	-			13
Relationship with ICG	Husband	Mother	Husband	Father in law	Grand mother	Mother
Living location	In a social apartment, with his spouse	In a nursing home	With his spouse, in their family house	In the apartment where live all the family	In the same apartment than her son and grand children	In the houses of the daughters
Health conditions	Mental disability	Bedridden	Demented (Alzheimer)	Heart disease	Bedridden and lightly demented	Bedridden and demented

Concerning the DEP, it is noticeable that most of them don't speak French or Dutch. This implies that they also depend on other people when they need access to the social and health services in Belgium:

> *« Ma maman ne savait pas parler le français ou le flamand… Chaque fois qu'elle avait un papier, un médecin ou un médicament, j'étais à côté. J'étais toujours là, j'étais obligée de m'occuper d'elle. Comme mes autres sœurs habitent à Gand, toute la paperasse, c'était pour moi… » (BXL_2_1A)*

> *« Il n'y avait pas de personne qui pouvait parler le français, le conduire… Aller chez le médecin, accompagner, les prises de sang, c'est moi aussi. » (BXL_4_1A)*

> *« On nous a conseillé d'aller en psychiatrie, mais comme elle ne parle pas français, elle va parler en turc et personne ne va la comprendre et elle va s'énerver. » (BXL_5_1A)*

As we'll see further, the non-native DEP are not only 'dependent' in their daily life because of their health conditions, but also in all other aspects of their life. Indeed, the access to existing supporting measures is often linked with some administrative steps with the local authorities. The DEP therefore need help from other people (from ICG) for administrative, legal, political, educational matters, particularly because in most of the situations, they do not speak French or Dutch. This is even more complicated when the ICG him/herself has also difficulties in speaking French or Dutch:

> *« Normalement, il peut toucher une allocation handicapé, mais ça fait dix ans que je cours à gauche et à droite. Quand on est allé chez le ministère des handicapés, à la bourse, ça fait longtemps, il y a un médecin qui est venu, et qui a dit qu'il avait la main pour manger, pour s'habiller, et alors il a refusé. J'ai raconté l'histoire au Dr V., et il 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)*

In the following sections, we make a synthesis of the data collected with non-native ICG. Their perceptions and experiences are compared with those living in other regions. The data are presented using the structure of the interview guide. This is divided into seven parts, related to the health conditions of the DEP, the role and the experience of the caregivers, the social support they receive, the tasks they perform for the DEP, the formal services the DEP receives, the formal services used by the ICG to relieve its support tasks and the income of the DEP. In a last section, we summarize the information in order to formulate recommendations.

Appendix 6.2. Part 2 – Coding of data related to the role, experiences of the ICG and relation with the DEP

In this section, we present data related to the role of ICG as perceived and experienced by the ICG themselves.

The reasons why the DEP needs care

The non-native DEP of our sample need to receive care from at least one informal caregiver because of their physical and/or mental health conditions combined with dependence for ADL or IADL:

> *« Cela fait huit ans maintenant à peu près que mon papa est atteint de la maladie d'Alzheimer. Au début, ça allait, il était complètement indépendant, il avait beaucoup plus de moments de lucidité que de moments de perturbation, on va dire. Il avait peut-être deux ou trois jours par mois où il était moins lucide, où il racontait n'importe quoi, où il ne savait pas ce qu'il faisait, il déposait des objets quelque part et il ne les retrouvait pas, mais maintenant, c'est tout comme s'il était grabataire. Cela fait maintenant plus ou moins deux ans qu'il est complètement dépendant de ma mère, dans le sens où il faut lui dire que maintenant on va manger, parce que sans ça, si on ne lui donne pas à manger en 24h il ne réclame rien, si on ne lui donne pas à boire il ne réclame pas… » (BXL_3_1A)*

> *« Je m'occupe de lui (DEP) depuis 2005… Il était déjà malade avant mais il n'y avait pas de personne qui pouvait parler le français, le conduire…Sa femme est aussi malade, mais elle sait prendre elle-*

> *même ses médicaments c'est la seule chose. Mais c'est mon beau-père qui est plus grave. Il a un diabète, il a un problème de rein, il y a un rein qui ne fonctionne plus, mais il ne fait pas de dialyse pour l'instant. Il a un problème avec sa tension artérielle, il a déjà des problèmes de mémoire, de personnes âgées etc. Il vient d'être opéré de la carotide. Il a des artères qui étaient bouchées. Il risquait d'avoir une thrombose s'il ne se faisait pas opérer. Mais après la dernière opération l'année passée, il est resté avec une paralysie de la bouche, des deux côtés. Il l'a jamais récupéré. Il s'est fait opérer deux fois… » (BXL_4_1A)*

> *« Cela fait longtemps, depuis qu'on est ici en Belgique en 2000 que je m'occupe d'elle, mais c'est devenu vraiment difficile depuis qu'elle est sortie de l'hôpital. C'est d'un coup qu'elle est tombée en fait, depuis le mois d'août (2013), parce que c'était une femme qui faisait tout, et en un jour, elle ne faisait plus rien, elle disait n'importe quoi… Avant, elle faisait tout elle-même, elle se promenait, elle faisait les courses… Elle a été une première fois hospitalisée par son médecin de la maison médicale, parce qu'elle vivait toujours en arrière, elle avait perdu sa mémoire. Avant, elle n'avait pas de problème cardiaque. Maintenant elle a un problème de cœur, elle a trop de tension… Après, elle a été une deuxième fois à l'hôpital. Parce qu'ils lui ont donné un autre médicament qui dilue le sang et, à cause du s**, elle avait un ulcère à l'estomac, mais on ne savait pas du tout, ni son médecin ni moi. Elle a perdu du sang, elle avait une hémorragie. Elle est restée trois semaines à l'hôpital. » (BXL_5_1A)*

> *« <u>Il n'y a même pas deux ans, elle marchait</u>. On la tenait, elle marchait et elle mangeait elle-même. Nous on faisait la cuisine, le ménage, mais elle parlait… <u>L'année d'avant, elle a eu une escarre à son pied</u>. Depuis qu'elle a eu ça, le kiné a dit qu'on n'allait plus la faire marcher. <u>Après, elle est devenue malade car elle n'arrivait plus à se nourrir</u>. Comme elle avalait de travers, ils ont dit qu'on allait lui mettre un tube dans son ventre, et c'est comme ça qu'elle se nourrit depuis deux ans. <u>Elle est restée quatre ou cinq mois à l'hôpital, où elle n'a pas marché, et avec le temps, elle a oublié un peu</u>… Elle est restée longtemps à l'hôpital, il y a deux ans… » (BXL_6_1A)*

The reasons why they became the ICG of the DEP

Between 'there' and 'here': the cultural models in tension

The ICG of the non-native dyads living in Brussels are all women. The main ICG is either the spouse, or either the daughter of the DEP, but <u>never the son</u>. This observation is broadly confirmed by the sociological and anthropological literature: this role as ICG is culturally attributed to female's members of the family. This situation could be viewed, according to the anthropologist Emmanuel Todd, as a result of the transformations of the traditional exogamic and patriarchal parenthood systems in the context of migration[dd]. This is clearly expressed by the caregiver of the dyad 2:

> *« Normalement, <u>chez nous, c'est toujours le garçon qui doit s'occuper des parents</u>, parce que la fille quitte la maison quand elle se marie, c'est toujours au garçon de s'occuper des parents… » (BXL_2_1A)*

In other words, 'there', where the traditional models of family organization are still in course, the care giving of the elderly is automatically the responsibility of the son and his wife (daughter in law of elderly) who lives with them. Dyad 4, where the ICG is the daughter in law of the DEP, illustrate this 'typical' situation:

> *« Mon beau-père a ici toute sa famille. Il a encore quatre garçons et une fille, ici en Belgique, mais ils ne s'en occupent jamais, ils ne viennent jamais, parce que <u>chez les Roumains, c'est le plus petit qui doit garder ses parents</u>, c'est la coutume. <u>Donc c'est mon mari</u> (qui devrait s'occuper de ses parents, mais), <u>malheureusement, il ne sait pas lire et écrire</u>, il ne sait donc pas donner les médicaments, même si le pharmacien écrit sur la boîte combien de fois il doit prendre par jour et quand. C'est la raison qui l'empêche de s'occuper de ses parents, (et donc), c'est tout qui tombe sur ma tête… » (BXL_4_1A)*

But 'here', in Belgium, the daughters in law do not accept to take care of her husband's parents. As a consequence, the youngest daughter mainly plays the ICG role:

[dd] See Todd E., Le destin des immigrés. Assimilation et segregation dans les démocraties occidentales. Paris, Seuil, 1994.

> *« Chez les garçons elle n'est pas allée, parce qu'elle dit que les belles-filles ne veulent pas d'elle… » (BXL_2_1A)*
>
> *« Mais ici, comme les belles-filles ne veulent pas les belles-mères, ça revient toujours à la fille. Quand il s'agit de s'occuper des parents une fois qu'ils sont âgés, qu'ils ne savent plus se débrouiller tout seuls, c'est à la fille que ça revient… » (BXL_3_1A)*
>
> *« Une femme ne va jamais accepter de s'occuper de sa belle-mère dans son ménage, par exemple. Les femmes des frères de mon père ne voulaient pas l'accepter chez elles… » (BXL_5_1A)*
>
> *« Sa femme, comme c'est la belle-fille, elle ne va pas la garder… » (BXL_6_1A)*

The 'privileged' relation between parents and the youngest daughter

The youngest child of the family is also the last person to leave the parent's house. The other children rely on her to take care of the older parents. Consequently, the elderly migrants live often with their youngest daughter when they became frail:

> *« J'avais deux ans quand mon papa est décédé. Nous étions sept dans la famille. J'étais la plus petite, ma maman m'allaitait encore et je suis restée avec ma maman… » (BXL_2_1A)*
>
> *« Comme j'étais la plus petite, j'étais la seule fille à habiter avec ma maman, pour moi c'était devenu une habitude, parce que c'est ma maman, je devais le faire, et pour eux c'était devenu moi qui étais toujours là pour elle… » (BXL_2_1A)*
>
> *« Moi je suis la petite dernière, donc c'est moi qui suis restée le plus longtemps chez mes parents, jusqu'à 29 ans. C'est toujours moi qui me suis occupée des tâches administratives, des courses et de tout ce qui s'en suit, puis des rendez-vous chez les médecins, etc. Donc, ça coulait de source que je sois l'aidante secondaire. C'est souvent comme ça, par facilité. Ah, la petite dernière, elle va bien se démerder, elle va tout faire… » (BXL_3_1A)*

In these "typical" situations (dyads 2 and 6) (where the DEP is looked after by the youngest daughter living with her husband), the capacity to keep the DEP "in the community" seems to depend on various elements: whether the daughter/ICG works or not, whether or not there is sharing of the care between several daughters/ICG as in the dyads 3, 5 and 6 .

The linguistic competencies of the ICG

Another reason mentioned, closely linked with the migration itinerary of these dyads, gives another explanation why the youngest daughter or daughter in law has to play the ICG role, i.e. she is also often the only child who learned to read and to speak French:

> *« J'étais toujours à côté d'elle. 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, il n'y avait personne à la maison pour m'aider. À la maison c'était turc, à l'école c'était français, alors j'ai eu assez dur. » (BXL_2_1A)*
>
> *" Mon mari ne parle pas le français, malgré qu'il est déjà quarante ans en Belgique, c'est aussi un souci, parce que c'est toujours moi… On s'est mariés, mais quand il est arrivé ici, il ne savait pas parler, pas écrire…" (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… C'est surtout moi pour les contacts avec le français, parce que tous les savent que c'est moi qui comprends mieux les explications et tout, ce qu'il doit faire, quand il doit se faire hospitaliser ou pas. » (BXL_4_1A)*

The gender of the DEP

The gender of the DEP (i.e. female) can also explain why the son never takes care of the DEP. In only one situation (dyad 5), the granddaughter of the DEP came to live with her father and her grandmother because, according to her, the mother-son relationship is not the same than the relationship between two women. In other words, she said that men are not 'good placed' to take care of a woman:

> *« On habite ici à quatre. Autour, il n'y a pas de famille. Ici, c'était mon papa et ma grand-mère qui habitaient, mais comme il n'y avait personne pour s'occuper d'elle et que moi j'habitais seule, j'ai déménagé pour venir habiter ici, comme ça je m'occupe d'elle, parce que les hommes, ce n'est pas la même relation avec les femmes. » (BXL_5_1A).*

As we can see, the reasons why the ICG have to play their role are thus variable, including conditions linked with their position as the youngest child in the migrant family.

The impact of these tasks on the ICG life

The ICG interviewed mentioned two major impacts of that role on their own life.

'A full-time job'

For most of the ICG interviewed, it is difficult to make an estimation of the time they spent to take care of the DEP. From their own point of view, they spend several hours per days, but from the point of view of others (children, husband…), this is a 'full-time job', especially at certain moments (hospitalization):

> *« Quand elle était dans la maison, parfois deux ou trois fois par jour je pouvais monter en haut pour passer une heure avec elle, mais quand je vais travailler, c'est seulement une heure par jour que je montais. Toujours le matin, parce que moi je vais toujours travailler l'après-midi. Et alors quand je rentre elle est déjà couchée. Si je voyais que la lumière était toujours allumée, je montais, mais sinon si je sais que pendant la journée elle va bien, je dirais que je ne montais pas… » (BXL_2_1A)*

> *« Je vais rester à peu près deux heures à l'hôpital avec lui, parce que à chaque fois qu'il a été hospitalisé, il ne veut pas rester seul à l'hôpital, il faut quelqu'un avec lui, maximum deux ou trois heures par jour, parce que sinon il va quitter l'hôpital. Il a déjà quitté l'hôpital sans l'annoncer, donc il a besoin de quelqu'un toute la journée pour rester avec lui. » (BXL_4_1A)*

> *« Mais au fil du temps, ma maman a dû faire de plus en plus de choses pour lui. C'est un travail à temps plein pour elle. Pour sa toilette, pour lui donner son bain, pour le coucher, pour l'emmener à la toilette, mettre son pyjama pour ses médicaments, le raser… donc c'est vraiment non-stop… 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, c'était une femme qui avait tout ce qu'elle voulait de 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. Je pense quand même, elle est beaucoup plus sur le qui-vive, elle est plus fatiguée, plus à cran. Je pense que tout doucement, elle devient dépressive par rapport au fait qu'elle doit non seulement s'occuper de mon papa, mais parce qu'elle n'arrive toujours pas à admettre sa maladie. Pour elle, mon papa va se remettre un jour. Quand ça arrive, je préfère l'éviter, parce que ce sont quand même des moments de confrontation… » (BXL_3_1A)*

The feeling to be 'stuck'

The second main perceived impact of the ICG role on their life is that they feel 'stuck' at home because the DEP needs 24 h/ 24 surveillance, they feel that they do no longer have time for themselves:

> *" Il y avait des tensions parce que le mari disait toujours aux autres que eux ils profitaient de la vie, et que nous on ne fait rien, on restait à la maison parce qu'on ne pouvait pas la laisser toute seule… Mon mari et moi il y avait des conflits entre nous parce qu'on se disait que nous on est coincés, on ne peut rien faire" (BXL_2_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)*

> *« Pour mon père, ce qui a vraiment changé, c'est qu'il doit rester à la maison toute la journée. Pour lui, c'est long, parce que de 11h à 20h30… Il se sent un peu coincé… Moi aussi, cela change quelque chose, parce que comme on n'ose pas la laisser toute seule à la maison, pour les courses et tout ça… » (BXL_5_1A)*

Facilitating elements to play this role

Some elements and organizational modalities of the care giving allows, nevertheless, to reduce the burden and supporting the ICG in this:

Sharing the care provision

As illustrated by the dyads 3, 5 and 6, the sharing of the informal care between different ICG can limit the burden of the ICG role. The non-native dyads illustrate two modalities of sharing the care: in the situations of dyads 3 and 5, the DEP living in the same house, and the surveillance is shared between several ICG; in dyad 6, the DEP 'moves' between her four daughters:

> *« Il faut se relayer, sinon c'est difficile… mais on se débrouille en interne. Quand on a un truc de prévu, quand ma maman a une activité ou quoi qu'est-ce, on demande à un des frères ou à ma sœur de venir la remplacer, et on fait ce que l'on a à faire, mais on n'a pas une aide extérieure. On essaie de trouver la solution en interne, comme on peut. (…) En temps normal, durant les heures de travail, c'est souvent ma maman qui est là. En soirée, mon frère descend donner un coup de main. Moi je passe souvent le lundi, mercredi, vendredi et dimanche, en soirée, parce que je travaille. J'ai un de mes frères qui passe tout le week-end, du vendredi au dimanche, parce que lui ne travaille pas le week-end. On est à cinq, et il y a aussi mon oncle qui vient souvent pour aller faire un tour avec mon père, c'est l'un de ses frères. » (BXL_3_1A)*

> *« Il y a toujours quelqu'un, c'est nécessaire. Depuis qu'elle est sortie de l'hôpital, vraiment, elle ne sait pas rester toute seule. Elle tombe, elle se sent pas bien alors elle ouvre la fenêtre, et elle crie, elle est agitée… On a fait comme un planning de travail, on a divisé. J'ai mon bus à 11h10, alors je m'en occupe avant 11h. À 11h, je sors pour aller travailler, et c'est mon papa qui prend la place. Mon papa prend la garde jusque 20h30. Le soir, il y a mon frère, qui est là aussi, et papa, on le libère, il peut aller où il veut. Samedi et dimanche, il est en congé. Mon frère, ses horaires changent. Aujourd'hui je crois qu'il va partir à midi, on le laisse dormir, mais quand il termine plus tôt, il vient plus tôt. Donc pour l'instant, ça va, je ne suis pas la seule… » (BXL_5_1A)*

> *« Disons un mois chez moi, parfois c'est un mois et demi, deux mois au plus, ça dépend, un mois chez l'autre, un mois chez la troisième… on se partage, comme ça, c'est pas trop lourd pour nous… Tout le monde veut garder sa maman, donc on se partage ça aussi… Je ne peux pas dire à ma sœur de la garder chez elle, elle aussi elle a besoin de sortir, de souffler un peu… (…) Sinon, j'ai une sœur âgée, son mari est décédé aussi depuis longtemps, elle a proposé qu'elle reste chez elle. Là où elle habite, ma maman a son appartement au rez-de-chaussée. Mais je trouve que c'est injuste, et c'est aussi notre mère, on veut aussi la garder, on va pas dire oui garde là et nous, on vient de temps en temps, ça ne se fait pas non plus… » (BXL_6_1A)*

Such a shared care giving organization helps to avoid the caregiver feeling to be ‘stuck’ at home and the ICG can still live their own life:

> *« C’est pas que c’est pas possible, mais on n’a pas de vie, on doit être tout le temps à la maison… Comme on a aussi une vie privée, on sort et tout, donc c’est mieux de partager… Si j’ai un rendez-vous, par exemple, j’appelle l’une de mes sœurs et elle reste à côté. On s’organise comme ça. Mais si c’est pour une demi-heure ou une heure, elle dort, je vais vite faire mes courses, mes enfants la surveillent… » (BXL_6_1A)*

The recognition from the DEP

The recognition by the DEP or by other close relatives of the role played by the ICG is one of the most frequently cited rewarding factor by the ICG. But some interviewees say that the DEP they care for consider as ‘normal’ all the care tasks they do for them and are not really grateful:

> *« On s’en occupe parce que on se sent obligé. Pour moi c’était devenu normal. C’est quelqu’un que plus tu t’en occupais plus elle te disait merci en mots gentils, tu fais pour moi ça, que tes enfants font ça pour toi. Ce sont des mots qui apaisent tout ce que tu as fait. C’était vraiment devenu quelque chose de normal de le faire. » (BXL_2_1A)*

> *« Oui, bien sûr, il y en a qui la félicitent parce que ce n’est pas une situation facile et que beaucoup de gens à sa place n’auraient pas pu tenir… c’est une battante. » (BXL_3_1A)*

> *« Eux considèrent que c’est normal, mais ils ne sont pas vraiment reconnaissants pour tout ce que je fais pour eux. J’aimerais qu’ils soient plus reconnaissants, cela me donnerait un peu plus de force pour courir partout… » (BXL_4_1A)*

The hope that the DEP will get better

Some ICG keep their motivation by hoping that the tasks they perform for the DEP will help the DEP to recover:

> *« Pour moi, même si des fois c’est pesant et c’est lourd, on le fait avec plaisir et amour, et on a toujours un espoir, même si c’est une illusion, on se dit toujours qu’en agissant de la sorte qu’un jour il redeviendra comme avant, même si au fond de nous-même on sait très bien que c’est impossible ce que je dis, que la maladie va continuer à avancer, mais c’est ce qui nous motive. Le point positif, parce qu’il y a des moments où il ne nous reconnaît pas du tout, c’est quand il nous demande comment on va ou quand il nous appelle par notre prénom, ben c’est un moment qui nous fait super plaisir.. » (BXL_3_1A)*

Elements that could lead to the interruption of the ICG role

Some complex situations, where several elements are intermixed, may lead to the interruption of the care giving or to its end because the ICG cannot find a good compromise between the different requests she receives from other family members or between her different social roles.

The lack of support from other family members

When the daughter/ICG is alone to take care of the DEP, such a situation may raise tensions between the ICG and her husband (the son in law of the DEP). These tensions can lead to the institutionalization of the DEP, as illustrated by the dyad 2:

> *« Eux (frères et sœurs) 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 me disait si toi tu tombais malade, qui est-ce qui va s’occuper de nous ? Il a dit que les autres enfants prennent aussi un peu en charge. Que chacun la prenne un mois à chacun son tour, cela se fait beaucoup. J’ai dit qu’au moins une des autres filles fasse autant que moi… mais mes sœurs ne voulaient pas, parce que chacune a déjà un certain âge. ‘Je suis malade’, ‘j’ai mes petits-enfants’, ‘j’ai pas de place’… 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)*

The tensions between the different social roles of the ICG

Despite the privileged relation she has with the DEP, the ICG is divided between her different social roles she plays as caregiver, spouse, mother… When there are conflicts with the husband on the time spent by ICG to take care of the DEP, the institutionalization of the DEP is sometimes the only way to avoid a relationship crisis:

> *« 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).*

Some ICG can only play this role because they're no longer professionally active or they are not workingwhich allows them to be available for the DEP. On the contrary, those who are professionally active meet difficulties to combine care giving and work:

> *« Comme je vous l'ai dit, j'ai fait une démarche de régularisation, mais je dois alors travailler avec un contrat de travail, à partir du mois de janvier. J'attends mon permis de travail pour avoir le papier, et je vais travailler 34 heures par semaine. Je vais être plus souvent partie… Ce qui va changer, c'est que je ne serai plus toute la journée à côté de lui. » (BXL_4_1A)*

> *« Si on travaillait (mes sœurs et moi), on devrait s'organiser autrement… » (BXL_6_1A)*

When the ICG has children, she cannot always be available for the DEP because she has to take care of them during some hospitalization episodes, for example.

> *" À un moment donné j'ai eu des soucis avec l'un de mes fils qui prenait de la drogue. Il a eu un accident de voiture et on s'en est rendu compte alors. Je m'en suis voulu, parce que je m'occupais tellement de ma maman que je ne m'occupais pas de mes garçons. Je ne me suis pas rendu compte qu'il fumait. 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. (…) Alors on l'a mise un peu de côté, c'était d'abord mon fils… Et quand il est sorti de là, mon mari a dit qu'on allait beaucoup plus l'entourer, s'occuper de lui, il faut que ta maman parte, il ne voulait plus que je m'occupe d'elle. Il voulait que je m'occupe uniquement du fils, parce que là on a eu une période de trois mois très difficile. D'abord avec les médecins à la maison, puis à l'hôpital, on allait le voir tous les jours, fin novembre, l'année passée…" (BXL_2_1A)*

> *« Le plus grand de mes enfants, celui qui a sept ans et demi, il a fait une chute dans l'escalier, il a donc été hospitalisé. Il a eu une fracture de la tête, la clavicule cassée, donc je suis restée avec lui. Durant cette période, j'ai laissé tomber les beaux-parents, c'est mon mari qui est resté à la maison. Je me suis réoccupé de lui (l'aidé) dès que je suis rentrée de l'hôpital… » (BXL_4_1A)*

Appendix 6.3. Part 3 – Coding of data related to support from non-professional individuals (from family members, friends…) that the ICG and the DEP receive

We collected very little information related to this topic, which seem to indicate that care activities are kept in the close private area, without asking help from outside the family. In fact, most of the informal help the non-native ICG receive comes from the inner family, rather than from neighbors or friends:

> *« On se débrouille en interne. Quand on a un truc de prévu, quand ma maman a une activité ou quoi qu'est-ce, on demande à un des frères ou à ma sœur de venir la remplacer, et on fait ce que l'on a à faire, mais on n'a pas une aide extérieure. On essaie de trouver la solution en interne, comme on peut. » (BXL_3_1A)*

> *« Quand j'ai besoin d'aide, je téléphone aux enfants de ma sœur, ils sont grands, le plus petit a quarante ans, quand j'ai besoin… Hier j'ai acheté une cuisinière, il est venu me la monter, je lui donne un petit peu alors, c'est normal, hein… mais c'est jamais le même… Sinon, personne… » (BXL_1_1A)*

In some situations, like in dyad 1, the ICG says she cannot count on her neighbours, even though they are also Muslims like her. The immigration context seems to have dislocated the traditional solidarities based on the religious ethics. This ICG says she has to count on God rather than on neighbors:

> *« On a les voisins ici, tous Marocains, y a personne qui vient. J'ai pas de problème avec, mais ils viennent pas… Je dis toujours que c'est Allah qui va m'aider. Je demande toujours à Allah, jamais à personne. Je m'en sors très bien… » (BXL_1_1A)*

Appendix 6.4. Part 4 – Coding of data related to tasks performed by the ICG

The ICG explain thatthey had to do everything for the DEP, the tasks they cited are listed in the table below.

Table 18 –Tasks performed by the ICG

Tasks	ICG 1	ICG 2	ICG 3	ICG 4	ICG 5	ICG 6
Household activities	Food preparation, cleaning the DEP, dressing	Washing, ironing, cleaning her apartment, shopping,	Food preparation, ironing, cleaning		Food preparation, ironing	Food preparation
Personal care		Physical help to make her toilet	Physical help to make her toilet,			Changing her nappies, Help for her toilet
Medical care	Giving drugs		Preparation and giving the drugs	Preparation and giving the drugs		Wound cleaning, insulin control, giving drugs
Practical support	Mobility outside the home	Mobility support in the stairs, contacting the GP when necessary, mobility outside the home	Mobility outside the home (mainly from home to hospital)		Mobility help inside the apartment (day and night)	Help for mobility inside the apartment
Surveillance		Yes	yes	yes	yes	yes

Household activities

Amongst the ‘household activities’, food preparation, cleaning, washing, ironing and shopping are the most frequently cited.

> *« Lui, il fait rien du tout… Je donne à manger tous les jours, ça oui, le petit-déjeuner et le soir… Je prépare le petit déjeuner… quand il est réveillé, il vient manger, et puis il vient à sa place, ici devant la télé. Je fais mon ménage… Pour le ménage, je partage : un jour je fais par –ci, hier j’ai fait le couloir… (…) C’est moi qui le lave, pas tous les jours, mais c’est moi que je fais tout ça, parce qu’il reste en pyjama, jour et nuit, et ça va pas, avec les couvertures et tout, alors avec le gant de toilette je le lave un petit peu, je lui change le pyjama, mais je ne fais pas sa toilette tous les jours, tous les deux ou trois jours… Parfois je prends rendez-vous avec le coiffeur, ici, marocain, alors je l’emmène pour le raser, parce que quand il fait très chaud, c’est pas beau… (BXL_1_1A)*

> *« Elle doit prendre une douche, par exemple, il faut l’aider à prendre sa douche, parce qu’elle risquait de tomber, c’était difficile pour elle. Son ménage, aspirer, ses poussières, laver ses vêtements, j’allais faire les courses, elle ne savait plus monter. Elle voulait un pain, il fallait aller le chercher. Les médicaments, il fallait les chercher. Le médecin il fallait lui téléphoner... Elle faisait souvent elle-même ses repas, du moment que j’allais acheter tout ce qu’il lui fallait, elle faisait encore elle-même. Parfois, quand il fallait la déplacer, on le faisait en voiture, il fallait toujours quelqu’un qui nous attende devant la porte pour la ramener en voiture, parce que à pied ce n’était pas possible. Tout, il fallait tout faire… » (BXL_2_1A)*

> *« « Mais au fil du temps, ma maman a dû faire de plus en plus de choses pour lui. Pour sa toilette, pour lui donner son bain, pour le coucher, pour l’emmener à la toilette, mettre son pyjama pour ses médicaments, le raser… Maintenant, il faut une surveillance non-stop à la maison, elle ne peut pas l’enfermer à la maison et sortir… » (BXL_3_1A)*

> *« C’est son petit déjeuner. Comme il est diabétique, il doit manger sans sel, sans sucre. C’est moi qui fais les repas, le repassage aussi, tout. Ma belle-mère, elle peut prendre ses médicaments et prendre son bain. Le reste, c’est moi. » (BXL_4_1A)*

> *« Pendant la journée, je crois que ça va pour aller à la toilette toute seule. Quand elle ne se sent pas bien, elle le dit. Quand elle se lève on la prend, on l’assied. Pour la laver, ça va aussi. Pour la nourriture, il faut lui préparer, mais elle mange tout… Avant, elle tricotait, elle faisait à manger, mais tout ça elle ne fait plus rien du tout… Je fais son repassage, mais sinon c’est chacun fait son linge. Pendant la nuit, il faut l’aider à se lever, parce que deux ou trois fois elle a fait dans son lit et tout ça…» (BXL_5_1A)*

> *« On la change, trois à quatre fois par jour, parce qu’elle est incontinente… Comme elle mange par son tube, on achète ça, on ne doit pas lui faire à manger. Le matin, je lui prépare sa nourriture, j’amène mon fils à l’école, quand je reviens je fais ses soins, je la lave, je la change, je la mets sur le côté, et l’après–midi je la mets sur l’autre côté… Vers quatre heures, je la mets sur la chaise, je l’amène ici, elle reste deux à quatre heures avec nous, comme ça. (BXL_6_1A)*

Personal care

Amongst the personal care tasks, those that result from the incontinence of the DEP, so related to the health condition of the DEP (changing nappies, cleaning the excrements) are either mentioned by ICG as tasks they don’t want to do or for which they want to for professional ask help. Interviewees say that if, in the future, the DEP became incontinent, that they’d ask a professional help to do this these tasks:

> *« Je suis déjà très contente qu’il va tout seul à la toilette, c’est ça le gros problème, parce que sinon, je sais pas, ou bien je demande à un infirmier qui vient tous les jours, parce que ça c’est difficile pour moi… pour ça j’ai besoin de quelqu’un… » (BXL_1_1A)*

> *« Je pense que s’il n’arrivait plus à se retenir, cela pourrait faire que maman ne pourrait plus… Je pense que ce sera le trop plein… » (BXL_3_1A)*

Medical care

The 'medical care tasks' performed by the ICG were mainly the arrangements of medication:

> *« Je lui donne les médicaments » (BXL_1_1A)*

> *« Elle le réveille à 9h parce que le matin il doit prendre ses médicaments, Puis à midi il a son dîner et il doit prendre ses médicaments. Au soir, à 18h, ils soupent, il prend ses médicaments. A 19h30, il prend ses derniers médicaments… » (BXL_3_1A)*

> *« C'est moi qui lui donne ses médicaments matin, midi et soir. Ils m'ont demandé (au centre médical) si j'avais besoin de quelqu'un pour les médicaments et tout ça, j'ai dit que non ça va, je peux le faire. » (BXL_4_1A)*

> *« Contrôler son insuline, c'est nous qui le faisons. Il y a une piqûre que l'on doit faire tous les jours, comme elle ne bouge pas beaucoup, c'est nous. Le pansement pour son escarre, quand c'est le week-end et qu'il n'y a personne qui vient, je le fais moi-même. Je donne aussi ses médicaments dans le tube… » (BXL_6_1A)*

Practical support

The tasks considered as 'practical support' include mobility support inside and outside the house like assistance with walking or wheelchair, looking for health care contacts, organizing help, physical aids:

> *« Quand il faut aller chez le docteur… Partout où il doit aller, je dois aller avec lui, parce que lui, il ne parle pas… » (BXL_1_1A)*

> *« Pour tout ce qui est médical, quand papa doit aller à l'hôpital ou chez le Dr V. ou chez le psychiatre, pour tout ce qui est extérieur c'est moi. J'ai une voiture privée, pour ça je n'ai pas de problème. (…) Elle (l'aidante) ne sait plus aller faire ses courses, elle ne sait plus aller faire son shoping, donc elle est tout le temps cloîtrée à la maison avec mon papa et quand elle a besoin de quelque chose elle nous téléphone, c'est moi qui vais faire les courses, comme ça elle a une épine en moins dans le pied, donc…» (BXL_3_1A's daughter)*

> *« Par exemple maintenant il faut l'emmener à l'hôpital mais comme on n'a pas de voiture… Je me suis renseigné (pour trouver un service de transport). 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. 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. Ils viennent avec une personne qui vient vous aider aussi, parce que quand on fait appel au taxi, il rouspète, parce que ce n'est pas loin, de Schaerbeek à l'hôpital… » (BXL_5_1A)*

Surveillance

Surveillance is needed in all situations, except in dyad 1.

> *« Moi je sors tous les jours. Je lui dis que demain je vais chez ma sœur, et puis je le trouve ici, calme… Seulement, il va dormir jusque deux heures, trois heures… Il est gentil, il dort tout le temps » (BXL_1_1A)*

> *« Il y avait des tensions parce que le mari disait toujours aux autres que eux ils profitaient de la vie, et que nous on ne fait rien, on restait à la maison parce qu'on ne pouvait pas la laisser toute seule. » (BXL_2_1A)*

> *« C'est surtout de la présence et de la surveillance… » (BXL_3_1A)*

> *« …Parce que sinon il va quitter l'hôpital. Il a déjà quitté l'hôpital sans l'annoncer, donc il a besoin de quelqu'un toute la journée pour rester avec lui. » (BXL_4_1A)*

> *« Pour l'instant, comme vous voyez, ça va. On la surveille, elle mange bien, il n'y a pas de problème. Mais au mois d'octobre, on l'a amenée à l'hôpital tellement elle était… elle ne mangeait pas, elle ne marchait pas, elle était… » (BXL_5_1A)*

> *« Mais si c'est pour une demi-heure ou une heure, elle dort, je vais vite faire mes courses, mes enfants la surveillent… » (BXL_6_1A).*

Appendix 6.5. Part 5 – Coding of data related to formal services used by the DEP

In this section, we present the ICG’s perception and experiences about the formal services received by the DEP at home.The first striking observation is that non-native dyads use very few regular formal services at home in comparison to the other regions investigated. The reasons for this seem linked with some cultural/religious factors. Some tasks, for example, are kept in the intimacy (and thus informal) area because they can affect the DEP’s dignity. In such a context, the formal services coming at home are perceived as invasive. Finally, as in most of the professional services, the recipient cannot choose the gender of the professional who will come at home. That can be a barrier to asking services for the DEP.

> *« 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 préférait 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... On a demandé une chaise percée, une tribune, mais elle ne veut pas » (BXL_5_1A)» (BXL_5_1A)*

Table 19 – Formal services the DEP receives(ed) at home

DEP 1	DEP 2	DEP 3	DEP 4	DEP 5	DEP 6
No home services	Physiotherapist, one time	Nurse visit once a week for medication preparation.			A Nurse visit once a week for prepare medi cation

Perceptions and experiences with formal services

Nurse visits at home

Visit of nurse at home is a key service for this population. Indeed, the medication arrangements cannot easily be done by the ICG alone. The nurses can also help the ICG with the toilet of the DEP. However, as mentioned below, the ICG prefers mostly to do this herself to respect DEP's intimacy.

> *« Avant, j'ai demandé pour qu'un infirmier vienne le laver. Il venait, il l'a lavé deux ou trois fois, puis il a dit qu'il n'avait pas besoin d'être lavé, et alors l'infirmier venait et le trouvait au lit, ne voulait pas le réveiller, je lui ai dit qu'il ne devait pas venir, parce qu'il venait pour rien » (BXL_1_1A)*

> *« On a un infirmier de la maison médicale qui vient une fois par semaine pour préparer son pilulier. 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 préférait garder cette tâche pour elle. A l'heure actuelle je pense qu'elle ne changerait pas de position, malgré que c'est une tâche assez lourde pour elle » (BXL_3_1A)*

> *« Ils m'ont proposé, mais j'ai dit que ça va. Il y a juste le Dr. P., qui vient une fois tous les mois, pour contrôler, et l'infirmier 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. Mais pour l'instant, je mets le seau, elle s'assied, pour l'instant, ça va, on n'a pas de grande difficulté» (BXL_5_1A)*

Physiotherapist at home

In two situations, a physiotherapist at home has been asked by the ICG but the GP considered that it was not necessary for the DEP:

> *« 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 le droit quand même, on a notre mutuelle et tout… » (BXL_6_1A)*

Domestic help

In only one situation (dyad 2), a cleaning home service was asked, just before the DEP was institutionalized. Besides helping the ICG for the specific task of cleaning, this was also viewed as maintaining a presence with the DEP:

> *« Mais les derniers mois, j'ai pris quelqu'un, je me suis renseignée à la maison médicale et là il y a eu une dame qui est venue nettoyer à la maison, par exemple, deux fois par semaine. C'était pas grand-chose, mais ça m'a soulagé d'un nettoyage que je ne devais pas faire. Et elle avait commencé à prendre cette habitude que quelqu'un venait nettoyer, elle commençait à attendre que la fille vienne » (BXL_2_1A).*

Formal services allowing to relieve the ICG

Respite services

The proposals of respite care services *at home* were rarely accepted by the ICG. They prefer to look after the DEP even this impedes them to go on holiday:

> *« Pour les vacances, il 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)*

> *« Non, 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 bien pour l'instant. Mais peut-être que plus tard je vais demander… » (BXL_5_1A)*

Day centers

The day centers are the only form of respite services used by the ICG. This is sometimes made possible through the GP or the social worker:

> *« 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…, il est resté là-bas vingt jours. Je lui ai demandé et il m'a envoyé chez une assistant sociale, c'est elle qui a fait tout pour moi. Il a réservé une chambre… Mais quand on est arrivé avec lui, on m'a montré une toute petite chambre, et je n'étais pas contente, parce que lui il est malade et tout, ça va pas, alors on a changé de chambre, mais c'était plus cher. Je lui ai dit que c'était rien. C'est la première fois l'année passée. Mais c'est cher, j'ai payé mille et quelque chose pour vingt jours, c'est moi que j'ai payé… j'avais pas de papier pour la mutuelle… » (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 shoping, 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)*

But if day centers are viewed as a service that allow the ICG to rest, it is also considered as an expensive service.

Appendix 6.6. Part 6 – Coding of data related to awareness of the existing policy measures

Awareness of existing measures targeting the ICG

In the different situations investigated, the social workers played a central role to inform the ICG about the existing measures and services, although the level of information varies from one situation to another. In dyad 5, for example, ICG is well informed about the measures that allow her to reduce her working time to take care of the DEP:

> *« 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)*

She is also well informed about the existence of mobility services which is a better solution than taxi, for example, when her grandmother has to go to hospital:

> *« 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)*

> *« 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)*

The GP and the social worker of the medical centers also play a key role as intermediary in the accessibility of the dyads to the local support system:

> *« 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. 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… » (BXL_1_1A)*

> *« 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. Si on peut traiter ici, sinon on me conseille d'aller là ou là… Si cela ne va pas, ils m'envoient à l'hôpital, pour une prise de sang… Parce que je connais les hôpitaux, je connais les médecins, je sais où je dois aller, donc…» (BXL_4_1A)*

> *« Je crois que une fois par an on reçoit de l'argent pour ses langes, mais il y a beaucoup de choses que nous on ne connaît pas, alors on demande au Dr V. » (BXL_6_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 the health sector, like the day center or like the allocation for elderly people:

> *« Le centre de jour, on l'a appris quand mon papa a été hospitalisé l'année passée, on nous a parlé d'un centre de jour. Le premier qu'on m'avait conseillé c'était un centre pour désintoxication, pour anciens alcoolos, toxicomanes, donc j'ai refusé. Ensuite, l'une de kiné qui s'est occupée de papa pendant son séjour à l'hôpital m'a conseillé le centre T. J'ai été faire la visite moi-même, et c'était nettement mieux » (BXL_3_1A)*

> *« On a introduit une demande auprès de l'APA, aide pour personnes âgées, ce qui a été accepté, on a déjà ça. Et 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-oreille et le on dit, qu'il faut un peu plus gratter, pour voir si c'est exact. J'ai tout complété moi-même avec l'aide du Dr. V. » (BXL_3_1A)*

> *« La maison médicale nous aide à nous diriger vers les spécialistes, on va dire, vers tout ce qui est médical… (Mais) je trouve qu'on ne parle pas assez de la démence, 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. On ne sait pas, par rapport à une maladie, il y a ça, vous pourriez avoir ceci, cela est envisageable, vous pouvez avoir cela comme aide…Non, il faut toujours aller soi-même vers l'information. » (BXL_3_1A)*

These data gives the overall picture of scattered information that ICG receive unequally from the different professionals. This depends from the circumstances, but also of the level of knowledge from the professionals.

Appendix 6.7. Part 7 – Coding of data related to the way the DEP/ICG benefit from existing financial measures

The income of the DEP

The low income of the DEP allows them to cover their current basic needs, but don't allow them to use expensive home services (home attendant, respite care, etc.), nor does it cover the day cost of a nursing home without financial help:

> *« On a tous les deux une pension… <u>on touche pas beaucoup</u>, tous les deux on touche mille quarante, mais Abdoullah, ça va… <u>Heureusement que le loyer c'est pas cher</u> (logement social), tu peux pas trouver un appartement comme ça pour 330 euros…» (BXL_1_1A)*

> *« Ma <u>maman avait sa pension</u>, elle était indépendante de son argent… <u>Sa pension lui suffisait</u>… (Mais)Pour le home, sa pension, ce n'est pas assez, le CPAS met 300 euros en plus de sa pension, tous les mois. » (BXL_2_1A)*

> *« 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… Le CPAS, je pense que de toute façon il ne l'aura pas, étant donné qu'il est propriétaire » (BXL_3_1A)*

> *« Comme mon père il ne travaille pas, il est à la Vierge noire, comme il a un problème de cœur aussi, il est bouché des veines et tout ça, il ne peut plus travailler. Et <u>au total ils touchent tous les deux mille cinq cent et elle quatre cent euros par mois</u>. Comme ils vivaient ensemble, ils sont cohabitant. (…) (Pour les frais médicaux), on paie rien du tout, c'est eux (la maison médicale) qui s'occupent de tout, parce qu'on est, depuis qu'on est arrivé elle est là-bas. C'est eux qui s'occupent de tout ça, ils s'arrangent avec la mutuelle, et si on a besoin d'un médecin de garde, on le paie, mais c'est eux qui nous remboursent. Pour les médicaments, comme ils sont tous les deux ensemble, ils sont tous les deux VIPO maintenant je crois. Donc tous ses médicaments sont presque gratuits. » (BXL_5_1A)*

> *« Elle reçoit la pension de mon papa qui est décédé. Elle a encore son appartement à payer, où elle vivait avant qu'elle ne soit comme ça. Elle a ses revenus, et donc quand nous on a besoin de quelque chose, on prend et on paie, ma sœur a accès à ses revenus. » (BXL_6_1A)*

The financial help measures

The main financial help interviewees cited are help from the health insurance (mutuelle) and allocation for elderly people (APA):

> *« La mutuelle intervient dans les frais de déplacement (entre le centre de jour et le domicile) mais qui est vraiment ridicule, c'est 32 cents par kilomètre, c'est à 8 kms d'ici, rien que le transport nous revient à 95 euros par mois, on va récupérer peut-être 8 euros de la mutuelle… On a introduit une demande auprès de l'APA, aide pour personnes âgées, ce qui a été accepté, on a déjà ça. » (BXL_3_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)*

> *« Elle bénéficie d'une <u>allocation pour personnes âgées</u> (APA)… » (BXL_5_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 and the ICG in the same way that these measures help anybody else: by providing an additional income or in reducing the costs of the day care center or in reducing the cost of care the DEP needs.

Appendix 6.8. Part 9 – Coding of data related to the impact/effect of these policy measures

In this section, we summarize the data related to the effect of the use of services and measures by the DEP/ICG on the continuity of care and on the maintenance of the DEP in the community.

On the continuity of care for the DEP

Different reasons may lead to an interruption of the care for the DEP. The first one cited by the interviewees is related to some occasional interruptions in the home visits by the professionals. This is in fact due to communication problems between home professionals and family members:

> *« 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)*

These interruptions can be explained by the support system put in place by the ICG, as in the case of dyad 6, where the DEP 'circulates' between the houses of her four daughters:

> *« Aujourd'hui par exemple, l'infirmier devait passer, parce que cela fait une semaine que maman est chez moi… Il passe une fois par semaine, pour faire le pansement (de la sonde ventrale qui alimente l'aidée) » (BXL_6_1A)*

When the care giving is shared between several ICG and thus between several places, it may be difficult to install the conditions allowing the deliverance of some professional services. In dyad 6, for example, a nurse who came regularly to prepare the medication and to make the toilet of the DEP asked one of the daughters/ICG to install a mechanical bed, in order to facilitate the manipulation of the DEP. But as the DEP 'circulates' between the homes of her four daughters, it was not possible to have a mechanical bed in each of the four houses and so the nurse stopped to make the toilet of the DEP:

> *« 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. On lui a dit alors qu'elle vienne faire les soins et que quelqu'un d'autre vienne la laver. Elle m'a dit qu'elle avait parlé avec les autres infirmières, qui sont tout à fait d'accord avec moi, il faut un lit… Et donc elle venait faire les soins et c'est tout. Je ne comprenais pas pourquoi pendant des mois elle a fait sa toilette et pourquoi elle a décidé ça… Alors que les autres infirmières qui sont venues demandaient pourquoi elles ne devaient pas la laver, parce que elles ça ne les dérangeait pas. Pour la laver, moi toute seule, c'est difficile. Maintenant j'ai l'habitude, mais je n'insiste plus pour que l'infirmier vienne faire sa toilette, parce que c'est comme une bataille, moi j'ai raison et toi tu as tort… Maintenant ça ne me dérange pas, mais quand on le faisait avec l'infirmière, c'était plus facile pour moi, je préparais tout, on la lavait en même pas dix minutes… Comme maintenant l'escarre est guérie, l'infirmier de la maison médicale vient une fois par semaine pour son pansement. » (BXL_6_1A)*

One last but 'specific' (of this population) cause of interruption of care is the regular stay of migrants in their origin countries. During these stays, which may last several months, the professional care services are interrupted until they come back in Belgium:

> *« 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)*

In the different dyads investigated, the continuity of care is mainly ensured by the ICG rather than by home professionals. No communication or coordination tools seem to be used by the home professionals to support the care process.

On the institutionalization process

For all the non-native ICGs interviewed, the institutionalization of the DEP is the last option. It is seen as 'normal' to care for their relatives, because 'it has always been like that'. They decision to institutionalize the DEP comes only as the last option.

> *« J'ai jamais rien fait pour qu'il aille dans un home, je ne sais pas moi, je ne peux pas le laisser ici tout seul… » (BXL_1_1A)*

> *« Elle voulait rester ici avec moi jusqu'à sa mort, elle ne voulait pas partir. Elle n'a jamais pensé aller dans un home, c'était comme ça, c'était toujours les enfants qui devaient s'occuper des parents, c'était comme ça, elle n'a peut-être jamais pensé que j'allais la mettre dans un home… » (BXL_2_1A)*

> *« Tout à fait. S'il faut réadapter la maison et prendre un lit d'hôpital, mais on ne veut absolument pas qu'il aille dans une maison de repos. » (BXL_3_1A)*

> *« C'est notre choix. Au début on était un peu inquiets, on a parlé avec l'assistant et tout ça… Pour nous, c'est mieux à la maison, sinon il faut la visiter et tout… on nous a aussi parlé d'une possibilité, si cela n'allait plus, qu'elle pouvait rentrer dans une maison communale, avec ascenseur et tout, pour que ce soit plus facile pour elle… (Mais) pour l'instant, comme vous voyez, ça va, c'est normal… Même si un jour elle reste tout le temps dans son lit, si je n'arrive plus à faire son soin, je vais quand même demander s'il n'y a pas un système, pour pouvoir la garder… peut-être qu'une infirmière vienne m'aider…» (BXL_5_1A)*

In the migration context investigated, the institutionalization of an elderly is always a source of family tensions and conflict. The cultural model that ascribes the care giving of the elderly parents to the youngest children enters in conflict with the (urban) living conditions (for example, women have to work rather than to stay at home and take care of her old parents). The conditions to maintain the DEP in the community, as it is traditionally done are thus no longer met in the migration context.

Nearly all ICG interviewed, who lived most of their life in Belgium, unlike the DEP they take care for, think it is 'normal' to end up in a nursing home when they will be elderly.

> *« Mon mari est venu par après en Belgique. C'est quelqu'un de là-bas. Moi je suis quelqu'un d'ici… 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)*

> *« 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… Mais pour elle (institutionalized DEP), c'est comme si ou lui disait qu'on ne voulait plus d'elle. Elle l'a reçu très mal. Elle a raconté cela tout autour d'elle, tous ceux qui venaient la voir, elle a dit qu'on ne voulait plus d'elle. Elle a vécu ça très mal. On me met dehors, on ne veut plus de moi, c'est comme si on ne l'acceptait pas» (BXL_2_1A)*

> *« Parce que nous on est éduqués comme ça j'ai vu que des personnes âgées étaient vraiment… là-bas, c'est pire qu'ici hein… il n'y a pas de chauffage. En Turquie, les personnes âgées sont dans les familles. Ma maman s'est occupée de son père, jusque 98 ans. Pendant 7 ans il est resté dans son lit… mais de plus en plus… » (BXL_5_1A)*

But when a DEP is institutionalized, it inevitably raises conflict of interpretations between those who are living 'there' and those who are living 'here'.

> *« Ce sont nos parents, on doit s'en occuper, je suis 100 % avec, mais à un moment donné, je pense que les enfants ont leur propre vie, il faut mettre les parents à côté, que ce soit dans un home ou dans un appartement où quelqu'un vient les voir pour les soigner ou pour s'en occuper, mais on a aussi notre vie et nos propres enfants. Mais pour ma maman, c'était toujours d'abord elle. Si on ne s'en occupait pas, il fallait mettre les enfants de côté, c'était en priorité maman. Donc il y a quelque chose qui n'allait pas ensemble… (…) C'est surtout à cause de ça qu'on a mis maman un peu à l'hôpital aussi, parce qu'on s'est dit que ça ne va pas ensemble, les deux… » (BXL_2_1A)*

Even if, in a nursing home, the continuity of care is better guaranteed than in the community, as illustrated by the following situation:

> *« 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… et mon mari est content… » (BXL_2_1A)*

Key points of these case analysis :

- **The 6 the non-native dyads were from mixed socio-economic conditions although having mainly a lower income than natives.**
- **All the non-native ICG are women, aged from 24 to 78 years old.**
- **The DEP, as well of the ICG are parts of a large and often recomposed family, whose members are often dispersed between several countries.**
- **Most of the DEP don't speak French or Dutch. As a consequence, they need help to access to social and health services.**
- **In the non-native dyads living in Brussels, the role of the ICG is mainly attributed to some female family members by cultural rules.**
- **As 'here', in Belgium, the daughters in law do not accept to take care of her husband's parents, it is generally the youngest daughter who mainly play this role, because of her position in the migrant family.**
- **In some dyads, the role and tasks of the ICG are shared between several ICG, which allows to limit its burden and avoid that it rests on the shoulders of only one caregiver.**
- **Conflicts within the different social roles played by ICG (i.e. caregiver, spouse, mother…) is a major hindering factor for the continuity of the care process.**
- **In non-native dyads, the caregiving tasks are kept as much as possible in the private (family) sphere.**
- **In the six non-native dyads, the ICG say they do as much as they can by themselves : household activities, arrangement of medication, practical support and, above all, surveillance.**
- **Personal care related to incontinence is cited by ICG as tasks they could not do and for which they should ask help outside the family.**
- **The nonnative dyads use very few regular formal services at home in comparison to the other regions investigated.**
- **The under use of formal services can partly be explained by 'cultural' reasons: the care tasks are kept as much as possible in the domestic/familial/private sphere because they affect the 'dignity' of the recipient. The formal home services are perceived as threatening the privacy, particularly because the recipient cannot choose the gender of the professional who will come at home.**

- **Although they are perceived as very expensive, the day centers are used as respite care services when there are no other solutions.**
- **The level of information on available services and allowances varies from one situation to another, depending on the dyads contacts with health or social professionals.**
- **The social workers as well the GP play a central role to inform the ICG about the existing measures and services. These profesionals play also a key role as intermediary in the accessibility of the dyads to the local support system but seem not equally informed or up to date about some services or measures outside the health sector.**
- **Beside the cultural reasons, the under use of formal care services by non native dyads can also be partly explained by socioeconomic reasons.**
- **The two financial support the interviewees cited are help from the health insurance and the allocation for elderly people.**
- **The continuity of care for the DEP is mainly ensured by the ICG rather than by professionals.**
- **No one communication or coordination formam tools seem to be used to support the care process.**
- **When the DEP still go regularly back to the country of origin, the risk of interruption of the care process is a real threat on the continuity of care.**
- **Institutionalization of the DEP may occur when there are conflicts between the different social roles of the ICG.**
- **Institutinalisation occurs only if they are no other solution. But because of the migration context in which the dyads live, the institutionalization of an elderly is always a source of family tensions and conflict.**

APPENDIX 7. FRANCE

In order to bring information about the impact of policy measures to assist Informal Care Givers (ICG) available in France, we have carried out an embedded multiple case study (Yin, 2008) aimed to illustrate, describe and compare the experiences and perceptions of the interviewed ICGs. The interviews were coded using an analytical grid (see chapter 3).

In this section, we present the descriptive results from the interviews conducted in France. The data are presented following the structure of the interview guide, divided into seven parts related to the role and the experience of the caregivers (2.1.), to the health conditions of the DEP (2.2.), to informal support from close family members or friends (2.3.), to tasks performed by the ICG (2.4.), to formal services the DEP receives (2.5.), to formal services used by the ICG to relieve its support tasks (2.6.) and to the financial support (2.7.). In a last section, we summarize the key information brought by the interviews to answer to the main research question.

Appendix 7.1. Introduction

Five dyads living in Southern France have been interviewed in November, 2013. The dyads were recruited through a local GP, two nursing services and an elderly home (see table demographics). We kept a mix between spouse and child caregivers. Two DEP were institutionalized for a period inferior to four months (of which 1 DEP with dementia), three were living in the community (of which one with a Parkinson in its final phase – i.e, full dependence and absence of communication, aggravated by neurological problems). Although we initially selected only one male caregiver, for one of the dyads, however, the answers of the husband of the main ICG, who fully shared this role with his spouse and was present during the interview, have also been coded.

Among the five dyads selected for France, 5 female ICGs were interviewed, and 2 male ICGs (1 as main caregiver, 1 as a joint main ICG: see: above). All but one ICG had family ties with the DEP. In one case, the ICG was not a relative of the DEP, but a former employee and neighbour. Differences in living conditions, educational background, employment and socio-economical status were particularly marked in our sample and heterogeneity between dyads was achieved according to the sampling frame (see table demographics in 1.3.1), providing the study with a relatively diverse and illustrative sample. It is yet to be emphasized that most of the interviews have been carried out in a rural area in Southern France. Nonetheless, urban areas were also represented through a large city and a smaller one, thus covering different situations with respect to the availability and typology of services and policies. Two ICG were living with the DEP. Out of the 5 ICG, two ICGs were on paid employment and three were retired (one remaining active through voluntary work).

Three DEP were interviewed. The interviews with the DEP presented specific difficulties due to their age (respectively 86, 87 and 95) and health conditions. Interviews with DEPs provided little added value as regards the core research questions of this study. However, these interviews brought interesting contextual elements, notably as concerns the degree of satisfaction of the DEP with formal services, her relation to the ICG and the decision made about institutionalization.

Appendix 7.2. Part 1 – Coding of data related to the role, experiences of the ICG and relation with the DEP

Table 20 – Profiles of the IGC for France

FRANCE	ICG 1	ICG 2	ICG 3	ICG 4	ICG 5
ICG demographics					
Gender	Female	Male	Female	Female	Female
Age	64	86	47	56	62
Education level	Secondary education	Primary education	Secondary education	Secondary education	B.A
Marital status	Married	Married	Single	Married	Married
Number of children	2	3	None	2	None
Number of grandchildren	1	7	None	None	None
Relationship with DEP	Other: former employee, successor in business,neighbour	Husband	Daughter	Daughter	Daughter
Living with DEP	No	Yes	Yes	No	No
Other persons living together with ICG	None	None	None	No	No
Current or past job occupation	Economically inactive (retired)	Economically inactive (retired)	Employed	Employed	Economically inactive
If employed % working	/	/	60%	100%	/
Type of work		/	Manual worker	Employee intermediate professions	/

Table 21 – Profiles of the DEP for France

France	DEP 1	DEP 2	DEP 3	DEP 4	DEP 5
DEP demographics					
Gender	Female	Female	Female	Female	Female
Age	95	86	87	87	87
Education level	Secondary education	Primary education	Primary education	Secondary	Higher education
Marital status	Widowed	Married	Widowed	Widowed	Widowed
Number of children	1	3	2	1	2
Number of grandchildren	Unknown	7	Unknown	2	None
Relationship with ICG	Former employer and neighbour	Spouse	Mother	Mother	Mother
Living location	At home (alone)	At home with ICG	At home with ICG	In a nursing home	In a nursing home (medical unit)
Health conditions	Post-CVA, no chronic disease	Post leg-fracture, no chronic disease	Advanced Parkinson	Post leg-fracture Potentially: light dementia	Alzheimer (end stage)

Circumstances for becoming ICG

In three out of 5 dyads, the loss of the DEP's husband features as the main variable triggering increased dependency. In those cases, psychological factors – loneliness, affective isolation, dependency as concerns administrative and financial issues, rather than physical ones, were initially at stake, soon followed by worsening health conditions.

> *« Ce qui a entraîné son départ des Bouches-du-Rhône, dont elle est originaire, c'est le décès de mon père ». (FR_4_1B_F)*

> *« C'est le décès de mon père. Ça faisait plus de soixante ans qu'ils étaient ensemble, et mon père était assez décisif, très décisif même et elle s'est trouvée (…) très désemparée, sans trop sans rendre compte, quoi (…). Elle commençait à avoir des difficultés motrices pour marcher ». (FR_5_1B_F)*

Cerebral Vascular Accident (CVA) happened to 2 elderly people. In both cases, however, this did not provoke the situation of physical and psychological dependency, but constituted an aggravating factor that changed the care relationships, deepening the need for assistance and therefore, multiplying the tasks to be carried out by the ICG.

> *« Et puis petit-à-petit, ça s'est dégradé d'une autre façon. (…). Le moment où on a compris réellement, c'est quand elle a eu un AVC, il y a deux mois, et là (…), on s'est bien rendus compte qu'il y avait quelque chose (…) et là bien sûr, après un AVC à 87 ans… »(FR_5_1B_F)*

> *« It became truly "mandatory" when she was 88 (…). There had been a long time before, when we helped her – my husband used to fix things at home for her (…) I used to help her to visit GPs or*

> *specialists. From 85, it worsened in that sense that she progressively became unable to cope with daily life. In January 2007, she had a CVA». (FR_01_1A_F)*

Domestic accidents, resulting in a broken femur, do constitute another triggering or aggravating factor.

> *« Cela date de la fin octobre 2011. On a eu un accident domestique et ma chute et mon intervention chirurgicale. Et mon épouse, sur cet incident domestique, s'est cassé le fémur en tombant dans les escaliers à l'hôpital de Banon (où elle lui rendait visite) ». (FR_02_1A_M)*

> *« L'été dernier (…) elle s'est cassé le col du fémur, en tombant. On ne sait pas si c'est suite à un malaise, car elle a été trouvée le matin (…). On sait pas (…). Elle a été hospitalisée (…) puis elle a été mise dans une maison de rééducation, qui se trouve être la même structure que la maison de retraite. (FR_4_1B_F)*

> *Elle a eu un souci au pied en 2003. 2004, ça a été la catastrophe (fracture du col fémur). Elle a les mains qui se rétractent. Il y a une déformation » (FR_3_1A_F)*

The reasons why they became the ICG of the DEP (the relationship between the ICG and the DEP)

Whereas this question did not bring about elaborated answers, it points out to a feeling of duty and moral responsibility as the main motivation for endorsing a care-giver role

> *« Nous sommes la génération qui découvre que nos parents (…) arrivent dans la grande dépendance et on doit – si on a un peu de sens moral, les accompagner là-dedans » (FR_1_1A_F)*

> *« C'est moi qui ai bien voulu la garder. Je n'ai jamais attendu de reconnaissance ». (FR_3_1A_F)*

> *« Mon rôle à moi, je l'apprécie davantage qu'au début, parce que je vous dis, je fais les repas. (…) J'ai un rôle qui est utile ». (FR_02_1A_M)*

> *« On y pense pas. On fait les choses, on y pense pas ». (FR_5_1B_M)*

Impact on ICG's life and ICG-DEP relationship

Beyond the psychological effects to witness a process of ageing and growing dependency, the reversal of the parent/children relationship and light tensions were also mentioned as consequences of the care situation on ICG-DEP relationship. In the case of the non-relative ICG, this relationship has been complicated by differences in social status and the background element constituted by the life annuity still paid by the ICG to the DEP as result of a 3-decades old transaction.

> *« Je n'acceptais pas qu'il y ait une inversion des rôles. Ca je l'ai très, très mal vécu pendant au moins deux ans ». (FR_3_1A_F)*

> *« C'est une personne d'une certaine catégorie sociale (…) et maintenant qu'elle a toutes ces personnes autour d'elle, il lui arrive dans une sorte de réminiscence, de les traiter – et même de me traiter moi quand elle perd la tête, comme si nous étions du petit personnel et comme si elle avait retrouvé des airs de grande dame avec des domestiques. On est toujours sur la corde raide ». (FR_01_1A_F)*

> *« Il y a des jours où ça coince un peu. J'ai toujours eu un caractère assez souple, mais il y a des jours où je dis « oh, là tu exagères un peu », vous voyez, sans vouloir imposer ma loi, comme on dit. (…) Alors je le dis ». (FR_2_1A_M)*

> *« C'est lourd, parce qu'elle (DEP) me reprochait de pas faire ce qu'il fallait. Parce que je faisais les choses différemment d'elle et elle n'acceptait pas, donc tu en prends plein la figure, ça va jamais. Ça, ça été dur, maintenant, c'est quelque chose d'autre qui est dur pour moi et je regrette presque quand je me faisais engueuler » (FR_3_1A_F)*

> *« Bien sûr que c'est fatiguant, psychiquement, parce que vos parents deviennent vos enfants. En plus on est pas très jeunes, nous-mêmes ». (FR_5_1B_F)*

In one dyad, the unbalance between the children of the DEP in assuming tasks related to care had a strong impact on their relationship.

> *« C'est vrai que j'avais un peu la colère après mon frère, parce que je trouvais qu'il aurait pu venir plus souvent, mais j'en ai pris mon parti aussi de ça. Des fois, j'ai un peu des reflux de colère contre lui, mais j'en ai pris mon parti ». (FR_3_1A_F)*

> *« Parmi les côtés positifs (de la situation) (…), la gentillesse (…) de la famille et des amis ». (FR_5_1B_F)*

As 3 out of 5 ICGs are retired, this role had a significant impact on the employment situation of the ICG only in one single case. In that case, the ICG had to reduce its dedication from 100 to 80, later 60% in order to cope with her role, with subsequent consequences on her incomes and financial independence. In another case, the ICG was on an illness-leave due to depression.

> *« Je travaille. J'ai toujours travaillé à 100%. Quand c'est arrivé à ma mère, qu'elle a commencé à être beaucoup plus fatiguée, j'étais toujours à 100%, mais après je suis passée à 80%. Mais voyant que je ne tenais plus, que j'étais trop fatiguée, je suis passée à 60%. Je travaille en cuisines, donc c'est quand même physique (…). 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)*

> *« Ça c'est sûr, j'ai pris une claque (financièrement) quand je suis passée à 80%. Parce que bon, le Conseil général, avec l'APA, il vous offre une aide (…) mais il faut changer les couches. Ne serait-ce que les lessives, on ne s'en sort plus (…). Mais c'est vrai que je ne calcule pas tout le temps… »(FR_3_1A_F)*

Impact on daily life (limited mobility, loss of sociability and leisure)

> *« Moi je jouais aux boules, je chassais, j'avais des chiens, j'avais une vie normale, active (…). Depuis, on est là, on vit, pas normalement, parce qu'on est contraint de rester à la maison ». (FR_02_1A_M)*

> *« Le mode de vie a changé complètement, au niveau déplacements (on ne se déplaçait) presque plus, sinon (dans) les environs proches ».(FR_5_1B_M)*

> *« C'est vrai que ça nous prend du temps, que c'est une contrainte. Tous les matins je me lève en pensant à ce que je vais faire à manger à Mme… donc c'est une contrainte ». (FR_01_1A_F)*

The impact of the care relationship on the ICGs' health is quite important in ours ample: a main ICG and her husband depict themselves as permanently tired over this period, and suffer problems of addiction (to alcohol). Alcoholism also features as a collateral damage of the care situation (although it is unclear to which extent it can be solely imputed to that variable) in another dyad. In one case, physical damages (dermatologic problems and lack of sleep due to stress) were obvious. Two cases can be related to depression (one of them diagnosed).

> *« On a été fatigués, tout le temps, au cours de cette période ». (FR_5_1B_M)*

> *« Mon lupus a flambé, mon cuir chevelu aussi, d'ailleurs. Et oui, une grosse fatigue morale, nerveuse ». (FR_3_1A_F)*

> *« La nuit, je manque beaucoup de sommeil. Déjà que je n'aie pas beaucoup de sommeil au départ, mais là, c'est explosif ». (FR_3_1A_F)*

> *« J'ai un peu capoté. J'ai fait une dépression et là je suis arrêtée pour dépression et je pense que bien involontairement, maman n'y est pas pour rien, entre le harcèlement involontaire qu'elle me mettait (…) » (FR_4_1B_F)*

Facilitating factors to play this role

Apart from geographical proximity, the main facilitating factor mentioned is the attention paid by health professionals intervening at the home of DEPs to ICG's psychological distress.

> *« Without proximity, it would be unfeasible. I am living 10 min away from Mrs…..» (FR_01_1A_F)*

> *« Heureusement qu'elles (nurses) sont là, parce qu'elles ont un rôle d'aidant aussi avec la famille. Je vous dis qu'on pourrait pas fonctionner sans elles, mais un peu à tous les niveaux » (FR_3_1A_F)*

> *« La kiné, elle m'aide beaucoup (…). Elle me laisse les trois-quarts du temps un petit mot, parce qu'elle sait que je suis une stressée. C'est vraiment un plus (…). Moi, ça me fait du bien ». (FR_3_1A_F)*

Information provided by social services

> *« 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 ». (FR_5_1B_M)*

Financial aspects

> *« On se demande si on a les moyens ou pas. Si on voit qu'on a les moyens… Si on y arrive, on y arrive. On est content d'y arriver » (FR_5_1B_M)*

> *« J'ai jamais pensé (au fait de recevoir une aide financière en tant qu'aidant), parce qu'on le fait car ce sont nos parents » (FR_5_1B_F)*

Recognition

All ICGs but one for which this situation was not relevant, acknowledged to be fully recognized in their role of care-givers by health professionals and other service providers intervening at the home of the DEP (including before the institutionalization). Similar statement were collected as concerns formal recognition by public authorities (notably through the benefit of the APA). Lack of recognition was only mentioned in the case of intra-family relationships ». (FR_1_1A_F)

> *« Je pense pas (que son rôle soit reconnu). C'est moi qui ai bien voulu la garder. Je n'ai jamais attendu de reconnaissance. Ni, d'ailleurs... de sa part (DEP), si, j'en ai attendu, et plus longtemps. De la part de mon frère, j'attends rien. C'est ça qui a été dur au début, justement, parce que je pensais pouvoir plus compter dessus, au début (...). C'est vrai qu'avec mon frère ça a clashé au début, il y a une dizaine d'année, ça a clashé entre nous. Après il est venu, pas régulièrement – des fois je le vois pas pendant trois mois. (...) La colère m'a un peu passé à ce niveau » (FR_3_1A_F)*

> *« Même les aides ménagères, elles nous aiment bien, parce qu'on reconnait ce qu'elles font – quand bien même des fois ont dit ci ou ça ne va pas, on est quand même conscients de ce qu'elles font. Les infirmiers aussi, par ce qu'ils savent qu'ils peuvent compter sur nous. Quoi qu'on nous demande, on accoure, on fait, on se débrouille… et le médecin aussi » (FR_01_1A_F)*

Appendix 7.3. Part 2 – Coding of data related to the health status and occupation of the DEP (2 A or B)

Accumulating health problems

> *« Elle a eu un souci au pied en 2003. 2004, ça a été la catastrophe (fracture du col fémur). Elle a les mains qui se rétractent. Il y a une déformation (…). A ce niveau-là, juste pour faire réchauffer un plat, ça allait, mais il fallait lui préparer toujours tout sur la table pour qu'elle n'ait plus qu'à se servir. (…) Elle arrivait encore à se mouvoir avec son cadre (déambulateur) » (FR_3_1A_F)*

> *« Mon père est mort le 7 Novembre, 2010. Et à partir de là, ma mère est restée trois mois ici, avec nous (…). Puis elle a dû être opérée de la vésicule biliaire, il y a eu un problème, elle est restée en maison de convalescence pendant deux mois ». (FR_5_1B_F)*

> *« Et puis petit-à-petit, ça s'est dégradé d'une autre façon (Alzheimer progressif). (…) Quand ça commence, on s'en rend pas bien compte (…), c'est difficile à discerner ». (FR_5_1B_F)*

Cerebral Vascular Accident (CVA) and Parkinson as recent evolutions

> *« Le moment où on a compris réellement, c'est quand elle a eu un AVC, il y a deux mois, et là (…), on s'est bien rendus compte qu'il y avait quelque chose (…) et là bien sûr, après un AVC à 87 ans… »(FR_5_1B_F)*

> *« Le docteur parle d'un Parkinson "galopant" »(FR_3_1A_F)*

As regards DEP being recently institutionalized, the decision resulted from a degradation of the DEP's health condition. In one case, CVA, following several health problems, including dementia, was the main triggering factor. In the second case, the risk (or ICG's fear thereof) to repeat a domestic accident and the subsequent fracture) was combined with recommendations from health professionals to opt for institutionalization

> *« Moi ensuite j'ai eu des entretiens avec les médecins, psychologues, toute l'équipe de la rééducation, et ils m'ont dit que ça n'était pas très prudent de la remettre chez elle, même si au niveau du col du fémur, c'était assez bien consolidé, bien qu'elle ait encore besoin d'une canne et d'un déambulateur. Parce qu'on se demande si c'est pas une absence qu'elle a eu. Elle a déjà fait des tests qui révélaient qu'elle avait des problèmes de perte de mémoire, de confusion (…) » (FR_4_1B_F)*

> *« On a écouté le corps médical, d'autant plus que je travaille, que je ne peux pas être là tout le temps et que je devrai travailler à (60 kms) bientôt, et j'ai estimé qu'il serait plus raisonnable de ne pas la ramener chez elle (…) On s'est dit qu'il fallait le faire dans la foulée, elle est passée de la maison de rééducation à la maison de retraite (…) » (FR_4_1B_F)*

> *« Elle était pas surveillée 24h/24h, on ne sait pas pourquoi elle est tombée (silence) Elle n'avait pas envie que quelqu'un vienne à la maison en plus, bien qu'elle ait été soignée par les infirmières d'ici. Même si elle a toujours dit qu'elles étaient gentilles. Après (…) c'est à la vigilance des voisins, si elle tombe encore, ce n'est pas évident » (FR_4_1B_F)*

> *« Moi, en travaillant, je la voyais le soir, mais je ne pouvais pas être là autant qu'elle en aurait eu besoin ». (FR_4_1B_F)*

> *« Moi, honnêtement, j'ai cru bien faire (en la mettant en maison de retraite) et je garde l'espoir qu'elle s'ouvre un peu aux autres et qu'elle se fasse des relations (…). Je sais que les animatrices sont très gentilles, et qu'elles vont arriver à l'intéresser à quelque chose, et qu'elle va essayer de repartir sur une nouvelle vie, si c'est possible » (FR_4_1B_F)*

> *« J'ai eu ça (une fracture) et je ne pouvais plus vivre seule, c'était pas possible. Sinon, j'aurais continué à vivre à côté de ma fille, puisque j'avais une petite maison, mais c'était plus possible, vraiment je pouvais pas ». (FR_4_2B_F)*

> *« Elle m'a dit qu'elle avait trouvé cette maison, alors j'ai dit 'OK', puisque de toute façon, il n'y avait pas d'autre solution » (FR_4_2B_F)*

> *« Et puis petit-à-petit, ça s'est dégradé d'une autre façon (Alzheimer progressif). (…) Quand ça commence, on s'en rend pas bien compte (…), c'est difficile à discerner ». (FR_5_1B_F)*

> *« Le moment où on a compris réellement, c'est quand elle a eu un AVC, il y a deux mois, et là (…), on s'est bien rendus compte qu'il y avait quelque chose (…) et là bien sûr, après un AVC à 87 ans… »(FR_5_1B_F)*

About life in institution (dissatisfaction of DEP/feeling of guilt of ICG)

> *« Elle n'est pas du tout contente d'être en maison de retraite » (FR_4_1B_F)*

> *« Le problème, là, c'est qu'elle me dit qu'il n'y a que des vieux. Elle a beau avoir 87 ans, elle ne se sent pas concernée (sourire), tandis qu'en rééducation, comme elle me le disait hier, il y avait des enfants (…), c'était beaucoup plus joyeux » (FR_4_1B_F)*

> *« Au début, elle ne réagissait pas trop, puis un jour elle m'a dit « j'ai compris, je suis foutue, je vais rester ici avec des vieux ». (FR_4_1B_F)*

> *« Je fais des va-et-vient, je vois les gens dans les couloirs, je parle un peu à droite à gauche, quoi. Et puis je me repose, parce que je suis fatigué » .(FR_4_2B_F)*

> *« Je me déplace pour aller manger, je reviens, je me repose, je range mes petites affaires, je regarde un journal. Mais je peu plus lire vraiment un livre ». (FR_4_2B_F)*

In all dyad, DEP expressed (or were reported having expressed) the willingness to stay at home

> *« Mme… me disait "je ne veux pas quitter ma maison". Mais c'est facile de dire ça ». (FR_01_1A_F)*

> *« Il est exclu d'aller dans une maison de retraite, nous n'avons pas les moyens (…) même avec une aide, c'est exclu » (FR_02_1A_M).*

> *« Nous ne souhaitons pas, mon mari et moi, aller en maison. S'il faut y aller, on ira, mais enfin, pour l'instant, on est bien chez nous (…). Nous l'envisagerions si notre état de santé se dégradait » (FR_02_2A_F)*

> *« Au début, il y a dix ans, il (brother/son) voulait qu'elle monte chez lui, mais elle ne voulait pas, elle n'a jamais voulu quitter chez elle. Et ça, il ne l'a jamais compris, il a toujours pensé que c'est moi qui voulait pas qu'elle vienne. Et pourtant, ne serait-ce qu'un WE, elle ne voulait pas, elle angoissait. Pour elle, ce n'était pas chez elle, c'était chez son fil et sa belle-fille ». (FR_3_1A_F)*

> *« Ma mère n'a jamais voulu personne à la maison. Pour lui faire accepter ne serait-ce que le SIAD vienne s'occuper d'elle – trois fois par semaine -, ça a été très dur de lui faire accepter. Idem pour les aides ménagères (…). Quand elle est rentrée de l'hôpital, il a bien fallu trouver une solution, vu que moi j'étais à 100% (…). Elle m'en voulait. Cette inversion des rôles ça revenait. Des fois, je me faisais copieusement insulter. C'est vrai que j'avais un peu la colère après mon frère, parce que je trouvais qu'il aurait pu venir plus souvent, mais j'en ai pris mon parti aussi de ça. (…) Au début, il y a dix ans, il voulait qu'elle monte chez lui, mais elle ne voulait pas, elle n'a jamais voulu quitter chez elle. Et ça, il ne l'a jamais compris, il a toujours pensé que c'est moi qui voulait pas qu'elle vienne. Et pourtant, ne serait-ce qu'un WE, elle ne voulait pas, elle angoissait. Pour elle, ce n'était pas chez elle, c'était chez son fil et sa belle-fille ».(FR_3_1A_F)*

Appendix 7.4. Part 3 – Coding of data related to support from non-professional individuals (from family members, friends…) that the ICG and the DEP receive

About the help the dyad receive from the family

In all but one situation, other family members are thought to be supportive. Dyads 1 and 2 particularly emphasized the support of family members (respectively ICG's husband and children)

> *« Mon mari va tous les jours porter les repas et y retourne souvent même dans l'après-midi ». (FR_01_1A_F)*

> *« Mon mari part en gros deux heures par jour chez Mme…. Il y va vers 11h-12h, puis à nouveau l'après-midi ou le soir, c'est obligatoire ». (FR_01_1A_F)*

> *« Il y a cette grande maison qui se déglingue de partout, parce qu'elle n'est pas entretenue (…), et on est sans arrêt appelés par les personnes qui viennent l'aider à propos de ce qui ne vas pas. Il s'occupe de tout ça, de répondre aux besoins (des aides ménagères) pour soulever Mme… Pour le chauffage, tout ça, il faut bien qu'il y ait un homme. Seule, je ne pourrais pas y arriver ».(FR_01_1A_F)*

> *« Parmi les côtés positifs (de la situation) (…), la gentillesse (…) de la famille et des amis ». (FR_5_1B_F)*

> *« (Ma fille) est présente pratiquement tous les jours. (…) La plus jeune qui habite jusqu'à présent à Saint-Michel, nous est précieuse parce que par exemple pour aller faire les courses, une visite chez le médecin (…). Quand elle sera à Manosque, vous savez, Manosque c'est à 16 kilomètres, elle sera aussi là, je veux dire on peut encore envisager de compter sur elle ». (FR_02_1A_M)*

> *« Et puis (ma fille) de Marseille se rend disponible à peu près toutes les trois semaines pour venir passer un WE. Alors elle cuisine, elle (…) remplit le congélateur, avec des petites barquettes ». (FR_02_1A_M)*

> *« C'est vrai que j'avais un peu la colère après mon frère, parce que je trouvais qu'il aurait pu venir plus souvent, mais j'en ai pris mon parti aussi de ça. Des fois, j'ai un peu des reflux de colère contre lui, mais j'en ai pris mon parti » (FR_3_1A_F)*

> *« Ah ben il y a son fils, quand même. Son fils se sent responsable de sa mère. Il est médecin à Paris, il exerce encore, donc il a du travail. Mais il téléphone tous les jours à sa mère (…). J'en réfère toujours (au fils) de tout ce qui se passe et (…) il est toujours au courant. Il approuve en gros, il ne désapprouve jamais les décisions que je prends (…) Là par exemple, il faut changer de kiné et je le consulte (…) Je ne veux pas du tout l'empêcher de tenir son rôle, je ne veux pas interférer ». (FR_01_1A_F)*

About the help from non-family members

Neighbours and friends of the ICGs also mentioned as providing assistance

> *« Une voisine de ma belle-mère, qui venait tous les jours la voir, quelque-soit le temps, pour boire un café et prendre des nouvelles. Il y a des gens qui sont vraiment gentils » (FR_5_1B_M)*

> *« L'autre jour, c'était une copine. Mais bon, je lui fais confiance. Elle gère parce qu'elle est apparentée au métier médical. Ou une autre copine qui est infirmière, ou bien une autre, mais qui ne veut plus venir parce qu'elle a peur qu'elle (DEP) fasse des fausses routes ». (FR_3_1A_F)*

In two cases, ICG is (or was) involved in another care relationship

> *« On s'est occupé de mon père assez longtemps, donc on les a aidés tous les deux ». (FR_5_1B_F)*

> *« C'est vrai que parmi les personnes dont on s'occupe, il y a le père de mon mari, qui a perdu sa femme il y a cinq ans, qui a maintenant 86 ans (…). Alors il passe 9 mois de l'année chez lui et 3 mois d'hiver chez ses enfants. Il a 3 enfants, alors on se le partage un mois chacun. Moi, je le supporte maintenant un peu difficilement et j'avoue qu'un vieillard plus un vieillard, ça commence à faire trop (…). Et puis ce qui est différent, la relation qu'il a avec son fils, c'est une relation privilégiée, ce qui est très bien (…), mais moi je suis exclue de ça et je me sens un peu comme la bonne, quoi. (…) Quand il s'agit de Mme…, ça se passe (chez elle), mais là ça se passe chez moi et c'est beaucoup plus lourd, parce que c'est constant ». (FR_01_1A_F)*

> *« J'ai une voisine qui a des problèmes psychiques récurrents. Je sers un peu de relais lorsqu'elle a ses crises (…) je n'interviens pas vraiment, je préviens, je suis là pour ça. Autour de nous, il y a des personnes que nous avons connus dans notre vie « antérieure » et qui sont devenues des personnes très âgées (…) Il y a un couple de personnes âgées que mon mari et moi avons accompagné pendant plusieurs années, qui avaient (une certaine) autonomie mais que nous avons aidées jusqu'à la mort du mari. Ensuite, la femme s'est suicidée et elle m'avait demandée d'être son exécuteur testamentaire (…) ça m'a pris trois ans avec les notaires pour répartir ses biens ».(FR_01_1A_F)*

Appendix 7.5. Part 4 - Coding of data related to tasks performed by the ICG

Due to the accessibility of domestic aid and healthcare services at home, the tasks carried out by main ICGs are both essential (in terms of presence, support, surveillance and coordination between services), and subsidiary to the latter. Groceries, administrative and accounting assistance, as well as the preparation of meals (to compensate for the poor quality of dietetic value of the meals delivered at home by domestic aid services), are the main daily tasks performed by ICGs. Beyond those practical assignments, permanent surveillance as well as coordination among (and negotiation with) formal services provides intervening at the home of the DEP, features as key responsibilities assumed by ICGs.

Household activities and personal care

« (C'était) un peu d'intendance, aussi, pour les courses, les vêtements, elle n'y arrivait plus. C'est-à-dire, c'est comme un enfant à ce moment-là ». (FR_5_1B_F)

« Toutes les courses. C'est très compliqué. Avant, lorsqu'elle était seule, ça ne posait pas problème (…), mais maintenant qu'on a tout ce panel d'aides ménagères (…) qui se succèdent. Actuellement, l'ADMR, pour assurer les repas de midi, m'envoie entre 8 et 9 filles par mois, différentes : ça jongle, plus deux l'après-midi. Ça fait 11 personnes, qui toutes vont avoir leurs petites idées sur tout ça. En gros, il faut qu'on aille en courses trois fois par semaine ». (FR_01_1A_F)

« Dès que le médecin est passé, il faut aller chercher les médicaments. On gère l'armoire à pharmacie, les pommades qu'il faut aller chercher en plus (…), les couches. Les couches c'est un énorme charroi, parce qu'on va les chercher tous les deux mois, en gros. Alors c'est un problème, parce que tel infirmier veut des couches comme ça, tel autre (autrement), alors on ne nous facilite pas toujours la tâche. Mais on essaie de répondre, sinon ça s'envenime ». (FR_01_1A_F)

« Je la fait goûter, aussi. Et puis la cuisine, c'est moi qui m'en occupe. Jusqu'il y a à peu près trois mois, je me faisais livrer les repas à domicile, et puis j'ai abandonné, parce que j'ai la passion, d'abord. Je suis pas un grand cuisinier, mais je varie, vous voyez. Alors là, je pense que je suis pratiquement indispensable, parce qu'il faut respecter des horaires (…). J'apporte quelque chose. Parce qu'il y a des fois où on a le sentiment qu'on ne sert plus à rien ». (FR_02_1A_M)

« Par exemple, aujourd'hui, je vais la faire déjeuner, ça va me prendre une bonne demi-heure et encore, c'est un bon jour. A midi, c'est pareil, je vais lui préparer son repas, je vais mixer, je vais prendre le temps de lui donner à manger, quand même. (…). Et le soir, rebelote ». (FR_3_1A_F)

« Tout ce qui est pédicure, coiffeur, c'est moi qui gère tout ça ». (FR_01_1A_F)

« Le soir par exemple – c'est le docteur qui nous l'a autorisé -, au lieu de la coucher de suite après les soins, à 7h, je la fais manger plus tard et puis je vais l'accompagner au lit « à plus », c'est-à-dire après le feuilleton (…) et là, je l'aide à se coucher. Alors il y a le lit médicalisé (…) qu'on peut mettre à niveau » (FR_02_1A_M)

« Je la change, je lui fais la petite toilette du bas pour la nuit, je la lève, je la fais manger, je la recouche ». (FR_3_1A_F)

« Ça s'était les professionnels (qui s'en chargeaient) » (FR_5_1B_F)

« Ça, ça a été très lourd. Déjà que j'ai du mal à gérer le mien de budget, alors en gérer un autre »…(FR_3_1A_F)

« Le matin, je veux que les filles (aides domestiques) aient tout de prêt. Les caisses de linge, les caisses de protection (…), qu'elles n'aient pas à chercher » (FR_3_1A_F)

« A partir du décès de mon père, ça l'a complètement… le décès de mon père a été soudain, elle n'a pas eu le temps de s'y préparer. C'est émouvant (…), mais elle m'a dit « je n'aurais jamais cru que ça arriverait ». Et c'est quand même mon père qui s'occupait de ses papiers et c'était son soutien » (FR_4_1B_F)

« Elle était autonome, à part la gestion des finances. C'est moi qui gère son patrimoine, parce qu'elle ne (pouvait) pas aller elle-même chez le banquier, sans quoi elle aurait cru tout ce qu'il lui aurait dit ». (FR_4_1B_F)

« Au début, on y comprend rien (…) On ne sait pas si les moyens financiers existent, il y a les problèmes de notaires (…) Donc ça a été continu : s'il y avait les moyens financiers de la maintenir chez elle, on ne savait pas, il a fallu vérifier ». (FR_5_1B_M)

Je suis là, parce que dans l'état où elle est, si jamais elle venait à tomber…Dans la maison, j'y suis constamment. (FR_02_1A_M)

> *La nuit – je couche à l'étage – lorsque j'entends qu'elle tousse, je descends. Si je n'étais pas là, ça ne serait pas évident que quelqu'un puisse le faire (FR_02_1A_M)*
>
> *J'ai un mari très gentil, la nuit il se lève deux fois pour venir me voir. (FR_02_2A_F)*
>
> *La coordination, c'est la présence. Le plus gros morceau, c'est ça, c'est la présence. (FR_01_1A_F)*

About surveillance tasks

> *« Puis le matin, quand je pars au travail, je suis jamais tranquille de savoir si j'ai oublié quelque choses (…). Des fois, tu es au travail et tu reçois un coup de fil (parce que) tu as oublié un cachet et qu'elles (aides domestiques) n'ont pas le droit de lui donner si ça n'a pas été préparé ». (FR_3_1A_F)*
>
> *« Parce que faut vous dire que la nuit je me lève, pour voir. Parce que des fois elle tousse, elle s'étouffe ». (FR_3_1A_F)*
>
> *« D'abord (c'était une) présence quasi permanente, pour voir que tout allait bien ». (FR_5_1B_F)*
>
> *« J'avais peur qu'elle se brûle (…) parce qu'elle avait parfois vraiment des absences et je pensais qu'elle était en danger ». (FR_5_1B_F)*
>
> *« L'angoisse du téléphone la nuit. Présence verte (alarm system) a appelé plusieurs fois – c'est-à-dire qu'elle appuyait par mégarde ou quelques fois par angoisse (…) ». (FR_5_1B_F)*

Care-related tasks are reported to take between 2 and 5 hours / day.

> *« Moi, tous les jours, j'en ai pour plus d'une heure (…). Pour mon mari, c'est environ deux heures par jour ». (FR_01_1A_F)*
>
> *« Je sois y passer, entre la préparation des repas, le linge, la changer, ma faire manger, moi je dirais, 4h par jour ». (FR_3_1A_F)*
>
> *« Au moins une demi-journée par semaine ». (FR_4_1B_F)*
>
> *« Beaucoup de temps. C'est-à-dire qu'on y passait tous les jours, plusieurs heures (about 1/3 of the day) » (FR_5_1B_F)*
>
> *« Il faut compter la moitié de la journée (3 or 4 hours). Je me lève à 7 heures (…), l'après-midi je prends un peu de repos avec mon épouse ». (FR_02_1A_M)*

Appendix 7.6. Part 5 – Coding of data related to formal services received at home and outside the home for the DEP.

Nursing home services

Nurses and/or nursing assistants intervening daily (up to 3 X a day). This service is delivered either by private nurses (but working at convention-based fares), or nurses/nursing assistants operating for local public hospitals in several municipalities.

> *« L'infirmier du matin va lever Mme… Avant il venait relativement tôt, mais maintenant (elle) est considérée comme grabataire et (…) n'est plus considérée comme prioritaire. Il fait la toilette au lit ». (FR_01_1A_F)*
>
> *« Dans la soirée, vient l'équipe infirmière du soir, ce ne sont pas les mêmes. Ils la toilettent, la changent » (FR_01_1A_F)*
>
> *« (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)*
>
> *« 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)*
>
> *« (Les aides-soignantes) reviennent à 12h, parce que elle (DEP) est changée trois fois par jour » (FR_3_1A_F)*
>
> *« 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)*

> *« (Nous avions aussi) les infirmières, car (ma mère) avec les médicaments faisait des cocktails terribles, elle se trompait complètement. Ça nous tranquillisait un peu ». (FR_5_1B_F)*

> *« (Le docteur) venait assez souvent, mais à un moment c'est devenu trop difficile pour lui (en termes de distance, en raison de l'isolement du village), alors on lui a demandé si ça le dérangeait qu'on passe sur un autre médecin plus près ». (FR_5_1B_F)*

> *« (service indispensable :) L'infirmière qui passait le matin et le soir pour les médicaments » (FR_5_1B_F)*

> *« Elles dépendent de l'hôpital. C'est un SIAD (Soins infirmiers à domicile) qui dépend de l'hôpital. Normalement, quand il y a des soins, des trucs comme ça, il y a un accord avec l'hôpital et des infirmières qui peuvent venir ». (FR_3_1A_F)*

Accessibility

> *« 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 servis 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)*

Physiotherapists at home

Physiotherapists have been reported to intervene on a regular (1 up to 3 X a week) in four out of five dyads. In rural areas, this service can be occasionally scarce or difficult to obtain, due to the lack of professionals.

> *« Dans l'après-midi vient un kiné, qui est censé la faire marcher. Le kiné vient quatre fois par semaine ». (FR_01_1A_F)*

> *« Une kiné qui vient trois fois par semaine. C'est pour mon épouse et pour moi. Pour mon épouse c'est surtout pour l'aide à la marche. On a aussi commencé le « clapping ».(FR_02_1A_M)*

> *« La kiné vient me voir, m'aider à la marche. Je fais des progrès. C'est un personnel très serviable ».(FR_02_2A_F)*

> *« La kiné intervient régulièrement, deux fois par semaine. En début d'après-midi » (FR_3_1A_F)*

> *« La kiné elle vient, elle fait pas mal de clapping. Elle l'aide à la faire marcher, avec le cadre (déambulateur), avec son soutien, avec le cadre à roulettes »(FR_3_1A_F)*

> *« La kiné, elle l'a très bien acceptée. Avec le premier, ça se passait bien. Il était très demandé, donc il venait irrégulièrement, donc on a changé de kiné et on est tombé sur quelqu'un de super. Mais c'est vrai qu'il y a trop peu de kinés. C'est la galère. (…) Il y a pas de kinés, il n'y a plus de kinés ». (FR_3_1A_F)*

Domestic aid

Domestic aid (either remunerated through the APA, the use of universal service cheques - Chèque emploi service universel, CESU - or local schemes), is mainly delivered by the ADMR (Aide à Domicile en Milieu Rural), both in rural and urban areas. Domestic aids intervene at the home of the DEP on a daily basis (up to 3 X a day). Local authorities (at the inter-municipal level) have also occasionally established "action committees" or similar structures to better organize service delivery (for instance, around the municipality of Forcalquier, 3,500 inhabitants, a Comité d'Action Sociale Intercommunal also participate to service delivery. Out from those schemes, in particular when the ICG/DEP are not entitled to the APA, recruiting a domestic aid can be initially complicated. Undeclared work, however, seems to be rather exceptional, as domestic aid is either covered by the APA or partially funded through locally-established services. The level of satisfaction of ICG/DEP towards these services is reported to be high, although the motivation or qualification of domestic aids can be occasionally low.

> *« 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)

« Je fais le repas par souci diététique pour Mme…(…) et aussi pour soulager les filles de l'ADMR, qui ensuite comme elles n'ont pas eu à faire le repas, écrivent sur le cahier qu'elles ont fait du relationnel (…). Suivant les personnes (…), on finit par créer des liens, connaitre les us et coutumes de la vie de Mme… et (ces personnes) peuvent discuter avec elle et ça lui donne ce temps d'échange et de convivialité ». (FR_01_1A_F)

« Ces femmes qui font ce métier de s'occuper des personnes âgées (…), je pense quand même que c'est pas un choix : c'est le seul travail qu'elles trouvent (…) Elles sont obligées d'accepter des horaires, des trajets (…) et elles sont aigries ». (FR_01_1A_F)

« (les aides domestiques) sont très gentilles et très dévouées. (Ma relation à ces personne) est très bonne, elle est excellente ». (FR_01_2A_F)

« Nous avons trois ou quatre personnes qui viennent régulièrement (…) Elles viennent environ 3heures par jour, de 10h à 12H, puis 1 h le soir. C'est le CASIC qui nous les procure. » (FR_02_1A_M)

« C'est parfait, parfait. On a pas à se plaindre. D'ailleurs, c'est des jeunes femmes d'ici en principe, alors elles nous connaissent, nous les tutoyons, elles nous tutoient. C'est réconfortant (…) C'est tout des gens que nous avons presque vu naître ». (FR_02_2A_F)

« 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)

« Maman n'a jamais voulu qu'on prenne une personne à la maison pour lui donner un petit coup main et surtout parler, car Maman a besoin de parler énormément. Et on connaissait une personne aide-ménagère agréé et tout. Et je lui avais dit cette femme est charmante, et je lui avais présentée en faisant le marché, je lui ai dit « vous pourriez faire à manger ensemble, prendre le repas ». Elle n'a jamais voulu (…) et elle s'est enfermée un peu toute seule ». (FR_4_1B_F)

« On a vu qu'elle ne se faisait plus à manger. Donc il a fallu trouver un système pour qu'on lui apporte des repas. On s'est adressé à l'hôpital local, ils ont mis un mois à se décider et nous, on a trouvé une dame qui tous les jours, apportait à manger, moyennant rémunération, bien sûr ». (FR_5_1B_M)

« Trouver une aide à domicile : d'abord, au départ, on sait même pas que ça existe. Ensuite, il y en a qui sont valables, il y en a qui ne le sont pas. Il faut prendre des RDV avec le système d'aide à domicile, et dire : « cette personne-là, elle vole ». (DEP) n'est pas en situation de se plaindre si quelque-chose ne marche pas, c'est à nous de le détecter ». (FR_5_1B_F)

« 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)

« Une personne de l'ADMR (…), qui est très bien, qui est vraiment impeccable ». (FR_5_1B_M)

« 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 étaient surpris (…). Et ça a duré tout le temps, jusque les derniers temps ». (FR_5_1B_M)

« Cette personne, on la rémunérait plus cher – 5 euros – pour aller chercher les repas, ce qui nous paraissait tout-à-fait normal ». (FR_5_1B_M)

« Les services qu'elle avait c'est une pédicure, une coiffeuse à domicile ». (FR_5_1B_F)

« Avec ma belle-mère, ça s'est très bien passé. C'est une sorte d'amour qu'ils avaient pour elle, d'amitié. C'était bien ». (FR_5_1B_M)

« Il s'est créé une sorte de rapport amical, forcément, c'est quotidien. Et puis c'est des gens courageux, franchement, parce que c'est facile pour eux ». (FR_5_1B_F)

> *« Même la dame qui portait les repas, elle ne faisait pas que porter les repas : ma belle-mère ne lavait pas la vaisselle, alors elle lavait les plats, parfois elle dressait la table ». (FR_5_1B_M)*

Accessibility

> *« 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)*

> *« Pour moi, il est évident que tout devait être déclaré, car il est évident qu'il y a trop de risque à laisser une vieille dame avec quelqu'un qui n'est pas déclaré. Et puis il faut reconnaitre qu'il y a des aides sociales, tout est fait pour que tout soit déclaré ». (FR_01_1A_F)*

ICT and home adaptation

Alarm system referred to only in two cases

> *« On a le petit bip, l'alerte. On appelle ça "allô oui ? ». Je n'en ai pas eu besoin pour le moment mais vous voyez avant-hier, ils ont essayé (…) et j'ai pas répondu (…) et le monsieur qui était au standard, a alerté ma fille. Alors j'ai rappelé celui qui était en poste à ce moment-là. On est suivis et s'il y a une petite alerte (…). On a une somme pratiquement dérisoire à payer chaque mois : trois euros (…) » (FR_02_1A_M)*

> *« On a fait mettre un système d'appel – Présence verte ». (FR_5_1B_M)*

> *« L'angoisse du téléphone la nuit. Présence verte (alarm system) a appelé plusieurs fois – c'est-à-dire qu'elle appuyait par mégarde ou quelques fois par angoisse (…) ». (FR_5_1B_F)*

Some adaptations have been made in DEPs' houses to ease daily life and increase safety. Beyond medical equipment (multi-position bed, wheelchair…), bathrooms have been also equipped of safety bars in two cases. Yet, no major transformations were realized, and for one of the ICG, there is a lack of information available to that respect, which contrasts with the situation in other EU countries (NL mentioned).

> *« La maison de mes beaux-parents, c'était une villa assez confortable, mais bon on a fait installer des portes qui s'ouvrent automatiquement, des volets automatiques, des grilles, parce qu'il y a eu un cambriolage. On a fait mettre un système d'appel – Présence verte. Des barres aussi, dans les toilettes, et pour se tenir dans les couloirs ». (FR_5_1B_M)*

> *« Avant de la rapatrier (de l'hôpital) on a eu 8 jours avec mon mari. Elle dormait avant dans les étages, on a dit il faut la mettre en bas. Il y avait un ancien salon qui servait de débarras. On a mis huit jours à tout vider. J'ai demandé à son fils de pouvoir faire retapisser en propre (…). Puis on a installé le lit médicalisé, ses propres meubles dans la mesure du possible. On a rien pu faire en ce qui concerne la salle de bain qui est dans les étages et il n'y a pas de WC (en bas). Si les pouvoirs publics veulent qu'il y ait plus de gens maintenus à domicile, de même que les familles, (c'est quelque chose à quoi il faut penser). J'avais trouvé il y a quelques années une revue néerlandaise (…) où on donnait des conseils (pour adapter une maison), et je suis effarée qu'on en voit pas, ni dans la presse, ni à la télé. Il faut aussi que ces femmes (de l'ADMR) travailleront mieux si les maisons sont adaptées ». (FR_01_1A_F)*

> *« On a une maison qui est assez confortable (…) Quand on a construit il y 34 ans, on avait prévu non pas notre vieillesse à nous, mais celle de la mère de ma femme ». (FR_02_1A_M)*

> *« Il y a le lit médicalisé, vous savez, qu'on peut mettre à niveau ».(FR_02_1A_M)*

> *« Le problème, c'est que c'est une vieille maison, qu'il fait froid et que niveau équipement, c'est pas le top. On a le fauteuil, la chaise-pot, bon on s'en sort ». (FR_3_1A_F)*

Missing (or no longer available) services

Orthophonist

> *« Quand les soins de l'orthophoniste se sont arrêtés parce que le médecin ça trouvé inutile, l'orthophoniste m'a alertée sur le fait qu'elle parlait beaucoup avec Mme…, ça faisait une présence. Alors ce qui serait bien et utile, c'est sûr, c'est de la présence humaine qui lui parlerait de son enfance, par exemple ». (FR_01_1A_F)*

Help for mobility

> *« Ça serait peut-être beaucoup demander, mais enfin, c'est surtout sa mobilité (qui nécessiterait de l'aide), mais il y a toujours un voisin qui vient nous donner un coup de main ». (FR_02_1A_M)*

Lack of training

> *« Il y a un manque de formation, même en ce qui me concerne. Moi, je ne suis pas soignante, et les filles (aides domestiques) non plus. Il faudrait qu'on soit plus au courant. Je trouve qu'il y a un manqué de formation, parce-que des fois tu sais plus comment faire, tu trouves un peu paumée ». (FR_3_1A_F)*

Adapting institutions

> *« Je pense qu'au lieu de faire de grandes maisons de retraites très luxueuses, dans les villes, il vaudrait mieux faire de petites maisons de retraite, à la taille des villages, qui permettraient aux personnes âgées de se voir – celle qui sont à l'intérieur et celles qui sont encore chez elles. Et les familles, les enfants en sortant de l'école (on pourrait passer). J'avais vu un programme télé où la mairie, de l'école et la maison de retraite étaient côte-à-côte et permettaient d'avoir un échange (…) de créer du lien entre les générations ». (FR_4_1B_F)*

Appendix 7.7. Part 6 – Coding of data related to formal services used to relieve support the ICG

Formal services delivered to the ICG at home

In two cases, the ICG also directly benefited from formal services (medical assistance and physiotherapist). Respite care, when it is referred to, is not reported having been used, mainly for psychological reasons (not leaving the DEP alone) or due to the risks this may entail for the DEP's health condition by disrupting routines. The main missing services referred to are psychological assistance and training.

> *« J'ai été hospitalisée mais je n'ai pas envisagé une seconde de faire appel à ça. (…) Je crois quand même que j'aurais des réticences (…) J'ai eu une vie professionnelle très lourde et j'aurais pu me permettre d'avoir une femme de ménage, mais je n'en ai jamais eu (…). C'est une question d'éthique, je ne considère pas normal que quelqu'un vienne nettoyer ma crasse (…)». (FR_01_1A_F)*

> *« (About herself as a potential future DEP) Moi ça me gênerait beaucoup de faire venir une femme chez moi, à titre personnel, d'autant qu'il n'y a même plus la relation « je te paie (pour cela) », mais que ce serait payé par d'autres ». (FR_01_1A_F)*

> *« (Les infirmières) me préparent les doses (de médicaments) pour la semaine.(…) Le médecin me les prescrit et ce sont les infirmières qui me les font prendre. Parce que vous savez, quand on vieillit (…). Les infirmières me préparent tout ça dans le semainier, pour le matin et le soir ». (FR_02_1A_M)*

About respite care

> *« Ici, c'est un peu lourd, la propriété, on ne peut pas s'échapper. La respiration, c'était de recevoir des amis, tous les trois mois quelques jours, d'aller les voir aussi parfois, si ça n'était pas trop loin ». (FR_5_1B_F)*

> *« 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)*

> *« 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)*

> *« 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)*

> *« Peut-être que je ne délègue pas facilement, j'en sais rien. (…) Avant, j'avais peur des chutes (…) ». (FR_3_1A_F)*

> *« 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)*

> *« 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)*

> *« 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)*

Missing services

Targeted information

> *« Si on nous avait aidés pour nous dire que l'ADMR existait, parce qu'on ne savait pas du tout, pour les repas (…) on était au courant de rien ». (FR_5_1B_F)*

> *« Si on nous avait donné les informations plus vite, ça nous aurait rassurés ». (FR_5_1B_F)*

Training

> *« Déjà une formation, ça (serait) impératif ». (FR_3_1A_F)*

Psychological support

> *« Ce qui me manquerait, c'est un soutien psychologique. Ah oui, ça c'est le gros manque. Ça c'est terrible, parce que vraiment tu es seule ». (FR_3_1A_F)*

> *« Peut-être un psychologue, qui serait spécialisé là-dedans, qui m'aiderait à appréhender à la fois son handicap à elle et m'aider moi à prendre du recul par rapport à la situation. Je pense que ça serait pas mal. D'ailleurs, maintenant, j'y vais chez le psy. Ça aurait peut-être évité que j'aie une deuxième dépression ». (FR_4_1B_F)*

Appendix 7.8. Part 7 – Coding of data related to the financial support of the ICG

Financial support (APA) and special leave

Special leave (congé de solidarité familial) used by 1 ICG in paid employment, with subsequent consequences on her incomes. Costs to be covered by the ICG for domestic aid generally reported to be low due to the APA. Yet, for one of the ICGs, the maximum amount of hours to be paid to informal care givers through the APA (58 hours/week) does not correspond to the reality. As a background element, it must be emphasized that the medical services delivered to the DEPs and the domestic services shared by the DEP and the ICG are mostly covered by the health insurance system, the APA and other local assistance schemes, i.e at a relatively low cost (if any) for the DEP/ICGs. In the case of domestic aid, financial support is nonetheless granted upon a condition of resources. Nevertheless, this financial support does not mainly consist in cash, and the idea to be remunerated for taking care of a DEP, especially of a relative, is not positively assessed.

> *« 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)*

> *« Ça c'est sûr, j'ai pris une claque (financièrement) quand je suis passée à 80% ». (FR_3_1A_F)*

« Au début avec l'ADMR, c'était gratuit, et puis ça a changé un peu et (c'est nous) qui avons pris en charge (l'aide à domicile) ». (FR_5_1B_M)

« 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)

« Cette personne, on la rémunérait plus cher – 5 euros – pour aller chercher les repas, ce qui nous paraissait tout-à-fait normal ». (FR_5_1B_M)

« On en a discuté (avec le Conseil général) quand il a fallu réévaluer pour que moi j'ai droit à des heures (d'APA). Parce qu'eux limitent à 58h par mois pour l'aide familiale. C'est-à-dire qu'ils disent pas plus de deux heures par jour pour éviter l'épuisement des familles (…). Bon ben je trouve que leur truc est un peu hypocrite. Mais après, tout dépend des pathologies (…), mais elle a une pathologie lourde ». (FR_3_1A_F)

« 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)

« Ça doit me faire (l'équivalent) d'un 80%, donc quoiqu'il en soit, j'ai 20% de salaire en moins ». (FR_3_1A_F)

« J'ai cinquante et quelques heures pour moi ». (FR_3_1A_F)

« C'est couvert (par le Conseil général). J'ai eu des dépassements à payer (...) sur les heures qu'elles (les aides domestiques) font ». (FR_3_1A_F)

« J'ai quand même une petite pension. Entre ce que j'ai et celle de mon épouse, nous avons 1.300 euros par mois (…). Mais j'ai la chance de ne pas payer de loyer, de ne pas payer la taxe d'habitation, la redevance, je suis exempt de tout ça ».(FR_2_1A_M)

« Ces heures (APA dont il bénéficie) 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)

« Au début, on me versait 70 euros par mois pour les couches, une somme assez importante. Ma fille m'a expliqué qu'aujourd'hui, c'est pris en charge directement. » (FR_2_1A_M)

« 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)

« Ça c'est sûr, j'ai pris une claque (financièrement) quand je suis passée à 80% ». (FR_3_1A_F)

« 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)

« On se demande si on a les moyens ou pas. Si on voit qu'on a les moyens… Si on y arrive, on y arrive. On est content d'y arriver ». (FR_5_1B_M)

« 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)

« Ma femme bénéficie de 53 ou 55 heures par semaine et moi de 25 heures environ (APA). 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 (…) 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)

« (Le reste à payer était pris en charge) par elle-même. C'était pris sur la retraite de mon père ». (FR_5_1B_F)

« Elle a une petite retraite de 500 euros par mois, mais avec (la pension) de réversion (de son époux défunt), elle arrive à 1.500 euros par mois et avec ça, on a calculé qu'elle pouvait s'en sortir. Ce qui était le cas. (…) Elle ne payait pas d'impôts, en fait ». (FR_5_1B_M)

« Quand on a vendu (house of DEP), moi j'étais soulagée, parce que je me disais, maman va avoir de l'argent, notamment pour être en maison de retraite, parce que comme vous savez, c'est loin d'être gratuit ». (FR_4_1B_F)

About the concept of a remuneration as caregiver

> *« Je serais bien placée pour dire oui, après tout (au fait de recevoir une aide financière de l'Etat en tant qu'aidante), mais en même temps, je trouve ça très dangereux (…) Parce que je me rends compte aussi que dans la position que j'ai auprès de Mme… avec mon mari, nous sommes intrinsèquement honnêtes, on abusera jamais de la situation, mais je me rends compte qu'on peut très facilement abuser de la situation, et je pense que si les pouvoirs publics encourageaient ce genre de chose (…), il y aurait beaucoup plus de maintien à domicile, c'est évident… Si une femme s'occupait de son vieux père et qu'elle (était) payée, tout cela ne serait plus une relation de don (…) Va y avoir des effets pervers. (…) On peut abuser de la situation très très vite ». (FR_01_1A_F)*

> *« Et puis (dans le cas où on rémunérerait les aidants proches), sur qui ça va retomber encore ? Sur les femmes ». (FR_01_1A_F)*

Appendix 7.9. Conclusions

Key elements of the analysis

- The main policy measures and benefits available in France do not fully fit within the typology of measures established for the purpose of this study. In particular, the APA – Aide Personnalisée d'Autonomie, awarded in 3 out of 5 dyads (3 DEPs + 2 ICGs) does not primarily consist in a cash allowance, but in a volume of (paid) hours for services delivered at home, both to the DEP and the ICG. It is also used to pay (directly from the APA funds managed by local authorities) for medical equipment and house adaptations.
- Granted to dependent individuals aged 60 years or older, upon resources and according to four levels of dependency (GIR 1-4), it gives access to different volumes of paid hours, depending from the respective situations of the DEP and the ICG. In our sample, the maximum amount of hours was approximately of 60 hours/month (for domestic aid) / beneficiary. In dyad 3, both the DEP and the ICG received approx. 60 hours-equivalent through the APA, i.e 120 hours/month. In this case, the APA also took the form of a cash allowance, compensating for the drop of ICG's incomes due to care-related reduced working hours (from 100% to 60%).
- Although this is a possibility opened by the APA, no labour contract was established with the informal caregiver in our sample.
- While the individuals receiving APA are exempted of paying social contributions, we tax-deduction or tax-credit for hiring home employees was not applicable in our sample, as domestic aid was provided through public services, and therefore not paid (and only partly for non-APA beneficiaries) by DEP/ICGs.
- For dyads entitled to the APA, it appears that the role of ICG, while conserving all its emotional weight and presenting heavy difficulties for ICGs (either due to their own age or activity), becomes complementary to the delivery of a fully-fledged range of services: typically, those services include 2, up to 3 visits by nurses/day (including on Sundays); 2 up to 3 visits/day by domestic aids; 2 up to 3 visits by a physiotherapist per week; 1 up to 2 visits by a general practitioner per month.
- ICGs are awarded APA either due to their own (lower) dependency or because of the impact of this caring role on their own finances/activity/living conditions
- The APA thus goes well beyond cash allowance, as it provides dyads with a fully-fledge care plan consisting in personalized and regular evaluation to adapt the level of help, facilitated access to information and a range of optional services (tele-alarm…).
- Yet, it must be also emphasized that in our sample, the situation of non-beneficiaries only relatively contrasts with APA-holders, as it appears that complementary services, also managed at the local level, are made available to DEP and ICGs.
- Indeed, the costs for services (in particular: domestic help) remains sustainable, as medical care at home is almost fully covered by the social security system and additional professional mutual insurances, whereas domestic aid can be funded up to 50% through local benefit systems, depending upon resources of beneficiaries.

- Leave arrangement can consist of the Congé de solidarité familiale. In dyad 2 of our sample, it took the form of a 60% part-time awarded for 3 months (renewable), without compensation for the drop of incomes, but indirectly compensated by the benefit of the APA.
- Respite care, although available in the form of day-care centres and short-stay institutionalization, were not used by ICGs of our sample, mainly for psychological reasons and the emotional nature of the care relationship.
- Psycho-social support, moreover, is largely missing for ICGs, who emphasized this situation. In absence of such a support, mostly provided at the margins by health professionals (nurses, in particular) intervening at home for the DEP, situations of true distress, including in our sample depression, stress with medical consequences and alcoholism are developing, apparently without a proper response from the system.
- Our field work – partly carried out in a rural and relatively remote area, also underlines the added value of local hospitals, which provide care services at home and medical transportation at lower costs than those of convention-based services (private nurses, private ambulances), but also a full and uninterrupted monitoring of the medical situation of DEP (especially as local GPs also serve in local hospitals). Local hospitals also enable to keep DEP who cannot be maintained at home, in the immediate vicinity.
- More generally, the very local dimension of services and assistance made available to DEP and ICGs in France, i.e, its management and delivery by local districts (Conseils généraux) and “intercommunalités”, improves the availability, quality and flexibility of the system. It also improves the availability of information for the beneficiaries. Beyond the APA, this notably includes medical care services at home delivered by local hospitals, with funding from the ‘intercommunalités” (SIAD, CASIC), reduced fares for medical transportation, as it results both from the interviews and the additional information provided by a local hospital manager, a nurse and a GP. It is complemented by the use of the Chèque Emploi-Service Universel, a system to remunerate domestic aid, partly financed by public authorities and leading to tax-reduction.
- This system also relies upon very institutionalized and professionalized domestic aid services, as the ADMR, which expanded its activities from rural to urban areas. The growth of these services, however, mainly draw upon an extremely flexible (scattered hours), ill-paid and occasionally low-motivated or qualified – almost fully female, personnel. It thus contributes to maintain the gendered dimension of care.
- Those services, as illustrated in our sample, nonetheless clearly help preventing early institutionalization. As a consequence, institutions primarily welcome heavy dependent persons, mostly following repeated domestic accidents (with broken femurs as a major triggering factor for institutionalization), with a majority of people suffering different forms of dementia.

APPENDIX 8. THE NETHERLANDS

To answer the research question: ”What are the effects from the informal caregivers´ point of view regarding policy measures to assist them”? an embedded multiple case study design is chosen. We describe and compare the experiences and perceptions of informal caregivers in seven cases with specific benefits for this group. In this part, the descriptive results of the interview data of the Netherlands case will be presented. Each case consists of dyads of dependent frail elderly (DEP) and the main informal care giver (ICG).

The dyads were recruited through a local GP, a nursing service and an elderly home (see table demographics). We kept a mix between spouse and child caregivers. Two DEPs were institutionalized but less then four months (at least 1 people with dementia), three were living in the community (at least 1 people with dementia), two caregivers are in paid employment and at least one male caregiver was selected.

An analysis grid was composed to code the interviews (see chapter 3 methods). This analysis grid is used to describe the analysis of the interviews for each case. During the analysis we focussed on the awareness of the ICGs of existing policy measures and on their perception of benefits from them. Thereafter, we described whether these policy measures have an impact/effect on ICG lives, on the continuity of care for the dependent elderly and the subsequent impact on the institutionalization process.

Table 22 – Demographics informal caregivers in The Netherlands

The Netherlands	ICG 1	ICG 2	ICG 3	ICG 4	ICG 5
ICG demographics					
Gender	M	M	F	F	F
Age	59	58	54	47	59
Education level	High school	Primary school	Secondary school LHVO?	Secondary school (MBO)	High school (HBO)
Marital status	Divorced	Single	Married	Single	Married
Number of children	1	0	1	0	3
Number of grandchildren	0	0	2	0	4
Relationship with DEP	Son	Son	Daughter	Daughter	Niece
Living with DEP	Lives with the DEP (mother)	ICG has a own house but lives with the DEP	No, institutionalised	No	No, institutionalised
If ICG co-resides with DEP: other persons living together with ICG	None	None	/	/	/
If ICG does not co-resides with DEP: other persons living together with the ICG	/	/	Husband	None	Husband
Current or past job occupation	Current: Sick leave / Painter Past: Teacher	Farmer	Current sick leave	Employed	Employed
If employed % working	Self employed, working if possible	100%	Cleaning 50%	Pharmacy assistant 100%	Child care teamleader100%
Type of work	Self employed	Self employed	Employee	Employee	Management

Table 23 – Demographics dependent elderly The Netherlands

The Netherlands	DEP 1	DEP 2	DEP 3	DEP 4	DEP 5
DEP demographic					
Gender	F	M	F	F	F
Age	84	86	84	80	96
Education level	Primary school	Primary school	Primary School	Primary school	Primary school
Marital status	Widowed since 5.5 months (7/6/2013)	Widowed since 2 years	Widowed since 14 years	Widowed since 18.5 years	Single
Number of children	2	3	5	4	0
Number of grandchildren	3	1	3	7	0
Relationship with ICG	Parent: Mother	Parent: Father	Parent: Mother	Parent: Mother	Unmarried Aunt
Living location	At home: ICG (son) lives with her	At home: ICG lives with him	Institutionalised since 28/10/2013	At home alone	Institutionalised since 7/5/2013 short stay + other nursing home and 1 month current nursing home
Dementia	Yes	No	No	No	Yes

Appendix 8.1. Introduction

For The Netherlands, 5 dyads were interviewed.

Within these five dyads, 3 female ICGs were interviewed, and 2 male ICGs. The ICGs all had family ties with the DEP. Differences in living situation, education, working situation and socio-economical status was present and heterogeneity between dyads is achieved according to the sampling frame (see table demographics in annex).

Two ICG were living together with the DEP. From out of the 5 ICGs, three ICGs were working, two were on sick leave, 2 employees (100%) and one was self employed.

Three DEPs were interviewed. The interviews with the DEP were difficult and there was insufficient added value on top of the ICG interviews. Data from the ICG interviews was confirmed by the DEP. Other aspects related to the DEP such as physical, psychologicall problems and age impeded answering the interview questions.

Appendix 8.2. Part 1 – Coding of data related to the role, experiences of the ICG and relation with the DEP

In all the dyads, there is a changing living situation. The DEPs are widowed recently or since a few years and are living alone (or institutionalised). One DEP is an unmarried aunt.

> *Mijn zoon slaapt ook meestal hier. Doet ie voor mij, ik heb niets meer. De boerderij is van hem. Hij heeft dat zoveel jaar geleden overgenomen. Mijn vrouw is nu 2 jaar geleden gestorven. Dat is nog kort, dat is nog alledag (NL_2_2A_time 3'18'')*
>
> *My son also sleeps here mainly. Take it from me, I have nothing left. The farm is his. He took it over several years ago. My wife died two years ago now. It's still very recent and I feel it every day (NL_2_2A_time 3'18'').*

> *Mijn vader is in ’95 overleden en sinds hij er niet meer is, heb ik die zorg eigenlijk wat overgenomen (NL_4_1A_time7’53’’)*
>
> *My father died in '95 and since he's been gone, I’ve acquired responsibility for the care. (NL_4_1A_time 7'53 ")*
>
> *Deze tante, kwam van de boerderij en is een zus van mijn vader en heeft vroeger bij mijn moeder ingewoond. Ze is een beetje een tweede moeder voor ons. Toen de boerderij overgenomen is, is ze naar een appartement gegaan. En naarmate ze ouder werd, had ze hulp nodig met boodschappen,… en omdat zij vroeger altijd voor ons heeft gezorgd, doen wij dat nu voor haar (NL_5_1B_time3’11’’)*
>
> *This aunt, came from the countryside, she’s my father’s sister and was taken in by my mother before. She is kind of like a second mother to us. When the farmhouse was taken over, she moved into a flat. As she’s become older, she’s needed help with the shopping…. And because she always looked after us before, we do that for her now (NL_5_1B_time3’11’’).*

The need for help increased after hospitalisation or due to the aging process; aging in terms of physical disabilities and/ or dementia.

> *Na de ziekenhuisopname heb ik hulp aan huis gekregen (NL_3_2B_5’10’’)*
>
> *After being taken into hospital, I received home-help (NL_3_2B_5’10’’).*
>
> *Mijn moeder is altijd mantelzorger geweest voor mijn vader. En op een gegeven moment kom je in een situatie waarin je zelf hulp nodig hebt (NL_1_1A_time 3’14’’)*
>
> *My mother has always been caregiver for my dad. And at some point you find yourself in a situation where you need help yourself. (NL_1_1A)*

The ICGs, in most dyads, systematically grow in the role of caregiver, it doesn’t happen from one day to the other, it is a process. The main reasons or circumstances for being or becoming an ICG are living nearby, being an only child , not married or a combination of one or more of these factors.

> *Dat is erin gegroeid. Ik ben enige dochter, dus automatisch komen ze toch bij de dochter terecht dan. Het is er wat ingegroeid, als ze ergens naartoe moest dan werd ik altijd gebeld, ook omdat ik het dichtste bij woon (NL_3_1B_time_a2’20”)*
>
> *It’s ingrained in me. I’m the only daughter, so automatically they go straight to the daughter. It’s somewhat ingrained, if she has to go anywhere then they always call me, because I live the closest by. (NL_3_1B)*
>
> *Ik doe de meeste dingen voor mijn moeder. Ik zeg dan zoals als het naar het ziekenhuis gegaan moet worden of boodschappen doen als het nodig is. Als er iets in huis moet gebeuren of zo. Laatst zat ze met haar arm in het gips. Dan kom ik afwassen, haar haar wassen. Het is er eigenlijk een beetje ingeslopen. Mijn broer zegt, jij bent alleen, jij hebt het lekker gemakkelijk (NL_4_1A_time2’26’’)*
>
> *I do most things for my mother. I mean, if we need to go to hospital, or run errands. If something must be done at home or whatever. Recently she had to have her arm in a plaster cast. So I came over to wash dishes or wash her hair. It's actually a little increase. My brother says you're alone, you have it nice and easy (NL_4_1A_time2'26 ")*
>
> *Toevallig, het is een samenspel. Het ging niet meer alleen en ik was de enige die er was .(NL_1_1A_time 4’25’’)*
>
> *Coincidentally, it was a combination of factors. It was no longer working, her being alone, and I was the only one there was. (NL_1_1A)*
>
> *Wij hebben zorg kunnen geven omdat het dicht bij is. En het is graag gedaan. Zij is goed geweest voor ons en wij zijn goed voor haar. (NL_5_1B_time 10’10’’)*
>
> *We were able to give care because it’s nearby. And it’s done graciously. She was good to us and we’ve been good to her. . (NL_5_1B)*

The personal commitment to take care of the DEP is a strong motivator for being an ICG. It is seen as a duty to take care of the family you love. All dyads had family ties. Reciprocity (the mutual obligation within a relationship to respond with a counter-gift a gift thus where family looks after each other) was strongly present within these dyads.

> *Ja, het was vanzelfsprekend dat ik langs kwam (NL_3_1B_time_a 13'40'')*
>
> *Yes, it was obvious that I would come by.(NL_3_1B)*
>
> *Ze is een beetje een tweede moeder voor ons. (NL_4_1B_time 3'11'')*
>
> *She's kind of like a second mother to us. (NL_4_1B)*

Being an ICG however has an impact on the relationship with the family. Being an ICG is not always easy. Often for the family (brothers and sisters) it is natural that, mostly one specific person, takes care of the DEP. Often this is an unmarried child or the daughter(s) that lives the closest to the DEP. The ICG has been assigned to a role where he/she can't always get out if she or he wanted to, it has more or less become a duty.

> *Ja, je bespreekt dat wel he. Ik bespreek dat met mijn man, met mijn dochter, met mijn broers. Maar mijn broers ervaren dat anders dan dat ik dat ervaar . Mijn ene broer die komt er veel en die begrijpt dat anders dan mijn andere drie broers. Die komen er alleen maar koffie drinken (NL_3_1B_time_a12'56'')*
>
> *Yes, you talk that over, don't you? With my partner, my daughter, my brothers. But my brothers' experience is different from mine. One of my brothers comes over a lot so he understands it more than my other three brothers – they only come to have a coffee! (NL_3_1B)*
>
> *Toen de tijd woonde zij dichtbij, maar mijn oudste zoon ook. Maar het is vooral ICG, die hebben vaak gedacht ICG is maar alleen, die regelt het wel. En toen was er iets met ICG. En toen ben ik kwaad geworden en heb ik gezegd, waarom is het altijd ICG. Ik heb 4 kinderen en waarom moet het altijd op 1 terecht komen (NL_4_2A_time 8'24'')*
>
> *Mijn broer zegt, jij bent alleen, jij hebt het lekker gemakkelijk. Jij hebt toch geen privé leven. Maar dat is natuurlijk niet waar. Maar het sluipt er wel zo in. (NL_4_1A_time 2'26'')*

The impact on the relationship with the DEP changes especially when dementia is diagnosed. Communication with the DEP is more difficult as the dementia progresses.

> *Je moet wel rekening houden met (stilte) Ik merk wel dat je toch eventjes zelf een andere levensstijl moet aannemen. Ze is soms wel wat koppig. Ik heb er wat over gelezen. En daar moet je mee leren omgaan in het begin ; dat is niet altijd gemakkelijk .(NL_1_1A_time 13'00'')*
>
> *You got to come to terms with it (silence). I realise that you yourself have to really take on a different way of life. She is sometimes a bit stubborn. I've read things about it. And you have to learn to deal with it in the beginning, it's not always easy (NL_1_1A)*

Not every ICG describes or feels that being an ICG has an influence on their daily life. When the ICG is living together with the DEP, in the early stage of the aging process or before the aging process has started, there is no influence on the daily life. However, when the ICG was working and taking care needed to be combined, there was an impact on the daily life as well as on the work situation. When you are working, raising children and spending free moments with the DEP, it needs a reorganisation at home.

> *Ik ben niet veel in mijn eigen huis, woon vooral hier. Omwille van de boerderij, maar ook omwille van mijn vader (NL_2_1A_time 1'50'')*
>
> *I 'm not often in my own home, I'm living mostly here because of the farm, but also because of my father (NL_2_1A_time 1'50'')*
>
> *Op het ogenblik niet, ik kan het wel zo runnen. Ik moet wel op de situatie letten hoor. Als je ervoor staat is het anders. Ik ben natuurlijk veel meer vrijheid gewend en moet me aanpassen aan haar behoeften en gewoonten (NL_1_1A_time 12'37'')*
>
> *Not at the moment, I can manage it like this. I have to pay attention to the situation, though. If you're doing it differently. I had obviously been accustomed to having a lot more freedom and have had to adapt to her needs and habits. (NL_1_1A)*
>
> *Nee, het is nog niet zo dat ik zo overdreven veel voor mijn moeder moet doen, dat het niet te combineren is. Ze is op zich nog redelijk*

> *veel zelfstandig. Het valt goed te combineren. Het is vaak in het weekend, of in de avonduren of op mijn vrije dag, op maandag. Maar het is niet zo dat ik inderdaad na mijn werk naar mijn moeder ga en dan pas om 10 u s avonds thuis ben, zo moet je het niet zien. (NL_4_1A_time 3'57'')*

> *No it's not yet as if I have to do a ridiculous amount for my mother, that it's impossible to combine everything. She's still pretty much independent. It's fine for me to juggle everything It is often at weekends or in the evenings or on my day off on Mondays. But it is not that I am indeed going to my mother's straight from work in the evening, and I'm home by 10pm so you don't notice it. (NL_4_1A_time 3'57 ")*

> *Ik was op dinsdag vrij. Ik kwam er op dinsdag en het weekend, zaterdag en zondag en soms ook wel s avonds. Ook kwam ik er wel eens 's middags, met mijn werk kon dat. Maar het was niet altijd gemakkelijk te combineren. Maar het heeft geen invloed gehad op mijn werk (NL_5_1B_time 7'34'')*

> *I was free on Tuesdays. I came on Tuesdays and at the weekend, Saturday, Sunday and sometimes also in the evenings. I also often came at lunchtime, that's possible with my work. But it wasn't always easy to combine – it has had an impact on my work. (NL_5_1B)*

There are facilitating and hindering elements that have an impact on this role as ICG and they are connected with the motivation and the circumstances of becoming an ICG.

Facilitating elements: If the DEP is a happy and thankful person, the communication with the DEP is going well and being with the DEP is seen as keeping each other company. Informal care is even more easy when the DEP is the coordinator of her own care. In one dyad it is the DEP who decides who will do what and when. She divides tasks between professional and informal care.

> *Ze is altijd een vrolijk opgewekt mens geweest. Veel gevoel voor humor. Mensen hadden veel voor haar over, en dan nog. Ze krijgt veel bezoek hoor (NL_5_1B_time 7'10'')*

> *She's always been a cheerful, upbeat person. A good sense of humour. People cared a lot for her, still do. She receives a lot of visitors, you know. (NL_5_1B)*

> *Zoveel zorg is het niet he. Het is meer gezelschap, anders zitten we alle 2 alleen en ik ben bij mijn werk (NL_2_1A_time 4'03'')*

> *It's not really 'care', mostly just companionship. Otherwise we'd both be alone, and I'm working (NL_2_1A_time 4'03'')*

> *Nee, ze had eerst een poetshulp maar dat wilde ze niet uit handen geven. Ze doen het niet goed genoeg. Zij moet dat leren. Ze heeft 200 % voor mijn vader gezorgd, echt een zorgtype. Dus het is voor haar afkicken. Maar ze aanvaard het van mij wel hoor .(NL_1_1A_time 21'24'')*

> *No, at first she had a cleaner but she didn't want to give it up. They didn't do it well enough. She has to learn (to accept) that. She took care of my father 200%, a real caring type of person. So it's really a case of kicking the habit for her. But she accepted it from me, y'know (NL_1_1A)*

> *Mantelzorg geven ging in goede harmonie met haar. Ze 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 harmony with her. She 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 direction we did together with her. (NL_5_1B)*

Hindering elements: The dementia process, the character of the DEP (not being social, not wanting to be independent) and negative previous experiences with informal care giving (no recognition of being an ICG in previous care, it is assumed that it is natural for brothers and sisters to be an ICG) makes giving informal care difficult. Also lack of arrangements at work an advantages from the employer are hindering elements.

Dementia

> *Je moet er wel mee leren omgaan. Zo gaat ze van de hak op de tak (dementie).(NL_1_1A_time14'24'')*
>
> *You do have to learn to deal with it. She goes from one thing to another (dementia). (NL_1_1A)*
>
> *De dementie was het meest moeilijke. Ze kende ons nog wel maar vergat meteen wat ze gezegd had (NL_5_1B_time 16'36'')*
>
> *The dementia was the hardest part. She still recognized us, but she'd immediately forget what she'd just said. (NL_5_1B)*

Character of DEP

> *Ze was heel dikwijls down. Ik kon ook niet meer met ons moeder praten, alles was negatief. En dat is nu niet meer. Ik ga er nu weer met plezier naartoe. Eerst ging ik ernaartoe van, ja ik moet ernaartoe want ik kan ze niet alleen laten, kijken of dat ze hulp nodig heeft (NL_3_1B_time_a 12'11'')*
>
> *She was very frequently down. I could no longer talk to our mother, everything was negative. That's no more the case, I go there with pleasure now. First I went there, out of, well I have to go there because I can't leave her alone.. to check if she needed help. (NL_3_1B)*
>
> *Als mijn kinderen me niet kunnen helpen omdat ze belet zijn, dan blijf ik gewoon thuis of heb ik geen eten. daar ga ik niet dood van (NL_4_2A_time 46'00'')*
>
> *If my children are not able to help, because they are busy. I just stay at home or I don't have diner. I won't die from that (NL4_2A)_*

Negative experiences

> *Het soms moeten, verplichtingen die je , waar je niet altijd zin in hebt en waar een ander het ook zou kunnen. Ik denk van ja, ze vinden het allemaal wel gemakkelijk als ik dat doe (NL_4_1A_time 9'45'')*
>
> *It may be an obligation that you, well you do not always feel like it, and where it could also be one of the others. yes I think, they find it all easy when I do everything (NL_4_1A_time 9'45'')*
>
> *Ik heb nog gezorgd voor een oud manneke, een vriend van ons pa. Hij had helemaal niemand. Ik deed voor hem de poets en de boodschappen. Maar als ik de boodschappen deed, dan moest ik op 5 verschillende plekken gaan, en het was nooit goed. En dan ben ik ermee gestopt, het was allemaal teveel. (NL_3_1Bb)*
>
> *I had previously cared for an elderly man, a friend of our father. He really had no-one. I did his cleaning and shopping. But if I did the shopping, I had to go to five different places, and it was never any good. So I stopped doing it, it became too much. (NL_3_1Bb)*
>
> *(waardering) Dat heb ik wel eens gedacht, want ik ben wel eens een tijdje dat ik daar kwaad over geweest ben, en ik dacht ik zal er eens een keer minder naartoe gaan (NL_3_1B_time_b2'56'')*
>
> *(appreciation/ recognition) I have often thought about that, because I was a bit upset about it for a while, and I decided I would go a bit less. NL_3_1B)*

Lack of advantages

> *De werkgever zou faciliteiten hierin moeten stellen vind ik. Dat er mogelijkheden zijn dat je voor ouders of iemand anders kan zorgen. In goed overleg natuurlijk. Maar er zouden mogelijkheden moeten voorzien worden. Als wij later oud zijn, wie gaat er voor ons zorgen? Dat is een beetje de toekomst he. Al faciliteren ze dat met een halve dag of zo. In Nederland is er zorgverlof, maar daar zou een werkgever wel iets aan kunnen doen. (NL_5_1B_time 8'36'')*
>
> *The employer should provide these options I think. That there is the possibility for parents or anyone else to provide care. In consultation of course. But opportunities should be foreseen. When we are old later, who's going to take care of us? That's a bit far off in the future eh. They already allow for this by allowing a half day or so. In the Netherlands there is care leave, but it's still up to the employer. (NL_5_1B_time 8'36")*

At least, if the balance between working, ones own life and family relations is unstable, recognition is an important issue for the ICG and not been taken for granted.

> *Gewaardeerd, ik weet niet of ik daar aan tekort kom of dat het teveel moeite is of niet. Het is meer vanzelfsprekend. (NL_2_1A_time 13'16')'*
>
> *Appreciated? I don't know if there's a lack, or if it's too much effort; it's just natural (NL_2_1A_time 13'16')'.*
>
> *(familie) Ik weet het eigenlijk niet. Het is niet zo, van dat heb je goed gedaan. Ze nemen het gewoon voor waar aan, van dat is vanzelfsprekend. Ja het is eigenlijk vanzelfsprekend. .(NL_1_1A_time 52'00'')*
>
> *(family) I don't know actually. It is not so, that you have done well by doing it. They just take it for granted, that's obvious. Yeah it's really obvious. (NL_1_1A)*
>
> *Nee, mijn moeder, daar krijg je geen waardering van. Het is allemaal maar, ja, ik weet niet. Een voorbeeld met de verhuis. De verhuis heb ik geregeld. Mijn broers hebben de verhuis meegedaan. (…) op een gegeven moment zegt ze wat zal ik de heren geven om meegewerkt te hebben ? (…) maar over mij wordt niet gepraat (NL_3_1B_time_a 16'59'')*
>
> *No, my mother? I don't get any recognition from her. It's everything, yes, I don't know.. An example was moving house. I organized everything. My brothers also helped. (…) At one point she said, what should I give the men for helping? (…) But she didn't mention me. (NL_3_1B)*
>
> *Nee nee (lacht) mijn zus en ik zeggen wel eens tegen elkaar dat is fijn dat je dat gedaan hebt. Maar mijn zus uit HD en mijn broer die nee hoor.(lacht) (NL_4_1A_time 32'44'')*
>
> *No no (laughs) I've spoken with my sister about it and we say to each other, it's great that you've done that. My sister from HD and my brother nothing, y'know (NL_4_1A_time 32'44'').*

Appendix 8.3. Part 2 – Coding of data related to the health status and occupation of the DEP (2 A or B)

Cognitive (dementia) and physical disabilities (less mobility and pain) increase the need for informal and formal care. All DEPs (exept one single DEP) were widowed. In the situation where the DEP lives alone, there is more need for care and coordination. Often the DEP is not able anymore to live on his/her own.

> *Ja evolutie sinds dood van mijn vader. Geestelijk en suiker. De hulp voor mijn vader heeft haar op de been gehouden. Ze heeft zich toen meer ingezet. Toen kwam ze in een leegte en opeens kan ze het allemaal niet meer .(NL_1_1A_time 3'58'')*
>
> *Yes, progression since my father's death. Mentally and diabetic. Caring for my father kept her going. She was so devoted then. Afterwards she felt empty and suddenly everything became too much for her. (NL_1_1A)*
>
> *Ik heb de laatste tijd heel erg veel pijn. Weggaan wordt dan steeds moeilijker. En ik durf daar niets van te zeggen. Ik heb altijd extra medicijnen bij. (NL_4_2A_time 39'50'')*
>
> *I have quite a lot of pain lately. Going away is getting harder and harder. And I daren't say anything. I always just take extra medicine (NL_4_2A_time 39'50'').*

Solutions to handle these situations were sought. Two DEP's moved to an apartment with extra facilities (lift, adapted bath room for wheel chairs,…). These facilities can be expanded if the need for care increases. Adaptions to the home are made if there are possibilities and if finances can cover it.

> *Lang geleden heb ik ook hier in het dorp gewoond. Maar toen had ik een eengezinswoning, en daar was geen gelijkvloers en dat mocht niet meer. Dus vanwege dat ik niet meer op de trap mocht ben ik naar de stad verhuisd. Dit (zorgflat met mogelijkheid tot uitbreiding zorg) was er toen nog niet. (NL_4_2A_time 3'43'')*
>
> *Long ago I lived here in the village. But I had a house then, and there was no ground floor and was no longer allowed. So because of that I*

> *was no longer allowed on the stairs I moved to the city. This (flat with possibility of extended care) was not yet here*
>
> *Het is een aanleunwoning. Ze kan aanspraak maken op een alarm rond je nek maar dat is nu nog niet nodig. (NL_4_1A_time 5'50'')*
>
> *It is a sheltered accommodation. She can request an alarm to wear around her neck, but that's not necessary for now. (NL_4_1A_time 5'50 '')*
>
> *We waren heel blij dat ze voor de wintermaanden haar flatje had, want de wintermaanden zijn toch altijd een beetje moeilijker voor oudere mensen als de zomermaanden (NL_3_1B_time_a 4'53'')*
>
> *We were so happy that she had her flat before/ for the winter months, since the winter months are always harder than the summer months, for the elderly (NL_3_1B)*
>
> *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 capability and costs. We already had some modifications done with my father, such as the elevator. (NL_1_1A).*

When the situation is getting worse, increasing need for help is presenting. This has an influence on the life of the ICG. If living alone isn't possible anymore, institutionalisation is unavoidable.

> *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 11'25'')*
>
> *Right before her admission, everything happened very fast. The procedure 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 give her up.*
>
> *Ze woont nu bijna 4 maanden in deze flat. Ze woonde van te voren in de stad, ook wel gewoon in een flat. Maar het is wel fijn dat ze nu dichter in 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 lived in the city previously, also just 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 a door further if it is necessary (a nursing or retirement home) (NL_4_1A_time 5'27'').*

Appendix 8.4. Part 3 – Coding of data related to support from non-professional individuals (from family members, friends…) that the ICG and the DEP receive

In all dyads, the ICGs were related to the DEP. Most of the time children offer informal care. In one dyad, the DEP had no children. The nieces from the DEP, divided the care tasks, according to their expertise and time.

> *We zijn met 2 kinderen, een is overleden. En mijn vader is recent overleden. Dus mijn moeder komt alleen te staan. .(NL_1_1A_time 2'10'')*
>
> *We were two children, one died. And my father passed away recently. So my mother came to be on her own. (NL_1_1A)*
>
> *Ik heb 4 broers. Een broer die woont ook hier in Baarle. Die gaat ook dikwijls naar ons moeder. De anderen trouwens ook, we komen allemaal dikwijls thuis hoor. We komen allemaal veel thuis. De anderen komen een gezelschapsbezoek doen. Mijn andere broer, die woont hier ook in Baarle en die zorgt ook mee voor ons moeder, wij zijn de twee die het meeste voor ons moeder doen (NL_3_1B_time_a 2'40'')*
>
> *I have four brothers. One of them lives here in Baarle as well. He often goes to our mother's too. The others too, sure, we all come home often, y'know. The others pay 'companion' visits. My other brother the one who lives in Baarle regularly comes and cares for our mother; we are the two who do the most for her. (NL_3_1B)*
>
> *Deze tante, kwam van de boerderij en is een zus van mijn vader en heeft vroeger bij mijn moeder ingewoond. Ze is een beetje een tweede*

> *moeder voor ons. Toen de boerderij overgenomen is, is ze naar een appartement gegaan. En naarmate ze ouder werd, had ze hulp nodig met boodschappen,… en omdat zij vroeger altijd voor ons heeft gezorgd, doen wij dat nu voor haar .(NL_5_1B_time 3'11'')*
>
> *This aunt, came from the countryside, she's my father's sister and was taken in by my mother before. She is kind of like a second mother to us. When the farmhouse was taken over, she moved into a flat. As she's become older, she's needed help with the shopping…. And because she always looked after us before, we do that for her now.(NL_5_1B)*
>
> *In het geven van mantelzorg bij mijn tante zijn er 4 mensen waaronder de taken verdeeld zijn. Ik heb altijd wel veel gedaan ja. Ze wonen allemaal vlakbij, de een doet de financiën, ik heb de zorg op mij genomen en dan deed er nog iemand de technische dingen .(NL_5_1B_time 1'19'')*
>
> *In terms of home-care at my aunt's, there are four people among whom the tasks are split. I have always done a lot, yeah. They all live nearby; one does the finances, I took on the care, and another one would do the technical things. .(NL_5_1B)*

Only in one dyad, a non family member offered help. The neighbours bring short visits once in a while to keep an eye on how things are going.

> *Gisteren is de buurvrouw nog geweest. Ze komt geregeld kijken. Ze is zelf vroeger nog verpleegster geweest. Dus die weet ongeveer wel wanneer wat komt. Ze zal zo ongeveer wel op pensioen zijn. We hebben niet veel contact, af en toe wel eens. Ze springt wel eens binnen om te vragen hoe het geweest is (NL_2_1B_time 16'50'')*
>
> *Yesterday the neighbour lady came. She comes to check up often. She used to be a nurse herself before. So she knows roughly what happens when. She's just about to retire. We did not have much contact, sometimes occasionally. She sometimes pops in to ask how things are (NL_2_1B_time 16'50'').*

One DEP describes the importance of a trusting relationship with the ICG.

> *Ik moet eerst een vertrouwensband hebben om een professionele vrijwilliger in huis te halen. Ik vind het altijd moeilijk. Ik heb liever mensen in huis die ik ken. (NL_4_2A_time 46'26'')*
>
> *I have to have trust first before I let a professional volunteer come to the house. I always find it difficult. I'd rather have people at home that I know (NL_4_2A_time 46'26'').*
>
> *ICG en DEP: wij zijn wel close hoor, altijd geweest .(NL_1_1A_time 1°02'02'')*
>
> *ICG and DEP: we are really close y'know, always have been (NL_1_1A)*

Appendix 8.5. Part 4 – Coding of data related to tasks performed by the ICG

Informal care is more than doing things. Is contains also communication. The ICGs give informal care, they are doing these tasks in addition to their own daily tasks. Informal care is a daily task/job. Household activities (doing groceries, making diner, doing laundry), practical support (administration, transportations) but also being there for the DEP are the most common tasks. One ICG mentions that besides doing tasks, the disease process had to be discussed and processed.

> *Mijn eigen huishouden gebeurt ondertussen ook he. Als ik onze pa zijn was doe, doe ik die van mij in persant ook he (NL_2_1A_time 5'21'')*
>
> *My own housework has to happen at the same time, hey. If I have done my father's then I do mine too hey (NL_2_1A_time 5'21'')*
>
> *Ik weet het niet; je doet dat automatisch. Ik kan wel zeggen een dagtaak maar. Je bent er wel de hele dag mee bezig. Eigenlijk dagelijks. .(NL_1_1A_time 16'51'')*
>
> *I don't know; you do it automatically. I would say it's a daily routine, you're busy the whole day. Indeed, every day. (NL_1_1A)*

> *Ik doe de meeste dingen voor mijn moeder. Ik zeg dan zoals als het naar het ziekenhuis gegaan moet worden of boodschappen doen als het nodig is. Als er iets in huis moet gebeuren of zo. Laatst zat ze met haar arm in het gips. Dan kom ik afwassen, haar haar wassen. Het is er eigenlijk een beetje ingeslopen. (NL_4_1A_time 2’26’’)*

> *I do most things for my mother. I mean, if we need to go to hospital, or run errands. If something must be done at home or whatever. Recently she had to have her arm in a plaster cast. So I came over to wash dishes or wash her hair. It's actually a little increase. My brother says you're alone, you have it nice and easy (NL_4_1A_time2'26 ")*

> *Ik had contact met de zorg en diegene die de huishoudelijke activiteiten deed. Wij hadden een dagboek, zij schreef daar in en wij ook. En we hadden 2 x per jaar een evaluatie gesprek met de zorg .(NL_5_1B_time 21’33’’)*

> *I had contact with the care staff and those who did household duties. We had a diary, she wrote in it, and so did we. And twice annually we had an evaluation talk with the healthcare .(NL_5_1B_time 21'33")*

> *Naast alles wat gedaan moet worden is er ook een proces gaande. Daar moet ook over gesproken worden. Dat is ook een zorg, dat hoort ook tot mantelzorg .(NL_5_1B_time 25’14’’)*

> *Next to everything that had to be done, there’s also a procedure going on. This also had to be discussed. That’s also a concern, it also comes under the home care. .(NL_5_1B)*

Personal and medical care is outsourced to formal services. In two dyads, the ICG described that she/he was not able to wash the DEP. The ICG finds it strange to wash his/her mother, it would change the relationship.

> *N. (ICG) zou het niet willen. Want toen ik in het gips zat zei ze dat doe ik niet. Vraag maar of de thuiszorg het doet, want douchen dat wil ik niet (NL_4_2A_time 35’58’’)*

> *N (ICG) wouldn’t want that. When I was in plaster, she said she wouldn’t do it. She told me to ask the home-care people because she refused to shower me. (NL_4_2A_time 35’58’’).*

> *Haar verzorgen, haar wassen daar zou ik het wel moeilijk mee hebben denk ik. Maar dat doet ze nu nog zelf .(NL_1_1A_time 18’06’’)*

> *to take care of her (personal care) , washing her – I think I would have difficulty with that; but she still does it herself (NL_1_1A_time 18’06’’).*

Appendix 8.6. Part 5 – Coding of data related to formal services received at home and outside the home for the DEP.

If there is a need for help, formal services (nurse help and family help) are the primary steps that are taken. As the need for help increases, formal services are used more often. The formal services that are used most often are: nurse care, family help, diner at home, personal alarm, transportation and services outside the home. The frequency of these services, depends on the independency and health situation of the DEP or if there has been an hospitalization.

> *Van de zorg komen mij 2 x per week wassen. En nu komen ze alle dagen, dat is nu vermeerderd. De laatste tijd wel, ik heb mijn pillen niet altijd ingenomen. Ze komen controleren of ik ze op heb. (NL_2_1B_time 5’57’’)*

> *From care someone comes twice a week to wash me. And now they come every day,that has increased. Lately though, I have not always taken my pills. They will check if I have taken them. (NL_2_1B_time 5’57’’).*

Information about these services is achieved from different channels; the internet, the town hall, from the tenant of the service flats, from the social assistant in the hospital (one Dutch DEP had a hospitalization in a Belgian hospital), from the daughter, from the GP or from the nurse. Often one service offers information about another service that can be helpful for the ICG and the DEP. In this way, information about help and support measures are easily given, from one person to another at the moment the information is needed (i.e. nursing help gives information about diner at home). There were no difficulties described in requesting help when needed.

> *De zus is verpleegkundige bij de thuiszorgorganisatie. Zij is nu ziek maar heeft deze hulp geregeld. (NL_2_1A)*

> *The sister is a nurse in the home care field. She is sick but organized for this help. (NL_2_1A)*

> *Via de sociale dienst van het ziekenhuis. Na de laatste opname enkele jaren geleden is er verpleging aan huis gekomen. (NL_3_1Bb)*

> *Through the social services at the hospital. After the last admission, a few years ago, nurses were sent to the house.*

> *Dat heeft de verpleegkundige in het ziekenhuis geregeld. Mijn moeder moest zelf proberen te katheteriseren, en dat ging niet. En die hebben ervoor gezorgd dat er een verpleegkundige aan huis kwam. En papierwerk en zo hebben hun allemaal gedaan. Ik heb daar in principe zelf niets voor hoeven doen. dat is wel heel fijn. (NL_4_1A_time (NL_4_2A_time 16'23'')*

> *The nurse arranged it via the hospital. My mother had to try to catheterize herself, and that was not working. And they ensured that a nurse came to the house. They did all the paperwork. I basically didn't have to do anything myself, which was lovely. (NL_4_1A_time 16'23")*

During holidays, continuity of care, was provided as much as possible. Continuity of personal care by professionals (nurse) was always guaranteed during the holidays. Professional family help happens to be absent, especially during holidays. Thus, during holidays, the ICG needs to help with cleaning, household,…

> *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 holiday leave in the health service, but we made it clear she couldn't do without it, so there were replacements. .(NL_5_1B)*

> *Ja er komen andere verpleegkundigen in de vakantie. Maar wel op regelmatige basis. Dat is goed geregeld .(NL_1_1A_time 33'41'')*

> *Yes, different nurses come during the holidays. But still on a regular basis. It's well-organised.*

> *Toen we een weekje weg zijn geweest, hebben we gewoon iemand van Groningen gehad. een week lang. Moesten we niet voor doen, gewoon doorgeven en ze hebben dat allemaal geregeld (NL_4_1A_time 21'10'')*

> *When we have been away for a week, we just had someone from Groningen. For a week. We didn't have to do anything for them, just pass it over and they arranged it all. (NL_4_1A_time 21'10")*

> *Toevallig zei ze dat haar hulp op vakantie gaat. We vragen dan wel vervangende hulp aan. Ze kunnen wel niet garanderen dat er dan hulp is. (NL_4_2A_time 6'56'')*

> *Coincidentally, she said that her help is going on vacation. We'll ask for replacement assistance. They can not guarantee that there will be help. (NL_4_2A_time 6'56'')*

> *En als er geen hulp is, zal ik mijn moeder dan moeten helpen met stofzuigen en zo (NL_4_1A_time 7'14'')*

> *And if there is no help, I will have to help my mother with vacuuming and so on (NL_4_1A_time 7'14")*

There are different opinions about the formal service "diner at home". In two dyads (two men and one demented) diner at home is used. The female DEP rather makes her own diner (as long as they are able to or have diner in the public place (of the care apartments).

> *We laten het eten brengen, s middags dan toch. En het brood kunnen we zelf nog wel snijden. Dat kunnen we nog he (NL_2_1B_time 5'02'')*

> *We have food delivered, in the afternoon anyway. And the bread we can still cut ourselves. We can do that still hey (NL_2_1B_time 5'02'')*

> *Nee, ze maakt haar eigen potje klaar. En af en toe gaat ze beneden eten in de openbare ruimte. Voordien thuis maakte ze ook haar eigen eten klaar. (NL_3_1Bb)*

> *No, she prepares her own meals. Sometimes she goes out to eat in public places. Previously she would also make her own meals herself. (NL_3_1Bb)*

> *Nou, ik denk dat ik het dan toch liever aan mijn dochter vraag dat die eten maakt en meekookt, dat ik daar dan geld aan geef. De maaltijden die ze brengen is allemaal werk dat in de magnetron moet en dat wil ik niet. Ik lust dat niet. (NL_4_2A_time 40'53'')*
>
> *Well, I think I'd still prefer to ask my daughter to make food, to cook herself, and that I would then give her money. The meals they bring all go in the microwave and I do not want that. I don't like them. (NL_4_2A_time 40'53'')*

An alarm is used when the DEP is living alone. If a personal alarm is used , this alarm gives a safe feeling for the DEP.

> *Iedere maand komen ze het controleren. Het geeft me een gevoel van veiligheid. Iedere nacht doe ik het aan. (NL_3_2B_time26'01'')*
>
> *They come to check it every month. It makes me feel safe. I turn it on every night. (NL_3_2B_time26'01'')*
>
> *Missing services are mentioned. One DEP was used to some services but since she has moved there are no longer available. Medication delivered at home is no longer possible. There is no pharmacy present that is connected with here health insurance company.*
>
> *In de stad brachten ze de medicatie thuis, maar hier niet. Dat is me tegengevallen dat ze dat hier niet aan huis brengen. De apotheek vindt dat niet nodig. Je kan het ook door de post laten brengen. Maar dat zijn geen erkende apothekers. En die spoelingen moeten speciaal gemaakt worden, en allemaal koel. Dat risico neem ik niet (NL_4_2A_time 27'07'')*
>
> *In the city, they brought the medication to the house, but not here. That's disappointing to me that they do not bring it to my home here. The pharmacy doesn't find it necessary. You can also get it through the mail. But they're not licensed pharmacists. And the rinses have to be specially made, and stay cool. I 'm not going to take that risk (NL_4_2A_time 27'07'')*

Also the possibility to take a taxi (with discount) is no longer present in the village where she lives. And travelling by bus of train is becoming difficult because of decreased mobility.

> *Ik rijd toch mee met jou. Ik betaal je tank. Vroeger ging ik met de trein en dan had ik een pasje. En toen ben ik eens gevallen en dan moet je zo hollen om de overstap te halen. Ik rijdt niet meer met de trein. De grond is veel te glad (NL_4_2A_time 31'09'')*
>
> *I drive with you really. I'll pay for the petrol. Before I went by train and I had a train pass. Then I fell once, running to reach the switch. So I don't go by train anymore, the ground is much too slippery (NL_4_2A_time 31'09'').*

Appendix 8.7. Part 6 – Coding of data related to formal services used to relieve support the ICG

Respite care (example short stay) is used when the DEP is not able to live alone anymore. Short stay is then used to bridge a period of time and to prevent institutionalization.

> *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 did take time before she (Dementing DEP) took it up but then she went twice a week to the day care. She did not want to go, but once when she was there, it was fine. .(NL_5_1B_time 22'32")*

When the ICG goes on holiday, informal care is continued by other family members.

> *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)*
>
> *Toevallig ben ik dit jaar op vakantie geweest. Met mijn oudste zus. En wij zijn net diegene die veel voor onze moeder zorgen. Ik trommel dan de hele familie op met mailtjes en telefoontjes. Van bel onze moeder geregeld. Ga even geregeld kijken en dit en dat. Puur inderdaad dat ik*

> *laat weten ik ben er niet houdt haar in de gaten. Uit zichzelf zal mijn moeder niet bellen, daar is ze te trots voor. Ze gaat dat dan zelf doen, en dan valt ze weer. (NL_4_1A_time 28'32'')*

> *Coincidentally, I was on vacation this year . With my oldest sister. And we are the ones who take the most care of our mother. I then bombard the whole family with emails and phone calls. Arranging everything for our mother by phone. Going to check everything's organised and this and that. Pure fact that I let them know I'm not here and can't keep an eye. My mum won't call herself, because she's too proud. She'd just do everything herself and that's not easy for her. (NL_4_1A_time 28'32 ")*

Respite care (care that allows the ICG to rest) is not frequently used. ICGs 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 which implies that using respite care is a difficult step and will not be used unless there are no other solutions.

Appendix 8.8. Part 7 – Coding of data related to the financial support of the ICG

Financial conditions

The costs necessary for formal services are paid by the health insurance. Often the widow or pension contribution is sufficient to pay these costs.

The DEP needs to pay a fixed amount (a year or a month) to the health insurance. This contribution contains services that are offered in a care package. Depending on the need for care, an extra contribution must be paid. The ICGs and DEPs are not aware if the frequency of formal services is fixed within this package.

> *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 get all for free. The cleaning staff is also free. The food you have to pay for. Maybe with the cleaning staff, a small contribution is paid by the government. This is free. (NL_2_1A_time 8'16")*

> *Ze betaalt dat zelf he. Ze betaalt 110 euro aan de zorgverzekering. 35 euro per maand betaalt ze extra voor al die zorgen (familiehulp, verpleging, dokter) en ze krijgt hier 88 euro van terug. Dat is omdat ze hulpbehoevend is. Ze betaalt dit met haar weduwe pensioen. (NL_3_1Bb)*

> *She pays for that herself. She pays 110 euros to the health insurance. Then 35 euros extra per month for all the care (family assistance, nursing, doctor) and she gets 88 euros back because she is in need of help. She pays using her widow's pension.*

> *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. (NL_4_2A_time 7'30'')*

> *It's real help from the foundation, because you are elderly. You receive a reduction. I get the bill here (NL_4_2A_time 7'30'').*

> *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")*

From the town, the DEP receives a WMO contribution, an amount for dependent elderly. DEP and ICG are not fully aware of the measures that are available. Often things are being arranged by home care services.

> *De gemeente betaalt iets. Effe kijken, daar heb ik me eigenlijk helemaal niet in verdiept, of niet goed genoeg in verdiept. De zorgorganisatie wordt door het ziekenfonds betaald, die zorg (NL_1_1A_time 34'50')'*

> *The council pays for some of it. Let's see, I haven't totally looked into it, not enough anyway. The care from the care organization is financed by the health insurance.*

> *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 nurse is on your insurance. And the cleaning, which 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")*

Financial protection

Being at home, or being on sick leave, was helpful for giving informal care. Information (care leave, time credit, flexible work hours) was not sought yet, they

did not need more information at this moment.

> *Ik heb nu een gedeeltelijke uitkering. Ik heb toen een burn out gehad en sindsdien heb ik een invaliditeitsuitkering tijdelijk .(NL_1_1A_time 8'05'')*

> *I receive partial benefits at the moment. Back then I had a burnout and since then I have received a temporary disability benefit.*

> *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 researched it so much. As it goes, I still haven't needed it too much for her; I try to keep it to hand, in the paper, or on TV. But it's true, the care is changing fast.*

> *When the ICG is working (employee) (2 ICG worked 100%, one was self employed) the possibility to take 'care leave for taking care' was known to them and could be requested. Care leave is made possible if the DEP is admitted to the hospital or needs to go to the doctor, yet it is unpaid. Nevertheless when the ICG was not a child of the DEP, she could not ask for care leave.*

> *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 12 days per year.*

> *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 can be with a sick child or so, and up to 3 months. But it is not reimbursed. And it does not apply to the care of a sick aunt. It is only within your own immediate family .(NL_5_1B_time 9'54")*

> *Also the financial situation of the ICG influences whether care leave could be used. Care leave is possible during 12 days a year, but is unpaid and so has financial implications for the ICG.*

> *Zorgverlof bestaat, maar dat geldt niet voor een ziekenhuis bezoek. Het is wel als ze in het ziekenhuis heeft gelegen en ze moet naar huis en ze heeft zorg nodig. Dan kan ik dit aanvragen. Maar ik denk dat het onbetaald is. En ik kan mijn salaris niet missen. Dat is toch wel een probleem. Het zou voor mij niet echt een optie zijn hoor (NL_4_1A_time 4'52'')*

> *Care leave exists, but that does not apply to a hospital visit. Only in the case that she has been in hospital and she needs to go home and she needs care. Then I can apply. But I think it is unpaid. And I couldn't live without my salary. That's a problem. It would really not be an option for me, you know. (NL_4_1A_time 4'52")*

Cash allowance

Not all DEPs and ICGs are aware of a cash allowance. Information however, is available on the internet, the town hall, or by formal services that come at home and who provide them with the necessary information.

> *Ik zou niet weten of er iets bestaat. Mijn zus heeft hier gepoetst en kreeg daar wat geld voor. En toen is die gestopt, nou ja gestopt, en toen is er poetshulp gekomen (NL_2_1A_time 10’10’’)*

> *I don’t know if we’re lacking anything. (NL_2_1A_time 10’10’’)*

> *Mijn moeder had zo een brief gehad. ik dacht vanuit de sociale verzekeringsbank. Dat is ook diegene waar mijn moeder haar AOW van ontvangt. (NL_4_1A_time 24’07’’)*

> *My mother received such a letter. I think from the social insurance. That is also the one where my mother gets her state pension. (NL_4_1A_time 24'07")*

> *Ik wist het via de gemeente .(NL_5_1B_time 36’44’’)*

> *I knew about it through the council .(NL_5_1B_time 36'44")*

If they were aware of the cash allowance, there were several reasons for not using it; the amount is too small or they needed to fill in several papers which were an obstacle to using it.

> *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)*

> *So, a home-care allowance. Two hundred euros per year, we just received that. We went out to eat with that money; my brother, his wife and us two. Because they also help our mother. (NL_3_1Bb)*

> *Maar dat is direct op he. De kosten krijg je daar niet mee vergoed. Die auto rijdt niet op water he. (NL_3_1Bb)*

> *But that went straight away, huh. The costs are not reimbursed.. the car doesn’t run on water, huh (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 settlement for home caregivers. But I haven’t looked any further into it. It’s not of much importance. We did look for support with materials, that sort of thing you follow up. .(NL_5_1B)*

> *Ik wist wel dat er een regeling was. Maar daar moest je behoorlijk wat dingen voor gaan aanvragen, en ik dacht nou van ja. .(NL_5_1B_time 36’16’’)*

> *I knew that there was a settlement. But you have to know what things you can reasonably request it for, and I thought, well, ok .(NL_5_1B)*

One dayd thinks it is just important to give informal care without being paid for it by the state.

> *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 find it important to home-care. And you should not be paid. But I can understand if you do not work or do not have work because you home-care, then it's another matter. .(NL_5_1B_time 37'20")*

Cash allowance doesn’t cover costs. DEP pays for costs that ICG makes. If there is a allowance available, DEP describes that ICG earns it.

> *Het zou een mooi ding zijn als de mantelzorger iedere maand een kleinigheidje kreeg. Financieel is het best, dan is het afgewerkt, want later, later. (NL_2_1A_time 10’31’’)*

> *It would be a nice thing if the caregiver got a little something each month. Financially is the best, then it is finished, because later, later. (NL_2_1A_time 10'31")*

> *Mijn moeder kreeg een brief dat ze 200 euro kon aanvragen. Ik heb die brief toen ingevuld, ze zie, vul lekker in, jij mag die aanvulling hebben. Het was maar 1 brief invullen, voor de rest heb ik er geen omkijken naar (NL_4_1A_time 18’16’’)*

> *My mother received a letter that she could apply for 200 euros I filled in the form, they say, fill it in well, you may get an allowance. It was only filling one form in, for the rest I have not bothered (NL_4_1A_time 18'16 ")*
>
> *Ik heb geen idee van waar die premie komt en of iedereen hetzelfde bedrag krijgt. Ik heb daar wel voor gebeld, waarom ik nu dat inderdaad wel kreeg en de andere jaren niet. Het komt wat hebberig over, zo bedoel ik het niet. Het enige wat ik wel hoorde was omdat mijn moeder nu verpleeghulp krijgt. Misschien dat je in een bepaalde categorie van zorg behoort (NL_4_1A_time 25’15’’)*
>
> *I have no idea where that premium comes from and everyone is getting the same amount. I called to ask, why do I receive this now and the other years not? It comes across as greedy; I do not mean it that way. The only thing I heard was because my mother now has nursing assistant. Maybe you belong to a certain category of care. (NL_4_1A_time 25'15 ")*

One dyad described that this allowance is paid in the last year.

> *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_2_1A)*

Also the perception that things do change too fast and that people cannot follow what kind of arrangements and or reimbursements are available. It is all very complex, so they don’t always make use of it because of the complexity.

> *Dingen veranderen zo snel in deze tijd, ik weet niet wat er in de plaats komt .(NL_1_1A_time 36’25’’)*
>
> *Things change so fast these days, I don’t know what will come in place (of the benefits). .(NL_1_1A_time 36’25’’)*

Key points of these case analysis for the Netherlands

- **The ICG is aware of existing support measures. These policy measures are accessible through the internet, experts, the health insurance, the town,….**
- **If the ICG and DEP need more information, they can request it on their own initiative.**
- **Not all dyads benefit from the policy measures. There are several causes. Care leave is unpaid. Not all ICGs have the possibility and financial reserve to take unpaid care leave. Care leave is only available if the DEP is a parent. Sick leave is helpful in giving informal care. When the combination working and giving care is unavoidable, support measures are sought.**
- **The impact of accessible information and the existing financial conditions make informal care giving more easy. 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, other help than included help, can be requested.**
- **Remuneration is not always asked. They did know about it, but did not always request the allowance because of the complexity to obtain the small amount of money. The cash allowance for the ICG is small. Informal care costs could not sufficiently covered with this allowance. In a few daydს, the DEP pays the ICG for costs that were made.**

APPENDIX 9. GERMANY

To answer the research question: ”What are the effects from the informal caregivers´ point of view regarding policy measures to assist them”? an embedded multiple case study design is chosen. We describe and compare the experiences and perceptions of informal caregivers in seven cases with specific benefits for this group. In this part, the descriptive results of the interview data of the German case will be presented. Each case consists of dyads of dependent frail elderly (DEP) and the main informal caregiver (ICG).

The dyads in the German case were recruited through a private mobile nursing service (Pflegedienst), a support group for Alzheimer/Dementia and private contacts of the interviewer (see table demographics). We kept a mix between spouse and child caregivers. Two DEPs suffering from dementia were institutionalized less then four months ago, three were living in the community, one caregiver is (still) in paid employment. One of the caregivers selected was male.

An analysis grid was compiled to code the interviews (see chapter 3 methods). This analysis grid is used to describe the analysis of the interviews for each case. During the analysis we focussed on the awareness of the ICGs of existing policy measures and on their perception regarding the benefits they could get. Thereafter, we described whether these policy measures have had an impact/effect on the lives of the ICGs, on the continuity of care for the dependent elderly and the subsequent impact on delaying the institutionalization process.

Appendix 9.1. Introduction

For Germany, 5 dyads were interviewed.

Within these dyads, 4 female and 1 male ICGs were interviewed. All ICGs had family ties with the DEP. Three ICG were the husband (1) or the wife (2) taking care of their partner. Two ICGs were daughters taking care of their mother. Differences in living situation, education, working situation and socio-economic status could be seen in the sample.Heterogeneity between dyads has been thus achieved according to the sampling frame (see table demographics in annex).

Three ICGs were living together with the DEP (all three husband/wife of DEP). The two ICGs that are from a different generation from the DEP (daughters), one ICG is working (100%) and the other gave up her job.

Two DEPs were interviewed. Data from the ICG interviews was mainly confirmed by the DEPs.

Table 24 – Demographics Informal caregiver Germany

Germany	ICG 1	ICG 2	ICG 3	ICG 4	ICG 5
ICG demographics					
Gender	Male	Female	Female	Female	Female
Age	77	75	56	56	81
Education level	superior	primary	superior	secondary	primary
Marital status	married	married	married	married	married
Number of children	2	8	0	1	0
Number of grandchildren	6	11	0	0	0
Relationship with DEP	husband	wife	daughter	daughter	wife
Living with DEP	Yes	Yes	Yes, then Institutionalized	No, then Institutionalized	Yes
Other persons living together with ICG	-	-	Husband	Husband and 2 children	-
Current or past job occupation	Economically inactive (retired)	Housewife/ Economically inactive	Employed, now self-employed	Employed, now housewife	Housewife/ Economically inactive
If employed % working	-	-	100	-	-
Type of work	Before: Management (engineer)	-	Before: Employed tax advisor, now: self-employed tax advisor	Before: Medical technical assistant, later nurse, now: housewife	-

Table 25 – Demographics dependent elder Germany

Germany	DEP 1	DEP 2	DEP 3	DEP 4	DEP 5
DEP demographic					
Gender	Female	Male	Female	Female	Male
Age	77	75	80	80	91
Education level	primary	primary	primary	primary	superior
Marital status	married	married	widowed	widowed	married
Number of children	2	8	2	2	0
Number of grandchildren	6	11	2	5	0
Relationship with ICG	wife	husband	mother	mother	husband
Living location	own apartment	rented apartment	institutionalized	institutionalized	own house
Dementia	no	no	yes	yes	no

Appendix 9.2. Part 1 – Coding of data related to the role, experiences of the ICG and relation with the DEP

The motives triggering the need for intensive care were a stroke (two cases), dementia along with physical disabilities (two cases) and a sports accident in young age (one case). In all cases, the ICGs considered themselves the “natural” caretakers, as they were the closest family members (spouse or daughter). Motives supporting this reasoning were affection and sense of responsibility. All the ICGs were quite convinced that providing care at home was “better” for the DEP and that it allowed the DEP to have more autonomy.

> *“Nach einem Schlaganfall 1998 war meine Frau linksseitig gelähmt. Der Professor in der Neurologie hat die Situation so negativ geschildert, dass wir erst einmal beide in ein Pflegeheim gezogen sind (...) Nachdem die Pflegesituation akut wurde, haben wir alles verkauft, was wir besaßen (Haus) und sind für 1,5 Jahre zusammen in ein Pflegeheim gezogen, meine Frau im Rollstuhl und die erste Zeit nur bettlägerig. (...) Dann sollte sie in eine Reha geben, wo nur Schwerstbehinderte waren. Das habe ich abgelehnt (...) Wir haben uns in dem Heim zwar wohlgeführt, aber man ist hinter einer Mauer und weniger selbstständig. Pflege ist nicht ausreichend, um Menschen zu mobilisieren (...). Nachdem wir unser Haus verkauft hatten, haben wir diese Wohnung gekauft und sie behindertengerecht umgebaut. Hier sind wir selbstständiger. (...) Wir sind schon seit über 50 Jahren verheiratet, da ist das ganz natürlich, dass ich mich um meine Frau kümmere. Vorher war es ja das ganze Leben umgekehrt und meine Frau hat alles für mich gemacht, zu 100%. Ich habe in meiner Ehe bis dahin nicht einmal eingekauft.” (DE_1_1A_M time 7’39’’)*

> *“After a stroke in 1998, my wife’s left side was paralysed. The neurology professor depicted the situation so negatively, that we decided to move in a home together (...) We sold everything and moved to the home, where we lived for one and a half year. My wife was only lying in bed and in her wheelchair at the time (...) Then they wanted to put her into a rehabilitation center, where there were only totally disabled people. I rejected that (...) We felt good at the home, but you still feel less autonomous and “locked away” behind closed walls. Simple care is not sufficient to get people mobilised (...) After we sold the house, we bought this apartment and did some renovations to make it barrier-free and suitable for handicapped. Here we are more autonomous.(...) We are married for more than 50 years now, it is only natural that I care for my wife. Before that, it was her who cared for me the whole time, 100%. I never went shopping in my entire marriage before.” (DE_1_1A_M time 7’39’’)*

> *“Vor zwei Jahren hatte mein Mann einen Schlaganfall. Der hat so viel, das kann ich alles gar nicht aufzählen (...) Rheuma, Diabetes, Nierenversagen (...) dann lag er ein halbes Jahr in der Klinik. Und dann kam er wieder nach Hause (...) Aber er will ja auch nur von mir gepflegt werden, die anderen machen es ihm nicht gut genug, von daher haben wir uns für die Pflege hier zu Hause entschieden.” (DE_2_1A_F time 1'42").*

> *“Two years ago my husband had a stroke. He has so much, I can’t even tell you everything(...) 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 a care at home.” (DE_2_1A_F time 1'42").*

> *“ Ab 2009 setzte bei meiner Mutter eine Demenz ein, erst leicht und dann schwerer. Sie hat lange eine Fassade aufrecht erhalten, so dass Fremde die Demenz erst gar nicht erkannt haben. Mein Vater und meine Mutter wollten immer alles alleine schaffen, keine anderen Leute belästigen. Sie haben sich gegen externe Hilfe gewehrt, so lange es ging und wollten nicht ins Heim. Da habe ich es zu Hause versucht. Meine Eltern und ich wohnten in einem Haus, das hat natürlich vieles leichter gemacht. Aber trotzdem war ich die einzige Tochter hier vor Ort.” (DE_3_1B_F time 2’01’’)*

> *“Beginning in 2009, my mother started to have signs of dementia. First only little signs, then more. She kept a facade for a long time, so that strangers would not recognize her illness. 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 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'')*

> *" Meine Mutter war immer selbstständig und gesund. Ab ca 2005 verschlechterte sich die Situation, da ging sie immer krummer und brauchte irgendwann einen Rollator. Dann hatte sie Rheuma und eine kaputte Hüfte, manchmal ist sie auch umgekippt. Und dann kam die Demenz. Meine Mutter hat sich immer wohl gefühlt in ihrem Haus, das wollte ich ihr nicht wegnehmen, so lange es ging.(...) Wir sind hier dörflich geprägt. Die Pflege zuhause war für uns ist hier noch eher eine Selbstverständlichkeit als in der Stadt. (...) Irgendwann wurde sie dann aber eine Gefahr für sich selbst und andere. Die Pflege konnte ich mir ja mit meiner Schwester teilen." (DE_4_1B_F)*

> *"My mother was always self-determined and healthy. But starting in 2005 her situation deteriorated, she walked with a hunchback and at a certain point she needed a walker (rollator). Then there was rheumatism and hip problems, sometimes she fell. And then came dementia. 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)*

> *" Die Behinderung meines Mannes war ja schon bei der Hochzeit 1959 existent und ich wusste, was auf mich zukommt. Da wir keine Kinder haben und ich nicht alleine leben wollte, pflege ich meinen Mann zu Hause. Urlaub habe ich nie vermisst." (DE_5_1A_F)*

> *"My husband's handicap existed at the time of our marriage in 1959 and I knew what I was getting into. Because we have no children and do not want to live alone, I care for my husband at home. Going on holidays was something I never missed much." (DE_5_1A_F)*

Family ties and living nearby were crucial factors for giving informal care. All ICGs live or lived with or close to the DEP.

As far as the impact of the care on the ICGs lives and the ICGs perceptions about it are concerned, these vary. Whether ICGs stressed positive or negative impacts of the care depends on their personal character, whether they found fulfilment in the care and also the level of dependency or physical and mental stress which this entailed.

Positive aspects focussed mostly on intensified relationships between the ICG and the DEP:

> *„Es gibt nichts, was mir besonders schwer fällt bei der Pflege meiner Frau. Unsere persönliche Beziehung hat sich intensiviert und ist besser geworden. Aber das ist ja nur die Feststellung von meiner Frau und mir, ich weiß nicht ob man das verallgemeinern kann" (DE_1_1A_M time 33'34'')*

> *"There is nothing which I dislike particularly about caring for my wife. Our personal relationship has been intensified and has improved. But that is only something my wife and I could say, I don't know if we can generalise that statement." (DE_1_1A_M time 33'34'')*

> *Ich pflege gerne. Ich bin schon immer so gewesen, ich versuche anderen Leuten zu helfen. Mein Mann sagt immer: Du kannst nicht die ganze Welt retten. Ich habe die Pflege größtenteils als positiv empfunden und es hat mich nicht gestört. Da ich die Pflege als Erfüllung empfunden habe, habe ich keine negativen Gedanken gehabt, das gehört halt zum Leben dazu. Man muss gegenüber seiner Mutter ja auch dankbar sein, die hat das ganze Leben für mich gesorgt." (DE_4_1B_F)*

> *I like to care. I have always been like that, I try to help other people. My husband always says: You can't save the whole world. I perceived the caring as something positive, and it did not bother me. Since I find personal fulfilment in the care, I never had negative thoughts, that is part of life. One has to be grateful to one's mother, she cared for me her whole life." (DE_4_1B_F)*

Negative aspects focus on activities or holidays trips which are or were not possible anymore, friends who don't come around anymore or a bad conscience for taking leisure time. One ICG simply said that she does not like to care.

> *“Viele Freunde sind nicht mehr da. Wir waren früher in vielen Vereinen aktiv, z.B. in Sportvereinen. Nachdem meine Frau ein Pflegefall wurde, wurden die Besuche weniger, da viele Menschen Berührungsängste haben. Es sind deshalb keine bösen Menschen, aber sie können sich nicht auf die neue Situation einstellen und haben Angst. Ein ganz kleiner Teil von “echten Freunden” bleibt bis zum Ende” (...) Hobbys gleich Null, restlos gekappt. Karitative Tätigkeiten hatten wir nicht, aber wir waren in Vereinen tätig, jetzt nicht mehr. Ich war sogar Geschäftsführer eines Vereins. (DE_1_1A time 21’57’’)*

> *“Many friends are not there any longer. We used to be actively involved in clubs, e.g. in sport clubs. After my wife became sick, the visits of those friends became less and less frequent, because people have fear of contact. They aren’t bad people, but they cannot adjust to the new situation and are afraid. A very small number of “real friends” stays until the end (...) Our hobbys were reduced to zero, nothing was left. We did not do charity, but we were involved in clubs, I was even the director of a club.” (DE_1_1A_M)*

> *„Das war ne große Umstellung für mich. Wir waren ein lustiges Volk und haben viel unternommen. Das müssen wir im Moment absagen. Früher haben wir gesungen und getanzt” (DE_2_1A time 24'58").*

> *“It was a big change for me. We used to be happy people and did a lot of things. Now we have to cancel everything. We used to sing and dance.” (DE_2_1A_F)*

> *“Ich bin kein ‘Pflegemensch’. Mir fällt das schwer. Ich streite mich mit der Beihilfe, ich streite mich mit der Krankenversicherung. Mir ist es sehr schwer gefallen, mich mit der neuen Situation zu arrangieren. Meine privaten Hobbys sind auf Eis gelegt seit der Krankheit meiner Mutter. Früher sind wir viel verreist, auch weiter weg. Jetzt verreisen wir nur noch innerhalb Deutschlands, damit ich kurzfristig zuhause sein kann. Ich habe ziemlich zurückgesteckt. Wenn ich mich im Freundeskreis umschaue und sehe, welche Weltreisen die in den letzten Jahren gemacht haben, dann kann ich da nicht mithalten Alle anderen Hobbys (Fotografien) habe ich nicht mehr. Entweder arbeite ich oder ich bin mit meiner Mutter beschäftigt Der Freundeskreis ist ziemlich dezimiert wg. Zeitmangel (...) Unser guter Vorsatz für 2014 ist, dass ein Sonntag im Monat frei sein muss. Wir haben privat seit drei Jahren fast nichts mehr gemacht. (DE_3_1B time 20’43’’)*

> *“I am not a “care-person”. It is difficult for me. I get upset with the administration, I get angry with the insurance. I found it hard to get used to the new situation. My private hobbys are put aside since my mother became sick. We used to travel a lot, also far distance. If I look around, I see my friends traveling around the world, I cannot do that. Either I work or I am busy with my mother. My friends have become smaller in number because of time shortages.(...) Our new years resolution for 2014 was to spend one Sunday a month privately, we did not have many private activities in the last three years (DE_3_1B_F)*

> *“Wir sind dann auch nur noch selten in Urlaub gefahren. Das ist natürlich eine Einschränkung, aber ich hätte dann immer ein schlechtes Gewissen gehabt.” (DE_4_1B)*

> *“From then on, we took holidays only very rarely. Of course that is a restriction, but I always had a bad conscience when I did it.” (DE_4_1B_F)*

As far as the impact of the care on the relationship between the ICG and the DEP is concerned, there are both positive and negative aspects:

> *“Unsere persönliche Beziehung hat sich intensiviert und ist besser geworden. Aber das ist ja nur die Feststellung von meiner Frau und mir, ich weiß nicht ob man das verallgemeinern kann. Ausschlag gebend ist jedoch hier, dass meine Frau eine besonders positive Einstellung zum Leben hat: kein Jammern, kein Klagen. Sie hat die Behinderung angenommen und sich damit identifiziert “(DE_1_1A time 33’34’’)*

> *“Our personal relationship has been intensified and has improved. But that is only something my wife and I could say, I don’t know if we can generalise that statement. What is crucial is that my wife has a very positive attitude towards life: no whining, no complaining. She has accepted her handicap and identified herself with it” (DE_1_1A_M)*

> *“Wir vertragen uns immer noch gut. Das wäre ja schrecklich, wenn wir Krach hätten. Der ist sehr dankbar, Gottseidank. Aber trotzdem ist*

> *mein Mann lustlos, depressiv und unmotiviert geworden, so kenne ich ihn überhaupt nicht. Früher waren wir sehr lustig. Er muss da durch, sagt er. Er hofft immer, dass das besser wird. Aber das geht nicht mehr.” (DE_2_1A time 22'21").*
>
> *“We still get along with each other. It would be terrible if we had fights. He is very grateful, thank God. But my husband became listless, depressed and unmotivated. We used to be very joyful. He has to go through this, he says. He hopes that it will get better, but it won’t.” (DE_2_1A_F).*
>
> *“Insbesondere das umgekehrte Verhältnis, also auf einmal Entscheidungen für die Eltern treffen zu müssen, fiel mir schwer. Die demente Person wurde auf einmal wieder zu einem Kleinkind. Oft hat meine Mutter mir Vorwürfe gemacht, dass ich mich zu wenig kümmere.Diese Vorwürfe verdrängt man Gottseidank im Laufe der Zeit» (DE_3_1B time 23’49’’).*
>
> *“Especially the inverse relationship, having to take decisions for one’s parents, was difficult for me. The dement person suddenly became a small infant. Often my mother accused me of not caring enough. Thanks to God I tend to forget these accusations in the course of time.” (DE_3_1B_F)*
>
> *“Das Verhältnis mit meiner Mutter ist intensiver geworden, sie ist sehr dankbar. Ich bin an der Pflege gewachsen. Gottseidank hat sie mich immer als ihre Tochter erkannt, das ist auch jetzt noch so.” (DE_4_1B)*
>
> *“The relationship with my mother got more intensive, she is very grateful. I like to take care. Thank god she always recognized me as her daughter, that is still the case.” (DE_4_1B_F)*

Negative aspects also concern the impact on the ICG’s own health. For instance, back problems, stress and insomnia have become part of their lives:

> *“Mir geht es gesundheitlich noch gut. Ich muss jetzt allerdings getrennt von meiner Frau schlafen, das Beatmungsgerät ist sehr geräuschintensiv und ich hätte sonst Schlafprobleme.” Schlafprobleme (DE_1_1A time 57’23’’)*
>
> *“My health is still good, but I have to sleep separated from my wife, the oxygen machine is quite loud and I would have sleeping problems otherwise.“ (DE_1_1A_M)*
>
> *“ Ich bin selbst alt und habe Probleme. Im Moment geht alles noch, aber das kann sich ja mal ändern. Aber ich will es schaffen. Schlecht schlafen tu ich schon. Gestresst bin ich auch. Das Heben tut mir manchmal richtig weh. Traurig bin ich schon öfter, dass das nicht mehr alles so ist, wie es früher war.” (DE_2_1A time 10'54")*
>
> *“I am old myself and have problems. Right now I am fine, but that can change. But I want to get it done. I do have sleeping problems. And I am stressed out. Lifting my husband causes pain. And I am sad more often, because things aren’t as they used to be.“ (DE_2_1A_F)*
>
> *“Ich habe Schlafprobleme. Die psychische Belastung wirkte sich auch auf meine physische Gesundheit aus, ich habe erhebliche Rückenprobleme. Meine Mutter ist zwar zierlich, aber das Heben des Körpers ist trotzdem ein Kraftakt für mich” (DE_3_1B time 28’34’’).*
>
> *“I have sleeping problems. The psychological challenge had an impact on my physical health, I had severe back problems. My mother is not that heavy, but lifting her was still very challenging.” (DE_3_1B_F)*
>
> *“Ich habe Rückenprobleme und einen Bandscheibenvorfall gehabt.” (DE_4_1B)*
>
> *“I have back problems and had a slipped disc in the cervical spine.” (DE_4_1B_F)*
>
> *“Das Heben aus der Badewanne ist schwierig und belastet mehr, je älter man wird. Ich muss aufpassen, dass ich im Winter nicht auf Eis ausrutsche oder meide große Menschenmengen, um keine Viren mit nach Hause zu bringen. Wenn ich krank bin, ist das eine Katastrophe.” (DE_5_1A)*
>
> *“Lifting my husband out of the bathtub is difficult and a heavy task, the older I get. I have to be cautious that I do not slip on icy roads in the wintertime. I also try to avoid big crowds so that I do not bring viruses home. When I get sick, it is a catastrophe.” (DE_5_1A_F).*

For some ICGs recognition is a crucial element for keeping providing informal care, which is mostly expressed by the DEPs themselves, sometimes expressed by external care personnel or family members, but rarely by friends or in the public debate. The lack of recognition from friends or within the public debate is taken with some regret since in some ICGs' views externals are not acknowledging informal care givers' contribution to society as they should.

> *"Anerkennung bekomme ich vor allem von unserem Hausarzt. Der hat mir einen Titel verliehen: "Schwester Bernhard". Schwester Bernhard hat Zugang zum Praxispersonal. Wer soll mir den sonst Anerkennung geben, die Bundeskanzlerin? (sarkastisch) Die wissen doch gar nicht, worum es geht." (DE_1_1A time 47' 57'')*
>
> *"I especially get recognition from our GP. He gave me a title: "Sister Bernhard". Sister Bernhard has access to the personnel of his office. Who else should give me recognition? The chancellor (sarcastic). They (the politicians) don't have a clue about what is going on." (DE_1_1A_M)*
>
> *"Die Frau Doktor hat mich sehr gelobt. Die hat gesagt, ich muss nur anrufen, wenn es nicht mehr geht. Mein Mann will ja nur, dass ich das mache. Der schreit ja schon im Krankenhaus: Frau komm rüber und tu mich waschen." (DE_2_1A time 5'38'')*
>
> *"Our doctor told me I was doing fine. She said I only have to call her, if there are problems. But my husband wants me to do it myself. When he was in the hospital, he called: Wife, come and wash me." (DE_2_1A_F)*
>
> *"Viele Nachbaren oder Freunde können die Krankheit Demenz nicht erkennen. Die haben mir dann gesagt: Ich habe doch eine viertel Stunde mit deiner Mutter telefoniert, die ist doch ganz normal. Demenzkranke haben eine wahnsinnige Fähigkeit, die Fassade als normal wirken zu lassen. Leute, die die eigene Erfahrung gemacht haben, können die Arbeit anerkennen. Auch nachdem meine Mutter im Heim war, brauche ich drei Stunden, um eine halbe Stunde mit meiner Mutter an die Luft zu gehen. Das versteht niemand, der das nicht kennt (...) Mich hat tierisch genervt, dass alle immer nur gefragt haben: Wie geht es deiner Mutter? Niemand hat gefragt, wie es mir geht. Ich reagiere sehr allergisch auf den Begriff "alleinerziehende Mutter". Ich bin "alleinpflegende Tochter", dieser Begriff steht nicht genug im Mittelpunkt der öffentlichen Debatte." (DE_3_1B time 68'36'')*
>
> *"A lot of neighbours and friends cannot detect dementia. They told me: I talked to your mother for a quarter of an hour on the phone, she is normal as ever. Dement people have an incredible capability to keep up a normal facade. People who have not had the same experiences cannot judge the burden of the caregiver and cannot recognize it. Even after my mother was institutionalized, it took me three hours in order to go for a walk with her for 30 minutes (to get dressed, etc.). Nobody who hasn't been in the same position can understand that (...) I got very angry when everybody was only asking about my mother's condition. Nobody asked how I felt. I react very allergic to the expression "single mother". I am a "single caring daughter", but that expression is never in the center of public debate" (DE_3_1B_F)*
>
> *"Meine Familie steht hinter mir, aber wir hatten ja auch schon Erfahrung mit der Pflege meines Schwiegervaters, da wussten wir, was das bedeutet." (DE_4_1A)*
>
> *"My family always was behind me, but we already had some experience with the care of my father in law, so we knew what we had to expect." (DE_4_1A_F)*

Appendix 9.3. Part 2 – Coding of data related to the health status and occupation of the DEP (2 A or B)

The illnesses and degrees of dependency vary, as well as the evolution after more intensive care started. In most cases, health conditions of the DEPs remained stable or deteriorated, in another case the care caused improvement

> *“Nach einem einem Schlaganfall 1998 war meine Frau linksseitig gelähmt. Der Professor in der Neurologie hat die Situation so negativ geschildert, dass wir erst einmal beide in ein Pflegeheim gezogen sind (DE_1_1A time 7’39’’). Eigentlich hat sich die Situation meiner Frau zunehmend verbessert, sowohl was ihre Mobilität als auch ihren Geist angeht. Die Ärzte sagen zwar, dass das, was man im ersten halben Jahr nach dem Schlaganfall versäumt ist, weg ist. Aber das stimmt nicht. Aber viele Dinge muss man meiner Frau neu beibringen, wie einem Kind, der Lernprozess wird natürlich länger, je älter man wird. (DE_1_1A time 46’50’’). Nachdem wir unser Haus verkauft hatten, haben wir diese Wohnung gekauft und sie behindertengerecht umgebaut. Es gab 2400 EUR von der Krankenkasse für Umbaumaßnahmen in der Wohnung. Da die Wohnung ein Rohbau war, konnte ich meine Frau in die Planung der Wohnung einbeziehen, das hat ihr wieder eine Aufgabe gegeben. Die Umbaumaßnahmen haben über 44.000 EUR gekostet. Das konnten wir nur machen, weil wir begütert sind. Menschen, die das nicht sind, bleiben zu 99% in einem Heim. (DE_1_1A time 10’04’’). Durch das Aneurysma im Kopf hat meine Frau ein gestörtes Verhältnis zur Zeit. Sie kann nicht mehr genau unterscheiden zwischen heute, gestern und morgen. Wir haben uns da Hilfsmittel gemacht, mit einem Kalender, da streicht sie jeden Tag durch, der vorbei ist. (DE_1_1A time 58’05’’).*
>
> *After a stroke in 1998 my wife was partially paralyzed on the left side. The professor at the neurological department said that chances for an improvement of the situation were little, so we moved into a stationary nursing home. (...) (DE_1_1A time 7’39’’). Actually my wife’s situation has improved continuously, her mobility but also her mind. The doctors said that most health improvements can happen in the first months after the stroke and that if they do not improve right away, things will not improve in the long run. But that is not true. But one has to teach everything to my wife, like a child, and the learning process takes more time, the older you get. (DE_1_1A time 46’50’’). After we sold the house, we bought this apartment and made it barrier-free and suitable for handicapped. Since it was an unfinished apartment, I could integrate my wife in the planning process, that gave her an occupation. The renovations costed more than 44.000 EUR. We only could do that, because we had enough money. People who do not have it, will stay in a home, 99% of them. (DE_1_1A time 10’04’’). My wife has an aneurysma in her head, that is why she has a distored perception of time. She is not capable of differentiating between today, yesterday and tomorrow. We made ourselves some tools, the calender, she crosses off every day that has passed. (DE_1_1A_M).*
>
> *“Es hat sich minimal verbessert, wenn auch in kleinen Schritten. Bis vor drei Monaten war mein linkes Bein durch das linke Bein ganz dick. Durch eine neue Tabletteneinstimmung durch meinen Mann ist das linke Bein wieder dünn wie das rechte. Selbst meine Therapeutin war erstaunt. (DE_1_2A time 61’33’’). Im eigenen Haus bin ich viel selbstständiger. Ich kann meinen Tag so strukturieren, wie ich möchte. Nach der Pflege am Morgen muss ich mich dann natürlich teilweise selbst beschäftigen, z.B. lerne ich etwas am Computer.” (DE_1_2A time 56’28’’)*
>
> *“It has improved, but in small steps. Until three months ago my left leg was very swollen. After my husband changed the medication it is back to normal. Even my therapist was astonished. (DE_1_2A time 61’33’’). In our own apartment, I am much more autonomous. I can structure the day as I wish. After the care in the morning, I have to entertain myself, e.g. I learn something in the computer.” (DE_1_2A_F)*
>
> *“Vor einem halben Jahr hatte er 1005 Zucker und Nierenversagen. Dazu noch Bluthochdruck und Prostata (DE_2_1A time 2'44"). Am 5. Mai vor zwei Jahren hatte mein Mann einen Schlaganfall. Da lag er ein halbes Jahr in der Klinik. (DE_2_1A time 3'50"). Er kann nicht laufen und nicht mehr spazieren gehen. Er kommt nicht mehr in die Schuhe rein, vom Schlaganfall steht der Zeh so hoch (DE_2_1A time 22'21"). Und das Wasser inne Beine. Hören se mal, der nimmt schon sieben Tabletten morgens und vier abends. Das sind zu viele*

(DE_2_1A time 5’34’’). Der kann sich kein Butterbrot schmieren und die Hose nicht hochziehen. (DE_2_1A time 21’29’’).

“Half a year ago he had 1005 sugar and kidney failure. Plus high blood pressure and prostate (DE_2_1A time 2'44"). On 5may, two years ago, he had his stroke. Then he was in the clinic for half a year. (DE_2_1A time 3'50"). He cannot walk anymore or go outside. He cannot get into his shoes, after the stroke his toes are crippled. (DE_2_1A time 22'21"). And he has water in his legs. He takes seven pills in the morning and four in the evening. Way too many. (DE_2_1A time 5’34’’). He cannot put butter on his bread and cannot pull up his trousers (DE_2_1A_F).

“Die Situation verschlechterte sich ab Anfang 2013 rapide, so dass wir einsehen mussten, dass es so nicht weiterging. Es machte sich erst an kleinen Dingen bermerkbar, die dann aber immer mehr wurden. Z.B. dass meine Mutter zwei Apfelkuchenrezepte verwechselte, Schlüssel ständig verlegte, sie die gleichen Dinge zweimal eingekauft hat, die Waschmaschine nicht mehr bedienen konnte.“ (DE_2_1B time 2’01’’).

“The situation got really bad in the beginning of 2013, so that we had to realise that it wasn’t going to continue like that. First there were small things, which got more and more. For example, my mother mixed up two apple cake recipes. She lost the keys all the times, bought the same things two times, did not know how to start the washing machine.” (DE_2_1B_F).

Appendix 9.4. Part 3 – Coding of data related to support from non-professional individuals (from family members, friends…) that the ICG and the DEP receive

Family help is provided if children, siblings or grandchildren are involved. However, most children are only involved to a limited extent, they serve as an “emergency solution” or substitute if the ICG is not capable of performing the services him or herself. Children are usually not involved in core services such as washing or medical matters.

> *“Wir haben zwei Kinder mit jweils drei Enkelkinder. Meine Tochter wohnt ein wenig entfernt von D., mein Sohn hat hier in der Nähe ein Haus gebaut. Wir telefonieren oft mit unseren Enkelkindern. Im Notfall können meine Kinder auch bei der Pflege helfen.” (DE_1_1A)*
>
> *“We have two kids with three grandchildren each. My daughter lives away from D., but my son built a house close by. We often have our grandchildren on the phone. In case of an emergency, our children can provide care.” (DE_1_1A_M)*
>
> *“Mein Sohn macht viel: Einkaufen, mal mit dem Vater ein bisschen spazieren gehen. Bankgeschäfte. Und auch Transporte ins Krankenhaus oder so, ich hab ja keinen Führerschein.” (DE_2_1A time 4'29")*
>
> *“My son does a lot: going shopping, going for walks with my husband. Banking. And also taking him to the hospital and so, I don’t have a driving license” (DE_2_1A_F)*

In one case, the ICG felt bad about bothering family members who were not that close although they would like to have company from other people once in a while:

> *« Wir haben keine Kinder. Und meine Familie kommt nicht hier aus dem Ort. Alle paar Wochen kommt mal die Nichte meines Mannes, oder als sie noch lebte seine Schwester. Aber je älter man wird, desto weniger Besuch bekommt man. Die haben ja auch alle ihre eigenen Leben…und man kann das nicht erwarten, nicht erzwingen, dass sie jeden Tag kommen. Aber schön wäre es schon, öfter Besuch zu haben. Nicht unbedingt für die körperliche Pflege, aber zur Unterhaltung, um den Tag bunter zu machen, um meinem Mann ein bisschen Ablenkung zu geben. » (DE_5_1A).*

> *"We don't have children. And my own family is not from here. Every other week, my husband's niece comes to our house, or his sister when she was still alive. But the older one gets, the less people visit us. They all have their own lives ... and I cannot expect it, cannot force them to come every day. But it would be nice to have visitors more often. Not just for the care in the medical sense, but for entertainment, to make the day more colorful, to give my husband some distraction." (DE_5_1A_F).*

Having close family members involved improves flexibility in the daily lives of the ICG:

> *"Wir haben drei Kinder. Meine Schwester hat zwei. Unser Familienzusammenhalt ist sehr gut, da wechselt man sich dann auch öfter mal ab und man konnte unkompliziert alles regeln. Meine Schwester und ich haben uns die Aufgaben möglichst gleichmäßig verteilt. Mein Mann hat manchmal auch geholfen, aber eher selten. Meine Kinder haben ihre Oma natürlich auch besucht, aber die meisten Aufgaben habe ich mit meiner Schwester gemeistert. Wenn Not am Mann war und ich verhindert war, konnten wir flexible Ersatzmöglichkeiten finden." (DE_4_1B)*

> *"We have three children. My sister has two. Our family relationship is very good, we took turns and everything could be arranged in an uncomplicated way. My sister and I shared tasks equally. My husband also helped, but to a lesser extent. My children visited their grandmother of course, but most tasks were done by my sister and myself.If things became urgent and I was not able to be there, we could find flexible arrangements and replace each other" (DE_4_1B_F)*

Also neighbours seemed to play a crucial role in the ICGs' daily lives, especially for the surveillance of the two dementia DEPs. Being able to rely on a social network is essential for taking care of the DEP:

> *" Es gab Unterstützung von einem netten Nachbarn, der selbst Krankenpfleger ist. Ich habe alle Nachbarn informiert, dass sie ein bisschen aufpassen. (...). Krank werden darf man als Angehöriger nicht. Viel läuft da über persönliche Netzwerke um im Notfall gewappnet zu sein, sonst funktioniert es nicht. (...) Im Heim habe ich Unterstützung von einer Schule. Es gibt ein Sozialprojekt der Gesamtschule S.. Ein 14jähriger, der sich eine Stunde mit einer Dementen beschäftigt, davor habe ich echt Hochachtung" (DE_3_1B time 25'30'").*

> *"There was support from a friendly neighbour, who is a caregiver, too. I informed all the neighbours, to have an eye open on my mother. (...) You must not fall sick as a caregiver. Much goes through personal networks to be prepared in emergency situations, otherwise it does not work. (...) In the nursing home I receive support from a school. There is a social project. A 14 year old boy entertains dementia patients for an hour, I have my highest respect." (DE_3_1B_F)*

> *"Später war sie (die 'DEP) sehr unruhig und ist im Nachthemd auf den Balkon gelaufen. Das haben die Nachbarn dann gesehen und haben mir Bescheid gesagt, wenn was war." (DE_4_1A)*

> *"Later she (the DEP) was very nervous and walked on the balcony in her nightgown. The neighbours saw it and informed me, when there was something going on." (DE_4_1A_F)*

Professional support for the DEP is considered to be essential, but less formal care, especially social support, seems to be lacking. As one of the ICGs noted, there is no organisation of volunteers which is specialised on dementia patients:

> *Was ich vermisst habe, sind nicht Pflegekräfte sondern wie man früher sagte "Hausdamen", also ehrenamtliche oder auch bezahlte Kräfte, die nur mal kommen, um spazieren zu gehen, einen Kuchen backen oder Karten spielen. Die habe ich damals verzweifelt gesucht und nicht gefunden. Die Pflege besteht nicht nur aus Hygienepflege etc., sondern viel mehr soziale Pflege. Dementen Menschen tut es so gut, wenn man einfach mal eine Geschichte vorliest. Im Krankenhaus gibt es "grüne Damen", aber das Problem ist, dass diese Damen schon sehr alt sind und es keinen Demenz-Schwerpunkt gibt. (DE_2_1B time 56'34''). (...) Es gibt keine Möglichkeit der Fortbildung für ehrenamtliche Kräfte, die sich mit Dementen beschäftigen könnten. (DE_2_1B time 58'27'').*
>
> *"What I missed are not nurses, but as one used to say in old times "house ladies", meaning volunteers or even paid people who only come by to go for a walk, to bake a cake or to play cards. I desperately looked for those (before the institutionalization) and did not find any. Care is not just about hygiene etc., but also social care. It is so good for dementia patients if you just sit by their side and read out a story. In the hospital there are "green ladies" (benevolent organisation), but they are very old themselves and there is no dementia focus. (DE_2_1B time 56'34''). (...) There is no possibility to get training for benevolents who want to be around dementia patiens." (DE_2_1B_F).*

Appendix 9.5. Part 4 – Coding of data related to tasks performed by the ICG

The following table illustrates the tasks being performed by the ICGs.

Table 26 – Tasks performed by informal caregivers

Tasks	ICG 1	ICG 2	ICG 3	ICG 4	ICG 5
Household activities (including food preparation, cleaning, washing, ironing, sewing, shopping and maintenance work…)	Completely: food preparation, cleaning, washing, ironing, shopping, etc.	Completely: food preparation, cleaning, washing, ironing, shopping, etc.	Before institutionalization: Completely: food preparation, cleaning, washing, ironing, shopping, etc.	First only limited (food preparation), later complete: also cleaning, washing, ironing, shopping, etc.	Completely: food preparation, cleaning, washing, ironing, shopping, etc.
Personal care	Going to the toilet, brushing teeth, personal cleaning and washing (on the weekend)	Going to the toilet, body cleansing and assistance while walking, lifting in and out of bed			Going to the toilet, body cleansing and assistance while walking, lifting in and out of bed
Medical care	• to prepare and give the medications (daily) • To prepare the oxygen machine • Food surveillance and blood sugar measurements (diabetes)		• To prepare the medications and to give them	• To prepare the medications and to give them	
Practical support	• Transportation and mobility outside the home		• To put the DEP to bed (with the home nurse)	• Transportation and mobility outside the home	
Surveillance and 'presence'	• Yes: constantly	• Yes: constantly	• Before institutionalization: 2 hours a day during the week, all weekends	• Before institutionalization: daily in the morning, at noon and before sleeping, more than 14 h a week	Yes: constantly

Tasks	ICG 1	ICG 2	ICG 3	ICG 4	ICG 5
Administrative	• In cooperation with DEP: banking accounts, insurances	• In cooperation with DEP: banking accounts, insurances	• Yes: Banking, insurances, etc.	• Yes: Banking, insurances, etc.	• In cooperation with DEP: banking accounts, insurances

Household activities and personal care:

All ICGs performed some kind of household services, mostly involving cooking, laundry, ironing and doing shopping. In the case of former housewives now being ICGs, the ICGs did not consider these household activities a burden since it is nothing new to them. As for the daughters and the male ICG, household activities meant additional work. As for gardening and cleaning, three ICGs received external help.

> *"Ich wasche Wäsche, koche Essen, bügel. Alle Transporte begleite ich, also zum Arzt. Einkäufe mache ich auch. (…) Vorher war es ja das ganze Leben umgekehrt und meine Frau hat alles für mich gemacht, zu 100%. Ich habe in meiner Ehe bis dahin nicht einmal eingekauft. (DE_1_1A_time 7'11'')» (DE_1_1A)*
>
> *"I do the laundry, I make the food, I iron. I accompany her to the doctor, I do the shopping.(…) Before that, it was her who cared for me the whole time, 100%. I never went shopping in my entire marriage before." (DE_1_1A_M)*
>
> *"Meine Mutter hatte ihre alte Putzhilfe. Das wurde dann aber auch schwierig, weil sie überfordert war." (DE_3_1B_F)*
>
> *"My mother had her own cleaning lady. But that became difficult, because she could not handle the situation" (DE_3_1B_F)*

Medical care:

Medical care activities vary. Most ICG only perform tasks where they judge themselves medically competent enough. If not, the mobile nursing service takes over those responsabilities.

> *„In Zusammenarbeit mit dem Hausarzt teile ich Tabletten ein für meine Frau. Wir haben die Tabletten von 18 auf 4 runter bekommen, weil wir viel durch Nahrungsumstellung erreichen, vor allem die Allergien sind weniger geworden. Nach dem Krieg hatten wir keine Geschmacksverstärker und keine künstlichen Zusatzstoffe, da hatten die Leute auch keine Allergien. So probiere ich es auch jetzt mit meiner Frau. (...) Die Diabetik ist im Griff ohne Tabletten. (...)Wenn Wundpflege gefragt ist, mache ich das, wenn ich es medizinisch verantworten kann, also Pflaster und Verbände. Alles weitere ist natürlich von Profis zu machen, meine Frau ist Marcumar-Patientin. (...) Wenn keine Krankenschwester zur Verfügung steht, messe ich die Blutzuckerwerte (...) Ich muss meiner Frau auch bei der Verkabelung und dem Beatmungsgerät helfen." (DE_1_1A)*
>
> *"In cooperation with the GP I arrange my wife's medication. We reduced the pills from 18 to 4, because we changed some of our nutrition to get of the allergies. After the war we had no flavour or artificial additives, and people had no allergies. That's what I try with my wife. (...) The diabetes is under control without pills (...) When there are wounds, I do everything what I think is responsible, band aids and other such easy things. Everything else has to be done by professionals, my wife is a marcumar-patient[ee]. (...) When there are no*

[ee] **Phenprocoumon** (marketed under the brand name **Marcumar**) is a long-acting oral anticoagulant drug, a derivative of coumarin, used for the

> *nurses available, I measure the blood sugar (...) I also have to help my wife with the tubes of the oxygen machine." (DE_1_1A_M)*

Practical support

Practical support involves transport activities:

> *"Wenn meine Frau zum Arzt muss schiebe ich sie zum Auto, dann helfe ich beim Einsteigen und beim Arzt wieder raus. Das ganze bei der Rückfahrt genauso." (DE_1_1A)*

> *"When my wife has to go to the doctor, I push her to the car, I help her to get in and to get out once we are at the doctor. The same on the way back." (DE_1_1A_M)*

Surveillance

Surveillance is mostly done by the ICG. In some cases, the ICG is supported by other family members, neighbours or electronic alarm systems. Nonetheless, it is important to highlight that the latter were not successful in all cases, either because the DEP was not able to use it, or because they were expensive to be kept.

> „Früher hatte ich jemanden, der hier war, wenn ich einkaufen war. Jetzt läuft das alles über ein Notrufsystem. Aber die Supermärkte und Ärzte sind alle in 150 m erreichbar, daher bin ich nicht lange weg." *(DE_1_1A time 32' 25'').*

> *"I used to have somebody who was here when I went shopping. Now everything works through an electronic emergency system. But the supermarkets and doctors are all reachable within 150m, so I am not away for a long time." (DE_1_1A_M).*

> „Solange mein Vater noch lebte war die Sache mit der permanenten Betreuung einfacher. *Aber nachher konnte mein Vater die Überwachung nicht mehr richtig leisten, da er selbst zu alt war. Es ging vor allem um eine Überwachung der Flüssigkeitszufuhr, damit meine Mutter nicht dehydriert:* Später haben wir allen Nachbarn Bescheid gesagt" *(DE_3_1B).*

> "As long as my father was alive the thing with the permanent surveillance was easier. But later he was to old to do it. We had to monitor her drinks so that she would not dehydrate. Later on the neighbours took care of it." *(DE_3_1B_F).*

> „Da meine Mutter nicht im gleichen Haus wie wir wohnte, konnte ich keine komplette Überwachung gewährleisten. Meine Mutter hatte diese Alarmeinrichtung, aber damit konnte sie nicht richtig umgehen." *(DE_4_1A_F).*

> *"Since my mother did not live in our house, I could not guarantee a complete surveilance. My mother had this alarm system, but she could not handle it." (DE_4_1A).*

> *"So ein Notrufsystem hatten wir, aber haben wir wieder abgegeben.Das wollte die Krankenkasse nicht bezahlen, das sollte ich privat bezahlen. Da hab ich gesagt: nehmen sie es wieder mit. 37 Euro müsste ich bezahlen pro Monat (DE_2_1A time 13'34"). Die wollten das nicht bezahlen, weil ich noch bei meinem Mann wohne. Wenn er alleine wohnen würde, dann würde das gehen." DE_2_1A time 13'54'')*

> *"We had this alarm system, but then we gave it back again. The insurance would not pay for it, they wanted me to pay for it. So I said: take it back, that would have been 37 Euro per Month (DE_2_1A_F).They did not want to pay it because I am still with my husband. If he was alone, it would be paid for." DE_2_1A_F)*

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prophylaxis and treatment of thromboembolic disorders. It is the standard coumarin used in Germany and has blood-thinning effects.

Time spent to perform these care tasks

The time devoted to the DEP can sometimes not be counted by the minute since some activities (such as surveillance) are not really perceived as care service. However, the categorizations of the MDK (the health insurance service which categorises and assesses care demands) and respective payments give a hint as to how much time should be devoted by the ICG (e.g. Pflegestufe 2 = mininimum 14 h per week).

> *“Täglich von morgens 5:45 bis abends um 20 Uhr.” (DE_1_1A)*
>
> *“Daily from 5:45 to 20 o’clock in the evening.” (DE_1_1A_M)*
>
> *“ 24 Stunden hänge ich an meinem Mann.“ (DE_2_1A)*
>
> *“24 hours I cling to my husband.“ (DE_2_1A_F)*
>
> *“Ungefähr zwei Stunden pro Tag an Werktagen, solange ich noch voll berufstätig war und ich Unterstützung durch meinen Vater hatte. Später mehr. Die Wochenenden meistens komplett.” (DE_3_1B time 32’20’’)*
>
> *“Approximately two hours each day on workdays, as long as I was working full-time and had support through my father. More later. The weekends completely.” DE_3_1B_F)*
>
> *“Am Anfang war das nur eine Stunde täglich. Später dann mehr, wir hatten auf jeden Fall genug für Pflegestufe 2 (14 Stunden pro Woche) und ich bin morgens, mittags und abends zu meiner Mutter gegangen.“ (DE_4_1A)*
>
> *“In the beginning, one hour daily. Later more, we were eligible for category 2 (14 hours a week) and I went to see my mother in the morning, at noon and in the evening.” (DE_4_1A_F)*
>
> *“Eigentlich fast immer....” (DE_5_1A).*
>
> *“Actually all the time...” (DE_5_1A_F).*

Appendix 9.6. Part 5 – Coding of data related to formal services received at home and outside the home for the DEP.

Nursing home services:

As mentioned in the introduction, recruitment was partly done through a mobile nursing service (Pflegedienst). Supply of services varies according to dependency level and needs. Mobile services were mainly used for basic hygiene and medical services (such as blood measurements) and thus supported the ICG in performing his or her tasks. Criticism was made about punctuality and reliability of these services.

Table 27 – Services reveived at home by the dependent elderly

DEP 1	DEP 2	DEP 3	DEP 4	DEP 5
• Mobile nursing service (ambulanter Pflegedienst) 5 times a week, except weekends • Physiotherapist • Nurse from the family doctor (blood checks)	• Mobile nursing service (ambulanter Pflegedienst) 5 days a week (in the morning and at noon), except weekends • Physiotherapist and ergo-therapist at home	• Mobile nursing service on a daily basis, first only in the morning, then also before going to bed • Essen auf Rädern (Meals on Wheels)	• Mobile nursing service only when ICG was on holidays, rarely	• Nursing home service: only when ICG was sick (rarely) • Nursing home service for changing the catheter

“Ich hatte in den letzten zehn Jahren mehr als drei Pflegedienste. Dieser wurde notwendig, nachdem wir wieder in eine eigene Wohnung gezogen sind. (...) Ich habe die Erfahrung gemacht, dass das Pflegepersonal zu 95% funktioniert. Wir haben in de letzten Jahren über 25 verschiedene Pflegekräfte gehabt. Bei dem jetzigen Dienst in zwei Jahren schon über 15 Pflegekräfte. Hier fängt die Problematik an: Das Problem liegt nicht bei den Menschen, die dort arbeiten. Klar, manchmal stimmt die “Chemie” nicht, aber das ist doch normal im Leben. Der Pflegedienst kommt der Person so nahe, so nahe kommen sich manchmal Eheleute nicht in den ersten Ehejahren. (...)Alle Pflegedienste scheitern an der Verwaltung und einer mangelhaften Personalführung und Unkenntnis in Planung, Zeitmanagement und terminlicher Zuverlässigkeit. (...)Den ersten Pflegedienst haben wir gewechselt, weil uns gesagt wurde, dass der Pflegedienst nicht für das Föhnen der Haare zuständig ist. Da wurde meine Frau einfach mit nassen, gekämmten Haaren in die Ecke hingesetzt. (...)Beim zweiten haben wir gewechselt, weil versucht wurde, uns zu entmündigen: Es wurden uns mehrmals Papiere vorgelegt, die wir unterschreiben sollten. Nicht jeder hat so viel Glück wie meine Frau, dass er oder sie so ausgiebig durch einen Ehepartner gepflegt wird. Ich habe erlebt, dass Menschen im Heim total abhängig sind. Man wird gedrängt, bestimmte Dinge zu akzeptieren, auch was Kosten angeht. Nach vier Wochen wurde mir dann gekündigt. (...)Meine Frau muss bei jeder Person eine persönliche Beziehung aufbauen. Wenn diese Personen dann so oft wechseln, ist das unmöglich. Dann ist meine Frau durcheinander und der ganze Tag ist im Eimer. Wenn sie weiss, dass morgen Johanna kommt, stellt sie sich die ganze Woche auf Johanna an. Diese Struktur und Verlässlichkeit ist unheimlich wichtig für meine Frau. (...)Das Unternehmen wo wir jetzt sind, hat einen sehr guten Ruf. Wir kannten die Eigentümer des Pflegedienstes durch Bekannte. (...)Es wird sich nicht an terminliche Absprachen gehalten. Darüber klagen auch viele Bekannte und Freunde von uns. (...) Ich als Techniker denke immer, dass man diese Probleme lösen kann. Darüber spreche ich auch mit dem Pflegedienst. Wenn wir Maschinen sekundengenau steuern kann, dann muss man doch auch 20 Pflegekräfte koordinieren können. Aber es gibt keine Verwaltungsschule für Pflegekräfte, zumindest ist mir nichts bekannt. (...)Es muss besser zwischen der zu pflegenden Person und den externen Pflegern kommuniziert werden. Es krankt an dieser mittleren Verwaltungsebene bei den Pflegediensten, auch bei unseren Bekannten. (...)Wenn man sich die Interna des Pflegedienstes anschaut, kann einem Angst und Bange werden. (...)Die Ausbildung des Pflegepersonals ist schon weitgehend reglementiert. Beschäftigt werden aber oft nur Angelernte, und keine Ausgebildeten, weil Personal fehlt. Leider gibt es auch nur wenig Deutsche, die den Beruf machen. Bei uns war das zwar kein Problem, aber ich kenne Bekannte, wo es auch sprachliche Schwierigkeiten gab. Die Gepflegten sprechen oft in einer Sprache, in der sie aufgewachsen sind, die ist manchmal für Ausländer nicht verständlich. Ob jemand schwarz oder gelb ist, ist mir total egal, ich behandele alle gleich, aber machmal kann es eben doch Verständigungsschwierigkeiten geben.” (DE_1_1A)

“I had more than three different mobile services. The service was necessary after we moved into our own apartment. (...) I made the experience, that the personnel is functioning in 95% of the cases. We had more than 25 different people. The service we have now, we had 15 people in two years. This is where the problems start: The problem does not lies with the people who work there. Of course, sometimes the “chemistry” is not right, but that is normal. The people get so close to one, so close some married people don’t even get in the first years. (...) All the services fail because of the administration and an insufficient staff management and insufficient planning, time management and punctuality. (...) The first service we changed because they told us that they were not responsible for drying the hair. They put my wife into a corner with wet hair. (...) The second we changed, because they wanted to deprive us of our rights. They wanted us to sign papers where I wasn’t sure what they meant. Not everybody is as lucky as my wife who has somebody who looks after her. I saw people in homes who are so dependent. They force you to accept certain things, also concerning the costs. After four weeks they canceled the contract. (...) My wife has to build up a personal relationship with the personnel. If they change the person so often, that is impossible. Then my wife gets confused and the whole day is ruined. If she knows that tomorrow it will be Johanna coming, then she

is comfortable. This structure and reliability are very important for my wife (...) The company we have now has a very good reputation. We knew the owner through friends. (...) I, as somebody with a technical mind, always think that problems can be solved. I talk about that with the nursing service. If we can steer machines on the exact second, it should be possible to manage 20 nurses. But there is no administrative training for those people, at least I don't know of (...) There should be a better communication between the patients and the caregivers. This administrative level is not working right, our friends have the same problems (...) When you look at internal matters of the care services, you should be afraid. (...) The education of the staff is reglemented. But often they hire untrained people, and no professionals, because there are not enough people who want to work in that profession. Unfortunately only few Germans want to do that work. That is no problem with us, but I know people who had language problems. The patients often talk in a language they grew up with and that is sometimes not understandable for foreigners. If somebody is black or yellow, I don't care, I treat everybody the same, but sometimes there could be language problems." (DE_1_1A_M).

Es ist schon viel, wenn immer eine andere Schwester kommt zu meinem Mann. Ich hab mir jetzt schon angewöhnt, selber den Blutdruck zu messen und die Blutzuckwerte zu messen. Samstag und Sonntag will ich niemanden im Haus haben, da will ich ausschlafen. (...) Der Pflegedienst kommt, um die Zuckerwerte zu messen und auch noch Pflege. Einmal morgens und einmal mittags. (...) Das sind so viele, die hier rein kommen...ach is egal. (...)Die Leute wechseln so oft. Das ist fies. Ich möchte meinen Sven haben, der Mann ist einmalig. Der kommt und fragt 'Wie geht's?' und hilft mir mit Frau Doktor. Und da gibts noch ne andere nette Schwester, aber so viele. (...)Da sind auch viele Ausländer dabei. Da gibt es aber keine Verständigungsschwierigkeiten (...)Meistens mach ich die Arbeit, dann gucken die nochmal schnell vorbei und sind wieder weg (DE_2_1A time 13'39")

"It is too much, everytime 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 (...) They are so many who come in here... oh whatever. (...) The people change so often. I don'T like that. I want to have my Sven, the guy is unique. He comes and asks "How are you?" and helps me with the doctor. And there is another nice nurse, but so many (...). There are many foreigners. But there are no language problems (...) Often I do the work, then the nurses only stop by and check whether everything is ok." (DE_2_1A_F)

Im Frühjahr 2013 war ich 14 Tage im Urlaub. Am 1.5. habe ich einen Pflegedienst angerufen. Da hat mein Vater dann gemerkt, dass es alleine nicht mehr ging. Der Pflegedienst kam erstmal nur vormittags bis September 2013. (...) Irgendwann klappte das Ausziehen und schlafen gehen nicht mehr. Ab diesem Zeitpunkt habe ich den Pflegedienst auch abends bestellt. Das hat damals nicht funktioniert und funktioniert heute immer noch nicht. Die kommen nicht rechtzeitig. Da hatte ich sehr sehr viel Ärger am Wochenende. Wenn mein Mann und ich uns mal einen freien Samstag leisten wollten, waren wir auf Pünktlichkeit angewiesen und wurden oft enttäuscht. Letztendlich habe ich die Sachen dann alleine gemacht und den Pflegedienst wieder weggeschickt, als er mit zwei Stunden Verspätung kam. Am Wochenende gab es oft Aushilfen. Ein Normalkranker kann noch kommunizieren und dem Pflegedienst sagen, was er benötigt. Das ist bei Dementen nicht möglich. Ich habe die Wohnung meiner Eltern mit Zetteln ausgestattet, damit der Pflegedienst wusste wo etwas ist. Im Endeffekt musste ich dann als Angehörige vor Ort sein, was den Pflegedienst überflüssig gemacht hat. (...)Wenn man nur vormittags einen ambulanten Pflegedienst benötigt, dann funktioniert es gut. Der Pflegedienst ist pünktlich und zuverlässig, es kommen immer die gleichen Pflegekräfte. Wenn man sie um 9 Uhr bestellt, sind sie auch um 9 Uhr da. Anders sieht es aus, wenn man abends Hilfe benötigt. Dann ist es katastrophal. Wenn der Pflegedienst abends zu spät gekommen ist, habe ich die Dinge selbst vorher selbst erledigt, damit ich rechtzeitig zu meinen Terminen konnte. Das war unheimlich stressig. (...)Der Pflegedienst hat meine Mutter gewaschen und angezogen und ein bisschen beim Essen, z.B. dem Frühstück. (DE_3_1B time 4'00'').

> *"In spring 2013 I was on holidays for 14 days. On May 1st I called the mobile nursing service. That was the moment when my father realised that we could not provide care on our own. At first, the care service only came before noon until September 2013 (...) But then changing the 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 puncutality 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. On the weekends they often had untrained people. A "normal" patient can communicate with the nurses and tell them what he or she needs. But that is not possible with a dementia patient. I equipped my mother's apartment with little notes telling the service where everything was. In the end I had to be there as a daughter, which made the nurses in some way superfluous. (...) If you only need the service in the morning, it funcions well. Then they are on time and reliable, they are always the same people. When they tell them to come at nine, they come at nine. This is different when you need help later in the day. That is catastrophic. It was in a lot of stress (...) The nurses washed my mother and helped her get dressed, and some food preparation, e.g. with the breakfast (DE_3_1B_F).*

> *„Den Pflegedienst haben wir nur in für Verhinderungspflege in genommen, also zum Beispiel als wir im Urlaub waren. (...)Wir sind persönlich befreundet mit den Inhabern des Pflegedienstes. Hier auf dem Dorf kennt man sich ja auch." (DE_4_1A)*

> *"We used the nursing service when we were on holidays (...) The owner of the local service is a friend of ours. In the village, everybody knows each other." (DE_4_1A_F).*

> *"Ich habe den Pflegedienst nur in Notfällen, z.B. wenn ich selbst krank war, in Anspruch genommen, und für das Wechseln des Katheters, also bei medizinischen Dingen, für die ich mich nicht kompetent genug fühle." (DE_5_1A)*

> *"I only used the nurse service in emergencies, e.g. when I was sick. Or for changing the catheter, when there were medical things and I thought I wasn't competent enough." (DE_5_1A_F)*

Physiotherapist at home

Three ICGs used physiotherapists at home. ICGs were mainly satisfied with the services offered.

> *« Ein Physiotherapeutin macht die Lymphdrainage und Bewegungsübungen. Das war eine große Hilfe, um nach dem Schlaganfall wieder aus dem Bett zu kommen, dann erst in den Rollstuhl und nachher wieder erste Schritte. Die Physiotherapeutin hat geschafft, dass meine Frau wieder halbswegs auf den Beinen ist. Nur die allein. Seit zehn Jahren kommt die "(DE_1_1A)*

> *"A physiotherapist comes to do the lymph drainages and physical exercices. That was a big help to get my wife out of bed after the stroke, first into the wheelchair and later the first steps. Thanks to the physiotherapist, my wife is more or less back on her legs. It was only the therapist, she comes since ten years." (DE_1_1A_M)*

> *"Da macht meine Freu mehr, als wie die machen. Wenn meine Frau sieht, wie die das machen, dann macht die das nach. (…) Die könnten mehr machen" (DE_2_2A)*

> *"My wife makes more than her (the physiotherapist). When my wife sees what she (the physiotherapist) does, she does the same afterwards (…) She (the physiotherapist) could do more." (DE_2_2A_M).*

Domestic help

Three ICGs receive(d) help from cleaning ladies. Only one ICG admitted she was paid “black”.

> *“Wir haben eine Haushaltshilfe zum Putzen, aber die kommt nicht regelmäßig.” (DE_1_1A)*
>
> *“We have a a help in the household to do the cleaning, but she does not come on a regular basis.” (DE_1_1A_M)*
>
> *“Meine Mutter hatte ihre alte Putzhilfe. Das wurde dann aber auch schwierig, weil sie überfordert war.” (ICG 3)*
>
> *“My mother had her own cleaning lady. But things became difficult, because she could not handle the situation” (DE_3_1B_F)*
>
> *“Wir haben eine Putzfrau, aber schwarz...” (ICG 5).*
>
> *“We have a cleaning woman, but she is (paid) black. (undeclared worker)” (DE_5_1A_F)*

Family help

See appendix 1.4 (Part 3) above.

ICT Support

Three ICGs use or have used ICT alarm systems, however financing seems a crucial issue.

> *„Früher hatte ich jemanden, der hier war, wenn ich einkaufen war. Jetzt läuft das alles über ein Notrufsystem. Aber die Supermärkte und Ärzte sind alle in 150 m erreichbar, daher bin ich nicht lange weg.” (DE_1_1A)*
>
> *“I used to have somebody to stay here while I was doing shopping. Now everything works through an emergency call system. But supermarkets and doctors are all reachable within a 150 m radius, so I am not gone for a long time.” (DE_1_1A_M)*
>
> *„So ein Notrufsystem hatten wir, aber haben wir wieder abgegeben.Das wollte die Krankenkasse nicht bezahlen, das sollte ich privat bezahlen. Da hab ich gesagt: nehmen sie es wieder mit. 37 Euro müsste ich bezahlen pro Monat“ (DE_ 2_1A_F)*
>
> *“We had a system like that, but we had to give it away again. The insurance would not pay for it, they wanted me to pay it myself. So I told them to take it away again. I would have to pay 37 Euro a month.” (DE_2_1A_F).*
>
> *„Meine Mutter hatte diese Alarmeinrichtung, aber damit konnte sie nicht richtig umgehen. Das bringt dann ja auch nicht wirklich was.“ (ICG 4)*
>
> *“My mother had this alarm thing, but she could not handle it. It didn’t really help much.” (DE_4_1B_F).*

Undeclared worker

Only one ICG mentioned an undeclared worker, however undeclared cleaning personnel in Germany is a common thing.

> *“Wir haben eine Putzfrau, aber schwarz...” (ICG 5).*
>
> *“We have a cleaning woman, but she is (paid) black. (undeclared worker)” (DE_5_1A_F)*

Others

Missing services

One ICG clearly mentioned that the provision with services for technical care such as hygiene and clothing is one side, the other side being social care in the sense of distraction, talking and entertainment. Apparently these services are missing.

> *Was ich vermisst habe, sind nicht Pflegekräfte sondern wie man früher sagte “Hausdamen”, also ehrenamtliche oder auch bezahlte Kräfte, die nur mal kommen, um spazieren zu gehen, einen Kuchen backen oder Karten spielen. Die habe ich damals verzweifelt gesucht und nicht gefunden. Die Pflege besteht nicht nur aus Hygienepflege etc., sondern viel mehr soziale Pflege. Dementen Menschen tut es so gut, wenn man einfach mal eine Geschichte vorliest. Im Krankenhaus gibt es “grüne Damen”, aber das Problem ist, dass diese Damen schon*

sehr alt sind und es keinen Demenz-Schwerpunkt gibt. (...)Es gibt keine Möglichkeit der Fortbildung für ehrenamtliche Kräfte, die sich mit Dementen beschäftigen könnten. (DE_3_1B time 58'27'').

"What I missed are not nurses, but as one used to say in old times "house ladies", meaning volunteers or even paid people who only come by to go for a walk, to bake a cake or to play cards. I desperately looked for those (before the institutionalization) and did not find any. Care is not just about hygiene etc., but also social care. It is so good for dementia patients if you just sit by their side and read out a story. In the hospital there are "green ladies" (benevolent organisation), but they are very old themselves and there is no dementia focus. (DE_2_1B time 56'34''). (...) There is no possibility to get training for benevolents who want to be around dementia patiens." (DE_2_1B_F).

"Generell sollte die Politik sich überlegen, dass die Altersstruktur der Gesellschaft sich ändert. Paare bekommen immer später Kinder. Dadurch werden die pflegenden Kinder jünger und haben manchmal selber noch Kinder. Also hat man dann evtl. Belastungen am unteren und oberen Ende der Alterleiter. Dann ist die Pflege überhaupt nicht mehr zu regeln. Man kann nicht gleichzeitig die eigenen Kinder versorgen und die eigenen Eltern versorgen. Das ist ein ganz gewaltiges Problem, was noch niemand richtig begriffen hat. Ich habe keine Kinder, aber in anderen Fällen kann das problematisch sein." (DE_3_1B time 65'48'').

"Generally speaking, the policitians should think about the changing demographic structure of society. Couples have their children later. So the caring children become younger and sometimes have little children at the time. That could lead to burdens on the lower and the upper end of the age scale. Like that care is not manageable. You cannot have small children and take care of your own parents at the same time. That is a big problem which nobody really has understood. I don't have children, but in other cases that could be problematic." (DE_3_1B_F).

Interruption of services, continuity of care

Interruption of services seems manageable for all ICGs, however they are afraid of that situation and rely on personal networks in emergency situations. .

„Krank werden darf man als Angehöriger nicht. Viel läuft da über persönliche Netzwerke um im Notfall gewappnet zu sein, sonst funktioniert es nicht" (DE_3_1B time 25'30''')

You must not fall sick as a caregiver. Much goes through personal networks to be prepared in emergency situations, otherwise it does not work." (DE_3_1B_F)

"Meine Frau darf nicht krank werden. Im Notfall haben sich dann die Schwiegertöchter abgewechselt" (DE_2_2A)

„My wife must not be sick. In emergencies my daughters-in-law took turns." (DE_2_2A_M)

"Wenn ich nicht mehr kann, dann bringt auch der Pflegedienst nichts. Dann müssen wir beide ins Heim, weil wir keine Kinder haben." (DE_5_1A)

"When I cannot do the work anymore, no mobile nursing service would help much. Then we both would have to go to the stationary home since we have no kids". (DE_5_1A_F)

Respite services

Respite services are known to most ICG and used by some ICGs in emergency cases but also to provide the ICG with some relief or give distraction to the DEP.

"“Wir hatten Tagespflege, als ich letztes Jahr ins Krankenhaus musste. Damit waren wir sehr zufrieden.(...) Die Tagespflege wird zum Teil von der Pflegeversicherung bezahlt. Das kann man auch machen, wenn der Pflegende in Urlaub geht, man hat pro Jahr Anspruch auf drei Wochen Urlaub, das haben wir aber noch nie gemacht. Aber den Rest muss man immer bezahlen, aber das wäre für uns jetzt kein großes Problem.” (DE_1_1A).

“We used respite care, when I had to go to the hospital last year. We were very content with it (…) The respite care is partly covered by the long-term care insurance. You can also use that when the caregiver wants to go on holidays, I think you can go on holidays for three weeks or so, but we never used that. The rest has to be payed, but that is manageable for us” (DE_1_1A_M).

“Ich hab Frau Doktor schon gesagt, dass mein Mann in eine Tagesklinik kommt. Dass die den mal holen und er mal was anderes sieht als ich. Dann kann ich auch mal was unternehmen und abschalten. Dann krieg ich so n Schein, dass das dann geht.”" (DE_2_1A time 16'09")

“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. The doctor told me that I will get a prescription or something similar, and then it should work out.” (DE_2_1A_F)

Appendix 9.7. Part 6 – Coding of data related to formal services used to relieve support the ICG

Flexible working arrangements

Only one ICG is currently professionally active (ICG 3). During the time she was taking care of the DEP, she felt the need to quit her job as an employee in order to become self-employed. This allowed her to enjoying greater flexibility in her daily life. She has a critical opinion about existing public support measures on flexible work arrangements:

“Bis Anfang 2013 war ich mit einer 40-Stunden-Woche bei einer Steuerberatungsfirma angestellt. Der hatte selbst eine Demenzerfahrung mit seiner Mutter und hatte daher Verständnis.Wir hatten eine informelle Vereinbarung, um mir eine größtmögliche Flexibilität zu ermöglichen. So konnte ich z.B. Akten mit nach Hause nehmen, manchmal eher gehen oder später kommen oder auch mal am Wochenende in die Firma, wenn mein Mann zuhause auf meine Mutter aufgepasst hat. Wenig später wurde die Firma verkauft an zwei junge Steuerberater. Die hatten überhaupt kein Verständnis und ich hatte sehr viel Ärger. Es kamen dauernd blöde Bemerkungen, warum man nicht um 8 Uhr am Schreibtisch sei, etc. Daher habe ich gekündigt. Flexibilität ist der Dreh-und Angelpunkt bei der Pflege einer Demenzkranken. Das funktionierte im Beruf nicht mehr. Seit meiner Kündigung bin ich selbstständig nach 25 Jahren Angestelltenverhältnis. Ich habe einen Buchhalterservice und eine Beratungsstelle für den Lohnsteuerhilfeverein. Da ich selbst gekündigt habe, bekam ich auch kein Arbeitslosengeld und musste mich sofort selbstständig machen. Es gab die gesetzlich garantierte Pflegezeit, aber: Dies gilt erst ab Unternehmen mit 15 Beschäftigten, andere freiwillig. Und bei meiner kleinen Kanzlei ging das nicht, wir waren nur 4 Leute im Büro. Ich kenne auch keine Fälle im Bekanntenkreis, wo Pflegezeit in Anspruch genommen wird. Es ist kaum bekannt und ist schwer in den Firmen organisatorisch zu regeln. Die Familienpflegezeit funktioniert auch nicht. Was der Gesetzgeber sich ausgedacht hat, ist Quatsch. Man kann nicht nur zwei Jahre flexible Arbeitszeiten machen. Eine Demenz ist im durchschnitt 10-12 Jahre lang, da kann man nicht zwei Jahre nur auf 15 Stunden reduzieren. Es

> *gibt gute und es gibt schlechte Tage bei Demenzkranken. Außerdem ist das alles freiwillig, der Arbeitgeber muss zustimmen. Es wäre für den Arbeitnehmer gut, wenn er den Anspruch auf diese Regelung auch durchsetzen könnte. Die staatlichen Maßnahmen, die Pflege und Beruf ermöglichen wollen, funktionieren meiner Meinung nach nicht richtig. Es wird solange nicht funktionieren, solange Frau Merkel nicht mal in die gleiche Situation kommt. (…) Meine Schulfreundin ist beruflich beim Verband der Chemie beschäftigt. Die großen Chemie-Firmen wie Bayer oder BASF haben da interne Regelungen, die wunderbar funktionieren. Da kann man auch länger als zwei Jahre raus. (DE_3_1B time 45'15'').*
>
> *"Until the beginning of 2013 I was working on a 40h basis with a tax advisory company. My boss had experiences with his dement mother and was very understanding for my situation. We had an informal deal for me to have as much flexibility as possible. I could take work from the office home, sometimes I could leave earlier or come later or I was working on the weekend in the office when my husband could look after my mother. Some time later the company got sold to two young guys. They had no understanding at all and I had a lot of trouble. There were always mean comments why I wasn't at my desk at 8 o' clock. So I quit my job. Flexibility is everything when caring for a dement patient. That did not work in my job. I quit my job after 25 years as an employee, now I am self-employed with a bookkeeping service and a consulting service for taxes. Because I quit unilaterally, I was not entitled for unemployment benefits and had to find a new job right away. 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 anyone of my friends who used this support scheme. It is little known to caregivers and is difficult to organise in the companies. 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, reducing work to 15 hours for only 2 years does not help. With dement 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. Public support measures don't work until Mrs. Merkel will experience the same situation. (…) My school friend works for an association of the chemical industry. The big companies like BASF and Bayer have come up with internal arrangements, that works very well. There you can use flexible working arrangements for more than 2 years" (DE_3_1B_F).*

There another caregiver still working. First she took an unpaid leave (Pflegezeit) for six months, started working again but later quitted her job because she had a bad conscience for not being there for her mother:

> *„"Ich hatte immer Frühdienst. Da war ich dann auf der Arbeit und habe gedacht: Jetzt hat deine Mutter kein Frühstück, eigentlich müsstest du zuhause sein" (DE_4_1A).*
>
> *"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_F)*
>
> *„Als ich meinen Schwiegervater gepflegt habe und nachher auch bei meiner Mutter hat die Pflegeversicherung meine Rentenbeiträge bezahlt. Das ist natürlich toll." (DE_4_1A)*
>
> *„When I cared for my father-in-law and afterwards when I cared for my mother, the government paid my pension contriutions. That of course was a good thing." (DE_4_1A_F)*

Appendix 9.8. Part 7 – Coding of data related to the financial support of the ICG

Regarding our main research question, the effects and the experience of the policy measures to assist the ICG as available in Germany, all receive some kind of financial support indirectly through direct payments to the DEP or indirectly through in-kind services. The degree of information about these support measures varies. Most ICGs have been informed by formal institutions (such as the family doctor or insurance representatives), or through more informal sources (such as support groups or "word-of-mouth prapaganda") or by own initiative through internet search. Some stated that there are enough sources, but that one has to actively consult them.

'Policy measures" and their effects / experiences as mentioned by the ICG during the interviews

Situation one

> *"Wir kannten die jetzige Pflegefirma durch persönliche Kontakte. Die hatte einen guten Ruf, daher haben wir uns letztendlich dafür entschieden. (…) Es gibt zwar Stellen von der Stadt Düsseldorf, wo man sich erkundigen kann. Aber das haben wir.nicht gemacht. Vieles läuft über Mund-zu-Mund Propaganda (…) Man kann die Krankenkasse fragen, wenn man Fragen im gesundheitlichen Bereich oder beim Pflegedienst hat (…) Hier in Düsseldorft gibt es auch noch Stadtteil-Büros, die pflegende Menschen unterstützen (…) Wer will, der bekommt die Hilfe. Aber wenn ein zu Pflegender ganz alleine ist, bringt das nicht viel. Die Ansprache muss immer aktiv erfolgen, es kommt niemand auf einen zu. Niemand. Eine solche Ansprache wäre gut bei Leuten, die alleine und hilflos sind (…) Es gibt bestimmt auch Berührungsängste, wenn man das Wort "Sozialamt" hört. (…) Informationen über den Pflegedienst hatten wir auch von dem Heim, in dem wir kurzzeitig gelebt haben. (DE_1_1A)*

> *"The mobile nursing service we have now, we knew through personal contacts. They had a good reputation, that's why we took them eventually. (…) There are information places from the municipality where you can get help, but we never did. A lot is done through mouth-to-mouth propaganda. (…) You can ask the health insurance if you have questions regarding health questions or the mobile nursing service. (…) Hier in D. there are also information services offered in the different quarters of town, to support caregivers. (…) Those who want to have help, will receive them. But if somebody is all on his own, that doesn't help much. You have to actively seek help, there is nobody who approaches you. Nobody. Such an approach would help people who are alone and helpless. (...) There might also be fear of contact, when people hear the word „welfare". (...) Information about the mobile service we also had from the stationary home where we lived for a short time." (DE_1_1A_M)*

Situation two

> *« Die Schwester von der Frau Doktor hat mir auch mal geholfen ein Schriftstück aufzusetzen, was ich nicht konnte. Das war sehr nett, auch in der Zusammenarbeit mit der Krankenkasse, als dann der Medizinische Dienst kam. Für die behindertengerechten Sachen hab ich alles von der Krankenkasse bekommen, den hohen Toilettensitz, Rollstuhl und sowas (...)Da musste ich aber auch laufen, dass ich das krich. Das war kompliziert (...)Mein Mann bekommt Pflegestufe 1, da krieg ich 235 Euro. Die Leute vom Pflegedienst regeln das alles für mich. Die Frau Schuppke wollte das irgendwie mit der Krankenkasse regeln. Aber da kann ich ihnen jetzt gar keine Auskunft geben. (…) Mehr Geld auf die Hand würde mir natürlich schon helfen. So ne hohe Rente haben wir ja auch nicht. Kleidung, Miete und so ist ja nicht wenig. Diesen besseren Rollator hab ich auch selbst bezahlt, weil die Krankenkasse das nicht übernommen hat. (…) Mir wäre lieb, wenn mein Mann auf Stufe 2 kommt. Aber das ist zwei mal schon abgelehnt worden. (…) Ich sollte das Geld kriegen. Ich pflege ja meinen Mann, keine andere. " (DE_2_1A_F).*

> *"The nurse from our GP's cabinet has helped me with some paperwork, which I found too difficult to do on my own. That was very nice, also in the communication with the health insurance and the MDK (Medizinischer Dienst der Krankenkassen, assesses care needs). The things I needed such as the high toilet seat and the wheelchair I got paid for by the insurance (…) But that was complicated. (…) My husband gets care level 1, so I get 235 Euro. The people from the mobile nursing service managed that for me. (…)*

More cash money would of course help me. Our pension is not that high. Clothes, rent, everything is not cheap. The better rollator I had to pay myself because the health insurance would not pay for it (…) I would like my husband to be in care level 2. But that was rejected two times (…) I should get the money. I care for my husband, and nobody else.” (DE_2_1A_F).)

Situation three

«Dadurch, dass wir lange Vorlaufzeit hatten, hatte ich mich vorab über das Internet informiert. Als die Situation akut wurde, hatte ich alle Unterlagen in der Schublade (…) Ich bin im Vorteil, da ich den Bürokratismus von meinem Job her gewöhnt bin. Im Freundeskreis sind viele vom deutschen Bürokratismus überfordert (...). Eine große Hilfe war die Demenz-Selbsthilfegruppe hier in M. Die konnte ich ganz unkompliziert auch nach 20 Uhr noch anrufen, wenn ich Zeit hatte. Das ist bei deutschen Behörden leider nicht möglich. Die Informationsveranstaltungen “Pflege für Angehörige” fanden in der Woche zwischen 8 und 17 Uhr statt. Das hat sich aber geändert, so dass man auch am Wochenende hingehen kann. Man muss bei den Krankenkassen und dem MDK immer auf Contra eingestellt sein. Es wird fast schon vorausgesetzt, dass bei einer Ablehnung und einem Widerspruch, es dann auch klappt. (…) Wenn ich jetzt selbst 200 Euro pro Monat mehr bekommen hätte, quasi als Gehalt, hätte das für mich keinen Unterschied gemacht. (…) Es wäre besser, wenn das Geld direkt an die pflegende Person ausbezahlt würde. In meinem Fall war es zwar unkritisch, weil ich eine Generalvollmacht hatte und über das Geld meiner Mutter verfügen konnte, aber in anderen Fällen ist das bestimmt komplizierter (…) Das meiste läuft über Google. Die Unterstützung durch meine Krankenkasse war katastrophal. Die Sachbearbeiter wissen teilweise selbst nicht, was Sache ist. Es gibt in Deutschland ein Pflegezeitgesetz. Das habe ich aufgrund einer beruflichen Fortbildung erfahren. Es stehen einem 10 Tage zur Verfügung, um den Bürokratismus zu erledigen. Es hat drei Tage gedauert, um mir eine Information darüber uzu geben, die wussten nicht, dass es sowas gibt (…) Die Hausärzte haben keine Zeit, um Informationen zu geben, obwohl meine Eltern Privatpatienten sind bzw. Waren (…) Es gibt auch Kurse von den Krankenkasse, die Schulungen anbieten, aber das habe ich nie gemacht. Die waren meistens nur in der Woche angeboten. (…) Von der Stadt M. gibt es überhaupt keine Unterstützung. Ich bezweifle, dass es da Unterstützungsangebote gibt. (ICG 3).

“Because I had some time before things got bad, I looked for information on the Internet. When the situation became acute, I had all the necessary documents in my desk (…) I am advantaged because I am used to bureaucracy through my job. But there are people among my friends who cannot manage German bureaucracy. (…) A big help was the support group for dementia here in M. I could contact them in an uncomplicated way, also after 8 p.m., when I had time. That is not possible with German public instutions. The information and trainings “care for family members” took place on weekdays between 8 a.m. and 5 p.m. That changed, so now you can go also on the weekends. As for the health insurance and the MDK (medizinischer Dienst der Krankenkassen, assesses care needs) you have to be prepared to give “contra”. They almost take it for granted that you go in revision anyway if a request gets rejected. (…) If I would get 200 Euros more per month, as a remuneration, that would not make a difference (…) It would be better if the money goes directly to the informal caregiver and not indirectly through the dependent person. IN my case it was not a problem because I had general legal authority for my mother, but in other cases that might be more complicated (…)Many information I got through google. The support through our health insurance was a catastrophe. In Germany there is the “Pflegezeitgesetz” (care time law). I got aware of it in the course of a training I had for my job. You have right to leave work for 10 days to take care of the bureaucracy. It took three days until I got information from my health insurance. The woman didn't know that it existed. (…) The GPs don’t have enough time, to provide information, even though my parents are privately insured (which usually means better care). (…) There are also training classes offered by the health insurance, but I never went there. They were offered mostly during the week. (…) From our city there was no support at all. I doubt that there are municipal services.” (DE_3_1B_F)

Situation four

> *“Ich habe am Anfang Informationsangebote der Caritas genutzt. Da gab es auch einen Gesprächskreis für pflegende Angehörige. Aber das meiste wusste ich schon, was da erzählt wurde, auch durch meine Tätigkeit im Pflegeheim. (…) Wir sind persönlich befreundet mit den Inhabern des Pflegedienstes. Hier auf dem Dorf kennt man sich ja auch.” (DE_4_1B)*

> *„In the beginning I also used information services offered by the 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 because I was working in the nursing home. (…) We have personal ties with the people who own the mobile nursing service.“ (DE_4_1B_F)*

Situation five

> *“Dass es Unterstützung gibt, ist klar. Vielleicht nicht jede Kleinigkeit, aber bei uns war das eine Mischung aus Hausarzt, Gespräche mit Bekannten, Krankenkasse und soweiter. (...)“Wenn der Pflegedienst permanent kommen würde, dann hätte ich 440 Euro weniger. Das wäre schon viel weniger. Ich weiß auch nicht, ob ich das Haus halten könnte, wenn das Geld weg ist, oder wenn mein Mann mal stirbt.”*

> *“That there was support, that was clear. Maybe not every small detail, but our information sources were a mixture of GP, talks with people we knew, insurance and others. (...) 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_F)*

Pension contribution

Only one ICG received pension contributions during an unpaid leave (ICG 4).

She appreciated that the fact of her pension contributions have been paid, but eventually gave up her job after the maximum time of unpaid leave had been reached (6 months).

> *„Als ich meinen Schwiegervater gepflegt habe und nachher auch bei meiner Mutter hat die Pflegeversicherung meine Rentenbeiträge bezahlt. Das ist natürlich toll.“ (DE_4_1A)*

> *„When I cared for my father-in-law and afterwards when I cared for my mother, the government paid my pension contributions. That of course was a good thing.“ (DE_4_1A_F)*

Financial advantages for the DEP/ Coverage of costs

The financial situation of the dyads varies. Only one ICG (3) works herself today. The others are more or less depending on their husbands income or (if retired) on retirement pension. Their financial situation ranges from wealthy to relatively poor. The amount of their income seems to influence their perception of support measures. 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. Another factor is the existence of additional pension schemes, such as for the retired public employees (Beamte), who receive a very good pension scheme for caring expenses (Beihilfe).

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 payed. This is because in the ICGs views he or she “deserves” to be paid or because it would make things easier as far as administration and financial issues are concerned.

The financial burden through the care and the coverage of expenses is depending on the level of care: frequency of the nursing service, price of institution (there seems to be a big difference between countryside and big towns) and whether children are made liable for contributions. Whereas a full-time working daughter has to pay high amounts to co-finance the institution (25000 EUR a year), a non-working daughter is not and co-financing is provided by public sources (since her husband supports the family financially and is not liable as a son-in-law). Therefore, the extent to which expenses are eligible to be covered depend on the particular situation of each ICG (e.g. their working status).

> *Der Pflegedienst wird teilweise durch das Pflegegeld gedeckt. Das was ich mache, bekomme ich nicht bezahlt. Aber das ist logisch, dafür habe ich irgendwann mal "Ja" gesagt, als ich meine Frau geheiratet habe. (…) Meine Frau wurde in Pflegestufe 1 eingestuft. Wir haben einen externen Pflegedienst, daher ist der Obolus vom Staat etwas größer, aber wir müssen noch zuzahlen zum Pflegedienst, das machen wir aus unserer Rente.(...) Die Tagespflege wird zum Teil von der Pflegeversicherung bezahlt. Das kann man auch machen, wenn der Pflegende in Urlaub geht, man hat pro Jahr Anspruch auf drei Wochen Urlaub, das haben wir aber noch nie gemacht. Aber den Rest muss man immer bezahlen, aber das wäre für uns jetzt kein großes Problem. (DE_1_1A time 41'05'').*
>
> *„The mobile care service was covered through the long-time care insurance (Pflegegeld). What I do, I do not get paid. But that is logical, that's why I said „Yes" when I married my wife (…) My wife was put in care level 1. We have an external care service, so we get money, but we have to pay some additional money from out regular pension. (…) The day care is partly covered by the long-term care insurance. You can do that when the caregiver wants to go on holidays, I think you have right to have 3 weeks, but we never did that. The rest you have to pay, but that is not a big problem for us." (DE_1_1A_M)*
>
> *Da mein Vater Beamter war, bekommen wir sehr gute Unterstützung von der Beihilfe. (…) Wir müssen für den Heimplatz meiner Mutter jährlich ca. 25.000 Euro dazuschießen (…) Aber das kann man steuerlich absetzen. Aber das ist auch ein großer Unterschied zwischen Stadt und Land. Wenn man kein Geld hat, darf man nicht in einer großen Stadt oder einem Ballungsraum alt werden. (…)* Die Pflegestufe 0 für Demenzkranke seit 2013 ist ein Witz *(...). Lassen sie sich beim Notar eine Generalvollmacht geben, das ist das am besten investierte Geld (DE_3_1B time 51'34'')*
>
> *„Because my father was a public employee, we now get a good extra support from the „Beihilfe" (pension) for my mother (…) But still we have to pay 25.000 EUR per year for my mother's nursing home place. (…) But you can deduct it from taxes. There is a big difference between cities and the countryside. If you don't have money you should not get old in a big city. (…) The additional care level 0 (introduced for dementia patients in 2013) is a joke (…). It's best to have a general legal authority, you have to do some legal work, but it is money well-invested. (DE_3_1B_F)*
>
> *„Das ging immer. Meine Mutter hatte eine kleine Rente, die geht jetzt natürlich fürs Heim drauf. Aber sie war niemals eine finanzielle Belastung.(...) Die Verhinderungspflege wurde komplett von der Pflegeversicherung übernommen. Es haben sich keine finanziellen Probleme ergeben. Da mein Mann voll arbeitet, reicht das Geld. Den Heimplatz jetzt bezahlt die Pflegeversicherung zum Teil, den anderen Teil übernimmt das Sozialamt, da die Rente meiner Mutter nicht ausreicht."*
>
> *"It always was manageable. My mother has a small pension, that 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)*

About the concept of a remuneration as caregiver

All caregivers interviewed in Germany do not consider themselves as “working” for the DEP (in the sense of delivering a paid service). Their motives are love, responsibility or “giving something back” (in the case of a parent-daughter relation).

As far as the reception of direct payments vs. in-kind payments are concerned, people with less financial capacity seem to favour more direct payments whereas wealthy ICGs are rather concerned with the improvement of in-kind services. Whether or not direct payments would make them keep the DEPs longer at home is speculation. The ICGs who already had their DEPs institutionalized claim that more cash would not have changed the moment of institutionalization but that the fact of not being capable of providing continuous surveillance to the DEP was crucial: the DEP had become a danger to him/herself and safety of the DEP was no longer assured without institutionalization.

> *“Eine längere Pflege zuhause kann mein meiner Ansicht nach nur erreichen, wenn man die Pflegedienste optimiert. Man kann es bestimmt nicht erreichen, wenn man der pflegenden Person mehr Geld auf die Hand gibt. Das wäre für mich zum Fenster rausgeworfen. (DE_1_1A time 41’29’’).*
>
> *“Delaying the moment of institutionalision 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_M).*
>
> *“Ich sollte das Geld kriegen. Ich pflege ja meinen Mann, keine andere.” (DE_2_1A time 21'30")*
>
> *“I should get the money. I care for my husband and nobody else.” (DE_2_1A_F)*
>
> *“Wenn ich jetzt selbst 200 Euro pro Monat mehr bekommen hätte, quasi als Gehalt, hätte das für mich keinen Unterschied gemacht.” (DE_3_1B time 34’35’’)*
>
> *If I would get, let’s say, 200 Euros more in cash, as a remuneration, it would not make a difference for me”. (DE_3__F)*
>
> *“Ich konnte einfach die körperliche Sicherheit meiner Mutter nicht mehr gewährleisten, sie ist zu oft gefallen. (…) Man wusste ja nie, ob sie die Herdplatten anstellt und vergisst. Das wäre ja auch eine Gefahr für andere gewesen. (…) Den Platz im Pflegeheim haben wir dann schnell bekommen” (DE_4_1B)*
>
> *“I simply could not guarantee my mother's safety any longer, she fell too often (…) I never knew if she turns on the cooking plates and forgets them. That would have been a danger fot other people as well (…) The place in the home we got it very quickly.“ (DE_4_1B_F)*

Adaptions to the home

In one case (dyad 1) there have been major architectual adaptations made to the home to made it suitable for handicapped. The ICG received money for these renovations, but they did not cover the costs:

> *“Für den behindertengerechten Umbau der Wohnung gibt es eine Informationsstelle bei der Stadt Düsseldorf, die schicken dann Architekten zur Begutachtung, die kostenlos sind (...). Nachdem wir unser Haus verkauft hatten, haben wir diese Wohnung gekauft und sie behindertengerecht umgebaut. Es gab 2400 EUR von der Krankenkasse für Umbaumaßnahmen in der Wohnung. Da die Wohnung ein Rohbau war, konnte ich meine Frau in die Planung der Wohnung einbeziehen, das hat ihr wieder eine Aufgabe gegeben. Die Umbaumaßnahmen haben über 44.000 EUR gekostet. Das konnten wir nur machen, weil wir begütert sind. Menschen, die das nicht sind, bleiben zu 99% in einem Heim.” (DE_1_1A time 10’04’’).*
>
> *“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_M)*

Key points of this case analysis

- **In Germany all the ICGs were aware of existing support measures and used them more or less extensively. Sources of information vary: most had been informed through their GP, the health insurance, care homes, mouth-to-mouth propaganda or local support groups. None of the ICGs complained about bad accessibility to information. No significant relationship between socio-economic status or education and accessibility could be seen in the interviews. According to the ICGs, there are enough sources of information, although the ICGs had to pro-actively consult them.**
- **The support measure most widely used was the mobile nursing service, which was either used on a daily basis or only temporarily in emergencies, to receive some relief when the ICG was on holidays or when family networks were not sufficient to provide continuous care. Indirect payments to the ICG through the money received by the DEP was widely recognised as a help. However, the respondents with a low income appreciated it more than those being wealthy. The latter group focused more on an improvement of existing in-kind services.**
- **Generally, the ICGs recognise services received at home as supportive, however most had to criticise the assessment needs by externals (the MDK) and the way the services operate (punctuality issues, inflexibilitly).**
- **Support schemes for flexible work arrangements seemed to have little effect on the continuity of care or the moment of institutionalisation. The only ICG working full-time gave up her job because legal possibilities to combine work and care have been judged inflexible and unrealistic by the ICG. The other ICG working gave up her part-time job.**
- **Most ICGs stated that the services received would help to keep the DEP longer at home. As for dementia, services seem to have a smaller impact since the services rendered could not guarantee continuous surveillance of the DEP and thus institutionalisation was inevitable.**

APPENDIX 10. LUXEMBOURG

Appendix 10.1. Introduction

For Luxembourg, five dyads were interviewed. Within these five, four female ICGs were interviewed and one male ICG. ICGs all had family ties with the DEPs.

The five dyads were rather different in socio-economical status even though they were much alike on an educational level. All ICGs were retired. One ICG was the daughter of the DEP, three ICGs were the wife and one ICG was the husband of the DEP. One DEP was institutionalised. Three DEPs were living with the ICGs and one DEP lives by her own but only 5 km from ICG. One DEP had slight dementia, and two other DEPs had cognitive impairments. Two DEPs were interviewed, but the first one was very weak and emotionally instable, the second one was not able to answer questions in an adequate manner.

Table 28 – Demographics informal caregiver Luxemburg

Luxemburg	ICG 1	ICG 2	ICG 3	ICG 4	ICG 5
ICG demographics					
Gender	F	F	F	M	F
Age	73	86	75	71	65
Education level	primary +3	primary	primary	primary	primary +2
Marital status	married	married	married	Married	married
Number of children	1	2	3	1	1
Number of grandchildren	0	5	6	2	0
Relationship with DEP	Spouse	Spouse	Spouse	Husband	Daughter
Living with DEP	No	Yes	Yes	Yes	No
If the ICG co-resides with the DEP, are other persons living together with them	-	-	-	-	-
If the ICG does not live with the DEP, are other persons living together with the ICG					1
Current or past job occupation	Teacher in kindergarten	employee	Employee (worked only 6 years)	Civil servant	employee
If employed % working	-	-	-	-	-
Type of work	Retired	Retired	Economically inactive	Retired	Retired

Table 29 – Demographics dependent elderly Luxemburg

Luxemburg	DEP 1	DEP 2	DEP 3	DEP 4	DEP 5
DEP demographic					
Gender	M	M	M	F	F
Age	82	89	81	75	90
Education level	primary	primary	primary	Primary	primary
Marital status	married	married	married	Married	widowed
Number of children	1	0	3	1	2
Number of grandchildren	0	0	6	2	3
Relationship with ICG	Husband	Husband	Husband	Spouse	mother
Living location	Institution	ICG	ICG	ICG	At home
Dementia	No	No	No	Probably	Light

Appendix 10.2. Part 1 – Coding of data related to the role, experiences of the ICG and relation with the DEP

In all dyads becoming an ICG is seen either as being normal, a personal duty or a commitment. Some ICGs also consider it as not having had a choice. Most of interview dyads were married.

> *There was no way I would consider institutionalisation. (L_2_1A_F)*
>
> *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_1B_F)*
>
> *We've been married for 49 years now, I think it's absolutely normal that I care for her. As long as possible. (L_4_1A_M)*
>
> *It's my mother; we always were very close and had a lot of contact throughout my entire life. I see it as my task to take care of her. (L_5_1A_F)*

The relationship with the DEP seems to remain quite stable as long as the DEP isn't showing any deviant behaviour.

> *There is a lot tension; she does things that make me really angry. e.g. she plays her own doctor, reads the leaflets of her medication and decides to not take them. She doesn't let me prepare her medication, if I check for it, we get in a fight. (L_4_1A_M)*
>
> *The relationship is somewhat affected by the ICG's fear of DEP aggressive outbursts. She says: "I suffered a lot, you should have seen it, nobody would believe it" "I had to shut up and that's all". (L_3_1A_F)*

There can be specific cases where the relationship grows stronger and more profound.

> *We always got along really well, but now it has become much more affectionate and tender. We now have a deeper bond. It is like being in love again. (L_2_1A_F)*

The impact of the situation of dependency isn't perceived as a break to social activities. Most dyads perceive the decrease of social life as a normal evolution of aging.

> *We were always very outgoing and also frequently invited friends to come for diner. With his diagnosis this all stopped. Our social life went from very rich to non-existing. But it isn't a big issue; because all our friends have more or less the same age and so have the same health problems. (L_2_1A_F)*

> *We're old, so we don't have that many friends anyway. (L_4_1A_M)*

The ICG is mostly alone, other family member will not really implicate themselves strongly in the process. At most they intervene in emergencies, they listen to the ICG and frequently drive the ICG or DEP around. But there is no operational/daily support to the ICG.

> *"Our daughter lives in Belgium and works in Luxemburg, she hasn't that much of time for us, but if we need her, if I send an SOS she comes immediately." (SOS: when I have called the ambulance to get her to hospital because of exhaustion.) (L_4_1A_M)*

> *There is no direct (physical) help from my part of the family but they are very supportive and understanding. (L_2_1A_F)*

> *There is no help from other family member, he quit most relations with his family, the son has enough issues in his life, an my sister is only a punctual moral support, a sporadic company (L_1_1B_F)*

> *There is his niece that is living in the same village, just some streets away. This niece drives the ICG (no driving licence) to the supermarket to do the grocery shopping. (L_2_1A_F)*

> *Since he (the DEP) wrecked the car, the daughters are now sometimes driving me to appointments or grocery shopping. (L_3_1A_F)*

> *My sister goes there on Sundays, spends some hours with her and then tells me that I exaggerate that it's not that bad. But she does see her when she's bad. (L_5_1A_F)*

When the ICG is not married to the DEP but has a family of his own, trying to combine the different roles creates extreme stress.

> *My husband is rather understanding, but I don't know for how many time. I progressively have to spend more and more time at her place. So I force myself to do a lot of activities with him, cinema, theatre, art galleries, visiting friends, hiking. It's all rather tiring. (L_5_1A_F)*

The described influence on daily life varies among ICGs, mostly they show signs of stress, anxiety and lack of time.

> *It didn't change my daily planning, nor the things that I did or didn't but it impacted on how I did them and in which mind setting. I was anxious at each moment I wasn't near him, I always though, what if he falls and hurts himself. So I did everything much faster (like grocery shopping) (L_1_1B_F)*

> *Well my life changed completely, I don't spend too much time outside the house anymore. We had a lot of routines together like doing our shopping on Thursdays, going to a bar belonging to friends, going to the "Book market". It had an impact on my hobby also. I used to read massively and to write short stories, I just don't have enough inner peace to continue doing it. My children asked me to write down the family history, it's just not feasible. (L_2_1A_F)*

> *"It had a tremendous impact, I was never at home, I never did household activities. You see, from one day to the other she couldn't do these things anymore, so I had to take care of those things." (L_4_1A_M)*

> *I'm under permanent pressure, everything I do I have to do fast under stress. I don't have any time. Because of this I make errors, just a week ago I took my car out of the garage but with the trunk lid open, so I damaged the car and the garage door. (L_5_1A_F)*

The major impact on the health of the ICG is bad quality of sleep and stress having an impact on the quality of life.

> *Sometimes my blood pressure shoots up, can't sleep without taking a pill. I'm terribly nervous and tired as well because the homecare nurses come at 7h15 in the morning I have to be awake and ready very early. (L_4_1A_M)*
>
> *It has also an impact on the quality of my sleep, as I worry a lot, and only sleep with one eye, because you never know if there won't be an emergency. (L_2_1A_F)*
>
> *At one point he just stopped sleeping at night (slept only in the morning) he began wandering around the flat at night. He frequently fell to the ground and hurt himself. That had a massive impact on my sleep quality; I was restless at night which of cause consequently reduced my wellbeing (L_1_1B_F)*
>
> *"I can be very nervous at sometimes" "He does strange scratch noises during the night, he scratches his nails over the sheets – it's not his fault" (L_3_1A_F)*

There are two major ways in becoming an ICG, it can be abrupt mostly as a consequence of a hospitalization, or it's a slow process of progressive decline of the DEP faculties.

> *It all started in 2011. He had a pulmonary embolism. In the hospital they diagnosed also a heart failure. After the embolism was treated, they send him home. Before the embolism, he was just doing fine, working around the house, always occupied and busy, but after his return from hospital he was in a permanent state of fatigue. We went to see the doctors. He was diagnosed with an inflammation of his blood, an inflammation of his bladder and finally prostate cancer. (L_2_1A_F)*
>
> *"My wife had breast cancer 2 years ago and got a really strong chemotherapy (…) As a result of this treatment she was down and without energy most of the time, the cancer is now cured but the extreme fatigue stayed." (L_4_1A_M)*
>
> *He suddenly started to fall, to lose his balance and to fall no matter under which circumstances. We went to see some MDs who diagnosed him with Parkinson disease. From there on, it all progressed rather slowly towards dependency. There was not a moment in time, which you could point out and say, that was the point of no return. (L_1_1B_F)*
>
> *The first thing I can remember was her forgetting to put the bins for waste removal on the street, it happened every now and then. Some time later she forgot to pay the rent (L_5_1A_F)*
>
> *She got weaker, got more and more tired, for ever longer periods. And right now she wouldn't even eat if I wouldn't prepare the meal and make sure that she ate it. (L_5_1A_F)*

Facilitating and hindering elements to play the role as ICG vary strongly among the dyads.

There are character issues:

> *All his life he kind of took me for granted. In the beginning of his illness there was no exception to this rule. He had quite a hard time accepting the diagnosis but that did not change our relationship in a significant manner. He always was a loner, with a rather harsh character. He is never satisfied and has no patience at all. In the institution he isn't nice to the employees either (L_1_1B_F)*
>
> *He is also somewhat complicated to manage: "He has his head, he is rather stubborn, it is hard to prohibit him to do things, so if I look away, he will take the ladder and try to climb into his apple trees... what if he falls from the ladder? " "Then sometimes is doesn't work out, he is not able to climb on the ladder and he smashes it to ground in anger" "How often did I find him lying in the garden among the potatoes?" (L_3_1A_F)*
>
> *She says: "He doesn't conceive his age or has forgotten about it and wants do things a much younger man could do." (L_3_1A_F)*

There are mental issues:

> *Then there are the mental problems, there are days, she cannot articulate, she cannot speak out words. I see she wants to speak but nothing comes out. She looks at me stunned… that's very depression » (L_4_1A_M)*
>
> *There are days she has terrible memory problems. When it's really bad, it happens sometimes, she can't even remember the name of our daughter. (L_4_1A_M)*
>
> *The worst is that we don't know what she has, we don't have a diagnosis, doctors don't find anything. But I have video material of her losing reason, not being able to speak, acting demented (L_4_1A_M)*
>
> *Worst for me is to observe her slow mental decline. She functions rather well in the normal surrounding but if she has to evolve in a different context, everything seems to fall apart. e.g. some month ago she had to spend 2 nights in hospital because she got a pacemaker, in the evening she ran through the corridor looking for her chicken. (L_5_1A_F)*

Living location can be an issue:

> *Well it's just 5 km but it takes times, in winter when it's dark it's not easy to find the motivation do go in the evening to check if she went to bed. (L_5_1A_F)*

Appendix 10.3. Part 2 – Coding of data related to the health status and occupation of the DEP (2 A or B)

The health status of the one DEP institutionalised recently actually improved after institutionalisation. This is apparently linked to the availability of more and different care staff (professionals compared to the ICG, like ergo-therapists).

> *He asked for institutionalisation as he realized that the ICG was far from being well of. So he worried of what would happen to him if something happened to her. Hence the institutionalisation was due to my health condition not his own. (L_1_1B_F)*

For those living at home, what they do, very much depends on their health status. One of the DEPs is bed-ridden and partly paralysed. Two other DEP are in a better period after changing doctor and therapy for one, after installing a pacemaker for the other. This makes it possible to have more activities, but which remain limited, to e.g. some gardening.

> *She lives like normal, has the garden and the chicken, the difference is that I do everything (L_5_1A_F)*
>
> *Much better now, you see I still have the Tele-Alarm (alarm button to wear on a bracelet), but I don't need it anymore, I don't fall anymore (L_3_2A_M)*

The most common adaptation to the house is the "Tele-Alarm" which is an emergency button the DEP wears on a bracelet.

Most of DEPs seem also to have been provided a hospital bed.

> *He has one room with a hospital bed in it. There will also be a staircase-lift installed by the end of the year. (L_2_1A_F))*

But the main concern of both DEP and ICG is often not the health condition of the DEP but that of the ICG. The ICG wants to keep the DEP as long as possible at home.

> *You know, young man, what bothers me is not the Parkinson, but my knee. (L_3_1A_F)*

> *Will only check DEP into institution if mental health decreases significantly or if I get more health issues myself. (L_4_1A_M)*

Appendix 10.4. Part 3 – Coding of data related to support from non-professional individuals (from family members, friends…) that the ICG and the DEP receive

Most of the ICGs were married to the DEP, the children and other family members aren't providing informal care to the DEP. They do however provide practical support or psychological support to the ICG.

> *There is his niece that is living in the same village, just some streets away. This niece drives the ICG (no driving licence) to the supermarket to do the grocery shopping. The niece sometimes drives her to the doctors. The man of the niece does the maintenance work in the house if needed (replacing bulbs, etc...) (L_2_1A_F)*

> *The daughters are now sometimes driving the ICG to appointments or grocery shopping. (L_3_1A_F)*

> *There is no help from other family member, he quit most relations with his family, the son has enough issues in his life, an my sister is only a punctual moral support, a sporadic company (L_1_1B_F)*

In two dyads there were persons who are not relatives who provide help, mostly by being a source of company for the DEP:

> *There is that girl who once had a summer job at Home care service (Home care service) that still comes to visit him every week. She sits with him an they talk. He's very social and talkative; not being able to move is quite a burden, so it is a welcome distraction when people come to visit. (L_2_1A_F)*

> *He also spends quite some time with a neighbour; they go to look at road and building construction site together. (L_3_1A_F)*

Appendix 10.5. Part 4 – Coding of data related to tasks performed by the ICG

Concerning household activities, in the cases where the ICG is the wife of the DEP, there is a great chance that the ICG performed all these tasks anyhow. So she continues, even if it tends to become more of burden because of her own age and the extra time needed to care for the DEP.

> *We are here in the context of a very classic gender role distribution; she did all household activities anyway.(L_1_1B_F)*

> *The only thing that changed somewhat is that he sometimes did some grocery shopping or accompanied her, he couldn't do it anymore. (L_1_1B_F)*

> *ICG did the household anyway (classic gender role distribution). As for odd jobs DEP does them still alone. ICG took more responsibility in the garden; It became her new hobby. (L_3_1A_F)*

Mostly depending on the mental and physical state of the DEP, the ICG has to perform all these tasks on his own. This can be a source of stress if the ICG wasn't used to performing these tasks in the past, or performed them partially.

> *"I am doing all the household management, all domestic tasks. It was very hard at the beginning because I wasn't used too, I never did that kind of stuff" "She really couldn't do it anymore from one day to the other" (L_4_1A_M)*

> *"There are 2 major problems I cannot cook and I cannot iron" (L_4_1A_M)*

> *Everything, it is impossible for him to do anything as he is bed-ridden. (L_2_1A_F)*

> *Everything, the whole household, chickens, garden, and the cat's litter box included. (L_5_1A_F)*

> *I mostly have to take her out of bed, to prepare breakfast, cook lunch and check that she eats it. If I weren't there she would simply stop eating. She also doesn't drink water, so I mix honey in the water and check that she drinks it. (L_5_1A_F)*

> *I do the shopping, am her driver, etc....(L_5_1A_F)*

Personal care is performed by the ICG as long as possible and outsourced to formal caregivers when the illness evolves and are permanently present. In emergency situations the ICG will have to cope with it on his/her own.

> *In the beginning she dressed undressed him, at some point she couldn't do it anymore because the Parkinson gained terrain and he could barely move anymore, so formal caregivers had to do it. She also washed his hair, but he could shave, eat, drink, etc... on his own, (L_1_1B_F)*

> *I dress and undress him as far possible. I also brush his teeth. I help him to get on the commode and of it during the day, several months ago he had diarrhoea for 3 weeks straight, it was a really tough time, it got me very close the limit of what is bearable to endure to me. (L_2_1A_F)*

> *About 4 times a week ICG helps DEP wash herself (one time week washed by nurse 1x week washed day care centre). ICG also helps dressing/undressing. ICG assists DEP to walk through the house, e.g. there is a staircase to get outside/inside, DEP cannot take staircase alone. (L_4_1A_M)*

> *ICG is only responsible for personal care (washing / dressing / etc...) when they are on vacation. They go on vacation once a year with the Parkinson asbl. (L_3_1A_F)*

All the ICGs have to deal with medication. It includes preparing it, making sure the receipts are updated, checking whether the DEP took it.

> *Controlling the intake (which produces frequently conflicts) DEP obviously is not able to monitor intake and preparation by herself, but if ICG want to help, DEP: "You don't let me do anything" "You take everything away from me". (L_4_1A_M)*

> *I arrange the medication in a weakly box. I also sometimes chance the urine bag (L_2_1A_F)*

> *I arrange the medication and make sure he takes it (L_1_1B_F)*

> *I prepare the medication, am in charge of the prescriptions and keep track of the blood thinners he has to take. Twice a week he gets blood taken to check the needed dose of blood thinner (INR analyse). So I get a phone call twice week with the new dosing, I keep track of it in a journal and tell the formal caregiver giving the shot the indicated dose. (L_3_1A_F)*

> *I check for medication, manage the doctors (L_5_1A_F)*

Two ICGs also care for wounds with the help of formal caregivers.

> *He currently has a quite fierce scab on his backside; I put creams and pomades on it. I also cream his whole body. (L_2_1A_F)*

> *ICG puts creams and lotions on the open wounds on legs. (L_4) (Diabetes)*

Appendix 10.6. Part 5 – Coding of data related to formal services received at home and outside the home for the DEP

Four dyads had help from formal health professionals on a regular basis. Those were clients of one of the major homecare services in Luxemburg. Mostly they were informed by a social assistant from a hospital while the DEP was being hospitalized or by the family doctor. Everything seems to happen quite automatically, the ICG basically only has to sign some papers.

> *The social assistant in hospital explained me everything and established the first contact. Then the team of the Home care service made the all paper work and took care of all administrative steps. (L_2_1A_F)*

> *All information was provided by the hospitals social assistant (L_1_1B_F)*

The most common formal caregiver is a nurse or nurse aid from a professional homecare service.

> *There is (name homecare organisation) that comes 4 times a day. The nurses and health aids wash him, check his blood sugar levels, make the insulin injections. (L_2_1A_F)*

> *In the morning they connect the urine bag for the day and in the evening they connect the one for the night (bigger one) (L_2_1A_F)*

> *They too look after the scabs. They also change the urinary tract catheter. Sometimes it doesn't work out and there are problems with the catheter... we had to go to hospital and so on. In such cases we call the ESSAD, with is like the SWAT Team of (name homecare organisation). These nurses go visit the persons that are really really ill. I have their phone number and when we have a severe problem during the night (mostly) I call them and they come immediately to take care of the issue. (L_2_1A_F)*

> *Nurses and health aids came twice a day everyday to dress/undress him, three times a week as they to wash him. They also provided medical interventions like injections. (L_1_1B_F)*

> *He had also to put on compression tight, the health aids has to put them on. (L_1_1B_F)*

> *Every second week a nurse came to take a blood sample to check the coagulation to keep the meds updated. (L_1_1B_F)*

> *Nurse and health aid from (name homecare organisation). They come in the morning for dressing (ICG does undressing) and for showering, they give the DEP the blood thinner (in form of shots) (L_3_1A_F)*

> *Once a day, in the morning a nurse/health aid from (name homecare organisation) comes to put on the compression stockings, take blood pressure and the blood sugar level, perform an insulin shot and wash her about once a week. (L_4_1A_M)*

Three dyads had a domestic aid but one ICG has hired a domestic aid that isn't provided by a homecare service.

> *I have a housekeeper that comes twice a week to help me. She has become a part of our family. I don't have the energy anymore to do all the cleaning. Of course the cleaning lady doesn't clean like I did. Also, she is too small to clean e.g. on the shelves but I'm really happy that we have her. She talks also a lot with him. (L_2_1A_F)*

> *Before having found her, I had a cleaning firm that came, those people really knew how to clean the house, they were very professional, but they send me different persons every week. I wasn't so comfortable with it. (L_2_1A_F)*

> *There is a cleaning lady from (name homecare organisation) that comes once a week, but she isn't cleaning, ICG asks her to do the ironing. "I learned how to clean the house, but I can't manage to do the ironing." (L_4_1A_M)*

> *Cleaning lady from (name homecare organisation) twice a week (L_3_1A_F)*

One dyad uses granny-sitting services, proposed by the Home care service. This can be considered as a form of respite care.

> *Well we recently started to use the "granny-sitting" service of (name homecare organisation). 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_1A_F)*

One dyad uses homecare services when ICG goes on vacation.

> *When I go on vacation, I ask for the homecare service organisation to come twice a day to check medication intake and if she didn't fall. (L_5_1A_F)*

One dyad uses family support when ICG goes on vacation

> *Last year I allowed myself to go on vacation. Twice, for one week each time. And my daughter came living with her. I only did it when she was doing really, really well. (L_4_1A_M)*

Some dyad had Tele-Alarm installed but couldn't get used to it. Service provided by the municipality.

> *She has Tele-Alarm, but doesn't use it, doesn't wear the bracelet with the emergency button. When she wears it she pushes the button accidentally, they then phone, she doesn't hear the phone if she hasn't her hearing aid on, they send an ambulance. It's quite complicated. (L_5_1A_F)*

> *He just never used the system and couldn't get used to it. (L_1_1B_F)*

The Tele-Alarm is very useful to one dyad where the DEP frequently falls and the ICG does not have the strength to lift him back up. It's a case in which the DEP refuses to use it and the ICG just pushes to button to get help.

> *Télé-alarm, from municipality, organised by (name homecare organisation), they pay 40€/Month out of own pocket. But he refuses to use it. ICG pushed the button several times when he was lying in the garden and couldn't get up. (L_3_1A_F)*

Meal delivery is used when there are some more problem, e.g. health problems of the ICG or e.g. the ICG cannot cook.

> *"Meals on wheels" delivers meals for ICG and DEP each day. "I never cooked in my life" (L_4_1A_M)*

> *"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_1B_F)*

As missing services, some dyads claim that the use of a stair lift would improve mobility and safety.

> *It's not necessary now but could become a necessity for keeping DEP at home in some time: a stair lift (L_3_1A_F)*

> *He has one room with a hospital bed in it. There will also be a staircase-lift installed by the end of the year. Has a commode (chaise percée) (L_2_1A_F)*

> *L_4_1A_M also spoke about it after the actual interview.*

Appendix 10.7. Part 6 – Coding of data related to formal services used to relieve support the ICG

Daycare centers are quite polarizing, some DEP refuse categorically to go, whereas others like to go.

> *There were services like "Daycare Center" or a similar service from the patient association for his disease, but he refused to go. He never wanted to have contact with other people and preferred to remain on his own. (L_1_1B_F)*

> *There could be day care centres and activities but he doesn't want to go or more accurately he cannot go. (L_2_1A_F)*

> *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_1A_M)*

> *DEP goes to facility of a patient organisation one day per week, but refuses to go to day-care centre(L_3_1A_F).*

> *They do activities, singing, handicraft, they do boxing (young persons from a detention centre wear foam gloves and the patients hit them) (L_3_1A_F)*

> *DEP likes those activities really a lot and gets there with the Nova bus (on call bus service) his wife accompanies him. (L_3_1A_F)*

Appendix 10.8. Part 7 – Coding of data related to the financial support of the ICG

Financial conditions

None of the dyads had financial issues. Four out of the five dyads received a cash allowance from the Assurance dependence. So they are paid to take care of the DEP. The amount of allowance they receive varies in function of the degree of dependence.

> *We get 220€ per month from Assurance Dépendance (L_4_1A_M)*
>
> *At first they got 980€ per month but after having taken the cleaning lady they receive 780€. (L_3_1A_F)*
>
> *The "Assurance Dépendance", gave us about 1000€ a month because I was taking care of him, that was when (name homecare organisation) came twice a day. Since he is partly paralysed they come four times a day, and we still get about 500€ each month. (L_2_1A_F)*
>
> *An employee of Assurance Dependence came to check out the situation and the degree of dependence to define the amount of the financial aid we could get but I do not remember how much it was. (L_1_1B_F)*

Overall the information and administrative procedures concerning this allowance is very easy for the user and is fully taken care of by other people, like social assistants of homecare services. So it is not a burden to the ICG.

> *It's a very good system, there is some 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_1A_M)*
>
> *It all went extremely fast, there was a man from Assurance Dépendance that came to assess the situation and the degree of burden, then the ICG only had a signature to do. The next month the money was there. (L_3_1A_F)*
>
> *Social Assistant from Assurance Dependence comes at home analysing the situations and the requirement. It goes really fast. (L_2_1A_F)*
>
> *It's the social assistant from the hospital that took care of it. (she lives about 500m of the hospital) (L_1_1B_F)*

The common perception is that it is nice to receive it, but that it wouldn't change anything if this allowance wasn't attributed to them. They would still take care of the DEP.

> *Were quite astonished, are glad to receive the money but they would keep him at home anyway (L_3_1A_F)*
>
> *It's nice but to us it wouldn't change anything if they didn't give it to us (L_2_1A_F)*

The only dyad in which a child takes care of the DEP, they didn't ask for cash allowance, they don't even know such a service exists and they don't see it as necessary. Looking after your family is a normal thing to do.

> *No, why? It's my mother, it's normal I look after her. (L_5_1A_F)*
>
> *Why should she or someone pay me for doing this? (L_5_1A_F)*

Key points of this case analysis

- **Most ICGs are aware of support measures for the DEPs and indirectly for them as well. The sicker a person gets the more they get made aware of it, mostly immediately at the hospital through social assistants when the person was hospitalized, or by the family doctor if s/he sees that the person needs further help.**
- **The persons are immediately put into contact (if they accept) to homecare services. The staff of those services do the assessment, define the care needs and deal with all the necessary paperwork.**
- **Four out of five dyads benefit from an allowance varying between 1000 Euro and 200 Euro per month depending on the degree of dependency and the number and type of services provided by formal caregivers.**

APPENDIX 11. CASE-TUDY ANALYSIS QUESTIONNAIRES

Basic questionnaire needs to be filled only by the informal caregiver. Some information about the dependent elderly will also be collected. Questions hereafter aim at providing some background for further analysis.

Appendix 11.1. Basic questionnaire the informal caregiver

1. What is your age? _______________ years
2. What is your gender? Male ________ Female_________
3. What is your highest education level that you completed? ___________________________
4. What is your marital status?
   - o Married/civil partnership/co-habiting ____________________
   - o Widowed ____________________
   - o Divorced ____________________
   - o Single ____________________
5. Do you have children? _________
   - o If yes, how many ________?
   - o Children age : 1) ______ 2)________ 3)_______ 4)________
6. Do you have grandchildren? _________
   - o If yes, how many ________?
   - o grandchildren age : 1) ______ 2)________ 3)_______ 4)________
7. What is your relationship with the dependent elderly
   - o Spouse/Parter ______________
   - o Parent ______________
   - o Grandparent ______________
   - o Other ______________
8. Does the dependent elderly live with you? ______________
9. Who else lives with you (choose all appropriate options) (eventually besides the dependent) elderly?
   - o Parents or parents in law _______________
   - o Husband /wife (or companion) _______________
   - o Children _______________
   - o Grandchildren _______________

   - Other persons _______________
   - Alone _______________

10. What is your relation to the dependent elderly? Select one of the following options:
    - Wife/husband (or companion) _______________
    - Son/daughter _______________
    - Other family link _______________
    - Friend or neighbour _______________
    - Other, who? _____________
11. What is your current work status? Select one of the following options:
    - Employed or self-employed _____________
    - Unemployed _____________
    - Economically inactive _____________ (e.g. retired, disable)
    - Housewife _____________
12. If your are currently employed or if you previously worked, do (did) you?
    - Work full-time? ________ (refers to working more than 35 hours per week)
    - Part-time? _______ If yes, how many hours per week? ________
13. What type of work do (did) you previously do?
    - Management and professional work
    - Employee intermediate professions (e.g. non managerial positions)
    - Manual worker
    - Self-employed

Appendix 11.2. Basic questionnaire about the dependent elderly

1. What is his/her age? _______________ years
2. What is his/her gender? Male ________ Female_________
3. What is his/her highest education level? _______________
4. If the dependent elderly is not your partner, what is his/her marital status?
    - o Married/civil partnership/co-habiting ___________________
    - o Widowed ___________________
    - o Divorced ___________________
    - o Single ___________________
5. If the dependent elderly does not live with you and resides at home, can you tell us with whom does he live?
    - o Wife/husband (or companion) _______________
    - o Son/daughter _______________
    - o Other family link _______________
    - o Friend or neighbour _______________
    - o Other, who? _____________

Appendix 11.3. Semi-structured interview guide for informal caregiver (ICG) looking after a dependent elderly (DEP) living in the community (version 1A)

Ethical reminder before starting the interview

- The information collected in this interview will be treated with confidentiality and your name as well as other details that may reveal your identity will be coded in the template as well as in the final report and in any in further publications

- The duration of the interview is more or less 1 hour and will be recorded with your permission.

- Make sure the person reads the informed consent form

- Not all individuals will understand what an “informal caregiver” means, be aware of this when you are explaining the research question

- Remember to fill in the basic information questionnaire with the ICG

Interview n°

Gender of the ICG :

Date of the interview :

Mode of recruitment :

Country / region :

Contact :

Part 1: Introduction to the research

Introduction question: We are conducting a study on the current situation of the ICG in different European countries, especially on what can support you in combining different roles (looking after the dependent elderly while being in paid employment, looking out for other family members)

I think that you are the main caregiver of *(say the name)*, is it correct he/she is (*say the family link husband, wife, daughter, son, friend…*)?

We are interested in your personal experience and perceptions because you are probably the best placed to tell us how the ICG is supported in this country and also in this region…

Notes for the interviewers:

You can explain what an informal caregiver (ICG) is based on the following definition but using a lay language: a person providing “long-term care or support lent on voluntarily basis (whether they are receiving remuneration) to a family member, friend, or acquaintance for physical or mental health problems or problems due to aging”

Be as concrete as possible when you address the different questions

Part 2: Description of the family, professional and living situation of the ICG (and of the DEP)

Notes for the interviewers:

This information is gathered to create a trusting climate for the interview but also to know the background of the situation. You might also need this information (like family relations) in order to have a natural flow for the interview.

Question 1: We’ll begin with some questions relating to yourself, can you tell me something more about yourself (your age, children,...) can you tell us what the composition of your family is ?

- ICG/DEP Age?
- Partner (if not the DEP), if any?
- Do you have children, grandchildren and parents (in addition to the DEP)?

Question 2: Do you live here, with… (the DEP she/he cares for)? (If the answer is no, then directly address the following questions)

- If it is not the case, what’s the distance between your house and the DEP’s house?
- Do other persons live with you? (If the ICG has children) Do your children live with you?

Question 3: Could you describe your current job situation or (previous) occupation (also if he /she does voluntary work)?

Notes for interviewers:

- The exact work occupation will be defined in the basic questionnaire, here we just want to describe the work situation and its evolution (see question below). The idea is that the care situation can have had an impact on the job situation of the caregiver.

- If the interviewee is retired, we need to know what he/she did before retirement.

Question 4: Has your situation changed since you've been caring (for the elderly) and how?

Notes for interviewers:

We want to know whether the job situation (retired, unemployment, worked part-time) changed since they have been caring for the elderly person (e.g. for instance whether they reduced their full time job to a part time job because of the burden of looking after the elderly).

Also, if the interviewee was engaged in voluntary work (e.g. church help), this might have changed since the other person became dependent.

Part 2: Caregiver role

Notes for interviewers:

This second part aims to depict the situation from the point of view of the caregiver, including the tasks he or she performs and the formal services that the DEP receives

Notes for the interviewers:

Questions 5 to 7 gather information on how long, how, why (the reason for help, so the type of health situation and the consequences of the health situation) and to whom the ICG provides care

Question 5: (care history) Since when did you start to take care of mr/mrs *(say the name)*? OR How long have you been providing care for mr/mrs *(say the name)*?

Question 6: How and why did you have to start caring for the mr/mrs *(say the name)*? Can you tell me something more about it, what led you to becoming his/her caregiver?

Notes for the interviewers:

The informal caregiver may identify an episode (e.g. a fall) as the departure point when he/she started providing care. However, the episode may be related to a previous condition or illness and the informal caregiver might have started looking after the dependent elderly before the episode. Therefore, both information needs to be collected.. If an “episode“ is mentioned then we need to collect information on the existing conditions.

Question 7: Are there other people you care for because of disability or because of old age, sickness, mental health problems,…?”

Question 8: Are there other people who help you with taking care of the elderly? For instance a another family member, friends,…?”

Notes for the interviewers:

In question 8 we are NOT talking about health professionals or domestic help. If the ICG talks spontaneously about professional help or domestic help, let the interview flow naturally but we come back to that later on in the interview. We want to identify other informal caregivers who we could eventually interview if necessary

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Question 9: Can you tell me a little more about your role as an informal caregiver, what are the positive experiences of this caregiving role and what are the negative experiences?

Notes for the interviewers:

It is important to ask for both the positive (e.g. good relationship, fulfilment …) and negative sides (e.g. effect on the family life, work, pressure, sleep disturbance, financial problems)

Question 10: As caregiver, which tasks are you doing specifically (tasks you are doing for the DEP because he/she can’t do these anymore by her/himself…) ?

Notes for the interviewers:

These issues might already have been discussed in the previous open question, which is fine, just make sure the big items are covered.

We want to have a list of general care tasks that the ICG is conducting, including:

household activities (including food preparation, cleaning, washing, ironing, sewing, taking care of and playing with children, shopping or maintenance work, odd jobs, gardening), personal care (dressing/undressing, washing, hair care, shaving, going to the toilet, mobility around the house, eating and drinking), **medical care** (including arrange medication or medical support performed by the ICG as for example cleaning a wound),

practical support (mobility outside the house including assistance with walking or wheelchair, visiting family or friends, seeing to health care contacts, organizing help, physical aids or house adaptations and taking care of financial matters, receiving formal caregivers)

Surveillance (this is more for the caregiver)…

It is important to get to know all the additional tasks performed by ICG since the person got ill (if she was doing household tasks before, that is not what we want to know, but if suddenly she/he has to do financial matters, she/he might not be used to it) as well as how it has affected previous tasks (e.g. less time to cook)

Question 11: According to you, how much time per week are you spending doing these tasks (in general, not per task)?

Notes for the interviewers:

We want to know how much time during the week the person considers that he/she provides care. Make sure you can identify whether the caregiver needs to be constantly by the side of the dependent elderly. In many cases, surveillance 24/7 is not identified as care time.

Question 12: In general, are some of these tasks more problematic than others and why? Which tasks do you feel most comfortable with and why?

Notes for the interviewers:

It is also important to find out how the informal caregiver feels about having to do these tasks as it might be very stressful for example to be responsible for making sure the DEP has taken his/her medication while other tasks might be easier to perform. For us it is also important to know which tasks are problematic as there may be a possibility (or policy measure, e.g. personal care) to get formal support for some tasks but not for others.

Question 13: How do these care tasks affect your daily life?

Notes for the interviewers:

We want to find out if specific tasks have a greater impact on employment, family life and relationships, leisure time, well-being (psychological and physical) We do not want to use a standardised list but just want to cover the main items.

It is important to know how the extra tasks the ICG has to perform, affect the tasks she/he was doing before (‘normal’ daily activities might suddenly become difficult to perform because of this extra tasks, for example doing grocery shopping as the ICG can’t leave the DEP alone at home…). This was probably addressed in question 10. But make sure that it has been covered already

Question 14: How do you cope with the new role and your new tasks? How does it help you that … (*mention the person in question 8 that also helps with the dependent elderly)* helps you with covering the needs of the dependent elderly (or name the person) ?

Notes for the interviewers:

With this question, we try to estimate the burden of the care tasks of the ICG and make a link with the next section.

Part 3: Formal services for the dependent elderly

Question 15: Which services (health professionals, domestic help, granny-sitting, undeclared worker, etc.) does *mr/mrs(say the name)* receive at home ? Are there other arrangements (e.g. with domestic help, health professionals, ICT support), adaptation to the house, other (undeclared worker)?

Notes for the interviewers:

Question 16 and 17 aim to gather information on "accessibility" to services. Be aware that the DEP may have already mentioned services in question 8. Make sure that you gather new information if needed. Undeclared worker (in Germany usually migrant populations looking out for DEP) refers to an individual looking after the DEP who does it on a "for-profit" base. Do not confuse with a neighbour for instance. In some countries, there is a thin line between the two as a neighbour can be paid without a formal contract.

Question 16: How or who informed you about the availability of those services?

Question 17: Did you had to follow any administrative procedure to access those services (for all of them)? Did somebody help h you to follow the administrative procedures?

Notes for the interviewers:

Question 16 and 17 aim to gather information on "accessibility" to formal services

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Question 18: Can you tell us whether in some situations the services for the dependent elderly were interrupted or could not be delivered? For example a nurse who couldn't come, in acute situation when *mr/mrs (say the name of the person)* needs extra help but you do not find more help than before. *(If the answer is yes, then directly ask how did you deal with it?*

Notes for the interviewers

Here we are dealing with the concept of continuity of care and of coordination of care, what happens to the ICG when one of the professionals doesn't show up, or is absent for a while. A bad relationship with the formal caregiver can also be included here.

Question 19: How are the costs of the professional services covered for?

Notes for the interviewers

This is to understand any financial interventions from the authorities, out-of-pocket expenses of the DEP, any well as financial intervention of the ICG. Be aware that in couples, the distinction between ICG or DEP out-of-pocket expenses may not be relevant.

Question 20: During the last six months, has the amount or type of services received by the *mr/mrs (say the name of the person)* changed? *(If the answer is yes, then directly ask how and why?*

Notes for the interviewers

It is important to find out what has changed over time in order to see what might have helped to delay or prevent institutionalization.

Question 21: Are there other services that should be helpful to cover the care need of *mr/mrs (say the name of the person)*, but he/she doesn't receive? *(If he/she mentions something, then ask directly what are the reasons for not using* them (financial reasons, poor quality, accessibility issues, values, bad reputation, the DEP does not want to)?

Part 4: Formal services for the informal caregiver

Introduction question to this part: "So far we have been talking a lot about the help that can be provided for *(mr/mrs say the name of the DEP)*. Now we want to talk a little bit more about support measures that have helped you or that could help you in the future, to look after *(mr/mrs say the name of the DEP)*. We are not talking about help from other family members, but we want to talk about measures that exist or can be developed by the local government, the state, in order to support you as an informal caregiver"

Notes for the interviewers

The following questions aims at having an in-depth perspective on services for the informal caregiver used by the ICG. Knowing whether they have benefited from different policy measures is important but we must have a larger perspective concerning their overall experience. In general we need to know:

- When and how did they learn that those measures existed? (In the beginning of the care process, by the GP)
- How did they deal with the administrative requirements to access those measures?
- How have the different measures helped them (or not helped them) in looking after the DEP and in avoiding institutionalization?

Be aware that this is very country specific and covers a lot of measures caregiver allowance, personal budget, pension contribution and unemployment benefits. It also be understood as reducing out-of-pocket expenses for care services (vouchers, tax-deductions)

In question 13 we already asked how being a caregiver has affected their daily life, so some of the following questions will be related to that question

Question 22: Do you benefit from home care services (e.g. nurse care, etc...) because you have a health related conditions?

Notes for the interviewers

These services may be simultaneously provided to the DEP and ICG. These services may also be used to help the person to cope with the care burden related to providing informal care (e.g. granny-sitting, psychological support). If the latter is the case then try to find more about it (since when do you have access to them? is it useful and why?)

Question 23: Can you tell me whether you have personally benefited from any financial protection or remuneration from local authorities related to looking after *mr/mrs (say the name of the person?*)? *(If the answer is yes, then directly ask how it has helped them to reduce any financial stress related to looking after the DEP)*

Notes for the interviewers

Ask the question in a very open way and leave it up to the ICG to talk freely. If there is no reply to this question or the ICG finds the question too difficult, use following prompts (see international comparison and YW check list which can help:

Caregiver allowance

Personal budget (used by the DEP to remunerate them)

Social protection (Pension contributions or flexibility in unemployment benefit conditions)

Employment, maintaining employment via workplace policies as well as national policies

Question 24: Have you considered whether the government may/should consider compensating your care work (how and why)? Would this reduce any difficulties that you are experiencing now when looking after mr/mrs? Can this influence the way you care for mr/mrs or your relationship with him/her?

Notes for the interviewers

This is possible in different countries but in different ways: from a labour contract, to just a small financial compensation. Be aware that the person may have mentioned in the previous question that he/she already benefits from some financial support. In addition, here we mention government intervention but sometimes the DEP determines the access to the financial support.

If the ICG already receives financial remuneration, we want to get a deeper view on how it has changed their life.

If the ICG does not receive financial support, we want to know what would be the impact of such a policy measure on the ICG life and in the way he looks after the DEP?

Question 25: Are there services available, that you may use or not use at the moment in order for you, to take a break from your care task, for instance when you are ill or if you want to go on holidays? Can you tell me more about those services (why do you us them, why do you not use them)? How did you find out about these services?"

Question 26: Have you had access to information on how to care for mr/mrs (say the name of the person)? (If the answer is yes, then directly ask who provided the information, the information content and how it has helped her/him.

Note for the interviewers

We want to find out about availability of services or information, explaining how, e.g. to provide personal care or deal with aggressive behaviour from the DEP, allowing the ICG to take better care of the DEP.

Question 27: Are there specific services that you receive at this moment without which it would be very difficult to care for mr/*mrs (say the name of the person)* in their home? Can you tell us why they are so important?

Question 28: What other services would be helpful to allow you to continue to look after mr/mrs*. (say the name of the person)* in the future?

Notes for the interviewers

Questions 26 and 27 will cover the help received, what is missing or needed (e.g. even if ICG is not aware of these measures)

Question 29: How do you feel that your contribution in caring for mr/mrs*. (say the name of the person)* is recognized by your social environment (e.g. family, friends? How about the recognition from health care professionals (partnership, awareness of difficulties)? And concerning the government?

Notes for the interviewers:

Here we want to find out whether the ICG feels that his/her role is officially and/or unofficially being recognized (appreciated). Being officially recognized as an informal caregiver gives you a right to certain benefits in all countries except France (but different benefits in different countries) but people might not be aware of this.

As a final question, I would like to ask you whether there is anything else you would like to add that has not been discussed yet in relation to your role as caregiver and that you feel might be of importance from your perspective or from your experience?

Thank you very much for your valuable input.

Appendix 11.4. Semi-structured interview guide for informal caregiver looking after a dependant elderly institutionalized (1B)

Ethical reminder before starting the interview

- The information collected in this interview will be treated with confidentiality and your name as well as other details that may reveal your identity will be coded in the template as well as in the final report and in any in further publications

- The duration of the interview is more or less 1 hour and will be recorded with your permission.

- Make the person read the informed consent form

- Not all individuals will understand what an “informal caregiver” means, be aware of this when explaining the research question

- Remember to complete the basic information questionnaire with the ICG

Make sure that you stress which situation you are talking about, sometimes the question is related to the home situation (before institutionalisation) and other questions are related to the institution

Interview n°

Gender of the ICG :

Date of the interview :

Mode of recruitment :

Country / region :

Contact :

Part 1: Introduction to the research

Introduction question: We are conducting a study on the current situation of the ICG in different European countries, especially on what can support them in combining different roles (looking after the DEP while being in paid employment, looking out for other family members)

I think that you are the main caregiver of *(say the name)*, is it correct he/she is (*say the family link husband, wife, daughter, son, friend,…*)?

We are interested in your personal experience and perceptions because you are probably the best placed to tell us how is the ICG supported in this country and also in this region.

Notes for the interviewers:

You can explain what an informal caregiver (ICG) is based on the following definition but using a lay language: a person providing “long-term care or support lent on voluntarily basis (whether they are receiving remuneration) to a family member, friend, or acquaintance for physical or mental health problems or problems due to aging”

Be as concrete as possible when you address the different questions

Part 2: Description of the family, professional and living situation of the ICG (and of the DEP)

Notes for the interviewers:

This information is gathered to create a trusting climate for the interview but also to know the background of the situation. You might also need this information (like family relations) in order to have a natural flow of the interview.

Question 1: We’ll begin with some questions relating to you, can you tell me something more about yourself (your age, children,...) can you tell us what your family composition is ?

- ICG/DEP Age ?
- Partner (if not the DEP), if any?
- Do you have children, grandchildren and parents (in addition to the DEP) ?

Question 2: Do you live here, with… (the DEP she/he cares for)? (If the answer is no, then directly address the following questions)

- If it is not the case, what’s the distance between your house and the DEP’s house?
- Do other persons live with you? (If the ICG has children) Do your children live with you?

Question 3: Could you describe your current job situation or (previous) occupation (also ask if he /she does voluntary work)?

Notes for interviewers:

- Exact work occupation will be defined in the basic questionnaire, here we just want to describe the work situation and its evolution (see question below). The idea is that the care situation can have had an impact on the job situation of the caregiver.

- If the interviewee is retired, we need to know what he/she did before retirement.

Question 4: Has your situation changed since you've been caring (for the elderly) and how? And has it changed again since institutionalisation?

Notes for interviewers:

We want to know whether the job situation (retired, unemployment, worked part-time) changed since they have been caring for the elderly person (e.g. for instance they reduced their full time job to a part time job because of the burden caused by looking after the elderly).

Also, if the interviewee was engaged in voluntary work (e.g. church help), this might have changed since the other person became dependent.

Part 2: Caregiver role

Notes for interviewers:

This second part aims to depict the situation from the point of view of the caregiver, including the tasks he or she performs and the formal services that the DEP received

Notes for the interviewers:

Questions 5 to 7 gather information on how long, how, why (the reason so the type of health situation and the consequences of the health situation) and to whom the ICG provides care

Question 5: How and why did you start caring for the mr/mrs *(say the name)*? Can you tell me something more about it, what led you to becoming his/her caregiver?

Question 6: Since when has the person you care for (name) been institutionalised? What had changed that made institutionalisation necessary?

Notes for the interviewers:

The informal caregiver may identify an episode (e.g. a fall) as the departure point when he/she started providing care. However, the episode may be related to a previous condition or illness and the informal caregiver might have started looking after the dependent elderly before the episode. Therefore, **both information needs to be collected.** If an "episode" is mentioned then we need to collect information on the existing conditions. We also want to know in question 6 what led to institutionalisation.

Question 7: Are/were there other people you care for because of disability, old age, sickness, mental health problems,… ?"

Question 8: Are there other people who helped you with taking care of the elderly? For instance a another family member, friends,…?"

Notes for the interviewers:

In question 8 we are NOT talking about health professionals or domestic help. If the ICG talks spontaneously about professional help or domestic help, let the interview flow naturally but we come back to that later on in the interview. We want to identify other informal caregivers who we could eventually interview if necessary

Question 9: Can you tell me a little bit more about your role as an informal caregiver before institutionalisation, what are or were the positive experiences of this caregiving role and what are/were the negative experiences?

Notes for the interviewers:

It is important to ask for both the positive (e.g. good relationship, fulfilment …) and negative sides (e.g. effect on the family life, work, pressure, sleep disturbance, financial problems)

Question 10: As caregiver, which tasks were you still doing specifically when mr/mrs was still living at home (tasks you are doing for the DEP because he/she can't do these anymore…) ?

Notes for the interviewers:

These issues might have come already in the previous open question, which is fine, just make sure the big items are covered. It is also important to ask what tasks the ICG is still doing now that the DEP is institutionalised.

We want to have a list of general care tasks the ICG conducts according to the DEP, including:

household activities (including food preparation, cleaning, washing, ironing, sewing, taking care of and playing with children, shopping or maintenance work, odd jobs, gardening), personal care (dressing/undressing, washing, hair care, shaving, going to the toilet, mobility around the house, eating and drinking), **medical care** (including arrange medication or medical support performed by the ICG as for example cleaning a wound),

practical support (mobility outside the house including assistance with walking or wheelchair, visiting family or friends, seeing to health care contacts, organizing help, physical aids or house adaptations and taking care of financial matters, receiving formal caregivers)

surveillance (this is more for the caregiver)…

It is important to get to know all the additional tasks performed by ICG since the person got ill or dependent (if she was doing household tasks before, that is not what we want to know, but if suddenly she/he has to do financial matters, she/he might not be used to it) as well as how it had affected previous tasks (e.g. less time to cook). We don't need to know what the person is still doing since institutionalisation as it is outside the scope of the project, of course when the ICG talks about the institutionalisation process you cannot just interrupt him/her.

Question 11: According to you, how much time per week did you spent doing these tasks (in general, not per task)?

Notes for the interviewers:

We want to know how much time during the week the person considered that he/ was providing care. Make sure you can identify whether the caregiver needed to be constantly by the side of the dependent elderly. In many cases, surveillance 24/7 is not identified as care time.

Question 12: In general, were some of these tasks more problematic than others and why? Which tasks did you feel most comfortable with and why?

Notes for the interviewers:

It is also important to find out how the informal caregiver felt about having to do these tasks as it might be very stressful for example to be responsible for making sure the DEP has taken his/her medication while other tasks might be easier to perform. For us it is also important to know which tasks were problematic as there may be a possibility (or policy measure, e.g. personal care) to get formal support for some tasks but not for others.

Question 13: How did these care tasks affected your daily life?

Notes for the interviewers:

We want to find out if specific task had a greater impact on employment, family life and relationships, leisure time, well-being (psychological and physical) We do not want to use a standardised list but just want to cover the main items.

It is important to know how the extra tasks the ICG had to perform, affected the tasks she/he was doing before (‘normal’ daily activities might suddenly become difficult to perform because of this extra tasks, for example doing grocery shopping as the ICG can’t leave the DEP alone at home…). This was probably addressed in question 10. But it is important to make sure that it was covered

Question 14: How did you cope with your new role and your new tasks? How did (*mention the person in question 8 that also helps with the dependent elderly)* help you in covering the needs of the dependent elderly ?

Notes for the interviewers:

With this question, we try to estimate the burden of the care tasks of the ICG and make a link with the next section.

Part 3: Formal services for the dependent elderly

Question 15: Which services (health professionals, domestic help, granny-sitting, undeclared worker, etc.) services did *mr/mrs(say the name)* receive at home? Were there other arrangements (e.g. with domestic help, health professionals, ICT support), adaptation to the house, other (undeclared worker)?

Notes for the interviewers:

Question 16 and 17 aim to gather information on "accessibility" to services. Be aware that the DEP may have already mentioned these services in question 8. Here you have to make sure that you are gathering new information if needed. Undeclared worker (in Germany usually means migrant populations looking after for DEP) refers to an individual looking after the DEP who does it on a "for-profit" base. Do not confuse with a neighbour for instance. In some countries, there is a thin line between the two as a neighbour can be paid without a formal contract.

Question 16: How or who informed you about the availability of those services?

Question 17: Did you had to follow any administrative procedure to access those services (for all of them)? Did somebody help you to follow the administrative procedures? Who and how?

Notes for the interviewers:

Question 16 and 17 aim to gather information on "accessibility" to formal services

Question 18: Can you tell us whether in some situations the services for the dependent elderly were interrupted or could not be delivered? For example a nurse who couldn't come, in acute situation when *mr/mrs (say the name of the person)* needed more help. *(If the answer is yes, then directly ask how did you deal with it?*

Notes for the interviewers

Here we are dealing with the concept of continuity of care and of coordination of care, what happens to the ICG when one of the professionals doesn't show up, or is absent for a while. A bad relationship with the formal caregiver can also be included here.

Question 19: How were the costs of the professional services covered for?

Notes for the interviewers

This is to understand financial interventions from the authorities, out-of-pocket expenses of the DEP, any well as financial intervention of the ICG. Be aware that in couples, the distinction between ICG or DEP out-of-pocket expenses may not be relevant.

Question 20: In the months before mr or mrs (name DEP) was institutionalised, did the amount or type of services received by the *mr/mrs (say the name of the person)* changed? *(If the answer is yes, then directly ask how and why?*

Notes for the interviewers

It is important to find out what had changed over time in order to see what might have led to institutionalization.

Question 21: Are there other services that should have been helpful to cover the care need of *mr/mrs (say the name of the person)*, but he/she didnot receive? *(If he/she mentions something, then ask directly what are the reasons for not using* them (financial reasons, poor quality, accessibility issues, values, bad reputation, the DEP does not want to)?

Part 4: Formal services for the informal caregiver

Introduction question to this part: “So far we have been talking a lot about the help that was provided for *(mr/mrs say the name of the DEP)*. Now we want to talk a little bit more about support measures that might have helped you or that could have helped you in looking after *(mr/mrs say the name of the DEP)*. We are not talking about help from other family members, but we want to talk about measures that exist or could be developed by the local government, the state, … in order to support you”

Notes for the interviewers

The following questions aims at having an in-depth perspective on services for the informal caregiver. Knowing whether they benefited from different policy measures is important but we must have a larger perspective concerning their overall experience. In general we need to know:

- When and how did they learn that those measures existed? (In the beginning of the care process, through the GP,…)
- How did they deal with the administrative requirements to access those measures?
- How have the different measures helped them (or not helped them) in looking to look after the DEP and in avoiding institutionalization?

Be aware that this is very country specific and covers a lot of measures: caregiver allowance, personal budget, pension contribution and unemployment benefits. It can also be understood as reducing out-of-pocket expenses for care services (vouchers, tax-deductions)

In question 13 we have already asked how being a caregiver has affected their daily life, so some of the following questions will be related to that question

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Question 22: Did you benefit from home care services (e.g. nurse care, etc..) because you have a health related conditions?

Notes for the interviewers

These services may be simultaneously provided to the DEP and ICG. These services may also be used to have helped the person to cope with the care burden related to providing informal care (e.g. granny-sitting, psychological support). If the latter is the case then try to find out more about it (since when did you have access to them? Was it useful?)

Question 23: Can you tell me whether you have personally benefited from any financial protection or remuneration from local authorities related to looking after *mr/mrs (say the name of the person?)*? *(If the answer is yes, then directly ask how it has helped them to reduce any financial stress related to looking after the DEP)*

Notes for the interviewers

Ask the question in a very open way and leave it up to the ICG to freely talk. If there is no reply to this question or the ICG finds the question too difficult, following prompts (see international comparison and YW check list) can help:

Caregiver allowance

Personal budget (used by the DEP to remunerate them)

Social protection (Pension contributions or flexibility in unemployment benefit conditions)

Employment, maintaining employment via workplace policies as well as national policies

Question 24: Have you ever considered whether the government could have considered compensating your care work (how and why)? Would this have reduced any difficulties that you were experiencing at that moment when you were looking after mr/mrs? Could this have influenced how you cared for mr/mrs or your relationship with him/her?

Notes for the interviewers

This is a possibility in different countries but in various ways: from a labour contract, to just a small financial compensation. Be aware that the person may have mentioned in the previous question that he/she already benefits from some financial support. In addition, here we mention government intervention but sometimes the DEP determines the access to the financial support.

If the ICG already received financial remuneration, we want to get an in depth view on how it had changed his/her life.

If the ICG did not receive financial support, we want to know what would have been the impact of such a policy measure on the ICG life and in the way he/she looked after the DEP?

Question 25: Were there services available, that you may have used or not used, to take a break from your care task, for instance when you were ill or that allowed you to go on holidays? Can you tell me more about those services (why did you us them, why did you not use them)? How did you find out about these services?"

Question 26: Have you had access to information on how to care for mr/mrs (say the name of the person)? (If the answer is yes, then directly ask who provided the information, the information content and how it has help her/him.

Note for the interviewers

We want to find out about availability of services or information, explaining how, e.g. to provide personal care or deal with aggressive behaviour from the DEP, allowing the ICG to take better care of the DEP.

Question 27: Were there specific services that you received without which it would have been very difficult to care for the *mr/mrs (say the name of the person)* in their home? Can you tell us why they were so important?

Question 28: What other services could have been helpful to allow you to continue to look after mr/mrs. *(say the name of the person) at home (and avoid institutionalisation)?*

Notes for the interviewers

Questions 26 and 27 will cover the help received, that was missing or needed in order to prevent institutionalization(e.g. even if ICG is not aware of these measures)

Question 29: Do you feel that your contribution in caring for mr/mrs*. (say the name of the person)* was recognized by your social environment (e.g. family, friends? How about the recognition from health care professionals (partnership, awareness of difficulties)? And concerning the government?

Notes for the interviewers:

Here we want to find out whether the ICG feels that his/her role was officially and unofficially recognized (appreciated). Being officially recognized as an informal caregiver gives you a right to certain benefits in all countries except France (but different benefits in different countries) but people might not be aware of this.

As a final question, I would like to ask you whether there is anything else you would like to add that has not been discussed yet in relation to your role as caregiver and that you feel might be of importance from your perspective or from your experience?

Thank you very much for your valuable input.

Appendix 11.5. Semi-structured interview guide for dependant elderly (DEP) living in the community (version 2A)

Ethical reminder before starting the interview

- The information collected in this interview will be treated with confidentiality and your name as well as other details that may reveal your identity will be coded in the template as well as in the final report and in any in further publications
- The duration of the interview is maximum 1 hour and will be recorded with your permission.
- Make sure the person reads the informed consent form
- Not all individuals will understand what an “informal caregiver” means, be aware of this when you are explaining the research question

Interview n°:

Gender of the DEP

Date of the interview:

Mode of recruitment:

Country / region:

Contact:

Part 1: Introduction to the research

Question 1: Can you tell us a little bit more how you organise your day? (What do you do and how do you do it)

Question 2: Have your care needs changed during the past 6 months? Why and how have they changed?

Note for the interviewer:

This first part aims to depict as accurately as possible the situation from the DEP’s point of view

We want to know whether there has been an evolution of the care needs of the DEP

Part 2: Needs covered by ICG

Question 3: We would like to talk about the help you receive from the people around you. We know that *mrs/mr (say the name)* cares for you. Can you tell us a little bit more what he/she does to support you since you became ill or since you became more dependent?

Note to the interviewers:

These issues might have come already in the previous open question, which is fine, just make sure the big items are covered.

We want to have a list of general care tasks the ICG conducts according to the DEP, including:

household activities (including food preparation, cleaning, washing, ironing, sewing, taking care of and playing with children, shopping or maintenance work, odd jobs, gardening), personal care (dressing/undressing, washing, hair care, shaving, going to the toilet, mobility around the house, eating and drinking), **medical care** (including arrange medication or medical support performed by the ICG as for example cleaning a wound),

practical support (mobility outside the house including assistance with walking or wheelchair, visiting family or friends, seeing to health care contacts, organizing help, physical aids or house adaptations and taking care of financial matters, receiving formal caregivers)

surveillance (this is more for the caregiver)…

Question 4: Can you think of anybody else who supports you or your *mrs/mr (say the name)* since you are ill or dependent?

Note for the interviewers:

This is an open question. They may talk about health professionals and other family members or friends

Question 5: Would you prefer that health professionals performed the tasks done by the ICG mrs/mr (say the name)? (Depending on the answer, directly address one of the following questions)

- If you would prefer that somebody else does these task, why is it not the case at the moment (financial, access reasons)?
- If you are happy with the help provided can you tell us a little bit more why?

Note to the interviewers:

It is also important to find out how the DEP feels about having to be cared for by his/her caregiver… because some tasks can be delicate, give an unwanted image of him/herself … Also to find out if some tasks practically or psychologically difficult to be performed by the ICG (from the DEP’s point of view) ?

It is important to ask for both the positive and negative sides of the situation (at relationship level, effect on the family, …)

Part 3: Formal services for the DEP

Question 6: Can you tell me a little bit more on what kind of professional help you get at home? *(Depending on the answer, directly address one of the following questions)*

- If he/she receives professional help then: How are these services paid (personal budget, personal out-of-pocket expenses, vouchers …)?

Note to the interviewers:

We are talking about the home care services (nurses, physiotherapist, occupational therapist, domestic aid, ICT, “granny-sitting” …), but also other professional help (cleaning services…). Also the informal caregiver may be paying for the services. This last point is important.

People can receive cash-for-care benefits and to use it according to their preferences. Be aware that cash-for-care benefits vary in each country.

Question 7: What’s your experience with these services? In what way do they help you to stay at home?”

Note to the interviewers:

We want to know the positive and negative aspects about being cared for at home

Question 8: Can you tell us whether you are happy being cared for at home and why? When and how could this change, when would you no longer feel comfortable to stay at home?

Note to the interviewers:

We want to know what their opinion is concerning being institutionalized and again on how formal services combined with ICG help can help in avoiding the institutionalization process

Question 9: In the past six months, has the help provided at home (health professional, ICT, informal caregiver (e.g. if he was sick what happened) changed? If yes, can you describe to us what lead to those changes?

Note to the interviewers:

Try to know if something has changed for the ICG, the why and how are important, has the care burden intensified (e.g. did the health condition get worst), did something else happen…

Question 10: Do you sometimes go outside your home to participate in organised activities or for example day care centre? *(Depending on the answer, directly address one of the following questions)*

- If yes, what is your experience with them (positive, negative)?
- If no, why haven't you considered using them (prompts with for example day care centres…)? (Financial, access reasons)?

Note to the interviewers:

This should be a understood as regular activities (note: exclusion of visits to physicians, physiotherapists,…). Does the DEP goes regularly in a day care centre, support activities that could offer respite to his/her caregiver

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Question 11: Are there other services that could be useful to help you but that you haven't got at the moment *(mention the tasks that he previously as being a weak point*)?

- If yes: Why would they be useful (e.g. what solution does it offer to financial problems, poor quality of current services, accessibility issues, values, bad reputation)?

Note to the interviewers:

You may propose some existing options in each country: domestic help, health professionals, ICT support (alarm system…), adaptation to the house ?

Part 4: Formal services for the ICG

Introduction discussion: So far we have been talking a lot about the help that you receive at home, but now we want to talk a little bit more about things that could help your caregiver to help you. We are not talking about help from other family members, but we want to look at things that exist from the local government, the state

Question 12: If *mrs/mr (say the name)* needs to go somewhere, needs something for himself, (for example he/she needs to go to the doctor or see a friend). What do you do or what happens? *)? (Depending on the answer, directly address one of the following questions)*

- If a services/professional provides company/surveillance to the DEP you may ask: What is your experience with these services?

Note to the interviewers:

We want to know here which services are used by the ICG that could relieve his/her burden, we are talking about TIME OUT for the informal caregiver (short time stay, day care,…).

Question 13: Are there some services or information that you have used to help your caregiver?”

Note to the interviewer:

For us as researchers it is important to know in what way these measures have helped the informal caregiver or have not helped him/her . Be aware of country specific advantages. Some services are granted to the caregiver if he is declared as an official ICG

Question 14: How would you feel about giving a financial remuneration to the person who cares for you?

Note to the interviewers

Being officially recognized as an informal caregiver gives you a right to certain benefits in all countries except in France (but different benefits in different countries) but people might not be aware of this

Most of this basic information for the dyads should have been filled by the informal caregiver (the interview with the informal caregivers comes first), in addition to the consent form, check at the end of the interview that everything was filled in (bring the basic questionnaire with you).

Question 15: As a final question, I would like to ask you whether there is anything else you would like to add that has not been discussed yet and that you feel might be of importance from your perspective or from your experience?

Thank you very much for your valuable input.

Appendix 11.6. Semi-structured interview guide for dependant elderly (DEP) living in institution (version 2B)

Ethical reminder before starting the interview and things to remember whilst doing the interview

- The information collected in this interview will be treated with confidentiality and your name as well as other details that may reveal your identity will be coded in the template as well as in the final report and in any in further publications

- The duration of the interview is maximum 1 hour and will be recorded with your permission.

- Make sure the person reads the informed consent form

- Not all individuals will understand what an "informal caregiver" means, be aware of this when you are explaining the research question

- Make sure that you stress which situation you are talking about, sometimes the question is related to the home situation (before institutionalisation) and other questions are related to the institution

Interview n°:

Gender of the DEP

Date of the interview:

Mode of recruitment:

Country / region:

Contact:

Part 1: Introduction to the research

Question 1: Can you tell us a little bit more how you organise your day here?

Question 2: Can you tell us whether you were happy being cared for at home and why? When and how did this change, when was it no longer possible for you to stay at home, what happened?

Note for the interviewer:

This first part aims to depict as accurately as possible the situation from the DEP's point of view

We want to know whether there has been an evolution of the care needs of the DEP before he/she went to the institution, was there a specific even that led to institutionalisation (like a fall, …)

Part 2: Needs covered by ICG

Question 3: We would like to talk about the help you received from the people around you when you were still living at home. We think that *mrs/mr (say the name)* cared for you. Can you tell us a little bit more what he/she did to support you since you became ill or dependent?

Note to the interviewers:

These issues might have come already in the previous open question, which is fine, just make sure the big items are covered.

We want to have a list of general care tasks the ICG conducts according to the DEP, including:

household activities (including food preparation, cleaning, washing, ironing, sewing, taking care of and playing with children, shopping or maintenance work, odd jobs, gardening), personal care (dressing/undressing, washing, hair care, shaving, going to the toilet, mobility around the house, eating and drinking), **medical care** (including arrange medication or medical support performed by the ICG as for example cleaning a wound),

practical support (mobility outside the house including assistance with walking or wheelchair, visiting family or friends, seeing to health care contacts, organizing help, physical aids or house adaptations and taking care of financial matters, receiving formal caregivers)

surveillance (this is more for the caregiver)…

Question 4: Can you think of anybody else who supported you or your *mrs/mr (say the name)* since you were ill or became dependent?

Note for the interviewers:

This is an open question. They may talk about health professionals and other family members or friends

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Question 5: Would you have preferred that health professionals performed the tasks done by the ICG *mrs/mr (say the name)? (Depending on the answer, directly address one of the following questions)*

- If you would have preferred that somebody else did these task, why was it not the case (financial, access reasons)?
- If you were happy with the help provided can you tell us a little bit more why?

Note to the interviewers:

It is also important to find out how the DEP felt about having to be cared for by his/her caregiver… because some tasks could have been delicate, gave an unwanted image of him/herself … Also to find out if some tasks practically or psychologically difficult to be performed by the ICG (from the DEP's point of view) ?

It is important to ask for both the positive and negative sides of the situation (at relationship level, effect on the family, …)

Part 3: Formal services for the DEP

Question 6: Can you tell me a little bit more on what kind of professional help you received when you were still living at home? *(Depending on the answer, directly address one of the following questions)*

- If he/she received professional help then: How were these services paid for(personal budget, personal out-of-pocket expenses, vouchers …)?

Note to the interviewers:

We are talking about the home care services (nurses, physiotherapist, occupational therapist, domestic aid, ICT, "granny-sitting" …), but also other professional help (cleaning services…). Also the informal caregiver may be paying for the services. This last point is important.

People can receive cash-for-care benefits and to use it according to their preferences. Be aware that cash-for-care benefits vary in each country.

Question 7: What was your experience with these services? In what way did they help you to stay at home?"

Note to the interviewers:

We want to know the positive and negative aspects about being cared for at home

Question 8: Just before you came to this institution, did the help provided at home (health professional, ICT, informal caregiver (e.g. if he was sick what happened) changed? If yes, can you describe to us what lead to those changes?

Note to the interviewers:

Try to know if something had changed for the ICG, the why and how are important, has the care burden intensified (e.g. did the health condition get worst), did something else happen…

Question 9: Did you sometimes go outside your home to participate in organised activities or for example day care centre? *(Depending on the answer, directly address one of the following questions)*

- If yes, what was your experience with them (positive, negative)?
- If no, why didn't you consider using them (prompts with for example day care centres…)? (Financial, access reasons)?

Note to the interviewers:

This should be a understood as regular activities (note: exclusion of visits to physicians, physiotherapists…). Did the DEP go regularly in a day care centre, support activities that could offer respite to his/her caregiver

Question 10: Were there other services that could have been useful to help you to stay at home? *(Mention the tasks that he previously as being a week point*)?

- If yes: Why would they have been useful (e.g. what solution did it offer to financial problems, poor quality of current services, accessibility issues, values, bad reputation)?
- If no: Why not?

Note to the interviewers:

You may propose some existing options in each country: domestic help, health professionals, ICT support (alarm system…), adaptation to the house?

Part 4: Formal services for the ICG

Introduction to this part: So far we have been talking a lot about the help that you received at home, but now we want to talk a little bit more about things that could have helped your caregiver to help you. We are not talking about help from other family members, but we want to look at things that exist from the local government, the state

Question 11: If *mrs/mr (say the name)* needed to go somewhere, needed something for him or herself, (for example he/she needed to go to the doctor or see a friend). What did you do or what happened*)? (Depending on the answer, directly address one of the following questions)*

- If a services/professional provided company/surveillance to the DEP you may ask: What was your experience with these services?

Note to the interviewers:

We want to know here which services were used by the ICG that could have relieved his/her burden, we are talking about TIME OUT for the informal caregiver (short time stay, day care…).

Question 12: Are there some services or information that you did use to help your caregiver?"

Note to the interviewer:

For us as researchers it is important to know in what way these measures have helped the informal caregiver or have not helped him/her . Be aware of country specific advantages. Some services are granted to the caregiver if he is declared…

Question 13: How would you feel about giving a financial remuneration to the person who cared for you?

Note to the interviewers

Being officially recognized as an informal caregiver gives you a right to certain benefits in all countries except in France (but different benefits in different countries) but people might not be aware of this

Most of this basic information for the dyads should have been filled by the informal caregiver (the interview with the informal caregivers comes first), in addition to the consent form, check at the end of the interview that everything was filled in (bring the basic questionnaire with you).

Question 14: As a final question, I would like to ask you whether there is anything else you would like to add that has not been discussed yet and that you feel might be of importance from your perspective or from your experience?

Thank you very much for your valuable input.

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