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# Informal care modelling: Economic evaluation and applications to an innovative support program and respite care for informal carers in the Lyon metropolitan area

Wilfried Guets

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Wilfried Guets. Informal care modelling: Economic evaluation and applications to an innovative support program and respite care for informal carers in the Lyon metropolitan area. Economics and Finance. Université de Lyon, 2021. English. NNT : 2021LYSE2028 . tel-03374388

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N° d'ordre NNT : 2021LYSE2028

## THESE de DOCTORAT DE L'UNIVERSITÉ DE LYON

Opérée au sein de

L'UNIVERSITÉ LUMIÈRE LYON 2

**École Doctorale : ED 486**

**Sciences économiques et de Gestion**

Discipline : Sciences économiques

Soutenue publiquement le 7 juillet 2021, par :

**Wilfried GUETS**

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### **Modélisation de l'aide informelle**

#### **Évaluations économiques et application au dispositif innovant d'accompagnement et de répit des aidants informels de la métropole de Lyon**

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UNIVERSITÉ DE LYON 2 - ECOLE DOCTORALE SCIENCES ECONOMIQUES ET GESTION

UNIVERSITÉ LUMIÈRE LYON 2

Groupe d'Analyse et de Théorie Economique - UMR5824

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Thèse de Doctorat en Sciences Economiques

*Présentée et soutenue publiquement par*

**Wilfried Guets**

*le 7 juillet 2021*

en vue de l'obtention du grade de docteur de l'Université de Lyon

délivré par l'Université Lumière Lyon 2

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MODÉLISATION DE L'AIDE INFORMELLE : EVALUATIONS  
ÉCONOMIQUES ET APPLICATIONS AU DISPOSITIF  
INNOVANT D'ACCOMPAGNEMENT ET DE RÉPIT DES  
AIDANTS INFORMELS DE LA MÉTROPOLE DE LYON

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# Avertissements

*University Lumière Lyon 2 is not going to give any approbation or disapprobation about the thoughts expressed in this dissertation. They are only the author's ones and need to be considered such as.*

# Dédicaces

*A ma Mère Victorine, à mon père Séraphin, à tous les GUETS pour tous vos sacrifices*

&

*A Arnelle, pour ton soutien et ta patience*

# Acknowledgements

Cette thèse de Doctorat représente la traversée d'un long périple initiatique à la recherche, dont l'aboutissement est un ensemble d'actions et de contributions individuelles et institutionnelles auxquelles je souhaite rendre hommage.

Je tiens tout d'abord à exprimer ma profonde gratitude à l'endroit de mon directeur de thèse Lionel Perrier pour l'encadrement durant ces quatre années de ma vie. Lionel, vous m'avez accueilli au sein de votre équipe du Centre de Lutte contre le Cancer Léon Bérard (CLB), sous votre supervision, et vous avez guidé mes pas tout au long de ce séjour. Lionel, vous avez été un acteur principal dans ce long processus, à travers lequel j'ai été initié à la recherche, au travail en équipe, au sens des responsabilités, aux enjeux et exigences dans la conduite des travaux de recherche. En plus des connaissances scientifiques et de la rigueur, vous avez aussi su me transmettre des qualités telles que la passion et la disponibilité. Particulièrement, la patience est une qualité que j'ai appris en travaillant avec vous, « ingrédient » nécessaire sur le volet de la valorisation scientifique, qui a souvent été un moment éprouvant. J'ai vraiment apprécié de faire partie de votre équipe, le pôle innovations et stratégies de santé au CLB.

Je tiens également à adresser mes sincères remerciements aux membres de mon jury de thèse. Je remercie particulièrement Isabelle Durand-Zaleski et Jean-Michel Josselin pour avoir accepté le rôle de rapporteur de cette thèse. De la même manière, je remercie Martine Audibert, Sonia Paty et Tao Wang.

Je souhaite remercier l'ensemble des équipes du Centre Léon Bérard, sous la direction de Jean-Yves Blay pour l'accueil et pour le séjour durant ces quatre années. Je remercie l'équipe de la Direction de la Recherche Clinique et de l'Innovation (DRCI), dirigée par David Pérol, où j'ai rencontré des professionnels du domaine médical et des disciplines

connexes et le département des sciences humaines et sociales dirigé par Marc Billaud. Je n'oublie pas de faire un clin d'œil et de remercier des personnes telles que Jérémy, Magali et Youhenn pour les multiples merveilleux moments passés en votre compagnie. Je remercie l'Institut de Recherche en Santé Publique (IReSP) et la Caisse Nationale de Solidarité pour l'Autonomie (CNSA) pour ce financement de thèse ("*PERRIER-AAP16-Hand7-25*"). En effet, cette recherche a bénéficié de l'aide de la Caisse Nationale de Solidarité pour l'Autonomie (CNSA), dans le cadre de l'appel à projets lancé par l'IReSP en 2016. Je remercie la *Fondation APRIL*, la *Fondation France Répét* et toute son équipe de travail, sans oublier tous les membres de l'équipe de recherche sur le "*Projet répét*". Je remercie la Direction de la recherche, des études, de l'évaluation et des statistiques (Drees) pour les invitations aux multiples séminaires des enquêtes CARE à Paris et l'accès aux bases de données des différentes enquêtes HSA (2008) et CARE (2015). Je remercie le programme ICPSR pour l'invitation à son école d'été portant sur le "*Secondary Analysis in Disability and Rehabilitation Research*" à l'Université du Michigan. Je remercie la *Westat*, la *Bloomberg School of Public Health* de l'Université Johns Hopkins et l'*Institute for Social Research* de l'Université du Michigan pour l'accès aux bases de données du *National Health and Aging Trends Study (NHATS)* et du *National Study of Caregiving (NSOC)*. A tous, trouvez en ces quelques mots l'expression de ma profonde gratitude.

J'exprime ma gratitude à l'Université Lumière Lyon 2 pour l'accueil et la formation d'excellence au sein de l'École doctorale ED486 SEG, Sciences économiques et gestion sous la direction de Isabelle Royer.

Dans la même veine, je remercie tout le personnel administratif, les chercheurs du laboratoire de recherche GATE Lyon Saint-Etienne (L S-E) sous la direction à laquelle se sont succédées Sonia Paty et Izabela Jelovac. Le cadre et les conditions de travail dont j'ai pu bénéficier m'ont permis de pouvoir réaliser mes travaux de recherche dans des conditions idéales. Travailler au sein des locaux du GATE durant des journées entières n'aurait pas connu le même engouement sans la présence de collègues doctorants (invités), post-doctorants, stagiaires auxquels je souhaite exprimer ma reconnaissance: Alice, Aurelie, Claire, Clément, Charlotte, Fabio, Idrissa, Jocelyn, Kamel, Julien, Maria, Marius, Maxime, Morgan, Rawaa, Rémi, Siwar, Sorravich, Thomas, Tiruo, Valentin, Vincent, Yao, etc.

J'exprime ma profonde gratitude à Hareth Al Janabi, pour la merveilleuse opportunité de collaboration scientifique et pour m'avoir accueilli et permis de découvrir la prestigieuse Université de Birmingham en Angleterre. Je me souviens encore de nos beaux moments de réflexion et de discussion qui se sont succédés tout au long mon immersion au sein de votre équipe de recherche scientifique. Votre simplicité, disponibilité, et sens de l'écoute ainsi que votre partage de connaissance ont été d'un apport inestimable durant ma phase d'initiation à la valorisation scientifique.

Je souhaite remercier l'École des Mines de Saint-Etienne, notamment du département Centre Ingénierie et Santé (CIS), avec à sa tête Vincent Augusto, pour l'accueil en tant que doctorant invité. Merci à Oussama Batata pour sa collaboration et son travail durant ce séjour très éprouvant, mais riche en nouvelles connaissances, notamment dans le domaines des techniques et des sciences de l'ingénieur. Je n'oublie pas de faire un clin d'œil à Denis Koala pour son expertise, son soutien et sa disponibilité.

Je voudrais remercier quelques personnes qui ont joué un rôle majeur à l'amorce de cette aventure. Merci à Samuel Fambon (*de regrettée mémoire*) pour son soutien inconditionnel. J'exprime toute ma gratitude à Albert Zeufack qui n'a cessé de me motiver sur ce sentier d'initiation à la recherche. Merci à André-Marie Tapue, Yann Tapsoba pour votre apport inestimable. Merci à toi Fadhi Dkhimi pour ton soutien et ton expertise. Merci à toi Marie-Pierre Alliod pour tout le soutien, la joie de vivre, l'amitié et la marque de confiance. Merci à toi Jeannot Patrick Ngoulma Tang pour tes précieux conseils, ton partage d'expérience de la vie et ta disponibilité sans faille. A vous Eric Poinsignon et Cassandre Debaud, durant ces quelques mois passés en votre compagnie, m'ont été donnés d'avantage d'inspiration et d'ouverture à d'autres horizons. A toi Eric, je suis reconnaissant du fait que tu m'as apporté tout ton soutien au moment où j'en avais vraiment besoin. Toi Pierre-Bernard Le Bas, à qui je dis merci, toute cette histoire n'aurait certainement pas été écrite de cette aussi belle manière et connue un tel retentissement si je n'avais pas fait ta connaissance. A vous tous, « *je ne vous oublierai Jamais* »!

L'espace et le temps ne me permettraient certainement pas de citer tout le monde. Je souhaiterais que tous trouvent ici l'expression de ma profonde gratitude et de ma reconnaissance infinie!

# List of Abbreviations

<b>AIME</b>	: Aidants de la Métropole de Lyon
<b>BPMN</b>	: Business Process Model and Notation
<b>CARE</b>	: (Enquête) Capacités, Aides et REssources des seniors
<b>CBA</b>	: Cost-benefit analysis
<b>CEA</b>	: Cost-effectiveness Analysis
<b>CG</b>	: (Informal) Carer or Caregiver
<b>CHEERS</b>	: Consolidated Health Economic Evaluation Reporting Standards
<b>CIS</b>	: Centre Ingénierie et Santé
<b>CLB</b>	: Centre Léon Bérard
<b>CLIC</b>	: Centre Locaux d'Information et de Coordination
<b>CMA</b>	: Cost-Minimisation Analysis
<b>CNSA</b>	: Caisse Nationale de Solidarité pour l'Autonomie
<b>CUA</b>	: Cost Utility Analysis
<b>CVM</b>	: Contingent Valuation Method
<b>DALY</b>	: Disability Adjusted Life Years
<b>DES</b>	: Discrete Event Simulation
<b>DRCI</b>	: Direction de la recherche clinique et de l'innovation
<b>DREES</b>	: Direction de la Recherche, des Études, de l'Évaluation et des Statistiques
<b>EE</b>	: Economic Evaluation
<b>FC</b>	: Formal Care
<b>GDP</b>	: Gross domestic product
<b>HDCS</b>	: Health and Disabilities Households survey
<b>HUI</b>	: Health Utilities Index
<b>HSA</b>	: (Enquête) Handicap-Santé Ménages
<b>HTA</b>	: Health Technology Assessment
<b>IACO</b>	: International Alliance of Carer Organizations
<b>IC</b>	: Informal Care
<b>ICER</b>	: Incremental Cost-Effectiveness Ratio
<b>INSEE</b>	: Institut national de la statistique et des études économiques
<b>IReSP</b>	: Institut de Recherche en Santé Publique
<b>ISPOR</b>	: International Society for Pharmacoeconomics and Outcomes Research
<b>IV</b>	: Instrumental Variable
<b>LTC</b>	: Long-Term Care
<b>MM</b>	: Markov Model
<b>NHATS</b>	: National Health and Aging Trends Study
<b>NIHR</b>	: National Institute for Health Research
<b>NSOC</b>	: National Study of Caregiving (NSOC)
<b>OECD</b>	: Organisation for Economic Co-operation and Development
<b>QALY</b>	: Quality Adjusted Life Years
<b>RC</b>	: Respite Care
<b>RCP</b>	: Respite Care Program
<b>SC</b>	: Standard Care
<b>SD</b>	: Standard Deviation
<b>WHO</b>	: World Health Organization

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# General Introduction

*“Caregiving can be one of the most rewarding aspects of the human experience, but it may be one of the hardest too. From a philosophical standpoint, it consists of a selfless contribution to the well-being and quality of life of those in need of care – a beautiful concept. However, in today’s society, the burden of caregiving on the health and well-being, access to the labour market, ability to balance paid work with care, and on the socialisation and education of informal carers is well documented.” (Eurocarers, 2020)*

The Eurocarers (European association working with and for informal carers), <sup>1</sup> assert that informal care can be burdensome and should be considered as a critical public health issue in most health systems. Caregiving does not influence only the carer health behaviour but also the care recipient.

## 0.1 Care recipients and informal carers: What have we learnt?

Technical and scientific progress that emerged in the 19<sup>th</sup> century brought about changes and many upheavals both economically and socio-demographically. Therefore, with improved medical knowledge and practices, we have seen a reduction in mortality, but also an increase in the longevity associated with complex chronic diseases and needs of the elderly. In this situation where more than half of the population attain 85 years and

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<sup>1</sup>In french, Eurocarers stands for « Association européenne travaillant avec et pour les aidants non-professionnels ».

beyond, the main challenge of Long-Term-Care (LTC) <sup>2</sup> is to support people through the maximum attainable life expectancy in good health.

These changes have resulted in an epidemiological or health transition pointed out by declining mortality, followed by a demographic transition. These transitions were preceded by an improvement in hygiene, nutrition and the organisation of health services and cause of death transformation in which infectious diseases have been gradually substituted by chronic and degenerative diseases and road traffic accidents. The shift from, the “age of pestilence and famine”, “age of pandemic decline”, to the “age of degenerative and societal diseases” was accompanied by the reduction of the mortality rate (Eggerickx et al., 2018). The quasi - disappearance of infectious diseases as the primary cause of death has been due to a surge in chronic diseases (cardiovascular diseases and cancers) and societal diseases (smoking, alcoholism, traffic accidents, suicides, etc.).

### 0.1.1 Demographic trends and socio-cultural evolution

Ageing is a global issue. Therefore, most countries are experiencing an increase in the elderly population (United Nations, 2015) <sup>3</sup> (Figure 0.1). The process of ageing has started more than a century ago in many high-income countries and continued into the 21<sup>st</sup> century, including some developing countries. An ageing population is increasingly one of the most critical social changes of the 21<sup>st</sup> century, affecting social sectors such as finance and labour markets, goods and services demand (social protection), and family structures and intergenerational relationship.

While ageing is in many ways a significant demographic fact driven by changes in fertility and mortality, the increasing number of elderly persons in the population can produce far-reaching economic and socio-political impacts. Therefore, in many countries, the number of elderly persons increases faster than that of the younger and active working population (OECD, 2020b). Governments and health ministries have reviewed policies and refocused investments to address the growing pressure and the cost burden put on the health systems. It induced the demand for health care services

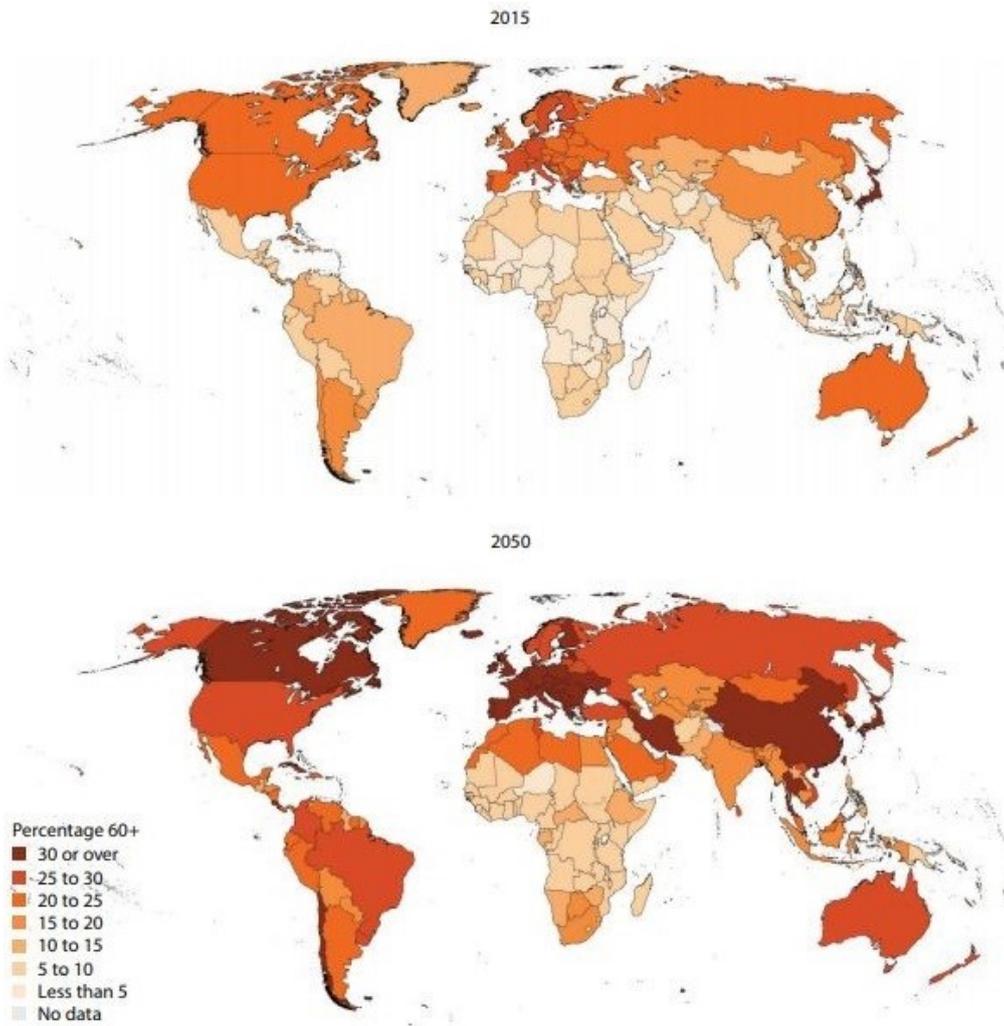
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<sup>2</sup>Long-Term Care (LTC) refers to a of range medical and non-medical support and services for patient or people with chronic illness and disabilities who cannot perform activities of daily living independently.

<sup>3</sup><https://www.un.org/en/development/desa/population/theme/ageing/index.asp>

and Assistive Technologies to prevent disability and avert non-communicable diseases and other chronic conditions by the elderly (Nations United, 2019). Countries might overcome these challenges by anticipating demographic changes and leveraging social capital in the family network.

**Figure 0.1** – Evolution of the population from 2015 to 2050



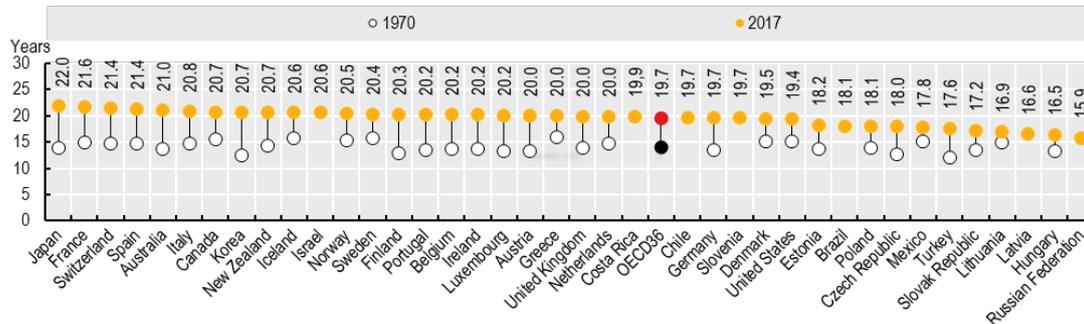
*Data source: World Population Prospects : The 2015 Revision*

Demographic evolution in OECD countries, for example, has shed light on many consequences related to the increase of LTC (Figure 0.2), such as the extension of the lifespan of people over 65 (elderly)<sup>4</sup>. Since the demand for health services for old people

<sup>4</sup><https://www.oecd.org/health/health-systems/long-term-care-workforce.htm>

has been increasing (PANAIT and Lavinia, 2012; Scheffler and Arnold, 2019), most health systems have raised concerns about resource availability, workforce sustainability and financial allocation to ensure care provision.

**Figure 0.2** – Life expectancy at age 65, 1970 and 2017 (or nearest year)

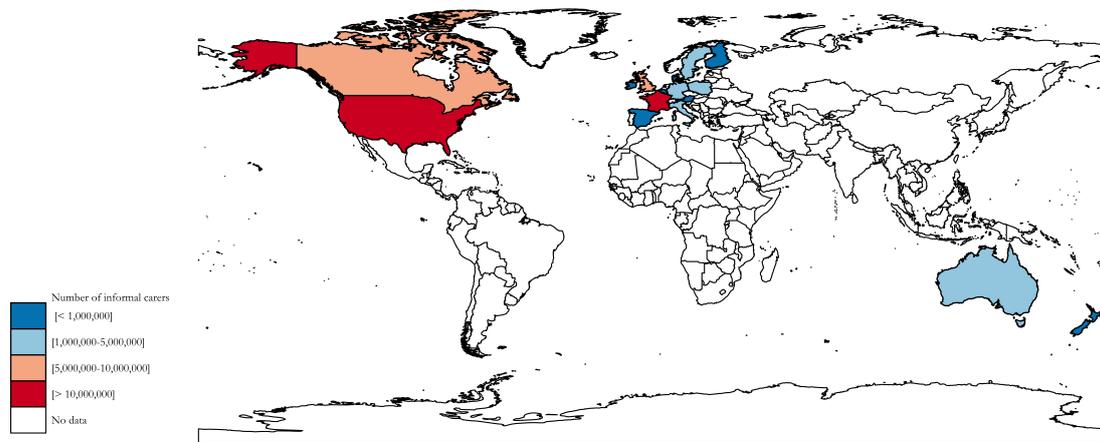


Source: OECD Health Statistics 2019 - OCDE (2019b)

To accommodate the structural changes and health policies dedicated to the elderly, strategies have been implemented which have progressively instituted care in the community settings. Thus, family and informal carers occupied a key role in family structure, socio-demographic, and cultural changes (Figure 0.3). With the transition to informal care, family members or close acquaintance occasionally or frequently experience more complex caregiving situations.

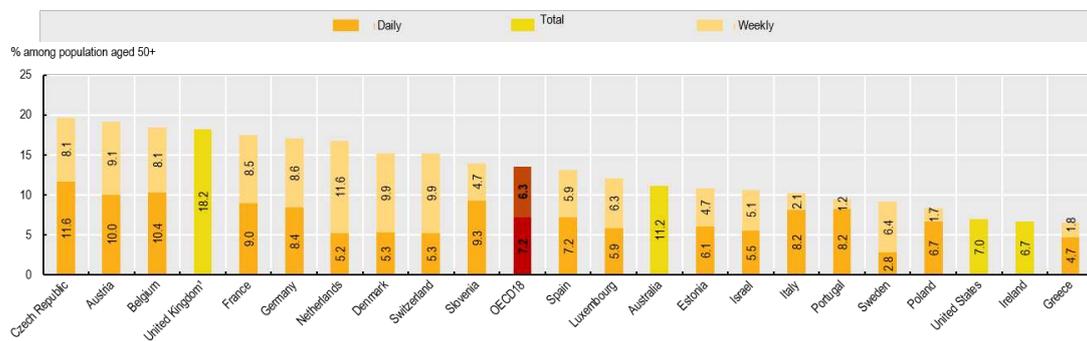
Informal carers are people who provide any help to the elderly, family members, friends and people in their social network, living in or out-home, in-need of assistance with daily tasks (OCDE, 2019a). In most OECD countries, informal carers represent an essential resource for care provision for people with LTC needs. Therefore, according to informal carer's ubiquity, the definition of informal carers differs from one country to another (Figure 0.4). Although Informal care provision generates a relative positive utility (Brouwer et al., 2005; Metzeltin et al., 2017; Pendergrass et al., 2019; Vernooij-Dassen et al., 2017), high caregiving intensity may have different consequences, such as reducing the labour force of carers at working age. These multiple consequences could increase the poverty level and prevalence of physical, psychosocial, and mental health problems.

Figure 0.3 – Informal carers mapping in the globe



Source: Author based on IACO carers facts

Figure 0.4 – Share of informal carers among the population aged 50 and over, 2017 (or nearest year)



Source: OECD Health Statistics 2019

The definition of informal carers differs between surveys (see Definition and comparability) - OCDE (2019d)

### 0.1.2 The support of older persons in LTC: The role of formal and informal care

With the population ageing across the world, many health care systems increasingly rely on the family structure as the primary support for older person, principally informal care provided in the community (Carrière et al., 2003; Verbakel, 2018). Then, the support

dedicated to older persons mobilises different resources such as formal and informal care. It is assumed that formal and informal care play a strategic role in the LTC, but there is no denying that informal care tends to be the most used resource. Some research indicated that informal care demand would increase in most OECD countries in the next decades (Van Houtven and Norton, 2004; Alders and Schut, 2019; Alders et al., 2019; Keegan et al., 2019).

Contrary to informal care provided by an unpaid informal carer, formal care is given by a health professional such as a nurse. Informal and formal care as LTC components can be assumed as complement or substitute (Bonsang, 2009; Burchardt et al., 2018; Chappell and Blandford, 1991; Van Houtven and Norton, 2004). For Bremer et al. (2017), the relationship between formal and informal care generally depends on the specific type of formal care considered. A higher informal care provision induces a lower demand for home care services and nurse visits but a significant proportion of outpatient visits (Bremer et al., 2017). Since the use of formal care conjointly with informal care by the recipient, in the situation of need and high chronic condition, and lack of an informal care network, formal (care) services should assist the informal care network. Thus, a complementarity between health systems is sought to share caregiving tasks' load, rather than a specific one (Burchardt et al., 2018; Chappell and Blandford, 1991; Suanet et al., 2012). However, factors influencing the preference in the choice of support services for the older person (formal and informal care) can also be the same for informal carers and the general population. Previous studies have investigated the factor associated with support services use, such as the availability or scarcity of services, cultural values, barriers, information (Hong et al., 2011; Ma and Nolan, 2017; Potter, 2016, 2018).

For Pickard et al. (2011), informal care provision divergences in European countries are affected by differences in socio-demographic factors and differences in long-term care systems between countries (Pickard et al., 2011). Therefore, there is an increase in LTC workers among family and informal carers in most OECD countries (Colombo et al., 2011). Many countries implement various packages regarding the increasing proportion of informal carers, including multiple components that focus on the informal carer, prioritising cash (i.e., financial assistance) and in-kind services (i.e., respite care).

### 0.1.3 Input and impact of informal care (in the society)

Given the prominence of informal care provision and its contribution to the health system, caring for an older person can be readily a factor of strain or a workload. Therefore, care provision induces a significant decrease in the labour force and participation in the labour market, necessarily for persons with a high burden of care. Research has shown that in addition to the work productivity reduction, informal care also generates absenteeism, coming late to work, lack of concentration at work (Fast et al., 1999; Gautun and Hagen, 2007). There is no doubt that health policies aiming to alleviate the workload and care provision burden for employed carers may increase their employability and adaptability to different situations engendered by care provision.

### 0.1.4 Recognition of informal carers: support services and policies

Since informal carers occupy a strategic role in the health system, it seems like it does not have a unanimous meaning across societies and the same recognition.<sup>5</sup> Various interventions are often implemented based on their importance and effectiveness, such as helping carers to combine caregiving responsibilities and labour work activity (i.e., flexible work arrangement) or reducing the physical and mental strain of care provision through support services (i.e., respite care, support group, counselling and training, and information) (Colombo et al., 2011).

#### 0.1.4.1 Work arrangement and care leave

**Work arrangement** The flexible work schedule is an alternative work arrangement (regular schedule) for people in the labour market by allowing employees to choose the beginning and the ending of their working days. It is considered an essential means to keep informal carers' productivity while ensuring their well-being and ability to continue the care provision. However, in some countries like Australia and the United Kingdom, informal carers who benefit from flexible working hours were less likely to receive a reduction of an hour for care. In Belgium, informal carers reported that having a flexible work schedule was enough to cope with care needs (Willemse et al., 2016).

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<sup>5</sup><https://www.embracingcarers.com/en/home/carerfacts/global-state-care.html>

Similar studies indicate that flexible work arrangement was more likely to facilitate the preservation of informal carers' (female) jobs and their presence in the labour market (Carmichael et al., 2005; Schneider et al., 2013). Those studies demonstrate that health policy should prioritise developing programs focusing on work scheduling flexibility (Chung et al., 2008).

**Care Leave** Other policies helping carers to combine care provision with paid work also rely on leave from work as a support scheme. Since the recognition of informal carers' role in most OECD countries, information on leave for carers is available for two-thirds of countries, even though conditions for leave tend to be limited and paid leave. Since parental leave was more prominent in most OECD countries, research indicates that it positively affects females' working hours and labour force participation for leave in the short term (Spiess and Wrohlich, 2008). However, having leave from work increases the demand for support services, particularly for a part of the day off per week, and respite care more generally (Koopmanschap et al., 2004).

Subsequently, to answer informal carers issues, the LTC system's reform has become necessary in most European countries. The cash-for-care schemes – allowances (and services provided to old-aged persons) represent a critical policy aimed at fostering care in the family and developing care markets, and limiting costs (Da Roit and Le Bihan, 2010). Therefore, cash-for-care benefits included cash transfers to the care recipient, carer, and household head to purchase or obtain care services (Colombo et al., 2011). Directed payments to carers can be included in cash benefits.

#### 0.1.4.2 Support services dedicated to informal carers

**Respite care** Respite care is one of the most popular support intervention used by family carers, consisting of a temporary relief service for families carers of people with disability (Levy and Levy, 1986; Warren and Cohen, 1985; Zirul et al., 1989). It can also be defined as temporary physical, emotional or social care to a person providing relief to informal carers from care provision to a person living with a disability (Gilmour, 2002). Respite is mostly sought when informal care become a burdensome activity and represent an alternative for care providers. The absence of respite care can exacerbate

specific informal carers' high risk of stress, mental and psychosocial troubles. Respite care can be different depending on the need of carers and type of "arrangement", meaning that respite care could be taken in-home, day-care or institution. The length of time for respite care influences the benefit of respite widely. According to the availability and use of respite care, assessing its effectiveness also sheds light on multiple issues such as caregiving's impact (physical and mental health) and arrangement choice preferences. Therefore, some research indicated that in-home respite has the merit of alleviating carers' constant sense of responsibility for their care recipients (Greenwood et al., 2012). Then, the use of adult day care by carers reduces the level of stress related to caregiving and leads to better psychological well-being (Måvall and Thorslund, 2007; Zarit et al., 1998). Several studies have been conducted on the impact of institutional respite care. The majority have shown the potential benefit of respite care for the carer and care recipient (Burdz et al., 1988; Larkin and Hopcroft, 1993; Scharlach and Frenzel, 1986; Seltzer et al., 1988; Smyer and Chang, 1999).

**Support group** The support group<sup>6</sup> is also recognised as an alternative to meet family and informal carers' needs (Schopler and Maeda, 1993). There is evidence about the potential benefit of the support group in the literature. Some empirical work indicates that the effect of a support group on carers of frail elderly did not reduce their subjective burden but seems to increase (Demers and Lavoie, 1996). It has been argued that cumulated and prolonged attendance in a support group positively affects carers' health (Dinkins, 2004). Then, carers below 55 years old are more likely to experience a positive effect of a support group than those aged 56 years old and above (Dinkins, 2004). However, participating in a support group influences the caregiving perception by accommodating self-identification as carers and a sense of personal competence (O'Connor, 2003; Wei et al., 2012).

**Counselling and training** Counselling and training are alternative support strategies that provide educative programs, short courses session programs, short courses, and exercises to carers (both carers and recipients) until they get sufficient knowledge and

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<sup>6</sup>The support group is defined as « a type of mutual helping group that comprises a group of people and a leader to share and deal some common need » (Nichols and Jenkinson, 2006).

skills to provide care. These interventions also aim to reduce the sense of burden and improve psychosocial outcomes in carers and recipients in the short run (Patel et al., 2004). Training can continue until informal carers deem to be sufficiently competent for caregiving. As it is the case for other different support services, carers are not always aware of their loved one's disease, and they sometimes assumed themselves to have enough training to ensure their caring role. Therefore, carers stress can be relieved through counselling (Pickard, 2004). Counselling and training programs are generally initiated at the local community level and are more available than respite care in informal settings. Since such programs' effects were not conclusive (Colombo et al., 2011), there is a need for more empirical findings.

**Information and coordination of services** Lastly, while informal carers may not always aware of services at their disposal, it is evident that they may struggle to find appropriate support in the context of a non-coordinate services supply. The implementation of information centres and the coordination of services represent a way of providing continuous assistance to carers. These services may assist carers in the caring role's perception and support orientation towards adapted and best support services. Many support centres provide information and assistance on all relevant issues related to population ageing and elderly needs and carers' needs. For example, there is the Local Centres of Information and Co-ordination (CLIC)<sup>7</sup> for the elderly and "*La Maison des Aidants*" for carers in France.<sup>8</sup>

An international view shows that health policies in many countries establish informal carers' initiative to address the consequences of population ageing and changes in family structure.<sup>9</sup> Then, a number of OECD countries have implemented multiple policies to support carers to mitigate the adverse effects of informal care. These measures include, in general, paid care leave (e.g. Belgium and France), flexible work schedules (e.g. Australia and the United States), respite care (e.g. Austria, Denmark, France, and Germany) and counselling/training services (e.g. Sweden) (Eurocarers, 2016; IACO, 2018; Zigante, 2018).

<sup>7</sup>In French, C.L.I.C : *Centre Local d'Information Coordination Gérontologique*

<sup>8</sup>Since 2018, the Respite care program in Lyon metropolitan area propose a coordinate supply of information and respite care to the carer-recipient dyad.

<sup>9</sup><https://www.embracingcarers.com/en/home/carerfacts.html>

### 0.1.4.3 Informal carers recognition

The majority of OECD countries implemented a variety of support strategies for carers recognition.<sup>10</sup> The Law on the Adaptation of Society to Ageing (*Loi relative à l'adaptation de la société au vieillissement*) is adopted in 2015 in France<sup>11</sup>. This law includes three main pillars: anticipating the loss of autonomy, the overall adaptation of society to ageing, and supporting people who are losing autonomy. Rapp et al. (2018) show that the institutionalisation of older people living with Alzheimer's disease may significantly reduce informal carers' psychological burden (Rapp et al., 2018). Subsequently, the ACT No. 2019-485 of May 22, 2019 was adopted to promote the recognition of family carers.<sup>12</sup> This law particularly empowers the use of carer leave and to secure the social rights of the carer. Since October 2020, all carers have the opportunity to have paid time off to provide care to a disabled or frail loved one (Ministère des Solidarités et de la Santé, 2020).<sup>13</sup>

Countries like the U.S. formally recognised informal carers, even though they are not considered as a protected class at the federal level. Based on government support<sup>14</sup>, carers can benefit from financial assistance, income, tax credit (Van Houtven and Norton, 2004). Since carers can apply for Social Security disability benefits for the recipient, there is still limited access to respite care through the federal program.<sup>15</sup>

Similarly, in the United Kingdom (UK), there is a formal recognition of informal carers. The Carers Allowance is the primary support for informal in the UK. However, they must meet some specific criteria to qualify and may not benefit from another

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<sup>10</sup>These policies included cash benefits to carers or cash-for-care allowances for recipients which can be used to pay informal carers, or periods of paid leave.

<sup>11</sup>The Government recognition includes: The Law on the Adaptation of Society to Aging (2015) and French Social and Family Action Code (2015).

<sup>12</sup><https://www.legifrance.gouv.fr/jorf/id/JORFTEXT000038496095?r=Erw6sqvRWI>

<sup>13</sup>Decree No. 2020-1208 of October 1, 2020 on the daily allowance for carers and the daily allowance for parental presence; <https://www.gouvernement.fr/le-conge-proche-aidant-est-devenu-une-realite>

<sup>14</sup>The Government recognition includes: Recognise, Assist, Support and Engage (R.A.I.S.E.) Family Caregivers Act ; The Lifespan Respite Care Act of 2006 ; Older Americans Act ; Family and Medical Leave Act ; Caregivers and Veterans Omnibus Health Services Act ; VA Mission Act.

The specific legislation includes: The Caregiver Advise, Record, Enable (C.A.R.E.) Act ; The Kupuna Caregivers Act in Hawaii ; Medicaid Consumer-Directed Care Program (also known as Cash and Counseling), available under Home- and Community-Based Services Waiver Program ; Paid Family and Medical Leave ; Older Americans Act - National Family Caregiver Support Program ; State Caregiving Task Force Legislation.

<sup>15</sup><https://acl.gov/programs/support-caregivers/lifespan-respite-care-program>

financial assistance additional to the Carers Allowance (Carers UK, 2018). For example, in England and Wales, the *Carers and Disabled Children Act 2000* provides direct payments to informal carers. It has a substitution (formal to informal care) based scheme for the periods when carers need to take time away (Mentzakis et al., 2009).

The informal care volume depends on many factors, including older people's living arrangements, the longevity of old-aged partner by marriage, and trends in the groups' labour-market participation in the informal carers' labour force (OECD, 2005). However, no doubt, dealing with dependent people may induce various consequences in the health system in terms of health expenditures.

## 0.2 Long-term-care expenditures: Which projections for the health system?

LTC includes various activities undertaken for persons not able to self-care on a long-term basis, by informal carers (family, friends, community), by formal carers (professionals and paraprofessionals), and by traditional carers and volunteers. Previous efforts have not been successful in devising relevant policy guidelines that may be adapted to the situation of middle-, high-income, and developing countries (Team and Organization, 2002).

Many European countries devised policies to address the long-term care expenditure,<sup>16</sup> notably to support informal (family) carers and the elderly. LTC expenditure is primarily covered by public funds and accounts for 1.7% of the GDP for OECD countries in 2017 (Figure 0.5). LTC systems mostly rely on carers (female carers), who are often assumed less costly than formal care or vouchers or other allowances to pay for formal care services. Thus, Informal care may contribute to the reduction of some component of public expenditure, where it reduces the need for publicly financed care (Barbieri and Ghibelli, 2019; Kehusmaa et al., 2013; Van Houtven and Norton, 2004). Therefore,

<sup>16</sup>Long term-care expenditure is the sum of two components: long-term care (health) and long-term care (social). (1) Long term-care (health) stands for medical or nursing care, and personal care services providing help with activities of daily living (ADL). It also include two main form of care provision: (i) Inpatient LTC (i.e., in nursing homes); (ii) Home-based LTC (Care is delivered at the care receipt home). (2) Long term-care (social) includes assistance services that enable a person to live independently. They are related to support with instrumental activities of daily living (IADL).

in some economies, the fact for informal carers being family members considerably reduced the annual public expenditure.<sup>17</sup> Thereby, informal care should be considered when eliciting LTC public policies (Kehusmaa et al., 2013). In LTC policy, informal care is recognized as the dominant form of care throughout the world (Team and Organization, 2002).

Nevertheless, the fiscal implication of informal caregiving can change depending on the care provider's employment status. With a non-taxpaying retired carer, there would be minimal effects on tax revenue. Then, income tax revenue loss generally covers informal carer of working age. Finally, in general, fiscal implications rely on informal carers' opportunities to participate in the labour market and the income level of care recipients using informal instead of formal care (Määttänen and Salminen, 2017).

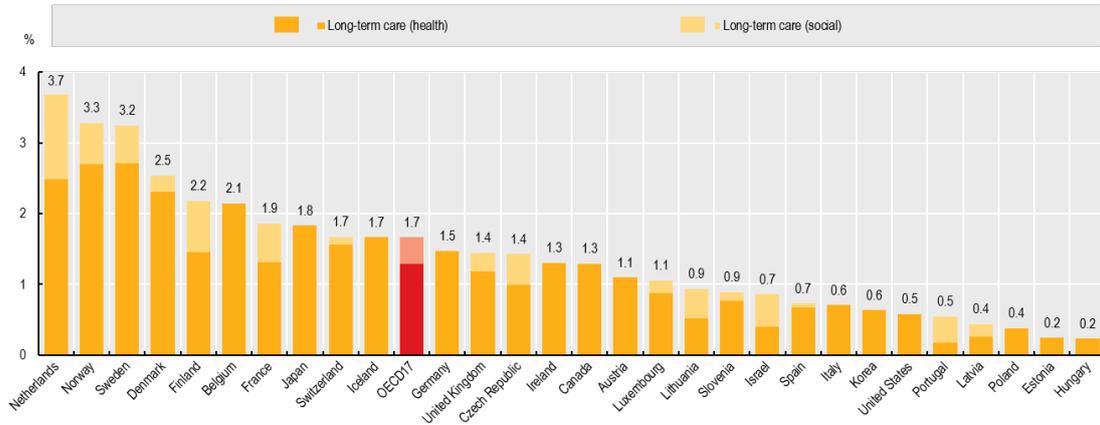
The implementation of the new LTC program, including cash-for-care, aims at providing the elderly more choice of LTC services. The demand and choices for LTC services are mostly driven by the health status and needs of the elderly. According to some projections, expenditure growth is likely to accelerate in the next decade, mainly due to more significant numbers of adults and a high increase of elderly people (Bovenberg and Zaidi, 2010). However, the evolution of mortality- across countries could have a crucial influence, and it should be observed in welfare policy planning (Costa-Font et al., 2008).

The recent OECD report shows that LTC spending has exceeded overall health expenditure and GDP growth in most OECD countries (OECD, 2020a). Figure 0.6 indicates that in the Netherlands, LTC spending has historically been very high, indicating the important accessibility of LTC by dependent people and living with a disability. LTC spending as a share of GDP has increased from 3.4% in 2005 to 3.9% in 2018, with a drop in 2015, corresponding to important LTC reforms. In Germany, a similar trend is observed. LTC spending as a share of GDP has increased from 1.5% in 2005 to 2.1% in 2018.

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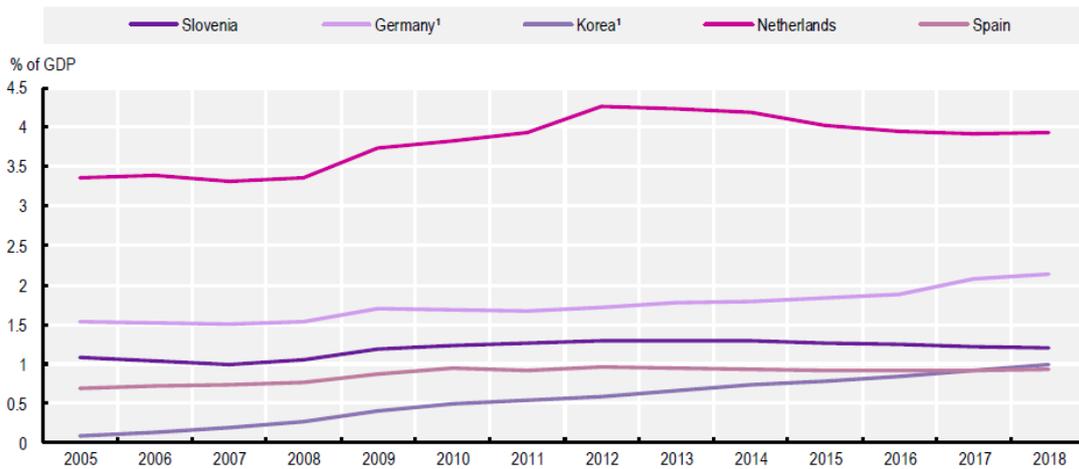
<sup>17</sup>Regarding the Finnish population, Kehusmaa et al. (2013) indicated that of formal care only dedicated for elderly had the highest expenditure at 25,300 Euros annually. But the combination of formal and informal care had an annual expenditure of 22,300 Euros. Finally, for an elderly receiving mainly informal care from a family member in cohabitation, the annual expenditure will be only 4,900 Euros and almost 6,000 Euros for a care recipient living alone and receiving informal care.

**Figure 0.5 – Long-term care expenditure (health and social components) by government and compulsory insurance schemes, as a share of GDP, 2017 (or nearest year)**



Note: The OECD average only includes 17 countries that report health and social LTC.  
 Source: OECD Health Statistics 2019 - (OCDE, 2019c)

**Figure 0.6 – Share of total long-term care spending in GDP - (2005-2018)**



Note: Country does not report LTC (social).  
 Source: OECD Health Statistics 2020 - (OECD, 2020a)

### 0.3 Theoretical and economic background of the thesis

The theoretical background of the thesis is based on welfare economics. For Culyer, welfare economics is a branch of economics that studies the identification of conditions that make for a good society and identifies changes in allocations of goods and services or arrangements for allocating goods and services better for society (Culyer, 2014).

### 0.3.1 The welfare economic theory: A microeconomics theory applied in health

We previously indicated that informal care could be considered (resource) contributing to LTC by caring for older persons with disability. This resource is mainly available naturally, even though it is essentially a limited good. The utilisation of informal care sheds light on the debate concerning the management of costs and benefits. Therefore, allocating this resource as other economic goods can raise economists' issue related to efficiency and social justice. Welfare economics approaches seem to be adapted to analyse their contribution while evaluating the individual and social situations and public decisions.

#### 0.3.1.1 The foundation of the welfare economics

Alfred Marshall developed the first work on welfare economics [Marshall \(1890\)](#) and followed by [Pigou \(1932\)](#). In the book entitled "The economics of welfare" (1920), Pigou studied the different optimal situations fostering individual and societal welfare maximisation ([Pigou, 1932](#)). In this welfare theory, individual utility <sup>18</sup> functions are based on the assumption of a cardinal measurement, which refers to utility intensity, instead of an ordinal measure where information about orders of preferences matters. In this founding approach of welfare economics, utility comparison between economic agents is possible, either in terms of level (i.e., happiness) or variation (i.e., well-being). Apart from the cardinality and comparability conditions, inducing specific definitions of utility functions ([Laffont, 1988](#)), interpretation of comparisons need some ethical and social considerations.

Then, utility comparisons can be made in terms of estimating the "surplus" which measures "the intensity of happiness of each individual and the society" ([Siroën, 1995](#)). Therefore, utilities can be expressed in monetary terms, and according to Pigou, money is the most appropriate measure, meaning that comparisons between agents are possible ([Pigou, 1932](#)). The value of a good or service, exceeding what an individual is ready

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<sup>18</sup>Utility is a term that was initially used by Bentham (Utilitarianism theory of Bentham). Then, the utility is the satisfaction or pleasure that an individual obtains when making a rational choice between two or more alternatives (i.e. consumption of good and services) ([Kahneman et al., 1997](#))

to pay defines his willingness to pay (WTP) based on his preferences. According to interpersonal comparisons, the social surplus assumed by Alfred Marshall can, therefore, be calculated from the surplus of an “average agent” and thus makes it possible to erase the problem of agent heterogeneity and to give operational meaning to comparisons (Baujard, 2017).

On the other side, the approach of welfare economics developed by Bergson (1938) and Lange (1942), also called “new welfare economics” establishes a clear separation between the study of the conditions of optimality of social situations and the study of the market functioning (Baujard, 2017). The new welfare economics is based on the approach of ordinal measure of the utility as a mathematical representation of orders of preferences. It does not need comparability of preferences between economic agents. The comparability of preferences and decline in individual marginal utility, which were mainly adopted in the first welfare economy approach, has been strongly criticised (Baujard, 2017; Robbins, 1932, 1938). As a result of this, the use of normative welfare criteria or value judgements is then rejected in favour of a more positive and scientific approach to minimise the ethical conception of utility.

The different social states are classified based on individual preferences. If there is unanimity between agents to rank an option as the best in terms of ordinal utility, then a social preference arises. The only “normative” criterion for resource allocation is the Pareto criterion, considered as an efficiency condition. A state, or an allocation, is optimal in the sense of Pareto if it is not possible to improve the welfare/utility of all economic agents without deteriorating the welfare/utility of at least one of them.<sup>19</sup> However, this criterion does not allow a decision to be made between two optima.

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<sup>19</sup>The two founding theorems of the welfare economy are: (1) An equilibrium of pure and perfect competition is a Pareto optimum. In other words, any market equilibrium corresponds to an optimal allocation of resources in the sense of Pareto. (2) Any Pareto allocation can be achieved through a competitive market. In other words, any Pareto optimum is an equilibrium.

### 0.3.1.2 Welfarism, extra-welfarism, individual and societal situations evaluation and health

One of the four principles of welfare economics is welfarism.<sup>20</sup> For Hurley (2000), “Welfarism is the proposition that the “goodness” of any situation (e.g., resource allocation) be judged solely on the basis of the utility levels attained by individuals in that situation. It excludes all non-utility aspects of the situation” (Hurley, 2000). Extra-welfarism refers to an alternative view of normative economic to conventional welfare economics (Table 0.1).

According to welfarism, a “self-fish” utility function is associated with individual motivation to maximise their welfare, independently of others (Richardson et al., 2005). On the other hand, others are less concerned about the unrestrained pursuit of their well-being but express the need and necessity to help their loved ones. Thus, carers consider their loved one’s health in their utility function, reflecting the optimistic view of human nature, a reference to the theory of moral feelings (Dupuy, 1992; Smith, 1999). This attitude is found in the analysis of informal carers’ behaviour with their recipients receiving care due to the loss of autonomy or disability problems. In this situation, social welfare is obtained based on a utility function whose maximisation can be sought and obtained as the sum of the individual utilities.

For the welfarism and extra-welfarism approaches, the primary assumption is that the utility is the maximand.<sup>21</sup> Thus, the utility criterion can be used as a basis for the analysis of well-being and allocation of resources. Besides, other than the utilitarian one, other criteria are also to be valued in the social welfare function (Sen, 1980). These include utility quality, capabilities, health, self-sacrifice, social relations or rules (Sen, 1993). Individuals are not seen as the sole source of social welfare assessment, nor can individual consumption of goods and services be the only one (Culyer, 1989). However, for Hurley (2000), health is an essential characteristic to maximise regarding the social welfare function (Arrow et al., 2000; Hurley, 2000). Subsequently, regarding Sen (2000), individuals have psychological capacities that influence the utility measurement.

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<sup>20</sup>There are four main principles of welfare economics (neo-classical) leading the understanding of the development of normative analysis in the health sector: utility maximization, individual sovereignty, consequentialism and welfarism.

<sup>21</sup>Maximand stand for a quantity or thing which is to be maximized.

Inequalities in capabilities are nevertheless observed among some people living with severe conditions (Nussbaum, 2001; Sen, 2000). Therefore, it is the capabilities of functioning that enter into social welfare assessment, based on opportunities of choice, and freedom of choice and responsibility for consequences. Functioning refer to what a person can aspire to, such as being healthy, working, participating in community life, eating, participating in political life (Sen, 2000). The set functions to which a person can have access are called capabilities. By resorting to the capabilities as a possible criterion of well-being, (Sen, 2000) and more particularly, the extra-welfarism approach also makes it possible to extend the rationality concept (Sen, 1977) to an individual's commitment, as an act devoid of selfishness. Therefore, the concept of rationality cannot be solely associated with the objective of maximising personal well-being (Richardson et al., 2005).

As stated in table 0.1, based on Richardson et al. (2005) and Gervès-Pinquié et al. (2014), for welfarism and extra-welfarism, the search for welfare may include necessarily maximum health gains, maximum utility combined with other criteria, capabilities, and finally, much more criteria associated with the two previous. Regarding welfarist and extra-welfarist theories, there are essential differences between the main criteria of individual well-being and social welfare. Nevertheless, some complementarities or combinations are possible, as suggested by Richardson et al. (2005).

**Table 0.1** – Individual behaviour, depending on the type of welfarism and related social situation evaluations

Meta preferences	Welfarism		Extra-welfarism			
Self-Motivation	Utility Maximisation		Utility Maximisation		Self-sacrifice (Duty, Religious Rule, etc.)	
	Selfish	Selfless	Selfish	Selfless		
Social Goal	The function of Utility (e.g. Utility Maximisation)		Health Maximisation	Utility Maximisation + Other	Other (e.g. Capabilities)	Other + Health Maximisation &/or Utility Maximisation
Role of Government	Coercion: A paternalistic attitude of public decision-makers (i.e. Taxation, market regulation, etc.)					
	Information and Correction: A liberal attitude of public decision-makers (i.e. Market failure corrections, etc.)					
	Minime: A libertarian attitude of public decision-makers (i.e. protection of private property, etc.)					
Equity and Justice	Maximisation of (weighted) Utility		Maximisation of the Health status, Utility, and/or other welfare criteria			
Application to informal carers	Selfish carer	Selfless carer	Selfish carer	Selfless carer	Committed/engaged carer	
	$U_i = U_i(X_i, H_i^c)$ With $U_i$ Utility of the carer $i$ ; $X_i$ Consumption of goods; $H_i^c$ Health of the carer $i$	$U_i = U_i(X_i, H_i^c, H_i^p)$ With $U_i$ Utility of the carer $i$ ; $X_i$ Consumption of goods; $H_i^c$ Health of the carer $i$ ; $H_i^p$ Health of the recipient's $j$	$E_i = E_i(X_i, H_i^c)$ With $E_i$ Utility of the carer $i$ ; $X_i$ Consumption of goods; $H_i^c$ Health of the carer $i$	$E_i = E_i(X_i, H_i^c, H_i^p)$ With $E_i$ Utility of the carer $i$ ; $X_i$ Consumption of goods; $H_i^c$ Health of the carer $i$ ; $H_i^p$ Health of the recipient's $j$	$C_i = C_i(L_i, H_i^p)$ With $C_i$ Index of the capability of the care; $L_i$ Index of liberty in the country of (i.e. social pressure, job access); $H_i^p$ Health of the recipient's	

Adaptation of Richardson et al. (2005), Gervès-Pinquié et al. (2014)

### 0.3.2 Economic evaluation in health technology assessment (HTA)

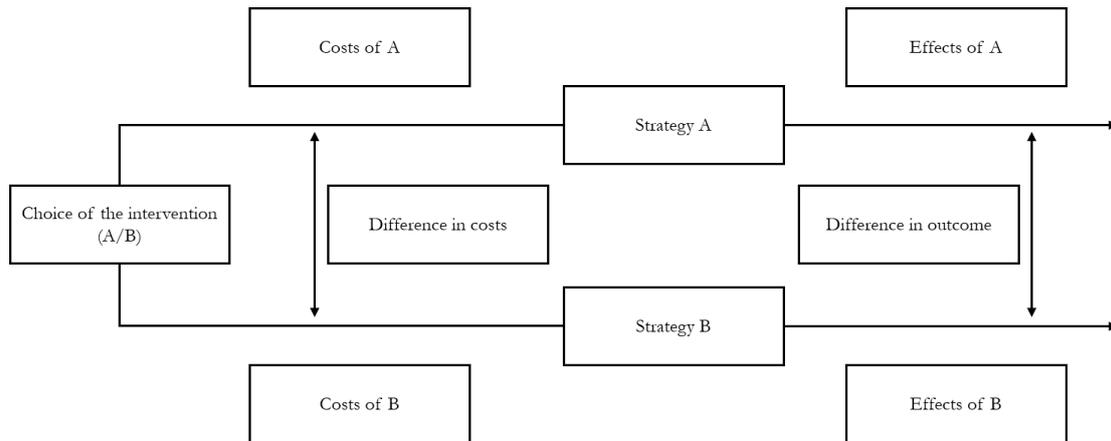
Economic Evaluation (EE) is the process of relating the costs of health strategies to their benefits over a given period to guide public decision-making towards the most cost-effective options considering the scarcity of resources. In other words, EE is a comparative analysis or evaluation of at very least two interventions in terms of costs and outcomes. There are several fields and areas of application of EE:

- *Health interventions* for preventive, curative, medical or surgical innovations. In this context, the different preventive and/or curative options will be compared;
- *Health products*, such as medicines and medical devices. Then, their access or conservation on the market of products reimbursed by the drug plan or paid by the collectivity, under certain conditions can be subject to EE;
- *Medical techniques*, such as medical imaging, transplant technical platforms, or telemedicine utilisation;
- *Information, screening, prevention, treatment or care actions* organised as part of a healthcare pathway.

In practice, EE has been found to be most often implemented on pharmaceuticals; hence the concept of “*pharmaco-economics*” refers to the EE of drugs (Claude and Pierre, 2018). However, among the various fields and areas of application mentioned above, support for carers cannot escape EE’s scope. Since the latter is an essential tool for appraising the economic feasibility and efficiency of health interventions, it contributes to prioritise innovative programs and ensure the best decision for an optimal allocation of resources.

However, the theoretical foundations of the economic evaluation date back to the 19<sup>th</sup> century. The principles of cost-effectiveness and cost-benefit analysis were refined, particularly by the Italian economist Vilfredo Pareto and the British economists Nicholas Kaldor and John Hicks (Johannesson, 1996).

Economic evaluation generally relies on methodological considerations that can determine the nature of the conclusions of assessments. Figure 0.7 summarises the EE presentation.

**Figure 0.7 – Structure of the economic evaluation**

Source :Claude and Pierre (2018)

### 0.3.2.1 Type of economic evaluation

Generally, four types of EE are often used in the literature: cost-minimisation ( 0.3.2.1), cost-benefit analysis ( 0.3.2.1), cost-effectiveness analysis ( 0.3.2.1), cost-utility analysis ( 0.3.2.1) (Drummond et al., 2015; Robinson, 1993a,d,b,c). As usual, the nature of the expected consequence (outcome) of the intervention under study could guide the methodological trade-off. Therefore, Drummond et al. assumed that all these four techniques could be considered as “full” economic evaluation method in that costs and outcome can be compared between two or more health intervention (Drummond et al., 2015).

**Cost minimisation analysis (CMA)** The Cost-Minimization Analysis (CMA) is an EE based on comparing costs of two interventions that are considered equally effective (same outcome). For example, a study comparing inpatient versus outpatient antibiotic treatment for persons with infective endocarditis may only consider the costs of the two strategies. Thus, the lowest cost strategy is the strategy that will be adopted. This approach is rarely used in medicine because it is challenging to assume identical efficacy between two settings (Briggs and O’Brien, 2001). Therefore, Briggs and O’Brien assumed the “death” of CMA by indicating the rare situation under which this technique deemed an appropriate analysis method. On the one hand, they argued that it is inappropriate for

separate and sequential hypothesis tests on differences in outcome and costs to determine whether incremental cost-effectiveness should be estimated. On the other hand, they further argued that the analytic focus should be on estimating the joint density of cost and outcome differences, the quantification of uncertainty surrounding the incremental cost-effectiveness ratio and the presentation of such data as cost-effectiveness acceptability curves (Briggs and O'Brien, 2001).

**Cost-benefit analysis (CBA)** Cost-benefit analysis (CBA) is a type of EE in which the consequences of strategies are assessed in monetary terms, allowing them to be directly compared with the costs (Hutton, 1992; Samson et al., 2018). This method assumes that benefits should be more significant than cost; then, benefits are important and justifying their costs and maximizing welfare (Drummond et al., 2015; Frew, 2010; Slothuus, 2000). CBA is not easily implemented in the health care sector, because of some difficulties with and limitations on methods for evaluating benefits in monetary terms. The (French) National Authority for Health (*HAS*) does not recommend cost-benefit analysis as a baseline analysis. However, the results of CBA can be presented as a supplementary piece of information (Haute Autorité de Santé, 2020).

**Cost-effectiveness analysis (CEA)** Cost-effectiveness analysis (CEA) is one of the most used EE (Byford and Sefton, 2003), in which the consequences of strategies are assessed using an indicator expressed in physical units. The outcome can be of several types such as “the number of life-years gained”, “the number of cases detected or a clinical criterion (blood pressure, cholesterol level...)” or “the number of cases or patients according to a specific health condition”. As presented above, the CEA is an analytical tool in which the costs and effects of a program (intervention) and at least one alternative solution is calculated and presented as an Incremental Cost-effectiveness Ratio (ICER). The CEA allows comparing health policies, programs or projects with each other; the goal is to identify the strategy or strategies that obtain the best results for a given cost (Drummond et al., 2015).

**Cost-utility analysis (CUA)** CUA is a methodological approach of EE whose objective (like CEA) is to compare health programs or interventions based on their costs and

outcomes. CUA is theoretically based on the fact that the outcome criterion is expressed in Quality Adjusted Life Years (QALYs) (Drummond et al., 2015; Garber, 1996; Garber and Phelps, 1997). QALYs are calculated as follows: the number of years weighted by the quality of life scores associated with health states. The utility scores, called utilities, or preference scores vary between 0 (i.e. death) and 1 (i.e. perfect health). Utilities are estimated to represent the intensity of individuals' preferences for their different health states. As a general rule, utility estimation can be done using the following three different approaches:

- *Direct measurement* stands for the use of the approach based on preferences. In principle, it asks what "sacrifice" people would be willing to make to recover perfect health. In practice, it is illustrated by the standard gamble method, which consists of asking a person to imagine that, in the event of illness, he could have an operation and live in perfect health if the operation is successful. It is well known that the operation represents a risk of death. Indeed, the person must indicate its usefulness, i.e., the maximum risk of surgical death that he is willing to accept in order to be treated. Therefore, the underlying principle is that the more severe the state of health, the higher the sacrifice (in this case, the risk of operative death) that one is prepared to make to try to regain health (Gafni, 1994). Other methods, such as the visual analogue scale, have been developed (Bleichrodt and Johannesson, 1997; Bowe, 1995; Torrance, 2006; Torrance et al., 1972).
- *Indirect measurement* is based on the use of health-related quality of life economic questionnaires. In practice, it consists of using, during the description stage of health states, economic quality of life questionnaires for which validated scores are available in France. This approach's primary constraint is that the description of health states must be done using generic quality of life questionnaires, unlike disease-specific or population-specific questionnaires. In the French context, only two economic questionnaires, i.e. those for which preference scores have already been estimated in the general population, have been validated. These are mainly the Euroqol (EQ-5D) (Andrade et al., 2020) and the Health Utility Index Mark 3 (HUI 3) (Chevalier and de Pouvourville, 2013; Costet et al., 1998; Le Galès et al.,

2001). In the last recommendations of the HAS, only the EQ-5D questionnaire should be used in base case analysis ([Haute Autorité de Santé, 2020](#)).

- An approach based on methods for converting clinical measures of quality of life can also be used. The latter, known as the “mapping” approach, establishes the link between clinical and economic measures of quality of life. A statistical tool consists of establishing algorithms for converting responses to the clinical quality of life questionnaire into utility scores, such as the generic SF-36 questionnaire ([Brazier et al., 2002](#)) or the cancer-specific QLQ-C30 questionnaire ([Kim et al., 2012](#)). Two main conversion methodologies exist in this case. On the one hand, the conversion of a clinical questionnaire to an existing utility measure. For example, [Kim et al. \(2012\)](#) propose an algorithm to convert the cancer questionnaire QLQ-C30 into EQ-5D utility scores. On the other hand, the construction of a new questionnaire suitable for EE from a clinical questionnaire. [Brazier et al. \(2002\)](#) developed the economic questionnaire SF-D from the clinical questionnaire SF-36.

Subsequently, there is also another utility metric called DALYs (Disability Adjusted Life Years). According to the World Health Organisation (WHO), <sup>22</sup> this measure quantifies disease burden based on mortality and morbidity. It captures the effect of conditions on both premature mortality and disability. By measuring years of disability-free life lost due to disease, the effects of the “global burden of disease” at the population level can be estimated relative to an ideal disease-free situation ([Murray et al., 2000](#)).

Most regulatory agencies recommend the use of CUA. However, there is no consensus on this choice regarding countries methodological guides. For many countries, the implementation of CUA through QALYs is the preferred methodological choice ([Agence canadienne des médicaments et des technologies de la santé, 2017](#); [Haute Autorité de Santé, 2020](#)). Furthermore, CUA based on QALYs does not seem systematically accepted by health policymakers or practitioners for several reasons: solidarity, equality and equity ([Institute for Quality and Efficiency in Health Care, 2009](#)).

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<sup>22</sup>Historically, the “DALYs” metric was developed from a public health perspective by the World Health Organization to measure the burden of disease and risk factors on people in all countries around the world.

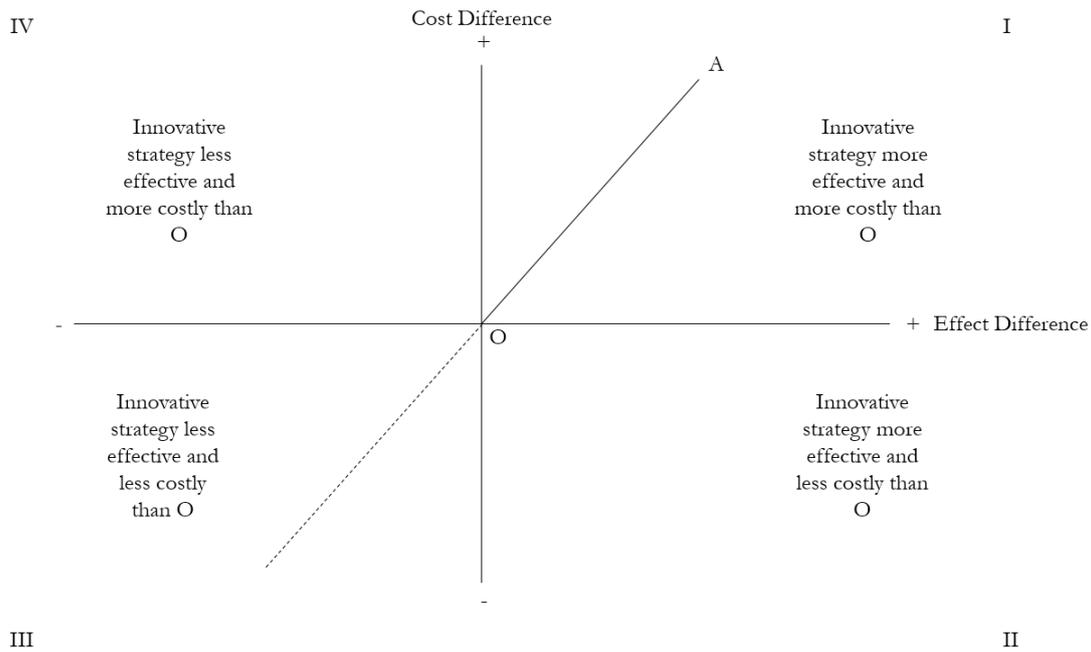
**Health economic evaluation and cost of informal care** The cost-effectiveness is assessed through an Incremental Cost-Effectiveness Ratio (ICER). It is expressed as follows:

$$ICER = \frac{C_1 - C_0}{E_1 - E_0} = \frac{\Delta C}{\Delta E} \quad (0.1)$$

With  $C_1$  and  $C_0$  respectively represent the costs of innovative and standard strategies.  $E_1$  and  $E_0$  represent the efficiency in the situation of the innovative strategy against the standard strategy. The overall ICER is expressed in a monetary unit per effectiveness gained. Figure 0.8 illustrates the different situation for which the innovative strategy can be considered as cost-effective.

The calculation of the ICER and their positioning in the cost-effectiveness plan will make it possible to know whether the innovative strategy is:

- Strictly dominant (more effective and less costly – quadrant “II” of the plan) compared to the standard strategy;
- Strictly dominated (less effective and more costly – quadrant “IV” of the plan) compared to the standard strategy.

**Figure 0.8 – The cost-effectiveness plane**

Source : [Black \(1990\)](#) and [Drummond et al. \(2015\)](#)

To handle uncertainty related to CUA, alternative approaches such as Net Monetary Benefit (NMB) emerged. First, this approach consisted of avoiding ICER problems when building confidence intervals for ICER ([Glick et al., 2001, 2014](#)). Secondly, with NMB, the joint distribution of cost and effectiveness represents an asymptotical normalised distribution. However, it is worth noting the drawback for NMB that the value of  $\lambda$  (Willingness to pay value - WTP) is unknown. To challenge this, it is possible to plot a NMB as a function of  $\lambda$  ([Glick et al., 2001](#)). Regarding the Bayesian approach, this function can be interpreted as a probability that an intervention is cost-effective for a given value of  $\lambda$  (With  $NMB > 0$ ) (see equation 0.4) ([Claxton et al., 2001](#)).

$$\frac{\Delta C}{\Delta E} < \lambda \quad (0.2)$$

$$\Delta E - \frac{1}{\lambda} \Delta C > 0 \quad (0.3)$$

$$NMB = \Delta C - \lambda \Delta E > 0 \quad (0.4)$$

Since the decision to care or not provide care depends mainly on carers and how they deal with care provision (Broese van Groenou and De Boer, 2016), informal care should be valued and included in economic evaluation (Goodrich et al., 2012; Hoefman et al., 2013; Krol et al., 2014). Some studies indicated that including informal care costs could influence economic evaluation findings (Krol et al., 2014). However, informal care is an activity that cannot be traded via a market price. It can induce negative economic consequences, such as direct (opportunity cost of care provision related to work cessation or leisure time) and indirect (worsening of carers health status; or a lack of interventions and services set to support carers or keep them in work). Therefore, there are several approaches to value informal care in economic evaluation. These include the opportunity cost method, the proxy good method, the contingent valuation method (CVM) and conjoint measurement CM (van den Berg et al., 2004).

The monetary valuation of support for informal care in Europe has been recognised through the 1980-1990 years. Recent economic evaluations studied informal care valuation and how it could be included in cost-effectiveness studies. Our first chapter (of the thesis) contributes through some evidence regarding intervention dedicated to informal carers (Garrido-García et al., 2015; Gervès-Pinquié et al., 2014; Grosse et al., 2019; Guets et al., 2020; Landfeldt et al., 2019; Oliva-Moreno et al., 2017; Van Den Berg et al., 2006).

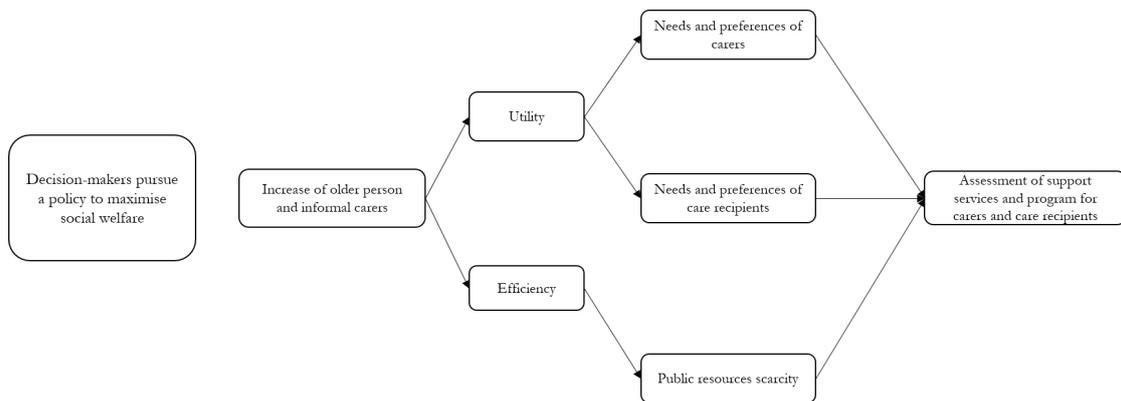
## 0.4 The objective of the thesis and overview of the chapters

Compared to respite strategies that have been assessed in the existing literature, the Lyon Metropolitan Area respite care facility represents the particularity of combining a Mobile Team and a Respite House. This setting (facility) stands as a major organisational innovation providing exhausted informal carers with support and respite care technology.

This thesis is of twofold interest. First, to identify characteristics of carers at risk of burnout who need respite, and how the volume of formal care affects the use of support services by informal carers. Then, to provide health authorities and decision-

makers with empirical evidence of the Lyon Metropolitan Area's Respite Care Facility (strategy) dedicated to supporting both carers and recipients (Figure 0.9). The settings and empowerment of support dedicated to informal carers are essential to maximising carer quality of life and social welfare.

**Figure 0.9** – Decision-Makers and the search of social welfare maximisation



The related literature shows a considerable drop in health at some exhaustion level of informal carers' induced important costs (due to treatments and loss of productivity) when comparing innovation and standard prevention scheme. The main question assessed in this thesis is understanding how to provide a coordinated support service for carers whose health states, needs and preferences change over time.

## Chapter 1

Demographic and epidemiological changes place an increasing reliance on informal carers. Some support programmes exist, but funding is often limited. There is a need for economic evaluation of interventions for carers to assist policymakers in prioritizing carer support. Our aim was to systematically review and critically appraise cost-utility analyses of interventions for informal carers, in order to assess the methods employed and the quality of the reporting. Then, a systematic review of databases was conducted using MEDLINE, EMBASE, PsycInfo, and Econlit of items published between 1950 and February 2019. Published studies were selected if they involved a cost-utility analysis of an intervention mainly or jointly targeting informal carers. The reporting quality of economic analyses was evaluated using the Consolidated Health Economic Evaluation

Reporting Standards (CHEERS) statement.

An initial set of 1,364 potentially relevant studies was identified. The titles and the abstracts were then screened, resulting in the identification of 62 full-text articles that warranted further assessment of their eligibility. Of these, 20 economic evaluations of informal carer interventions met the inclusion criteria. The main geographical area was the UK (N = 11). These studies were conducted in mental and/or behavioural (N = 15), cardiovascular (N = 3), or cancer (N = 2) clinical fields. These cost-utility analyses were based on randomized clinical trials (N = 16) and on observational studies (N = 4), of which only one presented a Markov model-based economic evaluation. Four of the six psychological interventions were deemed to be cost-effective versus two of the four education/support interventions, and four of the nine training/support interventions. Two articles achieved a CHEERS score of 100% and nine of the economic evaluations achieved a score of 85% in terms of the CHEERS criteria for high-quality economic studies. Our critical review highlights the lack of cost-utility analyses of interventions to support informal carers. However, it also shows the relative prominence of good reporting practices in these analyses that other studies might be able to build on.

## Chapter 2

The purpose of this study was to shed light on how the characteristics of informal carers affect the need for respite. We used data from a nationally representative survey, *Capacités Aides et Ressources des Seniors (CARE - ménage)*, collected in 2015 by the National Institute for Statistics and Economic Studies (*INSEE*) and the Directorate for Research, Studies, Assessment and Statistics (*DREES*). A probit model was used for econometrics modelling. Our study included N = 4,278 dyads of informal carers and care recipients, of which 40% were cohabitants. The mean age was 61 for carers. The majority of carers were female, married, the child of the care recipient. Almost 27% reported a need for respite. A worse health status, feeling of loneliness, having a lack of time for oneself and needing to provide more than 60 hours of care per month very significantly increased the need for respite irrespective of whether or not the carer lived with the care recipient ( $p < 0.01$ ). Conversely, however, being closely acquainted with the care recipient showed a reduced need for respite in comparison with that of carers who are married to their

care recipient ( $p < 0.05$ ). These findings provide useful information for policymakers, physicians and other health professionals for reducing carers' risk of exhaustion and burnout and for referring carers to the relevant service, e.g. psychological intervention, respite care support, training support and education support, at the right time.

An additional analysis based on the data from the Health and Disability Health survey (HSA, 2008) was conducted and is presented in the appendix of this chapter.

### Chapter 3

The role of informal carers in long-term care sheds light on the struggle related to population ageing and the increasing incidence of chronic disease. However, despite the increasing number of informal carers, most of them experienced the burden of caregiving. Since various policies have been implemented across countries to support informal carers, their attitude toward support services should be addressed. This research consisted of investigating how formal home care affected the utilisation of support services by informal carers. Data used stemmed from the 2015 Survey *Capacité Aide et Ressources des Seniors* ("CARE ménage") collected in France; and the National Health and Aging Trends Survey (NHATS) with the National Survey of Caregiving (NSOC) in the United States of America (U.S.). Andersen's health behavioural model of support services utilisation provided a conceptual framework for investigating predisposing, enabling, and need variables associated with informal carers services use. We used a *probit* model for econometrics modelling. We also checked for the endogeneity of formal care using characteristics of the care recipient as instrumental variables (IV).

A sample of  $N = 4,866$  in France and  $N = 1,060$  in the U.S. informal carers and care recipients' dyads were used in the study. In France, the care recipients' formal care utilisation does not influence the carer support service use. Comparatively, in the United States, formal care significantly increases the respite services utilisation by informal carers. This study provides important implications for Long-Term Care (TLC) dedicated to health policy, for an optimal trade-off between informal and formal care use, bearing in mind health system particularity. First, countries may spend more funds on innovative support programs to access care, because some carers may have difficulties accessing and using support services. Secondly, to provide and foster information campaigns to

raise awareness concerning the utilisation of various existing health services, to improve social welfare.

## Chapter 4

The last chapter aims to perform a cost-utility analysis of a respite care facility (RC), including a mobile team and a respite house for informal carers and recipients, compared to the standard care (SC). We developed a Markov model combined with a discrete-event simulation with a four-months' time horizon. Additionally, we used a Business Process Model and Notation (BPMN). Data from the connected observatory *Aldants de la METropole de Lyon - AIME 2*, including 30 carers in the Lyon metropolitan area (France), were used. A fictive cohort (N = 420) of carers with a high burden due to caregiving and their recipients was created. The health system and the societal perspectives were retained in base case and scenario analyses, respectively. Sensitivity analyses were conducted. In the base case, costs were €16,685 (SD± 17,737) and €15,878 (SD± 17,681) for RC and SC, respectively. The mean cost and effectiveness differences between RC and SC strategies were respectively €807 (95% CI: -1,544 – 3,157) and 0.004 (95% CI 0.002 - 0.005). The ICER was €204,308.7 per QALY gained. Based on the societal perspective, the ICER was €123,457.63 per QALY gained. For both perspectives, the probability for RC to be cost-effective was under 50% at the €100,000 threshold. Organisational parameters of RC should be revisited in order to increase the probability of being cost-effective. The Markov modelling combined with a discrete-event simulation seems particularly well adapted for innovations with a huge organisational dimension.

## Outline of the thesis

This thesis contains four chapters. First, Chapter 1 presents a systematic and critical review of the literature on carers interventions. According to carers and recipients' characteristics, Chapter 2 analyses the determinants of the need for respite for informal carers. Chapter 3 explores the relation between formal care use by care recipients and the utilisation of support services by informal carers. Finally, Chapter 4 presents an economic evaluation of a respite care strategy dedicated to informal carers.



## Chapter 1

# Cost-utility analyses of interventions for informal carers: A systematic and critical review

### Abstract

*Background.* Demographic and epidemiological changes place an increasing reliance on informal carers. Some support programmes exist, but funding is often limited. There is a need for economic evaluation of interventions for carers to assist policymakers in prioritising carer support.

*Objective.* To systematically review and critically appraise cost-utility analyses of interventions for informal carers, in order to assess the methods employed and the quality of the reporting.

*Methods.* A systematic review of databases was conducted using MEDLINE, EM-BASE, PsycInfo, and Econlit of items published between 1950 and February 2019. Published studies were selected if they involved a cost-utility analysis of an intervention mainly or jointly targeting informal carers. The reporting quality of economic analyses was evaluated using the Consolidated Health Economic Evaluation Reporting Standards (CHEERS) statement.

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This paper was published in the Journal *PharmacoEconomics* (2020)

*Results.* An initial set of 1,364 potentially relevant studies was identified. The titles and the abstracts were then screened, resulting in the identification of 62 full-text articles that warranted further assessment of their eligibility. Of these, 20 economic evaluations of informal carer interventions met the inclusion criteria. The main geographical area was the UK (N = 11). These studies were conducted in mental and/or behavioural (N = 15), cardiovascular (N = 3), or cancer (N = 2) clinical fields. These cost-utility analyses were based on randomized clinical trials (N = 16) and on observational studies (N = 4), of which only one presented a Markov model-based economic evaluation. Four of the six psychological interventions were deemed to be cost-effective versus two of the four education/support interventions, and four of the nine training/support interventions. Two articles achieved a CHEERS score of 100% and nine of the economic evaluations achieved a score of 85% in terms of the CHEERS criteria for high-quality economic studies.

*Conclusions.* Our critical review highlights the lack of cost-utility analyses of interventions to support informal carers. However, it also shows the relative prominence of good reporting practices in these analyses that other studies might be able to build on.

**Key points for decision makers:**

- Only 20 published cost-utility analyses of carer-focused interventions were identified in the literature.
- The main types of interventions were psychological, training/support, and educational/support interventions, with mixed evidence regarding the cost-effectiveness.
- Most of the studies adopted a societal perspective, but there were differences in terms of what costs and outcomes were included.
- The reporting quality of the studies was generally quite good and there appeared to be a tendency whereby the studies with better reporting deemed the intervention to be not cost-effective.

## 1.1 Introduction

The demographic and social changes associated with aging of the population and the increasing incidence of chronic diseases underscore the important role of informal carers (Goodrich et al., 2012; Mello et al., 2016; Paraponaris and Davin, 2015). Eurocarers defines a carer as “a person who provides – usually – unpaid care to someone with a chronic illness, disability or other long-lasting health or care need, outside a professional or formal framework.”<sup>1</sup> Therefore, carers have a ubiquitous and very substantial presence throughout the world. The International Alliance of Carer Organizations (IACO) estimates the number of informal carers to be approximately 43.5 million in the USA (2015) and 8.1 million in Canada (2012).<sup>2</sup> The estimates presented in the Eurocarers 2019 publication<sup>3</sup> are 5.5 million informal carers in the UK (2011), 3.2 million in Germany, 4 million in Italy, and 8.3 million in France (2008). Furthermore, as a result of significant changes in how people with disabilities around the world are cared for, informal carers play an increasingly important role in the activities of daily living of their loved ones (Colombo et al., 2011; Rahola, 2011). There is evidence suggesting that when carers experience challenges in end-of-life care, hospital admission becomes more likely (Hoare et al., 2019). Due to the prominence of informal carer, the time spent on care provision in household tasks and on activities of daily living may have a substantial influence on economic evaluations (Gheorghe et al., 2019; Hoefman et al., 2019; Landfeldt et al., 2019; Oliva-Moreno et al., 2017; Posnett and Jan, 1996; Werner B. F. et al., 1999).

Many varieties of interventions have been developed that are aimed at providing support to carers or to family carers/members. Some studies have tended to focus on a particular type of support intervention, such as psychosocial interventions (Akarsu et al., 2019; Baruch et al., 2018; Charlesworth, 2001; Cross et al., 2018; Hopwood et al., 2018; Robinson et al., 2009; Selwood et al., 2007; Stall et al., 2018; Thomas et al., 2017), education and training, support (Candy et al., 2011; Clarkson et al., 2017; Jones et al., 2012; Lopez Hartmann et al., 2012; Thomas et al., 2017; Vandepitte et al., 2016a,b), respite care (Mason et al., 2007; McNally et al., 1999; Shaw et al., 2009; Vandepitte et al., 2016a),

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<sup>1</sup><https://eurocarers.org/>

<sup>2</sup><https://internationalcarers.org/carers-facts/global-carer-stats/>

<sup>3</sup><https://eurocarers.org/download/6372/>

or patient-focused and multicomponent interventions (Bee et al., 2009; Maayan and Lee, 2014; Rigby et al., 2009; Sorensen et al., 2002). Although some support interventions for informal carers have been reported to reduce the burden of informal care provision (Lopez Hartmann et al., 2012), there is a need for further documentation of the value-for-money of these interventions. Furthermore, patient intervention may also affect the lives of family carers. Notably, most economic evaluations of patient interventions typically fail to include the spillover impact on carers and/or family (Grosse et al., 2019; Lin et al., 2019; Wittenberg et al., 2019).

The purpose of this study was to identify Cost-Utility Analyses (CUAs) of interventions for carers by means of a systematic review of the literature and to perform a critical appraisal using the CHEERS instrument checklist in order to assess the methods employed and the quality of the reporting of published CUAs.

## 1.2 Methods

The systematic review of published economic evaluations was conducted according to the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) guidelines (Moher et al., 2015).

### 1.2.1 Research strategy

We searched the literature for pertinent articles published between 1950 and February 2019, using the following list of electronic databases and search engines: health- or medical-related databases (MEDLINE, EMBASE, PsycInfo) and an economics database (Econlit). The search process consisted of combinations of four categories of potential identifying keywords using Boolean operators (e.g. “AND”/ “OR”). We searched for additional records using Google Scholar and the Global Health Cost-Effectiveness Analysis (GH CEA) Registry (the Center for the Evaluation of Value and Risk in Health (CEVR), Tufts Medical Center).

A list of keywords was generated based on items in the existing literature (Mcnally et al., 1999; Sorensen et al., 2002). The keywords selected for the search strategy are

listed in Table 1.1 according to the study design, the targeted population, the supportive interventions, and the health outcomes.

**Table 1.1** – The keywords used in the search

Study design keywords	Population keywords	Support program keywords	Health outcome keywords
Economic evaluation	Caregiver*	Support	QALY
Cost-effectiveness	Informal care	Program*	Quality-adjusted life years
Cost-benefit analysis	Carer	Intervention	EQ-5D
Cost-utility analysis	Caregiving	Respite care	DALY
Health economics	Family	Education	
	Family member	Training	
	Relatives	Psychology	

\* The asterisk is used as a truncation or wildcard operator in the search equation.

The search included all studies for which the titles and abstracts contained one or more keywords from each health outcome, population, support program, and study design category of interest to the review.

### 1.2.2 Inclusion criteria

The screening of studies from the initial database searches to the final list of studies included in the review was comprised of two steps:

**Step 1:** following screening of the titles and abstracts, articles were excluded if they met one or more exclusion criteria. We excluded studies that were not economic evaluations (e.g., reviews, systematic reviews, clinical effectiveness studies, costing studies, critical reviews and study protocols, or conference abstracts). Studies were excluded if they did not clearly comprise a cost-effectiveness analysis (no incremental cost per outcome), cost-consequence, and cost-benefit. We also excluded studies that did not clearly comprise a cost-utility analysis and that did not clearly relate to the economic evaluation of a carer intervention. Studies were excluded if population terms (e.g., family, carer, informal care) were not mentioned in a relevant part of the abstract. Studies in any language other than English were excluded.

**Step 2:** further assessment of the articles remaining from the screening in Step 1 was performed. Publications that did not use a measure of carer health utility were excluded; if the study met any other exclusion criteria from Step 1 of the review, and lastly if the study was inaccessible and did not explicitly specify in the title or the abstract that carer QALYs were included in the study.

### 1.2.3 Study selection

All of the authors reviewed a random sample containing 5% of the studies in order to validate the process of inclusion of articles in the review. Two of the authors then independently reviewed the remaining studies to verify whether they met the inclusion criteria mentioned above. For each article deemed to have met the inclusion criteria based on an independent screening of the titles and the abstracts in Step 1, the full-texts of the articles were accessed in order to identify eligible studies. In case of any discordance, a third author was consulted to settle the matter and to try to reach a consensus.

### 1.2.4 Data extraction

Two of the authors extracted the key characteristics of the selected studies, as presented in Table 1.2: the names of the authors; the year of publication; the country; the underlying condition; the disease area, the population subjected to the intervention, the intervention type including a brief description; and in Table 1.3: the perspective, the follow-up duration, the study design, the year of the cost valuation, the scope of the costs, the type of carers, the direct and indirect costs, the scope of the outcome, the instrument used for utility assessment, the type of sensitivity analysis performed, and lastly the incremental cost-effectiveness ratio (ICER). In keeping with related studies, we used different conventional thresholds to determine whether or not interventions were cost-effective: using the range £20,000–30,000 per QALY gain (McCabe et al., 2008), €30,000 per QALY gain, and \$50,000 per QALY gain (Griffiths and Vadlamudi, 2016). It should be noted that studies often make an adoption decision by comparing the cost-effectiveness ratio of an intervention to a predefined standard, i.e., the maximum acceptable cost-effectiveness ratio (Polinder et al., 2011).

### 1.2.5 Quality of reporting assessment and data summary

We used the Consolidated Health Economic Evaluation Reporting Standards (CHEERS) checklist to evaluate the quality of reporting assessment ([Husereau et al., 2013](#)). This checklist developed by the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) Task Force contains 24 items for scoring by means of a dichotomous answer (Yes/No). Two of the authors independently critically reviewed the selected articles by applying the CHEERS checklist. A random reading list of articles was assigned for critical appraisal by the two authors. Modelling-related criteria (i.e., items 15 and 16) were omitted for single study-based cost-effectiveness evaluations. Studies fulfilling the CHEERS criteria were scored 'Yes' and assigned a score of 1 per correct item ('No' was assigned a score of 0). As each item on the checklist can be scored as "Yes" or "No", the quality score of each study was calculated by adding up all of the points for questions answered with "Yes". The total score per study was divided by the total number of items (N = 22 items). An exception was made for one article that included a model-based economic evaluation for which the score was divided by (N = 24 items). All of the score calculations are expressed as percentages (%). To resolve any disagreement between the two reviewers, a consensus procedure was used. A third co-author was consulted when disagreements persisted. The overall score for each study was presented as a percentage score of the applicable items.

## 1.3 Results

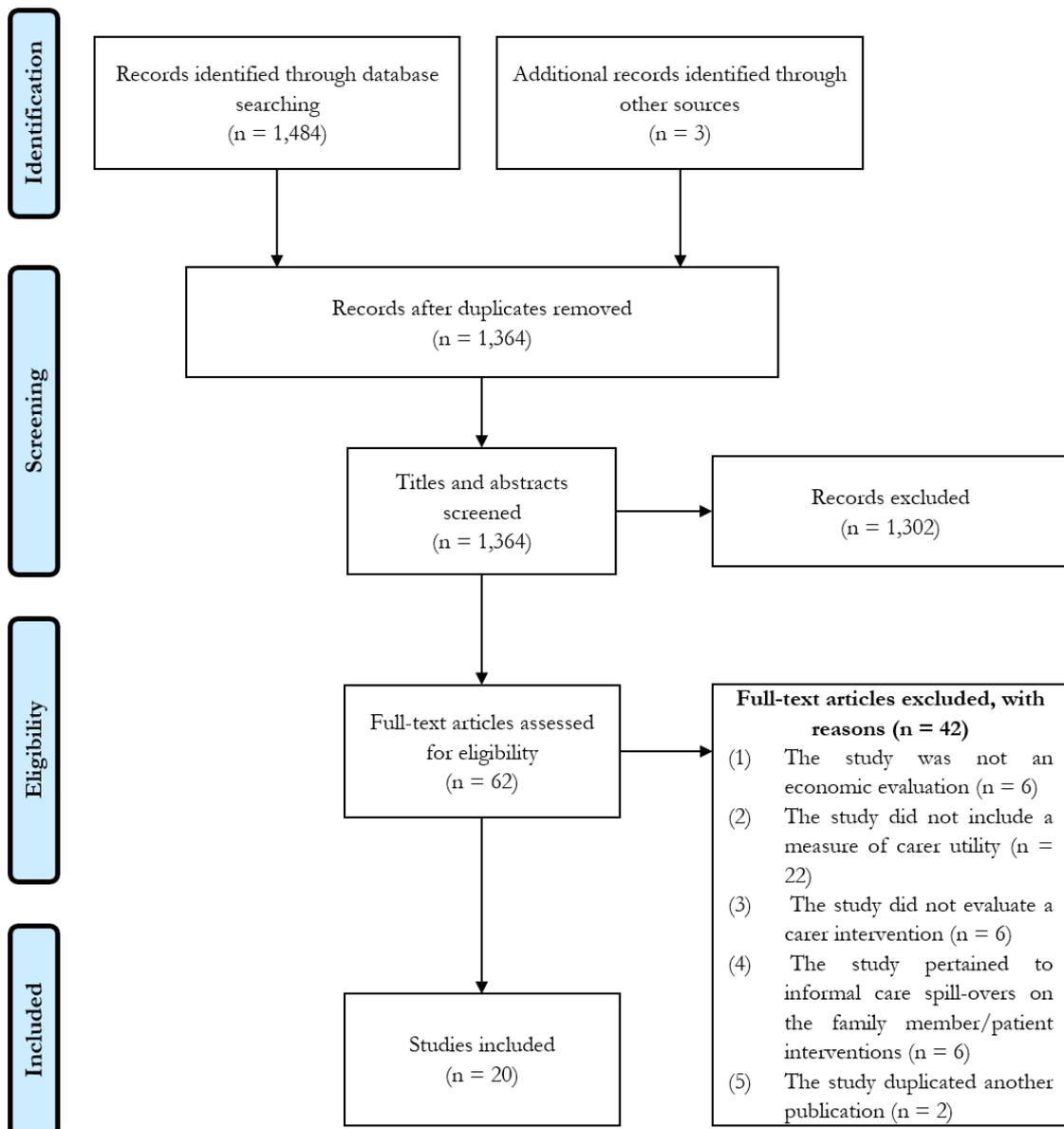
### 1.3.1 Search results

A total of 1,484 articles were identified in Medline, Embase, PsycInfo, and Econlit, and 3 additional studies were identified through Google Scholar and the Global Health Cost-Effectiveness Analysis (GH CEA) Registry (the Center for the Evaluation of Value and Risk in Health (CEVR), Tufts Medical Center). The literature search identified 1,364 studies (once duplicates had been removed) published between 1950 and February 2019. These articles were screened based on their titles and the abstracts, resulting in 1,302 being excluded. A total of 62 full-texts were identified that warranted further assessment

of their eligibility. We eliminated 6 studies that were not economic evaluations; 22 studies that did not include a measure of carer utility; 6 studies pertaining to informal care spillovers of patient interventions; and 2 articles were duplicates of other publications. We included the 20 studies that met the inclusion criteria for our final review.

Figure 1.1 summarizes the overall search and selection process by means of the PRISMA flow diagram.

**Figure 1.1 – PRISMA flow diagram**



### 1.3.2 Study characteristics

Table 1.2 and Table 1.3 report the characteristics of the included studies. The interventions were: psychological interventions (N = 6) (Charlesworth et al., 2008; Chatterton et al., 2016; Knapp et al., 2013; Livingston et al., 2014; Richards-Jones et al., 2019; Wilson et al., 2009), respite care/support (N = 1) (Drummond et al., 1991), training/support (N = 9) (Forster et al., 2013, 2015; Martikainen et al., 2004; Orgeta et al., 2015; Orrell et al., 2017; Patel et al., 2004; Sturkenboom et al., 2015; Woods et al., 2012, 2016), or education/support (N = 4) (Dahlrup et al., 2014; Joling et al., 2013; Sogaard et al., 2014; Vroomen et al., 2016). The majority of the studies (N = 15) were published between 2010 and 2019. A total of eleven studies took place in the UK (Charlesworth et al., 2008; Forster et al., 2013, 2015; Knapp et al., 2013; Livingston et al., 2014; Orgeta et al., 2015; Orrell et al., 2017; Patel et al., 2004; Wilson et al., 2009; Woods et al., 2012, 2016) and three studies were performed in the Netherlands (Joling et al., 2013; Sturkenboom et al., 2015; Vroomen et al., 2016). The most common disease areas were mental health and/or behavioural health (N = 15), i.e., Dementia (N = 14) (Charlesworth et al., 2008; Dahlrup et al., 2014; Drummond et al., 1991; Joling et al., 2013; Knapp et al., 2013; Livingston et al., 2014; Martikainen et al., 2004; Orgeta et al., 2015; Orrell et al., 2017; Sogaard et al., 2014; Vroomen et al., 2016; Wilson et al., 2009; Woods et al., 2012, 2016), Parkinson's disease (Sturkenboom et al., 2015), cardiovascular diseases (N = 3) (Forster et al., 2013, 2015; Patel et al., 2004), and cancer (N = 2) (Chatterton et al., 2016; Richards-Jones et al., 2019). A large proportion of the studies were based on Randomized Clinical Trials (RCT) (N = 16) (Charlesworth et al., 2008; Chatterton et al., 2016; Forster et al., 2013, 2015; Joling et al., 2013; Knapp et al., 2013; Livingston et al., 2014; Orgeta et al., 2015; Orrell et al., 2017; Patel et al., 2004; Richards-Jones et al., 2019; Sogaard et al., 2014; Sturkenboom et al., 2015; Wilson et al., 2009; Woods et al., 2012, 2016). A small proportion of the studies were observational studies (clinical trials) (N = 4) (Dahlrup et al., 2014; Drummond et al., 1991; Martikainen et al., 2004; Vroomen et al., 2016). Only one study using observational data employed a model-based economic evaluation. Martikainen et al. (2004) performed a modelling approach (a basic Markov model in three states) where the model parameters were derived from another publication (Neumann et al., 1999) for the economic evaluation of Alzheimer's disease in Finland. N = 13 studies adopted a societal perspective

(Charlesworth et al., 2008; Dahlrup et al., 2014; Forster et al., 2013, 2015; Joling et al., 2013; Knapp et al., 2013; Orgeta et al., 2015; Orrell et al., 2017; Patel et al., 2004; Søgaaard et al., 2014; Sturkenboom et al., 2015; Vroomen et al., 2016; Wilson et al., 2009).

**Table 1.2** – Characteristics of the interventions

Table 1.2: Characteristics of the interventions

References	Geographical area	Underlying condition	Disease areas	Intervention type	Population concerned by the intervention (age) <sup>(a)</sup>	Intervention name - Brief description of the intervention
Charlesworth <i>et al.</i> (2008)	UK	Dementia	Mental/behavioural	Psychological	Both Carers (68) Patients (78)	Befriending scheme for carers Befriender facilitator (BF) -based with charitable/voluntary-sector organisations, were responsible for local befriending schemes, including recruitment, screening, training, and ongoing support for befriending volunteers and for matching carers with befrienders. Their role was to provide emotional support for carers.
Chatterton <i>et al.</i> (2016)	Australia	Cancer	Cancer	Psychological	Both Carers (NS) Patients (NS)	Psychologist-led, individualised cognitive behavioural intervention (PI) Patients and carers received up to five weekly sessions of telephone-based counselling from a psychologist (2 to 5 years of experience in psycho-oncology) following the principles of cognitive behavioural therapy.
Dahlrup <i>et al.</i> (2014)	Sweden	Dementia	Mental/behavioural	Education/support	Both Carers (62) Patients (84)	Psychosocial intervention The psychosocial intervention consisted of educating and informing (provision of a support group) the family caregiver. The intervention started approximately one month after the person was diagnosed with dementia.
Drummond <i>et al.</i> (1991)	Canada	Dementia	Mental/behavioural	Respite care/support	Both Carers (66) Patients (77)	Caregiver Support Program (CSP) The experimental set of supportive interventions was aimed at helping the caregivers to enhance their competency at providing care. Caregiver support nurses (CSNs) were assigned to assist carers, and on a regular basis to schedule home visits with the carer's family physicians whenever the carer's health was deemed to be unstable. The CSP included a 4-hour block of scheduled weekly in-home respite, with additional respite on demand.
Forster <i>et al.</i> (2013)	UK	Stroke	Cardiovascular	Training/support	Both Carers (61) Patients (71)	Training programme for caregivers after stroke The intervention consisted of 14 training components (six mandatory) that were identified as important knowledge/skills that caregivers would need to be able to care for a stroke patient after discharge home. Training continued until the caregiver was deemed to be sufficiently competent.
Forster <i>et al.</i> (2015)	UK	Stroke	Cardiovascular	Training/support	Both Carers (61) Patients (71)	Longer-Term Stroke Care (LoTS) LoTS aim to meet the longer-term needs of patients with stroke and their carers living at home. The intervention comprised a framework of 16 structured assessment questions that pertained directly to longer-term stroke problems previously identified by patients with stroke and their carers and related prompts provided in a care plan.

Table 1.2: (Continued)

References	Geographical area	Underlying condition	Disease areas	Intervention type	Population concerned by the intervention (age) <sup>(a)</sup>	Intervention name - Brief description of the intervention
Joling <i>et al.</i> (2013)	The Netherlands	Dementia	Mental/behavioural	Education/support	Both Carers (68) Patients (73)	<p>Family Meetings Intervention</p> <p>Caregivers in the intervention group were invited to participate in six in-person counselling sessions. The family meetings consisted of providing psycho-education, teaching of problem-solving techniques, and mobilization of the existing family networks of the patient and primary caregiver in order to improve emotional and instrumental support. The total estimated time for the intervention was 6.5 hours per patient-caregiver dyad, including the time spent on the individual and family sessions (5.5 hours) and the administration and preparation time for the counsellor (1 hour). The intervention participants also had access to all of the usual types of care.</p>
Knapp <i>et al.</i> (2013)	UK	Dementia	Mental/behavioural	Psychological	Carers (NS)	<p>STrategies for Relatives (START)</p> <p>Family carers of people with dementia received eight sessions (in their home) delivered by psychology graduates, with no clinical training but trained to deliver the intervention by adherence to the manual added to usual treatment. Each carer received a manual and a compact disc to guide them with relaxation exercises.</p>
Livingston <i>et al.</i> (2014)	UK	Dementia	Mental/behavioural	Psychological	Both Carers (56) Patients (78)	<p>STrategies for Relatives (START)</p> <p>Family carers received eight sessions, usually in their home, without the patient being present in the room and at a time convenient to them. The intervention was individually tailored to address the particular problems the carer was experiencing with the person for whom they were providing care.</p>
Martikainen <i>et al.</i> (2004)	Finland	Alzheimer	Mental/behavioural	Training/support	Both Carers (NS) Patients (NS)	<p>Cognitive-behavioural family intervention (CBFI)</p> <p>The cognitive-behavioural family intervention provided to carers and patients consisted of short courses in rehabilitation centres with the comprehensive support of dementia family care coordinators. The courses included physical and recreational training for AD patients, and psychological as well as educational support and counselling for the caregivers.</p>
Orgeta <i>et al.</i> (2015)	UK	Dementia	Mental/behavioural	Training/support	Both Carers (66) Patients (78)	<p>Individual cognitive stimulation Therapy (iCST)</p> <p>The intervention consisted of one-on-one, home-based, structured cognitive stimulation sessions for people with dementia, provided by the family carer. Dyads were asked to complete up to three 30-minute sessions per week over 25 weeks. Seventy-five activity sessions focusing on different themes, such as being creative were provided, as well as resources including a manual, an activity workbook, a carer's diary, and a toolkit containing items such as compact discs.</p>

Table 1.2: (Continued)

References	Geographical area	Underlying condition	Disease areas	Intervention type	Population concerned by the intervention (age) <sup>(a)</sup>	Intervention name - Brief description of the intervention
Orrell <i>et al.</i> (2017)	UK	Dementia	Mental/behavioural	Training/support	Both Carers (67) Patients (80)	Support at Home - SHIELD CSP: peer support - RYCT: Joint group reminiscence - Combination SHIELD CSP-RYCT The SHIELD CSP intervention was based on peer support for family carers by family carers. The target number of meetings for the carer support intervention was for 12 weekly meetings (1 hour each), followed by meetings for the next 5 months. RYCT targeted both the family carer and the person with dementia invited to attend a local reminiscence group. Twelve weekly sessions (2 hours each) covered various themes. (3) Combined intervention (SHIELD CSP-RYCT).
Patel <i>et al.</i> (2004)	UK	Stroke	Cardiovascular	Training/support	Both Carers (NS) Patients (NS)	Caregiver training The intervention consisted of caregiver training in basic nursing and facilitation of personal care techniques compared with the absence of training.
Richards-Jones <i>et al.</i> (2019)	Australia	Cancer	Cancer	Psychological	Both Carers (NS) Patients (NS)	Proactive telephone outcall intervention The outcall intervention consisted of making telephone contact with the caregivers initiated by the Cancer Council nurses to reduce carer burden. The intervention comprised support service outcalls to carers from a trained oncology nurse, with outcall one at baseline, outcalls two and three at one and at four months, respectively, post-baseline.
Sogaard <i>et al.</i> (2014)	Denmark	Alzheimer	Mental/behavioural	Education/support	Both Carers (NS) Patients (≥50)	Psychosocial intervention Patients and carers were randomised to an intensive, multicomponent, semi-tailored psychosocial intervention programme with counselling, education, and support lasting 8–12 months after diagnosis and follow-up at 3, 6, 12, and 36 months.
Sturkenboom <i>et al.</i> (2015)	The Netherlands	Parkinson	Mental/behavioural	Training/support	Both Carers (71) Patients (67)	Occupational Therapy in Parkinson's Disease (OTiP) Patients and carers in the intervention group received 10 weeks (maximum, 16 h) of individualized therapy, delivered by 18 trained occupational therapists in the patient's home environment and focused on improving performance in daily activities selected and prioritized by the patient. The caregivers' needs in supporting the patients in daily activities were evaluated and addressed if required.

Table 1.2: (Continued)

References	Geographical area	Underlying condition	Disease areas	Intervention type	Population concerned by the intervention (age) <sup>(a)</sup>	Intervention name - Brief description of the intervention
Vroomen <i>et al.</i> (2016)	The Netherlands	Dementia	Mental/behavioural	Education/support	Both Carers (64) Patients (80)	Two Forms of Case Management (COMPAS) Case Management was provided within a given care organization (intensive case management model, ICMM: guiding and supporting people with dementia for long periods of time usually starting after diagnosis, and providing medical and psychosocial services); Case management whereby care was provided by different care organizations within one region (Linkage model, LM: collaboration between multiple care providers providing healthcare services in the region and a mandate to initiate case management services).
Wilson <i>et al.</i> (2009)	UK	Dementia	Mental/behavioural	Psychological	Carers (NS)	Structured befriending service Carers enrolled in a BECCA-managed befriending scheme had access to an employed BF, and they were offered contact with a trained volunteer befriender for the duration of the scheme. The stated expectation was that befriending visits by the trained volunteer befrienders would be weekly home visits for at least 6 months, with variations in the location, duration, and frequency of the contact negotiated between each carer volunteer pairing.
Woods <i>et al.</i> (2012)	UK	Dementia	Mental/behavioural	Training/support	Both Carers (69) Patients (78)	REMCARE: REMiniscence groups for PwD and CAREgivers The intervention consisted of joint reminiscence groups held weekly for 12 consecutive weeks, followed by monthly maintenance sessions for a further 7 months. The sessions followed a treatment manual and they were led by two trained facilitators in each centre, supported by a number of volunteers.
Woods <i>et al.</i> (2016)	UK	Dementia	Mental/behavioural	Training/support	Both Carers (70) Patients (77)	REMCARE: REMiniscence groups for PwD and CAREgivers The intervention joint reminiscence groups emphasised active and passive reminiscence by both carers and people with dementia. The group sessions were held weekly over 12 consecutive weeks, followed by seven monthly maintenance group sessions. The sessions were led by two trained facilitators in each centre, supported by trained volunteers.

Abbreviations. NS: Not specified; UK: United Kingdom; CSP: Caregiver Support Program; Population concerned by the intervention: Carer and/or Patient; Both (Carer and patient). PwD: Person with Dementia. (a) Mean

The majority of the CUAs (15 out of 20) used the EQ-5D instrument for the health utility assessment. Seven studies included QALYs for the carers only (Charlesworth et al., 2008; Drummond et al., 1991; Knapp et al., 2013; Livingston et al., 2014; Orgeta et al., 2015; Patel et al., 2004; Richards-Jones et al., 2019), whereas thirteen studies took into account both the carers and the patients in the QALYs calculation (Chatterton et al., 2016; Dahlrup et al., 2014; Forster et al., 2013, 2015; Joling et al., 2013; Martikainen et al., 2004; Orrell et al., 2017; Sogaard et al., 2014; Sturkenboom et al., 2015; Vroomen et al., 2016; Wilson et al., 2009; Woods et al., 2012, 2016).

In terms of the informal care cost methodologies, health/social care costs were included as direct costs in all of the studies, and the carer out-of-pocket costs were considered in N = 2 studies (Chatterton et al., 2016; Richards-Jones et al., 2019). Regarding indirect costs, N = 11 studies considered the time spent caring (Charlesworth et al., 2008; Forster et al., 2013, 2015; Joling et al., 2013; Orgeta et al., 2015; Patel et al., 2004; Richards-Jones et al., 2019; Sogaard et al., 2014; Sturkenboom et al., 2015; Wilson et al., 2009; Woods et al., 2012) and of these, N = 7 valued the productivity loss (Joling et al., 2013; Orgeta et al., 2015; Richards-Jones et al., 2019; Sogaard et al., 2014; Sturkenboom et al., 2015; Vroomen et al., 2016; Woods et al., 2012) and N = 2 valued the leisure time loss (Orrell et al., 2017; Richards-Jones et al., 2019). Seven studies did not take into account the indirect carer costs and they essentially considered the health/social care direct costs (Dahlrup et al., 2014; Drummond et al., 1991; Forster et al., 2015; Knapp et al., 2013; Livingston et al., 2014; Martikainen et al., 2004; Woods et al., 2016).

Most studies reported the incremental cost-effectiveness ratios (ICERs). The interventions for the informal carers were deemed to be cost-effective in eleven studies (Chatterton et al., 2016; Dahlrup et al., 2014; Drummond et al., 1991; Knapp et al., 2013; Livingston et al., 2014; Martikainen et al., 2004; Orgeta et al., 2015; Patel et al., 2004; Richards-Jones et al., 2019; Sturkenboom et al., 2015; Vroomen et al., 2016) and not cost-effective in nine studies (Charlesworth et al., 2008; Forster et al., 2013, 2015; Joling et al., 2013; Orrell et al., 2017; Sogaard et al., 2014; Wilson et al., 2009; Woods et al., 2012, 2016). Four of the six psychological interventions were deemed to be cost-effective (Chatterton et al., 2016; Knapp et al., 2013; Livingston et al., 2014; Richards-Jones et al., 2019) versus four of the nine training/support interventions (Martikainen et al., 2004; Orgeta et al.,

2015; Patel et al., 2004; Sturkenboom et al., 2015), and two of the four education/support interventions (Dahlrup et al., 2014; Vroomen et al., 2016). The respite/support intervention was deemed to be cost-effective (Drummond et al., 1991). Six of the thirteen CUAs with a societal perspective were cost-effective; Five of the twelve studies that included both the patients and the carers in the scope of the costs were cost-effective (Dahlrup et al., 2014; Orgeta et al., 2015; Patel et al., 2004; Sturkenboom et al., 2015; Vroomen et al., 2016), while two of the three CUAs that conjointly included both the patients and the carers in the scope of costs and the carers only in the scope of the outcomes were cost-effective (Orgeta et al., 2015; Patel et al., 2004). The single CUA that focused only on carer costs and outcomes was cost-effective (Knapp et al., 2013). Further details are provided in the additional file.

**Table 1.3** – Characteristics of the included studies (CUA)

Table 1.3: Characteristics of the included studies (CUA)

References	Perspective	Follow-up	Study design	Cost valuation year	Scope of costs <sup>(a)</sup>	Type of carer direct costs	Type of carer indirect costs	Scope of outcome	Instrument used for utility assessment	Type of sensitivity analysis <sup>(b)</sup>	ICER (#)	Conclusion
Charlesworth <i>et al.</i> (2008)	Society	15-months	RCT	2005	Both	Health/social care	Time providing care	Carers	EQ-5D	Probabilistic	£105,954/QALY	Not cost-effective
Chatterton <i>et al.</i> (2016)	Health sector	12 months	RCT	2011-2012	Both	Health/social care - Out-of-pocket	NS	Both	AQOL-8D	Deterministic and Probabilistic	£8,703 to 40,428/QALY	Cost-effective
Dahlrup <i>et al.</i> (2014)	Society inferred	60 months (5 years)	NRS	2010	Both	Health/social care	NS	Both	EQ-5D	NS	NS <sup>(c)</sup>	Cost-effective
Drummond <i>et al.</i> (1991)	Payers	6 months	NRS	1988	Both	Health/social care	NS	Carers	CQLI	NS	20,036 CAN\$/QALY	Cost-effective
Forster <i>et al.</i> (2013)	Health and social care - Society	6, 12 months	RCT	2009-2010	Both	Health/social care	Time providing care	Both	EQ-5D	Deterministic and Probabilistic	>£20,000/QALY	Not cost-effective
Forster <i>et al.</i> (2015)	Health and social care - Society	6, 12 months	RCT	2010-2011	Both	Health/social care	Time providing care	Both	EQ-5D	Probabilistic	NS <sup>(d)</sup>	Not cost-effective
Joling <i>et al.</i> (2013)	Society	12 months	RCT	2009	Both	Health/social care	Time providing care - Loss of productivity	Both	SF6D	Probabilistic	€157,534/QALY	Not cost-effective
Knapp <i>et al.</i> (2013)	Payers and Society	8 months	RCT	2009-2010	Carers	Health/social care	NS	Carers	EQ-5D	Probabilistic	£5,452/QALY	Cost-effective
Livingston <i>et al.</i> (2014)	Health and social care	4, 8, 12 and 24 months	RCT	2009-2010	Carers	Health/social care	NS	Carers	EQ-5D	Probabilistic	£11,200/QALY	Cost-effective
Martikainen <i>et al.</i> (2004)	Payers	5 years	NRS	2001	Patients	Health/social care	NS	Both	HUI:2 <sup>(e)</sup>	Probabilistic	NS <sup>(f)</sup>	Cost-effective

Table 1.3: (Continued)

References	Perspective	Follow-up	Study design	Cost valuation year	Scope of costs <sup>(a)</sup>	Type of carer direct costs	Type of carer indirect costs	Scope of outcome	Instrument used for utility assessment	Type of sensitivity analysis <sup>(b)</sup>	ICER	Conclusion
Orgeta <i>et al.</i> (2015)	Health and social care - Society	26 weeks	RCT	2012-2013	Both	Health/social care	Time providing care - Loss of productivity - Out-of-pocket	Carers	EQ-5D	Probabilistic	£3,100/QALY	Cost-effective
Orrell <i>et al.</i> (2017)	Health and social care - Society	5, 12 months	RCT	2011	Both	Health/social care	Leisure time lost <sup>(g)</sup>	Both	EQ-5D	Probabilistic	>£30,000/QALY	Not cost-effective
Patel <i>et al.</i> (2004)	Society	12 months	RCT	2001-2002	Both	Health/social care	Time providing care	Carers	EQ-5D	Deterministic and Probabilistic	NS <sup>(h)</sup>	Cost-effective
Richards-Jones <i>et al.</i> (2019)	Health sector	1, 6 months	RCT	2013	Both	Health/social care - Out-of-pocket	Time providing care - Loss of productivity - Leisure time lost	Carers	AQoL-8D	Probabilistic	-\$18,500/QALY	Cost-effective
Sogaard <i>et al.</i> (2014)	Society	3, 6, 12 and 36 months	RCT	2008	Both	Health/social care	Time providing care - Loss of productivity	Both	EQ-5D	Probabilistic	NS <sup>(i)</sup>	Not cost-effective
Sturkenboom <i>et al.</i> (2015)[56]	Society	6 months	RCT	N/A	Both	Health/social care	Time providing care - Loss of productivity	Both	EQ-5D	Probabilistic	NS <sup>(i)</sup>	Cost-effective
Vroomen <i>et al.</i> (2016)	Society	4, 8, 12 and 24 months	NRS	2010	Both	Health/social care - Time providing care	Loss of productivity	Both	EQ-5D	Probabilistic	€-425,349/QALY	Cost-effective
Wilson <i>et al.</i> (2009)	Society	15 months	RCT	2005	Both	Health/social care	Time providing care	Both	EQ-5D	Probabilistic	£105,954/QALY	Not cost-effective
Woods <i>et al.</i> (2012)	Public sector	10 months	RCT	2010	Both	Health/social care	Time providing care - Loss of productivity	Both	EQ-5D	Probabilistic	<sup>(k)</sup> £2,586/QALY	Not cost-effective
Woods <i>et al.</i> (2016)	Public sector	10 months	RCT	2010	Both	Health/social care	NS	Both	EQ-5D	Probabilistic	>£20,000/QALY	Not cost-effective

Abbreviations. RCT: randomized controlled trial; NRS: non-randomized study (observational study); ICER: Incremental Cost-Effectiveness Ratio, (#): The ICERS are as reported; EQ-5D: EuroQol – Five-Dimensions scale; CQIL: Caregiver Quality of Life Instrument; AQOL-8D: Assessment of Quality of Life – Eight-Dimensions; SF6D: Short-Form – Six-Dimensions; HUI:2: Health Utilities Index Mark 2NS: Not specified; (a) Carer and/or patient; (b) Deterministic and/or Probabilistic; (c): Not calculated. Authors' conclusion based on the cost and outcome analysis. Outcomes were interpreted to produce positive effects on family caregivers; (d): No cost–outcome combination suggested statistically significant between-group increases; (e) QALYs calculations were provided by another study (Neumann *et al.* 1999); (f): The CBFi program is more effective and less costly; (g) The costs of unpaid family carer inputs were calculated following the approach used for volunteers. For the societal perspective, the opportunity cost approach assumed that the unpaid carer would be able to find employment with a wage rate equal to the national minimum wage, and the replacement cost was estimated as the hourly cost of a healthcare assistant, under the assumption that a care worker would need to be hired to provide care if the unpaid family carer was unable to do so. (h); (i); (j); (k) The Confidence Interval (CI) at 95% was –20,280 to 24,340 and in light of this high level of uncertainty, the authors concluded that the intervention was not cost-effective.

### 1.3.3 Overall quality of the reporting

Table 1.4 provides the note of the articles per item of the CHEERS Statement. Six items (“Comparators”, “Choice of health outcomes”, “Measurement of effectiveness”, “Measurement and valuation of preference-based outcome”, and “Funding sources”) were reported in 100% of the studies. All of the included studies clearly exceeded more than a half (50%) of CHEERS items (N = 20) (Charlesworth et al., 2008; Chatterton et al., 2016; Dahlrup et al., 2014; Drummond et al., 1991; Forster et al., 2013, 2015; Joling et al., 2013; Knapp et al., 2013; Livingston et al., 2014; Martikainen et al., 2004; Orgeta et al., 2015; Orrell et al., 2017; Patel et al., 2004; Richards-Jones et al., 2019; Sogaard et al., 2014; Sturkenboom et al., 2015; Vroomen et al., 2016; Wilson et al., 2009; Woods et al., 2012, 2016), and two articles achieved CHEERS scores of 100% (Forster et al., 2013; Livingston et al., 2014). A total of nine economic evaluations (45%) had 85% or greater for quality reporting (Charlesworth et al., 2008; Forster et al., 2013, 2015; Joling et al., 2013; Livingston et al., 2014; Orgeta et al., 2015; Sogaard et al., 2014; Vroomen et al., 2016; Woods et al., 2012); one study (5%) achieved 82% of the CHEERS items (Woods et al., 2016). A total of six studies (30%) (Chatterton et al., 2016; Martikainen et al., 2004; Orrell et al., 2017; Richards-Jones et al., 2019; Sturkenboom et al., 2015; Wilson et al., 2009) had CHEERS score ranging from 73 to 79% quality reporting. A total of four studies (4%) (Dahlrup et al., 2014; Drummond et al., 1991; Knapp et al., 2013; Patel et al., 2004) had quality of reporting scores between 59 and 68%. Overall, the average quality score was 81.35%, with the lowest rating at 59% (Dahlrup et al., 2014). Of the ten studies that had a quality of reporting score higher than the average quality score, seven were in regard to the societal perspective (Charlesworth et al., 2008; Forster et al., 2013, 2015; Joling et al., 2013; Orgeta et al., 2015; Sogaard et al., 2014; Vroomen et al., 2016) and only two concluded that the interventions were cost-effective (Orgeta et al., 2015; Vroomen et al., 2016).

**Table 1.4** – Economic evaluation as assessed by the CHEERS Statement (per item)

**Table 1.4: Economic evaluation as assessed by the CHEERS Statement (per item)**

CHEERS items	Charlesworth <i>et al.</i> (2008)	Chatterton <i>et al.</i> (2016)	Dahlrup <i>et al.</i> (2014)	Drummond <i>et al.</i> (1991)	Forster <i>et al.</i> (2013)	Forster <i>et al.</i> (2015)	Joling <i>et al.</i> (2013)	Knapp <i>et al.</i> (2013)	Livingston <i>et al.</i> (2014)	Martikainen <i>et al.</i> (2004)	Orgeta <i>et al.</i> (2015)	Orrell <i>et al.</i> (2017)	Patel <i>et al.</i> (2004)	Richards-Jones <i>et al.</i> (2019)	Sogaard <i>et al.</i> (2014)	Sturkenboom <i>et al.</i> (2015)	Vroomen <i>et al.</i> (2016)	Wilson <i>et al.</i> (2009)	Woods <i>et al.</i> (2012)	Woods <i>et al.</i> (2016)	Yes	%	No	%	Total
1	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓	19	95	1	5	20
2	✓	✓			✓		✓	✓	✓	✓	✓		✓	✓	✓		✓	✓	✓	✓	15	75	5	25	20
3	✓		✓	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	18	90	2	10	20
4	✓		✓	✓	✓	✓	✓		✓	✓	✓	✓				✓	✓		✓	✓	13	65	7	35	20
5	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓		✓		✓	✓	17	85	3	15	20
6	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	19	95	1	5	20
7	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	20	100	0	0	20
8	✓				✓	✓	✓		✓	✓	✓		✓			✓	✓		✓	✓	10	50	10	50	20
9		✓			✓	✓			✓						✓		✓	✓	✓	✓	9	45	11	55	20
10	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	20	100	0	0	20
11	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	20	100	0	0	20
12	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	20	100	0	0	20
13	✓	✓		✓	✓	✓	✓		✓	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓	16	80	4	20	20
14	✓	✓	✓	✓	✓	✓	✓		✓		✓	✓	✓	✓		✓	✓		✓	✓	16	80	4	20	20
15 <sup>a</sup>										✓											1	100	0	0	1
16 <sup>b</sup>										✓											1	100	0	0	1
17	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	19	95	1	5	20
18	✓			✓	✓				✓		✓		✓			✓		✓	✓	✓	10	50	10	50	20
19	✓				✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓	16	80	4	20	20
20	✓	✓			✓	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓	15	75	5	25	20
21		✓	✓		✓	✓	✓		✓	✓	✓	✓			✓	✓	✓		✓	✓	14	70	6	30	20
22	✓	✓		✓	✓	✓	✓		✓	✓	✓			✓	✓		✓	✓		✓	13	65	7	35	20
23	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	20	100	0	0	20
24	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	19	95	1	5	20
CHEERS Score	91	77	59	64	100	86	91	64	100	79	95	73	68	77	86	77	95	77	86	82	Overall average CHEERS score: 81%				

<sup>a, b</sup> Only for model-based economic evaluation; “✓” = “Yes”

## 1.4 Discussion

This is the first systematic review of economic evidence (CUAs) that focuses solely on interventions to support informal carers. We searched for articles in four electronic databases using a set of key search terms. The systematic review conducted by two of the authors followed the gold standard recommendations (PRISMA) for conducting systematic reviews (Moher et al., 2015), and a critical appraisal through a validated checklist (Husereau et al., 2013). Only 20 published CUAs of carer-focused interventions were identified in the literature. The main types of interventions were psychological, training/support, and education/support interventions, with mixed evidence regarding the cost-effectiveness. Most studies adopted a societal perspective, but there were differences in terms of what costs and outcomes were included. The reporting quality of the studies was generally quite good.

Conducting CUA with carer interventions is subject to a number of methodological challenges, for instance, do the methodologists need to include both the carer and the patient costs? Should the measurement and the valuation of health benefits be carried out for both the carers and the patients? Our results show that both the carer and the patient costs were largely taken into account (seventeen out of the twenty studies), as well as both the carer and the patient outcomes (thirteen out of the twenty studies). These findings are of particular relevance for the methodological guidelines used in Health Technological Assessment (HTA) (EUnetHTA Joint Action 2, Work Package 7, Subgroup 3 et al., 2016).

The societal perspective was included in most of the studies (13 out of 20), and 12 out of 13 of these studies used the EQ-5D metric for the utility assessment (QALYs), which is in accordance with the national recommendations. The use of a common outcome measure and perspective facilitates comparison between carer interventions (Charlesworth et al., 2008; Dahlrup et al., 2014; Forster et al., 2013, 2015; Knapp et al., 2013; Orgeta et al., 2015; Orrell et al., 2017; Patel et al., 2004; Sogaard et al., 2014; Sturkenboom et al., 2015; Vroomen et al., 2016; Wilson et al., 2009).

Overall, there appeared to be a tendency whereby studies with better reporting deemed the intervention to be not cost-effective. More precisely, seven out of ten CUAs

exceeding the average quality score of CHEERS (81%) were designated as being not cost-effective (Forster et al., 2013, 2015; Joling et al., 2013; Sogaard et al., 2014; Woods et al., 2012, 2016), and they included both carer and patient costs and both carer and patient outcomes. It would have been interesting to know if a change in the scope of the costs and/or the outcomes would have changed the conclusion of the economic evaluation. This suggests that sensitivity analyses based on different methodological assumptions may be desirable (EUnetHTA Joint Action 2, Work Package 7, Subgroup 3 et al., 2016). It is also important to note that some CUAs of carer interventions omitted informal care costs, while (Richards-Jones et al., 2019) and (Woods et al., 2012) found that inclusion of the time providing care (and the value of the consequent loss of productivity) costs affected the cost-effectiveness results of the intervention. For studies that omitted informal care time, for example (Knapp et al., 2013), the incremental cost-effectiveness ratio (in this particular case £5,452/QALYs) might not truly reflect how costly (or cost saving) the intervention is to society (Gheorghe et al., 2019; Thomas et al., 2017).

Fourteen of the sixteen economic evaluations of interventions for patient and carer dyads with a randomized controlled trial (RCT) design were performed throughout the European geographical area, with 11 of the 16 in the UK (Charlesworth et al., 2008; Forster et al., 2013, 2015; Knapp et al., 2013; Livingston et al., 2014; Orgeta et al., 2015; Orrell et al., 2017; Patel et al., 2004; Wilson et al., 2009; Woods et al., 2012, 2016). The geographical focus of this review (UK, and to a lesser extent Netherlands) could be due to the focus on cost-utility analyses rather than other types of economic evaluation. It could also reflect the fact that certain countries (including the UK) have substantial government funding (National Institute for Health Research (NIHR) - Health Technology Assessment (HTA) Programme in the UK, for example) and use for economic evaluation of healthcare interventions.

Our study focused on a critical review of economic evaluations in order to identify cost-utility analyses of interventions for carers. Close comparisons of the relative cost-effectiveness of carer interventions are complicated by differences between studies in terms of the design, the interventions that were compared, the inclusion of direct/indirect cost of the carers, and other study characteristics listed above. Thus, although all of the selected economic evaluations measured the same health outcome

(QALYs), the transferability and generalizability of the results (across diseases: dementia, stroke, cancer, and Parkinson's disease) is limited. This is due specifically to the choice of the method; differences in intervention contexts and intervention costs; and the types of economic evaluations, such as decision models (simulation)-based and empirical (including trial-based) economic evaluations (Anderson, 2010), and cost-effectiveness thresholds (McCabe et al., 2008).

As we chose to focus on carer interventions assessed by a cost-utility analysis approach, several publications that used other approaches to economic evaluation were not considered (Gitlin et al., 2010; Sopina et al., 2017). However, because QALYs were systematically used as the measure of health benefits in this review, there is a better level of comparability of the results between interventions for informal carers. Nevertheless, differences in methodologies across studies remain significant, such as the degree to which the informal carer's time is costed and the methods employed to do this, for example.

Based on our review, we suggest the following recommendations for future cost-utility analyses of carer-focused interventions to improve comparability and transferability. Firstly, CUAs should employ both a healthcare and a societal perspective for the analysis. This is recommended by the 2<sup>nd</sup> US panel on cost-effectiveness (Sanders et al., 2016). Secondly, CUAs under the societal perspective should, at the very least, consider carer time costs, to avoid adversely cost-shifting care to family carers. Thirdly, CUAs should consider outcomes for both family carers and patients to ensure that societal health gains are maximised. Fourthly, CUAs should adhere as much as possible to the CHEERS guidelines in order to promote transparency in reporting.

## 1.5 Conclusion

Our review highlights the lack of cost-utility analyses regarding interventions to support informal carers, but, more positively, the relative prominence of good reporting practices. The main types of interventions were psychological, training/support, and educational/supporting interventions, with mixed evidence regarding the cost-effectiveness. There appeared to be a tendency whereby the studies with better reporting deemed the

intervention to be not cost-effective, compared to the studies with fewer items on the CHEERS checklist. Hence, some divergences in findings noticed across the studies cannot be attributed solely to differences in the type of interventions undertaken, but also to the methodological trade-off. Most studies adopted a societal perspective, but there were differences in terms of what costs and outcomes were included. Lastly, by stating fundamental methodological and structural specifications, it is likely that there will also be improvements in the consistency and the quality of health economic evaluations of informal care.

# Appendix

## Supplemental Materials - Table 1.2

Supplementary Table 1.2: Study characteristics.

Reference s	Geogr aphic al area	Disea se areas	Interv ention type	Intervention description	Sampl e size (n)	Type of patient cost	Study Sponsor	Relationship of patients with carers - Patient characteristics	Baseline demographic information	ICER	Threshold/crit eria of decision determining cost-effectiveness of EE
Charlesworth et al. (2008)	UK	Dementia	Psychological	The intervention was 'access to a befriender facilitator' (BF). BFs, undertaken with charitable/ voluntary-sector organisations, were responsible for local befriending schemes, including recruitment, screening, training, and ongoing support of befriending volunteers, and for matching carers with befrienders. The role of befrienders was to provide emotional support for carers. The target duration for befriending relationships was 6 months or more.	236	Health/social care	Health Technology Assessment (HTA) Programme	Cohabiting with - Elderly patients	Family carer (Female 64%; Kinship: spouse 67%; Cohabiting 86%; Retired 67%; Carer's age (years) 68); Patient age (years) 78.2; Duration of caring (years) 3.8	£105,954/QALY	£20,000–30,000 per QALY
Chatterton et al. (2016)	Australia	Cancer	Psychological	Participants were randomised to a psychologist-led, five-session, individualised, cognitive behavioural intervention or a nurse-led, single-session, self-management intervention. Randomisation was stratified by patient/carer status and state. The NI group was provided a single telephone support session with a nurse counsellor. The PI group was provided up to five weekly sessions of telephone-based counselling from a psychologist following the principles of cognitive behavioural therapy. The psychologists had 2 to 5 years of experience in psycho-oncology. Both the nurses and the psychologists received regular supervision and session reviews by accredited clinical psychology supervisory staff. Participants in both groups were mailed a self-management resource kit prior to the sessions.	690	Health/social care - Out of pocket expenses	Non-profit organization	Family carer - Elderly patients	NS	£8,703 to 40,428/QALY	\$50,000 per QALY
Dahlrup et al. (2014)	Sweden	Dementia	Education/support	A psychosocial intervention consisting of two components, education and provision of a support group for the family caregivers, was conducted from September 1999 to January 2004. The intervention started approximately one month after the person was diagnosed with dementia. Each group comprised approximately eight family caregivers, mainly spouses and adult children. The program, led by an RN and a counsellor, consisted of both an educational and a social component whereby the family caregivers could discuss the topics and share their experiences in a relaxed and social setting. The five sessions included information and education about dementia disorders, depression, and symptoms of delirium; handling of behavioural symptoms; medication; legislation; and services available in the community.	308	Health/social care	University (Medical Faculty)	Spouses, cohabitants, children - Elderly patients	Family carer (Age (years) Mean, range 62 (27-90); Female 61%; Spouse/partner 24.8%; adult children 59.5%); Individuals with dementia (Age (years) Mean, range 84 (57-101); Female 61%).	NS	Not calculated. Authors conclusion based on the cost and outcome analysis. Outcomes were interpreted to produce positive effects on family caregivers.
Strummond et al. (1991)	Canada	Dementia	Respite care/support	The experimental set of supportive interventions was directed at helping the caregivers enhance their competency at providing care and to achieve a sense of control in their roles as caregivers. Caregiver support nurses (CSNs) were assigned to caregivers, and they made regularly scheduled home visits at a time that was convenient to the caregivers. These visits were weekly but were adjusted upward or downward depending on the needs of the caregiver. The caregivers received education about dementia and caregiving using content and teaching methods tailored to their knowledge level, caregiving situation, and learning style.	60	Health/social care	Government	Family carer - Elderly patients	Family carer (Wife 47%, Husband 23%), Female 70%, Mean age 66.10, Mean months caregiving 39.80); Patient (Females 50%, Mean age 77.8)	20,036 CAN\$/QALY	\$50,000 per QALY

Forster et al. (2013)	UK	Stroke	Training/support	The intervention (the LSCTC) comprised a number of caregiver training sessions and competency assessment delivered by stroke rehabilitation unit (SRUs) staff while the patient was in the SRU and one recommended follow-up session after discharge. The control group continued to provide the usual care according to the national guidelines. Recruitment was completed by independent researchers and the participants were unaware of the SRUs' allocation.	900	Health/social care	National Institute for Health Research (NIHR)	Partner, Daughter/son, Other relative - Elderly patients	Family carer (Age (years), mean (SD) 61.1 (14.64); Male 31.1%; Retired 43.3%; Working full-time ( $\geq 30$ hours per week) 28.2%); Patient (Age (years), mean (SD) 71.0 (12.76); Male 57.1%; Retired 69.1%; Partner 69.8%; Daughter/son 26.2%; Other relative 3.8%; Cerebral infarction 84.4%).	> £20,000 /QALY	£20,000–30,000 per QALY
Forster et al. (2015)	UK	Stroke	Training/support	The SCC services allocated to the intervention group provided care according to the LoTS system of care. This comprises a framework of 16 structured assessment questions (linked to evidence-based treatment algorithms and reference guides) that directly relate to longer-term stroke problems previously identified by patients with stroke and their carers [13,14] and related prompts provided in a care plan. The trial used existing SCC referral pathways, as determined during the site set-up. The majority of patients were referred to an SCC service through predischarge inpatient referral. Recruitment of the trial participants was by independent research staff blinded as to whether they were recruiting within a control or an intervention service, and the SCCs were unaware which of their patients had consented to participate.	1008	Health/social care	National Institute for Health Research (NIHR)	Partner, Daughter/son - Elderly patients	Carer (Age – Mean (SD) 61.0 (15.02); Male 32.4%; Partner 64.8%; Daughter/son 30.6%; Other 4.6%; Living with patient post stroke 78.7%); Patient (Age, mean (SD) 70.9 (13.18); Male 53.6%; Formal education 94.8%; Cerebral infarction 85.0%; In-hospital stay, mean (SD) 38.9 (44.4); Living alone post stroke 29.4%).	NS	Incremental cost-effectiveness ratios were unnecessary because no cost–outcome combination suggested statistically significant between-group increases in either costs or outcomes.
Joling et al. (2013)	The Netherlands	Dementia	Education/support	Caregivers randomized to the intervention group were invited to participate in six in-person counselling sessions: one individual preparation session, followed by four structured meetings that included their relatives and/or friends (family meetings), and one additional individual evaluation session. The family meetings were held once every 2 to 3 months in the year following enrolment in the program. The aim of the family meetings was to offer psycho-education, to teach problem-solving techniques, and to mobilize the existing family networks of the patient and primary caregiver in order to improve emotional and instrumental support. The content of the sessions was guided by the needs of the caregiver.	192	Health/social care - Loss of productivity	Organization for Health Research and Development (ZonMw)	Cohabiting with - Elderly patients	Carer (Age, M (SD) 67.8 (9.8); Female 69.8%; Spouse of the patient 95.8%; Patient (Age, M (SD) 72.8 (9.1); Female 31.3%)	€157,534/QALY	No significant differences in costs and effects between the groups were found.
Knapp et al. (2013)	UK	Dementia	Psychological	Eligible family carers received the therapy over eight sessions at a location chosen by the carer (usually their own home), without the person with dementia being present in the room. The sessions were delivered by psychology graduates with no clinical training but trained to deliver the intervention by adherence to the manual. A clinical psychologist (PR, one of the authors) met with each team of therapists for 1.5 hours of group clinical supervision every two weeks and was also available for individual consultation as needed by the therapists. Each carer had a manual and was provided a compact disc to guide relaxation exercises	260	NA	Health Technology Assessment (HTA) Programme	Cohabiting with, children - Elderly patients	NS	£5,452/QALY	£20,000–30,000 per QALY

Livingston et al. (2014)	UK	Dementia	Psychological	Eight-session manual-based coping intervention delivered by supervised psychology graduates to individuals. The therapy took place in the carer's preferred location, usually their home, without the patient being present in the room and at a time convenient to them. It was individually tailored to address the particular problems the carer was experiencing with the person for whom they were providing care. Each session ended with a different stress reduction technique session. The carers were given homework tasks to complete between sessions, including relaxation, identifying triggers and reactions to challenging behaviours, and identifying and challenging negative thoughts.	250	NA	National Institute for Health Research (NIHR); HTA Programme	Spouse/partner, child, friend, daughter's/son's partner, nephew/niece, grandchild - Elderly patients	Carer (Age (mean) 56; Male 32%); Patient (Age (mean) 78; Male 42%); Spouse/partner 42%; Child 43%; Friend 2%; Daughter's/son's partner 5%; Nephew/niece 3%.	£11,200/QALY	£20,000–30,000 per QALY
Martikainen et al. (2004)	Finland	Alzheimer's	Training/support	The cognitive-behavioural family intervention (CBFI) program to help the informal caregivers (spouses or adult children) postpone the need to transfer AD patient to a nursing home. The CBFI program trial is designed to be an additional service for AD patients and their informal caregivers. Two alternative forms of treatment are the current practice, or the current practice combined with the CBFI program. The current practice consists of different forms of community services (Meals on Wheels, cleaning services, etc.) and periodical institutional care (1–2 weeks/period), while the informal caregivers are able to rest. The AD patients and their informal caregivers can obtain these services from the public or private sector, since private sector services are also covered by the national insurance schemes.	206	Health/social care	Foundation	Spouses/adult children - Elderly patients	NS	NS	Based on Table 2, the CBFI program is more effective and less costly
Orgeta et al. (2015)	UK	Dementia	Training/support	The intervention consisted of one-on-one, home-based, structured cognitive stimulation sessions for people with dementia, provided by the family carer. Dyads were asked to complete up to three 30-minute sessions per week over 25 weeks. The programme consisted of a total of 75 activity sessions, focusing on different themes, such as being creative, word games, and current affairs. Dyads were provided resources including a manual, an activity workbook, a carer's diary, and a toolkit containing items such as compact discs, dominos, and maps. Each dyad worked with an unblinded researcher who provided initial training and ongoing support to carers. Participants in the control group received TAU, which varied within and between centres and changed over time. In general, the services provided to this group were also available to those in the treatment group.	356	Health/social care	National Institute for Health Research (NIHR); HTA Programme	Spousal carer, non-spousal carer, cohabiting - Elderly patients	Carer (Female 52; Marital status Married/cohabiting/civil partnership 50%; Living situation Living with spouse/partner 50%; Highest level of education School leaver (14–16 years) 50%; mean age (SD) 66.01 (12.76)); Patient (Female 50%; Marital status Married/cohabiting/civil partnership 50%; Living situation 50%; Highest level of education School leaver (14–16 years) 53%; mean age (SD) 78.40 (7.30))	£3,100/QALY	£20,000–30,000 per QALY
Orrell et al. (2017)	UK	Dementia	Training/support	Peer support (SHIELD CSP) The focus of this intervention was on peer support for family carers by family carers. The participant carers allocated to this intervention were contacted by a local carer support co-ordinator who met to discuss the peer-support programme and to consider an appropriate match from a pool of trained carer support volunteers with experience of caring for a relative with dementia. The carer support co-ordinator then facilitated a first meeting between the supporter and the supportee. The target number of meetings for the carer support intervention was for 12 weekly meetings, each lasting 1 hour, followed by fortnightly meetings for the next 5 months. The meetings took place in the carer's own home or in a public venue such as a cafe. Carer supporters were encouraged to listen, encourage, and provide moral support. Meetings were arranged to include or exclude the person with dementia according to the family carer's preference. Joint group reminiscence (RYCI) for dyads was allocated to this intervention, and both the family carer	289	Health/social care	National Institute for Health Research (NIHR); HTA Programme	Spouse/partner, cohabiting with partner - Elderly patients	Carer (Female 68.04%; Married/cohabiting/civil partnership 87.63%; Relationship Spouse/partner 61.86%; Highest level of education School leaver (14–16 years) 61.86%; Age (years), mean (SD) 66.68 (12.30)); Patient (Female 50.52%; Marital status Married/cohabiting/civil	> £30,000/QALY	£20,000–30,000 per QALY

				and the person with dementia were invited to attend a local reminiscence group. Twelve weekly sessions, each lasting 2 hours, covered themes ‘across the lifespan’, following Schweitzer and Bruce’s RYCT programme. Each session explored its theme using multisensory triggers and activities, including group discussions, small group activities, handling objects, enacting or improvisation and singing songs. Each session was led by two experienced facilitators, supported by a team, including volunteers, health and social care staff and trainees, to facilitate small group discussions and activities, and to engage the individuals with dementia. During four of the sessions, the family carers met separately from the main group for approximately 45 minutes with the aim of developing listening and communication skills, and to consider how the activities and strategies used in the sessions could be extended to the home environment. Combined intervention (SHIELD CSP-RYCT): When participants were offered both contact with a carer supporter and the opportunity to attend the RYCT programme, the carer supporter was asked to attend the RYCT sessions prior to individual meetings with the carer. These carer supporters were also invited to an additional 2-hour training session on the topic of reminiscence at home, to enable them to better support the family carer with implementation of the strategies and advice provided during the RYCT carer’s sessions. The aim of this intervention was to extend the benefits of RYCT by means of the carer supporters bringing knowledge of the care dyad to the group, and by encouraging reminiscence in the family carer’s home.					partnership 70.10%; Cohabiting with partner 67.01%; Highest level of education School leaver (14–16 years) 74.23%; Type of dementia: Alzheimer’s disease 41.24% & Vascular dementia 20.62%; Age (years), mean (SD) 79.59 (7.87)		
Patel et al. (2004)	UK	Stroke	Training/support	Caregiver training in basic nursing and facilitation of personal care techniques compared with no caregiver training.	300	Health/social care	The National Health Service (NHS)	Family carer - Elderly patients	NS	NSe	Cost and outcome were not significant
Richards-Jones et al. (2019)	Australia	Cancer	Psychological	Dyads were randomly assigned in a 1:1 ratio to either the telephone outcall arm or the control arm, each of which comprised a sample of 108 dyads. The intervention arm comprised three 131120 information and support service outcalls to carers from a trained oncology nurse. The nurses followed a standardised protocol and checklist during each outcall, consisting of the administration of the Distress Thermometer (DT) followed by a tailored discussion of issues relevant to the carer. The tailored discussion comprised six topics (psychological distress, health literacy, health, family support, financial problems, and practical issues), raised by the 131120 nurse to address potential unmet carer needs and to direct carers to available health care resources if required.	108	Health/social care - Out-of-pocket	National Health and Medical Research Council	Family carer - Elderly patients	NS	\$18,500/QALY	\$50,000 per QALY
Sogaard et al. (2014)	Denmark	Alzheimer	Education/support	Psychosocial counselling and support lasting 8–12 months after diagnosis and follow-up at 3, 6, 12, and 36 months in the intervention group or follow-up only in the control group. Dyads of patients and their primary caregivers who were randomised to an intensive, multicomponent, semi-tailored psychosocial intervention programme with counselling, education, and support	330	Health/social care	National Board of Social Services	Family carer - Elderly patients	NS	NS	None of the observed cost and QALY measures were significantly different between the intervention and control groups,

Sturkenboom et al. (2015)	The Netherlands	Parkinson	Training/support	Patients and their caregivers in the intervention group received 10 weeks (maximum, 16 h) of individualized therapy according to the Dutch guidelines for occupational therapy in PD within the first 3 months after baseline assessment. The intervention was delivered by 18 trained occupational therapists in the patient's home environment and focused on improving performance in daily activities selected and prioritized by the patient. Caregiver needs in supporting the patient in daily activities were evaluated and addressed if required. The control group was not allowed to receive occupational therapy. Both groups could receive all other medical, psychosocial, or allied health care interventions as usual	371	Health/social care	Prinses Beatrix Spierfonds and Parkinson Vereniging	Mostly partner-relationship - Elderly patients	Carer (Partner-relationship to patient 88%; Age (y) 67 (57.0-73.0); Men 32%; In paid employment 28%); Patient (Age (y) 71.0 (63.3-76.0; Men 63%; In paid employment 13%; Disease duration (y) 6.0 (4.0-10.0))	NS	€40,000 per QALY; The estimated differences between groups in utility scores (EQ-5d) of patients, caregivers, and patient-caregiver pairs did not reach a level of significance but were in favour of the intervention group.
Vroomen et al. (2016)	The Netherlands	Dementia	Education/support	Case management provided within one care organization (ICMM), case management where multiple case management organizations are present within one region (LM), and a group with no access to case management (control). Case managers in the Intensive Case Management Model (ICMM) are appointed at an organization that is specialized in dementia care. They guide and support people with dementia for long periods of time, usually starting after diagnosis, and they provide medical and psychosocial services from within their own organization. The case manager works in collaboration with an 'in-home' multidisciplinary team to tailor the care needs of the person with dementia and the informal caregiver. The Linkage Model (LM) is a collaboration between multiple care providers (e.g. home care organizations, general practitioners, social care services) who were already providing health care services in the region and who were given the mandate to initiate case management services. After a formal diagnosis, persons with dementia are assigned to a case manager who provides educational, emotional, and practical support such as advice regarding disease-related issues, and who provides recommendations on the availability of supportive health and social services until the time of nursing home admission or death of the persons with dementia	521	Health/social care	Government	Family member cohabiting with spouse - Elderly patients	Carer ICMM (Age, mean (SD) 64.5 (12.8); Female 70.0%); Spouse 53.3%); Living together 55.5%; Education: Elementary/lower 16.0%; Secondary 61.8%); Carer LM (Age, mean (SD) 64.4(12.4); Female 63.6%); Spouse 45.6%); Living together 48.8%; Education 15.3%; Secondary 62.6%); Patient ICMM (Age, mean (SD) 79.9 (7.7); Female 52.4%; Married or in a relationship 56.4%; Living alone 40.5%; Living with another person 57.3%; Education: Elementary/lower 41.9%; Secondary 50.0%); Patient LM (Age, mean (SD) 81.0 (7.5); Female 62.%; Married or in a relationship 47.8%; Living alone 46.3%; Living with another person 51.2%; Education: Elementary/lower 49.5%; Secondary 40.5%)	€425,349/QALY	€30,000 per QALY

Wilson et al. (2009)	UK	Dementia	Psychological	Carers enrolled in the study were randomised to receive either: * the usual care plus enrolment in a voluntary sector-based, BECCA-managed Befriending Scheme; or the usual care only. "Usual care" received by carers and PwDs was care as provided in their area by health, social, or voluntary services, and included services such as community psychiatric services, day hospitals, day centres, home care or personal care, respite care and carer information or support groups. All participants were sent information regarding the services available to carers in their area. Carers enrolled in a BECCA-managed befriending scheme had access to an employed BF and an offer of contact with a trained volunteer befriender for the duration of the scheme. The stated expectation was that befriending visits by the trained volunteer befrienders would be weekly home visits for at least 6 months, with negotiated variations in location, duration, and frequency of contact.	236	Health/social care	NHS R&D Health Technology Assessment (HTA) Programme	Family carer - Elderly patients	NS	£105,954/QALY	£20,000–30,000 per QALY
Woods et al. (2012)	UK	Dementia	Training/support	The intervention consisted of joint reminiscence groups held weekly for 12 consecutive weeks, followed by monthly maintenance sessions for a further 7 months. The sessions followed a treatment manual, and they were led by two trained facilitators in each centre, supported by a number of volunteers. Up to 12 dyads were invited to attend each group.	350	Health/social care	National Institute for Health Research (NIHR); HTA Programme	Spouse - Elderly patients	Carer (Female carer 70%; Ethnicity: white 98%; Marital status: married 87%; Carer accommodation owner-occupied 84%; ages (years) mean: 69.55 (S.D. 11.7); Patient (Female person with dementia 47%; Ethnicity: white 98%; Marital status: married 72%; Owner-occupied accommodation 81%; age (years) mean: 77.72 (S.D. 7.4))	£2,586/QALY	£20,000–30,000 per QALY
Woods et al. (2016)	UK	Dementia	Training/support	The intervention followed the 'Remembering Yesterday, Caring Today' (RYCT) manual. Joint reminiscence groups emphasise active and passive reminiscence by both carers and people with dementia. Group sessions were held weekly over 12 consecutive weeks, followed by seven monthly maintenance group sessions. Sessions were led by two trained facilitators in each centre, supported by trained volunteers. The manual recommends a blend of activities for each session, based on core principles. Each session lasted two hours and focused on a different theme, including childhood, schooldays, working life, marriage, and holidays and travels. Dyads were encouraged to contribute with materials brought from home. The maintenance sessions followed a similar pattern. Each session blended work in large and small groups, and a range of activities including art, cooking, physical re-enactment of memories, singing, and oral reminiscence.	336	Health/social care	National Institute for Health Research (NIHR); HTA Programme	Mostly spouse, partner, female - Elderly patients	Carer (Age - 69.6 (S.D. 11.6); Female 70%; Married 87%); Patient (Age 77.5 (S.D. 7.3); Female 47%; Married 72%; Spousal relationship 70%)	>£20,000/QALY	£20,000–30,000 per QALY



## Chapter 2

# Determinants of the need for respite according to the characteristics of informal carers of old-aged people at home: results from the 2015 French national survey

### Abstract

*Objective.* The purpose of this study was to shed light on how the characteristics of informal carers affect the need for respite.

*Data and method.* We used data from a nationally representative survey *Capacités Aides et Ressources des Seniors (CARE - ménage)* collected in 2015 by the *National Institute for Statistics and Economic Studies (INSEE)* and the *Directorate for Research, Studies, Assessment and Statistics (DREES)*. A probit model was used for econometrics modelling.

*Results.* Our study included  $N = 4,278$  dyads of informal carers and care recipients, of which 40% were cohabitants. The mean age was 61 for carers. The majority of carers were female, married, the child of the care recipient. Almost 27% reported a need for

respite. A worse health status, feeling of loneliness, having a lack of time for oneself and needing to provide more than 60 hours of care per month very significantly increased the need for respite irrespective of whether or not the carer lived with the care recipient ( $p < 0.01$ ). Conversely, however, being closely acquainted with the care recipient showed a reduced need for respite in comparison with that of carers who are married to their care recipient ( $p < 0.05$ ).

*Conclusion.* These findings provide useful information for policymakers, physicians and other health professionals for reducing carers' risk of exhaustion and burnout and for referring carers to the relevant service, e.g. psychological intervention, respite care support, training support and education support, at the right time.

## 2.1 Introduction

Informal carers represent unpaid persons such as family members, neighbours, close acquaintances or other significant individuals who provide daily assistance to a family member or dependent old-aged person who cannot take care of himself or herself. Informal care represents an essential component of health care systems and long-term care. Therefore, a significant proportion of the population dedicates a particular part of their time to providing care to loved ones (parents, children and partners by marriage). Informal carers have a ubiquitous and very substantial presence throughout the world (The IACO provided the following figures of informal carers internationally: 43.5 million in the USA (2015), 8.1 million in Canada (2012), 6.5 million in the UK (2011) and more than 8 million people in France (2019)). Given the situation marked by the increase in expenditure for the health system in the majority of western countries due to ageing populations, the demand for informal care is likely to increase over the coming decades.

In France, according to the projections of the National Institute for Statistics and Economic Studies (*INSEE*), the proportion of people aged over 60 years will increase sharply until 2035. This sharp increase will be transitory and will correspond with the transition of the “baby-boom” generations. In 2015, 3 million people aged 60 or older living at home reported being regularly assisted with activities of daily living because of their age or health condition (Brunel et al., 2019). Simultaneously, among the high number of carers, individuals likely to be able and willing to provide care was probably reduced as a result of a range of socio-cultural trends, such as demographic changes, the increase of female participation in the labour force, cultural values and changes to family structures (Geerlings et al., 2005; Heath, 2002; Robine et al., 2007; Van Houtven and Norton, 2004; Wiles, 2003). Therefore, demographic and social changes associated with population ageing have resulted in much debate regarding how care is provided to the old-aged and/or people with disabilities (Davin et al., 2009; Karlsson et al., 2006).

Informal carers play a strategic role in the daily activities of their dependent loved ones. Although some carers view care provision as propitious and a generator of positive utility, it is nevertheless true that it can readily be seen to have lost these qualities (Brouwer et al., 2005; Hirst, 2005; Van Exel et al., 2002; Van Wijngaarden et al., 2004). When this happens, providing informal care produces negative consequences for carers as a result of a high risk of exhaustion (strain/burnout) if carers do not

receive external assistance. Generally, informal care negatively affects the carer's work productivity (Atsuhiko and Tadashi, 2016; Chadili et al., 2017; Hassink and Van den Berg, 2011; Li, 2017; Peyrache and Ogg, 2017; Sugawara and Nakamura, 2014) and their health (Antoine et al., 2010; McMillan and Mahon, 1994; Suzuki et al., 2008; van Exel et al., 2008; Yuda and Lee, 2016). Despite rapid impairments being observed in situations involving an overwhelming burden, there is more concern regarding the gradual worsening of carers' quality of life (Montgomery et al., 1985; Schulz and Beach, 1999; Stall et al., 2018). In light of this, it is clear that many carers need support services to improve their health and quality of life (Lopez Hartmann et al., 2012). This need is substantial for carers with a high risk of exhaustion, who remain without support at their disposal. As a result, the following situation may potentially lead to a "double boomerang" effect of one care recipient receiving informal care leading to two dependent individuals using formal care (van Exel et al., 2008).

Assuming that carers occupy an ambiguous position within the social care system (Twigg, 1989), the majority of services are predominantly structured around recipients. Therefore, many support services dedicated to carers have been developed across countries (Eurocarers, 2016; Jones et al., 2012), particularly respite care (Maayan and Lee, 2014; McNally et al., 1999). Respite care generally provides temporary relief to informal carers from continuing caregiving responsibilities and restores resilience and improves the quality of life and well-being of carers (Fung et al., 2019). The need and the claims for respite assistance are priority considerations in the debate regarding the prevention of frailty. Regarding this significant public health issue, it is essential to address this concern by identifying and understanding factors influencing the need for respite among carers, such as the health status (Casado, 2008).

Despite the rapid intensification of focused carer support programmes in recent decades, due to the increasing number of carers over this period, there are still many who become overwhelmed with the burden of providing informal care. Several studies have found the inadequacy of services on offer, ambivalence in carers' attitudes, a lack of available time (Thomas et al., 2005), and a feeling of guilt when carers request assistance (Ostrowski and Mietkiewicz, 2013; Pierron-Robinet et al., 2018).

Given the potential benefit of respite and the gradual recognition of this fact by health professional and policymakers, the assessment of respite programmes establishes

that the timing at which services were offered and then subsequently used by carers was deemed both “too little” (Willemse et al., 2016) and “too late” (Gottlieb & Johnson, 2000), even for overburdened carers (van Exel et al., 2006). Nevertheless, despite the low use of respite, many carers reported a significant need in general (Armstrong, 2000; Schofield et al., 1998), and particularly for day care (Armstrong, 2000; Phillipson and Jones, 2012).

In this paper, we provide an analysis of the need for respite amongst informal carers. Based on a very recent French nationwide database, we investigated the need for respite related to the characteristics of carers in particular. Therefore, this study aims to shed more light on carers’ preferences regarding the need for respite. Our paper constitutes an important contribution to the field because it provides a first exploratory analysis taking advantage of the large and recent national data set and a broad pattern of explanatory variables.

## 2.2 Theoretical framework: The demand for social services

The demand for social services for informal carers can depend on the same factors as the demand for care for old-aged persons, and the general population: mental and physical (burden) health, capacity to pay, and care accessibility. In the social production of welfare framework, social care demand is generally considered as a need (Netten and Davies, 1990). We considered the carer as a child and the recipient as a parent and household as a community regarding the new home economics (Ferber and Birnbaum, 1977). In this study, we assumed that child participate in the labour market; and the benefit, welfare or utility depend on the consumption  $C$ , leisure  $L$ , and informal care  $Z$ . Then, consumption services depend on both leisure and consumption goods  $X$ . Since the child marginal utility is increasing in consumption and leisure, it may be decreasing or increasing in informal care (Fevang et al., 2008; Norton, 2000).

The new home economics application in the consumption of social care provides a framework for a general model formulation. The main desire is to maximise one’s own and other’s welfare. Therefore, the utility primarily depends on commodities produced in the community; the time allocation across activities, and the welfare of the community.

The welfare maximisation program is subject to five different types of constraint: budgetary; technological/physical; Institutional; cooperative; and psychic (Netten and Davies, 1990).

- Budgetary refers to the total amount of time and allocation (income being lesser than or equal to individual resources);
- Technological/physical refers, for example, to the situation that informal care provided by a child is limited with the distance a parent. It induces more need for informal care for instrumental - activities of daily living (I-ADL) for the parent;
- Institutional, for instance, the weekly work time of child; the statutory age for retirement of a child
- Cooperative represents, for example, the need for somebody else for social interaction and avoid loneliness;
- Psychic refers to the feeling of duty towards the parent; guilt; reluctance towards support.

The utility model is now:

$$MaxU = U(Z_i, T_i, U_h) \quad (2.1)$$

Subject to:

- Budgetary constraint

$$Y = \omega T_\omega + rS + A \quad - \quad \text{Income: waged work, savings, pensions}$$

$$T = \sum_{i=0}^n T_i + T_\omega \quad - \quad \text{Time constraint}$$

$$K = K \quad - \quad \text{Capital is fixed}$$

$$Y = \sum_{i=0}^n p_i x_i \quad - \quad \text{Income constraint}$$

- Technical and cooperative constraint

$$Z_i = Z(x_i, T_i, K_i) \quad - \quad \text{Community technical efficiency}$$

- Psychic constraint

$$U_h = u(Z_i) \quad - \quad \text{The utility of other network members}$$

With,  $U$  = Utility;  $x_i$  = goods used in commodity  $i$ ;  $Z_i$  = output of commodity  $i$ ;  $p$  = price;  $T_i$  = time used in commodity  $i$ ;  $A$  = unearned income;  $K$  = capital;  $r$  = rate of return on savings;  $Y$  = money income;  $w$  = wage rate;  $T_w$  = time spent at work;  $S$  = savings.

To sum up, the child and parent maximise their welfare through an optimal level of informal care. Then, the demand for social services may occur when the burden threatens the informal care network's viability as a productive unit of commodities. In the majority, social services substitution of the informal care network in the community, yield indirect utility effect (improvement of increase of care provision) and direct utility effect (impact on health or behaviour). Beyond a certain level of fatigue/exhaustion, there is a considerable drop in carers' health and higher costs (treatments, loss of productivity, etc.) than effective prevention.

## 2.3 Material and methods

### 2.3.1 Data source

Data used in our study stemmed from the *Capacités Aides et Ressources des Seniors (CARE ménage)* (Ministère des Solidarités et de la Santé - DREES, 2016), a nationally representative survey carried out in France's metropolitan areas in 2015 by the INSEE and the Directorate for Research, Studies, Assessment and Statistics (DREES). We used both the data of carers (*Capacité Aides et Ressources des seniors (CARE ménages) - Volet aidants, 2015*) and care recipients (*Capacité Aides et Ressources des seniors (CARE ménages) - Volet seniors, 2015*). The carer survey (*CARE ménage - Volet "Aidants"*) was a supplementary section of *CARE ménage - Volet "Senior"* collected in 2015. The survey protocol favoured face-to-face data collection. The survey was conducted by phone when face-to-face contact was not possible.

The CARE survey focuses on the living conditions of people aged 60 or over living at home, their difficulties in carrying out the activities of daily living and the assistance they receive. About 15,000 older people were interviewed, including healthy people. A total of 10,628 care recipients among the elderly were included in the study. Informal carers made up for 6,201 (16 years of age or older) of those declared by recipients.

Regarding the need for respite (dependent variable), the carer had to answer “yes”/“no” to the following question: “Do you need respite? / Do you need more respite for longer periods of time?”

The characteristics, technical details and a full description of the CARE survey are available in the technical notice of the DREES website ([Ministère des Solidarités et de la Santé - DREES, 2015a,b](#)).

### 2.3.2 Methods

We used descriptive statistics to provide details on the study sample, including informal carers and care recipients. We used multivariate regressions to explore variables influencing the need for respite. We assumed that the need for respite depends on the health status, living arrangement and various socio-economic characteristics ([Casado, 2008](#); [Gervès-Pinquier et al., 2014](#); [Koopmanschap et al., 2004](#); [Mello et al., 2016](#); [van Exel et al., 2008](#); [Yuda and Lee, 2016](#)) (Table 2.4.1).

We modelled the  $Needforrespite_i$  (dichotomous dependent variable) through a *probit* model (model 1). The econometric specification of the  $Needforrespite_i$  in the model 1 as follows:

$$Needforrespite_i = \beta_0 + \beta_1 \times H_i + \beta_k \times X_i + \epsilon_i \quad (2.2)$$

Where  $H_i$  stands for the health status of the carers.  $X_i$  represents explanatory variables related to socioeconomic dimensions of the characteristics of informal carers and recipients.  $\beta_k$  represents the parameters to be estimated, and  $\epsilon_i$  represents the error term. The dependent variable  $Needforrespite_i$  was defined as:

$$Needforrespite_i = \begin{cases} 1, & \text{if } Needforrespite_i > 0 \\ 0, & \text{if } Needforrespite_i \leq 0 \end{cases} \quad (2.3)$$

We pay particular attention to the interest variable “health status”. It referred to a set of levels describing different carer health statuses: very good/good; fair/normal; poor; or bad/very bad. We assumed that a worse health status induces more need for respite.

Furthermore, we performed a second model (model 2) for robustness checks by using a composite index as a proxy of the health status (interest variable) of the informal

carers. Therefore, we built a Health Status Composite Index (HSCI) capturing the level of vulnerability related to negative consequences of the carers' health states (Kumagai, 2017), considered to be the interest variable. In keeping with the literature, the following indicators were retained: stress, anxiety, back problems, physical exhaustion, sleep disorders. The HSCI, which reflects a linear combination of such indicators, can also be assumed as a subjective burden of informal care. These selected variables were turned into the HSCI by computing the principal component analysis, which amounts to a substantial contribution to the main component. The Principal Components Analysis (PCA) was related to the strain of carers (this comprised high values for the most affected), with cumulative inertia in the first axis. We used Varimax rotation to change the PCA coordinates that maximise the variances of the sum of the squared loadings. Thus, all of the coefficients of each component became either large or close to zero, with few intermediate values. The goal was to capture the association of each variable with at the most one factor. As we only considered the first factor/axis, the composite index provided substantial related information. Finally, the econometric specification of model 2 of the *Needforrespite<sub>i</sub>* was determined as follows:

$$Needforrespite_i = \beta_0 + \beta_1 \times HSCI_i + \beta_k \times X_i + \epsilon_i \quad (2.4)$$

Where *HSCI<sub>i</sub>* represents the Health Status Composite Index capturing the carer vulnerability.

All variables and parameters remained unchanged compared with model 1, except for the variable "health status" which was replaced by the "HSCI" variable.

Both models 1 and 2 were based on the entire informal carers population and then on the cohabiting and non-cohabiting carers subgroups. We assumed that the living status of the carer (cohabitation vs non-cohabitation) impacts the nature and the type of care provision (Renaut, 2012), the attitude of carers toward respite.

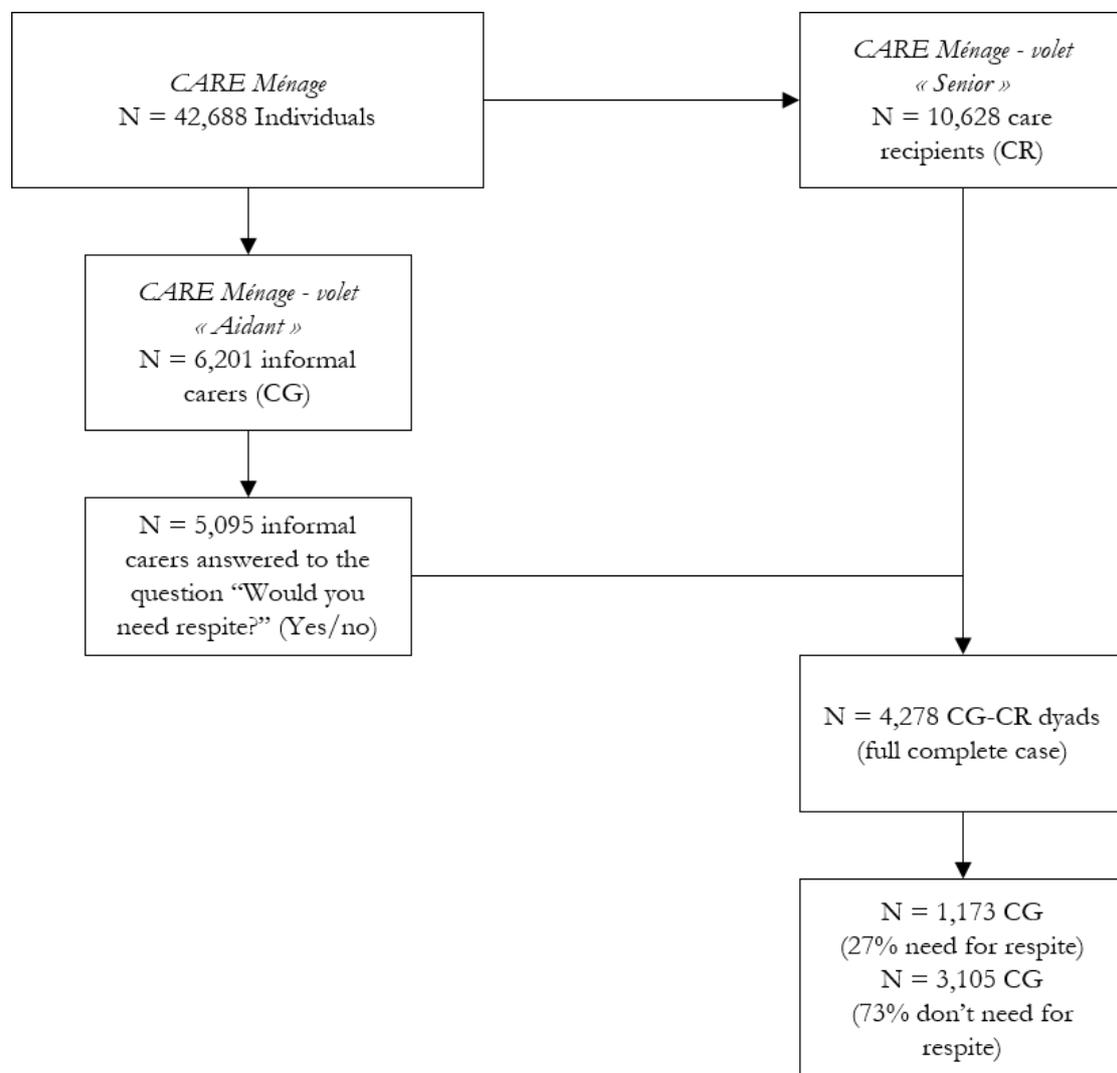
We carried out all of the statistical analyses with STATA SE-64 Statistical software 14.2 (StataCorp. LP, College Station, TX, USA).

## 2.4 Results

### 2.4.1 Descriptive statistics

Figure 2.4.1 describes the entire study population. The CARE survey contains 42,688 individuals, among which  $N = 6,201$  were informal carers and  $N = 10,628$  were care recipients. Carers' data were then matched with recipients' data to provide a dyadic sample study. Of those, only  $N = 5,095$  informal carers reported the need for respite (yes/no). Finally, our study included  $N = 4,278$  informal carer-care recipient dyads with the full complete case.

Figure 2.4.1 – Study population



Note: CG: informal carer; CR: care recipient; CARE Ménage - volet « Senior » and CARE Ménage - volet « Aidant » represent respectively the elderly and carers surveys.

Table 2.4.1 provides details of the characteristics of informal carers and care recipients for the entire population and for informal carers who did and did not need respite.

As indicated in Table 2.4.1, Of 4,278 informal carers, almost 62% reported a health status of “very good” or “good”. Almost 66% of carers were married. The mean age of carers was 61 years ( $SD \pm 14$ ) with a range of 18 – 96. Female carers accounted for 61%. Almost 41% of carers lived in cohabitation. The majority of carers (54%) were offspring of those for whom they were caring, 28% partner by marriage, 13% a family member and 5% a close acquaintance. Almost 77% reported the possibility of replacement in case of unavailability. Almost 57% of carers reported a length of time for care provision greater than five years. Informal carers who provided care for less than 30 hours per month represented 45%. Regarding the need/use for support services, 27% of informal carers needed respite while 11% used training services and 4% support groups. Regarding care recipients, the majority (85%) reported quite bad health status and 68% were female. The mean age was 81 years ( $SD \pm 9$ ) with a range of 60 – 107 and 68% were suffering from more than one chronic disease.

**Table 2.4.1 – Characteristics of informal carers and care recipients**

	Entire population	Needed respite	Did not need respite	Test of independence P-value <sup>e</sup>
	(N = 4,278)	(N = 1,173)	(N = 3,105)	
<b>Informal carers (CG) characteristics</b>				
Health status <sup>a</sup> %				
Very good and good	62	49	67	0.00
Fair, bad and very bad	38	51	33	
Income <sup>b</sup> %				
<1,800€	29	29	29	0.841
≥ 1,800€	71	71	71	
Marital status %				
Single	19	19	19	0.943
Married	66	65	65	
Divorced or Widowed	15	16	16	
Mean age (SD)	61 (14)	63 (13)	60 (14)	0.00 <sup>f</sup>
Sex %				
Female	61	67	60	0.00
Male	39	33	40	
Cohabitation %	40	55	35	0.00
Filiation %				
Partner by marriage	28	36	25	0.00
Child <sup>c</sup>	54	53	55	
Family member	13	10	14	
Close acquaintance	5	1	6	
Providing care to other persons	21	22	21	0.50
Replacement in case of unavailability	77	68	81	0.00
Length of care provision <sup>d</sup> %				
<1 years	5	5	4	0.27
1 – 5 year	38	36	39	
≥ 5 years	57	59	57	
Duration of care provision %				
<30H	45	20	54	0.00
30H-60H	17	17	17	
60H-150H	21	29	18	
>150H	17	34	11	
HSCI <sup>g</sup>	2(0.03)	1(0.06)	3(0.03)	0.00 <sup>f</sup>
Stress and anxiety %	36	59	27	0.00
Back problems %	24	43	17	0.00
Physical exhaustion %	33	63	22	0.00
Sleep disorders %	23	43	15	0.00
Feeling of loneliness %	42	68	32	0.00
Problem of lack of time %	35	79	18	0.00
Need for respite %	27	-	-	-
Use of support group %	4	6	3	0.00
Use of training %	11	20	8	0.00
<b>Care recipient (CR) characteristics</b>				
Health status <sup>a</sup> %				
Very good and good	15	8	18	0.00
Fair, bad and very bad	85	92	82	
Mean age (SD)	81(9)	81(9)	81(9)	0.02 <sup>f</sup>
Sex %				
Female	68	64	69	0.00
Male	32	36	31	
Number of diseases				
Less than one disease	32	30	33	0.09
More than one disease	68	70	67	

Notes: SD standard deviation; <sup>a</sup> Health status: 5 categories recoded into two categories; <sup>b</sup> Income level: 5 categories recoded into two categories; <sup>c</sup> Child: recoded item as daughter or son; <sup>d</sup> Length of care provision: categories recoded into two categories; <sup>e</sup> Chi2 statistical test; <sup>f</sup> Test of the difference of the means; CG: informal carer/caregiver CR: care recipient; <sup>g</sup> The correlation coefficient between the health status and HSCI was 0.403. It is not impossible that using them both variables in the same model could increase the risk of multicollinearity.

## 2.4.2 Econometric modelling

Table 2.4.2 reports the results of the econometric modelling for model 1. Our findings show that the poorest health status for informal carers significantly increased the need for respite ( $p < 0.05$ ). Moreover, the length of time providing care reduced the probability of needing respite when carers were in cohabitation with care recipients ( $p < 0.1$ ). Informal carers with a higher income were more likely to need respite ( $p < 0.1$ ). In terms of marital status, no significant result was identified concerning the need for the respite amongst married or widowed carers in comparison to the single carers' group. However, being a divorced informal carer raised the need for respite ( $p < 0.1$ ).

Children and family members living with the recipients of their care reported a greater need for respite than partners married to their care recipients; the need for respite differs significantly according to the living status of child and family member inducing a greater need amongst cohabitants and a lower need amongst non-cohabitants. The need for respite was significantly reduced for close acquaintances in cohabitation compared to partners by marriage ( $p < 0.05$ ). Providing care to other persons was likely to induce a greater need for respite ( $p < 0.05$ ). The cohabitation of the informal carer and the care recipient was likely to increase the need for respite ( $p < 0.1$ ).

Our results also indicate that the feeling of loneliness ( $p < 0.01$ ), the lack of time ( $p < 0.01$ ) and gender (female) ( $P < 0.1$ ) significantly increased the need for respite. Age was likely to affect carers' need for respite ( $p < 0.1$ ). We found 63 years (0.025/0.0004), as the age above which the potential existence of a non-linear relationship with respite is reversed. There was a higher need for respite for carers with the raise of the duration of care provided to recipients ( $p < 0.05$ ). Figure 2.4.2 illustrates this finding.

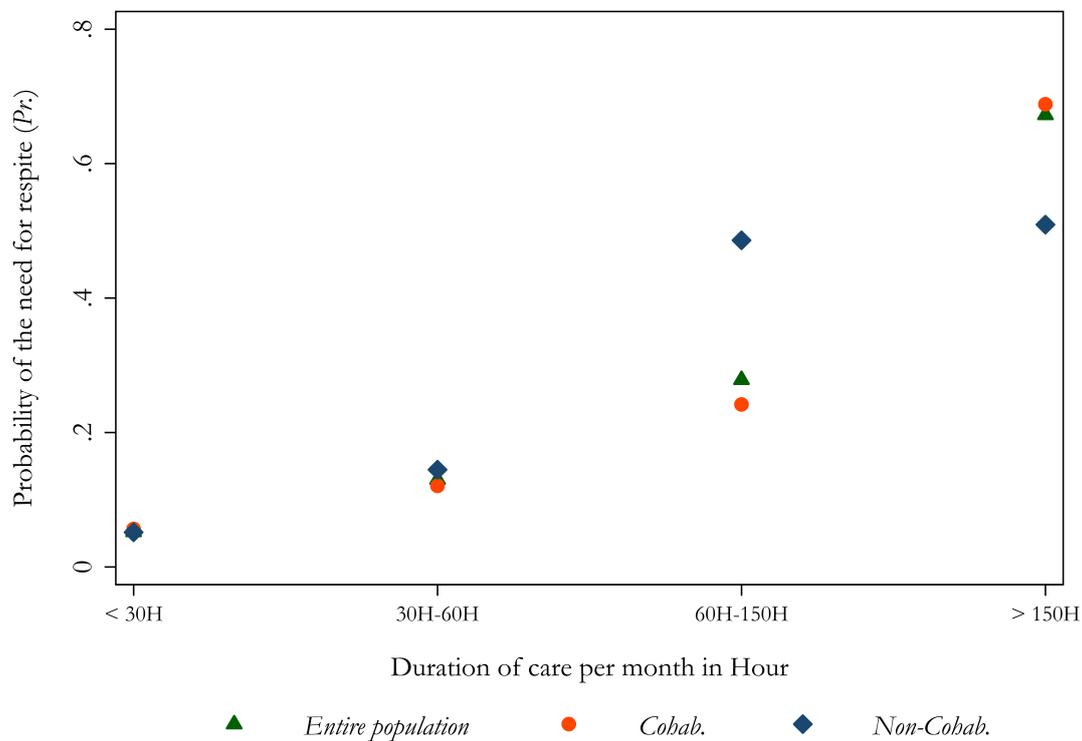
Regarding care recipients characteristics, the need for respite of carers is increased with the worsening of the health status of the recipients ( $p < 0.05$ ). Additionally, care recipients suffering from more than one chronic disease were more likely to create a higher need for respite ( $p < 0.1$ ).

**Table 2.4.2 – Model 1 - Determinants of the need for the respite of informal carers**

	(1)		(2)		(3)	
	Entire population	M.E.	Non-Cohabitation	M.E.	Cohabitation	M.E.
Health Status – (Very good)	(ref.)		(ref.)		(ref.)	
Good	0.210*** (0.079)	0.04	0.191** (0.092)	0.03	0.272* (0.156)	0.066
Fair	0.370*** (0.086)	0.08	0.332*** (0.105)	0.06	0.446*** (0.161)	0.11
Bad	0.490*** (0.110)	0.11	0.471*** (0.172)	0.09	0.528*** (0.177)	0.13
Very bad	0.814*** (0.257)	0.18	0.755 (0.484)		0.882*** (0.329)	0.22
Length of time for care - (<1 year)	(ref.)		(ref.)		(ref.)	
1 - 5 years	-0.138 (0.118)		-0.105 (0.163)		-0.183 (0.177)	
>5 years	-0.144 (0.116)		0.004 (0.159)		-0.324* (0.174)	-0.08
Income Level – (<800€)	(ref.)		(ref.)		(ref.)	
800€ - 1,200€	0.108 (0.166)		0.246 (0.220)		-0.110 (0.252)	
1,200€ - 1,800€	0.131 (0.147)		0.202 (0.204)		0.026 (0.216)	
1,800€ - 2,500€	0.130 (0.145)		0.173 (0.201)		0.067 (0.212)	
>2,500€	0.276* (0.142)	0.06	0.219 (0.199)		0.307 (0.209)	
Marital status – (Single)	(ref.)		(ref.)		(ref.)	
Married	-0.024 (0.077)		-0.014 (0.095)		0.033 (0.141)	
Divorced	0.216* (0.129)	0.05	0.218 (0.154)		0.161 (0.229)	
Widowed	-0.042 (0.100)		-0.021 (0.119)		-0.177 (0.183)	
Filiation – (Partner by marriage)	(ref.)		(ref.)		(ref.)	
Child	0.172* (0.100)	0.04	-1.014** (0.488)	-0.3	0.265* (0.141)	0.06
Family member	0.165 (0.112)		-1.040** (0.490)	-0.3	0.415** (0.174)	0.1
Close acquaintance	-0.481** (0.202)	-0.1	-1.747*** (0.531)	-0.4	-0.067 (0.340)	
Providing care to other persons	0.157** (0.061)	0.03	0.172** (0.074)	0.03	0.159 (0.105)	
Cohabitation	0.154* (0.079)	0.03				
Feeling of loneliness	0.426*** (0.053)	0.09	0.390*** (0.071)	0.08	0.455*** (0.082)	0.1
Lack of time	1.330*** (0.052)	0.29	1.289*** (0.071)	0.25	1.382*** (0.078)	0.33
Replacement in case of unavailability	-0.046 (0.060)		-0.020 (0.093)		-0.057 (0.080)	
Age (CG)	0.025* (0.013)	0.01	0.050** (0.025)	0.001	0.029 (0.018)	
Age squared (CG)	-0.000** (0.000)		-0.000** (0.000)		-0.000* (0.000)	
Female	0.099* (0.053)	0.02	0.118 (0.075)		0.064 (0.077)	
Care duration – (<30H)	(ref.)		(ref.)		(ref.)	
30H-60H	0.318*** (0.073)	0.07	0.380*** (0.085)	0.08	0.194 (0.145)	
60H-150H	0.470*** (0.072)	0.10	0.500*** (0.092)	0.11	0.429*** (0.131)	0.10
>150H	0.742*** (0.081)	0.18	0.477*** (0.137)	0.10	0.769*** (0.131)	0.20
Health status (CR) <sup>a</sup>	0.241*** (0.078)	0.05	0.194** (0.095)	0.04	0.300** (0.133)	0.07
More than one disease (CR)	0.096* (0.053)	0.02	0.061 (0.073)		0.132* (0.078)	0.03
Constant	-3.138*** (0.431)		-2.572*** (0.807)		-3.205*** (0.659)	
Number of observations	4,278		2,546		1,732	

Notes: Standard errors in parentheses; Source : Capacites, Aides et REssources des seniors (CARE) - 2015; \*  $p < 0.1$ , \*\*  $p < 0.05$ , \*\*\*  $p < 0.01$ ; M.E. stands for marginal effects; CG: informal carer; CR: care recipient; <sup>a</sup> included the categories: Fair, bad, and very bad (as reference, Very good; and Good).

**Figure 2.4.2** – Probability of the need for respite according to the duration that carers had been providing support to care recipients



Notes: "Cohab.": Living together; "Non-Cohab.": Not living together.

Table 2.4.3 reports the results of the model 2. First, The higher the strain (HSCI), the higher the need for respite whatever cohabitation or not ( $p < 0.01$ ). As in model 1, the other explanatory variables were also significant in model 2. A negative effect is quite noticeable for the length of time providing care on the need for respite ( $p < 0.1$ ) for cohabitants. As in model 1, the income level was statistically significant and positively influenced the need for respite, especially for higher-income carer groups ( $p < 0.1$ ). Divorced carers were more likely to need respite ( $p < 0.1$ ). The filiation variable was significant, with a positive effect for children and family members for the entire population of carers ( $p < 0.05$ ). At the same time, the close acquaintance was less likely to need respite, mainly for non-cohabitants ( $p < 0.05$ ). However, cohabitation was likely to create more need for respite for informal carers ( $p < 0.1$ ). The more carers reported the problem of lack of time ( $p < 0.01$ ) and the feeling of loneliness, the higher the probability of the need for respite ( $p < 0.05$ ). The age of the carer increased the probability of the

need for respite. The care duration positively affected the need for respite ( $p < 0.05$ ). The health status and chronic condition of care recipients significantly increased the need for respite ( $p < 0.05$ ).

**Table 2.4.3 – Model 2 - Determinants of the need for the respite of informal carers**

	(1)		(2)		(3)	
	Entire population	M.E.	Non-Cohabitation	M.E.	Cohabitation	M.E.
HSCI	0.172*** (0.015)	0.04	0.199*** (0.021)	0.4	0.149*** (0.021)	0.03
Length of time for care - (<1 year)	(ref.)		(ref.)		(ref.)	
1 - 5 years	-0.123 (0.116)		-0.079 (0.163)		-0.179 (0.174)	
>5 years	-0.141 (0.114)		0.024 (0.159)		-0.332* (0.172)	-0.08
Income Level – (<800€)	(ref.)		(ref.)		(ref.)	
800€ - 1,200€	0.130 (0.166)		0.283 (0.228)		-0.078 (0.249)	
1,200€ - 1,800€	0.128 (0.149)		0.230 (0.213)		0.015 (0.213)	
1,800€ - 2,500€	0.136 (0.146)		0.263 (0.209)		0.030 (0.209)	
>2,500€	0.267* (0.143)	0.05	0.275 (0.205)		0.270 (0.206)	
Marital status – (Single)	(ref.)		(ref.)		(ref.)	
Married	-0.037 (0.078)		-0.055 (0.095)		0.054 (0.145)	
Divorced	0.231* (0.133)	0.05	0.211 (0.158)		0.214 (0.244)	
Widowed	-0.083 (0.104)		-0.087 (0.125)		-0.180 (0.186)	
Filiation – (Partner by marriage)	(ref.)		(ref.)		(ref.)	
Child	0.215** (0.103)	0.04	-1.138** (0.483)	-0.3	0.317** (0.142)	0.07
Family member	0.263** (0.115)	0.05	-1.089** (0.485)	-0.3	0.511*** (0.178)	0.12
Close acquaintance	-0.372* (0.204)	-0.07	-1.795*** (0.527)	-0.4	0.027 (0.361)	
Providing care to other persons	0.114* (0.062)	0.02	0.115 (0.076)		0.138 (0.108)	
Cohabitation	0.149* (0.081)	0.03				
Feeling of loneliness	0.307*** (0.055)	0.06	0.230*** (0.075)	0.04	0.377*** (0.084)	0.09
Lack of time	1.187*** (0.054)	0.25	1.128*** (0.074)	0.21	1.252*** (0.080)	0.30
Replacement in case of unavailability	-0.020 (0.061)		0.015 (0.094)		-0.037 (0.082)	
Age (CG)	0.027** (0.013)	0.006	0.055** (0.025)	0.01	0.031* (0.018)	0.01
Age squared (CG)	-0.000** (0.000)		-0.001** (0.000)		-0.000* (0.000)	
Female	-0.020 (0.055)		-0.018 (0.078)		-0.046 (0.079)	
Care duration – (<30H)	(ref.)		(ref.)		(ref.)	
30H-60H	0.295*** (0.073)	0.06	0.364*** (0.086)	0.07	0.153 (0.147)	
60H-150H	0.422*** (0.074)	0.09	0.473*** (0.095)	0.1	0.353*** (0.132)	0.08
>150H	0.663*** (0.084)	0.15	0.382*** (0.145)	0.07	0.673*** (0.132)	0.17
Health status (CR) <sup>a</sup>	0.200*** (0.077)	0.04	0.126 (0.094)		0.290** (0.132)	0.07
More than one disease (CR)	0.116** (0.054)	0.02	0.092 (0.075)		0.135* (0.079)	0.03
Constant	-3.169*** (0.429)		-2.573*** (0.804)		-3.163*** (0.650)	
Number of observations	4,278		2,546		1,732	

Notes: Standard errors in parentheses; Source : Capacites, Aides et REssources des seniors (CARE) - 2015; \*  $p < 0.1$ , \*\*  $p < 0.05$ , \*\*\*  $p < 0.01$ ; M.E. stands for marginal effects; CG: informal carer; CR: care recipient; <sup>a</sup> included the categories: Fair, bad, and very bad.

## 2.5 Discussion

This study is based on a very recent nationwide database CARE, collected in 2015. From this point of view, it brings new and additional information to the published work of this relationship given the steady increase in the number of old-aged people and carers and the lack of quantitative research into the determinants of the need for respite in France (Bannerot et al., 2019; Casado, 2008; Koopmanschap et al., 2004; van Exel et al., 2008, 2006).

In this study, we used two different factors that relate to health: the health status of carers; and a measure of health status through a composite index (HSCI). We did this on purpose because these measures differ both in content and in measurement and focus on different but complementary aspects of health. Econometric modelling provides the finding that the health of carers is one of the most important determinants of the need for respite. The results of both models were relevant and quite similar in the sense that health status and HSCI turn out to be significant and had the same expected positive effect in explaining the need for respite. Thus, when informal carers experience poor health or strain, the need for respite increased. This finding could be explained by the fact that the negative consequences of informal care and its emotional impact widely affect carers' health (Besnard et al., 2019). However, one should be cautious with international comparisons of the results, as research showed that cultural values might vary considerably within and between countries.

Nevertheless, regardless of the cultural values or living status of carers, the association between the health status of carers and the need for respite seems evident and intuitive. Our findings chime with those of Gervès-Pinquieré et al. (2014), who found that the need for respite was associated with the health of carers in France. Some studies show that the need for respite depends not only on the health of carers and recipients but also on other carers characteristics. These findings accord with those reported in the Netherlands using data collected among Dutch informal carers (*respectively*  $N = 950$  and  $N = 273$ ) (Koopmanschap et al., 2004; van Exel et al., 2008) and in the U.S. based on community and informal carers survey data ( $N = 1,058$ ) (Casado, 2008).

Our findings also highlight that the living arrangement of carers with care recipients could significantly increase the probability of the need for respite. According to Schulz and Beach, certain forms of living arrangement increased the need for respite by 20%

(Schulz and Beach, 1999). However, the assumption that carers living with their care recipients experience a considerable burden and require more respite has been confirmed empirically (Mello et al., 2016).

In contrast, regarding filiation, “child” and “family member” reported the inverse of cohabitant and non-cohabitant. Carers not living with their recipient may have experienced less burden and less need, for instance. This result could be due to less informal care, considering the median volume of assistance provided by cohabiting carers is twice as high as that of non-cohabiting carers (Soullier and Weber, 2011; Soullier, 2012). However, in the multivariate analysis, after adjustment for the duration of informal support, the effect of cohabitation remains an independent factor. In other words, the presence around the immediate environment with the recipient could represent a mental burden for the carer. There is a lack of various respite interventions in the sense that some carers are not always aware of the availability of services. It sometimes appears that carers choose not to use support partially as a result of having difficulty accessing and using it and partially as a result of a lack of information (Hong et al., 2011; Kosloski and Montgomery, 1993; Potter, 2018).

Given the negative effect of the length of time providing care on the need for respite, it clearly appears that, in the case of a lack of respite assistance, informal carers, particularly those cohabiting with care recipients, have a sense of being stuck in a “trap” or they no longer need support. Therefore, it could not be at all surprising that some carers reported having renounced the need for respite mainly expressed by the feeling of reluctance (Coudin, 2004). Nonetheless, there is still a need for empirical evidence to support the assumption of the length of time providing care. Mostly, the feeling of guilt could discourage family members who are providing care from asking for in-home support for a relative (Pierron-Robinet et al., 2018). Conversely, the duration for caregiving may likely increase the need for respite. This result is quite intuitive in the sense that the volume of informal care could create a greater burden for carers, independently of their living status (Andrieu et al., 2003).

Moreover, considering the intergenerational relationship between informal carers and recipients, the situation is complicated because some children are generally not willing to provide care to old-aged dependants, even though they represent the majority of informal carers (Pickard, 2002; Soullier and Weber, 2011). At the same time, the

majority of old-aged dependants need assistance with daily activities (Weber, 2015). Our finding was in line with the assumption that the need for respite increases as the age of informal carers increases (van Exel et al., 2008). We identified a non-linear relationship between the need for respite and carers age at almost 63 years. Even though according to our analysis the increasing age of the cohabitant seems to have a limited association with the need for respite, there is no denying the fact that a carer has a high risk of premature bereavement before their care recipient (Thomas et al., 2005). In addition to this, the lack of time and the feeling of loneliness also determine the need for respite. Once again, this finding could be explained by a reluctance to place their loved one in a support service in order to spend some time away (Coudin, 2004).

Importantly, it has been shown that psychological, emotional responses to chronic diseases and illness of care recipients may sometimes be managed very poorly by informal care providers. This could reflect on carers the problem of the lack of training and awareness among those assuming a caregiving role, but also the fact that cultural values may differently affect informal carers.

Therefore, if policymakers want to rely on informal care as an essential input in health care in long-term care, they should first keep a close watch on the human capital, particularly on carers' health (Becker, 2007; Grossman, 2017). Following this, policymakers should identify strained carers at risk with high volume care through supervised learning to prevent carer exhaustion (Batata et al., 2018). Since the French health system cannot cover all formal and informal costs related to carer and recipient health, there is a need for tailor-made respite, psychological and training/support programmes based on carers' preferences. However, mixed evidence of the effectiveness of existing interventions should assist health policymakers (Colvez et al., 2002; Courtin et al., 2014; Guets et al., 2020; Jeon et al., 2005).

Some limitations were identified in our paper. First, there is no denying that econometric modelling gives rise to the endogeneity problem for at least two primary sources. One possible source of endogeneity is the two-way (reverse) causality between the need for respite and the health status. Another possibility is the unobserved individual heterogeneity. Informal carers can differently report their experiences of strain because of higher levels of impairment. As a result, some exogenous factors such as age, relationship and/or gender may induce informal carers to provide incorrect estimates

of the negative impact of care. Second, the dependent variable reflects a dichotomous measure (“yes” or “no”) of the need for respite. It has not been possible to assess the intensity on the preferences of carers (“never” or “sometimes” or “more often”). Third, future studies will want to analyse the demand for various supplies of support (respite) services and access how the characteristics of each carer enable or limit the preferences of carers. The utility function or behavioural model of informal carers towards the need for respite should be assessed in further investigations.

## **2.6 Conclusion**

Our study consists of an analysis of the data of the National French CARE survey, conducted in 2015. We show that the need for respite varies according to the characteristics of informal carers, as well as care recipients’ factors. This study has important health policy implications for the current ageing population crisis in the most OECD countries to prevent the high risk of exhaustion. A prioritisation scheme for policymakers could consist of conducting prevention policies to identify at-risk carers. Practically, the challenge for policymakers, physicians and other health professionals is to refer to the right service, e.g. psychological interventions, respite care support, training support, education support, at the right time. Dealing with the dyad’s quality of life, innovative interventions that aimed to provide support to carers and/or carers’ family members have to be developed. However, there is a need for more economic evaluations of respite interventions for carers to assist policymakers in prioritising carers support programmes.

# Appendix

## 2.A Additional analyses based on the Health and Disability Caregiver Survey (HSA, 2008)

### 2.A.1 Method and data

We performed a further analysis with another survey. We used data from a nationally representative survey carried out in France: The Health and Disability Caregiver Survey (HSA 2008), which is a supplemental section of the Health and Disability Household Survey (HSM) in ordinary households. As the *CARE* survey (2015), data were collected by the *DREES* and *INSEE*.

The HDCS provided information on the 5,040 informal carers who were over 16 years of age among the 29,954 DHS respondents in regard to the need for respite, socio-demographic characteristics, living status, consequences of care provision, etc. Regarding the need for respite, the individual had to answer Yes/No to the following question: “Can you manage a period of respite? (question I3)” if not “Would you say that you would need it? (question I3B)”. However, question I3B was not filtered as presented in the questionnaire. Only the subjects who answered “No” to question I3 should have been asked this question, but it was in fact presented to all of them. There were 1,381 informal carers who answered question I3B.<sup>1</sup> Of these, 564 informal carers answered “No” to question I3. Therefore, we present the situation with “I3B question not filtered” and “I3B question filtered”.

We used the same econometrics model and the same socio-demographic characteristic of carers. However, in the Health and Disability caregiver survey (*HSA*, 2008), we did not use the characteristics of the care recipient.

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<sup>1</sup>[http://www.progedo-adisp.fr/documents/lil-0495/lil-0495q\\_cohab.pdf](http://www.progedo-adisp.fr/documents/lil-0495/lil-0495q_cohab.pdf) (See Page 29-30)

## 2.A.2 Results

### 2.A.2.1 Question I3B was not filtered

**Descriptive statistics** A total of N = 891 informal caregivers with complete cases were included. The study population is described in Figure 2.A.1.

**Figure 2.A.1** – Study population – “Question i3b” (Not filtered)

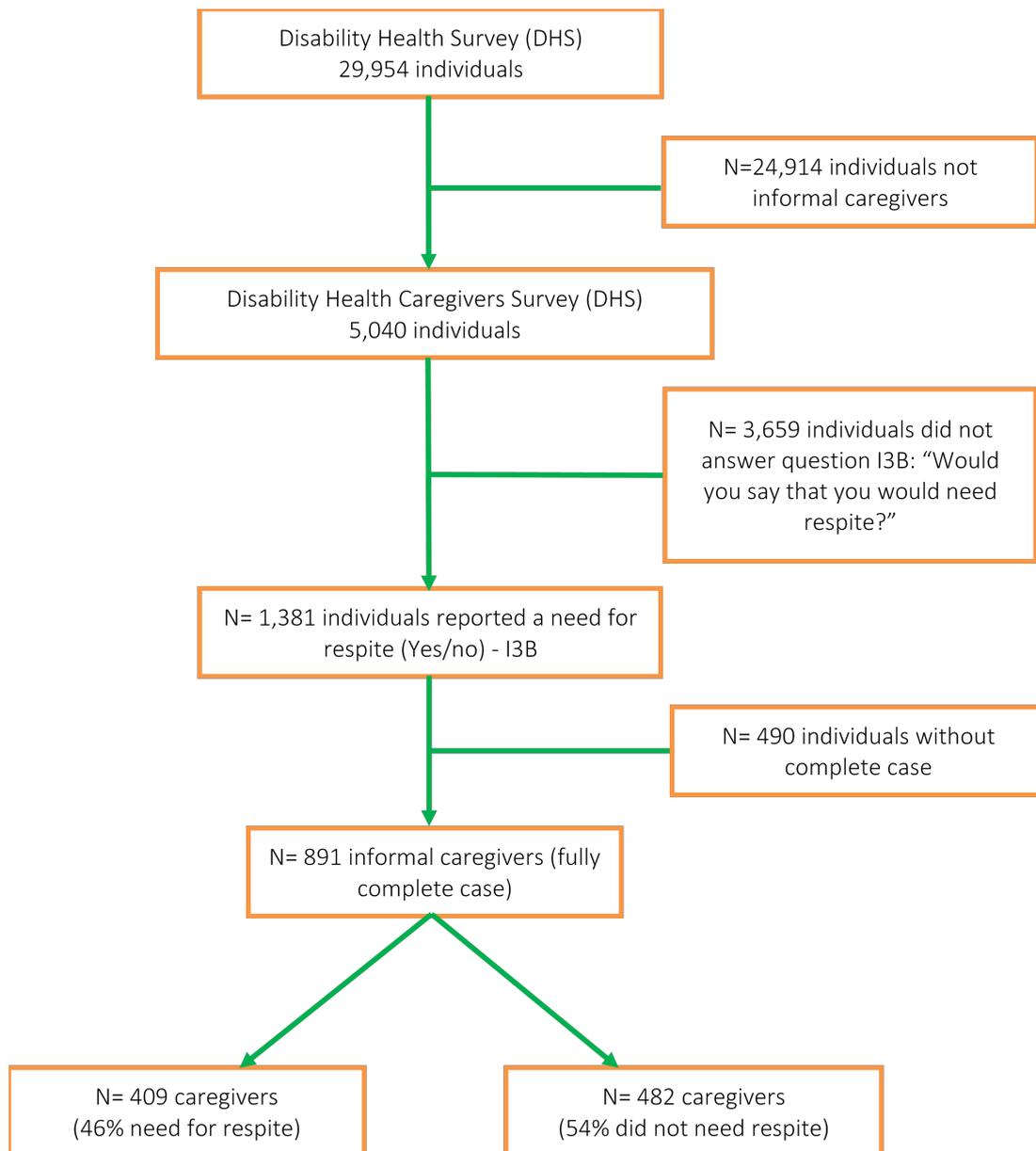


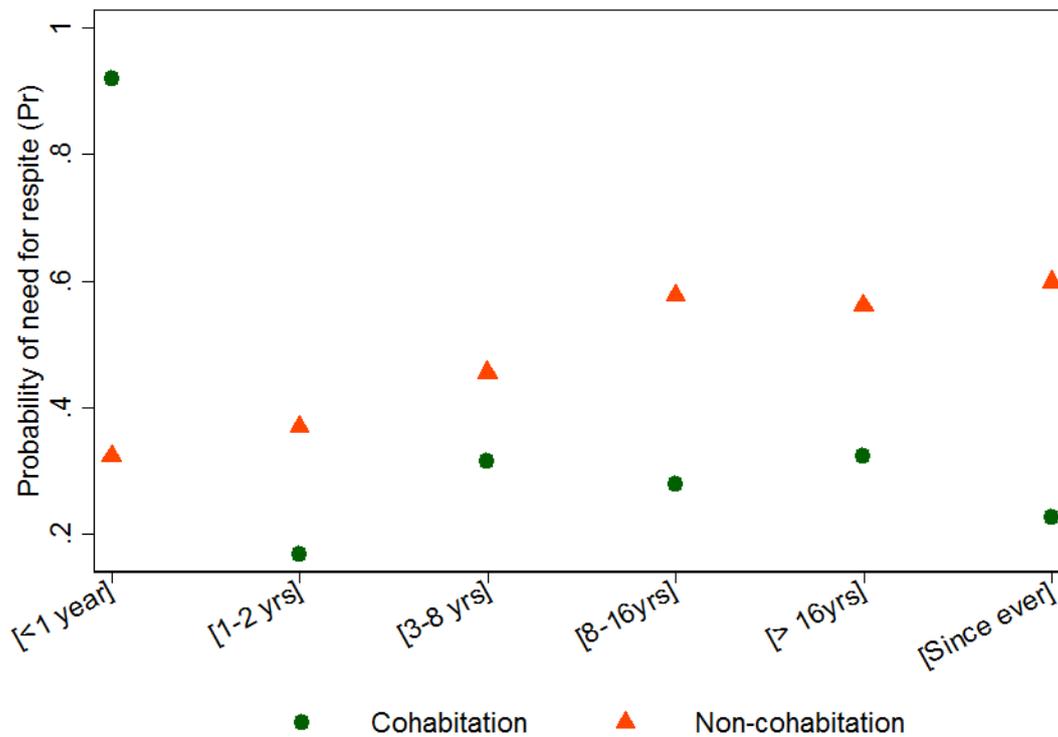
Table 2.B.1 provides details of the characteristics of the informal carers for the entire population and for the informal carers who did and who did not need respite care.

Of the 891 informal carers, 46% (409 carers) reported a need for respite (Figure 2.A.1). The mean age of the carers was 54 years (SD  $\pm$  16) with a range of 16 - 95. Almost half of the carers were less than 55 years of age; 24% were in the 55-64 years of age bracket, 14% in the 65-74 years of age bracket, and 13% in the 75-95 years of age bracket. As indicated in Table 2.B.1, almost 63% of the informal carers were female. Almost 63% of carers were married, 26% were single, while 11% were divorced or widowed. According to the carers-recipients' relationship, thirty-five percent provided care to their partner by marriage, 29% were child, 33% were a family member and 3% to a close acquaintance. The informal carers with a "very good and good" accounted for 57%. Table 2.B.1 also shows that 78% of the carers who suffered from physical exhaustion reported a need for respite. Seventy-three percent of them were women and 22% cohabitated with the care recipient (Table 2.B.1).

**Econometric modellings** Table 2.A.1 resents the results of the econometric modelling for the model 1 when question I3B not was filtered. Our results show that, the poorest health status for informal carers significantly increased the need for respite compared to carers with very good health status ( $p < 0.05$ ).

As shown in Table 2.B.2, the model 1 with interaction terms confirms this significant influence on the probability that carers need respite ( $p < 0.05$ ). Additionally, Figure 2.C.2 presents the increase in the probability of a need for respite care according to the carer's health status. Moreover, the length of time providing care negatively affected the probability of needing respite. This effect was significant when the carer cohabited with the care recipient ( $p < 0.01$ ). Figure 2.A.2 illustrates this finding.

**Figure 2.A.2** – Probability of the need for respite according to the length of time that carers had been providing support to care recipients



Cohabitation of the informal carer and their care recipient was likely to dramatically reduce the need for support. In terms of marital status, a single and a widowed carer's situation was identified to negatively affect the need for respite compared to the married carers' group; being a divorced informal care provider raised the need for assistance, especially for non-cohabitants. Conversely, female carers had a greater need for respite ( $p < 0.01$ ) than partners by marriage of care recipients. The burden of informal care increased as the number of people cared for increased ( $p < 0.1$ ). Our results also indicate that variables such as the lack of time ( $p < 0.01$ ), the lack of respite care institutions ( $p < 0.01$ ), and the feeling of being the only carer ( $p < 0.01$ ) had the same effect. They had a significant positive effect on the need for respite among cohabitants and also on carers as a whole. However, as shown in Table 2.A.1, we found no empirical evidence indicating that income and age affected the carer's need for respite.

The findings of the model 1 with multiple imputations were almost similar. Only the filiation (Daughter, Family) and the length of time engaged in providing care (1-2 years) variables differed. These results are presented in Table 2.B.4.

**Table 2.A.1** – Determinants of the need for the respite of informal carers (*Question I3B not filtered*) - (HSA, 2008)

Variables	Model 1						Model 2					
	Entire population			Living status			Entire population			Living status		
	(1)		(3)	(3)		(3)	(1)		(3)	(3)		
	Coef.	M.E.	Cohabit.	M.E.	Non-Cohabit.	M.E.	Coef.	M.E.	Cohabit.	M.E.	Non-Cohabit.	M.E.
Health Status – (Very good)	(Ref.)		(Ref.)		(Ref.)							
Good	0.233 (0.154)		0.282 (0.253)		0.0919 (0.207)							
Fair	0.65*** (0.165)	0.20	0.724*** (0.278)	0.19	0.479** (0.219)	0.15						
Bad	0.59*** (0.218)	0.18	0.594 (0.406)		0.445 (0.274)							
Very bad	0.869** (0.395)	0.27	1.053 (1.007)		0.660 (0.449)							
HSCI							0.61*** (0.0436)	0.14	0.701*** (0.088)	0.13	0.587*** (0.05)	0.14
Length of time for care - (<1 year)	(Ref.)		(Ref.)		(Ref.)		(Ref.)		(Ref.)		(Ref.)	
1 to 2 years	-0.73** (0.367)	-0.22	-2.146** (0.838)	-0.56	-0.208 (0.464)		-0.642 (0.407)		-1.729* (0.971)	-0.39	-0.35 (0.506)	
3 to 8 years	-0.510 (0.345)		-1.969** (0.819)	-0.51	-0.0114 (0.435)		-0.555 (0.384)		-1.664* (0.956)	-0.38	-0.26 (0.474)	
8 to 16 years	-0.429 (0.35)		-2.065** (0.822)	-0.54	0.0994 (0.441)		-0.336 (0.388)		-1.665* (0.954)	-0.38	0.0232 (0.480)	
>16 years	-0.569 (0.353)		-2.2*** (0.830)	-0.57	-0.0195 (0.445)		-0.609 (0.392)		-2.030** (0.971)	-0.45	-0.173 (0.485)	
Income Level – (<800€)	(Ref.)		(Ref.)		(Ref.)		(Ref.)		(Ref.)		(Ref.)	
800€-1,200€	-0.222 (0.211)		-0.441 (0.391)		-0.152 (0.264)		-0.183 (0.252)		-0.753 (0.493)		0.0540 (0.315)	
1,200€-1,800€	-0.210 (0.194)		0.0930 (0.360)		-0.327 (0.241)		0.0199 (0.230)		0.0637 (0.431)		0.00024 (0.286)	
1,800€-2,500€	-0.256 (0.197)		0.105 (0.373)		-0.397 (0.242)		-0.0398 (0.231)		0.102 (0.448)		-0.0760 (0.283)	
>2,500€	-0.199 (0.188)		0.0502 (0.369)		-0.199 (0.230)		-0.0104 (0.222)		0.147 (0.452)		0.0529 (0.272)	
Marital status – (Single)	(Ref.)		(Ref.)		(Ref.)		(Ref.)		(Ref.)		(Ref.)	
Single	-0.249* (0.136)	-0.07	-0.0477 (0.236)		-0.277 (0.186)		-0.0658 (0.161)		-0.168 (0.281)		0.0746 (0.222)	
Divorced	-0.194 (0.224)		0.431 (0.360)		-0.569* (0.292)	-0.17	-0.227 (0.252)		0.326 (0.440)		-0.471 (0.327)	
Widowed	-0.442* (0.244)	-0.13	-0.159 (0.408)		-0.591* (0.312)	-0.18	-0.337 (0.269)		-0.152 (0.446)		-0.455 (0.352)	
Filiation – (Partner by marriage)	(Ref.)		(Ref.)		(Ref.)		(Ref.)		(Ref.)		(Ref.)	
Daughter	0.70*** (0.185)	0.20	0.766*** (0.296)		0.610** (0.240)	0.19	0.75*** (0.214)	0.16	0.182 (0.333)		0.697** (0.276)	0.16
Family	0.49*** (0.151)	0.14	0.414 (0.302)		0.449*** (0.170)	0.14	0.606*** (0.180)	0.13	0.143 (0.338)		0.441** (0.200)	0.10
Son	0.275 (0.295)				0.254 (0.307)		0.454 (0.357)				0.283 (0.365)	
Close acquaintance	0.110 (0.268)				-0.0933 (0.552)		0.602** (0.300)	0.13			0.272 (0.627)	
Caregiving others	0.0988* (0.057)	0.03	0.0957 (0.0866)		0.146 (0.0896)		0.0480 (0.0722)		0.124 (0.119)		0.0196 (0.0955)	
Cohabitation	-0.72*** (0.143)	-0.22	NA NA		NA NA		-0.53*** (0.167)	-0.12	NA NA		NA NA	
Feeling of loneliness	0.771*** (0.105)	0.23	0.967*** (0.205)	0.24	0.726*** (0.127)	0.23	0.465*** (0.122)	0.10	0.562** (0.256)	0.10	0.444*** (0.147)	0.10
Lack of Institutions	0.624*** (0.127)	0.19	0.721*** (0.256)	0.18	0.627*** (0.154)	0.197	0.414*** (0.145)	0.1	0.415 (0.318)		0.450*** (0.172)	0.1
Lack of time	0.843*** (0.111)	0.25	0.710*** (0.200)	0.18	0.994*** (0.145)	0.31	0.489*** (0.133)	0.11	0.409 (0.251)		0.602*** (0.171)	0.14
Replacement in case of unavailability	0.037 (0.112)		-0.127 (0.226)		0.0881 (0.133)		-0.0391 (0.130)		-0.131 (0.280)		-0.00133 (0.152)	
Age	0.0035 (0.004)		0.0133 (0.0083)		0.00335 (0.0045)		0.00286 (0.0057)		0.0101 (0.0121)		0.00477 (0.00675)	
Constant	-0.763 (0.470)		-0.718 (0.973)		-1.080* (0.581)		-2.40*** (0.614)		-1.955* (1.133)		-2.82*** (0.719)	
Number of observations	891		305		586		891		305		586	

Notes: Standard errors in parentheses; \*  $p < 0.1$ , \*\*  $p < 0.05$ , \*\*\*  $p < 0.01$ ; M.E. stands for marginal effects

### 2.A.2.2 Question I3B was filtered

**Descriptive statistics** Regarding question I3B, a total of N = 391 informal carers with complete cases were included. The study population is outlined in Figure 2.A.3.

**Figure 2.A.3 – Study population – “Question i3b” (Filtered)**

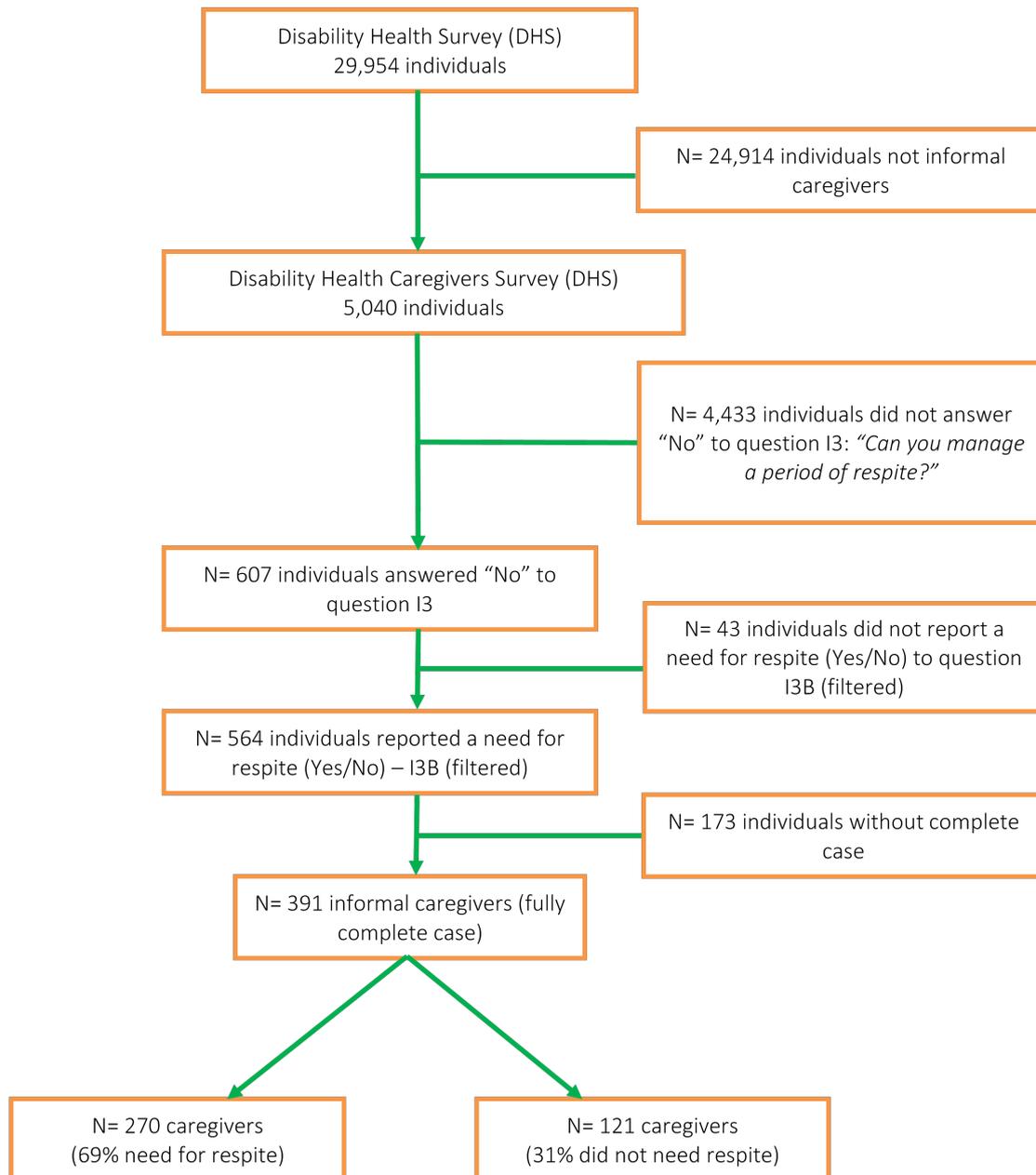


Table 2.B.1 provides details of the characteristics of the informal carers for the entire population and for the informal carers who did and who did not need respite care when question I3B was filtered.

Of the 391 informal carers, 69% (270 carers) reported a need for respite. The mean age of the carers was 55 years (range 16-95) with an S.D. = 16. Nearly half of the carers were less than 55 years of age; 20% were in the 55-64 years of age bracket, 16% in the 65-74 years of age bracket, and 14% in the 75-95 years of age bracket.

As indicated in Table 2.B.1, a total of  $N = 391$  informal carers were included, and 69% of the informal carers were female ( $N = 271$ ). Seventy-seven percent of them reported a need for respite care, 64% were married, 23% were single, and 13% were divorced or widowed. Thirty-two percent provided care to their husband, while 27% were the daughter, 36% were a family member, and 5% were the son or a close acquaintance of the care recipient. Fifty-four percent were less than 55 years of age. Table 2.B.1 also shows that 82% of the carers who suffered from exhaustion reported a need for respite. Seventy-two percent of them were women and 30% cohabitated with the care recipient.

**Econometric modelling** Table 2.A.2 presents the results of the econometric modelling for the baseline model when question I3B was filtered. Our findings show that for the entire population of carers ( $N = 391$ ), the poorest health status of the carer significantly increased the need for respite care compared to carers with a good or a very good health status ( $P < 0.05$ ). As shown in Table 2.A.2, the modelling based on the living status and the modelling based on the entire population with interaction terms confirmed the significant influence on the probability that a carer needed respite ( $p < 0.05$ ). Moreover, the length of time providing care negatively affected the probability of needing respite. This effect was significant when the carers cohabited with the care recipient ( $p < 0.05$ ). Indeed, cohabitation of the informal carer and their care recipient was likely to dramatically reduce the need for respite.

In terms of filiation, female carers had a greater need for respite ( $p < 0.05$ ) than partners by marriage of the care recipient. Our results also indicate that variables such as the lack of time ( $p < 0.001$ ), the lack of respite care institutions ( $p < 0.05$ ), and the feeling of being the only carer ( $p < 0.05$ ) had the same effect. They had a significant positive effect on the need for respite on the carers as a whole, especially the lack of time; whereas the feeling of loneliness and the lack of respite care institutions were not significant among cohabitants. However, as shown in Table 5, we did not find any strong empirical evidence indicating that income and age affected the carer's need for respite.

**Table 2.A.2** – Model 1 - Determinants of the need for the respite of informal carers (*Question I3B filtered*) - (HSA, 2008)

Variables	Entire population	Living status		Entire population with interactions
	Coef.	Cohabitation	Non-Cohabitation	Coef.
Health Status – (Very good and Good)	(Ref.)	(Ref.)	(Ref.)	(Ref.)
Fair, Bad, and Very bad	0.505*** (0.158)	0.678** (0.303)	0.424** (0.200)	0.475*** (0.159)
Length of time for care - (<1 year)	(Ref.)	(Ref.)	(Ref.)	(Ref.)
1 to 2 years	-0.928* (0.528)	-1.659* (0.941)	-0.260 (0.731)	-0.269 (0.803)
3 to 8 years	-0.966** (0.487)	-1.608* (0.904)	-0.452 (0.675)	-0.369 (0.767)
8 to 16 years	-0.537 (0.496)	-1.791** (0.879)	0.255 (0.708)	0.345 (0.797)
>16 years	-0.916* (0.499)	-2.003** (0.885)	-0.278 (0.698)	-0.200 (0.780)
Income – (>1800 €)	-0.137 (0.157)	0.00549 (0.331)	-0.0771 (0.191)	-0.100 (0.164)
Marital status – (Married)	(Ref.)	(Ref.)	(Ref.)	(Ref.)
Single	-0.139 (0.210)	-0.116 (0.343)	-0.0845 (0.298)	-0.0413 (0.253)
Divorced	0.0956 (0.380)	0.507 (0.647)	-0.136 (0.544)	-0.139 (0.625)
Widower	-0.544 (0.359)	-0.106 (0.684)	-0.816* (0.460)	-0.831** (0.343)
Filiation – (Partner by marriage)	(Ref.)	(Ref.)	(Ref.)	(Ref.)
Daughter	0.728** (0.293)		0.596 (0.409)	0.724** (0.303)
Family	0.582** (0.234)	-0.407 (0.381)	0.553** (0.276)	0.606*** (0.233)
Son and Close acquaintance	0.0912 (0.356)	-0.898* (0.510)	-0.0220 (0.480)	0.0331 (0.401)
Caregiving others	0.0337 (0.116)	0.380 (0.238)	-0.0598 (0.143)	0.0481 (0.134)
Cohabitation	-0.781*** (0.227)	NA NA	NA NA	0.740 (1.013)
Feeling of loneliness	0.603*** (0.170)	0.419 (0.349)	0.715*** (0.216)	0.642*** (0.172)
Lack of institutions	0.519*** (0.192)	0.420 (0.375)	0.605** (0.246)	0.479** (0.198)
Lack of time	0.935*** (0.179)	0.686** (0.328)	1.134*** (0.243)	0.944*** (0.181)
Replacement in case of unavailability	-0.0202 (0.170)	-0.432 (0.358)	0.129 (0.204)	-0.00773 (0.170)
Age	0.00702 (0.00583)	0.0210 (0.0128)	0.00693 (0.00715)	0.00946* (0.00566)
[1-2 yrs] # Cohabitation				-1.519 (1.108)
[3-8 yrs] # Cohabitation				-1.221 (1.047)
[8-16 yrs] # Cohabitation				2.052** (1.038)
[>16 yrs] # Cohabitation				-1.713* (1.0099)
Single # Cohabitation				-0.167 (0.405)
Divorced # Cohabitation				0.784 (0.761)
Widower # Cohabitation				0.864 (0.628)
Constant	-0.266 (0.626)	0.166 (1.084)	-0.792 (0.812)	-0.916 (0.829)
Number of observations	391	116	275	391

Notes: Standard errors in parentheses; \*  $p < 0.1$ , \*\*  $p < 0.05$ , \*\*\*  $p < 0.01$

## 2.B Additional statistics and econometrics table

**Table 2.B.1 – Characteristics of informal carers - HSA (2008)**

Variables	HSA (2008)							
	Full sample (I3B not filtered)				Sub-sample (I3B filtered)			
	Entire population (N = 891)	Needed respite (N = 409)	Did not need respite (N = 482)	Test of independence P-value <sup>§</sup>	Entire population (N = 391)	Needed respite (N = 270)	Did not need respite (N = 121)	Test of independence P-value <sup>§</sup>
The socioeconomic characteristics and the health status of the informal carers								
Health status <sup>a</sup> %								
Very good and good	57	45	67	0.00	47	40	60	0.00
Fair, bad, and very bad	43	55	33		53	60	40	
Income <sup>b</sup> %								
<1,800€	45	45	45	0.85	47	47	46	0.82
≥ 1,800€	55	55	55		53	53	54	
Marital status %								
Single	26	23	28	0.06	22	21	25	0.69
Married	63	66	61		66	67	64	
Divorced or Widowed	11	11	11		12	12	11	
Mean age (SD)	54 (16)	55 (16)	54 (17)	0.17 <sup>h</sup>	55 (16)	55 (17)	55 (17)	0.96 <sup>h</sup>
Sex %								
Female	63	75	54	0.00	69	77	51	0.00
Male	37	25	46		31	23	49	
The nature of the relationship of the informal carers with the care recipients								
Cohabitation %	34	74	58	0.00	30	27	35	0.10
Filiation %								
Partner by marriage	35	36	35	0.00	37	35	41	0.013
Child <sup>c</sup>	29	29	29		27	28	24	
Family member	33	33	27		32	35	27	
Close acquaintance	3	3	9		4	2	8	
Care other persons	17	21	13	0.00	19	21	14	0.099
Replacement in case of unavailability	70	68	72	0.22	65	63	69	0.22
Length of care provision <sup>d</sup> %								
<1 years	1	1	1	0.82	2	2	3	0.08
1 – 5 year	48	47	48		42	39	50	
≥ 5 years	51	52	52		56	59	47	
Impact of the care provision for informal carers								
Stress and anxiety %	46	73	24	0.00	61	77	27	0.00
Back problems %	40	60	23	0.00	52	63	28	0.00
Exhaustion %	47	78	22	0.00	65	82	28	0.00
Sleep disorders %	35	59	15	0.00	47	62	13	0.00
Feeling of loneliness %	44	62	28	0.00	56	65	36	0.00
Self-reported need/use for support								
Need for respite %	46	-	-	-	69 <sup>i</sup>	-	-	-
Need for support group % <sup>j</sup>	16	31	5	0.00	24	32	6	0.00
Need for training % <sup>j</sup>	16	29	5	0.00	23	30	8	0.00
Problems of lack of time and institutions <sup>e</sup>								
Problem of lack of institutions %	20	31	10	0.00	28	34	15	0.00
Problem of lack of time %	34	47	23	0.00	43	52	24	0.00

Notes: SD standard deviation; <sup>a</sup> Health status: 5 categories recoded into two categories; <sup>a</sup> b Income level: 5 categories recoded into two categories; <sup>c</sup> Child: recoded item as daughter and son; <sup>d</sup> Length of care provision: five categories recoded into two categories; <sup>e</sup> reported measure by binary variables; <sup>§</sup> Chi2 statistical test; <sup>h</sup> Test of the difference of the means; <sup>i</sup> 67% without missing data (N=376/564) reported a need for respite care (see <http://www.progedo-adisp.fr/documents/lil-0495/lil-0495dcode.pdf>); <sup>j</sup> refer respectively not to a "Need" but a "use" of a support group, and for training in the "CARE" survey.

**Table 2.B.2** – Models 1 and 2 with interaction terms (N = 891)

Variables	(1)	(2)
	Baseline model with interaction terms	Alternative model with interaction terms
Health status - Very good (Ref.)		
Good	0.209	NA
Fair	0.622***	NA
Bad	0.570**	NA
Very bad	0.779**	NA
HSCI <sup>a</sup>	NA	0.617***
[1-2 years] # cohabitation	-2.040***	-1.342
[3-8 years] # cohabitation	-2.003***	-1.312*
[8-16 years] # cohabitation	-2.138***	-1.608**
[>16 years] # cohabitation	-2.124***	-1.612**
Single # cohabitation	0.0222	-0.381
Divorced # cohabitation	0.984**	0.642
Widowed # cohabitation	0.553	0.446
Constant	-1.331**	-2.660***

Notes. \*  $p \leq 0.1$ , \*\*  $p \leq 0.05$ , \*\*\*  $p \leq 0.01$ ; <sup>a</sup> Health Status Composite Index (HSCI); Explanatory variables included: Length of time for care; Income; Marital status; Filiation; caregiving others; Feeling of loneliness; Lack of institutions; Lack of time; Replacement in case of unavailability; Age.

Table 2.B.3 – Sample data analysis

Variables		Unused sample <sup>a</sup>	Used sample <sup>b</sup>	Total	Chi2 statistic (P-value)
Health status	Very good	83 (17.1)	131 (14.70)	214 (15.6)	3.23(0.52)
	Good	211 (43.6)	377 (42.31)	588 (42.8)	
	Fair	146 (30.17)	296 (33.2)	442 (32.1)	
	Bad	34 (7.02)	73 (8.2)	107 (7.78)	
	Very bad	10 (2.07)	14 (1.57)	24 (1.75)	
	Total	484 (100)	891 (100)	1,375 (100)	
Length time for care	[<1 year]	16 (3.92)	15 (1.7)	31 (2.39)	10.2(0.04)
	[1-2 years]	59 (14.5)	101 (11.3)	160 (12.3)	
	[3-8 years]	137 (33.58)	302 (34)	439 (33.8)	
	[8-16 years]	83 (20.34)	218 (24.5)	301 (23.2)	
	[>16 years]	113 (27.7)	255 (28.6)	368 (28.3)	
	Total	408 (100)	891 (100)	1,299 (100)	
Income	<1,800€	144 (43.9)	402 (45.1)	546 (44.8)	0.14(0.7)
	>1,800€	184 (56.1)	489 (54.9)	673 (55.2)	
	Total	328 (100)	891 (100)	1,219 (100)	
Filiation	Partner by marriage	156 (33.7)	313 (35.1)	469 (34.6)	12.8(0.01)
	Daughter	112 (24.2)	228 (25.6)	340 (25.1)	
	Family	128 (27.65)	267 (30)	395 (29.2)	
	Son	12 (2.6)	27 (3.03)	39 (2.88)	
	Close acquaintance	55 (11.9)	56 (6.3)	111 (8.2)	
	Total	463 (100)	891 (100)	1,354 (100)	
Marital status	Married	276 (64.64)	564 (63.7)	840 (63.7)	0.6(0.74)
	Single	102 (23.9)	230 (25.8)	332 (25.2)	
	Divorced and Widower	49 (11.5)	97 (10.9)	146 (11.1)	
	Total	427 (100)	891 (100)	1,318 (100)	
Cohabitation	No	306 (62.45)	586 (65.77)	892 (64.6)	19.3(0.22)
	Yes	184 (37.55)	305 (34.23)	489 (35.4)	
	Total	490 (100)	891 (100)	1,381 (100)	
Feeling of loneliness	No	314 (68)	501 (56.2)	815 (60.2)	17.5(0.00)
	Yes	148 (32)	390 (43.8)	538 (39.8)	
	Total	462 (100)	891 (100)	1,353 (100)	
Lack of institutions	No	191 (74.6)	713 (80.02)	904 (78.8)	3.5(0.06)
	Yes	65 (25.39)	178 (20)	243 (21.2)	
	Total	256 (100)	891 (100)	1,147 (100)	
Lack of time	No	302 (69.6)	588 (66)	890 (67.2)	1.71(0.19)
	Yes	132 (30.4)	303 (34)	435 (32.8)	
	Total	434 (100)	891 (100)	1,325 (100)	
Replacement in case of unavailability	No	144 (30.57)	267 (30)	411 (30.2)	0.05(0.82)
	Yes	327 (69.43)	624 (70)	951 (69.5)	
	Total	471 (100)	891 (100)	1,362 (100)	
Age (mean)		52.85	54.32		0.01(0.92)

Notes. Values in parentheses represent frequencies in percentage (%); <sup>a</sup> Observation not used in the econometric modelling due to missing value; <sup>b</sup> Complete cases.

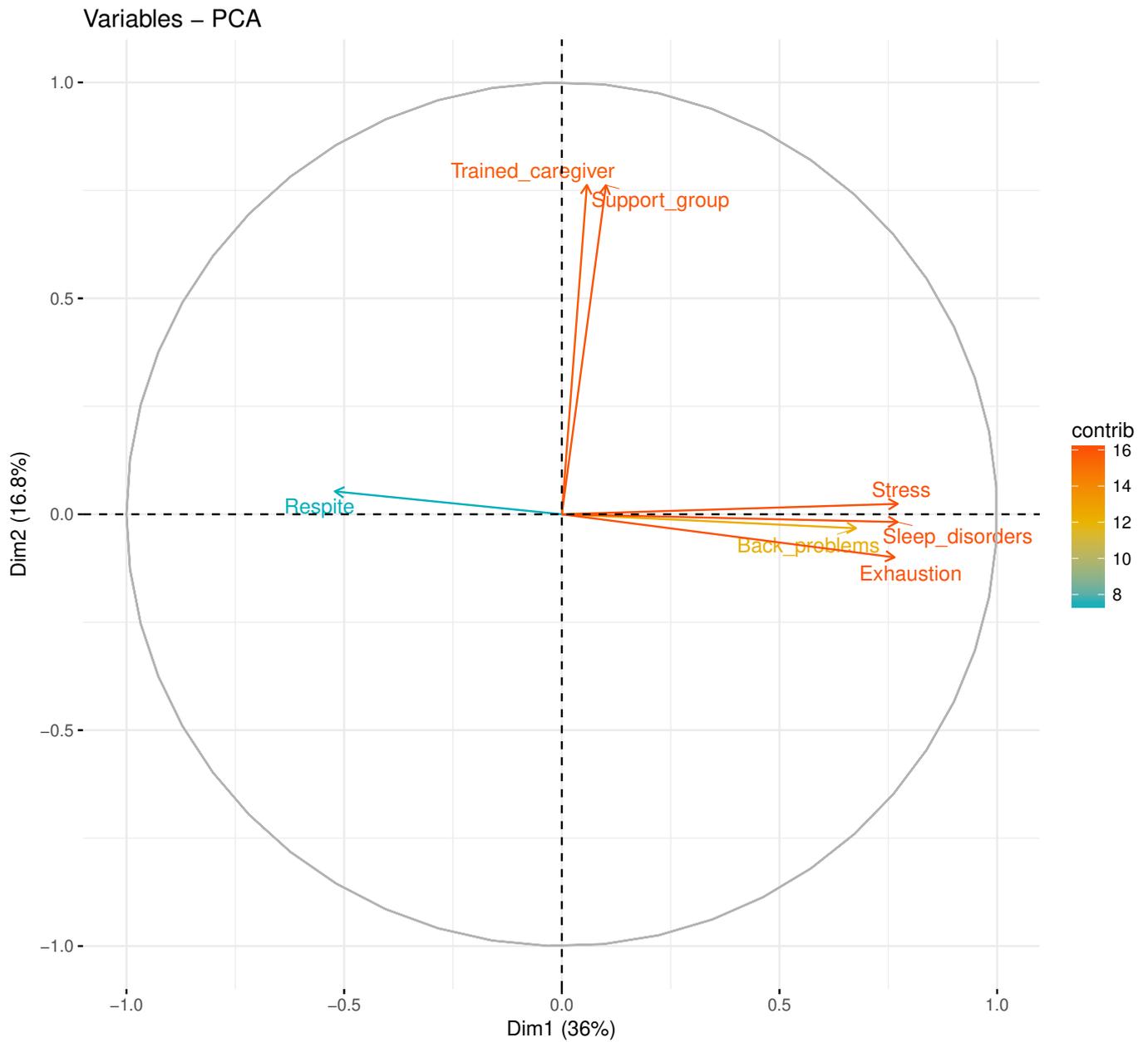
**Table 2.B.4** – Model of the need for respite care with multiple imputations (N = 1,381)

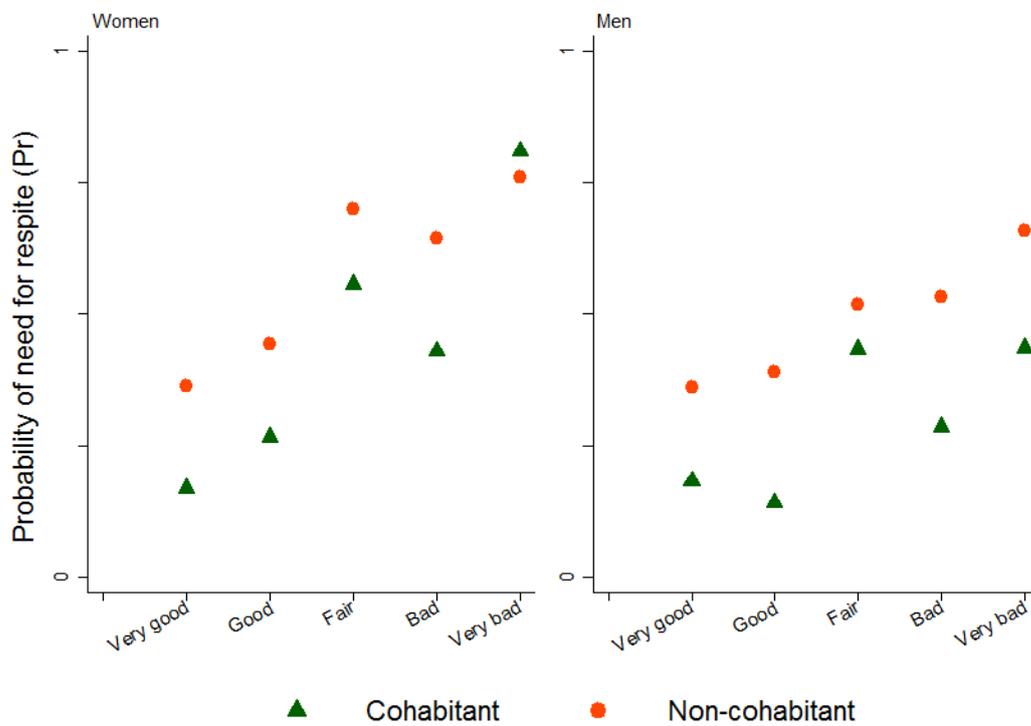
Variables	Coef.	Std. Err.	t	P >t	[95% Conf. Int.]	FMI <sup>a</sup>
Health Status – (Very good)	(Ref.)					
Good	0.082	0.121	0.68	0.495	-0.155 0.320	0.017
Fair	0.489	0.132	3.70	0.000	0.239 0.748	0.030
Bad	0.633	0.1798	3.53	0.000	0.281 0.985	0.027
Very bad	0.74	0.317	2.34	0.020	0.119 1.361	0.024
Length of time for care - (<1 year)						
[1-2 years]	-0.373	0.277	-1.35	0.178	-0.916 0.170	0.089
[3-8 years]	-0.15	0.261	-0.57	0.566	-0.662 0.362	0.104
[8-16 years]	-0.173	0.26	-0.65	0.517	-0.694 0.349	0.106
[>16 years]	-0.205	0.264	-0.78	0.438	-0.723 0.313	0.093
Income Level – (<800€)						
800€ - 1,200€	-0.189	0.18	-1.04	0.297	-0.544 0.166	0.109
1,200€ - 1,800€	-0.072	0.164	-0.43	0.665	-0.393 0.25	0.074
1,800€ - 2,500€	-0.118	0.17	-0.69	0.492	-0.45 0.218	0.127
>2,500€	-0.096	0.163	-0.59	0.557	-0.414 0.223	0.125
Marital status – (Married)						
Single	-0.243	0.113	-2.14	0.033	-0.465 -0.02	0.071
Divorced	-0.157	0.177	-0.89	0.375	-0.5031 0.189	0.050
Widowed	-0.271	0.204	-1.33	0.185	-0.671 0.129	0.090
Filiation – (Partner by marriage)						
Daughter	0.61	0.147	4.14	0.000	0.3212 0.898	0.032
Family	0.328	0.124	2.63	0.008	0.0839 0.572	0.041
Son	0.469	0.243	1.93	0.054	-0.008 0.945	0.046
Close acquaintance	-0.016	0.189	-0.08	0.934	-0.385 0.354	0.038
Caregiving others	0.077	0.047	1.64	0.100	-0.014 0.1693	0.008
Cohabitation	-0.701	0.111	-6.32	0.000	-0.918 -0.4839	0.024
Feeling of loneliness	0.8349	0.085	9.79	0.000	0.667 1.002	0.037
Lack of Institutions	0.5611	0.105	5.35	0.000	0.3556 0.766	0.168
Lack of time	0.7588	0.091	8.37	0.000	0.581 0.937	0.064
Replacement in case of unavailability	0.0651	0.09	0.73	0.468	-0.111 0.241	0.018
Age	0.0014	0.003	0.45	0.650	0-.0048 0.008	0.064
Constant	-0.992	0.366	-2.71	0.007	-1.71 -0.274	0.071

Notes:<sup>a</sup> FMI: Fraction of Missing Information

## 2.C Additional figures

Figure 2.C.1 – Correlation circle - PCA



**Figure 2.C.2 – Probability of the need for respite by gender and health status**

## 2.D Health and Disability Caregiver Survey questionnaire (Handicap Santé - Volet Aidants informels)-2008 - (Module I)

## Module i

### i1. En tenant compte de l'aide que [Prénom] reçoit déjà de la part de l'entourage ou de professionnels, avez-vous besoin d'être remplacé(e) ou assisté(e) pour aider [Prénom] ?

1. Oui.....  1
2. Non .....  2
98. R .....  98 } → i3
99. Nsp.....  99 }

### i2. Je vais vous citer certains moments de la journée. Dites-moi, en plus de l'aide que [Prénom] reçoit déjà, les moments où une aide supplémentaire serait nécessaire.

*Lire les modalités de réponses.*

	Oui	Non
1. Le matin	<input type="checkbox"/>	<input type="checkbox"/>
2. L'après-midi	<input type="checkbox"/>	<input type="checkbox"/>
3. Le soir	<input type="checkbox"/>	<input type="checkbox"/>
4. La nuit	<input type="checkbox"/>	<input type="checkbox"/>
5. Le week-end	<input type="checkbox"/>	<input type="checkbox"/>
6. Pendant vos vacances	<input type="checkbox"/>	<input type="checkbox"/>

### i3. Pouvez-vous vous ménager des moments de répit ?

1. Oui.....  1
2. Non .....  2 → i3B
98. R .....  98 } → i4
99. Nsp.....  99 }

### i3A. Quelles sont ces possibilités de répit ?

*Ne pas lire les modalités de réponses. Plusieurs réponses possibles.*

1. [Prénom] reçoit l'aide de la famille, des amis ou voisins .....  1
2. Il/elle est en halte-garderie ou à l'école .....  2
3. Il/elle travaille.....  3
4. Il/elle est en centre de vacances.....  4
5. Il/elle reçoit l'aide de professionnels .....  5
6. Il/elle reçoit l'aide de bénévoles .....  6
7. Il/elle est en hôpital de jour.....  7
8. Il/elle est en hébergement temporaire, accueil de jour, accueil de nuit .....  8
9. Il/elle est en établissement hébergeant des personnes en situation de handicap (foyer de vie, foyer d'accueil médicalisé, maison d'accueil spécialisée) .....  9
10. Autre moment, précisez : .....  10
98. R .....  98 } → i4
99. Nsp.....  99 }



**i3B. Diriez-vous que vous en auriez besoin ?**

1. Oui .....  1
2. Non .....  2
98. R .....  98
99. Nsp .....  99

**i4. Avez-vous suivi une formation pour assurer votre rôle d'aidant ?**

*Consigne: formation payée par l'aidant, par un organisme ou organisée par une association.*

1. Oui .....  1 → i5
2. Non .....  2
98. R .....  98 } → i5
99. Nsp .....  99 }

**i4A. Diriez-vous que vous en auriez besoin ?**

1. Oui .....  1
2. Non .....  2
98. R .....  98
99. Nsp .....  99

**i5. Avez-vous déjà participé à des groupes de paroles, d'échange, de soutien psychologique dans le cadre de votre soutien ?**

1. Oui .....  1 → i6
2. Non .....  2
98. R .....  98 } → i6
99. Nsp .....  99 }

**i5A. Diriez-vous que vous en auriez besoin ?**

1. Oui .....  1
2. Non .....  2
98. R .....  98
99. Nsp .....  99

**i6. Une ou plusieurs personnes s'occupe(nt)-elle(s) du bon fonctionnement de votre ménage (garde d'enfant, préparation des repas, ménage...) afin que vous puissiez libérer du temps pour aider ?**

1. Oui .....  1
2. Non .....  2
98. R .....  98
99. Nsp .....  99





## Chapter 3

# Does the formal home care provided to older adults affect the utilisation of support services by informal carers? An analysis of the French CARE and the U.S. NHATS/NSOC surveys

### Abstract

This research investigates how formal home care affects the utilisation of support services by informal carers. Using nationally representative data collected in CARE ménage (France) and NHATS/NSOC (the U.S.), we address the endogeneity of formal care using the care recipient's characteristics and community residential care choice. Andersen's health behavioural model of support service utilisation provides a conceptual framework for investigating the predisposing, enabling, and need variables associated with informal carers' service use. In France, the care recipients' formal care utilisation

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A preliminary version of the chapter was published in the GATE Working Paper Series: <http://dx.doi.org/10.2139/ssrn.3769126>

does not influence the carer's support service use. Comparatively, in the United States, formal care significantly increases the utilisation of respite services by informal carers. Through exploring the relationship between formal and informal care in France and the U.S., whereas informal care is a substitute for formal care in the U.S., we find no evidence of such a correlation in France.

### 3.1 Introduction

For the International Alliance of Carer Organizations (IACO), an informal carer is defined as “an unpaid individual, such as a family member, neighbour, close acquaintance or other significant individual, who takes on a caring role to support someone with reduced physical ability, a debilitating cognitive condition, or chronic life-limiting illness”. In general, informal carers provide care on a deliberated basis, stemming from a prior social relationship, and without monetary incentive or specific training (Hoefman et al., 2013). Based on this definition, the concept of the informal carer comprises multiple aspects and dimensions (Al-Janabi et al., 2008; Colombo et al., 2011; Hoefman et al., 2013). Therefore, informal carers have a ubiquitous and very substantial presence throughout the world, with figures estimating, for example, a total of 8.1 million carers in Canada (2012) and 6.5 million in the United Kingdom (2011).<sup>1</sup> Furthermore, due to this general trend in the incidence of disabilities throughout the world due to the population ageing in European societies, it is widely thought that informal carers play an essential role in their loved ones’ daily living activities (Colombo et al., 2011; Rahola, 2011).

Informal care is provided not only when the disabled person lives at home or in the community (Papastavrou et al., 2007) but also when the disabled person is admitted to an institution (long-term care facility) (Gräsel, 2002). In light of this, it appears that informal carers play a strategic role in the daily activities of their dependent loved ones (Willemse et al., 2016). Although some carers view care provision as propitious and a generator of positive utility, it is nevertheless true that it can readily be seen to have lost these qualities (Schulz and Beach, 1999). When this happens, providing informal care produces negative utility for the carer due to a high risk of exhaustion (burnout) if the carer does not receive any external assistance (Oliva-Moreno et al., 2018). Since informal carers experience a burden related to the caregiving tasks, there is no denying the high risk of death, thus leading to a reduction of labour dedicated to informal care. Despite the rapid negative changes that occur in the lives of carers that are observed in certain situations involving an overwhelming burden, there is more concern regarding the gradual worsening of the carer’s quality of life (Schulz and Beach, 1999).

This paper is one of the first to provide empirical evidence of formal care’s effect on informal carers’ support service utilisation in Europe (France) and the United States.

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<sup>1</sup><https://internationalcarers.org/carer-facts/global-carer-stats/>

This study is of particular interest because it provides an overview comparing two countries implementing interventions and strategic plans for supporting informal carers (and recipients), despite existing institutional differences between their respective health systems. The study focuses on informal care and medical care utilization in Europe and the U.S. (Barczyk and Kredler, 2019; Holly et al., 2007). While the relation between formal care and support services for carers is not intuitive, it has not received much attention in the empirical literature. This study's primary contribution is to analyse the effect of formal home care on the utilisation of support services by informal carers while categorising formal care by care recipients' characteristics and their choice for community residential care.

Using the data from two nationally representative surveys collected in 2015, *Capacités Aides et Ressources des Seniors (CARE ménage)* in France and the National Health and Aging Trends Survey (NHATS) in the U.S., we address the endogeneity of formal care through the care recipient's characteristics and community residential care choice. The extension of Andersen's health behavioural model of support service utilisation to include informal care provides a conceptual framework for investigating predisposing, enabling, and need variables to control for informal carers' support service utilisation.

Findings indicate that formal care does not influence the carer support service utilisation in France. Comparatively, in the United States, formal care significantly increases the respite service utilisation by informal carers. Here, I test and explore the relationship between formal and informal care. I find that formal care has no effect on informal care in France, whereas as my analysis of data from the U.S. indicates, informal care is a substitute for formal care. This means that formal care decreases the care provision duration for informal carers of old-age persons living at home. This result is consistent because care provision represents a perpetual challenge due to various factors that increase exhaustion for some informal carers. Therefore, most studies agree that geriatric care recipients need more long-term care towards the end of their life, and that informal carers could rely on support strategies to mitigate the burden of care.

Several research papers study the relationship between formal care<sup>2</sup> and informal care, focusing on children's characteristics to categorise informal care. The majority of research to date confirms the finding that informal care and formal care can be substitutes or complements (Balía and Brau, 2014; Bonsang, 2009; Gannon and Davin, 2010; Kemper, 1992; Lo Sasso and Johnson, 2002; Paraponaris et al., 2012; Van Houtven and Norton, 2004). But while some studies identify factors influencing carers' needs (Raivio et al., 2007; Zwaanswijk et al., 2013), the empirical relationship between characteristics and carers' support service utilisation has been rarely investigated with regard to issues of long-term care (LTC) (Hong et al., 2011). Since studies largely pay attention to the correlations between support service utilisation and the characteristics of informal carers (McKenzie et al., 2014), this paper extends this literature using the care recipient's characteristics and community residential care choice to analyse formal home care.

This paper is organised as follows: the next section (3.2) presents the background and the conceptual framework; section 3.3 is devoted to data sources and methodology; section 3.4 summarises the results of the empirical model; and section 3.5 contains the discussion of the results. The last section (3.6) is dedicated to the conclusion.

## 3.2 Background and conceptual framework

### 3.2.1 Institutional background

In France, the National Institute for Statistics and Economic Studies (*INSEE*) and the Directorate for Research, Studies, Assessment and Statistics (*DREES* - French Ministry of Health) have shown that the number of informal carers increased from 5 million to 8.3 million people between 1999 and 2008. Based on recent estimates, the number of informal carers was around 11 million people in 2017<sup>3</sup> The number of disabled/dependent people continues to rise. In 2015, 3 million people aged 60 or older living at home reported being regularly assisted in daily life because of their age or health condition (Brunel et al., 2019). Forecasting by the *INSEE* projects the number of people over 60

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<sup>2</sup>Formal care for older or elderly people usually refers to paid care services provided by a healthcare institution or individual for a person in need, whereas informal care refers to unpaid care provided by family members, close relatives, friends, and others within the recipient's neighbourhood. There are three different categories of formal care: (i) home-based care; (ii) community-based care (such as day-care centres with trained staff); and (iii) residential care in the form of nursing homes (Li and Song, 2019). In this analysis, by "formal care" I only consider the category related to home-based care.

<sup>3</sup><https://www.fondation-april.org/comprendre/barometre-et-etudes-aidants>

years of age living in France to increase from 12.8 million to 20.9 million between 2006 and 2035. Estimates in the United States (U.S.) population in 2015 showed 43.5 million informal carers, and 47.8 million old-age people of 65 and older <sup>4</sup> (almost 15% of the population). <sup>5</sup> According to the National Population Projection (NPP), the population of people aged 65 and above in the U.S. is expected to increase to 98.2 million (i.e. nearly one in four U.S. residents) by 2060.<sup>6</sup>

National policies implemented in the majority of EU countries to support long-term carers favoured two main types: financial assistance and in-kind services like home-based professional services, respite care, <sup>7</sup>, counselling, training <sup>8</sup> and support groups <sup>9</sup> (Peeters et al., 2010; Perren et al., 2006; Poel and Beek, 2006; Wijeratne, 1997).<sup>10</sup> Carers' support services like these are developed to relieve a sense of burden amongst carers (Koopmanschap et al., 2004; Thomas et al., 2017; Vandepitte et al., 2016c,a) and improve health and quality of life while continuing caregiving (Guets et al., 2020; National Academies of Sciences and Medicine, 2016; Scharlach et al., 2001; Zarit et al., 1999).

In the majority of cases, carers' support services are provided by the community organisations and/or local association as well as health care services. The strategies dedicated to informal carers vary across countries. In 2020 the French Ministry of Health announced the implementation of a "*plan national de renforcement et de diversification des solutions de répit*" (containing six priority and seventeen key points) to support informal carers. <sup>11</sup> €400 million of investment is anticipated between 2020 and 2022 for the fund, as well as €105 million being allocated for the promotion and popularisation of respite

<sup>4</sup>[https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=PEP\\_2015\\_PEPAGESEX&prodType=table](https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=PEP_2015_PEPAGESEX&prodType=table)

<sup>5</sup><https://www.census.gov/content/dam/Census/newsroom/facts-for-features/2017/cb17-ff08.pdf>

<sup>6</sup>According to these estimates, 19.7 million people will be aged 85 or older.

<sup>7</sup>Respite care (short-term breaks for carers) means taking a break from caring, while the care recipient is looked after by someone else. Respite care generally "refers to temporary relief services for families or primary carers of the disabled although the definition may be broadened to reflect distinctions between primary and secondary respite care" (Levy and Levy, 1986; Warren and Cohen, 1985). See Zirul et al. (1989) for further details.

<sup>8</sup>Training support is one of the pathways that build on the experience of informal carers in effectively helping informal carers to become more aware of their skills and to gain self-confidence and motivation in order to develop their competences even more. Training can help informal carers to improve their caring experience (Eurocarers, 2016).

<sup>9</sup>Support groups for carers are one of the few forms of services directly provided for carers. Such groups can be organised in a number of ways, like a day hospital or adult training centre, while others are free-standing.

<sup>10</sup>For example, in the French context, for Gervès-Pinquié et al. (2014) cash-for-care for elderly people appears to dominate the support dedicated to carers (Da Roit and Le Bihan, 2010) and the in-kind services were deemed underused (Coudin, 2004).

<sup>11</sup><https://www.gouvernement.fr/aidants-une-nouvelle-strategie-de-soutien>

services (Ministère des Solidarités et de la Santé, 2019)<sup>12</sup> Even though the access to support services may also be limited due to geographical matter (Whittier et al., 2005), the critical question remains how carers target the best support services. In the U.S., under the National Family Caregiver Support Program (NFCSP), a mechanism of funds is allocated proportionally to a state's number of residents aged 70 and older. This funding<sup>13</sup> for the NFCSP is dedicated to several categories of services: information about support services; assistance accessing support services; counselling; support groups; training; respite; and other supplementary services (e.g. transportation) (Potter, 2016).

### 3.2.2 Conceptual framework: extension of the Andersen behavioural model to assess informal carers' health service utilisation

Most previous studies on health care utilisation pay particular attention to the Andersen (1995) Behavioural Model (BM) (Andersen, 1995; Babitsch et al., 2012).<sup>14</sup> The extension of the Andersen (1995) model includes both carer and patient characteristics (Bass and Noelker, 1987). Theoretically, several factors are associated with health service use behaviour: (i) predisposing factors (age, gender, education, ethnicity, number of children, marital status); (ii) enabling factors (income/financial situation, health insurance); and (iii) need factors (health status, disease/chronic condition). Almost the majority of studies included the following characteristics: age, marital status, and gender as predisposing factors; income and health insurance as enabling factors; and, finally, health status as need factors (Babitsch et al., 2012). Although current policies pay particular attention to the increasing demand for LTC, in the literature, some studies addressed the issue related to the utilisation of support services by informal carers using the Andersen health behavioural model (Arksey et al., 2002; Hong, 2010; Malley, 2002). Figure 3.2.1 presents an adapted Andersen health services use model for informal care.

Carer support service use patterns have been assessed (Hong, 2010; Kosloski and Montgomery, 1994). Hong (2010) found that the needs of both care recipient and carer contribute to distinguishing different service use patterns (multiple service users, se-

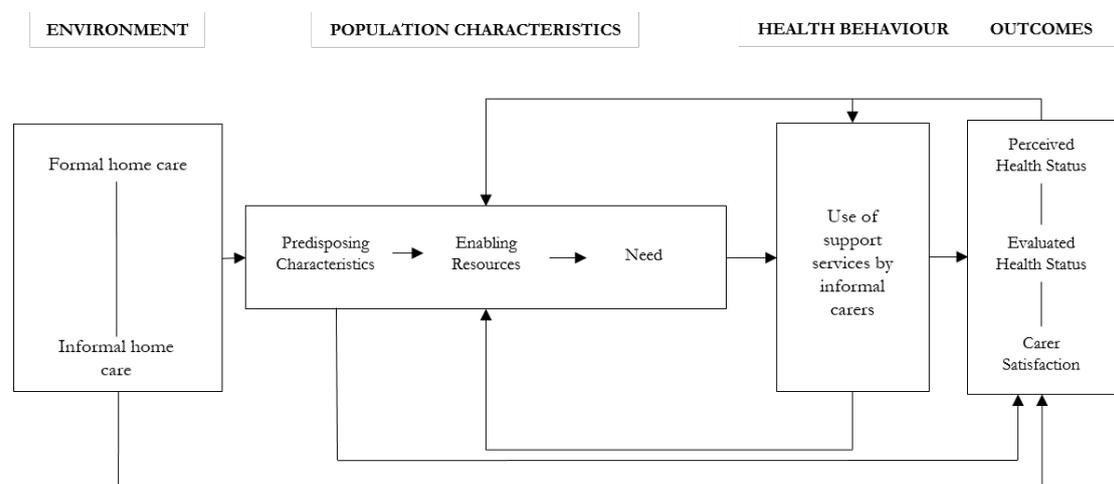
<sup>12</sup>[https://www.gouvernement.fr/sites/default/files/document/document/2019/10/dossier\\_de\\_presse\\_relatif\\_a\\_la\\_strategie\\_de\\_mobilisation\\_et\\_de\\_soutien\\_en\\_faveur\\_des\\_aidants\\_-\\_23.10.2019.pdf](https://www.gouvernement.fr/sites/default/files/document/document/2019/10/dossier_de_presse_relatif_a_la_strategie_de_mobilisation_et_de_soutien_en_faveur_des_aidants_-_23.10.2019.pdf)

<sup>13</sup>An initial endowment is anticipated of about \$150 million per year, although each state provides additional funds.

<sup>14</sup>The studies using the BM are mostly conducted in the U.S. and the United Kingdom.

lective in-home service users, and light service users). [Toseland et al. \(2002\)](#) identify predictors for the utilisation of health and human services amongst people with dementia residing in their community and their family carers. He finds that predisposing, enabling, and need variables explain 40.9% of the variance in service use, 29.8% of the variance in health service use, and 38.1% of the variance in the use of human services. [Liu et al. \(2000\)](#) argue that some respite services are rarely accessible to carers. Furthermore, [Toseland et al. \(2002\)](#) conclude that service utilisation is relatively low compared with the high needs of carers.

**Figure 3.2.1 – Behavioural Model (BM) and expansion for informal care**



Source: Adapted from [Andersen \(1995\)](#)

The analysis of predisposing, enabling, and need factors associated with carers' use and non-use of support services requires empirical evidence. Carers' use of services can be mainly considered as a cultural attitude ([Chiatti et al., 2018](#); [Scharlach et al., 2006](#)). For [Mensie and Steffen \(2011\)](#), at-home respite utilisation by family carers depends mainly on the caregiving dyad's past at-home respite usage.

Conversely, demographic predisposing factors (relationship, income) and need factors (behavioural dysfunction, functional impairments) are not associated with hours of respite utilisation over three months, nor is the level of the carer's depressive symptoms ([Mensie and Steffen, 2011](#)). Additionally, being adult offspring of the recipient, being Black or Hispanic, providing intensive care, living in metropolitan areas, and being residents of states spending more on increasing access to carers' services are all associated with the presence of unused services ([Potter, 2018](#)).

An international comparison across European countries clearly illustrates the specificities of national health systems. For example, in Belgium, some factors making it difficult for individuals to access support include the lack of information given by informal carers (Willemse et al., 2016).<sup>15</sup> Whereas, in the U.S., several service barriers<sup>16</sup> prevent informal carers from using support services, amongst which a low awareness of and little thought of such services are the most prevalent (Hong et al., 2011).

### 3.2.3 Hypothesis

Given our conceptual framework, our analysis leads us to test some main hypotheses. First, we posit the existence of a relationship (substitutability or complementarity) between informal and formal care. Second, carers' use of support services will vary according to recipients' utilisation of formal care. This second hypothesis is not intuitive. Therefore, we assume that informal and formal home care are complementary in the sense that the marginal benefits of support services to the carer's health will increase with professional care to the care recipient. Overall, we expect the presence of at-home formal care for older adults to increase carers' support service use by significantly reducing time spent on caregiving.

## 3.3 Data and methodology

### 3.3.1 Data sources

Our analysis focuses on two nationally representative surveys based on two different datasets. First, we use the data collected in the French survey, *Capacités Aides et Ressources des Seniors (CARE ménage)*,<sup>17</sup> including surveys of both elderly care recipients (*Capacité Aides et REssources des seniors (CARE ménages) - Volet seniors, 2015*) and carers (*Capacité Aides et REssources des seniors (CARE ménages) - Volet aidants, 2015*). This French survey was conducted in 2015 by the *INSEE* and *DREES* with support from

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<sup>15</sup>The lack of timely access to reliable information about formal and informal services in order to proactively support the informal carer, leading to a need for the individual to navigate his or her way through the health system.

<sup>16</sup>According to the authors, service barriers include availability, awareness, affordability, staff quality, privacy violation, complex bureaucracy, language barriers, qualification of each programme, and no thought of service.

<sup>17</sup><https://drees.solidarites-sante.gouv.fr/etudes-et-statistiques/open-data/personnes-agees/article/les-enquetes-capacites-aides-et-ressources-des-seniors-care>

the National Solidarity Fund for Autonomy (CNSA). Our main objective is to better understand older adults' living conditions, their relationships with their family and friends, their difficulties in carrying out certain everyday activities, and the financial and human assistance required to overcome these difficulties.

The "*CARE ménage – Volet senior*" includes older adults aged 60 or over at the start of the survey living permanently in the community. It accounts for the carers (18 years of age or older, living in France metropolitan area) declared by elderly people. The survey protocols favoured face-to-face collection of the data. Nevertheless, the survey was conducted by phone where the carer was not present at home during the interview of the elderly person being interviewed. Almost 10,628 elderly persons (aged 60 and over) responded to the survey, while 6,201 informal carers (over 18 years of age) of at-home older adults responded to the informal carer section.

Secondly, we use data from the National Health and Aging Trends Survey (NHATS)<sup>18</sup>, a nationally representative survey of Medicare beneficiaries aged 65 years or older<sup>19</sup>; and the National Survey of Caregiving (NSOC)<sup>20</sup>, a survey of informal carers conducted in the United States of America (U.S.) in 2015 (round 5)<sup>21</sup>.

The NHATS is a unique national resource for the scientific study of functioning in later life in the U.S.<sup>22</sup> The NHATS aims to foster research that will design achievement to a diminished disability, enhance health and independent functioning, and finally improve the quality of life of the elderly. NHATS participants provide information about all family/non-family carers who assisted with household chores, mobility tasks, or self-care activities.

The NSOC included 2,204 informal carers identified by the 8,334 NHATS participants in 2015. We consider as the primary carer the person providing the most hours to the care recipient. The NHATS user guide contains further details and definitions of variables

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<sup>18</sup><https://www.nhats.org/scripts/DataCollInstrPage.htm>

<sup>19</sup>Medicare beneficiaries aged 65 and older living in the contiguous United States in 2011 and in 2015. In follow-up years (e.g. 2012-2014 and 2016-2018), the sample represents survivors of the original cross-section of interest.

<sup>20</sup><https://www.nhats.org/scripts/DataCollInstrPageNSOC.htm>

<sup>21</sup>The initial sample was first interviewed in 2011. Replenishment of the sample to maintain its ability to represent the older Medicare population was undertaken in 2015.

<sup>22</sup>NHATS is being supported by the National Institute on Aging under a cooperative agreement with the Johns Hopkins University Bloomberg School of Public Health (U01AG032947), with data collection by Westat.

(Kasper and Freedman, 2016), and the NSOC user guide (Kasper et al., 2016).<sup>23</sup> Informal carers participating in the NSOC are interviewed via telephone.

For our analysis, we combine both carer and recipient datasets based on the standard ID. Figure 3.4.1 represented the dyadic data with complete cases.

### 3.3.2 Variables

#### 3.3.2.1 Dependent variables

The “CARE ménage” and NHATS–NSOC surveys provide information on the utilisation of support services. The choice of explanatory variables was driven in the large part by the Andersen behavioural model applied to carers’ utilisation of services (Andersen, 1995; Hong, 2010; Hong et al., 2011; Potter, 2018). We consider the use of support services as dependent variables. Carers answered “yes/no” to the questions as presented in the survey.

For the French data, we use the following variables: “Can you give yourself some time off (period of respite)?” (Respite care); “Have you participated in a support group to discuss the help you provide to take on your role as a carer?” (Support group); “Do you think that (other) training would be useful to you in your role as a carer?” (Training); “Do you regularly receive – because of your health status or your age – financial support from a loved one?” (Financial support).

When analysing the U.S. data, we use the following variables: “In the last year, have you used any service that took care of SP so that you could take some time away from helping?” (Respite care); “In the last year, have you gone to a support group for people who give care?” (Support group); “In the last year, have you received any training to help you take care of SP?” (Training); “In the last year, have you found financial help for SP, including helping him/her apply for Medicaid also known as STATE NAME FOR MEDICAID PROGRAM in SP STATE?” (Financial support).

#### 3.3.2.2 Independent variables

We are interested in the impact of formal care on support service utilisation by carers. Formal care indicates whether or not the care recipient had used at-home support from

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<sup>23</sup><https://www.nhats.org/scripts/dataArchivedDocs.htm>

professional carers for some Activities of Daily Living (ADL)<sup>24</sup> Fuentes-García (2014); Katz et al. (1963) or Instrumental Activities of Daily Living (IADL)<sup>25</sup> (Lawton and Brody, 1969). The survey asks the elderly person: “for which activity did you receive one or more professional carers?” The formal care variable has the value one if the older adults receive one or more professional carers for ADL/IADL, and 0 otherwise. Our model controls for the following factors: predisposing (filiation, cohabitation/co-residence, age); enabling (income, length of time for care); need (health status, the feeling of loneliness, lack of time, chronic diseases/conditions) (Babitsch et al., 2012).

We built a composite measure (*frailty*) related to informal care’s subjective burden based on care provision consequences (Bayen et al., 2013). This index captures the level of vulnerability related to caregiving outcome (mainly negative) but also depending on care provision intensity (Kumagai, 2017). The composite measure reflects a linear combination of related indicators. These selected variables are turned into the *frailty* variable by computing the Principal Component Analysis (PCA), which substantially contributes to the main component.<sup>26</sup> The Principal Component Analysis related to the carers’ *frailty* comprises high values for the most affected. Subsequently, we use *Varimax* rotation to change the PCA coordinates that maximise the sum of the variances of the squared loadings. Thus, each component’s coefficients became either large or close to zero, with few intermediate values. Hence, the goal is to capture the association of each variable with at the most one factor.

### 3.3.3 Statistical and econometric analysis

Detailed information on informal carers and care recipients are provided through descriptive statistics. First, we use the test of independence and test of the mean difference between carers’ and recipients’ characteristics.<sup>27</sup> Secondly, we use multivariate modelling through equations 3.1, 3.2, 3.3 and 3.4 to explore the effect of formal care ( $FC_i$ )

<sup>24</sup>As indicated in the survey report, ALD represent: bathing or showering; Dressing; eating; using the toilet; walking across a room; getting in or out of bed.

<sup>25</sup>As indicated in the survey report, IALD represent: shopping for groceries; preparing a hot meal; doing work around the house or garden; administrative tasks; taking medications; leaving home or taking transportation or finding one’s way when out; using a phone.

<sup>26</sup>In keeping with the literature and the data collection, we selected the following as variables: physical fatigue; sleep disorders; morally tired or discouraged; sometimes feeling alone; feeling depressed; feeling anxious, stressed, overworked; back problems; palpitations, tachycardia, etc.

<sup>27</sup>“Number of consequences of care provision” is split into two categories (“< 2” and “≥ 2”) to differentiate whether there is an association between highly affected carers (“≥ 2” caregiving consequences) and their socio-demographic characteristics.

and carers' and recipients' socio-demographic characteristics ( $X_i$ ) on support services utilisation, dichotomous variables). We estimate four different *probit* models, where  $a_k, b_k, c_k, d_k$  represents the parameters to estimate in each equation, and  $\epsilon_i, \phi_i, \delta_i, \pi_i$  represent the error terms. We estimate the following equations for France and the U.S.:

$$\text{Respite care}_i = a_0 + a_1 \times FC_i + a_2 \times X_i + \epsilon_i \quad (3.1)$$

$$\text{Support group}_i = b_0 + b_1 \times FC_i + b_2 \times X_i + \phi_i \quad (3.2)$$

$$\text{Training}_i = c_0 + c_1 \times FC_i + c_2 \times X_i + \delta_i \quad (3.3)$$

$$\text{Financial support}_i = d_0 + d_1 \times FC_i + d_2 \times X_i + \pi_i \quad (3.4)$$

We perform the Hosmer-Lemeshow test (HL test) to check the goodness-of-fit (assuming the number of group = 10) (Hosmer Jr et al., 2013) after the *probit* model.<sup>28</sup> We also calculate the Area Under the ROC<sup>29</sup> Curve (AUC)<sup>30</sup> to indicate the model's quality.

We first estimate our models considering formal care as an exogenous variable. However, this specification may reflect a biased predicted probability of support service utilisation due to the potential problem of endogeneity of formal care. Therefore, there might be an existing potential bias due to omitted variables or error measurement. Lastly, there is no denying the possible *reverse causality* of formal care.

### 3.3.4 Instrumental variable (IV) approach

Theoretically, since we identify a variable as endogenous (formal care), we need to find at least two different instruments (vector  $Z_i$ ), partially correlated with formal care (endogenous regressor)  $\text{Corr}(FC_i, Z_i) \neq 0$  (hypothesis of relevance) and uncorrelated

<sup>28</sup>A goodness-of-fit test shows how well the data fit the model. Specifically, the HL test calculates if the observed event rates match the expected event rates in population subgroups. The test is only used for binary response variables (a variable with two outcomes like the need for respite, yes or no).

<sup>29</sup>ROC stands for Receiver Operating Characteristic.

<sup>30</sup>The Area under ROC Curve (AUC) measures the entire two-dimensional area underneath the entire ROC curve from (0, 0) to (1, 1). AUC values range from 0 to 1. A model with an AUC equal to 0 means that predictions are 100% wrong, whereas as a model whose predictions are 100% correct has an AUC equal to 1.

(orthogonal) with the error term  $\text{Corr}(\epsilon_i, Z_i) = 0$  (hypothesis of exogeneity) in the use of support services equation (Wooldridge, 2016).

In the existing literature, the instrumental variables (IV) approach is mostly developed for informal care in Europe (Balía and Brau, 2014; Bolin et al., 2008; Bonsang, 2009; Ciani, 2012; Gannon and Davin, 2010), in the U.S. (Van Houtven and Norton, 2004), and both Europe and the U.S. (Barczyk and Kredler, 2019; Holly et al., 2007). However, less concern is given to analysing instrumental variables for formal care (Hartley et al., 1991).

With regard to France, Barnay and Juin (2016) discuss the endogeneity and effect of formal care and informal care on the (mental) health of dependent older adults using the French Disability and Health Survey (*Enquête Handicap Santé Ménage, 2008*) (Barnay and Juin, 2016). They use “the proportion of daughters”, “having at least one child who has no child” to analyse informal care. For formal care, “the percentage of individuals over 75 receiving the Personal Autonomy Allowance (PAA)<sup>31</sup> at the departmental level in 2008” instrument is used.

In the U.S., Spillman (2014) also treats the endogeneity of informal care and formal care. The National Long-Term Care Survey (NLTCs)<sup>32</sup> data collected in 2004 are used to estimate the effect of informal care hours, formal care hours, and high carer stress on nursing home entry and expected days of care. Spillman analyses informal care, formal care, and carer stress; and variables like “the recipient lives alone”, “the number of daughters living within 1 hour of the recipient”, “primary carer has minor children” are the main instrumental variables for informal care. Lastly, for formal care he adopts three measures: “home health agencies per 1,000 persons 65 or over in county of residence”; “recipient lives in community residential care”; “the number of executive function-related limitations (out of 4)”.

Similarly, I select various measurements for formal care received by care recipients in our study. This choice is guided by the literature (Barnay and Juin, 2016; Spillman, 2014). In France, I use: (i) receiving the PAA; (ii) Mental Health Inventory (MHI 5); and (iii) having at least one limitation upon Activities of Daily Living (ADL). In the U.S., we use: (i) living in community residential care; and (ii) having at least one limitation upon Activities of Daily Living (ADL). Therefore, the PAA seems to be a valid instrument

<sup>31</sup>In French, Allocation Personnalisée d’Autonomie (Apa).

<sup>32</sup>The NLTCs is a nationally representative longitudinal survey focusing on disability and long-term care in the Medicare population aged 65 or older for two decades prior to its discontinuation after the 2004 survey year.

because, in the majority, it is used by the care recipient to pay professional carers. Despite benefiting PAA, an average of €80 per month remains paid by at-home dependants, beyond expenses included in assistance plans (Fizzala, 2016). Assuming informal care and formal care are substitutes (Barczyk and Kredler, 2019; van den Berg et al., 2004), informal care may reduce home health care utilisation and delay admission to a nursing home (Van Houtven and Norton, 2004). Finally, according to Spillman (2014), the recipient living in community residential care variable represents a valid measure for formal care.

The model with instrumental variables is used to solve endogeneity bias. Therefore, in Stata, the *ivprobit* programme particularly estimates asymptotical efficient standard errors. Based on this econometric approach, the first-stage estimation considers the endogenous explanatory variable as a linear function of the instruments and the exogenous variables. The second stage estimation (*Newey's two-step estimator*) includes the prediction from the first stage as a covariate in the main equation instead of using the endogenous explanatory variable. In contrast to the maximum likelihood estimation developed by default in Stata, we also perform the Newey's estimator with the "two-step" option (Newey, 1987; Wooldridge, 2016).

A Wald statistic testing the correlation between the error term in the first stage and the error term in the primary model is not sufficiently robust to test for exogeneity.<sup>33</sup> The test of over-identification is used to indicate the validity of instruments, assuming there is no association between the IV and the error term in the second equation.<sup>34</sup> After estimating the model with IV, we perform the Amemiya–Lee–Newey statistic test results for over-identifying restrictions through the *overid* command (Baum et al., 2016; Lee, 1992).

Subsequently, considering the only endogenous regressor, we perform the "rivtest" programme after the instrumental variable has modelled which instruments are robust and which are weak. Instead of analysing the *Lagrange multiplier (LM)* test and the *J overidentification* tests separately, we use the *LM-J* combination test, which tests the hypotheses of exogeneity of the instrument simultaneously.

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<sup>33</sup>It is not possible to test that it is indeed exogenous with a single instrument. Wald statistics are only comparable with weak instrument robust statistics when the Newey two-step estimator is used.

<sup>34</sup>Considering the test of over identification, the null hypothesis (H<sub>0</sub>) stands for "The instruments are all exogenous".

We performed all statistical analyses with STATA SE-64 Statistical software 14.2 (StataCorp. LP, College Station, TX, USA).

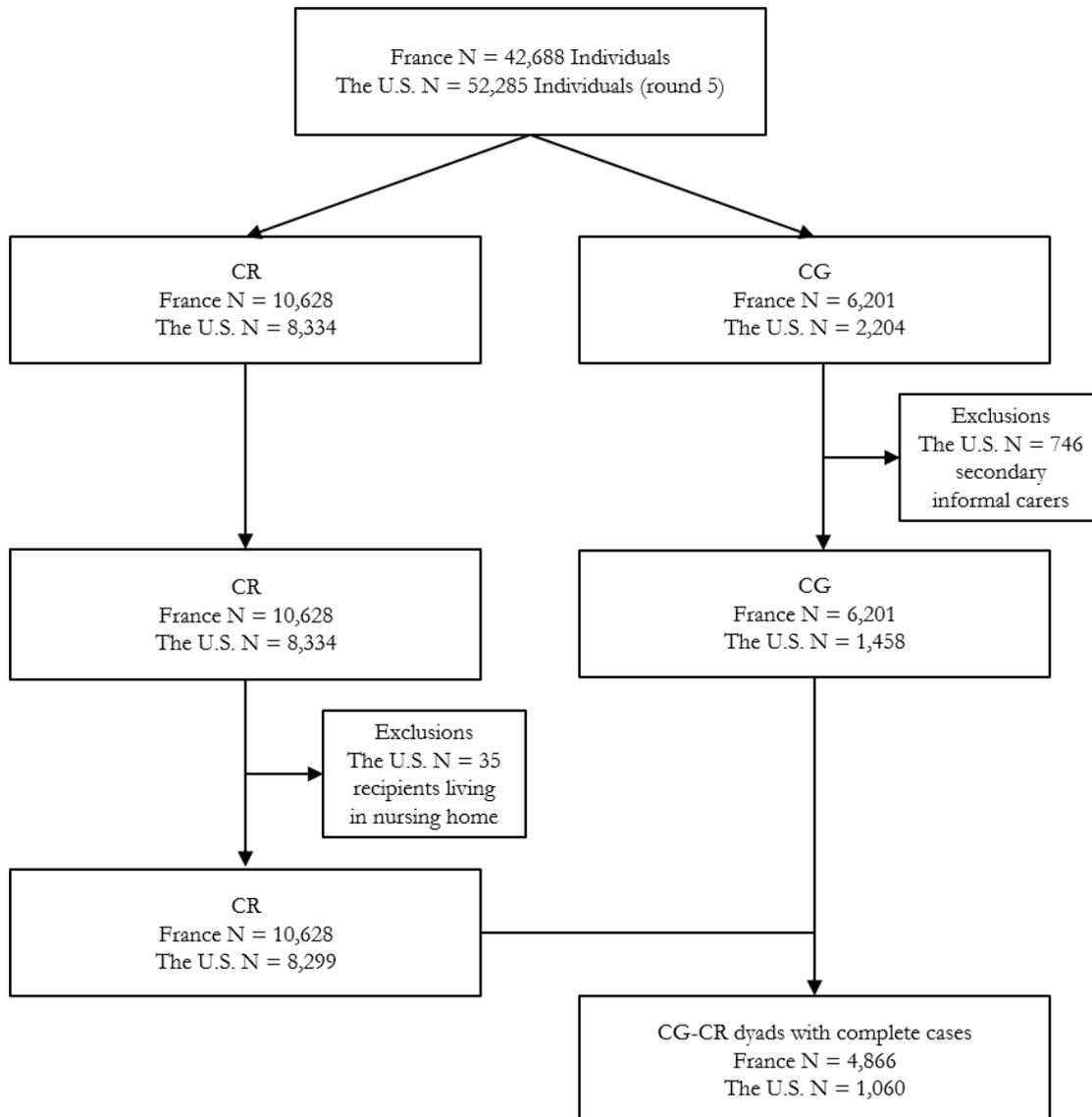
## 3.4 Results

### 3.4.1 Descriptive statistics

Figure 3.4.1 2 describes the study sample based on  $N = 42,688$  individuals in France and  $N = 52,285$  individuals in the U.S. in 2015. In France, we found  $N = 10,628$  care recipients,  $N = 6,201$  informal carers. In the U.S., the NHATS survey indicates  $N = 8,334$  care recipients (round 5), and  $N = 2,204$  carers among which we exclude  $N = 746$  other carers. We then only consider individuals who are primary carers. After merging carer and recipient data, the study sample indicates  $N = 6,201$  dyads for France and  $N = 1,458$  dyads in the U.S. Finally, we use  $N = 4,866$  dyads for France and  $N = 1,060$  dyads for the U.S. without missing data.

Table 3.4.1 details carers' characteristics distinguished by caregiving consequences more or less equal to two (fatigue, stress, etc.).

The majority of informal carers report a quite good health status. In the U.S., carers with excellent/good health status experience more negative consequences. More than 60% of married carers experience several consequences due to caregiving, compared to single, divorced, and widowed carers. The majority of female subjects included are carers and are mostly affected by caregiving. The mean age of carers is 61 years in both countries with a slight range difference between France (range 18 - 96) and the U.S. (range 18 - 97). Care providers who report several consequences of caregiving are less than 64 years old in both countries. A total of 40% of informal carers declare themselves to be affected by at very least two negative consequences due to caregiving in France, compared to 74% in the U.S. The use of respite care is different between countries: 75% of informal carers in France, compared to 18% in the U.S. Less than 4% of carers in each country use a support group. Less than 10% of carers use training for care provision. Only 2% of carers receive financial support in France, compared to 15% in the U.S. Carers cohabiting with their care recipient in France (56%) are more affected by caregiving than carers in the same circumstances in the U.S. (38%). Less than 29% of care providers are the partner by marriage of the recipient. The majority of carers are offspring, and those

**Figure 3.4.1** – Study sample – France (N = 4,866) and the U.S. (N = 1,060)

Note CR care recipient; CG informal carer/caregiver; The U.S. The United States of America.

providing less than 30 hours per month in France are less affected by the care burden. Carers with a lack of time and who are affected by caregiving consequences accounted for 55% in France and 58% in the U.S.

Table 3.4.2 describes in detail care recipients' characteristics. More than 60% of recipients are aged 80 and above. Female recipients represent almost 68%. Almost 37% (N = 1,665) in France use formal care for ADL/IADL, while only 19% (N = 204) do so in the U.S. A large proportion of female recipients (nearly 70%) use formal care. Almost 82% of recipients with the worst health status use formal care in France, compared to

31% in the U.S. Recipients report experiencing chronic conditions, such as high blood pressure (approximately 36% in France and 32% in the U.S.), pain/chronic afflictions (26% in France and 66 in the U.S.), diabetes (19% in France, 15% in the U.S.), osteoporosis (11%), and cancer (9% in France and 14% in the U.S.). The mean number of chronic diseases is approximately three in France and two in the U.S.

The p-value of Table [3.4.1](#) and Table [3.4.2](#) indicates the existence of independence (or not) between the carer/care recipient characteristics.

**Table 3.4.1** – Descriptive statistics of the characteristics of the informal carers (CG)

	France				The U.S.			
	Entire population (N = 4, 866)	Number of consequences of care provision		p-value <sup>d</sup>	Entire population (N = 1,060)	Number of consequences of care provision		p-value <sup>d</sup>
		<2 (N = 2,944)	≥ 2 (N = 1,922)			<2 (N = 280)	≥ 2 (N = 780)	
Health status <sup>a</sup> %								
Very good and good	63	75	44	0.00	84	95	80	0.00
Fair, bad, and very bad	37	25	56		16	5	20	
Income <sup>b</sup> %, in quantiles								
Q1	30	28	32		23	29	25	
Q2	24	24	25	0.00	27	24	28	
Q3	31	33	30		25	32	22	0.03
Q4	15	16	13		25	24	25	
Marital status %								
Married	66	63	70		64	66	64	
Single	19	21	16	0.00	13	15	13	0.24
Divorced	5	6	4		16	13	17	
Widowed	10	10	10		7	5	7	
Sex %								
Female	60	55	69	0.00	67	71	66	0.1
Male	40	45	31		33	29	34	
Age, mean (SD)	61 (14)	59 (14)	64 (13.5)	0.00 <sup>e</sup>	61 (15)	60 (14.5)	62 (15)	0.16
Stress and anxiety %	32	7	70	0.00	36	2	48	0.00
Back problems/limited strength in hips %	21	3	49	0.00	29	3	39	0.00
Exhaustion %	30	5	67	0.00	29	2	38	0.00
Sleep disorders %	20	1	50	0.00	44	11	56	0.00
Feeling of loneliness %	39	25	60	0.00	16	2	21	0.00
Number of care provision consequences %								
< 2 consequences	60	-	-	-	26	-	-	-
≥ 2 consequences	40	-	-		74	-	-	
Respite care %	75	73	80	0.00	18	15	19	0.16
Support group %	3	2	5	0.00	4	2	4	0.25
Training %	10	6	16	0.00	8	5	9	0.03
Financial support %	2	1	2	0.00	15	14	16	0.35
Cohabitation %	40	30	56	0.00	36	30	38	0.01
Filiation %								
Partner by marriage	29	20	42		27	19	29	
Child <sup>c</sup>	53	56	48	0.00	50	51	50	0.00
Family	13	16	8		17	21	16	
Close acquaintance	5	8	2		6	9	5	
Length of time providing care%								
<1 years	5	4	5		8	8	8	
1 to 5 years	38	40	37	0.15	47	50	46	0.43
>5 years	57	56	58		45	41	46	
Duration of care in hour/month <sup>f</sup> %								0.02
<30H	48	61	29		19	20	19	
30H - 60H	17	17	17	0.00	19	21	18	0.29
60H - 150H	19	14	27		32	31	31	
>150H	16	8	27		29	25	31	
Lack of time %	30	14	55	0.00	51	34	58	0.00
Profession %								
Retired	52	47	58		29	27	30	
Employed/Student	36	41	29	0.00	36	41	34	0.09
Unemployed/Inactive	12	12	13		35	32	36	
Carer receiving IC %	31	25	41	0.00	24	22	25	0.36
Education %								
High school/less	-	-	-		37	31	38	
Some post-high school	-	-	-	-	34	37	34	0.09
College degree/greater	-	-	-		29	32	28	

Notes: CR care recipient, SD standard deviation, IC Informal Care. <sup>a</sup> Health status: 5 categories recoded into two categories. <sup>b</sup> Income level: all categories divided into four quantiles; The variable Income for the U.S. is a continuous variable containing 47% missing observations; <sup>c</sup> Child: recoded item as daughter and son; <sup>d</sup> Chi2 statistical test; <sup>e</sup> Test of the difference of the means. The number of care provision consequences includes carers who reported: physical fatigue; sleep disorders; morally tired or discouraged; sometimes feeling alone; feeling depressed; feeling anxious, stressed, overworked; back problems; palpitations, tachycardia. <sup>f</sup> We used the categorical variable of the time spent on care provision per month because of the prominence of missing values. Subsequently, we used monthly data concerning the time spent providing care rather than daily or weekly due to missing value (many respondents may also have refused to answer the questions during the survey).

**Table 3.4.2** – Descriptive statistics of the characteristics of the care recipients

	France				The U.S.			
	Entire population (N = 4,866)	Formal care use		p-value <sup>d</sup>	Entire population (N = 1,060)	Formal care use		p-value <sup>d</sup>
		No (N = 3,201)	Yes (N = 1,665)			No (N = 856)	Yes (N = 204)	
Age, mean (SD)	81 (9.5)	80 (9.3)	83 (9.4)	0.00 <sup>e</sup>	-	-	-	-
60 – 64 %	8	9	6		-	-	-	
65 – 69 %	8	10	6		6	7	3	
70 – 74 %	7	9	5		12	14	7	
75 – 79 %	16	17	12	0.00	17	18	10	0.00
80 – 84 %	19	21	17		20	21	16	
85 – 89 %	22	21	25		21	21	22	
>90 %	19	14	27		22	18	42	
Sex %								
Female	68	67	70	0.09	67	67	69	0.00
Male	32	33	30		33	33	31	
Number of daughters, mean	0.04	0.04	0.05	0.02 <sup>e</sup>	1.7	1.8	1.5	0.00 <sup>e</sup>
PAA %	5	1	11	0.00	-	-	-	-
Formal care <sup>a</sup> %	37	-	-	-	19	-	-	-
Health status <sup>b</sup> %								
Very good and good	17	16	18	0.22	55	51	69	0.00
Fair, bad, and very bad	83	84	82		45	49	31	
Number of diseases <sup>c</sup> , mean (SD)	3 (2)	2.4 (1.7)	4 (2.2)	0.00 <sup>e</sup>	1.6(1.9)	1.6(1.9)	1.4(1.8)	0.23
Disease/chronic conditions %								
Myocardial Infarction	3	3	4	0.00	9	10	7	0.16
High blood pressure	36	32	44	0.00	32	33	28	0.24
Stroke	4	2	9	0.00	11	12	9	0.18
Diabetes	19	15	26	0.00	15	16	11	0.09
Osteoporosis	11	8	15	0.00	11	12	11	0.9
Pain/chronic afflictions	26	22	35	0.00	66	67	60	0.04
Cataract	13	9	20	0.00	-	-	-	-
Bladder control problems (Incontinence)	13	7	24	0.00	-	-	-	-
Kidney problems	7	5	12	0.00	-	-	-	-
Parkinson's disease	2	1	5	0.00	-	-	-	-
Alzheimer's Disease and other	1	0.2	3	0.00	10	10	11	0.60
Depression	14	9	24	0.00				
Cancer	9	7	13	0.00	14	14	16	0.46
ADL restrictions								
At least one %	20	21	20	0.36	14	14	16	0.45
Number (0 – 6), mean	0.5 (1.1)	0.5 (1.1)	0.5 (1.2)	0.92 <sup>e</sup>	0.4(1.3)	0	2.4(2.1)	0.00 <sup>e</sup>
IADL restrictions								
At least one %	68	68	69	0.42	13	0	70	0.00
Number (0 – 7), mean	1.8 (1.9)	1.8 (1.9)	1.8(1.9)	0.51 <sup>e</sup>	0.4(1.1)	0	2(1.8)	0.00 <sup>e</sup>
MHI-5 <sup>f</sup> , mean (SD)	66 (22)	72 (20)	56 (22)	0.00 <sup>e</sup>	-	-	-	-
Level of education %								
High school/less	82	82	83		-	-	-	-
Some post-high school	9	9	9	0.48	-	-	-	-
College degree/greater	9	9	8		-	-	-	-

Notes: SD standard deviation; <sup>a</sup> Proportion of elderly receiving formal care for ALD/IADL; <sup>b</sup> Health status: 5 categories recoded into two categories; <sup>c</sup> Number of chronic diseases; <sup>d</sup> Chi2 statistical test; <sup>e</sup> Test of the difference of the means; <sup>f</sup> MHI-5: Mental-Health Inventory (0-100), with 100 representing the score of optimal mental health.

## 3.4.2 Econometrics model

### 3.4.2.1 Specification tests and instrumental validity

Table 3.4.3 and Table 3.4.4 summarise the results of the support service econometric models (respite, support group, training, and financial support) both with and without formal care treated as endogenous. Therefore, we also report the model results, with statistics (LM-J test rejection indicator, Amemiya–Lee–Newey statistic (p-value) chi-square statistic, using “*twostep*” option). According to the LM-J over-identification test, the null hypothesis is not rejected at 5% level of significance in all models<sup>35</sup>. According to the econometric specification, at least one or quasi-majority instrument passed the over-identification tests. Therefore, instruments listed in section 3.3.4 (“benefit of PAA”; “MHI-5”; “recipient lives in community residential care”; “having at least one limitation”) variables are valid IV. Results indicate that the empirical model with instruments is better than the one without instruments.

Regarding the strength of instruments, it is not possible to test for the relevance of each IV. However, we argue that the quasi-majority of our IV are exogenous ( $p < 0.05$ ): (i) receiving the PAA; (ii) the MHI5; (iii) recipient lives in community residential care; and (iv) having at least one limitations. Appendix 3.A.3 provides the full estimation of the model treating the formal care as an endogenous regressor with the maximum likelihood method. Regarding the first stage (Formal care) equation, the PAA has a positive and significant ( $p < 0.01$ ) effect on formal care. This finding underlies the principal assumption that recipients make effective use of the majority of financial support for the needs related to professional care. The level of limitations is positive and significant ( $p < 0.01$ ). Finally, improvement of the recipient’s mental health significantly reduces formal care ( $p < 0.01$ ). Regarding the U.S. results, the variables of recipients living in community residential care and having at least one limitation imply using more formal care resources ( $p < 0.01$ ).

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<sup>35</sup>Note the *overid* command in Stata performs the over identification test with the two-step method. Like Sargan and Basman single-equation statistics, the test statistic is distributed as Chi-squared with (L-K) degrees of freedom under the null hypothesis that the instruments are valid.

### 3.4.2.2 Formal care and support service utilisation by informal carers: Main results

*France.* Our findings show that for the entire carer population ( $N = 4,866$ ), the utilisation of formal care by the recipient did not affect the carer's use of support services. The poorest health status for informal carers significantly increases their use of support services, especially for carers who are receiving training ( $p < 0.05$ ) and financial support ( $p < 0.05$ ) compared to carers with an excellent health status. Carers with the middle high-income level are likely to use respite, support groups, and training but are less likely to receive financial support ( $p < 0.05$ ). Informal carers providing care for a length of time greater than five years are more likely to use respite services. Moreover, being the offspring of the recipient increased the use of respite ( $p < 0.01$ ) but reduced the use of support groups ( $p < 0.01$ ) compared to amongst carers who were their care recipient's partner by marriage.

The carers reporting a lack of time are more likely to use respite ( $p < 0.01$ ) or a support group ( $p < 0.01$ ) and participate in training ( $p < 0.01$ ). The use of respite ( $p < 0.01$ ), a support group ( $p < 0.01$ ), and training ( $p < 0.01$ ) significantly increases with the age of the CG. However, the probability of receiving financial help reduces with age ( $p < 0.1$ ). We identify a nonlinear relationship between the carer's age and their use of support services, meaning that carers are less likely to use support services as they grow older.

*The U.S.* Our findings show that care recipients' use of formal care increases the carers' use of respite ( $p < 0.05$ ). In cases of a caregiving period of longer than five years, carers are more likely to need respite care ( $p < 0.1$ ). Being the child of the care recipient ( $p < 0.01$ ) and another type of family member ( $p < 0.1$ ) providing care is positively associated with the use of respite care. Carers who report a lack of time are more likely to use respite care ( $p < 0.01$ ), a support group ( $p < 0.05$ ), and financial support ( $p < 0.1$ ). The carer's age significantly increases their use of support services. This effect is particularly significant for the need for training ( $p < 0.1$ ) and those receiving financial support ( $p < 0.01$ ).

### 3.4.2.3 Relationship between informal care and formal care: substitute or complement?

In this section, we consider the empirical relationship between the formal and informal care utilisation by the recipient. In so doing, we empirically assess the substitutability and complementarity relationship between informal and formal care. There appears to be no significant relationship between informal and formal care in France, even though formal care shows a positive sign in the model. Results show that informal care and formal care can be substituted for one another in the U.S. ( $p < 0.01$ ). Regarding instruments in the econometric model, it is worth noting that in France, recipients receiving PAA and having at least one limitation are more likely to use formal care ( $p < 0.05$ ). At the same time, we notice an improvement of the recipient's mental health with formal care ( $p < 0.05$ ). In the U.S., it appears that living in the community increases recipients' use of formal care ( $p < 0.05$ ) (see Appendix [3.A.1](#)).

### 3.4.2.4 Factors associated with carers subjective burden

We analyse socio-economic and demographic characteristics associated with the frailty of carers. In the econometric model (multivariate), we also include our dependent variables (support service use) to find an association with carers' frailty. For both countries, it appears that the health status, the feeling of loneliness, and a lack of time positively increase carers' frailty ( $p < 0.01$ ). Conversely, the filiation (relationship) between carers and recipients produces a positive outcome by reducing carer frailty ( $p < 0.1$ ) (see Appendix [3.A.2](#)).

**Table 3.4.3 – Effect of formal care on support service utilisation by informal carers in France**

	Probit model without IV				Probit model with IV			
	(1) Respite care	(2) Support group	(3) Training	(4) Financial support	(1) Respite care	(2) Support group	(3) Training	(4) Financial support
Formal care (CR)	-0.041 (0.045)	0.060 (0.080)	0.035 (0.059)	0.078 (0.106)	0.051 (0.046)	-0.070 (0.090)	-0.010 (0.058)	-0.116 (0.120)
Health Status – (Very good)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)
Good	-0.043 (0.045)	-0.038 (0.080)	0.073 (0.059)	0.172 (0.106)	-0.041 (0.057)	-0.039 (0.108)	0.072 (0.075)	0.165 (0.171)
Fair	-0.018 (0.065)	0.038 (0.120)	0.312*** (0.084)	0.440** (0.176)	-0.019 (0.065)	0.042 (0.119)	0.311*** (0.083)	0.442** (0.176)
Bad	-0.148* (0.087)	0.205 (0.154)	0.373*** (0.113)	0.979*** (0.196)	-0.148* (0.087)	0.206 (0.149)	0.374*** (0.112)	0.974*** (0.189)
Very bad	-0.151 (0.210)	0.214 (0.368)	0.602** (0.236)	1.033*** (0.335)	-0.155 (0.214)	0.219 (0.354)	0.602** (0.258)	1.035*** (0.339)
Income Level – (Q1)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)
Q2	0.116** (0.054)	0.138 (0.102)	0.076 (0.072)	-0.217* (0.121)	0.114** (0.054)	0.141 (0.107)	0.076 (0.073)	-0.211* (0.123)
Q3	0.109** (0.052)	0.307*** (0.096)	0.169** (0.068)	-0.309** (0.124)	0.105** (0.052)	0.312*** (0.098)	0.170** (0.067)	-0.299** (0.126)
Q4	0.057 (0.064)	0.140 (0.126)	0.206** (0.082)	-0.131 (0.154)	0.060 (0.065)	0.137 (0.126)	0.205** (0.082)	-0.140 (0.154)
Length of time for care - (<1 year)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)
1 - 5 years	0.162* (0.091)	0.039 (0.170)	-0.050 (0.120)	-0.177 (0.210)	0.150 (0.092)	0.051 (0.169)	-0.045 (0.120)	-0.148 (0.215)
>5 years	0.195** (0.090)	-0.123 (0.170)	-0.152 (0.119)	0.022 (0.202)	0.186** (0.090)	-0.113 (0.168)	-0.148 (0.118)	0.041 (0.206)
Filiation – (Partner by marriage)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)
Child	0.216*** (0.082)	-0.580*** (0.147)	0.163 (0.103)	0.069 (0.179)	0.202** (0.081)	-0.559*** (0.155)	0.168 (0.105)	0.093 (0.182)
Family member	0.150 (0.092)	-0.344** (0.163)	0.061 (0.120)	0.077 (0.197)	0.136 (0.092)	-0.322* (0.177)	0.068 (0.122)	0.102 (0.208)
Close acquaintance	-0.071 (0.110)	-0.172 (0.194)	0.114 (0.153)	0.423* (0.223)	-0.072 (0.109)	-0.166 (0.204)	0.115 (0.152)	0.417* (0.225)
Cohabitation	-0.044 (0.066)	-0.109 (0.130)	-0.123 (0.079)	0.121 (0.146)	-0.040 (0.067)	-0.114 (0.133)	-0.124 (0.080)	0.109 (0.144)
Feeling of loneliness	-0.081* (0.043)	0.042 (0.076)	0.347*** (0.055)	-0.131 (0.100)	-0.081* (0.044)	0.042 (0.081)	0.346*** (0.056)	-0.127 (0.106)
Lack of time	0.167*** (0.046)	0.332*** (0.079)	0.368*** (0.056)	0.033 (0.107)	0.167*** (0.048)	0.328*** (0.081)	0.368*** (0.057)	0.033 (0.110)
Age, ln (CG)	5.076*** (1.563)	12.712*** (4.159)	5.060** (2.393)	-5.522* (2.930)	5.191*** (1.557)	12.572*** (4.120)	5.030** (2.149)	-5.652* (3.121)
Age, ln, squared (CG)	-0.641*** (0.201)	-1.653*** (0.520)	-0.733** (0.307)	0.662* (0.388)	-0.659*** (0.200)	-1.630*** (0.519)	-0.728*** (0.278)	0.684* (0.405)
Disease (CR)	-0.007 (0.010)	-0.031 (0.019)	-0.019 (0.014)	0.003 (0.023)	-0.018 (0.012)	-0.015 (0.023)	-0.015 (0.016)	0.026 (0.029)
Constant	-9.595*** (3.014)	-25.927*** (8.289)	-10.169** (4.616)	9.028* (5.415)	-9.760*** (2.997)	-25.740*** (8.145)	-10.139** (4.123)	9.192 (5.945)
Number of observations	4,866	4,866	4,866	4,866	4,866	4,866	4,866	4,866
Hosmer-Lemeshow - p-value (a)	0.10	0.54	0.34	0.32				
AUC	0.60	0.69	0.70	0.76				
LM-J test rejection indicator (b)					#	#	#	#
Amemiya–Lee–Newey p-value (c)					0.46	0.78	0.92	0.37

Notes: CR care recipient; Standard errors in parentheses; \*  $p < 0.1$ , \*\*  $p < 0.05$ , \*\*\*  $p < 0.01$ ; (a) Hosmer-Lemeshow - goodness-of-fit statistic indicated the model good fit ( $p > 0.05$ ); Our models fit reasonably well on the validation sample. The models' discrimination in the validation sample is quite higher; Area Under ROC curve (AUC) denoted a good classifier; The instrumental approach contains all the listed variables in table section 3.3.4; (b) '#' stand for "null hypothesis ( $H_0$ ) not rejected at 5% level" (the instruments are valid); (c) Amemiya–Lee–Newey statistic ( $p$ -value) chi-square statistic.

**Table 3.4.4** – Effect of formal care on support service utilisation by informal carers in the U.S.

	Probit model without IV				Probit model with IV			
	(1)	(2)	(3)	(4)	(1)	(2)	(3)	(4)
	Respite care	Support group	Training	Financial support	Respite care	Support group	Training	Financial support
Formal care (CR)	0.242** (0.115)	0.369** (0.183)	0.132 (0.156)	0.076 (0.133)	0.034** (0.014)	0.026 (0.023)	0.001 (0.020)	0.011 (0.016)
Health Status – (Very good)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)
Good	0.059 (0.105)	0.109 (0.172)	0.324** (0.132)	0.009 (0.113)	0.058 (0.108)	0.104 (0.173)	0.329** (0.133)	0.015 (0.115)
Fair	-0.079 (0.139)	0.121 (0.212)	0.159 (0.164)	0.121 (0.135)	-0.079 (0.137)	0.117 (0.212)	0.150 (0.168)	0.126 (0.136)
Length of time for care - (<1 year)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)
1 - 5 years	0.212 (0.180)	-0.198 (0.266)	-0.197 (0.210)	0.045 (0.209)	0.232 (0.197)	-0.174 (0.270)	-0.207 (0.217)	0.050 (0.200)
>5 years	0.376** (0.180)	-0.057 (0.265)	-0.129 (0.210)	0.281 (0.211)	0.383* (0.198)	-0.058 (0.269)	-0.143 (0.217)	0.282 (0.199)
Filiation – (Partner by marriage)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)
Child	0.698*** (0.206)	0.073 (0.298)	-0.192 (0.245)	-0.101 (0.209)	0.675*** (0.211)	0.108 (0.307)	-0.156 (0.258)	-0.108 (0.220)
Family member	0.430** (0.215)	0.159 (0.298)	-0.088 (0.253)	-0.170 (0.235)	0.412* (0.227)	0.187 (0.341)	-0.062 (0.284)	-0.174 (0.243)
Close acquaintance	0.293 (0.267)	0.417 (0.377)	-0.425 (0.331)	-0.007 (0.282)	0.259 (0.272)	0.461 (0.363)	-0.406 (0.375)	-0.031 (0.282)
Cohabitation	0.040 (0.155)	0.373* (0.225)	0.062 (0.192)	-0.080 (0.162)	0.037 (0.156)	0.382* (0.231)	0.068 (0.197)	-0.077 (0.166)
Feeling of loneliness	0.107 (0.129)	-0.133 (0.219)	0.041 (0.160)	0.054 (0.133)	0.117 (0.129)	-0.140 (0.222)	0.031 (0.158)	0.064 (0.135)
Lack of time	0.243** (0.096)	0.415*** (0.152)	0.177 (0.120)	0.182* (0.101)	0.247*** (0.096)	0.406** (0.164)	0.178 (0.122)	0.183* (0.101)
Age, ln (CG)	2.101 (3.630)	-0.267 (4.514)	7.361** (3.710)	11.488*** (3.365)	2.320 (3.652)	-0.829 (5.096)	6.935* (4.093)	11.770*** (3.529)
Age, ln, squared (CG)	-0.216 (0.469)	0.016 (0.589)	-1.042** (0.489)	-1.603*** (0.444)	-0.246 (0.472)	0.094 (0.666)	-0.982* (0.538)	-1.642*** (0.463)
Disease (CR)	0.020 (0.024)	-0.034 (0.037)	0.051* (0.028)	0.046* (0.025)	0.003 (0.024)	-0.047 (0.042)	0.044 (0.029)	0.037 (0.025)
Constant	-6.883 (6.966)	-1.416 (8.532)	-14.143** (6.991)	-21.395*** (6.354)	-7.237 (7.001)	-0.415 (9.638)	-13.389* (7.696)	-21.886*** (6.647)
Number of observations	1,060	1,060	1,060	1,060	1,060	1,060	1,060	1,060
Hosmer-Lemeshow - p-value (a)	0.88	0.25	0.65	0.005				
AUC	0.70	0.68	0.66	0.68				
LM-J test rejection indicator (b)	-	-	-	-	#	#	#	#
Amemiya–Lee–Newey p value (c)	-	-	-	-	0.08	0.48	0.24	0.05

Notes: CR care recipient; Standard errors in parentheses; \*  $p < 0.1$ , \*\*  $p < 0.05$ , \*\*\*  $p < 0.01$ ; <sup>(a)</sup> Hosmer-Lemeshow - goodness-of-fit statistic indicated the model good fit ( $p > 0.05$ ); Our models fit reasonably well on the validation sample. The models' discrimination in the validation sample is quite higher; Area Under ROC curve (AUC) denoted a good classifier; The instrumental approach contains all the listed variables in table section 3.3.4; <sup>(b)</sup> '#' stand for "null hypothesis (H0) not rejected at 5% level" (the instruments are valid); (c) Amemiya–Lee–Newey statistic (p-value) chi-square statistic. Note: the income variable contained 43% of missing observations and was not estimates. The variable "Health status" contained no observation on the categories "Bad" and "Very bad" in the final sample.

### 3.5 Discussion

Our study's main contribution is to empirically estimate how formal care affects carers' use of support services in France and the U.S. Our results indicate no significant effect of formal care on carers' tendency to use support services in France. By contrast, in the U.S. formal care significantly increases carers' utilisation of support services, for instance, respite care.

Regarding our French results, no significant relationship has been identified between formal care and the carer's use of services. This result is all the more remarkable because no significant relationship is found between formal and informal care. Conversely, in the U.S., our study shows that carers of elderly people who benefit from formal care are more likely to use support services. This is an important point, because formal and informal care can be substituted for one another. In this light, it is worth noting that both health behaviour and carer utility within the care provision widely determine LTC arrangement decision. Second, there is no denying the complexity of the health system. Since 2002, both France and the U.S., two highly rated health care systems ([World Health Organization, 2000](#))<sup>36</sup>, in countries in which the proportion of elderly people is growing steadily ([Dutton, 2002](#)), have spent more than 11% of GDP on health (France 11.3% and the U.S. 17.1%) ([OECD, 2017](#)). Both systems have got private insurance as well as government insurance (for instance, National Health Insurance (NHI) in France, and Medicare/Medicaid in the U.S.), where insurance is provided through the employer ([Dutton, 2007](#)). A principal dissimilarity across the health systems considered here is universal health coverage (UCH) in France. In the U.S., the health expenditure is paid by household (out-of-pocket), and almost 40% of citizens do not have access to adequate health insurance. France has the most expensive health care system in the world, although the U.S. system is the most costly ([Lorenzoni et al., 2014](#)).<sup>37</sup>

However, the Organisation for Economic Cooperation and Development (OECD) countries have different approaches for managing different forms of care in LTC. It remains hard to precisely quantify how many countries differ in various formal and informal forms of care ([Bakx et al., 2015](#)). The lack of information and data on the burden

<sup>36</sup>According to a report from the WHO, France is ranked 1st whereas the U.S. is 37th regarding overall health system performance.

<sup>37</sup>France spends about half of what the U.S. spends annually on health care. In 2011, in France spending came to \$3,359 per capita in PPP. In the U.S., it is \$7,212 per capita in PPP.

of care (intensity) may have limited research in some countries in which population ageing does not mean the same due to social norms (Barczyk and Kredler, 2019). Therefore, LTC policies in some OECD countries mostly rely on informal care and cohesion inside the family. Social norms and institutional quality and incentives therefore seem to be the only drivers behind the LTC arrangement. Since family cohesion possesses a central position and merely reflects policy, (Barczyk and Kredler, 2018) found that the U.S. has strong policies supporting informal care arrangements because informal care is of utmost importance.

Furthermore, the U.S. appears to be a reference where informal care takes place owing precisely to limited LTC coverage, in contrast with the European culture of individualism (Barczyk and Kredler, 2019). The setting and implementation of LTC programmes are also quite particular regarding the framework and current health policy. Potential spending funds allocated in LTC do little to increase access to services in different countries in the same way. Therefore, if health policies want to continue to rely on informal care for LTC to maximise social welfare, more funds should be invested in the respite programme targeting carers with frailty. Nevertheless, financial and in-kind assistance should also be provided to carers with a high informal care burden, even for vulnerable persons in the community.

A mapping of LTC in most OECD countries shows potential inequality regarding access to care (Waitzberg et al., 2020). While some European countries face the problem of the low utilisation of support services by carers (Lethin et al., 2016), in the U.S. barriers limit access to service utilisation. They might not always be aware of various support services, in case of information asymmetries, but also when there are some barriers to service utilisation, the support service itself is not always aware of these barriers (Hong et al., 2011). Some support services remain underused because informal carers do not always identify themselves as informal carers, or they would have merely neglected the burden of care provision (Eifert et al., 2015). Access to information could remain one of the essential support needs for families to foster care provision efficiency (Wilkes et al., 2000) and ensure the social benefit through the welfare of informal carers (Alwin et al., 2019). Regarding the care recipients, it appears that a chronic condition (e.g. cancer, mental health, dementia, etc.) would have an influence on the ability to predict carers' utilisation of support services (Potter, 2018). In the U.S. informal carers of elderly people

living with chronic diseases would have found positive utility with services such as training and financial support.

The instrumental validity indicates that the model with formal care as endogenous is relevant. The majority of control variables remains significant and maintained the same sign in both models (whether using instrumental variables or not). The two-step model, Amemiya–Lee–Newey statistic (p-value) and over-identification tests help to validate instruments. The instrumental strategy results are then in line with some findings in the literature (Barnay and Juin, 2016; Spillman, 2014). For instance, “PAA” and “MHI5” in France (Barnay and Juin, 2016) and “recipient lives in community residential care” and “having at least one limitations” in the U.S. Spillman (2014) are associated with formal care. Beyond two-stage least squares, our modelling also explores limited information maximum likelihood (more robust to weak instruments). These findings are quite similar to the two-steps model method. The LM-J statistics combination testing the hypothesis of the exogeneity of instruments simultaneously is more robust than two separate tests (Lagrange multiplier (LM) and J over-identification).

According to Andersen’s model, factors such as predisposing (filiation, cohabitation/co-residence, age), enabling (income, duration of care), and need (health status, the feeling of loneliness, lack of time, chronic condition of the recipient) influence the use of support service. Previous findings indicate that predisposing and/or enabling factors are less closely associated with service utilisation than need factors. However, the findings show some inconsistencies in the strength and direction (sign) of the association. The econometric models based on the Andersen framework indicate that carers who are the offspring of their care recipients are more likely to use respite services. Intuitively, the use of services seems to increase with age. That assumption is not verified in France, where financial support decreases with age. Therefore, these results could be explained by the local organisation and community’s existence to support family carers. Nevertheless, Potter (2018) indicates that demographic factors that act either to predispose or enable are unimportant compared to other factors, such as culture. This may go some way to explain why it would appeared that Black and Hispanic carers are hesitant in taking up respite services.

Some limitations are identified throughout the study. First, we use a subjective and dichotomous measurement of the use of support (“Yes” or “No”). Therefore, it is

not possible to use and assess the different level of preferences of the use of support (intensity, such as: "No, not at all"; "Yes, a little bit"; "Yes, a lot). Future research should consider this point. Second, the analysis of the use of support choices of carers is assessed separately. The preferences for respite, support group, training, and financial support utilisation are not assumed in the compelled decision in which carers' characteristics are assessed conditionally. Our study did not explore the matter of barriers or bottleneck that carers face when trying to make use of support services. Geographical barriers differentiating the use of support services for carers and recipients have received very little attention in recent research. Future research should aim to support policymakers by evaluating different types of support that carers find most useful and pay attention to other potential sources of inequality and geographic variation in service utilisation in light of these results. In our survey data, dependent variable, such as "training" would not have been formulated in the same way in both countries surveys questionnaires. These discrepancies may have indeed biased the answers and choices of carers. Therefore, based on these inconsistencies, it is not easy to build a reliable comparison regarding this dependent variable in both countries; nevertheless, we should be cautious interpreting these results.

### **3.6 Conclusion**

This study outlines essential implications for Long-Term Care (LTC) dedicated to health policy, for an optimal trade-off between informal and formal care use, while bearing in mind the specificities of particular health systems. First, countries should consider spending more on innovative support programmes in improving access to care, because some carers may have difficulties in accessing and using support services. Secondly, policymakers should provide means to create information campaigns designed to raise awareness concerning the utilisation of various existing health services and to improve and maximise social welfare. A prioritisation scheme for policymakers could consist of conducting studies to identify the population of carers at risk and provide assistance to those affected by the high burden due to informal care provision.

# Appendix

## 3.A Additional tables

**Table 3.A.1 – Relation between Informal Care (IC) and Formal Care (FC)**

	France		The U.S.	
	(1)	(2)	(1)	(2)
	Informal care	Formal care equation	Informal care	Formal care equation
Formal care	0.064 (0.091)		-0.048*** (0.010)	
Instrumental variables (IV)				
PAA (CR)		1.056*** (0.109)		
MHI5 (CR)		-0.013*** (0.001)		
Having at least one limitation (CR)		0.807*** (0.047)		
Recipient lives in community residential care (CR)				0.804** (0.355)
Having at least one limitation (CR)				8.330*** (0.294)
Number of observations	4,866	4,866	1,060	1,060

Notes: CR care recipient; Results of the ordered logistic model (France and the U.S.) using the simultaneous equations model. This table summarises the joint estimations of IC, (Eq. (1), ordered probit model of informal care duration per month), and the formal care utilisation (Eq. (2), probit model) with the assumption that both equations have a multivariate error term distribution. The estimation technique is based on the “cmp” Stata package, Roodman, 2019 (Roodman, 2019). Dependent variables: Health Status; Income Level, Filiation; Cohabitation; Feeling of loneliness; Lack of time; Age (CG); Chronic disease (CR). Standard errors in parentheses; \*  $p < 0.1$ , \*\*  $p < 0.05$ , \*\*\*  $p < 0.01$ ; Informal care: Duration of care per month in Hour.

Table 3.A.2 – Factors associated with the frailty of informal carers

	France	The U.S.
	(1)	(2)
	Frailty	Frailty
Respite care	0.236*** (0.049)	0.061 (0.107)
Support group	0.337*** (0.120)	0.207 (0.221)
Training	0.546*** (0.071)	-0.121 (0.158)
Financial support	0.107 (0.163)	0.005 (0.117)
Duration of care - (<30H)	(ref.)	(ref.)
30H-60H	0.103* (0.061)	-0.010 (0.131)
60H-150H	0.355*** (0.063)	0.052 (0.119)
>150H	0.687*** (0.074)	0.180 (0.122)
Health Status – (Very good)	(ref.)	(ref.)
Good	0.259*** (0.059)	0.517*** (0.094)
Fair	0.955*** (0.067)	0.961*** (0.117)
Bad	1.599*** (0.093)	-
Very bad	1.789*** (0.233)	-
Income Level – (Q1)	(ref.)	-
Q2	-0.057 (0.057)	-
Q3	0.011 (0.055)	-
Q4	-0.053 (0.068)	-
Length of time for care - (<1 year)	(ref.)	(ref.)
1 to 5 years	-0.069 (0.100)	-0.047 (0.155)
>5 years	-0.021 (0.098)	-0.000 (0.156)
Filiation - (Partner by marriage)	(ref.)	(ref.)
Child	-0.310*** (0.085)	-0.320* (0.177)
Family member	-0.515*** (0.097)	-0.359* (0.191)
Close acquaintance	-0.769*** (0.118)	-0.421* (0.223)
Cohabitation	-0.005 (0.072)	0.027 (0.139)
Feeling of loneliness	0.745*** (0.046)	2.054*** (0.113)
Lack of time	1.196*** (0.051)	0.577*** (0.083)
ln, Age (CG)	3.735** (1.712)	6.652** (2.684)
ln, Age squared (CG)	-0.499** (0.220)	-0.934*** (0.351)
Disease (CR)	-0.002 (0.010)	0.019 (0.022)
Constant	-6.369* (3.301)	-12.351** (5.071)
Number of observations	4,866	1,060
R-Squared	0.414	0.391

Notes: CR care recipient; Results of the linear regression model (Multivariate analysis in France and the U.S.). The frailty variable (consequence) stand for the composite measure of the subjective burden. Section 3.3.2.2 indicates in details the measurement of this indicator. Standard errors in parentheses; \*  $p < 0.1$ , \*\*  $p < 0.05$ , \*\*\*  $p < 0.01$ .

Table 3.A.3 – IV model - Formal care effect on the need for support of informal carers

	France				The U.S.			
	(1) Respite care	(2) Support group	(3) Training	(4) Financial support	(1) Respite care	(2) Support group	(3) Training	(4) Financial support
Formal care (CR)	0.051 (0.046)	-0.070 (0.090)	-0.010 (0.058)	-0.116 (0.120)	0.034** (0.014)	0.026 (0.023)	0.001 (0.020)	0.011 (0.016)
Health Status – (Very good)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)
Good	-0.041 (0.057)	-0.039 (0.108)	0.072 (0.075)	0.165 (0.171)	0.058 (0.108)	0.104 (0.173)	0.329** (0.133)	0.015 (0.115)
Fair	-0.019 (0.065)	0.042 (0.119)	0.311** (0.083)	0.442** (0.176)	-0.079 (0.137)	0.117 (0.212)	0.150 (0.168)	0.126 (0.136)
Bad	-0.148* (0.087)	0.206 (0.149)	0.374*** (0.112)	0.974*** (0.189)	-	-	-	-
Very bad	-0.155 (0.214)	0.219 (0.354)	0.602** (0.258)	1.035*** (0.339)	-	-	-	-
Income Level – (Q1)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)
Q2	0.114** (0.054)	0.141 (0.107)	0.076 (0.073)	-0.211* (0.123)	-	-	-	-
Q3	0.105** (0.052)	0.312*** (0.098)	0.170** (0.067)	-0.299** (0.126)	-	-	-	-
Q4	0.060 (0.065)	0.137 (0.126)	0.205** (0.082)	-0.140 (0.154)	-	-	-	-
Length of time for care - (<1 year)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)
1 - 5 years	0.150 (0.092)	0.051 (0.169)	-0.045 (0.120)	-0.148 (0.215)	0.232 (0.197)	-0.174 (0.270)	-0.207 (0.217)	0.050 (0.200)
>5 years	0.186** (0.090)	-0.113 (0.168)	-0.148 (0.118)	0.041 (0.206)	0.383* (0.198)	-0.058 (0.269)	-0.143 (0.217)	0.282 (0.199)
Filiation – (Partner by marriage)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)
Child	0.202** (0.081)	-0.559*** (0.155)	0.168 (0.105)	0.093 (0.182)	0.675*** (0.211)	0.108 (0.307)	-0.156 (0.258)	-0.108 (0.220)
Family member	0.136 (0.092)	-0.322* (0.177)	0.068 (0.122)	0.102 (0.208)	0.412* (0.227)	0.187 (0.341)	-0.062 (0.284)	-0.174 (0.243)
Close acquaintance	-0.072 (0.109)	-0.166 (0.204)	0.115 (0.152)	0.417* (0.225)	0.259 (0.272)	0.461 (0.363)	-0.406 (0.375)	-0.031 (0.282)
Cohabitation	-0.040 (0.067)	-0.114 (0.133)	-0.124 (0.080)	0.109 (0.144)	0.037 (0.156)	0.382* (0.231)	0.068 (0.197)	-0.077 (0.166)
Feeling of loneliness	-0.081* (0.044)	0.042 (0.081)	0.346*** (0.056)	-0.127 (0.106)	0.117 (0.129)	-0.140 (0.222)	0.031 (0.158)	0.064 (0.135)
Lack of time	0.167*** (0.048)	0.328*** (0.081)	0.368*** (0.057)	0.033 (0.110)	0.247*** (0.096)	0.406** (0.164)	0.178 (0.122)	0.183* (0.101)
In, Age (CG)	5.191*** (1.557)	12.572*** (4.120)	5.030** (2.149)	-5.652* (3.121)	2.320 (3.652)	-0.829 (5.096)	6.935* (4.093)	11.770*** (3.529)
In, Age squared (CG)	-0.659*** (0.200)	-1.630*** (0.519)	-0.728*** (0.278)	0.684* (0.405)	-0.246 (0.472)	0.094 (0.666)	-0.982* (0.538)	-1.642*** (0.463)
Disease (CR)	-0.018 (0.012)	-0.015 (0.023)	-0.015 (0.016)	0.026 (0.029)	0.003 (0.024)	-0.047 (0.042)	0.044 (0.029)	0.037 (0.025)
Constant	-9.760*** (2.997)	-25.740*** (8.145)	-10.139** (4.123)	9.192 (5.945)	-7.237 (7.001)	-0.415 (9.638)	-13.389* (7.696)	-21.886*** (6.647)
Formal care Equation								
Health Status – (Very good)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)
Good	-0.026 (0.045)	-0.026 (0.045)	-0.026 (0.045)	-0.026 (0.045)	0.200* (0.102)	0.200* (0.102)	0.200* (0.102)	0.200* (0.102)
Fair	0.057 (0.051)	0.058 (0.051)	0.058 (0.051)	0.057 (0.051)	-0.021 (0.127)	-0.021 (0.127)	-0.020 (0.127)	-0.019 (0.127)
Bad	-0.001 (0.070)	-0.001 (0.070)	-0.001 (0.070)	-0.001 (0.070)	-	-	-	-
Very bad	0.058 (0.177)	0.058 (0.177)	0.058 (0.177)	0.058 (0.177)	-	-	-	-
Income Level – (Q1)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)
Q2	0.036 (0.043)	0.036 (0.043)	0.036 (0.043)	0.036 (0.043)	-	-	-	-
Q3	0.090** (0.041)	0.090** (0.041)	0.090** (0.041)	0.090** (0.041)	-	-	-	-
Q4	-0.029 (0.051)	-0.029 (0.051)	-0.029 (0.051)	-0.029 (0.051)	-	-	-	-
Length of time for care - (<1 year)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)
1 - 5 years	0.112 (0.076)	0.112 (0.076)	0.112 (0.076)	0.112 (0.076)	-0.286* (0.169)	-0.286* (0.169)	-0.286* (0.169)	-0.285* (0.169)
>5 years	0.088 (0.074)	0.088 (0.074)	0.088 (0.074)	0.088 (0.074)	-0.197 (0.170)	-0.198 (0.170)	-0.197 (0.170)	-0.196 (0.170)
Filiation – (Partner by marriage)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)	(ref.)
Child	0.139** (0.065)	0.139** (0.065)	0.139** (0.065)	0.139** (0.065)	0.214 (0.194)	0.214 (0.194)	0.214 (0.194)	0.213 (0.194)
Family member	0.156** (0.073)	0.156** (0.073)	0.156** (0.073)	0.156** (0.073)	0.148 (0.208)	0.148 (0.208)	0.147 (0.208)	0.147 (0.208)
Close acquaintance	0.067 (0.089)	0.067 (0.089)	0.067 (0.089)	0.067 (0.089)	0.107 (0.246)	0.107 (0.246)	0.109 (0.246)	0.109 (0.246)
Cohabitation	-0.023 (0.052)	-0.023 (0.052)	-0.023 (0.052)	-0.023 (0.052)	0.016 (0.152)	0.016 (0.152)	0.016 (0.152)	0.016 (0.152)
Feeling of loneliness	0.024 (0.035)	0.024 (0.035)	0.024 (0.035)	0.024 (0.035)	-0.214* (0.123)	-0.214* (0.123)	-0.214* (0.123)	-0.214* (0.123)
Lack of time	-0.045 (0.037)	-0.045 (0.037)	-0.045 (0.037)	-0.045 (0.037)	0.108 (0.090)	0.108 (0.090)	0.108 (0.090)	0.107 (0.090)
In, Age (CG)	-0.376 (1.295)	-0.376 (1.295)	-0.376 (1.295)	-0.376 (1.295)	-0.044 (2.931)	-0.044 (2.931)	-0.044 (2.931)	-0.017 (2.931)
In, Age squared (CG)	0.080 (0.166)	0.080 (0.166)	0.080 (0.166)	0.080 (0.166)	0.026 (0.384)	0.026 (0.384)	0.024 (0.384)	0.022 (0.384)
Disease (CR)	0.069*** (0.009)	0.069*** (0.009)	0.069*** (0.009)	0.069*** (0.009)	-0.020 (0.024)	-0.020 (0.024)	-0.020 (0.024)	-0.021 (0.024)
Instruments (IV)								
FAA (CR)	0.069*** (0.009)	0.069*** (0.009)	0.069*** (0.009)	0.069*** (0.009)	-	-	-	-
MH15 (CR)	-0.007*** (0.001)	-0.007*** (0.001)	-0.007*** (0.001)	-0.007*** (0.001)	-	-	-	-
Having at least one limitation	0.403*** (0.034)	0.405*** (0.034)	0.404*** (0.034)	0.403*** (0.034)	8.334*** (0.147)	8.334*** (0.147)	8.328*** (0.147)	8.319*** (0.147)
Recipient lives in community residential care	-	-	-	-	0.796*** (0.181)	0.796*** (0.181)	0.807*** (0.181)	0.827*** (0.181)
Constant	0.461 (2.502)	0.460 (2.502)	0.463 (2.502)	0.460 (2.502)	-0.143 (5.532)	-0.142 (5.532)	-0.159 (5.531)	-0.188 (5.532)
Number of observations	4,866	4,866	4,866	4,866	1,060	1,060	1,060	1,060

This table estimates the effect of formal home care on support service utilisation by informal carers based on instrumental variables (IV). Wald test not robust to weak instruments when performing IV model with maximum likelihood. We checked this by using other tests like the LM-J over-identification and the Amemiya–Lee–Newey statistic using the two-step method (An alternative method which produces similar results). Standard errors in parentheses; \*  $p < 0.1$ , \*\*  $p < 0.05$ , \*\*\*  $p < 0.01$

## Chapter 4

# Cost-utility analysis of a respite care facility using a combined Markov modelling and discrete event simulation approach

### Abstract

*Objective* This study aims to perform a cost-utility analysis of a respite care facility (RC), including a mobile team and a respite house for informal carers and recipients, compared to the standard care (SC).

*Method* We developed a Markov model combined with a discrete-event simulation with a four-months' time horizon. Additionally, we used a Business Process Model and Notation (BPMN). Data from the connected observatory AIdants de la METropole de Lyon - AIME 2, including 30 carers in the Lyon metropolitan area (France), were used. A fictive cohort (N = 420) of carers with a high burden due to caregiving and their recipients was created. The health system and the societal perspectives were retained in base case and scenario analyses, respectively. Sensitivity analyses were conducted.

*Results* In the base case, costs were €16,685 (SD± 17,737) and €15,878 (SD± 17,681) for RC and SC, respectively. The mean cost and effectiveness differences between RC and SC strategies were respectively €807 (95% CI: -1,544 – 3,157) and 0.004 (95% CI 0.002 - 0.005). The ICER was €204,308.7 per QALY gained. Based on the societal perspective,

the ICER was €123,457.63 per QALY gained. For both perspectives, the probability for RC to be cost-effective was under 50% at the €100,000 threshold.

*Conclusion* Organisational parameters of RC should be revisited in order to increase the probability of being cost-effective. The Markov modelling combined with a discrete-event simulation seems particularly well adapted for innovations with a huge organisational dimension.

**Keywords:** *Business Process Model and Notation; Cost-effectiveness analysis; Discrete-event simulation; Informal carers; Markov model.*

**Abbreviation:** *BPMN: Business Process Model and Notation; ICER: Incremental cost-effectiveness ratio; DES: Discrete-event simulation; MM: Markov model; RC: Respite care; SC: Standard care; SD: Standard deviation; QALY: Quality-adjusted life years.*

## 4.1 Introduction

The world population is ageing, and the proportion of old adults is likely to increase in the coming years. In Europe particularly, where the percentage of older adults aged 65 and above represented 20% of the total population in 2019 ([The World Bank, 2019](#)), the demand for long-term care is increasing, putting informal carers on the front line. Informal carers represent an important actor in the health system and long-term care, although their role is not always well recognised. Recent estimates indicate that the number of informal carers has steadily increased in developed economies. In France, there were between 8 and 11 million informal carers in 2019 <sup>1</sup>, and 3.9 million carers reported by a person aged 60 or above living at home providing regular assistance due to a health problem or ageing. The volume of care provision associated with caring can be burdensome and constitute an enabling factor to the negative impacts of caregiving. Likewise, cohabiting carers experience a worse standard of life than those who are non-cohabiting, especially since almost 47% of carers reported a negative impact due to providing care ([Besnard et al., 2019](#)). Regular care for dependent persons may sometimes represent a critical factor of exhaustion for the carer [Andrieu et al. \(2003\)](#); [Bayen et al. \(2013\)](#); [Mello et al. \(2016\)](#); [Metzelthin et al. \(2017\)](#). Overburden for care provision jeopardises the mental and physical health of carers. In some situations, over-exhausted carers use more health and medical care when their physical health is affected ([Serrano-Aguilar et al., 2006](#)). In the majority, states of exhaustion appear as stressed periods in which many carers report more feelings of depression, lack of coping mechanisms, and concerns about their poor quality of life. When exhaustion is combined with the decreasing number of physical functions, it becomes urgent that this burden should be alleviated in order to ensure the continuity of care provision and reduce a significant proportion of the demand for long-term care ([Garcés et al., 2010](#); [Rodríguez-González et al., 2021](#)).

Then, a variety of support interventions has been developed to enhance the carer's capacity in caregiving. For [Schulz et al. \(2020\)](#), the most common categories are psychological or multicomponent intervention, including education, information about resources, training, counselling and social support. Other types refer to physical activity and psychotherapeutic methods, e.g. meditation-based mindfulness. Another profes-

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<sup>1</sup><https://www.fondation-april.org/comprendre/barometre-et-etudes-aidants>

sional service is based principally on interventions like case management and respite care. Support services like training, support groups, information and respite care were the most assessed (Mason et al., 2007; McNally et al., 1999; Shaw et al., 2009). Even if there is no consensus concerning the carers intervention classification (Gaugler et al., 2005), a broad set of support initiatives has been developed to support carers in their caregiving duty. It seems that there is no consensus among such different interventions in alleviating the sense of burden due to informal care making it possible to enhance the care duration (Vandepitte et al., 2016a). Services such as “day care” are likely to effectively reduce carer burden and behavioural problems in patients with dementia, but they also contribute to accelerating time to nursing home admission (Vandepitte et al., 2016a). However, the respite experience is for carers and is one way to mitigate the negative impacts of caregiving (Strang and Haughey, 1998).

In France, the Ministry of Health implements a support strategy for 2020 – 2022 estimated at €400M. Then, additional funding (€105M) in the “*plan national de renforcement et de diversification des solutions de répit*” was dedicated to reinforcing support for the carers at home and diversifying the supply of respite services at local level (community-dwelling) like “*Balluchonage*” (Ministère des Solidarités et de la Santé, 2019). Additional easing measures to get access to the respite services were indicated concerning the administrative procedure. In the same vein, the first establishment of its kind in France is the Lyon Metropolis’s respite house. It offers a regular place and time to rest, be supported and prepared for a more peaceful return home for sick or disabled people and their family carers aged 0 to 60 in need living in the Lyon metropolitan area.

A limited number of full economic evaluations of respite care and other support interventions for informal carers have been published to date (Bring et al., 2020; Forster et al., 2015, 2013; Joling et al., 2013; Michalowsky et al., 2019; Sogaard et al., 2014; Vandepitte et al., 2020; Woods et al., 2012, 2016).

In this framework, there is still a need for economic evaluation to support the evidence concerning the cost-effectiveness of the respite care programme for carers (Guets et al., 2020; Vandepitte et al., 2016a). This study aims to perform a cost-utility analysis of a respite care facility (RC), including a mobile team and a respite house for informal carers and recipients compared to the standard care (SC), using a Markov model combined with a discrete-event simulation (DES) in a four-month time horizon.

## 4.2 Methods

### 4.2.1 Clinical data input

The related transition probability used in the Markov model was extracted from the survey's data *Aidants de la Métropole de Lyon -AIME 2, an online observatory of the situation, needs and expectations of informal carers in the Lyon metropolitan area* (Appendix 4.C)<sup>2</sup>. The survey aims to develop a dynamic support and monitoring system based on 30 informal carers from the Lyon metropolitan area (France). It was conducted with an online platform<sup>3</sup> through software for a qualitative survey between June and November 2017. The inclusion criteria were being an informal carer, an adult, providing at least 5 hours of care per week, living in the Lyon metropolitan area, able to read, write and understand French, having consented to participate in this study, available for the duration of the study and connecting to the online platform for 2.5 hours per month. Since the training was given to the carer, the data were collected according to different themes, e.g. carer recognition, carer exhaustion, carer lacks/needs, support dedicated to the carer. The main objective of *AIME 2* was to assess situations, needs and expectations in terms of dedicated services for informal carers on a monthly basis. Thereby, the target population represents carers with a medium and/or high risk of exhaustion due to caregiving. As individuals aged 60 or older were not eligible to benefit from the respite house, carers and their recipients with an illness and/or disability aged from 0 to 60 years living in the Lyon metropolitan area were the populations targeted by the study.

### 4.2.2 The respite care facility

The “*Foundation France Répit*” and “*Foundation OVE*” carried out an innovative project to create a RC facility as a combination of a mobile team and a respite house in the Lyon metropolitan area. This project is dedicated to carers who take care of a family member with a disability and/or an in-home patient who is dependent due to a chronic disease (e.g. cancer). Nevertheless, in the metropolitan area, almost 170,000 informal carers, with 35,000 over-solicited, are concerned by the high burden of informal care provision.

<sup>2</sup>“*Observatoire en ligne de la situation, des besoins et des attentes des aidants informels de la métropole de Lyon vis-à-vis des services qui leurs sont dédiés*” (*Observatoire connecté des aidants 2017*). ; <https://www.france-repit.fr/activite-scientifique/recherche/>

<sup>3</sup>The online platform “*StudioOnline*” was developed by the company Kernwert.

Since October 2018, the RC has provided support to carers and recipients. The core of the RC is the presence of the mobile team within the respite house scheme. First, the mobile team provides a variety of duty and home supports to carers living with families. The mobile team is formed of physicians, psychologists, nurses, a social worker and a secretary. It offers counselling, home interventions, medical-psychological assessments, guidance and accompaniment. It is an interface between the home and the “before-and-after” respite house, making it possible to offer a real break and support to the family. The respite house provides medical care (e.g. identical application of home prescriptions, prescription of emergency medicines) and a 24-hour medical on-call duty.

The respite house has a capacity for 15 people (5 children and 10 adults) and can also welcome their carers. The mission of the respite house aimed at taking into account the needs and exhaustion of carers. Thus, the use of respite house may avoid hospitalisations and allow better management of their health problems, a probable decrease in work stoppages, and a decrease in family tensions at home. The maximum length of stay is 30 days per carer-recipient dyad. As previously mentioned, the respite house is intended for all carers supporting persons under 60 years old who are very fragile or dependent due to an illness or disability. These organisational and administrative constraints have been taken into account in the present evaluation.

### 4.2.3 Model design

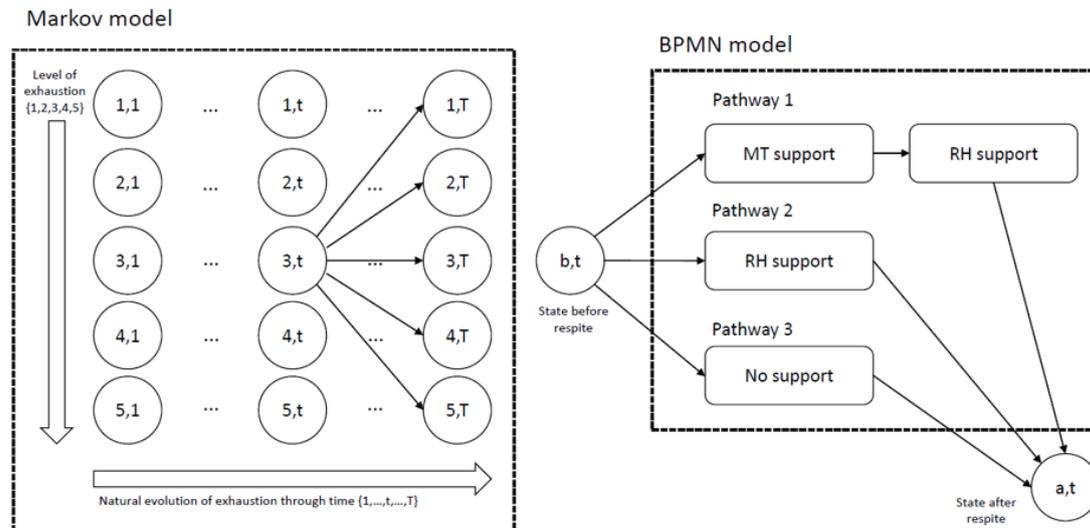
#### 4.2.3.1 Simulation framework

Figure 4.2.1 illustrates the structuration of the Markov and Business Process Model and Notation (BPMN) models as a general simulation framework. The **Markov model** simulates a population’s natural exhaustion and generates requests of the need for respite. Nevertheless, it also models the impact of respite use by reducing exhaustion level over time (for example, a day). For each request, an entity is generated and simulated using the **BPMN model**, allowing the calculation of indicators. Three pathways are considered: (i) with mobile team and respite house (pathway 1), (ii) without mobile team, but with respite house (pathway 2)<sup>4</sup>, (iii) neither mobile team nor respite house (pathway 3).

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<sup>4</sup>The pathway 2 was not considered in the economic evaluation.

Figure 4.2.1 – The simulation Framework



Note: MT: mobile team; RH: respite house

A respite request is modelled using frequencies. Let ( $f_{MT}$ ) (resp.  $f_{rpt}$ ) be the respite request frequency to access Pathway 1 (resp. Pathway 2 and 3). The respite impact for the carer is evaluated at the end of each pathway, and the next state is determined.

For example, a carer in states (4,3) has a level of exhaustion of 4 at the time (day) 3.<sup>5</sup> He/she undergoes Pathway 1 and benefits from both mobile team and respite house support. At the end of the respite pathway, the carer moves from the state (4,3) to state (1,4): the respite stay allowed the carer to recover from his/her exhaustion (move from level 4 to level 1).

#### 4.2.3.2 Markov model

A Markov model (left part of Figure 4.2.1) was developed to describe the natural evolution and carers' behaviour through different exhaustion levels and the respite care process (Beck and Pauker, 1983; Sonnenberg and Beck, 1993). We used a model based on five states according to the level of exhaustion (outcome) reported by informal carers: "No exhaustion" (1); "Mild exhaustion" (2); "Moderate exhaustion" (3); "High exhaustion" (4); "Extreme exhaustion" (5). In any time period, carers were classified into one of five levels of exhaustion according to the AIME 2 measurement of the level of exhaustion. The

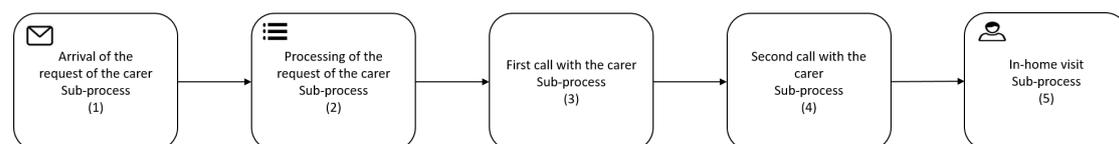
<sup>5</sup>The levels of exhaustion were defined as follow: level 1 no exhaustion; level 2 mild exhaustion; level 3 moderate exhaustion; level 4 high exhaustion; level 5 extreme exhaustion.

simulation starts with an initial distribution of carers in assigned states, and transition probabilities are computed recursively over time to simulate the evolution of carers' exhaustion level. For example, a carer initially in the moderate exhaustion state in the respite house may remain in the same state or progress into one of several alternative states (e.g., high to extreme exhaustion). We did not consider "death" as a state because we assumed that carers' extreme distress did not influence the overall survival in the short term.

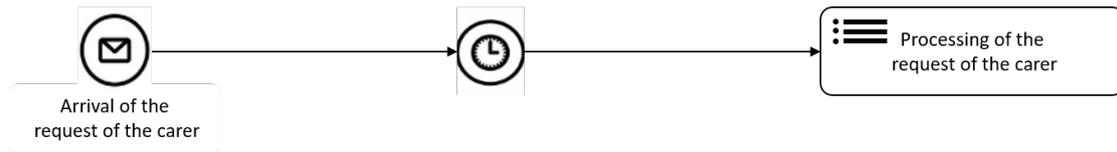
In the model, the primary outcome (exhaustion) is the mean of carers' time in a state multiplied by the level of distress of related states. Then, costs per Markov cycle (each day) are obtained by multiplying costs used by the volume of support services during which carers remain in that state. We constructed a fictitious cohort of 420 people representing informal carers and recipients, comparing the RC and SC. Appendix 4.A.1 presents parameters used in the simulation.

#### 4.2.3.3 Mobile team intervention process model using BPMN

We used a BPMN model to represent the mobile team intervention, i.e. the workflow from the first request of carers until their admission to a respite house (right part of Figure 4.2.1). The process used to represent the support provided by the mobile team is:



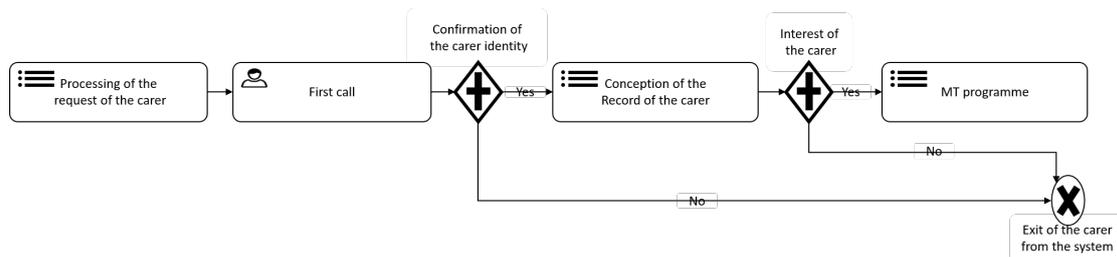
- Sub-process (1) refers to the "Arrival of the request of carers". The mobile team receives many requests for support from carers in need. Different channels are used to receive requests: e-mail, phone, postal mail. Since the mobile team is mainly based on physicians, clinicians, psychologists, and volunteer associations, carers' requests are devoted to the secretary. Sub-process (1) can be represented as follow:



The arrival of the carer request to the mobile team is modelled as a respite ( $f_{EM}$ ) which is approximated by a discrete uniform distribution and depends on the level of exhaustion. Then, the higher the level of exhaustion, the higher the impact of respite.

- Sub-process 2 is related to “the first contact with the carer” and implies two specific steps:
  - *The creation of the carer record.* The mobile team contacts the carer to verify his/her identity. Then, the mobile team creates the carer’s record containing socio-demographic and medical information of the carer-patient dyad. Finally, the mobile team asks the informal carer if he/she is interested in undertaking the mobile team programme. The duration of a call  $d_{r,1}$  is approximated by a uniform distribution.
  - *If the carer’s identity is not confirmed or the carer refuses the mobile team’s support,* then he/she is removed from the system. Conversely, the carer will be supported by the mobile team. Let  $P_{int}$  be the probability that the carer benefits the mobile team support.

Sub-process (2) can be represented as follow:

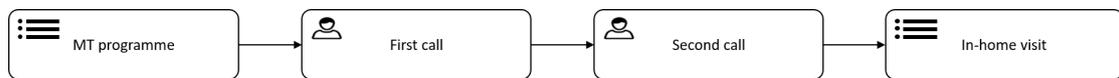


- Sub-process (3) deals with the “planning of the carer in-home visit” through the following steps:
  - *Second call.* The mobile team assesses the needs of the carer and patient before the in-home visit. The carer needs are mainly medical, psychological and

legal (according to the informal care recognition). The duration of the second call  $d_{r2}$  follows a uniform distribution and estimated by the staff of the mobile team.

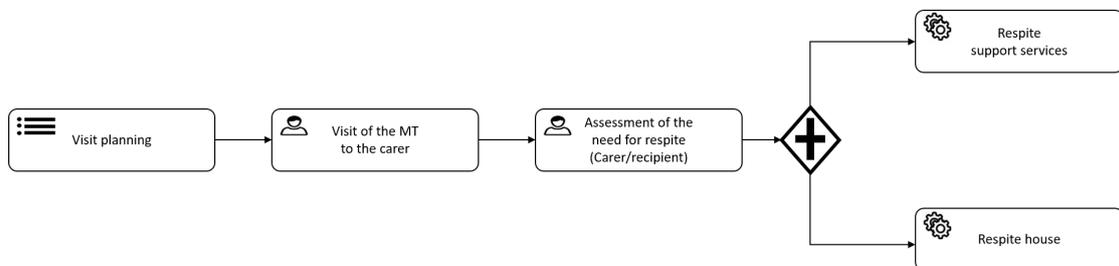
- *Visit planning*. The mobile team organises the in-home visit. This visit relies primarily on carer needs and the availability of the mobile team resource. In the simulation, the visit is organised according to the mobile team staff and the carer’s availability.

Sub-process (3) can be represented as follow:



- Sub-process (4) deals with “In-home visit”, the mobile team proceeds in two steps after the planning:
  - *The visit of the mobile team to the carer*. Travel times are approximated using a uniform distribution fitted using the visit history of the mobile team.
  - *The assessment of the need for respite*. During the in-home visit, the carer benefits from mobile team support (medical assistance, psychological, etc.). The need for respite is assessed for the carer-patient dyad, and the most tailored support service is proposed, including the respite house. A uniform distribution approximates the time spent in the home of the carer  $d_{vst}$ .<sup>6</sup> The probability of admitting the carer to a support service or respite house are respectively  $P_{sr}$  and  $P_{mr}$ .

Sub-process (4) can be represented as follow:



<sup>6</sup>All the different forms of statistical distribution applied to the RT work were based on the discussion and suggestion of experts in our project.

Finally, the different parameters used to simulate the mobile team's support to carers and recipients are reported in Table 4.2.1.

**Table 4.2.1** – Parameters related to the simulation of the mobile team support

Parameters	Notation
Frequency of respite for the carer	$f_{EM}$
Duration of mobile teams first call to the carer	$d_{r1}$
Probability of admission of the carer to the mobile team	$P_{int}$
Duration of the second call of the mobile team to the carer	$d_{r2}$
Duration of the visit of the mobile team to the carer's home	$d_{vst}$
Probability of admission of the carer to a respite support service	$P_{sr}$
Probability of admission of the carer to the respite house	$P_{mr}$

#### 4.2.3.4 The discrete-event simulation model

Law (2015) introduces DES as a modelling approach to a system where states are likely to change over time. This related evolution refers to situations in which state variables change at some specific point/time when events occur whose instantaneous occurrence can change the system and evolves over time. In the literature, the DES has been used to address complex healthcare issues (Jacobson et al., 2006). In health economics, the DES model has been the second most common approach to health intervention in health economic evaluations (HEE) (Zhang, 2018). In particular, in DES modelling for the respite care programme, agents or entities (informal carers) are assumed to be independent entities in the simulation, each of which can be given associated attribute information. The simulation allows multiple "what if?" scenarios to investigate, such as the standard care or other potential existing support services.

In this study, we used DES to simulate the system dynamic considering the presence and/or the absence of the RC. In the workflow, the respite process is triggered by the level of exhaustion, particularly the "high" and "extreme" exhaustion levels. The situation of exhaustion importance conditioned the frequency of agent arrival in the respite pathway. Agents with the level of exhaustion as mentioned above received, firstly, the mobile team intervention and, secondly, a referral to admission in the respite house under the organisational and administrative constraints. In the same vein, informal

carers who stayed in the “high” and “extreme” exhaustion states for a longer five days without receiving respite were in the situation to send their care recipient to the hospital in order to take a time away. The DES combined with the simulation process made it possible to accommodate different “what-if” scenarios, e.g. the effect of changing staffs levels capacity on the availability of overall resources. The workflow of the DES includes different blocks (Appendix 4.A.2). The block “enter” represents the agent entering the process. The mobile team accommodates the agent after the queuing process in the block “mobileTeam”. After releasing the agent from the mobile team, those in the emergency were referred to the “respiteHouse” block. After benefitting from respite care, the agent is returning to the situation with “no exhaustion”.

This study combines DES and Markov modelling to evaluate informal carers’ pathway to benefit from mobile team and respite house support in the Lyon Metropolitan area. The following approach accommodates the system dynamic’s complexity, especially on the simulation process’s stochastic aspects. Appendix 4.A.2 presents the model combining Markov modelling and the DES approach.

#### 4.2.4 Cost data

The health system perspective was retained in the base case analysis. Regarding the time horizon of four months, neither costs nor efficiency data were discounted (Haute Autorité de Santé, 2020). All costs are expressed in € for 2018, all taxes included.

*Mobile team and respite house:* In the absence of available tariffs, a micro-costing top-down approach is implemented (Tan et al., 2009). Resources are provided by the establishment project of the respite house; costs and prices expressed in € for 2018 by the accounting department of the Cancer Centre Léon Bérard (CLB), who provided medical and nursing staff. All cost components and unit costs are reported in Appendix 4.A.3.

*Hospitalisations:* Production costs are valued from the National Cost Study (ENC 2017)<sup>7</sup>. The Diagnosis-Related Group (DRG) associated with the recipient’s hospital care due to the carers’ exhaustion is sought. The public/private weighting is taken into account. The costs were then adjusted in euros for 2018 using the *consumer price index - Base 2015 - All households - France - Health services*<sup>8</sup>. Details are provided in Appendix 4.A.4.

<sup>7</sup><https://www.scansante.fr/applications/enc-mco>

<sup>8</sup><https://www.insee.fr/fr/statistiques>

*Transportation:* A transportation cost is affected for each hospitalisation. A round trip's estimated cost is calculated from the 2016 social security review report on health transport expenditure in 2016 based on data for 2015 in France ([Inspection Générale des Affaires Sociales \(IGAS\), 2016](#))<sup>9</sup>. The costs were then adjusted in euros for 2018 using the *consumer price index - Base 2015 - All households - France - Health service*. Details are provided in Appendix 4.A.5.

*Fatigue management:* We distinguished between grades 1 and 2, then 3 and 4. The costs for grades 1 and 2 are based on publication [Mickisch et al. \(2010\)](#) and those for grades 3 and 4 on publications [Banz et al. \(2011\)](#); [Chouaid et al. \(2019\)](#). The costs were then adjusted to 2018 euros using the *consumer price index - Base 2015 - All households - France - Health services*. We assumed that a level 1 exhaustion score does not generate any fatigue management costs. We apply the cost of fatigue management grades 1, and 2 for exhaustion scores 2 and 3, respectively and the cost of fatigue management grades 3 and 4 for exhaustion scores 4 and 5, respectively. Details are provided in Appendix 4.A.6.

Finally, indirect costs taken into account in the scenario analysis were estimated based on publications [Gupta et al. \(2015\)](#) and [Chevreul et al. \(2013\)](#). Table 4.2.2 reports the cost items used in the model.

**Table 4.2.2 – Cost inputs**

Input	Costs (€ 2018)	Source
<b>Direct costs</b>		
Mobile team (per person)	687.90	Establishment project of the respite house and accounting department of the Cancer Centre Léon Bérard
Respite house (per day and per person)	817.39	
Hospitalisations (per person)	1,488.77	National Cost Study <sup>a</sup>
Transport (round trip per hospitalisation)	85.69	Ministry of budget <sup>b</sup>
Fatigue (per episode)		
Grade 1 or 2	39.78	<a href="#">Mickisch et al. (2010)</a>
Grade 3 or 4	596.96	<a href="#">Chouaid et al. (2019)</a>
<b>Indirect costs</b>		
	19.23	<a href="#">Gupta et al. (2015)</a>
Loss of productivity (per day)	132.56	<a href="#">Chevreul et al. (2013)</a>
	140.24	<a href="#">Chevreul et al. (2013)</a>

Notes: <sup>a</sup> ENC 2017 (*Études Nationale de Coûts*)

<sup>b</sup> *Inspection Générale des Affaires Sociales. Rapport - Revue des dépenses relatives aux transports sanitaires* <https://www.budget.gouv.fr/>

<sup>9</sup><https://www.budget.gouv.fr/>

Costs were calculated for each carer-patient dyad of the fictive cohort and then mean costs for RC and SC strategies.

#### 4.2.5 Quality of life and QALY calculation

The utility scores were drawn from the literature (Nafees et al., 2008; Swinburn et al., 2010), as recommended by the French National Authority for Health (HAS) (Haute Autorité de Santé, 2020). We assumed that the disutility varies according to the exhaustion score (from 1 (no exhaustion) to 5 (extreme exhaustion)). More precisely, for exhaustion scores 2 and 3, a utility decrement of -0.073 was applied (respectively -0.204 for an exhaustion score of 4 and 5). We also hypothesised that fatigue did not impact overall survival. The quality-adjusted life year was calculated for each carer of the fictive cohort using the following formula:

$$QALY_i = \sum_{d=1}^{120} \frac{Utility_d}{365} \quad (4.1)$$

Then, mean QALYs were calculated for RC and SC strategies. The incremental cost-effectiveness ratios (ICERs) were expressed in cost per QALY gained. Additional information is provided in Appendix 4.A.7 and Appendix 4.A.8.

#### 4.2.6 Sensitivity and scenario analysis

The uncertainty surrounding the ICERs was captured by a probabilistic analysis using non-parametric bootstrap methods as recommended by the French National Authority for Health (HAS) (Haute Autorité de Santé, 2020). 1,000 simulated bootstrap samples were generated by independent draws with replacement from pairs constituted by the mean cost difference and the mean effectiveness difference between both for RC and SC strategies. Ellipses represented confidence regions for these pairs at the 50% and 95% level.

For more robustness checks, uncertainties around ICER were taken into account by calculating the probability that belonged to each of the quadrants of the cost-effectiveness plane, in addition to confidence ellipses described (Briggs, 2000; Fenwick et al., 2004; Glick et al., 2014). Cost-effectiveness acceptability curves (CEAC) were plotted (Barton et al., 2008; Löthgren and Zethraeus, 2000). In the scenario analysis, we have moved

from the health system to the societal perspective. Loss of productivity was applied when exhaustion scores 4 and 5 occurred.

Markov and discrete-event simulation models were developed using *AnyLogic*® software (version 8.7.1.). All statistical analyses were performed using *STATA*® version 16.0 LP, College Station, Texas, USA.

## 4.3 Results

### 4.3.1 Base case Analysis

Table 4.3.1 reports the results of the base case analysis. The average costs were estimated at €16,684.72 for RC and €15,878.06 for SC; the incremental cost was €806.7 (95% CI: -1,543.67 – 3,156.99). The RC yielded more QALY (0.299) than the standard strategy (0.295), with an average effectiveness difference of 0.004 (95% CI 0.002 - 0.005). The ICER was €204,308.7 per QALYs gained.

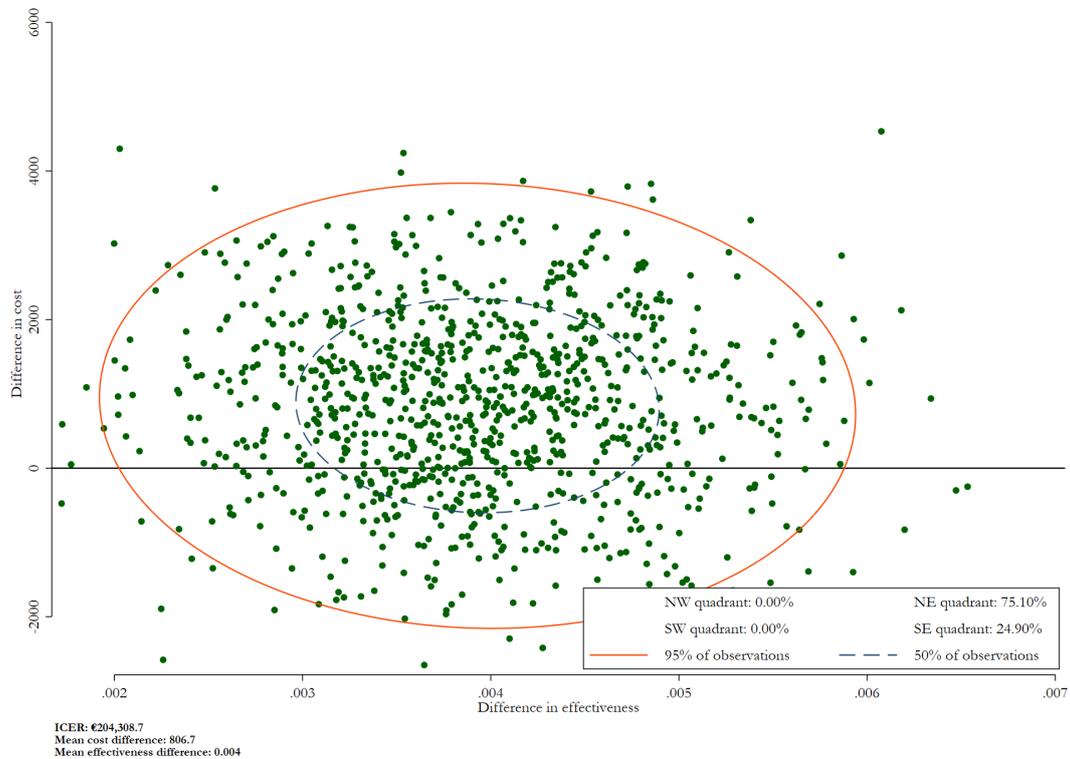
**Table 4.3.1** – Incremental cost-effectiveness ratio (ICER) of RC versus SC (Base case)

	SC (n = 420)		RC (n = 420)		Difference (RC – SC)		ICER
	Cost (€ 2018)	Effect (QALYs)	Cost (€ 2018)	Effect (QALYs)	Cost (€ 2018)	Effect (QALYs)	
Mean	15,878.06	0.295	16,684.72	0.299	806.7	0.004	€€204,308.7 per QALY gained
Standard deviation	17,681.13	0.014	17,736.93	0.01	1,222 <sup>a</sup>	0.001 <sup>b</sup>	
Correlation						0.083	

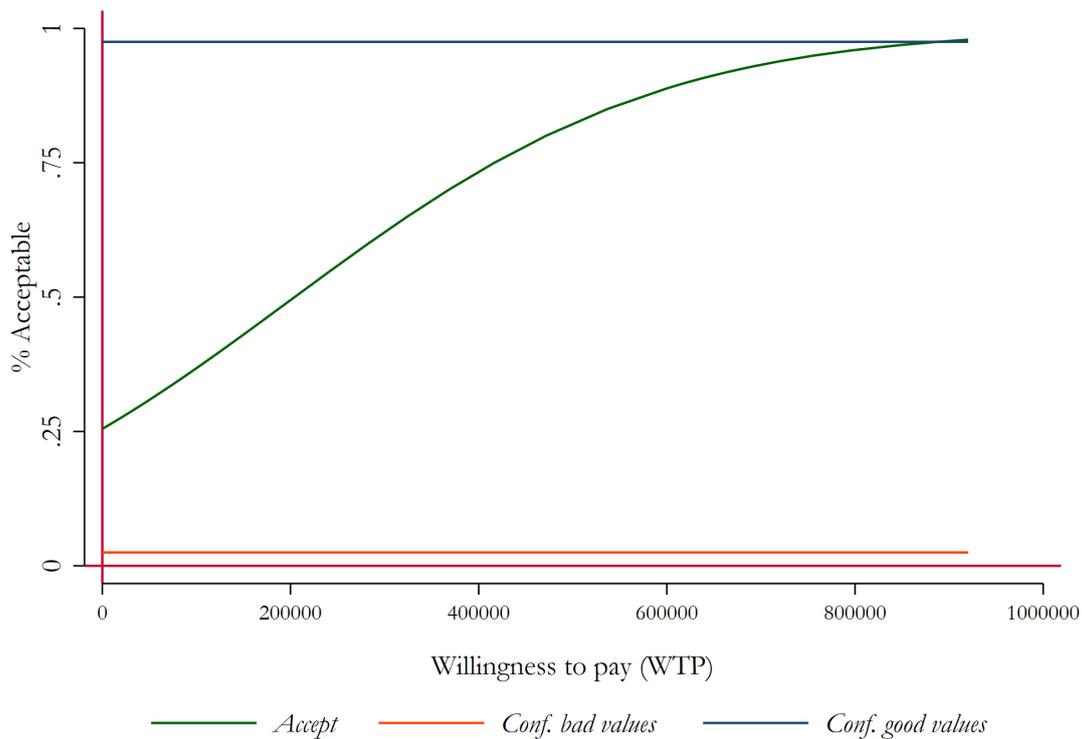
Notes. RC: respite care, SC: standard care; QALYs: Quality-adjusted life years; <sup>a</sup>SE: difference in cost; <sup>b</sup>SE: difference in effect

The probability of the ICER belonging to each quadrant of the cost-effectiveness plane is reported in Figure 4.3.1. The probability reached 75% for the northeast quadrant in which the RC is both more costly and more effective than SC and 25% for the southeast quadrants (RC less costly and more effective compared with SC).

**Figure 4.3.1** – Probabilistic analysis of the ICER: scatter of points and confidence ellipses (Base case)



As the ellipse falls within the northeast and the southeast quadrants, the cost-effectiveness acceptability curve (CEAC) drawn in Figure 4.3.2 does not cut the y-axis at 0 because 25% of the joint density involves cost-savings. Nevertheless, the probability that the RC strategy is cost effective compared with SC is under 50% regarding QALYs gained at the €100,000 threshold. Further details on the variation of WTP value and proportion (%) of acceptability are presented in 4.A.9.

**Figure 4.3.2** – Cost-effectiveness acceptability curves (Base case)

The expected value of perfect information (EVPI) is presented in Appendix 4.B.1. We calculated EVPI for values of willingness to pay that range from 0 to 1,000,000. In the base case, EVPI reaches a local maximum (486.45) for a WTP equal to the point estimate of the cost-effectiveness ratio (204,321).

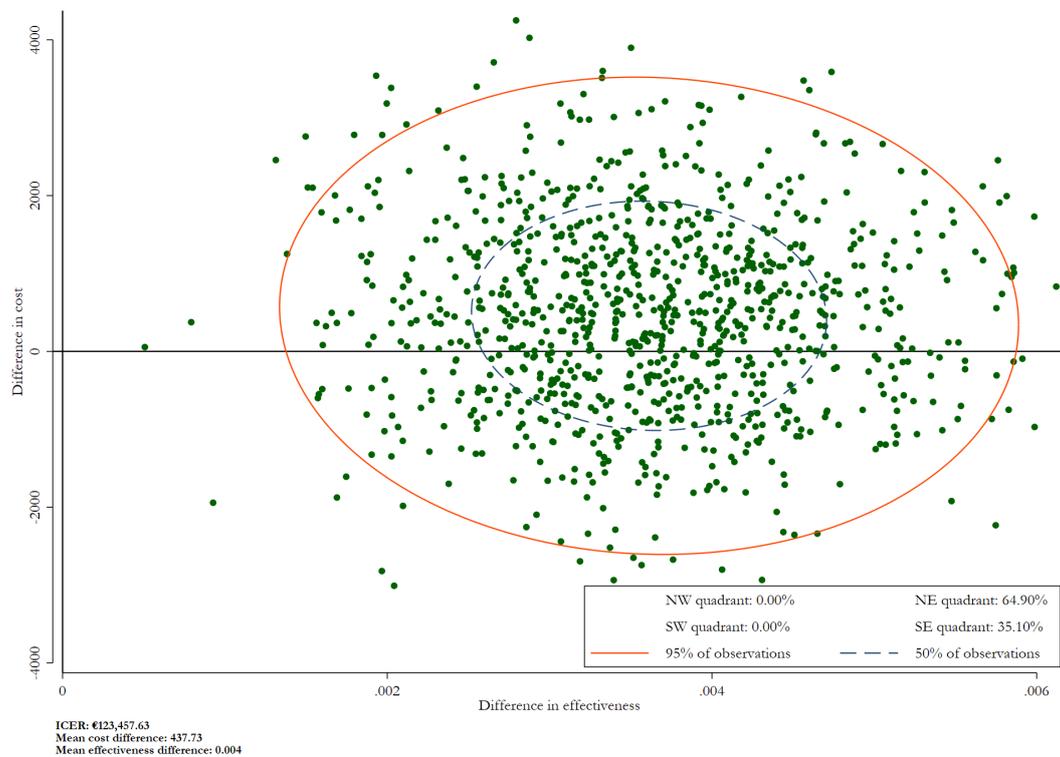
### 4.3.2 Scenario analysis

In the scenario analysis, the mean costs were €16,868.47 and €16,430.74 for RC and SC strategies, respectively. The incremental cost was €437.73 (95% CI: -1,937.55 – 2,813.02). The ICER was €123,457.63 per QALYs gained.

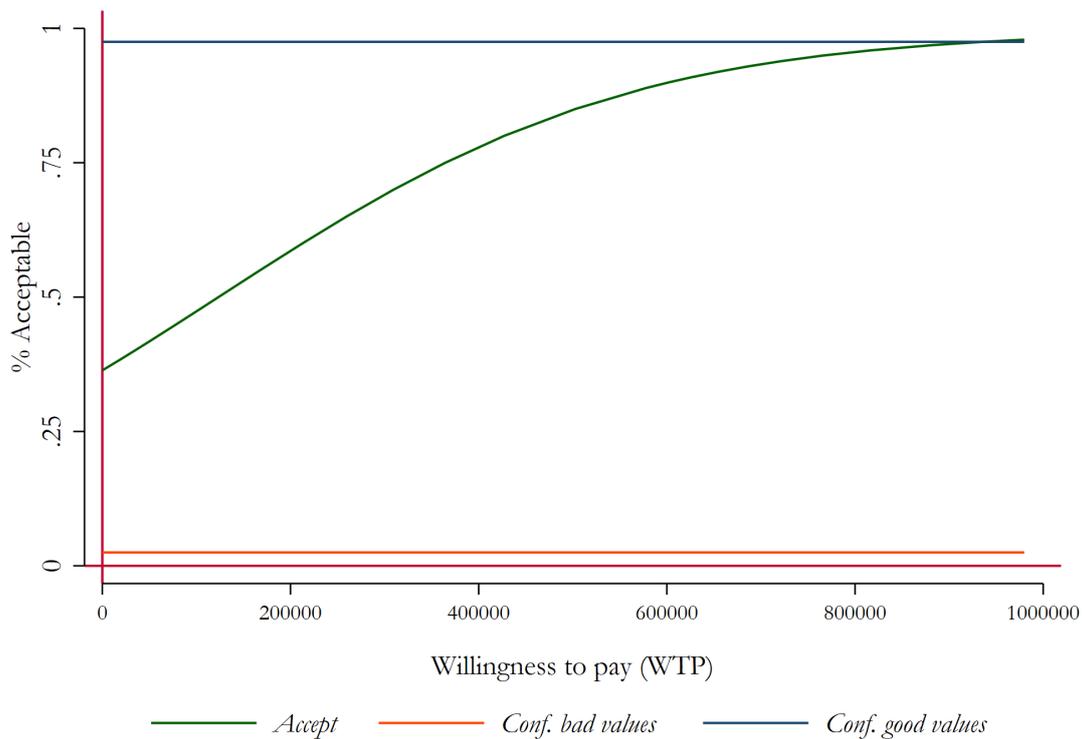
The probability of the ICER belonging to each quadrant of the cost-effectiveness plane is reported in Figure 4.3.3. The probability reached 65% for the northeast quadrant and 35% for the southeast quadrant.

As for the base case, the ellipse falls within the northeast and the southeast quadrants. Hence, as Figure 4.3.4 shows, the CEAC does not cut the y-axis at 0 (35%) of the joint density involves cost savings. Nevertheless, the probability that the RC strategy is

**Figure 4.3.3** – Probabilistic analysis of the ICER: scatter of points and confidence ellipses (Scenario)



cost-effective compared with SC is still under 50% regarding QALYs gained at the €100,000 threshold. Further details on the variation of WTP value and proportion (%) of acceptability are presented in Appendix 4.A.9.

**Figure 4.3.4** – Cost-effectiveness acceptability curves (Scenario)

The EVPI of the scenario analysis presented in Appendix 4.B.2 follows the same pattern as in the base case. EVPIs reach a local maximum (497.46) for a WTP equal to the point estimate of the cost-effectiveness ratio (123,443).

## 4.4 Discussion

### 4.4.1 Study findings and comparisons

In this study, we investigated the cost-effectiveness of the RC intervention compared to SC in a chronic disease framework. This project was initiated in a context marked by a reduction in hospitalisation duration and home care development. However, they appear to be strictly medically appropriate and do not systematically address family carers' physical and psychological exhaustion over the long term. Our findings indicate a small variation in costs and effectiveness for both the health system (€806.7 [95% CI: -1,543.67 — 3,156.99]) and societal (€437.73 [95% CI: -1,937.55 — 2,813.02]) perspective over a time horizon of 4 months. The findings show that the RC compared to SC does

not appear to be cost-effective for a wide scale. Therefore, revisiting the organisational parameters of the RC, such as increasing the length of stay above 30 days per carer-recipient dyad in the respite house and/or increasing the capacity of the mobile team, should be explored. Nevertheless, it appears important to note that the ICER decreases when moving from the health care payers to the societal perspective. Indirect costs are indeed not as high for the RC as for the SC.

Our findings seem in line with other economic evaluations of carer interventions assessed in the literature. In fact, there are mainly interventions such as psychosocial support (Charlesworth et al., 2008), a training programme for carers after stroke (Forster et al., 2013, 2015), family meetings intervention (Joling et al., 2013), which were also considered as not cost-effective by the authors. On the other hand, Martikainen et al. (2004) concluded that a cognitive-behavioural family intervention was cost-effective for patients with mild Alzheimer's disease (Martikainen et al., 2004). Interestingly, (Vandepitte et al., 2020) found that an in-home respite care programme associated with standard community-based care was also cost-effective compared to standard community-based care (Vandepitte et al., 2020). In fact, we may recommend combining the RC with other interventions or components. More extensive studies are needed in this fast-expanding field.

#### 4.4.2 The added value of a combined Markov and DES approach

Unlike most studies that accommodate either Markov modelling or DES in economic evaluation (Standfield et al., 2014), this study combines both methods. This combination of the DES and the Markov model is of particular interest for multiple reasons. The mobile team and the respite house organisation include different steps or events at each cycle. This original approach allows model queuing for unlimited or limited numbers of resources or agents; to capture individual agent, i.e. informal carers in this study,) histories at the end of the process; to accommodate complexity and uncertainty in the interaction with the Markov model; to simultaneously accommodate a large number of events among a population of agents with a time flexibly. This approach offers the possibility to accommodate, over time, the complexity and the dynamic of this innovative RC organisation.

Additionally, this combination allows individual tracking and the main outcome to be accrued during the simulation. It integrates a greater level of details and variables, and/or parameters. Also, this combination allows greater flexibility for additional variables used for sensitivity analysis. Furthermore, this model could also be used to better accommodate the flow of carers who are in a state of exhaustion.

Nevertheless, one can report that this combined approach, where the flexibility is increased, may lead to model over-specification and become more complex than necessary to obtain precise results. Finally, one potential pitfall of this approach is data requirements to fuel the process promptly (over time) to adjust to changes in other parameters in the model.

#### **4.4.3 Limitation, generalizability, and recommendations**

Our study used a time horizon of four months, which is relatively short, to capture the full potential benefit of respite care supportive intervention. Comparatively, other studies considered a relatively larger time frame to investigate the impact of informal carer interventions, mostly 12 months (Guets et al., 2020). Our combined model should be expanded to consider a longer time horizon and including a “death” state. It should also be based on more detailed and robust data, ideally a randomised clinical trial. Indeed, a recent literature review shows that most of the cost-utility analyses related to informal carer interventions are based on a randomised clinical trial (Guets et al., 2020). For further research, specific socio-demographical characteristics, such as health status, access to health care, the utilisation of eHealth services or information, should be taken into account.

When assessing the generalisability, the limitations are mainly due to the heterogeneity of the interventions for informal carers related to psychological, education support, respite care support, or training support. Also, economic methods and assumptions used, e.g. the perspective, the time frame, the scope of costs and outcomes. In this study, QALYs of recipients were not considered. Additional economic evaluations based on more robust data should undoubtedly increase the robustness of our findings.

## 4.5 Conclusion

Based on a combined approach using Markov modelling and DES, this study assessed the cost-effectiveness of RC compared to SC. The results indicated that RC did not provide the expected benefit for carers. A randomised control trial (RCT) should be performed in order to support our results.

# Appendix

## 4.A Supplemental information

### 4.A.1 Parameters of the simulation

Table 4.A.1 – Parameters of the simulation (Assumptions)

Parameters	Value	Uncertainty	Source
Markov chain			
Carer population	420	-	RC data
States (N)	5	-	RC data
Max. period of time without respite care	5 days	-	RC data
Respite programme			
Respite house – Number of stays (30 days/year)	9 days for 4 months	-	RC data

Notes. RC: Respite care

### 4.A.2 AnyLogic University software screenshot

Figure 4.A.1 – Markov model

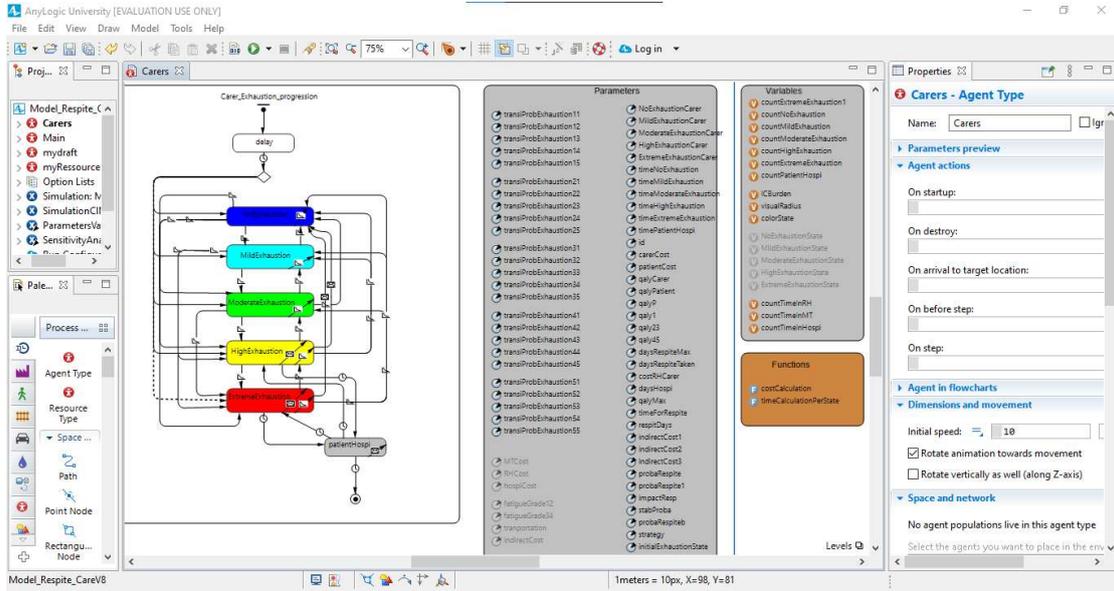
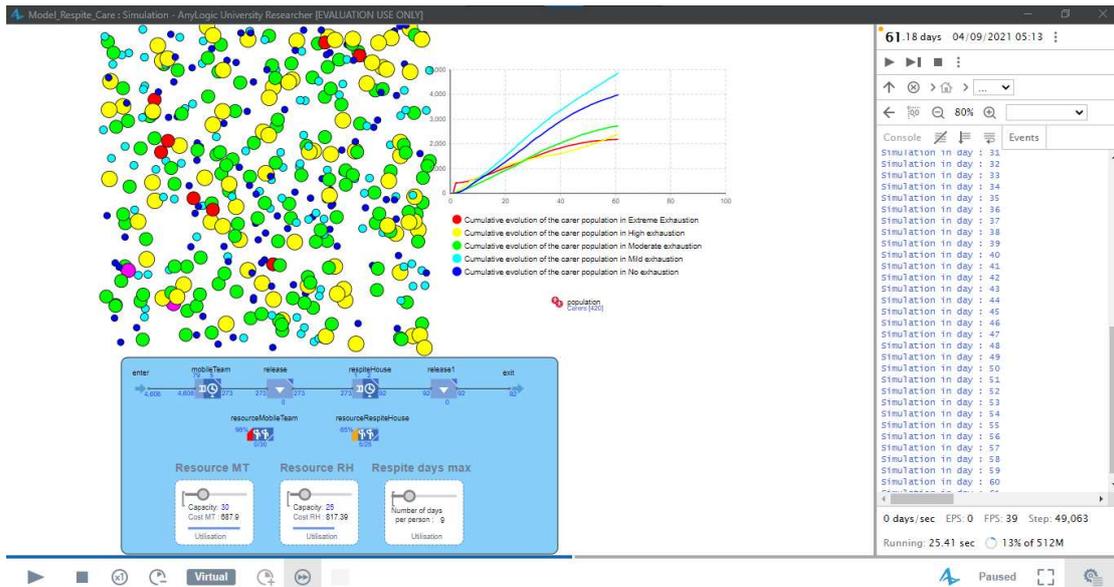


Figure 4.A.2 – Combination of the Markov model with the discrete-event simulation



## 4.A.3 Detailed costs of the RC strategy

Table 4.A.2 – Mobile team

Cost items	FTE	Costs	Costs*FTE
Staff			
Specialist physician	0.3	145,181.03	43,554.31
Nurse	1	54,600.56	54,600.56
Psychologist	0.75	57,382.61	43,036.96
Social worker	0.5	54,600.56	27,300.28
General practitioner	0.25	145,181.03	36,295.26
Secretary	0.25	41,496.42	10,374.11
Documentalist	1	29,000	29,000
Total staff costs	4.05		244,161.46
Others			
Depreciation of buildings/Rent			15,000
Vehicle			16,000
Total costs (overhead costs excluded)			275,161.46
Overhead costs (20%)			55,032.29
Total cost (overall costs included)			330,193.76
Number of situations handled			480
<b>Average total cost</b>			<b>687.90</b>

Notes. Full-time equivalent (FTE)

Table 4.A.3 – Respite house

Cost items	FTE	Costs	Costs*FTE
Staff			
Specialist physician	0.3	145,181.03	43,554.31
Nurse	7	54,600.56	382,203.89
Psychologist	0.25	57,382.61	14,345.65
Social worker	0.5	54,600.56	27,300.28
General practitioner	0.25	145,181.03	36,295.26
Secretary	0.25	41,496.42	10,374.11
Territory Manager	0.1	148,000	14,800
Deputy Director	1	148,000	148,000
Executive Assistant	0.5	98,000	49,000
Formal care	11.5	41,496.42	477,208.86
Corporate executive	1	68,250.69	68,250.69
Physiotherapist	0.5	54,600.56	27,300.28
Worker	0.25	36,582.37	9,145.59
Volunteer manager	0.5	54,600.56	27,300.28
Total staff costs	23.9		1,335,079.19
Others			
Depreciation of buildings/Rent			156,666.67
Total costs (overhead costs excluded)			1,491,745.86
Overhead costs (20%)			298,349.17
Total cost (overall costs included)			1,790,095.03
<b>Average total cost</b>			<b>817.39</b>

*The respite house per year treats almost 2,190 (6 \* 365) carers and/or recipients.*

## 4.A.4 Cost estimation of care recipient hospitalisation

Table 4.A.4 – Cost estimation of care recipient hospitalisation (in € 2017)

Status	HHSG	MDC	MDC label	Number of stays	DRG Average costs	ALS	DRG Average costs	Number of days
						(per day)	(per day)	
Public (EX DGF)	7986	23M16Z	Convalescences and other social reasons	1,914	3,830.22	8.6	445.37	16,460.4
Private (EX OQN)	7986	23M16Z	Convalescences and other social reasons	0	0	0	0	0
Public (EX DGF)	7996	23M16T	Convalescences and other social reasons, very short stay	1,501	590.42	0.7	843.46	1,050.7
Private (EX OQN)	7996	23M16T	Convalescences and other social reasons, very short stay	0	0	0	0	0
Public (EX DGF)	7989	23M20T	Other symptoms and reasons for seeking care for MDC 23, very short stay	141,760	761.66	0.3	2,538.86	42,528
Private (EX OQN)	7989	23M20T	Other symptoms and reasons for seeking care for MDC 23, very short stay	20,197	625.47	0.4	1,563.68	8,078.8
Public (EX DGF)	7990	23M20Z	Other symptoms and reasons for seeking care for MDC 23	84,471	2,502.07	4.7	532.36	397,013.7
Private (EX OQN)	7990	23M20Z	Other symptoms and reasons for seeking care for MDC 23	30,842	2,326.94	3.8	612.35	117,199.6

Note: ALS: Average length of stay or *Durée moyenne de séjour (DMS)*; Major diagnostic category (MDC) or *catégorie majeure de diagnostic - CDM*;

Homogeneous hospital stay group (HHSG) or *Groupe homogène de séjours (GHS)*. Costs in € 2018 were 1,488.77 (after updating:  $1,467.63 \times 1.0144$ )

#### 4.A.5 Costs of transportation

**Table 4.A.5 – Costs of transportation in € 2015 and 2018**

	Number of trips in 2015	Reimbursement amount	Average costs per trip
Ambulance	14,547,132	1,321,738,525	90.9
Light medical vehicles	20,860,009	684,841,667	32.8
Taxis	27,919,779	1,366,326,774	48.9
Total trip (without ambulance)	48,779,788	2,051,168,441	81.7
Average cost per trip (round trip)		42.02 (84.03 in € 2015)	
Average cost per round trip, after updating (84.03 × 1,0198)		85.69 in € 2018	

Source: Author based on CNAM (Statutory health insurance scheme).

#### 4.A.6 Costs of fatigue

**Table 4.A.6 – Costs of fatigue in euro per level of exhaustion**

Level of exhaustion	Fatigue	Value	Discounted value for 2018	Source
1	-	-	-	-
2	Grade 1	36	39.20	<a href="#">Mickisch et al. (2010)</a>
3	Grade 2	36	39.20	<a href="#">Mickisch et al. (2010)</a>
4	Grade 3	586	595.55	<a href="#">Chouaid et al. (2019)</a>
5	Grade 4	586	595.55	<a href="#">Chouaid et al. (2019)</a>

#### 4.A.7 Utility scores per level of exhaustion

Table 4.A.7 – Utility scores per level of exhaustion

Level of exhaustion	Disutility	Utility	Sources
1	1	1	
2	0.073	0.927	<a href="#">Nafees et al. (2008)</a>
3	0.073	0.927	<a href="#">Nafees et al. (2008)</a>
4	0.204	0.796	<a href="#">Swinburn et al. (2010)</a>
5	0.204	0.796	<a href="#">Swinburn et al. (2010)</a>

#### 4.A.8 Utility scores per level of exhaustion over time

Table 4.A.8 – Utility scores per level of exhaustion over time (Months)

Level of exhaustion	Utility (per year)	M1	M2	M3	M4
1	1	0.083	0.167	0.25	0.33
2	0.927	0.07725	0.1545	0.23175	0.309
3	0.927	0.07725	0.1545	0.23175	0.309
4	0.796	0.066	0.133	0.199	0.265
5	0.796	0.066	0.133	0.199	0.265

#### 4.A.9 Variation of WTP

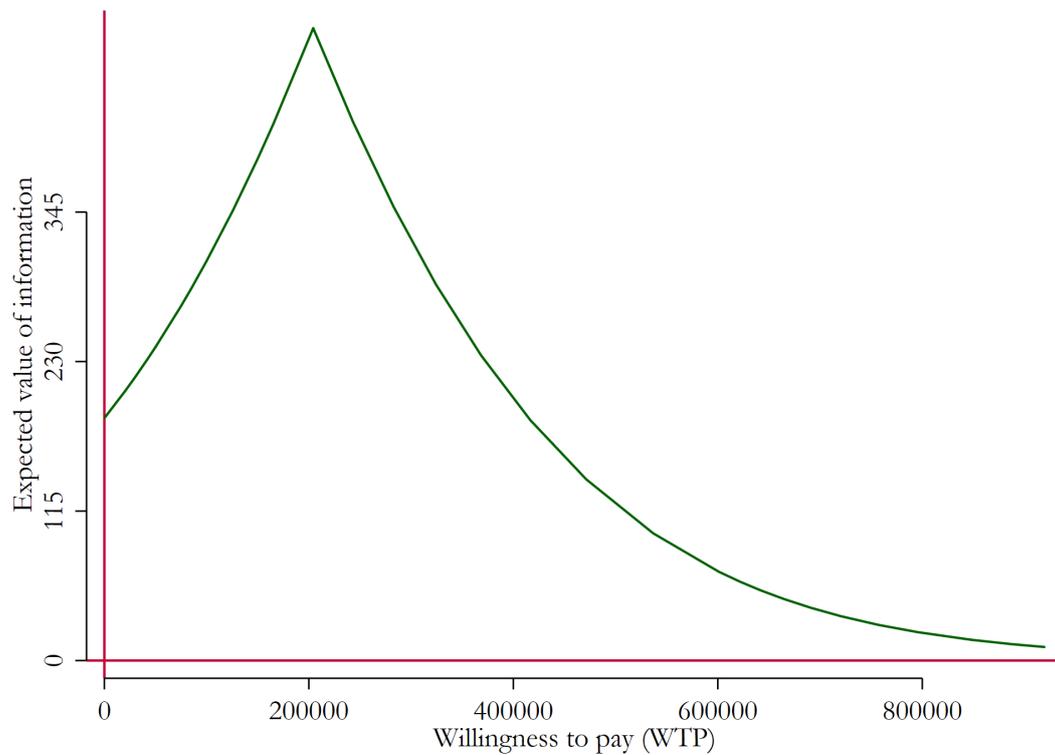
Table 4.A.9 – Variation of WTP value and proportion (%) of acceptability

WTP( $\lambda$ )	Base case		Scenario	
	% Accept	P-value	% Accept	P-value
$\lambda = 30,000$	0.28645	0.5729	0.39564	0.7913
$\lambda = 50,000$	0.30871	0.6174	0.41751	0.8350
$\lambda = 100,000$	0.36766	0.7353	0.54236	0.47345

### 4.B Expected value of perfect information (EVPI) Figures

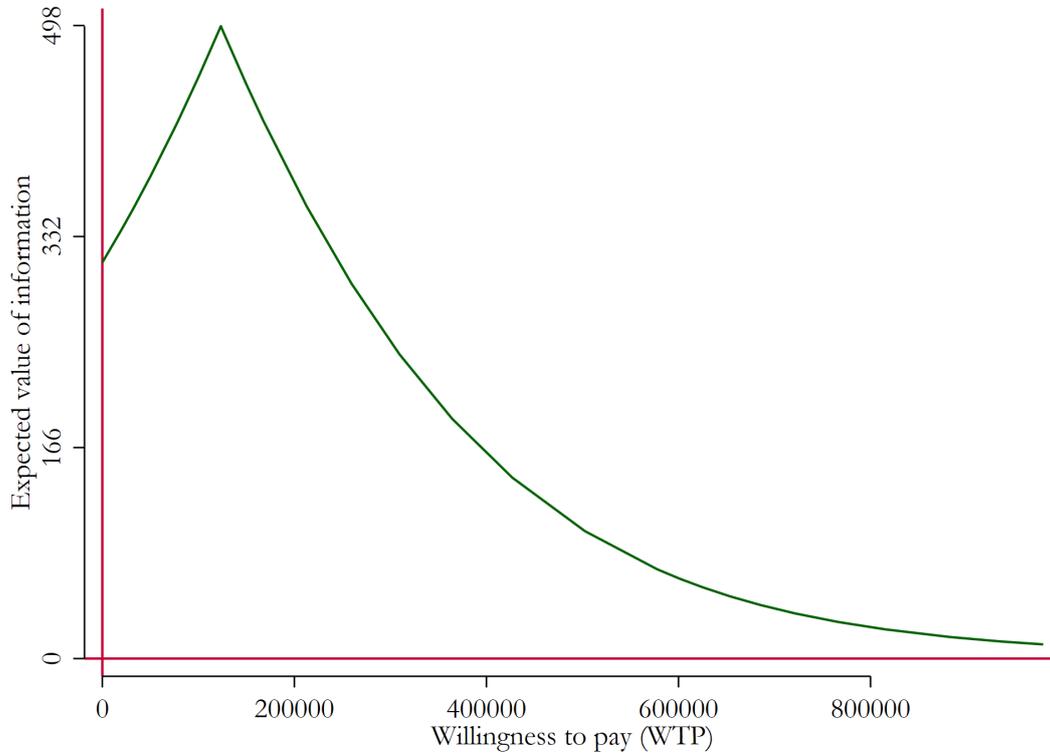
#### 4.B.1 Expected value of perfect information (EVPI) (Base case)

Figure 4.B.1 – Expected value of perfect information (EVPI) (Base case)



### 4.B.2 Expected value of perfect information (EVPI) (Scenario)

Figure 4.B.2 – Expected value of perfect information (EVPI) (Scenario)



### 4.C *Aidants de la METropole de Lyon (AIME 2)* - Online observatory of the situation, needs and expectations of informal carers in the Lyon metropolitan area

## 1. Type d'étude

Il s'agit d'une expérimentation en sciences humaines et sociales dans le domaine de la santé, observationnelle, prospective, d'une durée de 5 mois consécutifs répartis en 5 périodes de 1 mois, avec recueil de données qualitatives et quantitatives, en ligne, menée auprès de 30 aidants informels de la métropole de Lyon.

## 2. Calendrier de l'étude

L'étude débutera en juin 2017, durera 5 mois et se terminera en novembre 2017.

# I. Objectifs

L'objectif de cette étude est de contribuer, avec l'aide de 30 aidants informels de la métropole de Lyon, à la mise en œuvre des objectifs de recherche de la Fondation France Répit tels que définis ci-dessus.

# II. Matériels et Méthodes

## 1. Site d'étude

L'étude se déroulera en ligne et impliquera 30 aidants de la métropole de Lyon.

## 2. Populations

Tous les participants présenteront les caractéristiques suivantes :

- Aidant informel principal d'une (ou plusieurs) personne(s) atteinte(s) de maladie chronique et/ou handicap et/ou perte d'autonomie
- Adulte
- Consacrant au moins 5 heures/par semaine de son temps à l'accompagnement de son(ses) proche(s) aidé(s)
- Domicilié au sein de la métropole de Lyon
- Capable de lire, écrire et comprendre le français
- Ayant consenti à participer à la présente étude
- Disponible pour s'investir pendant la durée de l'étude et pour se connecter à la plateforme en ligne à raison de 2h30 par mois pendant 5 mois (du 6 juin 2017 au 5 novembre 2017).

## 3. Echantillonnage

La population sera échantillonnée selon la technique des quotas, selon les critères suivants :

CRITERES	QUOTAS
<b>SEXE DE L'AIDANT</b>	60 % (n=18) d'aidants femmes 40 % (n=12) d'aidants hommes
<b>AGE DE L'AIDANT</b>	20 % (n=6) d'aidants [18-35 ans[ 20 % (n=6) d'aidants [35-45 ans[ 20 % (n=6) d'aidants [45-55 ans[ 20 % (n=6) d'aidants [55-65 ans[ 20 % (n=6) d'aidants ≥ 65 ans
<b>LIEU D'HABITATION PRINCIPAL DE L'AIDANT</b>	Mixer entre Lyon intra-muros et périphérie au sein de la métropole de Lyon
<b>SITUATION DU PROCHE AIDE</b>	33 % (n=10) de proches aidés atteints d'une maladie chronique 33 % (n=10) de proches aidés atteints d'un handicap 33 % (n=10) de proches aidés atteints d'une autre dépendance (perte d'autonomie, dépendance liée à l'âge, etc.)
<b>AGE DU PROCHE AIDE</b>	33 % (n=10) de proches aidés [0-18 ans[ 33 % (n=10) de proches aidés [18-60 ans[

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 33 % (n=10) de proches aidés ≥ 60 ans
 

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## 4. Déroulement de l'étude

### a. Généralités

Chaque participant se connectera au minimum 2h30/mois à la plateforme en ligne par l'intermédiaire d'un ordinateur, d'une tablette ou d'un smartphone.

### b. Mois 1 - Caractérisation de l'échantillon – Thème n°1 : la reconnaissance de l'aidant

N°	Questions	Dates	Activités
Q1	Avez-vous déjà entendu parler des « aidants » ?	mardi 6 juin	Radio buttons : modalités "Oui" "Non"
Q1.1	Si oui, où et quand ? Dans quelles circonstances ?		Champ de texte
Q2	Vous considérez-vous comme un aidant ?		Radio buttons : modalités "Oui" "Non"
Q2.1	Pour quelles raisons ?		Champ de texte
Q3	Quels mots associez-vous au terme aidant ?	mardi 6 juin	Sociogramme avec "Aidant" au centre et champs de texte
Q4	Que signifie pour vous le mot « aidant » ? Comment définissez-vous le terme aidant ?		Forum. Définition à établir en premier lieu de façon individuelle puis collective. Consignes : illustrer avec photos et vidéos
Q5	Qu'est ce qui fait qu'un aidant se reconnait comme tel ? Quels sont les facteurs favorisant l'auto-reconnaissance de l'aidant ?	lundi 12 juin	Champ de texte
Q6	Où et quand vous êtes-vous senti(e) reconnu(e) en tant qu'aidant(e) ?		Champ de texte
	Disponibilité pour le chat de synthèse de la période 1		Question du jour
Q7	Passation du questionnaire volets 1 à 3	vendredi 16 juin	Questionnaire quanti
Q8	Etes-vous devenu(e) aidant(e) par choix ou par obligation ?	lundi 19 juin	Curseur
Q9	Quelles sont les raisons qui vous ont conduit à devenir aidant ?		Champ de texte
Q10	Racontez-nous votre parcours "aidant".		Carte d'expérience
Q11	Comment évaluez-vous l'impact de l'aide que vous apportez à votre proche sur ... : votre moral ? votre physique ? votre vie de couple ? votre vie de famille ? votre vie sexuelle ? votre sentiment d'être libre de faire ce que vous voulez ? votre sommeil ? votre vie professionnelle ? la pratique d'une activité physique ou sportive ? vos loisirs ? vos relations amicales ?		Matrice avec commentaires sur les items : - Abscisse : « extrêmement négatif » à « extrêmement positif » - Ordonnée : « aucun impact » (= origine du repère) à « impact extrêmement fort »
Q12	Au cours du mois qui vient de s'écouler, vous êtes-vous senti(e) épuisé(e) ?	vendredi 23 juin	Echelle de Likert : "Pas du tout", "Un peu", "Modérément",

			"Beaucoup", "Extrêmement"
Q13	Passation du questionnaire volet 4 (qualité de vie et état émotionnel de l'aidant)		Questionnaire quanti
Q14	Au cours du mois qui vient de s'écouler, avez-vous ressenti le besoin de prendre un temps de repos dans votre relation d'aide à votre proche ?		Echelle de Likert : "Pas du tout", "Un peu", "Modérément", "Beaucoup", "Extrêmement"
Q15	Synthèse du mois	Vendredi 23 juin Lundi 26 juin Mardi 27 juin	Chat de 30 minutes

### c. Mois 2 – Thème n°2 : l'épuisement de l'aidant

N°	Questions	Dates	Activités
	Disponibilité pour le chat de synthèse de la période 2		Question du jour
	Les personnes qui aident au quotidien un proche malade, handicapé ou dépendant évoquent parfois des périodes plus difficiles au cours desquelles elles se sentent épuisées.		
Q1	Avez-vous déjà traversé ce genre de période ?		Radio buttons : modalités "Oui" "Non"
	<b>-&gt; Si oui :</b>		
Q2.1	Quelles en étaient les circonstances ? Pouvez-vous décrire votre situation à cette(ces) période(s) ?		Texte libre
Q2.2	Quand vous repensez à cette(ces) période(s), quels mots vous viennent spontanément à l'esprit ?		Liste de mots
Q2.2.1	Pouvez-vous représenter cette période ?		Moodboard
Q2.3	Si vous en avez eu, pouvez-vous décrire les manifestations physiques qui sont apparues ou se sont intensifiées au cours de cette(ces) période(s) comme par exemple des problèmes pour dormir, des douleurs, etc. ?		Texte libre ou Liste de mots
Q2.3.1	Pouvez-vous positionner ces manifestations physiques à l'endroit qui correspond le mieux à votre ressenti au moment où vous les avez vécues ?		Matrice avec commentaires sur les items : - Abscisse : « très délétère pour moi » à « très bénéfique pour moi » - Ordonnée : « aucune manifestation » (=origine du repère) à « très forte manifestation »
Q2.3.2	Pouvez-vous représenter ces manifestations physiques sur la silhouette ?		Silhouette

Q2.4	Et au niveau de votre moral, comment décririez-vous votre état à ce moment-là ?		Texte libre ou Liste de mots
Q2.4.1	Pouvez-vous positionner ces manifestations psychologiques à l'endroit qui correspond le mieux à votre ressenti au moment où vous les avez vécues ?		Matrice avec commentaires sur les items : - Abscisse : « très délétère pour moi » à « très bénéfique pour moi » - Ordonnée : « aucune manifestation » (=origine du repère) à « très forte manifestation »
Q2.4.2	Pouvez-vous représenter ces manifestations psychologiques sur la silhouette ?		Silhouette
Q2.5	Pensez-vous que certaines circonstances ont pu être à l'origine ou déclencher cet état d'épuisement ?		Radio buttons : modalités "Oui" "Non"
Q2.5.1	Si oui, pouvez-vous décrire ces circonstances ?		Texte libre ou Liste de mots
Q2.5.2	Pouvez-vous positionner ces circonstances selon l'impact qu'elles ont eu sur la survenue de votre épuisement ?		Sociogramme avec épuisement au centre
Q2.6	A ce jour, êtes-vous parvenu(e) à sortir de cet état ?		Radio buttons : modalités "Oui" "Non"
Q2.6.1	Si oui, selon vous, qu'est-ce qui vous a permis de sortir de cet état ?		Texte libre ou Liste de mots
Q2.6.2	Avez-vous mis en place des techniques ou des règles de vie pour éviter de repasser par ce genre de période ?		Radio buttons : modalités "Oui" "Non"
Q2.6.2.1	Si oui, quelles techniques ou règles de vie avez-vous mis en place ?		Texte libre ou Liste de mots
	De plus en plus, l'expression « épuisement de l'aidant » est utilisée par les professionnels pour nommer ce genre de période.		
Q2.7	Cette expression vous semble-t-elle appropriée ?		Radio buttons : modalités "Oui" "Non"
Q2.7.1	Si non, comment qualifieriez-vous cet état ?		Texte libre ou Liste de mots
Q2.8	Pouvez-vous nous donner dans vos propres mots une définition de cet état d'« épuisement de l'aidant » ?		Forum. Définition à établir en premier lieu de façon individuelle puis collective.
	<b>-&gt; Si non :</b>		
Q3.1	Pouvez-vous décrire ce qui, dans votre vie, vous aide à ne pas vivre ce genre de période ?		Texte libre ou Liste de mots
Q3.2	Au contraire, selon-vous, quelles circonstances pourraient vous faire basculer dans un état d'épuisement tel qu'il vous serait difficile de continuer à aider votre proche ?		Texte libre ou Liste de mots
	<b>Questions à tous les participants</b>		
Q4	Selon vous, à quel(s) signe(s) peut-on identifier qu'un(e) aidant(e) est épuisé(e) ?		Texte libre ou Liste de mots
Q5	Au cours du mois qui vient de s'écouler, vous êtes-vous senti(e) épuisé(e) ?		Echelle de Likert : "Pas du tout", "Un peu",

			"Modérément", "Beaucoup", "Extrêmement"
Q6	Passation du questionnaire volet 4		Questionnaire quanti NB : à voir si on le fait compléter uniquement à M1, M3 et M5
Q7	Au cours du mois qui vient de s'écouler, avez-vous ressenti le besoin de prendre un temps de repos dans votre relation d'aide à votre proche ?		Echelle de Likert : "Pas du tout", "Un peu", "Modérément", "Beaucoup", "Extrêmement"
Q8	Si variation de l'une des évaluations à Q5 et/ou Q7 entre les périodes 1 et 2, échanges individuels avec le participant pour tenter d'expliquer les facteurs ayant conduit à cette variation		Forum privé
Q9	Synthèse du mois		Chat de 30 minutes

#### d. Mois 3 – Thème n°3 : les manques / les besoins de l'aidant

Travail sur les dimensions de besoin suivantes :

- \* Santé et soins de l'aidant et de l'aidé
- \* Soutien psychologique et émotionnel
- \* Information - Formation
- \* Vie sociale – Travail - Finances
- \* Futur – Deuil – Spiritualité
- \* Soutien instrumental – Répit
- \* Satisfaction - Reconnaissance

N°	Questions	Dates	Activités
	Disponibilité pour le chat de synthèse de la période 3		
Q1	Avez-vous déjà éprouvé ce manque / ce besoin au cours de votre expérience d'aide ?		
Q2	Actuellement, éprouvez-vous ce manque / ce besoin ?		
Q3	Si oui à l'une au moins des 2 questions précédentes : Dans quelle(s) situation(s) ce manque / ce besoin s'est-il fait ressentir ?		
Q4	Si oui à l'une au moins des 2 questions précédentes : Avez-vous trouvé une/des solution(s) pour assouvir ce manque / ce besoin ?		
Q4.1	Si oui, quelle(s) solution(s) avez-vous mis en œuvre ou à quel(s) service(s) avez-vous eu recours pour assouvir ce besoin ?		
Q4.2	Est-ce que cette/ces stratégie(s) a/ont été efficace(s) ?		
Q4.3	Si non, quelle(s) solution(s) idéale(s) aurait(ent) pu être mise(s) ou à quel(s) service(s) aurait pu être mobilisé(s) pour assouvir ce besoin ?		
Q5	Au cours du mois qui vient de s'écouler, vous êtes-vous senti(e) épuisé(e) ?		Modalités : "Pas du tout" / "Un peu" / "Modérément" / "Beaucoup" / "Extrêmement"

Q6	Passation du questionnaire volet 4		Questionnaire quanti
Q7	Au cours du mois qui vient de s'écouler, avez-vous ressenti le besoin de prendre un temps de repos dans votre relation d'aide à votre proche ?		Echelle de Likert : "Pas du tout", "Un peu", "Modérément", "Beaucoup", "Extrêmement"
Q8	Si variation de l'une des évaluations à Q5 et/ou Q7 entre les périodes 2 et 3, échanges individuels avec le participant pour tenter d'expliquer les facteurs ayant conduit à cette variation		
Q9	Synthèse du mois		

#### e. Mois 4 – Thème n°4 : le répit

N°	Questions	Dates	Activités
	Disponibilité pour le chat de synthèse de la période 4		Question du jour
Q1	Avez-vous déjà entendu parler du « répit » ?		
Q1.1	Si oui, quand et où en avez-vous entendu parler ?		
Q2	Que signifie pour vous le mot répit ? Comment définissez-vous le répit		
Q3	Quels mots associez-vous au terme répit ?		
Q4	A qui s'adresse le répit ?		
Q5	Quelles solutions de répit connaissez-vous ?		
Q6	Eprouvez-vous ou avez-vous déjà éprouvé un besoin de répit ?		
Q7	Avez-vous déjà bénéficié d'une solution de répit ?		
Q8	Comment peut-on offrir du répit aux aidants ?		
Q9	Quelle serait pour vous la meilleure solution de répit ?		
Q10	Quel(s) bénéfice(s) la mise à disposition de solutions de répit pourrait-elle apporter aux aidants ?		
Q11	Quel(s) bénéfice(s) la mise à disposition de solutions de répit pourrait-elle apporter à la société ?		
Q12	Au cours du mois qui vient de s'écouler, vous êtes-vous senti(e) épuisé(e)?		Modalités : "Pas du tout" / "Un peu" / "Modérément" / "Beaucoup" / "Extrêmement"
Q13	Passation du questionnaire volet 4		Questionnaire quanti NB : à voir si on le fait compléter uniquement à M1, M3 et M5
Q14	Au cours du mois qui vient de s'écouler, avez-vous ressenti le besoin de prendre un temps de repos dans votre relation d'aide à votre proche ?		Echelle de Likert : "Pas du tout", "Un peu", "Modérément", "Beaucoup", "Extrêmement"
Q15	Si variation de l'une des évaluations à Q12 et/ou Q14 entre les périodes 3 et 4, échanges individuels avec le participant pour tenter d'expliquer les facteurs ayant conduit à cette variation		
Q16	Synthèse du mois		

### f. Mois 5 – Thème n°5 : La Maison de répit de Lyon de Lyon

N°	Questions	Dates	Activités
	Disponibilité pour le chat de synthèse de la période 5 et de l'observatoire		Question du jour
	<b>Présentation détaillée de l'Equipe Mobile de répit</b>		
Q1	A quel(s) manque(s) / besoin(s) l'Equipe mobile de répit répond-elle ?		
Q2	Quelles sont, selon vous, les attentes des aidants vis-à-vis de l'Equipe mobile de répit ?		
Q3	Quelles sont, selon vous, les attentes des proches aidés vis-à-vis de l'Equipe mobile de répit ?		
Q4	Quelles sont, selon vous, les exigences des aidants vis-à-vis de l'Equipe mobile de répit ?		
Q5	Quelles sont, selon vous, les exigences des proches aidés vis-à-vis l'Equipe mobile de répit ?		
Q6	Sur quels critères doit-on évaluer l'efficacité de l'Equipe mobile de répit ?		
Q7	Quels sont les objectifs à atteindre ?		
Q8	Souhaitez-vous avoir recours à l'Equipe mobile de répit ?		
Q9	Qu'est-ce qui pourrait freiner le recours des aidants-aidés à l'Equipe mobile de répit ?		
Q10	Qu'est-ce qui pourrait favoriser le recours des aidants-aidés à l'Equipe mobile de répit ?		
Q11	Si oui, combien seriez-vous prêt à payer pour avoir recours à l'Equipe mobile de répit ?		
Q12	Quels bénéfices la mise à disposition de l'Equipe mobile de répit va-t-elle apporter aux aidants ?		
Q13	En quoi cette nouvelle offre de service va modifier le quotidien des aidants ?		
Q14	Quels bénéfices la mise à disposition de l'Equipe mobile de répit va-t-elle apporter à la société ?		
	<b>Présentation détaillée de la Maison de répit de Lyon</b>		
Q15	A quel(s) manque(s) / besoin(s) la Maison de répit de Lyon répond-elle ?		
Q16	Quelles sont, selon vous, les attentes des aidants vis-à-vis de la Maison de répit de Lyon ?		
Q17	Quelles sont, selon vous, les attentes des proches aidés vis-à-vis de la Maison de répit de Lyon ?		
Q18	Quelles sont, selon vous, les exigences des aidants vis-à-vis de la Maison de répit de Lyon ?		
Q19	Quelles sont, selon vous, les exigences des proches aidés vis-à-vis de la Maison de répit de Lyon ?		
Q20	Sur quels critères doit-on évaluer l'efficacité de la Maison de répit de Lyon ?		
Q21	Quels sont les objectifs à atteindre ?		

Q22	Souhaitez-vous avoir recours à la Maison de répit de Lyon ?		
Q23	Qu'est-ce qui pourrait freiner le recours des aidants-aidés à la Maison de répit de Lyon ?		
Q24	Qu'est-ce qui pourrait favoriser le recours des aidants-aidés à la Maison de répit de Lyon ?		
Q25	Si oui, combien seriez-vous prêt à payer pour avoir recours à la Maison de répit de Lyon : - Pour un séjour de votre proche aidé ? - Pour séjourner avec votre proche aidé au sein de la Maison de répit ?		
Q26	Quels sont à vos yeux les éléments essentiels à retrouver au sein de la Maison de répit de Lyon ?		
Q27	Quels services / activités à destination des aidants la Maison de répit de Lyon pourrait-elle proposer ?		
Q28	Quels services / activités à destination des proches aidés la Maison de répit de Lyon pourrait-elle proposer ?		
Q29	Quels bénéfices la mise à disposition de la Maison de répit va-t-elle apporter aux aidants ?		
Q30	En quoi cette nouvelle offre de service va modifier le quotidien des aidants ?		
Q31	Quels bénéfices la mise à disposition de la Maison de répit va-t-elle apporter à la société ?		
Q32	Au cours du mois qui vient de s'écouler, vous êtes-vous senti(e) épuisé(e)?		Modalités : "Pas du tout" / "Un peu" / "Modérément" / "Beaucoup" / "Extrêmement"
Q33	Passation du questionnaire volet 4		Questionnaire quanti
Q34	Au cours du mois qui vient de s'écouler, avez-vous ressenti le besoin de prendre un temps de repos dans votre relation d'aide à votre proche ?		Echelle de Likert : "Pas du tout", "Un peu", "Modérément", "Beaucoup", "Extrêmement"
Q35	Si variation de l'une des évaluations à Q32 et/ou Q34 entre les périodes 4 et 5, échanges individuels avec le participant pour tenter d'expliquer les facteurs ayant conduit à cette variation		
Q36	Synthèse du mois		
Q37	Synthèse de l'observatoire		

#### **4.D Quality of reporting Consolidated Health Economic Evaluation Reporting Standards (CHEERS) - CHEERS Checklist/ Statement**

The CHEERS Checklist can be found via *Value in Health* or the ISPOR Health Economic Evaluation Publication Guidelines – CHEERS: Good Reporting Practices webpage or via [Equator Network](#)

The following table provides a critical appraisal of this study per item based on the CHEERS Checklist.

Section/item	Item N°	Recommendation	Reported on Page N°	Justifications
<b>Title and abstract</b>				
Title	1	Identify the study as an economic evaluation or use more specific terms such as “cost-effectiveness analysis”, and describe the interventions compared.	Page 129	“Cost-utility analysis of a respite care facility using a combined Markov modelling and discrete event simulation approach”
Abstract	2	Provide a structured summary of objectives, perspective, setting, methods (including study design and inputs), results (including base case and uncertainty analyses), and conclusions.	Page 129	“Objective. This study aims to perform a cost-utility analysis of a respite care facility (RC), including a mobile team and a respite house for informal carers and recipients, compared to the standard care (SC).”
<b>Introduction</b>				
Background and objectives	3	Provide an explicit statement of the broader context for the study. Present the study question and its relevance for health policy or practice decisions.	Pages 130 - 131	“A limited number of full economic evaluations of respite care and other support interventions for informal carers have been published to date [...]. This study aims to perform a cost-utility analysis of a respite care facility (RC), including a mobile team and a respite house for informal carers and recipients compared to the standard care (SC), using a Markov model combined with a discrete-event simulation (DES) in a four-month time horizon.
<b>Methods</b>				
Target population and subgroups	4	Describe characteristics of the base case population and subgroups analysed, including why they were chosen.	Page 132	“The survey aims to develop a dynamic support and monitoring system based on 30 informal carers [...] “
Setting and location	5	State relevant aspects of the system(s) in which the decision(s) need(s) to be made.	Page 132	“ [...] inclusion criteria were being an informal carer, an adult, providing at least 5 hours of care per week, living in the Lyon metropolitan area, able to read, write and understand French, having consented to participate [...].”

Study perspective	6	Describe the perspective of the study and relate this to the costs being evaluated.	Page 139	“The health system perspective was retained in the base case analysis”
Comparators	7	Describe the interventions or strategies being compared and state why they were chosen.	Page 132, 135	“[...] carried out an innovative project to create a RC facility as a combination of a mobile team and a respite house in the Lyon metropolitan area. This project is dedicated to carers who take care of a family member with a disability and/or an in-home patient who is dependent due to a chronic disease [...]”; “We constructed a fictitious cohort of 420 people representing informal carers and recipients, comparing the RC and SC.”
Time horizon	8	State the time horizon(s) over which costs and consequences are being evaluated and say why appropriate.	Page 132	“It was conducted with an online platform [...] between June and November 2017.”
Discount rate	9	Report the choice of discount rate(s) used for costs and outcomes and say why appropriate.	Page 139	“Regarding the time horizon of four months, neither costs nor efficiency data were discounted”
Choice of health outcomes	10	Describe what outcomes were used as the measure(s) of benefit in the evaluation and their relevance for the type of analysis performed.	Page 141	“The utility scores were drawn from the literature [...], as recommended by the French National Authority for Health (HAS) “
Measurement of effectiveness	11a	<i>Single study-based estimates:</i> Describe fully the design features of the single effectiveness study and why the single study was a sufficient source of clinical effectiveness data.	NA	NA
	11b	<i>Synthesis-based estimates:</i> Describe fully the methods used for identification of included studies and synthesis of clinical effectiveness data.	Page 141	“The utility scores were drawn from the literature [...]”
Measurement and valuation of preference based outcomes	12	If applicable, describe the population and methods used to elicit preferences for outcomes.	Page 132	“The related transition probability used in the Markov model was extracted from the survey’s <i>data Aidants de la Métropole de Lyon - AIME 2</i> , an online observatory of the situation, needs

				and expectations of informal carers in the Lyon metropolitan area”
Estimating resources and costs	13a	Single study-based economic evaluation: Describe approaches used to estimate resource use associated with the alternative interventions. Describe primary or secondary research methods for valuing each resource item in terms of its unit cost. Describe any adjustments made to approximate to opportunity costs.	NA	NA
	13b	Model-based economic evaluation: Describe approaches and data sources used to estimate resource use associated with model health states. Describe primary or secondary research methods for valuing each resource item in terms of its unit cost. Describe any adjustments made to approximate to opportunity costs.	Page 139	“Resources are provided by the establishment project of the respite house; costs and prices expressed in € for 2018 by the accounting department of the Cancer Centre Léon Bérard (CLB), who provided medical and nursing staff.”
Currency, price date, and conversion	14	Report the dates of the estimated resource quantities and unit costs. Describe methods for adjusting estimated unit costs to the year of reported costs if necessary. Describe methods for converting costs into a common currency base and the exchange rate	Page 139	“All costs are expressed in € for 2018, all taxes included.”
Choice of model	15	Describe and give reasons for the specific type of decision analytical model used. Providing a figure to show model structure is strongly recommended.	Page 139	“This study combines DES and Markov modelling to evaluate informal carers’ pathway to benefit from mobile team and respite house support in the Lyon Metropolitan area. The following approach accommodates the system dynamic’s complexity, especially on the simulation process’s stochastic aspects.”; “Figure The simulation framework”
Assumptions	16	Describe all structural or other assumptions underpinning the decision-analytical model.	Page 134	“[...] model based on five states according to the level of exhaustion (outcome) reported by informal carers: “No

				exhaustion” (1); “Mild exhaustion” [...] (4); “Extreme exhaustion” (5), [...].”
Analytical methods	17	Describe all analytical methods supporting the evaluation. This could include methods for dealing with skewed, missing, or censored data; extrapolation methods; methods for pooling data; approaches to validate or make adjustments (such as half cycle corrections) to a model; and methods for handling population heterogeneity and uncertainty.	Page 141	“The uncertainty surrounding the ICERs was captured by a probabilistic analysis using non-parametric bootstrap methods [...]. 1,000 simulated bootstrap samples were generated [...]. Ellipses represented confidence regions for these pairs at the 50% and 95% level.”
<b>Results</b>				
Study parameters	18	Report the values, ranges, references, and, if used, probability distributions for all parameters. Report reasons or sources for distributions used to represent uncertainty where appropriate. Providing a table to show the input values is strongly recommended.	Page 140	Table Cost inputs
Incremental costs and outcomes	19	For each intervention, report mean values for the main categories of estimated costs and outcomes of interest, as well as mean differences between the comparator groups. If applicable, report incremental cost-effectiveness ratios.	Page 142	“Table 3 reports the results of the base case analysis. The average costs were estimated at €16,684.72 for RC and €15,878.06 for SC; the incremental cost was €806.7 (95% CI: -1,543.67 – 3,156.99).”
Characterising uncertainty	20a	Single study-based economic evaluation: Describe the effects of sampling uncertainty for the estimated incremental cost and incremental effectiveness parameters, together with the impact of methodological assumptions (such as discount rate, study perspective).	NA	NA
	20b	Model-based economic evaluation: Describe the effects on the results of uncertainty for all input parameters, and uncertainty related to the structure of the model and assumptions.	Page 142	“The probability of the ICER belonging to each quadrant of the cost-effectiveness plane is reported in Figure 2 Probabilistic analysis of the ICER [...]”

Characterising heterogeneity	21	If applicable, report differences in costs, outcomes, or cost-effectiveness that can be explained by variations between subgroups of patients with different baseline characteristics or other observed variability in effects that are not reducible by more information.	NA	NA
<b>Discussion</b>				
Study findings, limitations, generalisability, and current knowledge	22	Summarise key study findings and describe how they support the conclusions reached. Discuss limitations and the generalisability of the findings and how the findings fit with current knowledge.	Page 148	“When assessing the generalisability, the limitations are mainly due to the heterogeneity of the interventions for informal carers related to psychological, education support, respite care support, or training support.”
<b>Other</b>				
Source of funding	23	Describe how the study was funded and the role of the funder in the identification, design, conduct, and reporting of the analysis. Describe other non-monetary sources of support.	NA	NA
Conflicts of interest	24	Describe any potential for conflict of interest of study contributors in accordance with journal policy. In the absence of a journal policy, we recommend authors comply with International Committee of Medical Journal Editors recommendations.	NA	NA

Note: NA: Not applicable



# General Conclusion

Considering the proportion of older people is increasing in the majority of countries across the world and in the search for sustainable solutions to address the central issue of LTC with the contribution of carers, this thesis contributes:

- To reinforce the economics literature through (i) a systematic review and critical appraisal of cost-utility analyses of intervention for informal carers, and (ii) the achievement of cost-utility analysis in order to evaluate the efficiency of an innovative support program and respite care facility for informal carers in the Lyon metropolitan area.
- To provide an original modelling approach, i.e. a Markov model combined with a discrete-event simulation applied to health economics.
- To explore a recent French nationwide database, *Capacités Aides et Ressources des seniors (CARE)* and the National Health and Aging Trends Survey (NHATS) with the National Survey of Caregiving (NSOC), a US database using econometrics.

In this conclusion, we shed light on the main findings and then propose some policy implications and recommendations. Finally, we indicate some limitations.

## Main findings

The purpose of the first ( 1) chapter was to identify, through a systematic review and critical appraisal, cost-utility analyses of intervention for informal carers in order to assess the methods employed and the quality of reporting. Our findings show that 20 studies met the inclusion criteria and were in the majority conducted in the UK. The main types of interventions were psychological, training/support, and educational/

support interventions, with mixed evidence regarding the cost-effectiveness. More than half of cost-utility analyses were based on randomised clinical trials. The majority of studies adopted a societal perspective. There were differences in terms of what costs and outcomes were included. In terms of the informal care cost methodologies, health/social care costs were included as direct costs in all of the studies. Time spent caring was found to be the most incorporated indirect costs. The reporting quality of the studies was generally quite good, and there appeared to be a tendency whereby the studies with better reporting deemed the intervention to be not cost-effective. Our critical review highlights the lack of cost-utility analyses of interventions to support informal carers. However, it also shows the relative prominence of good reporting practices in these analyses that other studies might be able to build on. This research has been published in the Journal *Pharmacoeconomics* (Guets et al., 2020).

Chapter two ( 2) studied how informal carers characteristics affect their need for respite care. Data were drawn from the survey Capacités Aides et Ressources des seniors (CARE) collected in 2015. We show that the mean age was 61 for carers. Carers and recipients in the majority were female, married and child. Almost 27% reported a need for respite. Our findings reported that worse health status, feeling of loneliness, lack of time for oneself, and needing to provide more than 60 hours of care per month significantly increased the need for respite irrespective of whether or not the carer lived with the care recipient. Conversely, being closely acquainted with the care recipient showed a reduced need for respite compared to that of carers married to their care recipient. The length of time engaged in providing care decreased the need for respite for cohabitants only. Being a close acquaintance also reduced respite need. The health status of care recipients and chronic conditions increase the need for respite. Regarding the living arrangement, we found in further analysis that cohabitation may reduce the need for respite based on another survey data (HSA, 2008). The negative sign obtained in comparison results could be due to the fact that in 2008, the recognition of informal carers was not effective. Some informal carers, particularly those living in the same house as their patient, were not aware of the existence of respite services dedicated to them; they may have relied on family cohesion to support care recipients. Since carers not living with the recipient may have experienced less burden and less need, it is clear that less informal care, considering the median volume of assistance provided

by cohabiting carers, is twice as high as that of non-cohabiting carers. It is also worth mentioning the negative effect of the length of time providing care on the need for respite. It seems evident that, in case of a lack of respite assistance, informal carers, in particular, those cohabiting with care recipients, have a sense of being stuck in a trap. Therefore, it could not be surprising that some carers reported the most significant disinterest related to the need for respite, mainly expressed by the feeling of reluctance. This research is currently under revision in the *BMC Health Services Research* journal.

The third chapter ( 3) investigates how formal home care affects the utilisation of support services by informal carers in France, and the U.S. Using nationally representative data collected in CARE ménage (France) and NHATS/NSOC (the U.S.), we address the endogeneity of formal care using the care recipient's characteristics and community residential care choice. Andersen's health behavioural model of support service utilisation provides a conceptual framework for investigating the predisposing, enabling, and need variables associated with informal carers' service use. In France, the care recipients' formal care utilisation does not influence the carer's support service use. Comparatively, in the United States, formal care significantly increases the utilisation of respite services by informal carers. Through exploring the relationship between formal and informal care in France and the U.S., whereas informal care is a substitute for formal care in the U.S., we find no evidence of such a correlation in France. This research has been published in the *Working papers GATE Lyon Saint-Etienne* (Guets, 2021).

The last chapter ( 4) of this thesis deals with a cost-utility analysis of a respite care facility (RC), including a mobile team and a respite house for informal carers and recipients, compared to the standard care (SC). This economic evaluation was based on an original Markov model combined with a discrete-event simulation with a four-months' time horizon. Costs were €16,685 (SD± 17,737) and €15,878 (SD± 17,681) for RC and SC, respectively. The mean cost and effectiveness differences between RC and SC strategies were respectively €807 (95% CI: -1,544 – 3,157) and 0.004 (95% CI 0.002 - 0.005). The ICER was €204,308.7 per QALY gained. Based on the societal perspective, the ICER was €123,457.63 per QALY gained. For both perspectives, the probability for RC to be cost-effective was under 50% at the €100,000 threshold. Organisational parameters of RC should be revisited in order to increase the probability of being cost-effective. The

Markov modelling combined with a discrete-event simulation seems particularly well adapted for innovations with a huge organisational dimension.

## **Policy implications and recommendations**

Regarding evidence provided by this thesis, it is clear that informal carers occupied a strategic role in the care recipient life. Therefore, decision-makers for better management of population ageing in the LTC arrangement should continue to pay more attention to care recipients and carers' support services. Health professionals should prioritise reducing carers' risk of exhaustion and burnout by referring carers to the relevant service (e.g. psychological intervention, respite care, training support and education support) at the right time. Then, one should prioritise short-term strategy to optimise the trade-off between informal and formal care use regarding the particularity of the health system. First, countries government may spend more funds on innovative support programs (Respite Care Facility) because some carers may have difficulties in accessing and using support services. By relying on the government recognition of the role of informal carers through different acts (*Law on the Adaptation of Society to Aging (2015)*; *French Social and Family Action Code (2015)*; *Handicap Law (2005)*; and *Labor Law (2016)*) provide more ways for carers to support themselves, mainly middle-aged adults participating in the labour market and likely to be in a situation of distress and exhaustion as a result of informal care. Subsequently, we can mention such plan like "*plan national de renforcement et de diversification des solutions de répit*" (France), National Family Caregiver Support Program (NFCSP) in the U.S.; Secondly, to provide and foster information campaigns to raise awareness concerning the use of various existing health services, to improve and maximise social welfare.

In a much broader sense, four essential points look essential to survey thoroughly for health policies that rely much on informal carers' LTC process. First, to preserve the well-being, welfare as well as health of informal carers. Second, to reduce the financial burden of carers. Third, to enable information and education access so that carers learn through campaign what informal care is purposing on. Lastly, one should create more flexible workplace and educational environments precisely for carers in distress.

This thesis also has several implications for developing countries, given that most of the world's countries are experiencing an increase in old-aged person. Developing

countries are likely to increase their whole population within the next decade, including people above 65 years. Are they prepared for this great upheaval? Relying on the family structure and a supportive environment will be sustainable when it is well known that the support given to dependent people could produce absolute satisfaction for family carers? It is also essential to report that this support can also have psychological, emotional and mental consequences for family members. These repercussions could generate direct and indirect costs for the society, including absenteeism, loss of productivity, and professional sick leave among those occupying a caring role. Indirectly, population ageing would also induce an augmentation of health care spending allocated to cover dependent and/or disabled person, which would be detrimental in the fight against inequalities and poverty. Therefore, governments of low- and middle-income (L- MIC) countries should anticipate this highly likely event through policies oriented actions such as national strategic plans and short-run prevision of population ageing dealing mostly with LTC arrangement ([Team and Organization, 2002](#)).

## Limitations and further research

This thesis also contains some potential limitations that were identified through different chapters.

The first chapter investigates a list of support interventions dedicated to informal carers. We focused on a critical review of economic evaluations in order to identify cost-utility analyses of interventions for carers. Therefore, we reported a lack of studies (only 20), and this may have produced some biased findings regarding the overall cost-effectiveness of interventions for carers. Then, close comparisons of the relative cost-effectiveness of carer interventions were complicated by differences between studies in terms of the design, the interventions that were compared, the inclusion of direct/indirect cost of the carers, and other study characteristics. Thus, although all of the selected economic evaluations measured the same health outcome (QALYs), the transferability and generalizability of the results (across diseases: dementia, stroke, cancer, and Parkinson's disease) is limited. This is due precisely to the choice of the method; differences in intervention contexts and intervention costs; and the types of economic evaluations, such as decision models (simulation)-based and empirical (including trial-based) economic evaluations ([Anderson, 2010](#)), and cost-effectiveness thresholds

(McCabe et al., 2008). As we chose to focus on carer interventions assessed by a cost-utility analysis approach, several publications that used other approaches to economic evaluation were not considered, e.g. cost description, cost analysis, cost-benefit analysis (Gitlin et al., 2010; Sopina et al., 2017). However, because QALYs were systematically used as the measure of health benefits in this review, there is a better level of comparability of the results between interventions for informal carers. Nevertheless, differences in methodologies across studies remain significant, such as the degree to which the informal carer's time is cost and the methods employed to do this.

In the second chapter, we notice some potential limitations that could influence the results. First, there is no denying that our econometric modelling gives rise to a degree of endogeneity for at least two overall primary sources that can be solved by a two-stage least square (2SLS) model. Firstly, one possible source of endogeneity is the two-way (reverse) causality between the need for respite and the health status. Secondly, another possibility is the unobserved individual heterogeneity. Informal carers can differently report their experiences of strain because of higher levels of impairment. Subsequently, some exogenous factors such as age, relationship, and/or gender may induce informal carers to misestimate care's negative impact. Second, our dependent variable reflects a dichotomous measure ("yes" or "no") of the need for respite. It has not been possible to assess the intensity of the preferences of carers ("never" or "sometimes" or "more often"). Third, future studies should analyse the demand for various support supplies (respite) services and access how each carer's characteristics enable or limit carers' preferences. Therefore, informal carers' utility function or behavioural model towards the need for respite should be assessed in other investigation.

Some limitations are identified throughout the study. First, we use a subjective and dichotomous measurement of the use of support ("Yes" or "No"). Therefore, it is not possible to use and assess the different level of preferences of the use of support (intensity, such as: "No, not at all"; "Yes, a little bit"; "Yes, a lot). Future research should consider this point. Second, the analysis of the use of support choices of carers is assessed separately. The preferences for respite, support group, training, and financial support utilisation are not assumed in the compelled decision in which carers' characteristics are assessed conditionally. Our study did not explore the matter of barriers or bottleneck that carers face when trying to make use of support services. Geographical barriers

differentiating the use of support services for carers and recipients have received very little attention in recent research. Future research should aim to support policymakers by evaluating different types of support that carers find most useful and pay attention to other potential sources of inequality and geographic variation in service utilisation in light of these results. In our survey data, dependent variable, such as “training” would not have been formulated in the same way in both countries surveys questionnaires. These discrepancies may have indeed biased the answers and choices of carers. Therefore, based on these inconsistencies, it is not easy to build a reliable comparison regarding this dependent variable in both countries; nevertheless, we should be cautious interpreting these results. Barriers in the utilisation of support services have not received much attention in the literature. Since they significantly impact carers’ behaviour on informal carers’ needs and wants, future studies should focus on the main pitfalls.

According to chapter four, it appears that the majority of studies using the modelling approach mostly faced some critical limitations, such as data availability and related hypothesis. Our study used a time horizon of four months, which is relatively short (less than one year), to capture the full potential benefit of respite care supportive intervention. Comparatively, other studies considered a relatively larger time frame to investigate the impact of informal carer interventions, mostly 12 months. Our combined model should be expanded to consider a longer time horizon and including a “death” state. It should also be based on more detailed and robust data, ideally a randomised clinical trial. Indeed, a recent literature review shows that most of the cost-utility analyses related to informal carer interventions are based on a randomised clinical trial. For further research, specific socio-demographical characteristics, such as health status, access to health care, the utilisation of eHealth services or information, should be taken into account.

When assessing the generalisability, the limitations are mainly due to the heterogeneity of the interventions for informal carers related to psychological, education support, respite care support, or training support). Also, economic methods and assumptions used (e.g. the perspective, the timeframe, the scope of costs and outcomes (are both carer and the patient costs included?)) chosen. In this study, QALYs of recipients were not considered. The future economic evaluation should undoubtedly increase the robustness of findings of the cost-effectiveness of respite care interventions. Economic

evaluation based on randomised control trials could help health policymakers to adapt funding to support program dedicated to informal carers. Our findings show that the RC intervention alone, as defined compared to the standard strategy, would not seem to be cost-effective for a wide-scale used regarding existing information. First, the study was conducted in the framework where informal carers dyads can take 30 days/year of respite. Second, there is no denying a shortage of human resources assisting informal carers and recipients. In this situation, it is clear that informal carers' management, considering the large population concerned in this study, further oriented-policies should focus on case management.

Further research should investigate the economic valuation of informal carers towards respite care facility. For example, assess the carers' willingness to pay (or accept) to benefit from support services. Among different methods of economic valuation, the choice of the conjoint measurement would receive particular attention.

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# Conferences, visiting scholar and publications

## Conferences

- European Health Economics Association, [EuHEA 2020 conference](#), 7-10 July 2020 in Oslo, Norway. (Abstract accepted for presentation and published in the conference website – Conference cancelled due to COVID-19 pandemic)
- International Society for Pharmacoeconomics and Outcomes Research (ISPOR) Annual European Congress, [Europe 2019 Conference ISPOR](#), November 2019, Copenhagen, Denmark
- Annual workshop of the Doctoral school ED 486 Economics, [Annual Workshop for second year doctoral students \(D2\)](#), April 2019, Lyon, France
- 21st International Society for Pharmacoeconomics and Outcomes Research (ISPOR) Annual, [European Congress, Europe 2018 Conference](#), November 2018, Barcelona, Spain
- 12th European Health Economics Association (EuHEA), [EuHEA 2018 Conference](#), July 2018, Maastricht, The Netherlands
- 17th Annual International Conference on Health Economics, Management & Policy (Atiner), [Atiner 2018 Conference](#), June 2018, Athens, Greece

## Visiting scholar

- University of Michigan - [Inter-University Consortium for Political and Social Research \(ICPSR\)](#), Summer Program, Ann Arbor, USA, Short Visit, June 2019
- University of Birmingham - [Institute of Applied Health Research](#), Birmingham, UK, Short Visit, February - March 2019
- School of MINES Saint Etienne, Saint-Etienne, France [Health and Engineering Center \(CIS\)](#), April - November 2019

## Publications, Working papers and paper under review

### Publications

- Wilfried Guets, Hareth Al-Janabi, and Lionel Perrier. "Cost–Utility Analyses of Interventions for Informal Carers: A Systematic and Critical Review." *PharmacoEconomics*. 2020 Apr;38(4): 341-356. DOI: [10.1007/s40273-019-00874-6](https://doi.org/10.1007/s40273-019-00874-6).  
<https://pubmed.ncbi.nlm.nih.gov/31853801/>

### Working paper

- Guets, Wilfried, Does the Formal Home Care Provided to Old-Adults Persons Affect Utilization of Support Services by Informal Carers? An Analysis of the French CARE and the U.S. NHATS/NSOC Surveys (January 19, 2021). *GATE, WP 2105* – January 2021, Available at SSRN: <https://ssrn.com/abstract=3769126> or <http://dx.doi.org/10.2139/ssrn.3769126>

### Under review

- Wilfried Guets, and Lionel Perrier. "Determinants of the need for respite according to the characteristics of informal carers in France: results from the CARE 2015 survey." (Under review in the Journal [BMC Health Service Research](#)).

TITLE: INFORMAL CARE MODELLING : ECONOMIC EVALUATION AND APPLICATIONS TO AN INNOVATIVE SUPPORT PROGRAM AND RESPITE CARE FOR INFORMAL CARERS IN THE LYON METROPOLITAN AREA

Wilfried Guets

### **Abstract**

This thesis includes four chapters. The first chapter provides a systematic review and critical appraisal of cost-utility analyses of interventions for informal carers. The latter described the methods used and assessed the quality of the studies. Twenty cost-utility analyses were included. The interventions were mainly psychological, training and education support programmes. The quality of the studies was generally quite good. However, we noted that there appeared to be a tendency whereby the studies with better reporting deemed the intervention to be not cost-effective. This work was published in the journal *PharmacoEconomics* (2020). The second chapter focuses on identifying the main determinants of informal carers' need for respite in France. Based on the French representative survey CARE (2015), statistical and econometric analyses were conducted. The results show that worse health status, cohabitation, being a female carer, but also the volume of care provision and age significantly increase the need for respite. This work is under review in the journal *BMC Health Services Research*. The third chapter examines how formal home care affects informal carers' use of support services. Using nationally representative data from CARE (France) and NHATS/NSOC (USA), we address the endogeneity of formal home care by the characteristics of the care recipient and the choice of care at the community level. In France, formal care does not influence the use of carer services. In contrast, in the United States, it significantly increases the use of respite care by informal carers. This work has been published in the *GATE Working Papers series* (2021). The last chapter proposes a cost-utility analysis of an innovative respite care facility for informal carers, including a mobile team and a respite house. In an innovating way in health economics, a Markov model, combined with a discrete event simulation original model, was developed. The findings show that the probability that this innovative support programme is cost-effective is less than 50% at the €100,000 threshold. This method seems particularly well adapted to organisational innovations.

**Keywords:** Economic evaluation; Informal care; Informal carers; Respite care; Support services

TITRE: MODÉLISATION DE L'AIDE INFORMELLE : EVALUATIONS ÉCONOMIQUES ET APPLICATIONS AU DISPOSITIF INNOVANT D'ACCOMPAGNEMENT ET DE RÉPIT DES AIDANTS INFORMELS DE LA MÉTROPOLE DE LYON

### **Résumé**

Cette thèse comprend quatre chapitres. Le premier chapitre propose une revue systématique et une évaluation critique des analyses coût-utilité des interventions destinées aux aidants informels. Cette dernière a permis de décrire les méthodes employées et d'évaluer la qualité des études. Vingt analyses coût-utilité ont été incluses. Les interventions étaient majoritairement des soutiens psychologiques, des formations et programmes d'éducation. La qualité des études était généralement assez bonne. Nous avons toutefois noté que les études de meilleure qualité tendaient à conclure que l'intervention n'était pas coût-efficace. Ce travail a été publié dans la revue *PharmacoEconomics* (2020). Le deuxième chapitre s'intéresse à identifier les principaux déterminants du besoin de répit des aidants informels en France. En s'appuyant sur l'enquête française représentative CARE (2015), des analyses statistiques et économétriques ont été conduites. Les résultats montrent qu'un état de santé dégradé, la cohabitation, être un aidant de sexe féminin mais aussi le volume d'aide et l'âge augmentent significativement le besoin de répit. Ce travail est en révision dans la revue *BMC Health Services Research*. Le troisième chapitre étudie comment l'aide formelle à domicile affecte l'utilisation des services d'accompagnement par les aidants informels. En utilisant les données représentatives nationales de CARE (France) et NHATS/NSOC (États-Unis), nous traitons l'endogénéité de l'aide formelle par les caractéristiques de l'aidé et le choix de l'aide au niveau communautaire. En France, l'aide formelle n'influence pas le recours aux services d'aide aux aidants. En revanche, aux États-Unis, elle augmente de manière significative l'utilisation du répit par les aidants informels. Ce travail a fait l'objet d'une publication dans la série des *Working Papers du GATE* (2021). Le dernier chapitre propose une analyse coût-utilité d'un dispositif innovant de soins de répit pour les aidants informels, ce dernier comprenant une équipe mobile et une maison de répit. De façon originale en économie de la santé, un modèle de Markov, combiné à un modèle de simulation à événements discrets, a été développé. Les résultats montrent que la probabilité que ce dispositif innovant soit coût-efficace est inférieure à 50% au seuil de 100 000 €. Cette méthode semble particulièrement bien adaptée aux innovations organisationnelles.

**Mots Clés:** Aide informelle; Aidants informels; Evaluation économique; Services d'accompagnement; Soins de répit