

Pierre GÉRAIN

CARING UNTIL IT HURTS



An investigation of informal caregiver burnout



Caring until it hurts

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Abstract

Informal caregivers are people who provide (unpaid) assistance to a parent or relative because they cannot perform certain tasks themselves. Informal caregiving has been shown to be a rewarding role in many ways, but it also carries with it the potential for negative consequences. The understanding of these consequences has been studied primarily through the concept of the "burden" of being an informal caregiver, but this area of research suffers from several limitations, including conceptual and empirical heterogeneity. This work therefore proposes to adapt the concept of burnout to the context of informal care, in order to better understand how these deleterious consequences can occur. This adaptation is achieved through a qualitative and quantitative synthesis of existing evidence, but also through theoretical and empirical research. As a result, this work highlights that informal caregivers are at risk of experiencing some form of burnout and proposes a new framework for addressing the issue of informal caregiver burnout itself. Based on this framework, empirical investigations support its relevance, while contributing to a better understanding of this phenomenon. Based on these findings, several refinements to this model and key issues in the adaptation of burnout to informal care are discussed. Overall, this work provides new insights into the field of informal caregiver burnout research and a new framework for studying its determinants and consequences. In doing so, it aims at better understanding how informal care can take a deleterious turn, but also to provide keys to intervene when necessary.

Résumé

Les aidants sont des personnes qui fournissent des « soins informels », une aide (non rémunérée) à un parent ou à un proche parce que ceux-ci ne peuvent pas accomplir certaines tâches eux-mêmes. Il a été montré qu'être aidant est un rôle gratifiant à bien des égards, mais que cela comporte également un risque de conséquences néfastes. La compréhension de ces conséquences a été principalement étudiée à travers le concept de « fardeau » d'être un aidant, mais ce domaine de recherche souffre de plusieurs limites, notamment en raison de son hétérogénéité conceptuelle et empirique. Le présent travail propose donc d'adapter le concept de burnout au contexte des soins informels, afin de mieux saisir comment ces conséquences délétères peuvent se produire. Cette adaptation est réalisée grâce à une synthèse qualitative et quantitative des preuves existantes, mais aussi au moyen de recherches théoriques et empiriques. Ces travaux soulignent le risque que les aidants naturels sont à risque de burnout et proposent un nouveau cadre pour l'étude de la question-même du burnout des aidants. À partir de ce cadre, des études empiriques viennent appuyer la pertinence de celui-ci, tout en contribuant à une meilleure compréhension de ce phénomène. Sur base de ces résultats, plusieurs améliorations de ce modèle et des questions clés suscitées par l'adaptation de l'épuisement professionnel aux soins informels sont discutées. Dans l'ensemble, ce travail fournit de nouvelles perspectives dans le domaine de la recherche sur le burnout des aidants et un nouveau cadre pour étudier ses déterminants et ses conséquences. Ce faisant, il vise à mieux comprendre comment les soins informels peuvent prendre une tournure délétère, mais aussi à fournir des clés pour intervenir lorsqu'il est nécessaire de le faire.

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“Vita brevis, ars longa.”

Hippocrates, *Aphorisms*

“Science sans conscience n'est que ruine de l'âme.”

François Rabelais, *Pantagruel*

General introduction

General Introduction

The present work¹ takes its roots in 2016, following a presentation at the dawn of research on parental burnout. In this presentation, Professors Mikolajczak and Roskam stressed the need to take into account the difficulties that parents may face in their role and how this can lead to parental burnout. Despite our interest in the subject, we could not ignore the idea that something else was missing. When we looked at the history of burnout research, the studies first focused on burnout in professional settings, with an emphasis on health professionals. It then spread to other contexts, both inside and outside of work. And now, studies are focusing on the burnout of other people who give their time and are committed to others, parents. But a third category of providers seemed to be missing: family members, friends, the "invisible ones", i.e. the informal caregivers. Like health professionals, they provide a wide range of care and services to people in need due to loss of autonomy, disability or illness. Like parents, they take care of relatives, especially members of the family. Informal caregivers are therefore at the crossroads of the two roles of caregivers and yet receive much less attention.

1. Informal caregivers

Informal caregivers are individuals, voluntarily and mostly free of charge, caring for a relative or a friend (i.e., the care-recipient) facing disease, disability, or any condition requiring particular attention (Schulz and Tompkins, 2010). This definition seems rather simple, but hides the reality of a complex continuum where individuals are involved in a wide range of tasks and an even wider range of demands. This continuum ranges from helping their mom clean the floor because of her arthritis, to bathing their father with Alzheimer's disease, along with accompanying their disabled child to physiotherapist appointments. The role of the natural caregiver is complex because it involves providing care as well as maintaining and adapting the relationship with the care-recipient, while personally coping with these changes in their life.

2. Informal caregivers in the healthcare system

In addition to gravitating around the care-recipient, informal caregivers are one of the main pillars of health systems (OECD, 2013). Several studies have attempted to capture the proportion of informal caregivers in the population. Taking the example of Europe, the results show that between 6 and 34% of the population could be considered as informal caregivers (Verbakel, Tamlaagstrønning, Winstone, Fjær, & Eikemo, 2017). Although these estimates must be carefully weighed and discussed under different definitions of informal care, these results highlight that informal caregivers are more common than we would have thought.

¹ Part of this introduction was published in a French book chapter (Westrelin, Gérain, & Mikolajczak, 2019).

Statistically, everyone is in contact with caregivers in their daily lives, whether they know it or not.

The presence of informal caregivers allows the care recipient to stay at home or in an outpatient service. Their (theoretical) absence would represent a significant deficiency in the functioning of long-term care. Several studies have attempted to estimate the cost if each informal caregiver were to be replaced by a formal caregiver (Oliva-Moreno, Trapero-Bertran, Peña-Longobardo, & Pozo-Rubio, 2017). Even when taking the most conservative estimators, the results highlight the significant impact of informal care on the economy, and in particular on the financing of the health system. If the United States were to replace informal caregivers with unskilled and skilled paid care, it would represent an additional cost of 220 billion to 642 billion, respectively 1.4 and 4% of the US GDP (Chari, Engberg, Ray, & Mehrotra, 2015).

3. A growing issue

Most of the studies on informal care come from so-called "Western" countries. Beyond the potential self-centrism of academic research, it also reflects the fact that these societies are and will face the challenge of increasing the burden of disease due to longer life expectancy and lower mortality from chronic diseases. As some authors point out, the need for informal caregivers is likely to double by 2050 (Plöthner, Schmidt, de Jong, Zeidler, & Damm, 2019). At the same time, it is expected that the number of available informal caregivers will decline, resulting in a significant decrease in the "caregiver support ratio" (the number of potential caregivers per dependent person), due to demographic trends (Redfoot, Feinberg, & Houser, 2013).

From a public health standpoint, the centrality of their role in the provision of daily care makes it essential to support them in order to have sustainable health systems. But from a psychological point of view, being a caregiver can also be a significant emotional challenge. Thus, even if they do not fail from a long-term care perspective (i.e., leave their role), each caregiver experiences difficulties in their role, which can have negative consequences.

4. A high-risk role

The study of the health consequences of informal caregiving has shown that informal caregivers are at high risk of morbidity such as depression, anxiety disorders, drug abuse, cardiovascular disease and lower levels of cognitive functioning (Capistrant, Moon, & Glymour, 2012; Pinquart & Sörensen, 2003; Pottie, Burch, Montross Thomas, & Irwin, 2014; Sallim, Sayampanathan, Cuttilan, & Chun-Man Ho, 2015; Vitaliano, Murphy, Young, Echeverria, & Borson, 2011). Some (older) studies have even shown that being an informal caregiver can represent an increased risk of mortality (Schulz & Beach, 1999). Recent research has challenged this widespread view that being a caregiver is a risk for all of them, and calls for a finer understanding of what caregivers are undergoing (Brown & Brown, 2014; Roth, Fredman, & Haley, 2015). Beyond the risk associated with the simple label of

"informal caregiver", the recommendation is therefore to understand what can make them more at risk and by which mechanisms.

Research on such mechanisms quickly converged on what is now called the *burden* of being an informal caregiver (Montgomery, Gonyea, & Hooyman, 1985). This term includes the difficulties encountered by the informal caregiver when providing care to a relative, but also the perceived consequences of caregiving on their own life and well-being. Theoretical developments have therefore distinguished two different types of burden: objective and subjective burden (Lawton, Kleban, Moss, Rovine, & Glicksman, 1989). Objective burden refers to the characteristics of the caregiving environment, the intensity of objective difficulties that caregivers may experience, such as having to perform tedious tasks, waking up at night or bringing the care-recipient to recurring medical appointments. Subjective burden refers to caregivers' perceptions of their own situation, the changes due to the caregiving in their emotional, physical, social and financial lives (Zarit & Zarit, 2015).

The first trend in studies investigating a mechanism by which being a caregiver could take a negative turn has therefore focused on the study of *subjective burden*. The concept itself will be discussed in Chapters 2 and 3, but the problem is that, although it is the most widely studied, the subjective burden is nevertheless a heterogeneous concept. It provides a good overall assessment of caregivers' perceptions of their experience, but it also includes elements too different to make it conceptually coherent, as it is at the same time an assessment of the impact of care on daily life, well-being, physical health and finances (Mosquera et al., 2016). This heterogeneity makes its use difficult in observational or intervention research and, to a greater extent, in policy making.

In this context, the introduction of the concept of burnout in caregiver research addresses many of these criticisms, but it has remained relatively modest for a long time. It is in the 80s that a group of researchers published an article entitled "Spouse burnout syndrome" (Ekberg, Griffith, & Foxall, 1986). In this research, the authors met 30 spouses of patients with chronic disease and observed that they had symptoms comparable to those reported by health professionals in the emerging burnout literature. With this article, Ekberg and her colleagues laid the groundwork for an investigation of informal caregiver burnout, an area of research that will only emerge in the 2000s (e.g., Angermeyer, Bull, Bernert, Dietrich, & Kopf, 2006; Cross, Garip, & Sheffield, 2018).

5. Current questions

Adapting the concept of burnout to the context of informal care seems to be a promising concept for capturing the (negative) outcomes that informal caregiving can have. However, this research remains rare and scattered. Therefore, it is necessary to provide a good overview of the current literature on the association between informal care and burnout, but also to provide theoretical keys to study it in the future. The implementation of such a framework would improve research and interventions by clarifying their objectives and the processes they target. Once this framework has been developed, additional steps in its study can be taken to continue to better understand this phenomenon.

6. The Present Thesis

6.1 Section 1: Do informal caregivers experience more burnout?

The first aim was therefore to investigate the existing studies bridging informal care and burnout. A systematic literature review identified a surprisingly large number of studies addressing burnout and informal care. Among them, a group of studies was identified that compared caregivers and non-caregivers using measures of family and professional burnout. This led to an examination whether, overall, being a caregiver leads to an increase in burnout (**chapter 1**). To do so, meta-analyses were conducted in order to have a summary of all the evidence reported by the studies. It clarified whether caregivers are at greater risk of burnout than non-caregivers in family and work settings.

6.2 Section 2: Informal caregiver burnout

This literature review also highlighted a significant number of studies adapting burnout to informal care, which led to the consideration of informal caregiver burnout *per se*. First, and based on the same literature review used in chapter 1, **chapter 2** is a narrative literature review (in French) on the determinants and consequences of informal caregiver burnout. This chapter provides an up-to-date picture of the studies investigating informal caregiver burnout by summarizing their evidence. Building on these reviews, **chapter 3** develops more in depth the rationale of the adaptation of the concept of burnout to informal caregivers. It also proposes a theoretical framework to conceptualize it. This framework is based on two central models originating from the literature on informal caregiving and on professional burnout.

6.3 Section 3: Empirical investigations of the Informal Caregiver Burnout

After setting up a theoretical framework in chapter 3, **Section 3** presents three studies investigating informal caregiver burnout and its determinants. Chapters 4 and 5 are based on the same dataset. This dataset was collected between in 2018 and 2019 through online surveys. It gathered up to 500 questionnaires of informal caregivers with diverse backgrounds (e.g., different nationalities, relationship of kinship with the care-recipients, and care-recipients' health issues). Its aim was to adapt a measure of burnout to the context of informal care (the Maslach Burnout inventory) and to investigate potential determinants and consequences of the informal caregiver burnout. Chapter 4 investigated determinants based on the model presented in chapter 3 by looking at the impact of care-recipient's dependency, caregiver emotional intelligence, and solitude on informal caregiver burnout, through a mediation of the appraisal and of the relationship quality between caregiver and care recipient. Chapter 5 focused on the impact of informal caregiving burnout by looking at its associations with depression, subjective health, and violence towards the care-recipient.

Chapter 6 focused on the comparison of the determinants of parental burnout among parents of children with and without children with special issues. The first aim of that study

was to investigate the determinants of parental burnout in a large sample of parents ($n = 900$). Among them, some ($n = 175$) appeared to have children with “special issues”, meaning that they had one or more children with an emotional, developmental, or physical trouble. This study determined whether, and how, parents with children with special issues are more at risk than parents with typical children, by comparing their parental burnout scores. Among the determinants examined, the importance of the subjective perception of the childcare situation was also compared to the contribution of objective factors in the risk of parental burnout.

7. Key concepts

Several concepts are the backbone of the present manuscript and should be clearly defined:

- **Informal caregivers:** Informal caregivers are individuals, voluntarily and mostly free of charge, caring for a relative or a friend (i.e., the care-recipient) facing disease, disability, or any condition requiring particular attention (Schulz and Tompkins, 2010).
- **Informal caregiver burnout:** as it will be clearly stated in chapters 2 and 3, informal caregiver burnout can be defined as a tridimensional syndrome in response to the stress that the caregiving context may represent (Gérain & Zech, 2019). The three dimensions are: emotional exhaustion, the feeling of being emotionally drained when facing the caregiving situation and the care-recipient ; depersonalization, the detached response in the relationship to the person being cared for ; personal accomplishment, the dimension of self-fulfillment and meaning found through the caregiving experience.
- **Subjective burden:** Subjective burden refers to caregivers' perceptions of their own situation, the changes due to the caregiving in their emotional, physical, social and financial lives (Zarit & Zarit, 2015). Chapters 2 and 3 will discuss how subjective burden and informal caregiver burnout differ.
- **Depression:** Depression (or major depressive disorder) is a mood disorder characterized by a persistent period of depressed mood or loss of interest or pleasure (anhedonia), accompanied with additional symptoms (American Psychiatric Association, 2013). Depression is often seen as one of the main negative consequences of informal care (Pinquart & Sörensen, 2003).

Section 1

**Do informal caregivers experience more
burnout?**

Do informal caregivers experience more burnout?

When beginning the present work, the objective was to see what was already investigated in the literature in terms of burnout and informal caregiving. Preliminary contacts with the literature led to a first observation: the term “caregiver” is polysemous. It relates to informal caregivers, but it also covers healthcare professionals, educators, foster care parents, and, to some extent, parents in general. More restrictive keywords such as “informal caregivers” or “family caregivers” could have been used. These keywords, however, led to fewer references, which led to the omission of those that were relevant in preliminary explorations, such as studies referring to “caregivers” or using specific terms like “dementia caregivers”. Therefore, the word “caregiver” was preferred, in addition to “carer”, “parent”, “father” and “mother”. The number of references was important (more than 11.000), but ensured to have a maximum of relevant references included.

Among these references, a specific set of studies bridging informal caregiving and burnout appeared – along with the expected studies focusing on informal caregiver burnout (which will be further discussed in Chapter 2). This specific set of studies investigated if being an informal caregiver increased the risk of different forms of burnout. To do so, these studies compared informal caregivers and non-caregivers using measures of burnout in different contexts: work, parenting, and spousal role. The synthesis of the results of all these studies provides a clearer picture of whether being a caregiver puts people at risk of burnout in the investigated contexts. This paper, which has been submitted for publication under the title “Do informal caregiver suffer from burnout? A meta-analytic study”, summarizes and meta-analyzes these studies.

Chapter 1

Do informal caregivers experience more burnout? A meta-analysis

Informal caregivers often report difficulties when providing care, especially in terms of exhaustion, which can be related to forms of burnout. Yet, there is no systematic inventory of studies comparing caregivers and non-caregivers in terms of burnout. For the present meta-analysis, studies from online databases were screened and included if they were written in French or English, compared burnout in informal caregivers and non-caregivers and reported or provided enough information to compute effect sizes. Two categories of studies investigating burnout were found: those on family care burnout (parental or spousal) and those on professional burnout (mostly in healthcare). For family care burnout studies, informal caregivers reported more emotional exhaustion, and, to a lesser extent, depersonalization and reduced personal accomplishment than non-caregivers. For studies on professional burnout, workers providing informal care also reported more emotional exhaustion than workers not providing such a care. Overall, the results indicate that providing informal care represents a risk for role burnout. The present results showed an increase of role burnout when providing informal care. In family care burnout studies, these results confirm the assumption that providing informal care adds extra weight on the individuals' shoulders. In professional burnout, these results support the role accumulation theory, pointing that an additional weight in one's role, i.e., providing informal care, has an impact on another role, work. This work emphasizes the consideration of the multifaceted impact that the caregiving role can have on the individual. Beyond this, it also paves the way to consider an informal caregiving burnout, the adaptation of burnout to informal caregiving contexts.

Reference: Gérardin, P., & Zech, E. (2019). Do informal caregivers experience more burnout? A meta-analysis. *Manuscript under Review*.

Do informal caregivers experience more burnout? A meta-analysis

1. Introduction

Informal caregivers are key actors in efficient long-term care settings (Verbakel, Tamlagsrønning, Winstone, Fjær, & Eikemo, 2017). Informal caregivers are individuals, voluntarily and mostly free of charge, caring for a relative or a friend (i.e., the care-recipient) facing disease, disability, or any condition requiring particular attention (Schulz and Tompkins, 2010). Informal caregiving encompasses a wide variety of situations, ranging from shopping for a great aunt's groceries to providing daily care to a child with disability or a spouse with chronic illness. Even if caregiving has rewarding and meaningful dimensions for the caregiver – positive consequences which are increasingly documented (Carbonneau, Caron, & Desrosiers, 2010) –, such positive dimensions may not make up for its deleterious consequences (Lawton, Moss, Kleban, Glicksman, & Rovine, 1991). The investigation of the health consequences of informal caregiving has shown that some caregivers, due to the role they take, are more prone to psychopathology than the general population (Pinquart & Sörensen, 2003; Pottie, Burch, Montross Thomas, & Irwin, 2014; Sallim, Sayampanathan, Cuttilan, & Chun-Man Ho, 2015).

A growing number of qualitative studies indicate that some caregivers feel worn down or mentally and emotionally exhausted because of their caregiving activity (Goodwin, McCormack, & Campbell, 2017; Thompson, Kerr, Glynn, & Linehan, 2014). These qualitative reports relate to the abundant literature on how some caregiving settings might represent a burden on the caregivers' daily life, and thus become a chronic stressful situation (Chiao, Wu, & Hsiao, 2015). This stress, along with reported exhaustion, echoes similar elements found in terms of burnout among both health professionals and parents (Maslach, Jackson, & Leiter, 1996; Mikolajczak, Raes, Avalosse, & Roskam, 2018).

Burnout is a measure of role strain. Three dimensions of burnout were defined by Maslach, Jackson, and Leiter (1996): emotional exhaustion, depersonalization, and reduced personal accomplishment. Emotional exhaustion is defined as the individuals' feeling of no longer being able to give of themselves at a psychological level, the depletion of the person's psychological resources. Depersonalization describes the detached response to the beneficiaries of one's activity. Reduced personal accomplishment depicts the feeling of incompetence and reduced sense of achievement in one's activity. Burnout has been mostly investigated in occupational contexts, and more recently in parenting settings (Mikolajczak et al., 2018; Roskam, Raes, & Mikolajczak, 2017; Sánchez-Rodríguez, Perier, Callahan, & Séjourné, 2019).

2. Objective of the present review

To date, there exists no systematic investigation of research conducted to examine whether informal caregivers suffer from more burnout than non-caregivers. Beyond the common assumption that caregivers may have a higher risk of burnout when compared to non-caregivers, the presence of chronic stressors and exhaustion among informal caregivers calls for a clear summary of evidence supporting or disregarding this. Therefore, the objective of the present meta-analytic review was to investigate whether informal caregivers do indeed experience more burnout than non-caregivers.

3. Method

The PRISMA guidelines were followed and checked (Liberati et al., 2009).

3.1 Eligibility criteria

To be eligible, studies had to allow (1) a comparison between informal caregivers and non-caregivers, regardless of the design, using (2) quantitative measures of forms of burnout, (3) provide enough information to compute effect sizes (ES), and (4) be reported in French or English.

3.2 Information sources

Five databases in health and psychological fields were exploited (i.e., PubMed, MedLine, PsycInfo, PsycArticles, and Scopus) in February 2017 with updates in November 2017 and in April 2019. To investigate the gray literature, two general databases of theses and manuscripts (i.e., OATD and NDLTD) were explored during March 2017 (with an update in April 2019), references of articles were screened, and relevant authors of the field contacted.

3.3 Search strategy

A preliminary online search conducted in December 2016 has led to the construction of a list of keywords. Initially, the restrictive use of the terms “family caregiv*” or “informal caregiv*” was preferred but this appeared too restrictive regarding previously found studies (e.g., “psychosis caregiver” or simply “caregiver”). Additionally, the use of the terms father* and mother* was added to the parent* term due to studies focusing only on one parent. The final keywords used for caregiver were caregiv*, parent*, mother*, father*. The keywords used for burnout were “burnout”, “exhaustion”, “burn-out”, “Maslach”, “Shirom”. A second wave was performed using the keywords “carer” and “caring” for the caregiver.

3.4 Study selection

Online references were downloaded. Duplicates were identified through an adapted version of existing methods (Bramer, Giustini, de Jonge, Holland, & Bekhuis, 2016).

Remaining studies were screened by title, then by abstract, and then based on the full manuscript, when available.

3.5 Data collection process

All data were first extracted by one of the authors (P.G.) and then checked independently by the other (E.Z.). Coding spreadsheets were used on Excel. Authors were contacted and some provided useful information allowing the inclusion of additional studies.

3.6 Data items

Information was extracted from each study regarding: publication type, recruitment procedures, countries where the study took place, care-recipient's issue, sample size, caregivers' gender proportion and mean age, burnout measure used.

3.7 Risk of bias in individual studies

Due to a lack of consensus on a suitable tool for assessing observational studies (Sanderson, Tatt, & Higgins, 2007), the Research Triangle Institute (RTI) item bank on risk bias and precision was used (Viswanathan & Berkman, 2012). Four items were used: (1) non-retrospective design, (2) clear inclusion/exclusion criteria, (10) attempt to match participants in control and caregiving group, (20) control at baseline between caregiving and controls.

3.8 Summary measures

The standardized difference between two means (i.e., Cohen's *d*) was used to compare the score of the caregiving group with the score of the control group in each study. These effect sizes (ES) were computed using an online effect size calculator (Wilson, 2018). The ES were calculated based on the means, SD, and N of the two groups or by a ratio of no burnout/burnout when the studies reported the occurrence of burnout in each group (Lipsey & Wilson, 2001).

3.9 Synthesis of results

Meta-analyses were conducted to compute effect-size means. A random restricted maximum likelihood effect model was preferred to a fixed one due to the variety of contexts in which the studies took place (Borenstein, Hedges, Higgins, & Rothstein, 2009; Cooper, Hedges, & Valentine, 2009). The computation of the effect-size means was performed with JASP 0.9.2, an open-source R-based software (JASP Team, 2018).

3.10 Risk of bias across studies

To assess possible publication biases, funnel plots were used to assess visually the distribution of studies based on their standard errors and computed means. To draw more precise conclusions, three statistical methods were used (Borenstein et al., 2009; Cooper et

al., 2009): the rank correlation for plot asymmetry, the regression for funnel plot asymmetry (Egger Test), and the classic fail-safe N.

3.11 Additional analyses

Random meta-regressions using the restricted likelihood method were performed for both categorical and continuous moderators (López-López, Marín-Martínez, Sánchez-Meca, Noortgate, & Viechtbauer, 2014). The impact of the type of burnout scale used (i.e., if the burnout scale was specific to one role or was a general measure of burnout), the quality score, the relationship between the caregiver and the recipient, the mean caregiver's age and gender proportion, and publication year and the scientific journal ranking from SCImago were analyzed. The sampling of the control group was also investigated: studies where the control group was randomly selected or where informal caregivers were identified within a wider sample were considered as using a random control group. The studies where the control group was not clearly identified as random were considered as having a potentially oriented sampling.

4. Results

4.1 Study selection

The study selection process is presented with a flowchart on Fig. 1. At the end of the process, 93 studies remained as well as four studies from authors' recommendations and personal communications. The 97 studies used a burnout measure on informal caregivers. Among these, 18 studies compared caregivers and non-caregivers. Two distinct sets of studies were identified: eleven studies using family care burnout measures (i.e., burnout measure adapted to non-working roles such as parenting or being a spouse) and seven studies on professional burnout (i.e., studies investigating the impact of being an informal caregiver on professional burnout).

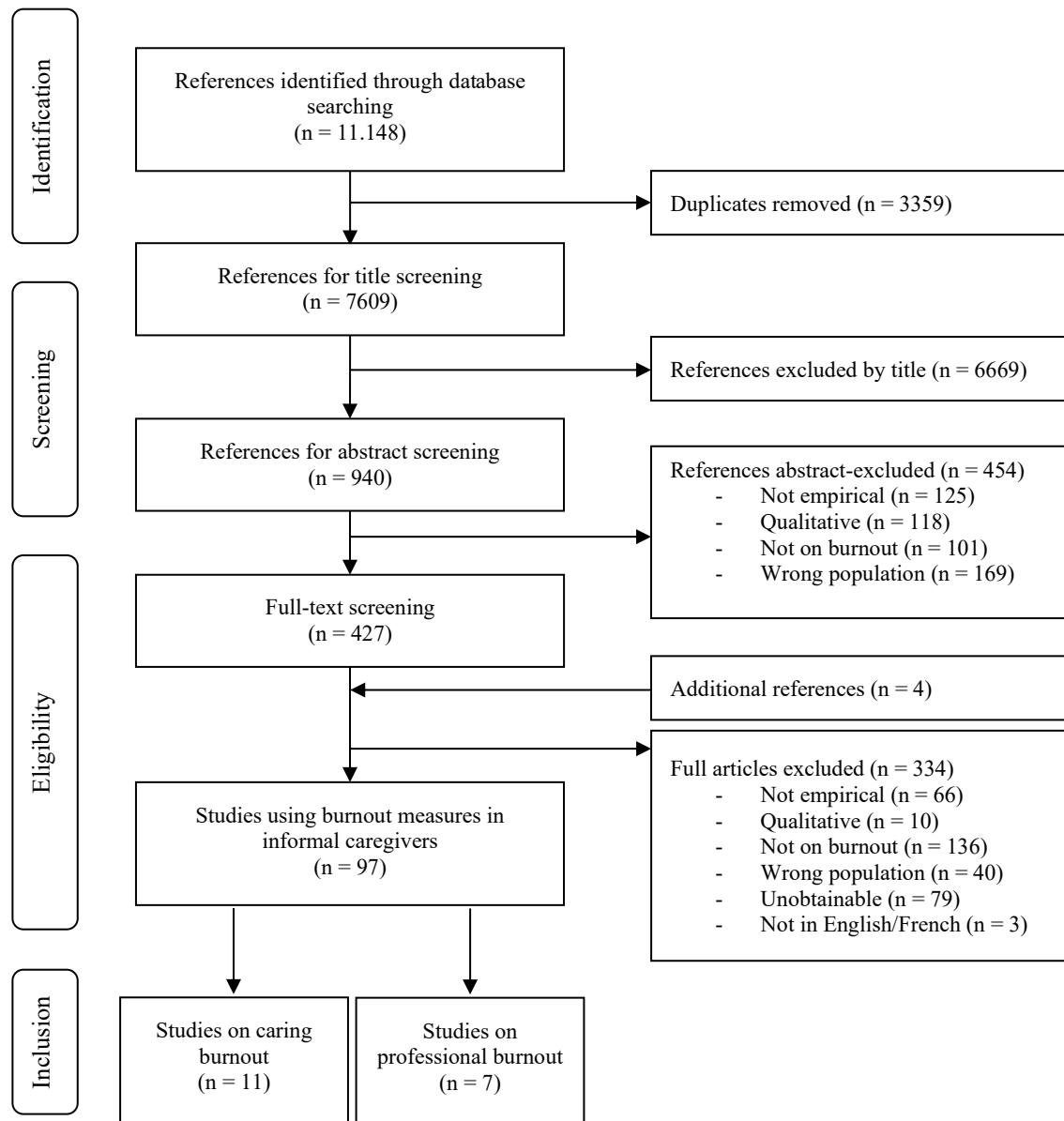


Fig. 1. PRISMA flowchart of the inclusions process of the studies.

4.2 Study characteristics

Table 1 shows the characteristics of the eighteen works included. Among the family care burnout studies, one study focused on caregiving to a spouse with PTSD (Klarić et al., 2010), while the other 10 focused on parenting a child with special needs (Basaran, Karadavut, Uneri, Balbaloglu, & Atasoy, 2013; Duygun & Sezgin, 2003; Gérain & Zech, 2018; Lindahl Norberg, 2007; Lindahl Norberg, Mellgren, Winiarski, & Forinder, 2014; Lindström, Åman, & Norberg, 2010; Mikolajczak et al., 2018; Séjourné, Sanchez-Rodriguez, Leboulenger, & Callahan, 2018; Weiss, 2002). Among the studies on professional burnout, six studies focused on double-duty caregivers (i.e., healthcare professionals who are at the same time informal caregivers) (Boumans & Dorant, 2014; DePasquale, Mogle, et al., 2018; DePasquale, Polenick, Davis, Berkman, & Cabot, 2018; DePasquale, Zarit, et al., 2018; Häusler, Bopp, & Hämmig, 2017; Yank et al., 2019), and one focused on white-collar workers who also provide informal care (Dorant & Boumans, 2016). This latter study presented two subsamples but one was already presented in another included study on double-duty (Boumans & Dorant, 2014).

Table 1. Characteristics of the included studies.

Authors	Publ. Year	Type	Sample's origin	Sampling	Recipient's issue	Type of caregiving	BO scale	N IC	N control	% Female IC	IC age
Family care burnout studies (parental and spouse caregivers)											
Basaran et al.	2013	Article	Turkey	Purposive	Cerebral Palsy	Parent	MBI-P	143	60	44.1	33.3
Benutto	2016	Thesis	Online (Eng)	Purposive	Cerebral Palsy	Parent	MBI-P	106	101	98.5	30.0
Duygyn & Sezgin	2003	Article	Turkey	Purposive	Mental disab.	Parent	MBI-P	118	121	100.0	34.0
Géran & Zech	2018	Article	Online (Fr/Eng)	Random	Unspecific	Parent	PBI	132	717	86.5	38.2
Klaric et al.	2010	Article	Bosnia & Herz.	Purposive	PTSD	Spouse	MBI-S	153	77	100.0	45.1
Lindahl N. et al.	2007	Article	Sweden	Random	Cell transplant	Parent	SMBQ	44	259	54.5	41.0
Lindahl N. et al.	2014	Article	Sweden	Random	Brain tumour	Parent	SMBQ	278	403	56.4	n.m.
Lindström et al.	2010	Article	Sweden	Random	IBD & TD IM	Parent	SMBQ	289	124	56.4	43.3
Mikolajczak et al.	2018	Article	Online (Fr)	Random	Unspecific	Parent	PBI	194	1529	89.2	42.6
Séjourné et al.	2018	Article	France	Random	Unspecific	Mix	BMS-P	27	236	100.0	36.7
Weis	2002	Article	USA	Purposive	Autism & MR	Parent	MBI-P	80	40	100.0	n.m.
Professional burnout studies (double duty caregivers and office workers)											
Boumans & Dorant	2014	Article	Netherlands	Random	Unspecific	Double-Duty mix	UBOS	93	235	90.3	47.6
DePasquale, Mogie et al.	2018	Article	USA	Random	Unspecific	Double-Duty adult	MBI	300	672	92.4	37.4
DePasquale, Polenick, et al.	2018	Article	USA	Random	Unspecific	Double-Duty adult	MBI	152	394	100.0	43.1
DePasquale, Zarti, et al.	2018	Article	USA	Random	Unspecific	Double-Duty adult	MBI	34	89	0.0	35.3
Dorant & Boumans*	2016	Article	Netherlands	Random	Unspecific	Office workers	UBOS	62	499	64.5	44.9
Häusler et al.	2017	Article	Switzerland	Random	Unspecific	Double-Duty adult	CBS	112	1294	94.6	n.m.
Yank et al.	2019	Letter	Online (USA)	Random	Unspecific	Double-Duty mix	MZBS	918	4695	100.0	40.7

Note. BO scale = Burnout scale used as a base for the questionnaire. IC = Informal Caregivers. * Dorant & Boumans had two distinct samples: one in a care company (CC) and one in a financial company (FC). IBD = Inflammatory bowel disease. TDIM = Type 1 Diabetes Mellitus. MR = Mental Retardation. MBI = Maslach Burnout Inventory. MBI-P = Maslach Burnout Inventory adapted to parenting. MBI-S = Maslach Burnout Inventory adapted to spouse. SMBQ = Shirom Melamed Burnout Questionnaire. PBI = Parental Burnout Inventory. BMS = Burnout Measure Short form adapted to parenting. UBOS = Utrecht Burn Out Scale. CBS = Copenhagen Burnout Inventory. MZBS = Mini Z Burnout Survey.

4.3 Risk of bias within studies

All studies used cross-sectional design and none matched participants between caregiving and control groups. Variability lied in clear inclusion criteria and control at baseline. Eight studies had a score of 2/4 and ten had 3/4.

4.4 Synthesis of results

4.4.1 Emotional Exhaustion in Family Care Burnout

Because only one study was not focusing on parental burnout, the analyses for emotional exhaustion were first performed on parental burnout studies only, and then including the additional adult study.

Summary Effect Size. Fig. 2a presents the results of the meta-analysis for emotional exhaustion. One study (Weiss, 2002) was considered an outlier because its ES was more than ten SE larger than the average ES. This study was thus excluded from all analyses. The remaining ten studies were included with ES ranging from small ($d = 0.11$) to very large ($d = 1.20$) (Cohen, 1992; Sawilowsky, 2009).

For parent-studies only, the summary effect size was medium ($d = 0.43$, 95% CI = [0.26; 0.59], $k = 9$, $Z = 5.14$, $p < .001$). Indicators highlighted heterogeneity between the studies ($Q(8) = 34.24$, $p < .001$, $I^2 = 77.69$). When including the adult study, the summary effect size was slightly higher ($d = 0.51$, 95% CI = [0.30; 0.72], $k = 10$, $Z = 4.82$, $p < .001$, see Fig. 2b) and indicators highlighted more heterogeneity between the studies ($Q(9) = 64.17$, $p < .001$, $I^2 = 87.39$). The inclusion of the adult study thus led to a higher mean ES, but higher heterogeneity.

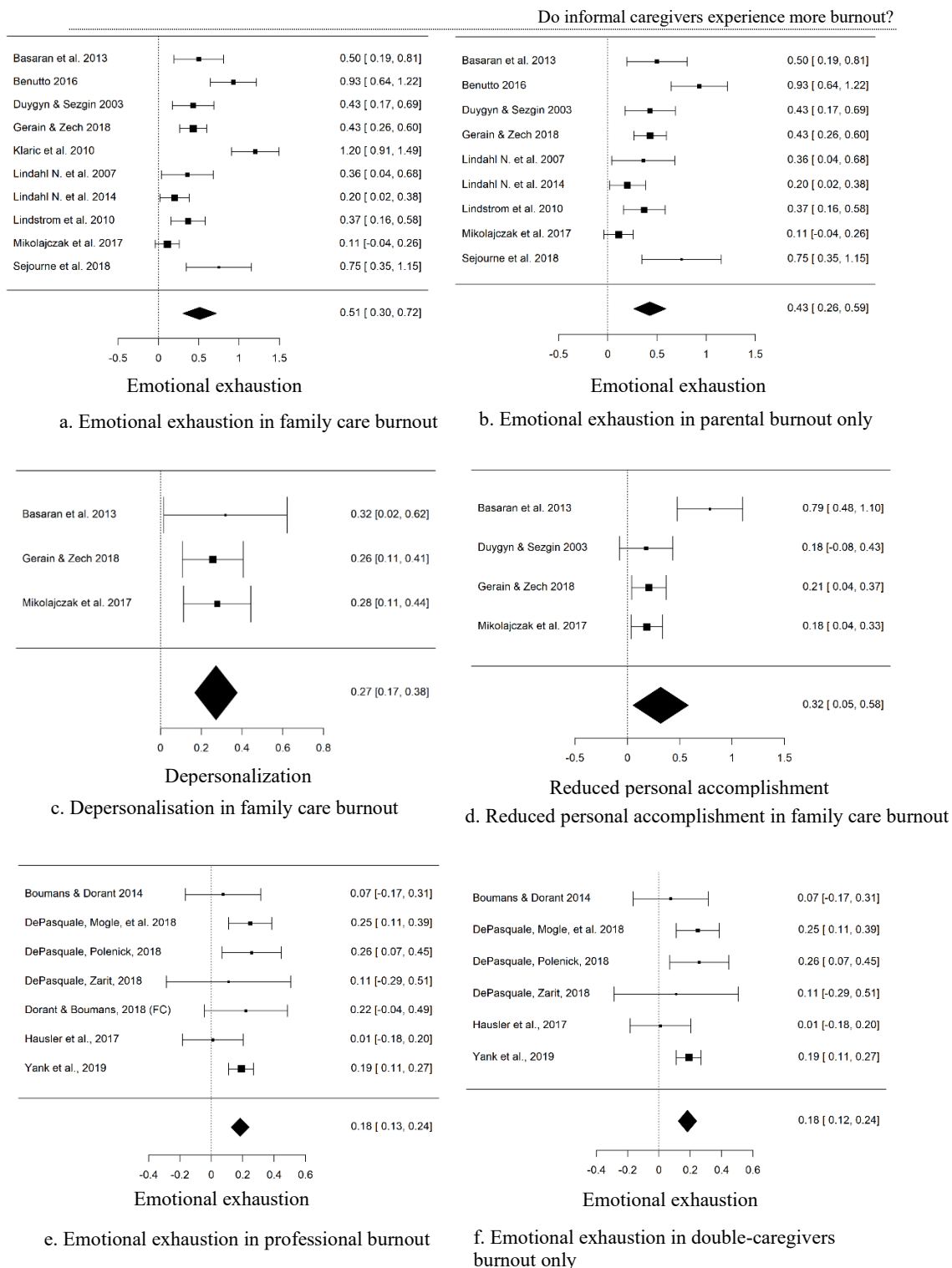


Fig. 2. Summaries of the differences in means between informal caregivers and non-caregivers in different contexts.

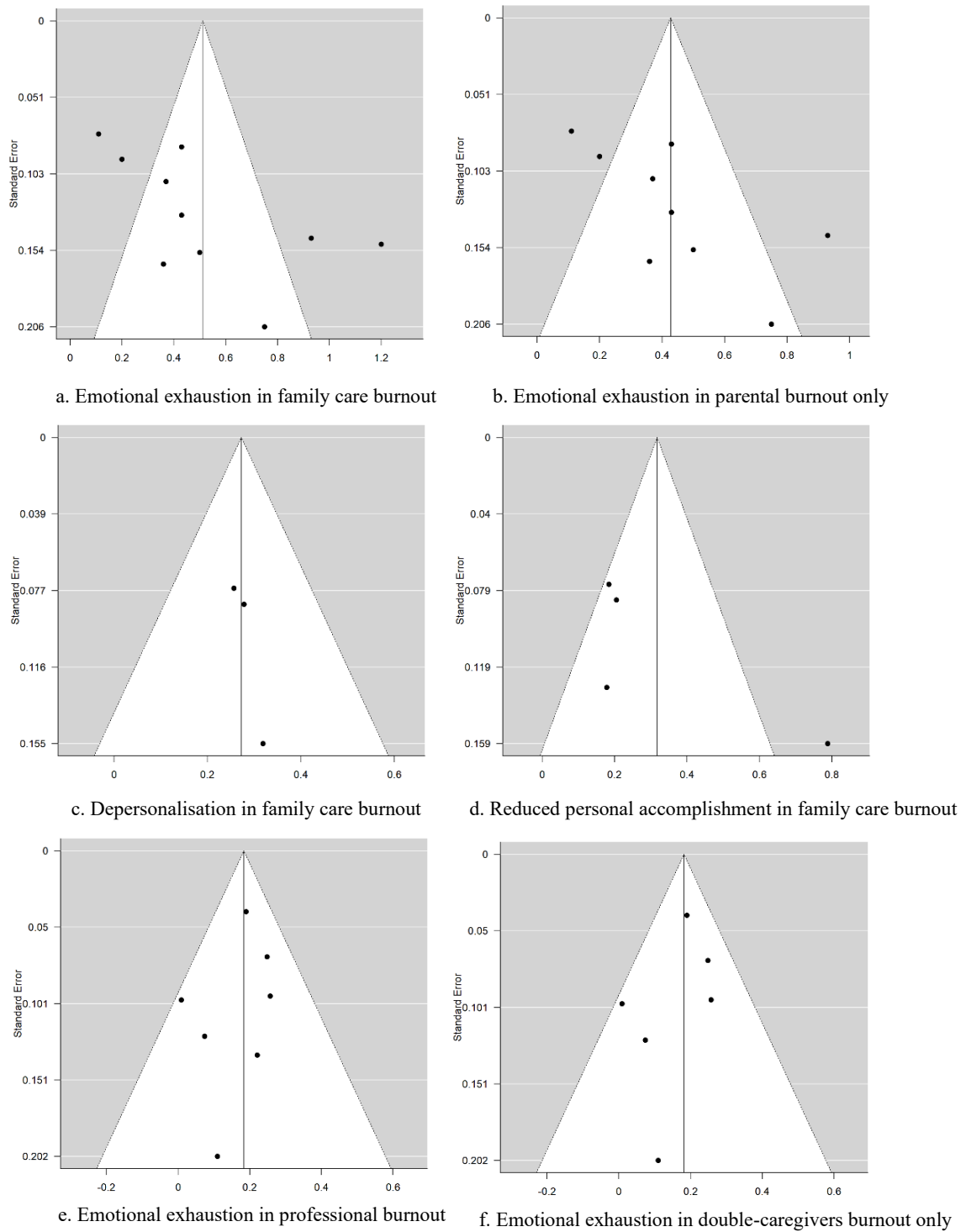


Fig. 3. Funnel plots of the included studies.

Risk of Bias. Figure 3a shows a potential asymmetry, which was disconfirmed by the rank correlation test (Kendall Tau = 0.39, $p = .180$) and confirmed by the regression for funnel plot asymmetry ($Z = 2.57$, $p = .010$). Fail-safe was of 342 to null ES. When including the adult study, results were comparable (Kendall Tau = 0.47, $p = .073$, $Z = 2.29$, $p = .022$, Fail-safe = 546, see Fig. 3b).

Moderator Analyses. Moderators analyses are presented in table 2. The scale had no impact on ES, but the relation with the care-recipient was significant and indicated that caring for an adult leads to higher ES than for a child. Finally, the potential purposive sampling also led to higher effect-sizes.

4.4.2 Depersonalization

Summary Effect Size. Fig. 2c presents the results of the meta-analysis for depersonalization. Three studies were included with ES ranging from small ($d = 0.26$) to mid-small ($d = 0.32$). The summary effect size was mid-small ($d = 0.27$, 95% CI = [0.17 ; 0.38], $k = 3$, $Z = 5.13$, $p < .001$). Indicators highlighted an absence of heterogeneity between the studies ($Q(2) = 0.14$, $p = .933$, $I^2 = 0$), but it is most likely related to the small number of studies.

Risk of bias. Fig 3c shows an absence of asymmetry, which seems confirmed by the rank correlation test (Kendall Tau = 1.00, $p = .333$) and regression for funnel plot asymmetry ($Z = 0.35$, $p = .730$). Fail-safe was of 26 to null ES.

Moderator analyses. Moderators analyses could not be performed due to the small number of included studies ($k = 3$).

4.4.3 Reduced personal accomplishment

Summary effect size. Fig. 2d presents the results of the meta-analysis for reduced personal accomplishment. Four studies were included with ES ranging from small ($d = 0.18$) to large ($d = 0.79$) (Cohen, 1992; Sawilowsky, 2009). The summary effect size was medium ($d = 0.32$, 95% CI = [0.05 ; 0.58], $k = 4$, $Z = 2.36$, $p = .018$). Indicators highlighted heterogeneity between the studies ($Q(3) = 12.83$, $p = .005$, $I^2 = 84.71$).

Risk of bias. Fig. 3d shows a possible asymmetry, which tends to be confirmed by the rank correlation test (Kendall Tau = 1.00, $p = .083$) and regression for funnel plot asymmetry ($Z = 1.85$, $p = .065$). Fail-safe was of 43 to null ES.

Moderator Analyses. Moderators analyses are presented in table 2. Only the proportion of women appears to have an impact on ES, the more caregiving women in the sample, the smaller was the Reduced Personal Accomplishment when caregiving. The age and the sampling did not have a significant impact.

Table 2. Moderator analyses.

Moderator	Family Care burnout						Professional burnout								
	Family care Exhaustion (k = 10)			Parental exhaustion (k = 9)			Family care RPA (k = 4)			Double duty exhaustion (k = 6)			Professional exhaustion (k = 7)		
	B	Z	p	B	Z	p	B	Z	p	B	Z	p	B	Z	p
Adult recipient or mix	0.60	2.83	.005												
Specific Scale	0.30	1.32	.187	0.19	1.06	.288									
Purposive Sampling	0.42	2.40	.016	0.28	1.83	.067	0.27	0.99	.324						
Caregiver mean age	-0.01	-0.35	.723	-0.04	-3.25	.001	-0.04	-1.00	.317	-0.01	-0.77	.440	-0.01	-0.67	.504
%WomenCg	0.01	1.58	.114	0.00	1.05	.296	-0.01	-3.45	.001	0.00	0.48	.628	0.00	0.32	.746
Study Quality	0.33	1.72	.085	0.22	1.40	.163	0.28	1.01	.315	0.19	1.84	.066	0.12	1.36	.173
Publication Year	-0.00	-0.04	.970	0.02	0.35	.726	0.00	0.05	.963	0.03	1.22	.223	0.02	1.05	.293
Scimago Journal rank	-0.36	-0.98	.326	-0.07	-0.31	.758	0.12	0.23	.819	0.01	0.57	.566	0.01	0.57	.566

Note. No moderator analyses could be performed on depersonalization/emotional distancing due to the small number of included studies ($k = 3$). Family care burnout encompasses the studies in parental exhaustion plus the adult study, Klancic et al. (2010). Professional exhaustion studies encompass double duty exhaustion studies, plus Dorant & Boumans (2016), the white-collar study. RPA = Reduced Personal Accomplishment. %WomenCg = proportion of female caregivers. Specific Scale = Burnout scale specific to one role.

4.4.4 Professional Emotional Exhaustion

Most of the included studies on professional burnout focused on comparing double-duty caregivers (i.e., healthcare professionals also providing informal care) with healthcare professionals not providing informal care. Because of that, the analyses for professional exhaustion were first performed on double-duty studies only, and then including the additional white-collar study (where white-collar workers providing informal care were compared to those not providing such care). Among the seven double-duty studies, four considered that individuals were double-duty caregivers if they had a child, regardless of the presence of an illness, disability, or any trouble requiring special care (DePasquale, Mogle, et al., 2018; DePasquale, Polenick, et al., 2018; DePasquale, Zarit, et al., 2018; Häusler et al., 2017). In those cases, individuals having a child without illness, disability, or any trouble were considered as part of the control group and not as double-duty caregivers. One study presented adjusted rather than raw means (Boumans & Dorant, 2014). Standard errors were thus converted to standard deviations in order to compute the effect size in a more conservative way (Altman & Bland, 2005).

Summary Effect Size. Fig. 2e presents the summary effect size for professional emotional exhaustion. In the six studies on double-duty caregivers, effect-sizes ranged from null ($d = 0.01$) to small ($d = 0.26$). The summary effect-size was small but highly significant ($d = 0.18$, 95% CI = [0.12; 0.24], $k = 6$, $Z = 6.11$, $p < .001$). Indicators did not highlight heterogeneity between the studies ($Q(5) = 5.54$, $p = .353$, $I^2 = 0$). The inclusion of the white-collar study led to comparable results ($d = 0.18$, 95% CI = [0.13; 0.24], $k = 7$, $Z = 6.32$, $p < .001$, $Q(6) = 5.62$, $p = .467$, $I^2 = 0$, see Fig. 2f).

Risk of Bias. For double duty caregiving studies, Fig. 3e did not seem to present asymmetry, which seems confirmed by the rank correlation test (Kendall Tau = -0.33, $p = .469$) and by the regression for funnel plot asymmetry ($Z = -0.89$, $p = .372$). The Fail-safe was of 50. The inclusion of the white-collar study led to comparable results (Kendall Tau = -0.24, $p = .562$, $Z = -0.72$, $p = .472$, Fail-safe = 64, see Fig. 3f).

Moderator Analyses. As shown in Table 2, moderator analyses for double-duty caregivers did not highlight any significant moderator. Comparable results were highlighted when including the white-collar study.

5. Discussion

The present study aimed at investigating if informal caregivers experience more burnout than non-caregivers. To do so, a literature review highlighted eighteen studies, eleven on family burnout (i.e., spouses and parents) and seven on professional burnout (i.e., double-duty caregivers and white-collar workers). For family burnout, meta-analyses showed a significant increase of emotional exhaustion, depersonalization, and personal accomplishment when providing care for a relative. For professional burnout, meta-analyses have highlighted a significant increase in professional burnout when providing informal care.

In regard to the role accumulation theory, such findings suggest that the addition of the caregiving role does put an additional weight on the individuals (Bastawrous, 2013).

Most of the family burnout studies were investigating parental burnout. The analyses support that caring for a child with special needs represent a risk of parental burnout. This area of research is growingly investigated (Sánchez-Rodríguez et al., 2019). This impact is small to moderate, which could explain why some studies did not identify a significant role of caregiving in their initial studies (Lindahl Norberg et al., 2014; Mikolajczak et al., 2018). An important amount of heterogeneity remains to be considered to refine the understanding of their experiences.

On the opposite, few studies investigated spousal burnout. The concept of spousal burnout does not represent a widespread field of research in itself, despite some research on couples (Pines & Nunes, 2003) or marital burnout (Leaman, 1983). Most research has focused on the “crossover of burnout”, the impact of professional burnout on the worker’s spouse health (Bakker, 2009) or the spouse as a social resource when facing burnout (Appel & Kim-Appel, 2008).

Most of the studies in professional burnout included in the present review focused on double or triple-duty caregivers (i.e., healthcare professionals also providing informal care). The present results highlight the permeability of an individual among its different roles (Bianchi, Truchot, Laurent, Brisson, & Schonfeld, 2014). Although the effect sizes remain quite small, these results highlight the necessity to consider that professional burnout is not solely job related (Schaufeli & Taris, 2014), and that caring professionals might be prone to be impacted by informal caregiving. Future studies should investigate more in depth how double-duty caregivers might experience this double-caring overload and what could make them particularly at risk (Ward-Griffin, St-Amant, & Brown, 2011).

It appears that little research has been performed on the impact of informal caregiving on professional burnout, apart from double-duty caregivers. In addition to the included study (Dorant & Boumans, 2016), one investigation has quantitatively examined burnout in the “sandwiched generation” (i.e., having a child at home and at the same time providing informal care to a parent) (Pines, Neal, Hammer, & Icekson, 2011). This study did not include a control group and was thus not included but it indicated that informal care stressors were one of the elements leading to professional burnout, even more than stressors related to parenting. Regarding our present results, future research on various forms of burnout should therefore, at minimum, control for the presence of informal caregiving and at best try to understand in which ways it interferes with their different other roles.

The online research of articles led to finding more than ten thousand references. The 97 finally screened studies indicated that terms used to describe caregivers are very diverse (e.g., caregivers, partners, mothers, parents, significant others, primary caregivers, care-providers). The term caregivers covers many roles outside of informal caregiving, the two main involving being either a parent or a nurse. This polysemy and the profusion of terms underscore the need to have a better reporting of studies investigating informal or family caregiving. The terms of double or triple-duty caregiving also appear ambiguous. Indeed,

several studies considered that parents of typical children could be considered as double caregivers, while other studies considered only parents of children with a disability or an illness as potential double-duty caregivers. In the present work, we used only the latter definition since it is more representative of having an additional strain or double duty in such cases. However, such conceptual ambiguity could lead to misunderstandings in this emerging literature.

6. Perspectives

Beyond parents, spouses, white-collar workers, and formal caregivers, the present results mostly pave the way of extending the consideration of non-professional burnout to informal caregivers. Although the origin of burnout is solely professional, chronic stress – and, as a consequence, burnout – is not exclusive to work (Bianchi et al., 2014). This kind of approach has led to the consideration of forms of burnout such as parental or student burnout, and now allows to consider the existence of the informal caregiver burnout (Gérain & Zech, 2019). The present literature screening has permitted to identify a rising number of studies using burnout measures to investigate caregiving strain. This use of burnout measures could be a way to answer criticisms regarding the actual ways of apprehending caregiving strain (Bastawrous, 2013; Mosquera et al., 2016).

7. Conclusions and implications

The present results support the increase of strain experienced when someone informally provides care to a relative. This was clearly shown for parents and formal caregivers, and to a lesser extent for spouses and white-collar workers. The direct implication of these results is to better understand one aspect of the impact of the pressure exerted on the caregiver, as long-term care systems rely more and more on them. In terms of public policies, showing the global impact of informal care on other spheres (such as parenting, or work), also highlight the necessity to consider informal care as a key-element throughout the system and not only when focusing on the care recipient's health.

The second main implication is the necessity to directly address the possibility of a form of burnout applied to informal caregivers. The present summary provides strong indicators that informal caregiving has an impact on other roles burnout. It thus calls for a necessary consideration of informal caregiving burnout in itself.

Section 1

Conclusive note

This chapter intended to investigate the studies comparing informal caregivers and non-caregivers with burnout measures. Two set of studies were identified. The first set focused on studies investigating “family” burnout, which is the reunion of parental and spousal burnout. Most of these studies investigated (emotional) exhaustion, and some of them also used measures of depersonalization/emotional distancing and personal accomplishment. The summary of the results of the eleven studies let to the conclusion that being an informal caregiver did lead to an increase of “family” burnout, and in particular to parental burnout for the three dimensions.

The second set of studies investigated if being an informal caregiver led to an increase in professional burnout. Most of these studies focused on double-duty caregivers who are healthcare professionals also providing informal care outside of their work. Only one study investigated it among white-collar workers. The summary results did highlight an increase of burnout when providing informal care, although this effect remained relatively small.

These results suggest that being a caregiver may, overall, represent a risk of family and work burnout. Nevertheless, this meta-analysis remained descriptive and provided no key to understanding why such a risk could be observed. It was therefore a call for a more in-depth investigation into the difficulties faced by informal caregivers.

Section 2

A theoretical approach of informal caregiver burnout

A theoretical approach of informal caregiver burnout

Section 1 highlighted that informal caregiving could represent a risk factor of burnout, mostly among healthcare professionals and parents. But these results were only descriptive and provided no key to understand *how* such issue could occur. Moreover, part of the studies found in the literature review were investigating directly informal caregiver burnout. There was therefore a need to have a clear picture on what is existing in research on informal caregiver burnout.

To answer that, and based on the same literature review used in chapter 1, a qualitative review of the literature is first presented in order to have a picture of the present state of research on the correlates of informal caregiver burnout (chapter 2). This review was published in a French book under the title “*Les antécédents et conséquences du burnout chez les aidant.e.s*” (2020). This book aimed at understanding and addressing different forms of burnout, mainly for a mental healthcare audience.

The second part of this section (Chapter 3) presents the rationale for studying informal caregiver burnout *per se*, and why it is a response to the current struggle to measure the negative consequences of informal caregiving. It was published in 2019 under the title “*Informal Caregiver Burnout? Development of a Theoretical Framework to Understand the Impact of Caregiving*” in *Frontiers in Psychology*. The aim of this paper was to propose a theoretical framework to address the informal caregiver burnout and find ways to investigate it. To do so, existing models are discussed and a new one, the Informal Caregiving Integrative Model (ICIM), is proposed, as an answer to previous models’ strengths and limits.

Chapter 2

Les antécédents et conséquences du burnout chez les aidant.es

Several studies have already investigated informal caregiver burnout. These studies focused on different caregiving settings and investigated variables, but have all adapted burnout to informal care. The present narrative literature review in French summarizes their finding on determinants and consequences of informal caregiver burnout. The determinants can be clustered in three domains: the caregiver's characteristics, the care-recipient's characteristics, and the context. In these three domains, some determinants appear as unchangeable (and little can be done about them) but others provide promising ways to tackle informal caregiver burnout. Outside of these three categories of determinants, two particular elements stand out: the relationship quality with the care-recipient and the subjective evaluation of caregiving. They appear to be clearly distinct from the others because they are determinants of informal caregiver burnout, but are defined by the other determinants involved, suggesting a mediator role. The overview of the consequences suggests that informal caregiver burnout can affect the caregivers themselves in terms of physical and mental issues, but also the care-recipient, whether it is neglect of violence behaviour, or intention to leave the caregiving role. Overall, these results suggest that informal caregiver burnout has significant consequences and is the product of a complex set of determinants which can be addressed.

Reference

Gérain, P., & Zech, E. (2020). Les antécédents et conséquences du burnout chez les aidant.es. In M. Mikolajczak, E. Zech, & I. Roskam, *Burn-out professionnel, parental et de l'aidant : Comprendre, prévenir et intervenir*. De Boeck.

Les antécédents et conséquences du burnout chez les aidant.es

1. Introduction

Comme énoncé plus tôt, la recherche s'est longtemps centrée sur la mesure du fardeau – tant objectif que subjectif – que pouvaient rencontrer ceux-ci pour comprendre ce qui vulnérabilise les aidants. Le fardeau objectif est la pénibilité objective du rôle d'aidant, alors que le fardeau subjectif est la perception que l'aidant a de ce rôle, de sa pénibilité et ses potentielles conséquences (Zarit & Zarit, 2015). Cette focalisation a néanmoins éclipsé les recherches qui pointaient que mesurer le fardeau n'était pas suffisant et qu'il était nécessaire de considérer sa conséquence en termes de souffrance psychologique : le burnout de l'aidant. La recherche sur le burnout de l'aidant reste moins étendue que celle portant sur le burnout professionnel. Néanmoins, de plus en plus de recherches sont réalisées et permettent de mieux comprendre le burnout de l'aidant, et quelles en sont les causes et les conséquences (Gérain & Zech, 2019).

Au même titre que pour le burnout professionnel, parler du burnout de l'aidant au singulier serait réducteur au vu de la diversité des situations rencontrées. Comparer un aidant d'une personne avec une maladie neurodégénérative avec un parent d'un enfant ayant un cancer peut paraître inapproprié. Cette hétérogénéité, si elle doit questionner tant la pratique que la recherche, n'empêche pas d'identifier des éléments et des tendances communes à toutes les situations d'aide. Aussi, les éléments présentés dans le présent chapitre considèrent les aidants dans ce qu'ils ont en commun. Les nuances, quant aux spécificités des situations d'aide, ne sont faites que lorsque des données contradictoires ont été publiées ou lorsqu'une distinction est nécessaire. Dans tous les cas, il est important de considérer que les déterminants et conséquences présentés sont autant de pistes d'investigations pour le praticien, mais n'ont pas force de vérité.

Dans ce chapitre, les antécédents du burnout de l'aidant seront d'abord évoqués. Ceux-ci se distinguent en trois ensembles ; (1) les aidants en tant qu'individus, (2) la situation d'aide et (3) le contexte dans lequel aidant et aidé évoluent. Avant de passer aux conséquences du burnout de l'aidant, deux éléments-clés seront ensuite évoqués ; (1) la relation avec la personne aidée et (2) l'évaluation subjective de l'aidant.

Il faut noter que la distinction entre antécédents et conséquences est parfois très fine. Si certains antécédents se distinguent comme tels (par exemple, le genre de l'aidant est clairement un antécédent car ne change pas au cours du temps), d'autres peuvent être autant des antécédents que des conséquences du burnout de l'aidant. Si, d'une manière ou d'une autre, un antécédent a un impact sur le risque de burnout de l'aidant, il peut, dans certains cas, être à son tour impacté par l'état émotionnel de celui-ci. La conséquence devient alors l'antécédent, ouvrant à une causalité circulaire, qui pourrait, dans certains cas, être un cercle vicieux.

2. Les principaux antécédents du burnout de l'aidant

2.1 Chez l'aidant

Avant d'être dans une situation d'aide, l'aidant est une personne à part entière. Aussi, ses traits de personnalité propres peuvent avoir un impact sur sa manière de gérer la situation d'aide et les émotions qu'elle engendre. Ces caractéristiques personnelles à l'aidant peuvent ainsi faciliter, ou au contraire prévenir, le burnout de l'aidant.

2.1.1 Caractéristiques de l'aidant

Les aidants sont de tous les âges car ils sont parfois conjoints, parents, grands-parents, enfants, ou simplement amis ou voisins. Les recherches n'ont pas établi de lien entre l'âge de l'aidant et son risque d'épuisement émotionnel (Onwumere et al., 2015). Les résultats sont moins uniformes quant à l'impact du *genre*. En effet, une partie des études ne montre pas de différence entre les hommes et les femmes (Kokurcan, Özpolat, & Göğüş, 2015; Yılmaz, Turan, & Gundogar, 2009) alors qu'une autre pointe que les femmes sont plus à risque de burnout (Angermeyer, Bull, Bernert, Dietrich, & Kopf, 2006; Truzzi et al., 2012). Si être une femme n'est pas systématiquement synonyme de burnout de l'aidant, elles présentent néanmoins un profil plus à risque, ne fut-ce que parce qu'elles demeurent plus facilement désignées comme aidantes que les hommes (Verbakel, Tamlagsrønning, Winstone, Fjær, & Eikemo, 2017).

Sachant que comme célibataire, j'avais plus de temps à y consacrer que mon unique frère (père de plusieurs enfants), chaque soirée, weekend et tous mes congés ont été consacrés à aider ma mère. *Aidante s'occupant de sa mère ayant une maladie d'Alzheimer*

Les *aidants célibataires* sont plus souvent désignés comme l'aidant principal. Les études n'ont pas montré de risque particulier selon la situation matrimoniale (Angermeyer et al., 2006; C. Lindström, Åman, & Norberg, 2011). Toutefois, une recherche a montré que les aidants mariés sont plus à l'abri d'une perte du sentiment d'accomplissement personnel que les personnes seules (Angermeyer et al., 2006). Dans le même ordre d'idées, le *niveau d'éducation* semble avoir un impact sur l'accomplissement personnel en tant qu'aidant. Plus les aidants ont un niveau d'éducation élevé, plus ils sont à même de trouver du sens dans leur action (Kokurcan et al., 2015; Yılmaz et al., 2009). Être marié et avoir un haut niveau d'éducation joueraient donc un rôle protecteur pour la perception de la situation d'aide, sans avoir d'impact sur l'épuisement émotionnel en soi.

2.1.2 Le temps et le travail

Abordant la question de la durée de temps à accorder à l'aide, plusieurs initiatives, légales ou sociales, invitent les aidants à prendre un « congé d'aidant » ou une *pause carrière* pour pouvoir s'occuper de son proche afin de ne pas devoir jouer sur plusieurs plans en même temps. Pourtant, continuer à travailler peut représenter tant un facteur de risque qu'un facteur de protection. Les recherches empiriques ont montré que ceux qui maintiennent une activité professionnelle sont moins sujets au burnout que ceux qui sont aidants à temps plein

(Kokurcan et al., 2015). Travailler semble alléger le poids de l'aide. Une recherche a, par ailleurs, pointé que les aidants travaillant (ou retraités) ont plus d'accomplissement dans leur rôle d'aidant que ceux restant au foyer (Yilmaz et al., 2009). Mais continuer à travailler peut aussi signifier devoir jongler entre plusieurs responsabilités, amenant une multiplication des formes de stress, avec un risque que le bateau ne prenne l'eau de tous les côtés (C. Lindström et al., 2011). Travailler permet donc, si ce n'est pas une trop grande source de stress, de se distraire, de changer d'air, de s'accomplir et de diminuer son risque de burnout. Il faut néanmoins noter que cet effet protecteur du travail peut aussi cacher une réalité différente. En effet, l'aidant qui travaille peut avoir déchargé certaines de ses responsabilités d'aidant sur une autre personne et ce sont à nouveau les femmes qui optent plus souvent pour une diminution de leur temps de travail pour aider un proche (Verbakel et al., 2017). Dans tous les cas, changer sa situation professionnelle n'est pas sans impact financier. Diminuer son temps de travail amène à une diminution du revenu qui peut causer d'autres sources de stress, notamment quant à la situation financière. L'aspect financier sera abordé plus loin dans ce chapitre.

A un moment je me suis dit, je dois retourner au travail parce que j'ai besoin d'une distraction (Basnyat & Chang, 2016). *Une aidante de son parent souffrant de la maladie d'Alzheimer*

L'accumulation des rôles, comme par exemple être parent en même temps qu'être aidant, met également un poids supplémentaire sur les épaules des aidants (de Almeida Mello et al., 2016; Stephens, Townsend, Martire, & Druley, 2001). Des recherches ont par exemple pointé qu'être aidant augmente le risque de burnout parental (Gérain & Zech, 2018; C. Lindström et al., 2011; Séjourné, Sanchez-Rodriguez, Leboulenger, & Callahan, 2018). Être aidant a donc un impact sur ses autres rôles, et inversement. Une situation particulière est celle des « *double aidants* » qui travaillent dans le domaine de la santé et sont également aidants en dehors du travail. Ils exercent une profession qui est particulièrement à risque de burnout professionnel (Angermeyer et al., 2006) et y ajouter une charge informelle fait d'eux des « aidants perpétuels ». Quand ils quittent le travail, c'est pour rejoindre une autre situation d'aide. De fait, les recherches sur le burnout professionnel pointent que ces doubles aidants sont plus à risque de craquer que les autres (Anjos, Ward-Griffin, & Leipert, 2012). Ils sont plus à même d'être chargés par les autres membres de la famille d'aider le proche car ils ont des compétences (para)médicales parfois nécessaires pour prendre en charge la personne aidée, ce qui peut d'autant plus amener à les surcharger (Anjos et al., 2012).

Etant soignante [...], j'avais toutes les ficelles pour tout mettre en place. Je m'y suis cassée la gueule. *Fille d'une femme atteinte de cancer*

2.1.3 Régulation des émotions et coping

Les émotions jouent un rôle important dans le burnout de l'aidant (Kindt et al., 2015). Dans le burnout professionnel, la gestion des émotions est centrale et le cas des aidants ne fait pas exception – bien au contraire. En effet, l'aidant doit d'abord faire face aux stress du quotidien (organiser la vie quotidienne, composer avec les symptômes, etc.), mais doit également gérer les émotions suscitées par la relation à la personne aidée. Face à cela, les aidants ayant plus de difficultés à décrire et à identifier leurs émotions (dits alexithymiques)

sont plus à même de s'épuiser émotionnellement et de manifester de la dépersonnalisation. Ces résultats suggèrent un rôle des *compétences émotionnelles* chez les aidants (Katsifaraki & Wood, 2014), ce qui fait écho aux études pointant le rôle protecteur de bonnes compétences émotionnelles dans le burnout professionnel et parental.

Si certaines recherches abordent les tendances générales de la gestion des émotions, d'autres se sont centrées sur les manières plus spécifiques dont chacun gère ses émotions. De manière générale, plus l'aidant dispose d'un large éventail de stratégies de gestion des émotions, mieux il se porte (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014). Plus particulièrement, des recherches ont permis de mettre en avant le rôle (non)adaptatif de plusieurs stratégies. Les stratégies cognitives représentant un facteur de risque de burnout pour l'aidant sont le *blâme de soi* (Elçi, 2004) et les *attributions externes* (Yilmaz et al., 2009). Ces deux stratégies concernent les attributions causales, c'est-à-dire à la perception des causes des événements. La première réfère au fait de s'attribuer la responsabilité des événements à soi-même, même lorsque ce sont des éléments extérieurs qui sont en cause (« c'est de ma faute ») et la seconde réfère au fait d'attribuer la responsabilité des événements à des facteurs extérieurs, même lorsque l'individu serait à même de les modifier (« je suis victime des événements, il n'y a rien que je puisse faire »). Ce type d'attribution dite « externe » amène à un manque perçu de contrôlabilité sur l'environnement. À l'opposé, une approche réaliste, mais globalement optimiste et confiante, est un facteur de protection face au burnout de l'aidant (Yilmaz et al., 2009). À niveau comportemental, la distraction semble exercer un rôle protecteur pour l'aidant (Okabayashi et al., 2008). Il est ici plus à même de gérer ses émotions quand il peut prendre du temps pour faire autre chose et/ou se divertir. Cela fait écho aux recherches pointant la nécessité de s'accorder du temps libre ; les aidants ne s'accordant pas de temps libre présentent plus de symptômes de burnout que ceux qui prennent ce temps (Lindström et al., 2011). Néanmoins, pouvoir prendre du temps n'est pas toujours (perçu comme) possible et les personnes doivent parfois composer avec la culpabilité de prendre du temps pour soi, point qui sera abordé plus loin.

J'étais frustrée. Je suis devenue très soupe au lait et irritable. Je suis devenue émotive. Je ne pouvais pas aller au cinéma ou simplement m'asseoir et lire un livre. *Fille d'une femme ayant une démence* (Basnyat & Chang, 2016)

2.1.4 Motivation et perfectionnisme

Les raisons qui ont amené l'aidant à remplir cette fonction d'aide peuvent également représenter un facteur de risque. Aider un proche est souvent une tâche exigeante qui met d'autant plus l'aidant à l'épreuve si celui-ci a l'impression que cette situation lui a été imposée. De fait, la recherche montre que, si l'aidant remplit sa fonction par motivation intrinsèque, c'est-à-dire pour des raisons personnelles et pas parce que cela lui a été imposé, il est moins sujet au burnout (Kindt et al., 2015). Ces résultats sont, bien sûr, à pondérer avec la (sur)implication qui peut en résulter par la suite.

Les aidants sont souvent très impliqués affectivement dans leur activité d'aide. Aussi, la volonté de (trop) bien faire est très présente. De fait, le *perfectionnisme* de certains aidants peut les mettre à risque de développer un burnout par des standards élevés, voire

inatteignables. Cela est corroboré par les résultats pointant que l'importance accordée au fait de se voir comme un bon aidant est lié au burnout de l'aidant (C. Lindström et al., 2011). Enfin, avoir besoin de souffler face au sentiment d'être surchargé par la tâche est parfois évoqué comme une faiblesse, ce qui impose encore plus les standards élevés (Tebbani, 2016). Ce genre de (sur)implication a été mis en évidence comme facteur de risque chez les professionnels (Freudenberger, 1974). Les aidants ayant des standards élevés et qui s'impliquent en conséquence sont plus à risque de burnout, malgré leur volonté de faire le meilleur pour la personne qu'ils aident. Cela peut aussi amener l'aidant à *ne pas vouloir déléguer*, à rester le seul acteur dans la situation d'aide soit parce qu'il estime être la seule personne habilitée à aider, soit par manque de confiance dans les autres proches.

Quand [mon mari] sait qu'il est clair que c'est son tour de prendre ses responsabilités, alors il le fait. Sinon, il me fait confiance pour le faire. Ou peut-être que je ne fais confiance qu'à moi-même pour être la personne qui le fait et donc je ne lui permets pas de le faire. Je ne sais pas.
Mère d'un enfant avec diabète (Caisa Lindström, Åman, Norberg, Forssberg, & Anderzén-Carlsson, 2017)

2.1.5 La santé physique de l'aidant

L'état physique d'un individu détermine sa capacité à pouvoir endosser le rôle d'aidant ; ceux en meilleure santé étant plus souvent désignés comme aidants (Pinquart & Sörensen, 2007). Mais cette apparente bonne santé ne demeure pas toujours stable une fois la personne devenue aidante. La présence de *troubles somatiques, de maladies ou de douleurs chroniques* exerce une pression importante sur les aidants qui sont alors plus sujets au burnout (Demirhan et al., 2011 ; Hattori et al., 2001 ; Hattori et al., 2000). Si cette situation est particulièrement aiguë pour les aidants vieillissants, elle demeure toutefois un aspect déterminant de la capacité de tous à fournir de l'aide et des difficultés auxquelles ils peuvent être confrontés.

2.1.6 La religion

Le fait de se revendiquer d'une religion n'a pas d'impact direct sur le burnout de l'aidant (Bachner, O'Rourke, & Carmel, 2011 ; Götze, Brähler, Gansera, Schnabel, & Köhler, 2015). Néanmoins, il apparaît qu'utiliser sa religion comme soutien (appelé *coping religieux*) constitue un facteur de protection face à l'épuisement émotionnel, comme cela a pu être mis en évidence chez des Chrétiens, des Musulmans et des Bouddhistes (Cantwell-Bartl & Tibballs, 2017 ; Falb & Pargament, 2013 ; Sharifi & Fatehizade, 2012). Si des recherches sont encore nécessaires pour les autres confessions, il apparaît que toute ressource de cet ordre peut constituer un facteur de protection. Au-delà de la religion, avoir une confiance générale dans le monde comme étant cohérent et ayant du sens représente un facteur de protection face au burnout de l'aidant (Goetzmann et al., 2012b).

2.2 Dans la situation d'aide

Au-delà d'être influencé par des facteurs individuels, l'aidant est également affecté par les caractéristiques de la situation d'aide. Dans cette situation, la place de la personne aidée et sa limitation d'autonomie y est centrale. Si des facteurs objectifs comme les symptômes

de la maladie peuvent avoir un impact sur le burnout de l'aidant, des facteurs subjectifs comme la qualité perçue de la relation avec la personne aidée jouent également un rôle important.

2.2.1 Caractéristiques de la personne aidée

Les études n'ont, à l'heure actuelle, pas mis en évidence de lien entre l'âge ou le genre de l'aidé et le burnout de l'aidant (Cuijpers & Stam, 2000; Kokurcan et al., 2015; C. Lindström et al., 2011). S'occuper d'une personne plus ou moins âgée, homme ou femme n'apparaît donc pas en soi un facteur de risque.

2.2.2 Temps consacré à aider

Le temps consacré à porter assistance à son proche ne semble pas lié au burnout chez l'aidant. En effet, une seule étude a pointé un rôle – faible – entre les symptômes d'épuisement émotionnel chez l'aidant et la durée de la maladie psychiatrique du proche. Si la maladie perdurait depuis plus de deux ans, le risque de burnout de l'aidant augmentait (Cuijpers & Stam, 2000). Si ce résultat va dans le sens attendu – un aidant impliqué depuis un long moment dans l'aide est plus à risque – d'autres études n'ont pas mis en avant de lien entre durée de l'aide et burnout de l'aidant (Kokurcan et al., 2015 ; C. Lindström et al., 2011 ; Sugihara, Sugisawa, Nakatani, & Hougham, 2004). Il faut néanmoins noter que cet élément peut être considéré dans l'autre sens également, indiquant qu'un nouvel aidant n'est pas spécialement plus à risque qu'un aidant « vétéran », mais que, si risque il y a, il est à chercher dans d'autres facteurs que le simple facteur temps. Si cela n'a pas d'impact direct sur le burnout de l'aidant, il n'en demeure pas moins que le temps peut contribuer à aggraver la perception que l'aidant peut avoir de son rôle (Adelman et al., 2014 ; Pinquart & Sörensen, 2003a). Se percevoir comme aidant depuis longtemps peut entraîner des sentiments renforcés d'être bloqué dans la situation et de ne pas avoir d'horizon différent.

Un autre de ces facteurs pourrait être celui du volume-horaire passé à aider. Si le nombre d'heures passées à aider peut apparaître comme un facteur de risque évident, les recherches tendent à montrer un impact limité de ce volume-horaire sur le burnout de l'aidant (Truzzi et al., 2012). La seule recherche pointant un impact du volume-horaire comme prédicteur de l'épuisement émotionnel a montré que son impact est, en fait, marginal (Angermeyer et al., 2006). Cet impact sur l'épuisement émotionnel pourrait surtout avoir un effet indirect par un alourdissement de la perception de la situation de soin comme exigeante et une diminution du temps pour soi, conduisant au burnout (Adelman et al., 2014; Pinquart & Sörensen, 2007).

2.2.3 De la nature de la perte d'autonomie vers l'intensité des symptômes

À l'heure actuelle, les recherches ne permettent pas de déterminer si certaines situations d'aide sont plus à risque que d'autres. En effet, ces travaux demeurent, la plupart du temps, cloisonnés dans leur domaine d'expertise (le problème de la personne aidée) avec un manque d'une vision transversale. Comme elle était évoquée plus tôt, la diversité des situations et des symptomatologies rend difficile la définition d'un cadastre des problématiques et de leur

impact spécifique sur le burnout de l'aidant. Il est néanmoins possible d'identifier des tendances permettant d'appréhender l'impact que peut avoir le type de difficulté de l'aidé sur l'aidant.

Cet impact peut se décliner en deux tableaux. Le premier concerne le niveau d'autonomie de l'aidé. Une personne avec une maladie neurodégénérative subira, par exemple, une baisse de son autonomie suivant l'évolution de la maladie. Cette perte progressive d'autonomie amène donc un besoin d'aide de plus en plus important. Cette augmentation n'est pas sans conséquence sur l'aidant qui est alors davantage mis à contribution et donc plus à risque de développer un burnout. Ces éléments sont confirmés par les recherches qui pointent un risque plus important de burnout de l'aidant dans les situations de forte *perte d'autonomie de la personne aidée*. Moins la personne est autonome, plus l'aidant est à risque d'épuisement émotionnel (Yan, 2014; Yilmaz et al., 2009). Il faut également noter que la diminution de l'autonomie de l'aidant peut finir par avoir un effet bénéfique sur l'épuisement de l'aidant en sa qualité de déclencheur de la mise en place de dispositifs d'aide. Si la mise en place de ces dispositifs n'a pas toujours des effets positifs sur la surcharge de l'aidant – comme on l'évoquera plus loin – cela peut néanmoins le soulager dans sa tâche.

Fortement liée à l'importance de l'autonomie, le second tableau d'impact concerne les symptômes ou difficultés que présente l'aidé et la gestion de ceux-ci. Les aidants sont affectés par les symptômes de la maladie de leur proche ; leur augmentation les mettant plus à risque de burnout (Benutto, 2016; Kokurcan et al., 2015). La recherche s'est surtout centrée sur l'étude d'aidants de personnes avec une maladie neurodégénérative plutôt que d'autres type de situations de dépendances. Ils ont pointé *que plus les symptômes chez l'aidé sont importants*, plus l'aidant est à risque d'épuisement émotionnel (Truzzi et al., 2012; Yan, 2014). Ces symptômes typiques de la maladie vont de la répétition de questions à l'agression physique en passant par les déambulations, la perte de repères et la non-reconnaissance des proches. Ces symptômes nécessitent de la part de l'aidant une résistance émotionnelle particulière pour pouvoir y faire face et une attention de tous les instants pour pouvoir réagir à temps quand cela est nécessaire.

Elle m'a aussi confondu avec mon père, avec tout cela ce que comporte de souffrances de sa part. [...] Les dégradations tant physiques que mentales, pleurs, gémissements, cris [...] restent encore en mémoire. Je me suis senti incapable de l'aider, complètement impuissant.

Fils d'une femme souffrant de la maladie d'Alzheimer

2.2.4 Sur le qui-vive

Outre ces symptômes, il a été constaté dans plusieurs recherches que l'épuisement émotionnel de l'aidant est corrélé de manière importante avec des symptômes de peur et d'anxiété (Yilmaz et al., 2009). Ces résultats se comprennent à la lumière du vécu de certains aidants qui sont confrontés à des situations nécessitant soit un monitoring constant, soit une imprévisibilité de l'évolution de la maladie ou des symptômes. Prenant l'exemple d'un aidant s'occupant de son parent touché par une maladie neurodégénérative, ce dernier va devoir être surveillé de plus en plus à un certain stade de sa maladie, pour éviter toute fugue, chute ou comportements qui peuvent s'avérer dangereux. Cela résulte en une tension constante chez

l'aidant d'être toujours attentif, à savoir où se trouve son parent et ce qu'il fait. Mais au-delà de cette attention constante en présence de la personne aidée, les *inquiétudes concernant la sécurité de la personne aidée* contribuent également à augmenter le risque de burnout (Cuijpers & Stam, 2000). La tension est donc constante tant en présence de la personne aidée qu'en son absence. Dans le même sens, un besoin de contrôle important sur la maladie est une charge importante pour l'aidant (C. Lindström et al., 2011) et *être en monitoring perpétuel*, y compris la nuit, met également à risque l'aidant d'épuisement émotionnel (C. Lindström et al., 2011; Truzzi et al., 2012).

Je pense qu'[être en état de constante vigilance] est destructeur. Cela peut être destructeur tant pour l'aidant que pour l'aidé. *Épouse d'un homme ayant eu un AVC* (Lond & Williamson, 2017)

Dans le cas de l'imprévisibilité de l'évolution de la maladie, le cas des blessures cérébrales acquises est un exemple représentatif. L'aidant de la personne touchée par ces blessures vit dans l'angoisse de l'aggravation des symptômes déjà présents, tout en devant soutenir la personne aidée qui, elle-même, fait face à ses propres angoisses (Lond & Williamson, 2017). Ainsi, être dans l'*inquiétude quant à l'avenir de la personne et à l'évolution de sa maladie* mettent l'aidant à risque d'épuisement émotionnel (Cuijpers & Stam, 2000). Dans certains cas, l'inquiétude peut également venir du « quand je ne serai plus là, qu'arrivera-t-il à la personne que j'aide ? ». Cette *inquiétude de la disparition de l'aidant*, couplée à sa perception que sa présence est indispensable (que cela soit fondé ou non), peut être une source de détresse importante également (Tebbani, 2016).

C'est le plus gros problème : Je ne peux pas lâcher prise. Je ne peux pas, c'est tout. Je pense que j'aimerais avoir [ma fille] avec moi tout le temps. *Mère d'un enfant avec diabète* (Caisa Lindström et al., 2017)

2.2.5 Le contexte

L'aide ne se réalise pas uniquement dans le cadre du duo aidant-aidé, mais s'inscrit également dans un contexte dont l'importance n'est pas à négliger. Que ce soit au niveau de la cohabitation avec la personne aidée ou le recours à des services d'aide, le contexte intervient directement dans le rôle d'aidant et peut avoir un impact sur leur risque de burnout. Mais le contexte importe également pour comprendre le soutien que peut recevoir (ou non) l'aidant à titre individuel et l'isolement qui peut être ressenti.

2.2.6 Habiter avec la personne aidée

De toutes les études investiguant l'impact d'habiter avec l'aidé sur le burnout de l'aidant, une seule a montré que les cohabitants sont plus à risque d'épuisement émotionnel (Cheung & Chow, 2011). Une seconde étude a pointé que plus l'aidant habite depuis longtemps avec la personne aidée, plus l'aidant est à risque de dépersonnalisation (Yan, 2014), suggérant un épuisement au cours du temps. D'autres n'ont néanmoins pas trouvé de différence entre les cohabitants et les non-cohabitants (Bachner, O'Rourke, Davidov, & Carmel, 2009; Cuijpers & Stam, 2000). Si habiter sous le même toit ne représente donc pas « en soi » un facteur de risque pour l'épuisement émotionnel avec la personne aidée, il faut relativiser cette absence de résultats. Ne pas habiter avec la personne car elle est placée peut diminuer la charge des

activités à réaliser, mais augmenter le temps de trajet ou la qualité de relation avec l'aidé, n'ayant donc pas d'impact positif direct sur le burnout.

Je vais lui rendre visite [à la maison de repos] tous les deux jours et il réclame de rentrer chez lui à chaque fois ! *Epouse d'un homme souffrant de la maladie d'Alzheimer*

2.2.7 Accès à des services et situation financière

Que ce soit au domicile ou pour le placement, les aidants ont un rapport complexe avec les services d'aide. En effet, même si la demande est en constante augmentation, on constate que les aidants y ont encore trop peu recours et ont des réticences à les solliciter (Coudin, 2004). Si on peut penser que les dispositifs d'aide (les aides à domicile par exemple) sont autant de leviers pour alléger la charge de l'aidant, il convient de considérer que c'est un outil à double tranchant. En effet, les recherches montrent que plus les aidants sont en épuisement émotionnel, plus ils font appel à des services d'aide (Sugihara et al., 2004). Cela peut se comprendre par le temps que les aidants attendent avant de solliciter ces services (les amenant, dès lors, à s'épuiser avant de demander de l'aide extérieure, mais aussi peut-être à prendre conscience qu'ils pourraient également en bénéficier). Plus ils sont dépassés par la situation, plus ils sont épuisés émotionnellement et donc plus à même de faire appel à ce genre de service. De surcroît, il a été constaté que les aidants minimisent souvent leur besoin d'aide, voire n'osent pas demander ou imposer de l'aide d'eux-mêmes, à moins que le bien-être de la personne aidée ne soit engagé (Tebbani, 2016).

Pour durer ensemble, il faut des moments de respiration, l'apnée permanente conduisant à la mort. *Époux d'une femme souffrant de la maladie d'Alzheimer*

Le pendant de cette vision est que l'aidant est souvent l'expert de l'aide à son proche. C'est lui qui centralise les informations médicales, les coordonne, mais c'est aussi la personne qui sait le mieux s'occuper de la personne en situation de dépendance. Avoir recours à des services d'aides peut ainsi causer de la crainte (« je le laisse seul avec je ne sais qui »), de l'anxiété quant à la préparation de l'assistance (« je dois penser à tout écrire et tout préparer pour que cela se passe bien ») et des difficultés à déléguer (« pourquoi aurait-il besoin de quelqu'un d'autre ? »). L'impact du service d'aide sur l'aidant reste souvent basé sur sa perception du bien-être apporté à la personne aidée (Tebbani, 2016), ce qui justifie le manque de résultats clairs statuant sur les bénéfices de ces services sur le bien-être de l'aidant (Vandepitte et al., 2016).

Il est difficile de trouver des personnes de confiance pour nous seconder. [...] Il ne reste donc aucune possibilité pour avoir une activité extérieure pour se ressourcer. *Mère d'un enfant ayant une maladie orpheline*

Ces services d'aide peuvent également représenter un coût important dans le budget déjà diminué de l'aidant et avoir un impact émotionnel non désiré, voire négatif. Ces inquiétudes, quant à la situation financière, sont liées à plus de burnout chez les aidants (Cuijpers & Stam, 2000). Néanmoins, ils offrent l'opportunité de rééquilibrer la vie de l'aidant entre l'aide et d'autres activités (Basnyat & Chang, 2016). Comme cela avait été mentionné plus tôt, pouvoir se sortir émotionnellement de sa situation d'aide de temps en temps soulage l'aidant

qui peut se retrouver à risque de burnout (C. Lindström et al., 2011). Une utilisation judicieuse de ces services dans un contexte économique adapté peut donc aider l'aidant et le soulager émotionnellement.

2.2.8 Qualité relationnelle du couple, soutien social, isolement

Un élément qui ressort souvent est le sentiment de l'aidant d'être isolé (Basnyat & Chang, 2016), que ce soit être seul dans l'aide, *ne pas se sentir soutenu dans cette activité*, ou simplement *se sentir isolé*. Avoir sa place dans un réseau social soutenant est capital pour le bien-être de l'aidant. Et de fait, moins les aidants rapportent être satisfaits de leur réseau social, plus ils rapportent des symptômes d'épuisement émotionnel (Takai, Takahashi, Iwamitsu, Oishi, & Miyaoka, 2011).

Je me sens seule terriblement seule, aucune personne de nos familles ne prend des nouvelles, ne propose d'aide [...] je ne sais pas combien de temps je vais tenir le coup. *Épouse d'un homme sénile*

Dans beaucoup de cas, c'est souvent une seule personne qui porte la majorité du poids d'aide sur ses épaules, malgré la présence d'autres aidants (Caisa Lindström et al., 2017). Néanmoins, avoir d'autres personnes qui peuvent donner un coup de main de temps en temps est une ressource qui soutient les aidants dans leur tâche. Par exemple, être dans une grande fratrie représente un facteur de protection face au burnout de l'aidant car cela permet de répartir les tâches entre les différents membres (Kokurcan et al., 2015). Mais si une plus grande disponibilité d'autres proches peut représenter un facteur de protection face au burnout, cela peut aussi être une source de stress supplémentaire à cause des dissensions et conflits que cela peut causer. Et il a été montré que les *conflits dans le système d'aide* augmentent de manière importante le risque de burnout de l'aidant (Almberg, Grafström, Krichbaum, & Winblad, 2000).

Au-delà de la disponibilité des aidants, avoir un réseau social soutenant peut être un facteur de protection du burnout chez l'aidant (Choi & Sok, 2012; Kokurcan et al., 2015) et diminue la pénibilité perçue de ce rôle (Adelman et al., 2014 ; Choi & Sok, 2012). Différentes formes de soutien existent. Les deux principales sont « aider concrètement » (soutien instrumental) et « être présent pour accueillir les émotions de l'autre et l'aider à faire face à ses émotions » (soutien émotionnel). Recevoir un soutien pratique (instrumental) diminue le risque de burnout chez l'aidant en diminuant la charge qui pèse sur lui (Lindgren, 1990; C. Lindström et al., 2011), en lui donnant du temps libre, ou en remplissant des tâches que l'aidant aurait dû faire lui-même ou seul. Le soutien d'ordre émotionnel est surtout lié à une diminution de la dépersonnalisation chez les aidants (Lindgren, 1990). Avoir l'occasion de partager ses émotions offre donc l'opportunité aux aidants de ne pas trop se distancier émotionnellement des personnes aidées. Mais chez les femmes, cela aide également face à l'épuisement émotionnel (C. Lindström et al., 2011). Si ces derniers résultats peuvent paraître caricaturaux, ils pointent surtout l'importance d'avoir un réseau qui répond à ses besoins au moment opportun. Si une personne (homme ou femme) a besoin de pouvoir parler de ses émotions librement sans être jugée, mais que ce besoin n'est pas rencontré, cela peut amener à un sentiment d'incompréhension, voire de solitude. De même, des aidants peuvent avoir un

rapport ambivalent à leurs proches, ne voulant pas demander de l'aide ou voulant garder une façade du « tout va bien ». Si les motivations peuvent varier, il n'en demeure pas moins que cet exercice d'équilibriste est autant délétère pour l'aidant que pour son entourage qui constate, soit sur le moment, soit plus tard, que l'aidant est dans une détresse sans oser le solliciter. A ce titre, les groupes de soutien (en face-à-face ou en ligne) entre aidants apparaissent comme un des moyens qui permettent de partager des expériences comparables et d'oser tomber le masque (Perkins & Hewitt, 2016).

J'en parle très peu avec les personnes de mon âge car elles ne comprennent pas la situation dans laquelle je me trouve, ne montrent aucune empathie ou n'ont tout simplement pas envie d'en parler (car ce n'est pas un sujet de conversation très joyeux). Je me sens donc très seule. *Fille d'une femme atteinte de fatigue chronique*

C'est épuisant. Je mords ma lèvre. J'essaye de rester forte, je suis vraiment terrifiée que quelqu'un gratte la surface... « Non, je vais parfaitement bien [dis-je] ». (Caisa Lindström et al., 2017)

Si le soutien social est en général important, la qualité du climat dans le couple est également capitale. Si cette dimension est centrale dans l'accompagnement d'un enfant malade (Gérain & Zech, 2018 ; Riva et al., 2014), il n'en reste pas moins que le couple peut représenter une source de soutien très importante dans toute situation d'aide. Aussi, le climat qui y règne peut promouvoir un épanouissement de l'aidant, un sentiment de ne pas être seul dans son aide – même si le conjoint ou la conjointe n'a pas de participation active dans l'aide. A contrario, un *climat délétère dans le couple* (C. Lindström et al., 2011; Riva et al., 2014) et un *désintérêt du conjoint pour la situation de soin* (Demirhan et al., 2011) sont liés à plus de symptômes de burnout de l'aidant.

Je n'ai pas beaucoup de temps avec mon mari, je n'ai pas beaucoup de temps avec mes enfants. Cela m'affecte, cela affecte mon mari, cela affecte mes enfants. (Basnyat & Chang, 2016)

De manière générale, la perception d'avoir limité sa vie sociale, voire d'avoir perdu de vue des amis depuis qu'on est aidant est liée à plus d'épuisement émotionnel (Almberg, Grafstrom, & Winblad, 1997; Lindgren, 1990). Poussé à l'extrême, l'aidant a l'impression d'être simplement seul. Ce sentiment, très fort, va au-delà de ne pas être satisfait du soutien reçu ; l'aidant constate plutôt qu'en dehors de la relation avec la personne aidée ne subsiste que peu à pas de relations sociales.

Je ne sors pas et ne rencontre pas de personnes car je ne peux pas sortir de la maison. Ma vie et mon cercle social tournent autour de [ma mère]. J'ai réalisé que si [elle] n'était plus là, je n'ai plus de vie. *Fille d'une personne ayant une démence* (Basnyat & Chang, 2016)

2.2.9 Le contexte culturel

Bien que cela reste encore trop peu investigué, les aspects (inter)culturels liés au rôle d'aidant doivent néanmoins être pris en compte dans la compréhension de leur vécu (Chiao, Wu, & Hsiao, 2015 ; Pinquart & Sörensen, 2005). En fonction de leur culture, certains individus perçoivent la transition vers leur rôle d'aidant comme un processus normal ou, au contraire, comme un fardeau (Sutter et al., 2016). Il en est de même pour les tâches à effectuer

en tant qu'aidant et les sacrifices personnels que cela peut demander (Chiao et al., 2015), pour aller également jusqu'à la réticence à demander de l'aide et avoir recours aux services de soutien (Scharlach et al., 2006). Même si beaucoup reste à investiguer dans ces aspects, il n'en demeure pas moins que les *aspects culturels* jouent souvent un rôle insoupçonné chez les aidants qui devrait particulièrement attirer l'attention des intervenants de terrain (Parveen et al., 2018).

2.3 La relation avec la personne aidée

La place de la relation est importante dans le contexte de l'aide informelle car c'est elle qui définit l'aidant. Au-delà de cela, elle est un élément-clé dans le vécu quotidien de l'aidant. Contrairement à un soignant professionnel, l'aidant ne le devient que par la relation qu'il partage avec la personne qui reçoit l'aide. De par l'arrivée de la maladie ou la perte d'autonomie et le déséquilibre que cela peut causer dans l'équilibre relationnel, la qualité de la relation peut être impactée. Une bonne relation avec la personne aidée représente un facteur de protection de l'épuisement émotionnel de l'aidant (Cuijpers & Stam, 2000; Kindt et al., 2015), et ce particulièrement chez les conjoints-aidants (Ybema, Kuijer, Hagedoorn, & Buunk, 2002). A l'inverse, *une mauvaise relation avec l'aidé* augmente le risque de burnout. Ce lien se comprend à la lumière de l'implication émotionnelle qu'a l'aidant du fait même de sa relation avec la personne aidée. Là où un soignant aura des difficultés avec une personne aidée et passera à autre chose, l'aidant est beaucoup plus touché de par son implication affective avec elle.

Mon mari ne s'est jamais plaint, il a gardé longtemps son beau sourire et ce sourire m'a aidée plus que tout. [...] Je n'aurais pas tenu sans la bienveillance, l'amitié autour de nous et l'amour de mon mari. *Epouse d'un homme souffrant de sclérose latérale amyotrophique bulbaire*

Un sous-élément pointé par les recherches tient dans la perception par l'aidant de passer au second plan dans la relation, donc que tout tend vers l'aidé. C'est particulièrement aigu dans le couple où l'aidant a l'impression d'être moins considéré que son partenaire. Ce sentiment n'est pas sans conséquence pour l'aidant ; plus ce dernier a *l'impression d'être moins considéré que son conjoint*, plus il est à risque développer un burnout (Ybema et al., 2002). A l'inverse, une relation avec l'aidé qui permet de faire face ensemble aux difficultés et de s'ajuster l'un avec l'autre est une ressource très précieuse pour l'aidant (Rottmann et al., 2015). Si ces résultats concernent surtout les couples où l'aidant s'occupe de son partenaire, l'importance de la relation reste centrale dans chaque situation.

Enfin, il faut constater que la relation ne doit pas, par essence, se baser sur des critères objectifs de communication. La plupart du temps, une diminution de la communication verbale a un effet délétère sur la qualité de la relation (Watson, 2018), mais ce n'est pas toujours le cas. Si l'aidant a l'impression d'avoir une bonne communication avec l'aidé, c'est ce ressenti qui compte plutôt que la réalité de la communication existante. Cela peut, par exemple, être le cas lorsque la personne aidée a un problème d'élocution ou n'a jamais eu l'opportunité de verbaliser. Que l'aidant ait mis en place des moyens de communications formels (comme une forme de code) ou non, la qualité de la relation n'est pas toujours diminuée par la perte de la communication verbale telle qu'elle était (Riedijk et al., 2008).

Elle m'a un moment appelé papa. [...] J'ai tenté de comprendre jusqu'au jour où l'idée m'est venue que le mot « papa » ne désignait pas une personne mais une qualité de relation : « je suis bien avec toi, comme j'étais avec mon papa, étant petite. » À partir de là, la parole est devenue comme une onde porteuse dont le sens était à chercher au-delà des mots. *Epoux d'une femme avec une maladie neurodégénérative*

2.4 L'évaluation subjective

Au final, un déterminant central du burnout de l'aidant reste le ressenti subjectif de la personne (Galiatsatos et al., 2017). Comme cela a été évoqué, la recherche s'est longtemps concentrée sur la notion de « fardeau » subjectif, c'est-à-dire l'évaluation de pénibilité de son rôle d'aidant. Ce *fardeau subjectif* apparaît comme un antécédent majeur du burnout de l'aidant (Akinci & Pinar, 2014 ; Angermeyer et al., 2006 ; Choi & Sok, 2012 ; Götze et al., 2015 ; Kasuya, Polgar-Bailey, & MPH Robbyn Takeuchi, 2000 ; Salama & El-Soud, 2012 ; Truzzi et al., 2008). Dans le contexte professionnel, on parlerait de mesure du stress perçu ou de la (sur)charge subjective. Si les facteurs objectifs de la situation de soins comme les activités à réaliser ou le temps passé sont importants, ils doivent être nuancés avec la perception que la personne en a. D'autres sentiments subjectifs négatifs peuvent également être ressentis, comme le sentiment d'être piégé dans le rôle d'aidant.

Bien que cela ait été moins investigué par le passé, il ne faut pas négliger l'évaluation positive de son rôle d'aidant et les bénéfices que l'aidant peut en tirer. Sans surprise, percevoir son rôle comme positif est lié à un meilleur bien-être (Yamamoto-Mitani et al., 2004). Mais parler de l'évaluation positive est surtout l'occasion de ne pas considérer le rôle d'aidant comme quelque chose d'uniquement négatif, ce qui est encore trop souvent le cas (Brown & Brown, 2014). Enfin, il est également important de pointer que, bien que les évaluations négative et positive sont inversement liées, elles ne s'annulent pas pour autant et contribuent à une évaluation globale complexe de l'expérience de chaque aidant (Lawton, Moss, Kleban, Glicksman, & Rovine, 1991).

3. Les principales conséquences du burnout de l'aidant

Après avoir passé en revue les principaux antécédents du burnout de l'aidant, nous allons à présent passer en revue ses conséquences. Force est de constater que le burnout fragilise l'aidant, tant personnellement que dans la situation d'aide. Cette fragilité facilite la survenue d'autres problèmes, physiques et mentaux, mais augmente également le risque d'avoir des comportements non souhaités, comme consommer des substances psychoactives ou avoir des comportements violents. Comme cela avait été mentionné plus tôt, certains éléments qui apparaissent comme des conséquences du burnout de l'aidant sont en réalité des éléments d'un système de rétroaction ; la conséquence devenant en partie la cause avec un risque d'emballement.

3.1 Chez l'aidant

3.1.1 Satisfaction et détresse

Les aidants présentant des symptômes de burnout sont affectés à plusieurs niveaux. Plus le burnout augmente, plus ils rapportent une *détérioration de leur qualité de vie* en général (Takai et al., 2011), un *moindre bien-être* (Bachner, 2016) et une *plus faible satisfaction de vie* (Kindt et al., 2015; Lee & Singh, 2010). Tous ces éléments pointent vers une répercussion large du burnout, au-delà du rôle d'aidant, avec une détresse pouvant toucher beaucoup d'autres facettes de la vie.

Oui il y a une limite de tolérance ou de circonstances auxquelles on sait faire face. Mais [...] en tant qu'enfants, nous sommes tenus de prendre soin de nos parents. *Fille d'une personne ayant une démence* (Basnyat & Chang, 2016)

L'augmentation de symptômes de burnout peut aussi amener une forme de *culpabilité* liée à la survenue du burnout dans sa vie. En effet, se sentir au bout du rouleau peut amener des pensées contradictoires ; d'une part vouloir prendre ses distances avec la situation (ce qui peut être recommandé par les proches et par les professionnels de la santé), et d'autre part se sentir trahir la personne aidée et avoir le sentiment de l'abandonner. Dans une moindre mesure, un sentiment de honte peut également être ressenti, la honte d'une part d'avoir craqué – comme cela peut être constaté dans le contexte professionnel –, et d'autre part de son incapacité à remplir son rôle alors que d'autres parviennent à le faire et à continuer. Tout cela peut générer une détresse importante, qui vient s'installer sur une fragilité déjà présente.

Au-delà de cela, le burnout peut également avoir des répercussions sur la santé mentale des personnes aidantes à proprement parler. Le burnout est souvent annonciateur d'une moindre santé mentale (Goetzmann et al., 2012b). De fait, les recherches relèvent un lien important entre l'augmentation de l'épuisement émotionnel et la *symptomatologie anxio-dépressive* (Götze et al., 2015; Kindt et al., 2015), accompagnée d'une moindre qualité de vie psychologique (Takai et al., 2011).

3.1.2 Dépression et consommation de substances

Plus spécifiquement, et comme cela a été mis en avant dans le cas du burnout professionnel et parental, des études ont montré un lien important entre le burnout et la *dépression* (Bachner et al., 2011; Yilmaz et al., 2009). La dépression est un trouble de l'humeur marqué par une récurrence des émotions négatives et une moindre capacité à ressentir des émotions positives. Contrairement au burnout, ce trouble touche la personne dans son entièreté engendrant une détresse transversale aux différentes sphères de la vie. Certains auteurs ont mis en évidence que le burnout de l'aidant serait un facteur de risque majeur dans l'apparition de symptômes dépressifs (Lee & Singh, 2010). Il a également été observé que plus les aidants sont en burnout, plus ils ont des *idéations suicidaires* (Truzzi et al., 2012). L'épuisement des ressources émotionnelles de l'aidant ferait donc le lit de la dépression, et donc du débordement de difficultés liées à la situation d'aide sur la vie entière de l'individu. Enfin, il a été montré également dans certains travaux que des aidants présentent des symptômes dépressifs indépendamment de la pénibilité de leur situation d'aide

(Ostlund, Wennman-Larsen, Persson, Gustavsson, & Wengström, 2010). Cette hétérogénéité des profils de santé mentale appelle à une approche nuancée de chaque situation et une prise en compte des facteurs communs et distincts nourrissant ces deux difficultés psychologiques.

Dans ces moments, où c'est vraiment trop [...], la survie est tout simplement impossible. Alors oui je pense au suicide car il n'y a pas d'issue... *Maman d'un enfant atteint d'autisme*

Ces conséquences délétères sur la santé mentale peuvent également amener l'aidant à se tourner vers une *consommation de substances*. Même si cela reste peu mentionné, une proportion importante d'aidants consomme des substances psychotropes et des antidépresseurs (Sallim, Sayampanathan, Cuttilan, & Chun-Man Ho, 2015). Plus ceux-ci éprouvent des symptômes d'épuisement émotionnel, plus ils sont à risque de consommer ce genre de substances (Truzzi et al., 2012). Si ces produits visent à soutenir les aidants, cela n'est qu'une béquille pour un temps et qui ouvre la porte à d'autres addictions, qu'elles soient chimiques, comportementales ou psychologiques. Parmi celles-ci, il faut aussi considérer les autres produits – alcool et tabac – qui peuvent remplir des fonctions similaires au quotidien et qui risquent également de voir leur consommation augmenter face aux difficultés émotionnelles.

Chaque jour devient de pire en pire [...] je prends de Xanax pour me mettre dans un état second et moins vivre la réalité. *Épouse d'un homme sénile*

3.1.3 Santé physique

Le burnout de l'aidant est souvent accompagné d'une *détérioration de la santé physique*. Globalement, plus les aidants rapportent des symptômes de burnout, plus ils se voient comme ayant une mauvaise santé (Goetzmann et al., 2012b; Valente et al., 2011). Cela se manifeste aussi par la perception d'avoir une moins bonne qualité de vie (Takai et al., 2011), en étant moins satisfaits de leur condition physique. Parallèlement, ils rapportent aussi plus de problèmes physiques, comme des douleurs chroniques ou un manque de vitalité (Demirhan et al., 2011; Goetzmann et al., 2012b). Si ces conséquences au niveau physique devraient encourager l'aidant à consulter un professionnel de la santé, force est de constater que ce n'est pas le cas. En effet, les aidants ont tendance à reporter leurs propres consultations car ils sont soit centrés sur la maladie de l'autre (s'effacent), soit ils doivent reporter faute de temps (Tebbani, 2016). L'aidant est alors à risque d'avoir des problèmes physiques limitant son autonomie, ouvrant la voie à un aidant qui devient lui-même malade.

Je pense que je suis tombé malade et que je ne pouvais pas m'en remettre parce que j'étais au bout du rouleau. *Époux d'une personne ayant eu un AVC* (Lond & Williamson, 2017)

3.2 Dans la situation d'aide

Les conséquences du burnout de l'aidant ne se limitent pas à l'aidant lui-même. Si l'aide fournie est le « stresser chronique », il n'en demeure pas moins que si l'aidant craque, la situation d'aide – et donc la personne aidée – en pâtit directement.

3.2.1 La relation avec la personne aidée

Son rôle d'aidant étant à la fois sa motivation et son stresser, l'aidant présentant des symptômes de burnout se retrouve coincé dans une situation qui devient délétère et cela se manifeste directement dans la relation avec la personne aidée. Plus les symptômes d'épuisement émotionnel sont présents, plus on observe une *détérioration de la qualité de la relation avec la personne aidée* (Goetzmann et al., 2012a). L'aidant est de moins en moins à l'écoute et disponible car il se sent au bout du rouleau, ce qui a une influence directe sur la relation avec la personne aidée, qui devient d'autant plus perçue comme la source de cette détresse. La perception de sa situation d'aide est également impactée par le burnout, avec une moindre satisfaction d'être aidant (Lynch, Shuster, & Lobo, 2017) et une moindre volonté d'y mettre le meilleur de soi-même dans l'aide (Okabayashi et al., 2008). Conséquemment, le burnout de l'aidant est aussi lié à un *moindre bien-être chez la personne aidée*, à une plus grande détresse (Kindt et al., 2015). Force est de constater que le burnout de l'aidant est aussi lié aux symptômes dépressifs (Ybema et al., 2002) et anxio-dépressifs (Kindt et al., 2015) de l'aidé. Le burnout vient donc ajouter de la détresse à chacun, aidant ou aidé, en troublant un équilibre dont ils bénéficiaient.

3.2.2 Risque d'abus et négligences

Malgré le lien affectif positif qui lie, la plupart du temps, l'aidant et l'aidé, le risque d'*abus* et de *négligence* demeure réel dans la situation d'aide (Acierno et al., 2010) et la santé mentale des aidants joue une place importante dans la maltraitance (Wiglesworth, Mosqueda, & Mulnard, 2010). Tout comme le burnout parental augmente les comportements de négligence et de violence vis-à-vis de ses enfants, le burnout de l'aidant facilite les comportements d'abus vis-à-vis de la personne aidée (Yan, 2014). Particulièrement, la sous-dimension de dépersonnalisation représente un facteur de risque important, tant pour les violences physiques que verbales. Une difficulté importante tient aussi dans le risque d'*engrenage de la violence*. En effet, avoir des comportements violents (tant psychologiques, verbaux que physiques) amène souvent à des émotions de honte ou de culpabilité. Ces émotions sont très fortes et ajoutent encore plus au fardeau émotionnel de l'aidant, qui augmente d'autant plus le risque d'épuisement, faisant le lit d'abus futurs.

Il faut noter que le curseur des comportements jugés abusifs est différent chez chacun. Si un aidant estime ne pas avoir de comportements abusifs ou de négligence malgré des indicateurs objectifs, cela peut être sincère. De même, les comportements abusifs et de négligence couvrent un large éventail de comportements, allant de retarder le repas ou la toilette alors que la personne aidée en a besoin, jusqu'à la violence physique et sexuelle, en passant par les abus financiers et psychologiques (insultes, dénigrement). Enfin, parler de (et admettre) ce genre de comportement demeure difficile. Il est d'autant plus important que les professionnels de la santé, qui peuvent constater ce genre d'abus ou être dépositaires de leur aveu, offrent un cadre d'accueil à cela. Dans ce cadre, la personne pourra plus librement aborder cette thématique, voire exprimer et oser dévoiler son propre vécu. S'il est exclu de banaliser, il faut s'abstenir toutefois de juger. Si elle sent qu'elle sera jugée, la personne aidante aura plutôt tendance à garder ça pour elle, avec un risque que la spirale continue.

3.3 En dehors de la situation d'aide

Le burnout peut donc causer des tumultes importants dans le cercle fermé de la situation d'aide. Mais cet impact ne se limite pas seulement à cette situation. Il touche également le système de soins. Dans la relation au personnel médical, l'aidant épuisé peut trouver une ressource pour sortir la tête de l'eau, ou rencontrer des difficultés. Le burnout détériore la relation avec les soignants (Almberg et al., 2000). L'aidant épuisé perd plus facilement patience, est de plus en plus exigeant et juge plus négativement les décisions du corps médical (Goetzmann et al., 2012a). En raison de cela, l'aidant épuisé s'isole de plus en plus de ses personnes-relais et ressources alors qu'il devrait, au contraire, s'en rapprocher pour obtenir l'aide dont il a besoin. Souvent, les aidants ont besoin d'une reconnaissance de leur statut et de la souffrance qui en découle (Tebbani, 2016). Reconnaître l'aidant dans sa souffrance pourrait donc lui éviter de se couper du milieu de soins et diminuer l'impact de la pénibilité de l'aide tout en ouvrant la porte à la mise en place d'interventions qui permettent à l'aidant de mieux vivre ce rôle.

Parallèlement, la santé mentale des aidants est aussi liée à la (ré)admission des patients dans les services concernés (Longacre, Wong, & Fang, 2014). Les recherches montrent, en effet, que les aidants plus épuisés sont plus à même de souhaiter que la personne aidée soit institutionnalisée (Yilmaz et al., 2009). Plus l'aidant se sent à bout, plus il aura tendance à souhaiter être déchargé de cette tâche. Cependant, il convient de pondérer ces résultats car, si l'épuisement de l'aidant peut amener au souhait, voire à l'accomplissement de cette (ré)institutionnalisation, celle-ci ne signifiera pas pour autant la levée de la pression sur l'aidant, comme abordé plus tôt. En effet, de nouvelles tâches et inquiétudes se substituent à celles présentes auparavant. Après avoir dû mener soi-même les tâches, il incombe alors à l'aidant de multiplier les trajets, de contrôler que tout se passe bien et partager avec l'équipe soignante ses propres apprentissages. Enfin, l'aidant doit également gérer son éventuelle culpabilité d'avoir « laissé » son proche auprès d'autres, de s'être « déchargé(e) » de sa « tâche », de son rôle. Cela peut amener à un rapport ambivalent au personnel médical. D'une part, une relation plus compliquée avec eux, et d'autre part un besoin d'aide, voire d'institutionnalisation, qui apparaît de plus en plus pressant.

4. Conclusion

L'aidant est un acteur central du système de soins et souvent la personne la plus proche de la personne en perte d'autonomie. Nombreux sont les facteurs qui viennent menacer l'équilibre précaire dans lequel peut se retrouver l'aidant. À ceux développés ici, s'ajoutent d'autres, spécifiques à chaque contexte, rendant chaque situation d'aide unique. Au-delà de la santé de la personne aidée, il convient au professionnel de la santé d'élargir sa considération à tout le système de soins – incluant les aidants – car laisser ces derniers sombrer finira par causer un enchaînement de problèmes à court et moyen terme. Un constat semblable tient pour l'aidant lui-même qui, s'il se néglige, finit par menacer sa santé mentale et physique, mais aussi le bien-être de la personne qu'il vise à aider. Il est donc important pour l'aidant de trouver un équilibre entre garantir le bien-être de la personne aidée et tout en

préservant le sien. Loin d'ajouter une injonction additionnelle aux aidants et aux professionnels, ce chapitre avait pour objectif de pointer la diversité des facteurs de risque et de protection du burnout de l'aidant, invitant chacun et chacune à agir au mieux dans la limite de ses moyens pour le bien de toutes les personnes impliquées dans la situation d'aide.

Chapter 3

Informal caregiver burnout? Development of a theoretical framework to understand the impact of caregiving

Informal caregiving is a rewarding but demanding role. The present theoretical framework proposes to adapt the tridimensional concept of burnout to informal caregiving as a way to address the potential consequences of caregiving. This adaptation reflects caregivers' reported difficulties, as well as empirical findings on emotional exhaustion, depersonalization, and personal accomplishment as caregiving outcomes. But to understand burnout in informal caregiving contexts, it is also necessary to find ways to model it. The Informal Caregiving Integrative Model (ICIM) is thus proposed. This model is based on the integration of elements from literature on both informal caregiving stress and professional burnout. The goal of the ICIM is to emphasize the importance of every category of determinants of informal caregiver burnout (i.e., relating to the caregiver, the caregiving setting, and the sociocultural context), with a key mediating role for the caregivers' appraisal of their situation and their relationship with the care-recipient. This article is a first integrative step in the consideration of a form of burnout specific to informal caregivers and supports the design of empirical and interventional studies based on the theoretical foundation that the ICIM proposes.

Reference

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Informal Caregiver Burnout? Development of a Theoretical Framework to Understand the Impact of Caregiving

1. Introduction

1.1 Informal caregivers

Informal caregivers are individuals, voluntarily and mostly free of charge, caring for a relative or a friend (i.e., the care-recipient) facing disease, disability, or any condition requiring particular attention (Schulz and Tompkins, 2010). Across the literature and in the media, it is widely accepted that being an informal caregiver puts a person at risk of poorer mental (Pottie et al., 2014; Sallim et al., 2015) and physical health (Kiecolt-Glaser et al., 2003; Känel et al., 2006; Capistrant et al., 2012). Although this consensus is contested (Brown and Brown, 2014; Roth et al., 2015), it nevertheless appears that being an informal caregiver can represent, in many ways, an experience that puts the individual under stress (Revenson et al., 2016).

The present work first proposes to adapt the concept of burnout to the context of informal caregiving as a means of addressing the consequences of such stress. As will be discussed, this adaptation is in response to concerns expressed in the literature about the measurement of the caregiving impact, currently driven by the study of the subjective burden. To drive future research on informal caregiver burnout, a new conceptualization must be constructed. To do so, two major models of caregiving stress and occupational burnout will be reviewed to identify their strengths and limitations. The Informal Caregiving Integrative Model (ICIM) will then be presented. The ICIM is designed to capture what makes existing models of professional burnout and informal caregiving stress so valuable, while trying to address their potential weaknesses.

1.2 Informal caregivers' burnout

Burnout is a tridimensional syndrome in response to chronic stress (Maslach et al., 1996). The concept is mainly used in the study of well-being at work, but it is interesting to note that one of the clinical observations at the origin of its conceptualization was not based on workers, but on volunteers at a support center (Freudenberger, 1974). This was a first step in considering that burnout could occur outside the occupational context (Schaufeli and Taris, 2005). This observation later led to the consideration of burnout in other settings, such as among parents (Mikolajczak et al., 2018), or students (Gustafsson et al., 2017).

The first reference to burnout in informal care was made in 1986. A study drew attention to "Spouse Burnout Syndrome," because some spouses of patients with chronic diseases showed symptoms comparable to those experienced by formal caregivers in burnout (Ekberg

et al., 1986). Despite its promising premises, this work received little attention for a long time. Since the first decade of the new millennium, however, an increasing number of studies have adapted burnout measures to assess informal caregivers' strain. In line with Ekberg's study in 1986, these studies have highlighted that some informal caregivers face strains comparable to the experiences of professionals in burnout (Angermeyer et al., 2006; Thorson-Olesen et al., 2018).

In this view, caregiver burnout can be defined as a tridimensional syndrome in response to the stress that the caregiving context may represent. Emotional exhaustion can be defined as a feeling of overload, of no longer being able to continue, of being emotionally drained when facing the caregiving situation and the care-recipient (Thompson et al., 2014; Goodwin et al., 2017). Depersonalization describes the detached response in the relationship to the person being cared for. Taken to the extreme, this can go as far as the reification of the latter. Personal accomplishment encompasses the positive dimension of the helping experience. This dimension of personal achievement goes beyond the notion of evaluation by highlighting that the caregiver may gain a sense of fulfillment through his or her care work and find meaning in it (Cross et al., 2018). In the context of burnout, this positive sense of accomplishment tends to be reduced.

This tridimensional transposition must, of course, be empirically investigated. Although this is only an indirect indicator, studies that have transposed burnout measures into the informal help context do not seem to have any major psychometric problem, and the internal consistency indicators seem comparable to those found in the literature on professional burnout (e.g., Truzzi et al., 2012; Akinci and Pinar, 2014; Katsifaraki and Wood, 2014; Yan, 2014). In the literature, emotional exhaustion is often highlighted in studies of informal caregivers under the heading of general exhaustion. This exhaustion can occur at both physical and mental levels, but remains primarily emotional in nature (Galiatsatos et al., 2017). There is little evidence of cases of depersonalization in informal caring contexts, except for studies adapting the Maslach Burnout Inventory, the most frequently used burnout scale. Other studies have shown that some caregivers put an emotional and psychological distance between themselves and the person they are caring for in order to preserve themselves (Cross et al., 2018). This distance can take the form of a more pragmatic and distant style of care and relationship in the face of significant stress (Hubbell and Hubbell, 2002). Personal accomplishment has been investigated in terms of personal growth resulting from the caregiving role, positive impact on the care-recipient, and caregivers' sense of acting in accordance with their values (Cross et al., 2018). Although the positive and negative impacts of informal care are related, the positive impact may be relatively unaffected by the negative caregiving experience and flourish independently (Lawton et al., 1991; Appleton et al., 2018). All these elements suggest that informal caregiver burnout is a promising concept to assess the impact of caregiving.

1.3 The burden-burnout relationship

Despite this promising position, the literature studying the negative impact of informal care remains focused on the concept of subjective burden. Subjective burden is the subjective

assessment of the stress that the helping situation can represent (Galiatsatos et al., 2017). It is the caregiver's appraisal of the objective experience (Lawton et al., 1991). Despite this seemingly clear definition, the concept of burden has been strongly criticized, with researchers pointing out that burden remains poorly defined and its assessment too vague (Mosquera et al., 2016). Depending on the definition used by authors, subjective burden may refer to the physical, psychological, emotional, social, and/or financial consequences of caregiving. This conceptual heterogeneity leads to diverse forms of assessment (Van Durme et al., 2012), and renders its use in public policy or research too ambiguous (Bastawrous, 2013). A concept defined too heterogeneously makes it difficult to draw clear conclusions. Contributing to this confusion, authors use the notions of subjective burden and caregiver burnout without distinction by measuring burden and reporting that they have measured burnout (and vice versa) (e.g., Schoenmakers et al., 2009; Kokurcan et al., 2015; Ghane et al., 2016).

The present work reflects the suggestion in the literature that subjective burden should be considered as the subjective experience of the caregiver, their perception of their caregiving role (Zarit and Zarit, 2015). Thus, subjective burden can be seen as an appraisal, an evaluation of how much the situation represents a source of stress for the individual, taking their resources into account (Lawton et al., 1991). This appraisal reflects the primary and secondary evaluations in Lazarus and Folkman's stress theory (Lazarus and Folkman, 1984). The use of the appraisal, and of Lazarus and Folkman's theory, is often a common basis for the different informal caregiver stress models (Schulz and Sherwood, 2008). The subjective burden thus appears as a key mediator between the demands of caregiving and the caregiving outcomes, such as informal caregiver burnout (Revenson et al., 2016).

1.4 Understanding caregiver burnout: Existing models

Studying informal caregiver burnout requires a theoretical basis on which to build an understanding of the burnout process. Existing studies addressing informal caregiver burnout seem to do so without this theoretical basis. The aim of the present work is thus to propose a theoretical model to guide future research on informal caregiver burnout. Such a model will need to combine elements of existing models from the literatures on caregiving stress and occupational burnout. In informal caregiving, the adaptation of Lazarus and Folkman's stress model has been preponderant in most research; by contrast, various models have been investigated in occupational burnout, although over the past decade, the Job Demands-Resources (JD-R) Model has provided a clear framework for research (Schaufeli and Taris, 2014).

1.4.1 Model of Carer Stress and Burden

Several researchers have conceptualized and evaluated models to understand how caregiving stress occurs and affects the individual. Two models have been particularly investigated. The first one of these, which has been widely used, is the stress process model (Pearlin et al., 1990), and the second is the appraisal model (Lawton et al., 1991). A combination of these two models was proposed by Sörensen et al. (2006) in the Model of

Carer Stress and Burden, an integrative model of the caregiver stress in the case of neurodegenerative disease. The model breaks down the process into six different interacting elements (see Figure 4). (1) Primary stressors are all objective elements in the caregiving setting, such as the type and intensity of symptoms, the tasks to perform or the intensity (hours/week spent caregiving). These primary stressors cause (2) secondary stressors, the consequences of the objective elements (e.g., lack of free time, family conflicts, financial strain). These are the mediators between the primary stressors and (3) the appraisal. The appraisal is the caregivers' subjective assessment of their situation. According to Lazarus and Folkman's theory (1984), this is an evaluation of the equilibrium between demands and resources. This evaluation leads to (4) the outcomes. These outcomes are psychosocial (e.g., depression or well-being), but could also be behavioral (e.g., substance consumption), or physiological (e.g., health issues related to chronic stress). This linear succession is influenced by (5) exacerbating and mitigating factors. These are all the elements other than primary and secondary stressors that modify the relationships between the variables. Coping strategies, personality facets, and other resources are among the factors modifying the relationships between primary and secondary stressors, appraisal, and outcomes. Finally, (6) background and contextual factors such as sociodemographic and cultural or ethnic determinants frame the caregiver's experience.

The Carer Stress and Burden Model and the two other models it takes its origin from make a crucial distinction between primary and secondary stressors, acknowledging the distinct role of primary stressors and their consequences (Pearlin et al., 1990). They also emphasize the central mediator role of appraisal between objective stressors and outcomes (Lawton et al., 1991). However, this model only focuses on caregiving stress. Caregivers' psychological and social determinants are considered peripheral, although they play an important role in their appraisal and experience of caregiving strain (Adelman et al., 2014). The dyad is not considered, neglecting the relation between caregiving strain and the relationship with the care-recipient (Spruytte et al., 2002; Kindt et al., 2015). The appraisal is only defined by secondary stressors and background elements, yet primary stressors, the relationship with the recipient, and the caregiver's individual characteristics may also contribute to this appraisal (Cuijpers and Stam, 2000). Dispositional and situational coping strategies are not explicitly integrated in the model, even though it is based on Lazarus and Folkman's work, and despite the crucial role played by coping strategies in the caregiving stress regulation (Pinquart and Sörensen, 2005). Subjective burden is considered as an outcome and not an appraisal. Finally, there are few feedback loops, suggesting that all of the caregiving stress model elements lead to outcomes without any impact of these outcomes on caregiving in return.

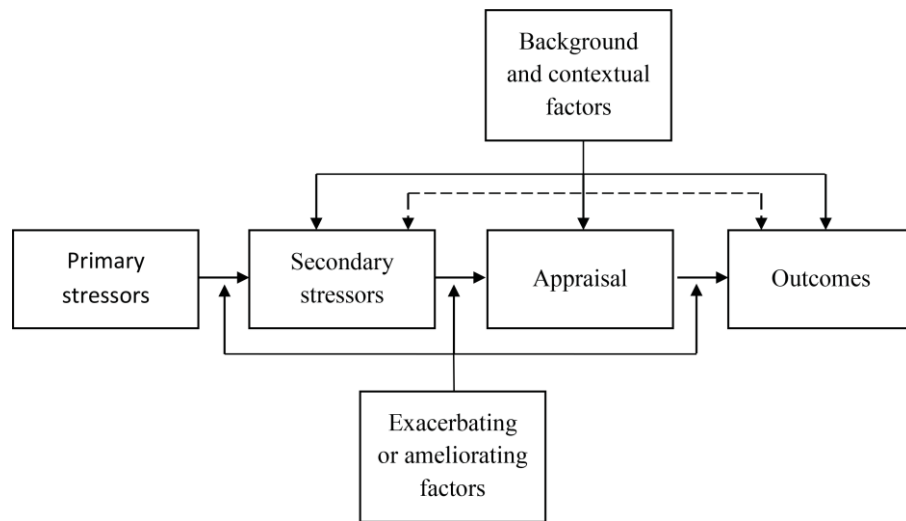


Fig. 4. Model of Carer Stress And Burden [adapted from Sørensen et al., 2006 Copyright (2006), with permission from Elsevier].

1.4.2 The Job Demands-Resources Model

In the burnout literature, one model synthesizes the way burnout appears in occupational contexts: the Job Demands-Resources Model (Demerouti et al., 2001). This model presents burnout as a two-dimensional process. On the one hand there is exhaustion, the wearing down of levels of energy, and the depletion of the caregiver's emotional resources. On the other hand there is engagement in the job, the willingness to perform well and to find new positive and constructive challenges within the work. In this view, burnout is caused by demands (stressors) and is diminished by resources (see Figure 5).

This model presents the role of burnout as a mediator between demands/resources and outcomes: the stressors (and resources) have a direct impact on burnout, which in turn causes outcomes. It also makes it clear that negative processes (e.g., burnout) do not obliterate positive ones (Broese van Groenou et al., 2013). Although this has not been assessed directly (except for parental burnout: see Mikolajczak and Roskam, 2018), the model postulates an equilibrium between demands and resources. It is the imbalance between persistent demands and insufficient resources that will, in the end, lead to burnout. Although this balance is a core element in the JD-R, it is not directly incorporated in the model, and direct effects of demands and resources are emphasized instead. However, this balance could be thought of as similar to Lazarus and Folkman's appraisal, which is explicitly included in caregiving stress models.

The conceptual difference between demands and resources is questionable (Schaufeli and Taris, 2014). The rationale is that demands are negatively appraised while resources are positively appraised and contribute to a more positive experience. However, meta-analytic studies have shown that using a dual set of positive and negative determinants is simplistic and reductive (Crawford et al., 2010), and this has led to a multiplication of versions of the model (Bakker and Demerouti, 2017). Moreover, the conceptual difference between low demands and high resources (and vice versa) can sometimes be subtle. If the (im)balance between demands and resources is crucial to understanding the experience of caregivers, a clear distinction between the two may thus prove less useful.

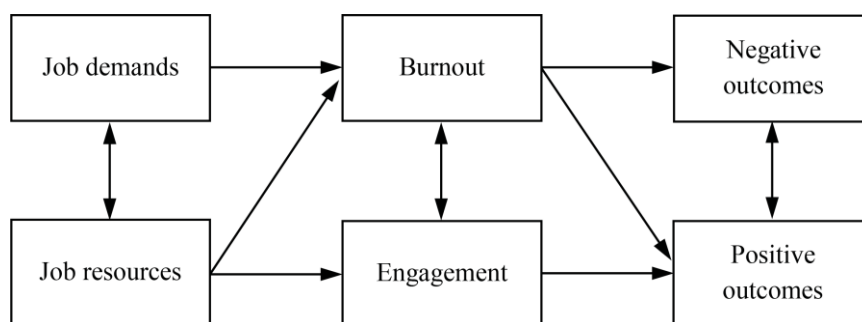


Fig. 5. The Job Demands-Resources Model [adapted by permission from Springer Nature, Springer ebook by Schaufeli and Taris, 2014].

1.5 The Informal Caregiving Integrative Model

The consideration of both the caregiver stress model and the JD-R model has made it possible to identify important factors to consider when building an understanding of informal caregiver burnout. Such a conceptualization should: (1) consider stressors and resources not only in the caregiving setting but also in the caregiver's psychosocial characteristics, (2) take into account the relationship with the care-recipient as a critical component in the understanding of the caregiving experience, (3) consider burnout as a key mediator between stressors and outcomes, (4) integrate the caregiver's appraisal as a core element in the model, (5) consider subjective burden as a measure of appraisal, and (6) include feedback loops. In addition, the consideration of determinants of caregiving should not focus on the often arbitrary distinction between demands and resources, but rather aim at understanding the processes by which these determinants may impact the caregiver's strain and appraisal.

To respond to these requirements, the Informal Caregiving Integrative Model (ICIM) is proposed as a theoretical framework to guide future research (see 6). The rationale of the ICIM is to consider the different determinants of informal caregiver burnout (i.e., the caregiving setting, the caregiver, and the environment) on the same footing. Burnout is conceived of as a key mediator between these determinants and general outcomes, and the impact of the determinants on informal caregiver burnout is mediated by both the caregiver's appraisal and his or her relationship quality with the care-recipient.

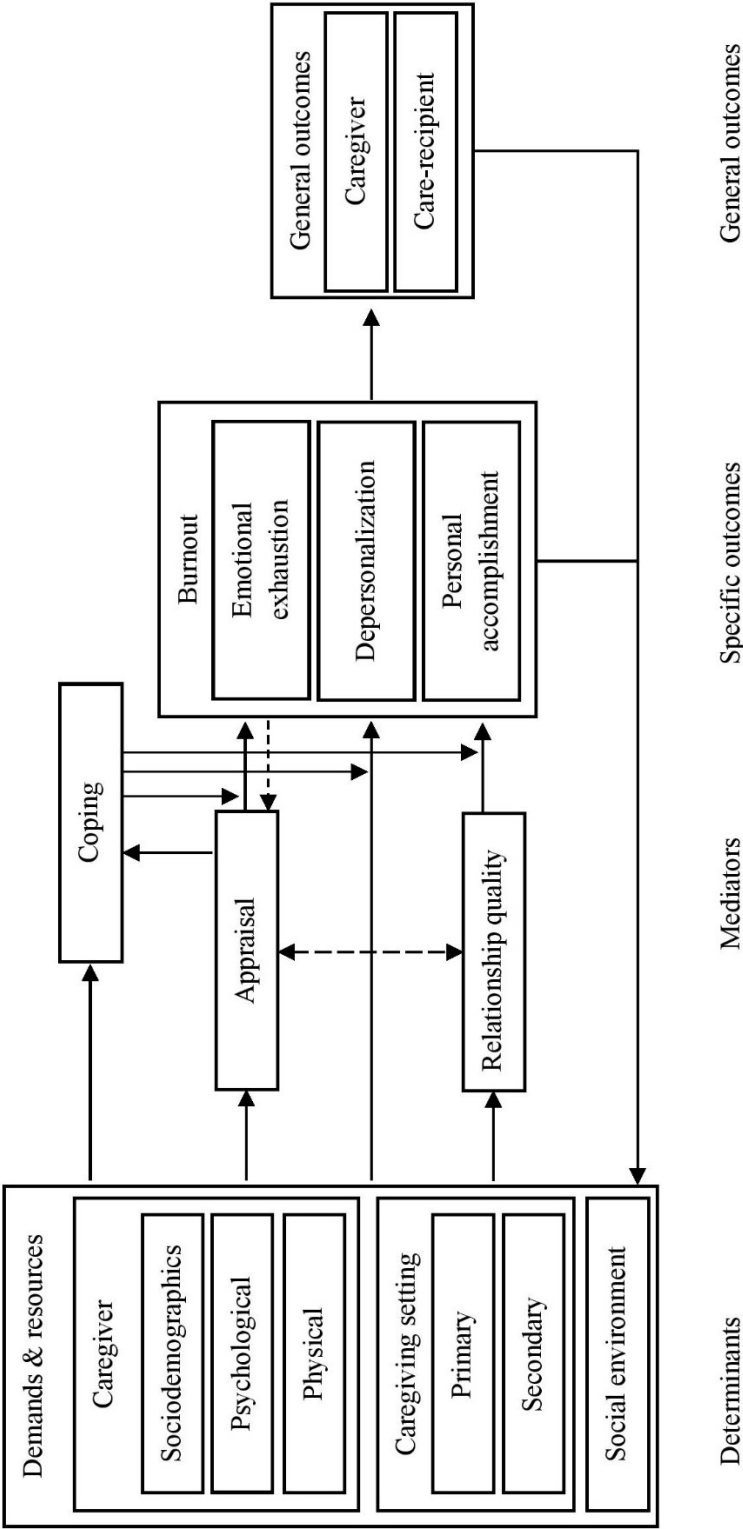


Fig. 6. The Informal Caregiving Integrative Model (ICIM).

To date, several elements of the model have already been explored by studies that focus on informal caregiver burnout. Because the ICIM is a theoretical model aiming at framing future research, the elements described in each section of the model do not aim at being exhaustive. The present goal is rather to illustrate the model with existing studies, mainly on informal caregiver burnout, and to suggest future directions for research in this field.

1.5.1 Determinants: Caregiver's Characteristics

The first set of determinants of caregiver burnout are the caregiver's characteristics. Caregivers remain individuals with personal cognitions, emotions, and motives that should be considered when aiming at understanding informal caregiver burnout. The characteristics of the caregiver can be divided into three main groups: background and sociodemographic, psychological, and physical factors.

1.5.2 Background and Sociodemographic Factors

The caregiver faces several elements that cannot be changed but still influence his or her caregiving strain. Being a female caregiver has been found to be associated with a heavier burden (Salama and El-Soud, 2012) and more burnout (Angermeyer et al., 2006; Truzzi et al., 2012). Often, the effect of gender has been confused with the effect of other gendered issues such as caregiving being more frequent among women than men (Revenson et al., 2016), and this has led to other studies finding no relation between gender and caregiver burnout (Kokurcan et al., 2015; Onwumere et al., 2017). Regarding the caregiver's age, no stable effect has been found (Demirhan et al., 2011; Truzzi et al., 2012; Yan, 2014; Onwumere et al., 2017). However, a difference may lie in the type of relationship with the recipient, reflecting that assuming the caregiving role has different implications at different life stages (Broese van Groenou et al., 2013; Perkins and Hewitt, 2016).

Still working while providing informal care may represent a protective factor in the sense that it relieves the caregiving strain by providing an emotional distraction, even if it is likely to exposes to work-related stressors (as suggested by Kokurcan et al., 2015). This protective effect of working may, however, be biased since caregivers sometimes take early retirement or a career break to provide care. The remaining working caregivers would thus be the ones with less caregiving responsibilities and less caregiving stress (Williams et al., 2016). In a similar way, it is important to note that keeping working is often related to gender disparity: women are more likely to become caregivers than men, and to reduce their working time to do so (Verbakel et al., 2017). Regardless of the cause, the impact of professional status remains entangled with financial matters and caregivers experiencing financial strain are more prone to subjective burden and burnout (Lindström et al., 2011; Chiao et al., 2015; Götze et al., 2015). In light of all these elements, the impact of the professional status is therefore much more complex than it may seem.

Research on role theory has suggested the significant impact of the caregivers' multiple roles (Bastawrous, 2013). The accumulation of roles, such as being a parent at the same time as being an informal caregiver, also adds to the caregiver's strain (Stephens et al., 2001; de Almeida Mello et al., 2016). Recent studies have shown such patterns in professional burnout.

Double-duty caregivers – being a formal and informal caregiver at the same time – are at higher risk of professional burnout than work-only caregivers (Häusler et al., 2017; DePasquale et al., 2018). In the same way, being an informal caregiver has been shown to increase the chances of parental burnout (Lindström et al., 2011; Gérard and Zech, 2018; Séjourné et al., 2018). The informal caregiving role thus seems to affect the caregiver's other roles. This permeability is probably bidirectional, and the impact of the other roles on caregiving strain must be investigated to fully understand what is at stake in caregiver burnout.

As with gender or professional status, the relevance of studying background or sociodemographics lies not in the variable itself but rather in what it implies. The impact of gender would rather reveal gender discrimination, professional status may represent a resource or a demand, and role accumulation can be a major risk factor for multiple aspects of life. Future studies integrating these determinants should therefore investigate their meaning rather than the variable itself.

1.5.3 Psychological Factors

Many psychological factors have been investigated among informal caregivers. Individuals experience a diverse set of emotions when caregiving, related to the relationship with the recipient, the gravity of the recipient's condition, the caregiving role, and their own life. Emotion regulation is thus particularly essential to them and plays an important role in their caregiving experience. One study highlighted that alexithymia was a risk factor for burnout, especially for emotional exhaustion and depersonalization (Katsifaraki and Wood, 2014). Similarly, emotional competencies appear to be a promising resource for the caregiver. Emotional competencies have been found to play a role in preventing professional and parental burnout (Görgens-Ekermans and Brand, 2012; Mikolajczak et al., 2018) and identified as a promising target of intervention to reduce informal caregivers' psychological distress (Weaving et al., 2014). More broadly, personality traits also seem to have an impact on subjective burden and informal caregiver burnout (Chiao et al., 2015; Gérard and Zech, 2018).

One of the ways to consider emotion regulation is in terms of individuals' ways of coping. Caregivers who have a submissive or helpless approach (Duygun and Sezgin, 2003; Yılmaz et al., 2009) or who engage in denial (Onwumere et al., 2017) appear more prone to caregiver burnout than caregivers with coping strategies such as confident and optimistic approaches (Yılmaz et al., 2009) or positive reappraisal and active coping (Onwumere et al., 2017). More generally, the use of a wider range of coping strategies appears to lead to less subjective burden (Adelman et al., 2014). However, these coping styles are global dispositions regarding emotion regulation. The investigation of the coping strategies used when actually experiencing the situation – e.g., through ecological momentary assessment – would allow us to understand if they are effective responses to the stress caregivers face.

Cognitions, especially (dys)functional thoughts and perceived competence, also play an important role in the caregiving experience. Perceived ability to cope with the care-recipient's illness or behaviors is a predictor of burden and burnout (Cuijpers and Stam,

2000). It is directly related to caregivers' needs for knowledge regarding the recipient's health issue (Zarit and Zarit, 2015), and to self-efficacy (Ducharme et al., 2011).

Regarding the caregiving role, lack of choice in becoming the caregiver is associated with higher subjective burden (Adelman et al., 2014). Intrinsic motivation to care appears to be a protective factor for informal caregiver burnout (at least for emotional exhaustion, in Kindt et al., 2015). Constant worrying and need for control in the caregiving role appear to be risk factors, as they require chronic alertness on the part of the caregiver (Cuijpers and Stam, 2000; Lindström et al., 2011). More generally, a strong sense of coherence appears to be a protective factor against burnout (Goetzmann et al., 2012; Götze et al., 2015).

All these studies point to the necessity to consider psychological factors when studying caregiver burnout. While some of them are more related to trait elements (e.g., personality) that would be hard to modify, others could be targeted by interventions to help exhausted caregivers or to prevent future problems. Future research should thus fully identify the psychological processes involved in informal caregiver burnout in order to identify those with the greatest impact and those which are most promising for interventions.

1.5.4 Physical State

The physical health of caregivers is a factor that determines their involvement in caregiving. Healthy caregivers often take more responsibility in caregiving (Pinquart and Sörensen, 2007). The experience of somatic disorders, illness, or chronic pain has been shown to put pressure on caregivers, making them more prone to burnout (Hattori et al., 2000, 2001; Demirhan et al., 2011). While this is especially acute for aging caregivers, it is a factor in all caregivers' capacities to provide care and in the difficulties they may face. Future research should thus consider more closely how the evolution of caregivers' physical state could affect their ability to manage the situation and impact their mental health.

1.5.5 Determinants: Caregiving Setting

As pointed out in the Sörensen's Model of Carer Stress and Burden, a distinction needs to be made between primary and secondary stressors in the caregiving setting. Primary stressors are all the demands (and potential resources) *defining* the caregiving role. They are mostly referred to in the literature as "objective burden" (Brouwer et al., 2004). Secondary stressors are all the demands and resources *caused by* the primary stressors.

1.5.6 Primary Stressors

Time since start of caregiving (duration) is often considered as a central element in caregiving strain. Yet it appears that there is no relationship between duration of care and burnout (Sugihara et al., 2004; Lindström et al., 2011; Kokurcan et al., 2015), and only a weak link to burden (Pinquart and Sörensen, 2003; Adelman et al., 2014). A similar pattern appears regarding time spent caregiving per week (intensity) (Angermeyer et al., 2006; Truzzi et al., 2012; Adelman et al., 2014; Kokurcan et al., 2015), and living with the care-recipient

has also been highlighted as an inconclusive stressor for subjective burden and burnout (Cuijpers and Stam, 2000; Cheung and Chow, 2011; Yan, 2014; Chiao et al., 2015).

Being a spouse appears to be a risk factor (Cuijpers and Stam, 2000; Sugihara et al., 2004), and caring for a man appears to be more demanding than for a woman (Goetzmann et al., 2012; Onwumere et al., 2017). The reason behind the increased risk of caring for a man has not been investigated yet, but the low effect size of this association suggests that intensive investigation is not required.

Informal caregivers provide care to individuals with a wide diversity of health issues. Most studies, however, consider informal caregivers in the context of one particular health issue (e.g., neurodegenerative diseases, chronic pain, or disability) in order to control for a significant form of variability. Some studies have compared different populations in their sample (often one by one) (e.g., Weiss, 2002; Ybema et al., 2002; Lindström et al., 2010; Tramonti et al., 2019), but not enough to conclude about a particular risk profile. The autonomy (or functional impairment) of the care-recipient is a factor often related to caregiving subjective burden and burnout (Cheung and Chow, 2011; Yan, 2014; Chiao et al., 2015; Lynch et al., 2018), but this variable remains specific to some populations (e.g., dementia). The common ground is the intensity of the symptoms in each health issue, which appears to be more related to caregiving subjective burden (Chiao et al., 2015). Such evidence has also been highlighted for informal caregiver burnout in caregivers of individuals with mental illness (Kokurcan et al., 2015) or dementia (Cheung and Chow, 2011; Truzzi et al., 2012; Yan, 2014), and in caregivers of children with disability (Demirhan et al., 2011; Basaran et al., 2013), chronic disease (Riva et al., 2014), or comorbid issues (Gérain and Zech, 2018). Beyond the health issue itself, correlative analyses have also shown a relationship between recipient's well-being and depressive symptoms on the one hand and subjective burden and informal caregiver burnout on the other, which suggests a mutual influence of the emotional states in the dyad (Ybema et al., 2002; Yilmaz et al., 2009; Adelman et al., 2014; Kindt et al., 2015).

Primary stressors thus seem to have an impact on informal caregiver burnout. However, this impact appears mostly related to the health issue and not to descriptive characteristics of the caregiving role. Future research should therefore focus not only on the objective stressors, but also on what they entail (i.e., secondary stressors), and what they represent for the caregivers (i.e., their appraisal).

1.5.7 Secondary Stressors

Secondary stressors are often investigated less than primary stressors when exploring caregiving stress and its impact, yet studies have shown a significant role of these stressors in caregiving strain. Some have highlighted that informal caregivers reporting high levels of informal caregiver burnout perceived themselves as having a more disturbed daily life due to the illness, less free time and time for themselves (Lindström et al., 2011), or hypervigilance regarding the occurrence of new symptoms in the case of unpredictable illnesses (Lond and Williamson, 2017). Informal caregiver burnout was also found to be related to having a reduced social life and the loss of friends (Lindgren, 1990), and more globally the feeling

on the part of caregivers of having had to give up important things for themselves due to the care-recipients' problem (Gérain and Zech, 2018). Beyond the emotional strain, such feelings could also have an important impact on the relationship with the recipient, with a mixed feeling of duty and resentment toward the care-recipient (Williams et al., 2016).

Although it has not been widely investigated yet, the existence of secondary resources remains open to consideration. From this perspective, a resource arises because of the presence of a primary stressor, such as more social support or less isolation, due to caregivers' support groups or an increase in regular social support (Sakakibara et al., 2015).

1.5.8 Determinants: Social Environment

The caregivers' social environment can be considered in three distinct ways: informal and partner support, professional support, and the sociocultural environment. Informal social support appears to diminish burden (Choi and Sok, 2012; Adelman et al., 2014) and burnout (Choi and Sok, 2012; Riva et al., 2014; Kokurcan et al., 2015), but this protective role is more important when the support responds to a caregiver's specific need (Lindström et al., 2011). Because caregivers often take sole responsibility for care, the presence of other informal caregivers may represent a resource (Peeters et al., 2010). However, such a resource could also translate into more stress due to additional conflicts, perceived inequities, worries, or diverging opinions (Williams et al., 2016). Outside the caregiving setting, the face-to-face or online support of other caregivers also seems to be beneficial for caregivers because they share comparable experiences (Perkins and Hewitt, 2016).

The partner is not always directly involved in caregiving but it appears that their support is essential to the provision of informal care (e.g., DePasquale et al., 2018). Research on support between parent-caregivers – parents providing care to one of their children – has shown that an unsatisfactory marital relationship and disagreements with the partner are related to burnout, highlighting the need for parents to face this challenge together (Lindström et al., 2011; Riva et al., 2014; Gérain and Zech, 2018). Besides parent-caregivers, it may also be interesting to consider the quality of the relationship with the partner in the context of caring for a relative, other than a child, to understand how the caregiving situation modifies the dynamic in the couple. The particular situation of being the partner's informal caregiver will be addressed in the section on the relationship with the care-recipient.

Whether from the couple or the social network, the question of social support raises the broader and complex issue of caregivers' isolation. This isolation may originate from the social environment or from the informal caregiver (Priestley and McPherson, 2016; Lindström et al., 2017). Whichever is the case, it affects the caregiver in an overall sense and could contribute to the caregiver's burnout, whether directly or indirectly through his or her appraisal (Vasileiou et al., 2017). Regarding professional support, one study has shown that difficult relationships with healthcare professionals are related to caregiver burnout (Almberg et al., 2000). There is no clear evidence of the impact of the use of support and respite services (Vandepitte et al., 2016). Certain in-home services seem to diminish the burden, but informal caregivers calling on such services who have waited a long time before doing so tend to be more exhausted than average (Sugihara et al., 2004). It is difficult to be sure how useful a

resource it could represent for caregivers in general, especially given the potentially deleterious impact on the caregiver's experience, due to the additional stress it might bring. Further research should focus on ways of improving support for informal caregivers and understanding the motives of informal caregivers who call on formal support.

The sociocultural environment of the individual is too often neglected in burnout research (Pines et al., 2011), and informal caregiver burnout is no exception. Culture seems to be an important factor in the consequences of informal caregiving (Pinquart and Sörensen, 2005; Chiao et al., 2015). At first, depending on their cultural norms, individuals could see their transition to the caregiving role as a normal process, or on the contrary experience it as a burden (Sutter et al., 2016). Later on, the perceived normality or abnormality of the caregiving tasks performed and the trade-off made due to caregiving may also impact their appraisal (Chiao et al., 2015; Konerding et al., 2018). As the care-recipient's health issue progresses, an unwillingness to delegate tasks and receive assistance due to cultural reasons may lead to burnout in the caregiver (Scharlach et al., 2006). More broadly, there is a strong need to consider the cultural perspective and to be aware of the need to include groups often under-represented in research (Parveen et al., 2018). Future research focusing on cultural aspects and their implications in caregiving will lead to a more precise understanding of caregivers' experience in different contexts and how it affects their well-being (Bastawrous, 2013). In light of existing studies, such future work should try to understand the mechanisms by which culture affects caregiver stress and burnout (e.g., Knight and Sayegh, 2010).

1.5.9 Caregiving Appraisal

In the Informal Caregiving Integrative Model, all the determinants are held to have a direct impact on the caregiving appraisal. Absent from the JD-R, this appraisal is the subjective evaluation of the caregiving experience by the caregivers themselves. It is the evaluation of the balance or imbalance between demands and resources and is thus the weighting of the determinants. This evaluation is a mixture of positive and negative assessments, but its most investigated aspect in research is the subjective burden (Galiatsatos et al., 2017). Close correlations have been found between subjective burden and emotional exhaustion, while less significant relationships have also been found with depersonalization and personal accomplishment (Kasuya et al., 2000; Angermeyer et al., 2006; Kyung-Bock and Kim, 2008; Truzzi et al., 2008; Özlü et al., 2009; Choi and Sok, 2012; Salama and El-Soud, 2012; Akinci and Pinar, 2014; Götze et al., 2015). These results suggest that the impact of the appraisal on outcomes could be mediated by burnout (Lee and Singh, 2010). Other appraisal elements such as feeling trapped in the caregiving role have not been investigated yet, but are probably related to caregiver burnout (Sörensen et al., 2006).

Future work should focus on a more homogeneous definition of what form a positive appraisal could take, as opposed to the long-standing focus on subjective burden. A positive appraisal appears to have a positive impact on caregiver well-being (e.g., Yamamoto-Mitani et al., 2004), but this has not been investigated in connection with informal caregiver burnout. Focusing on positive appraisal could also have the broader goal of moving away from the

long-standing view of caregiving as an ultimately negative experience, to a more balanced view in which positive appraisal is at the core of the evaluation (Brown and Brown, 2014).

1.5.10 Relationship Quality

The relationship quality has been little considered in caregiving stress models, but the relationship with the recipient is the reason why an individual becomes a caregiver and remains a central element when considering either the care-recipient or the caregiver (Revenson et al., 2016). The occurrence of an illness or a disability modifies the roles and the relationship in the dyad between the future care-recipient and the future caregiver (Spruytte et al., 2002; Bastawrous et al., 2015). As the caring process progresses, the relationship quality remains a core-element in the caregiving experience. Of course, relationship quality with the care-recipient is determined by many elements, such as the relationship before caregiving or attachment style, but the key is to consider the impact caregiving may have on this relationship. Poor relationship quality has been found to be related to burden (Cuijpers and Stam, 2000) and burnout (Goetzmann et al., 2012; Kindt et al., 2015). Inequity in the relationship is also a key factor for caregivers of a spouse, particularly when the caregiving spouse feels like he or she is of minor importance in the couple, having been overshadowed by the other partner's health issue (Ybema et al., 2002). One study has highlighted the need to take into account the disease's temporal characteristics when exploring further the impact of this relationship (Fauth et al., 2012). Relational closeness appears to be a resource when the disease is manageable, and death remains a distant prospect. But when death appears closer, there may be a need to prepare for the separation.

Future research should focus on developing a deeper understanding of how the relationship quality could be a mediator between determinants and caregiver burnout. Dyadic coping has not been investigated in the context of informal caregiver burnout, but it appears to be a promising area for research in light of existing results (e.g., Rottmann et al., 2015). Investigation should also be broadened to the dyadic processes involved in caregiving, and to dyads other than couples (Revenson et al., 2016). It should also address the relationship between appraisal and relationship quality and its evolution over time. If positive relationships could alleviate part of the subjective burden (Lea Steadman et al., 2007), other elements such as perceived fairness or unfairness or modifications in roles could also impact the caregiver's appraisal (e.g., McPherson et al., 2010).

1.5.11 Informal Caregiver Burnout

Informal caregiver burnout is the key element of the ICIM. It is expected to be the consequence of the different sets of determinants, either directly or through the mediation of the appraisal and the relationship quality with the care-recipient. Caregiver burnout is also viewed as a key mediator between demands and various more general outcomes, as highlighted in several studies (Lee and Singh, 2010; Kindt et al., 2015).

As pointed out in work on professional burnout, the negative impact of caregiving may overshadow the positive impact, but this does not mean that the latter cannot exist in presence

of the former (Schaufeli and Taris, 2014). Positive and negative caregiving impacts could both be present, leading to different combinations of caregiving strain (along similar lines to recent developments in the study of professional burnout, see Leiter and Maslach, 2016). From this perspective, future research could consider personal accomplishment as a dimension that may counterbalance the other two negative dimensions and lead to different outcomes.

Future studies should also investigate the conceptual proximity of informal caregiver burnout to comparable concepts, in particular, compassion fatigue or satisfaction. Compassion fatigue is often referred to as “the [professional] caregiver’s cost of caring” (Sorenson et al., 2016, p. 457) and compassion satisfaction “reflects the positive feelings that result from one’s ability to help others” (Lynch, 2018, p. 9). Some studies have adapted the concept of compassion satisfaction to the informal caregiving context as a measure of caregiving impact (e.g., Day et al., 2014; Lynch et al., 2018). Their results suggest that it is relevant to use it in informal care, but its overlap with informal caregiver burnout should be clarified. In occupational health research, this overlap between the two concepts is still being discussed, although compassion fatigue is often seen as a precursor of burnout (Sorenson et al., 2016). Theoretically, compassion fatigue seems to be close to emotional exhaustion and compassion satisfaction to personal achievement, but this proximity should be examined in future work.

1.5.12 General Outcomes

Beyond the specific impact of caregiving, more general outcomes can occur in reaction to or as a result of caregiver burnout. General outcomes of the caregiving impact are twofold: on the caregivers themselves and on the care-recipients. For the caregiver, informal caregiver burnout could lead to physical and psychological issues. In general, caregiver burnout is related to lower well-being, more psychological distress (Götze et al., 2015; Kindt et al., 2015; Bachner, 2016), more negative and less positive emotions (Kindt et al., 2015), and lower quality of life (Ostlund et al., 2010; Takai et al., 2011). In terms of psychopathology, some studies have highlighted a moderate relationship between burnout and anxiety (Yılmaz et al., 2009; Truzzi et al., 2012; Riva et al., 2014). As pointed out in the literature on professional burnout and on caregiving burden, the direction of these relationships is difficult to settle (Adelman et al., 2014; Chiao et al., 2015). Anxiety could be a consequence of burnout and the caregiver’s exhaustion, but trait anxiety could also lead to higher vigilance and overcaring, thus facilitating the occurrence of burnout. There is also a strong relationship between burnout and depression (Truzzi et al., 2008, 2012; Yılmaz et al., 2009; Lee and Singh, 2010; Katsifaraki and Wood, 2014; Bachner, 2016). Caregiver burnout could also have an impact on other spheres, for example by putting the individual at risk of professional burnout (as shown for parental burnout in Greaves et al., 2017). Informal caregiver burnout could also be a key mediator between subjective burden and decreased social activity (Adelman et al., 2014): caregivers experiencing burnout are less likely to seek social contact. In terms of physical health, caregiver burnout is related to poorer subjective health (Valente et al., 2011; Choi and Sok, 2012; Goetzmann et al., 2012), and to more reported somatic symptoms (Weiss, 2002; Truzzi et al., 2012). Future research should further investigate the role of caregiver burnout in the erosion of the caregiver’s physical

health and the mechanisms by which this impact occurs (e.g., health behaviors, psychoneuroendocrinology). Informal caregiver burnout could have a direct impact on the well-being of the care-recipient (Kindt et al., 2015). Beyond that, caregiving strain could have an indirect impact through the onset of mistreatment (Wiglesworth et al., 2010; Fang and Yan, 2016). Despite the affective bond, the risk of neglect and abuse remains a reality (Acierno et al., 2010). Caregiver stress appears to be an important risk factor for the occurrence of physical or verbal violence (Johannesen and LoGiudice, 2013). Early results have shown a link between burnout and violence, in both formal (Truchot et al., 2013) and informal contexts (Yan, 2014).

Preliminary results highlight a potential relationship between the caregiver's mental health and (re)admission rates of the patient (Longacre et al., 2014) as well as the likelihood of placement in nursing homes (Covinsky et al., 2003). No study has directly examined the impact of burnout on institutionalization. Similar to "turnover intention" in occupation contexts, a study has shown that caregivers of individuals with Alzheimer's disease who stated that they would prefer their care-recipient to be in a nursing home reported higher burnout scores than those preferring to keep the care-recipient at home (Yılmaz et al., 2009). Future studies should thus expand these results to add to our understanding of the potential consequences of informal caregiver burnout on the care-recipient, and, to a larger extent, how these consequences affect the health care system.

1.5.13 Circularity

Beyond the consequences themselves, caregiver burnout and more general outcomes will in turn have an impact through feedback loops and modify elements regarding the caregiver, the caregiving context, and the social environment. This circularity has often been neglected in models created to understand caregiving strain (as well as in the JD-R model), but it is critical in addressing how caregiving strain may evolve. The modification of one element will have a global impact on caregiving strain through a direct and indirect modification of the caregiving experience. Longitudinal studies should thus investigate these loops and understand their pathways.

2. Conclusion

The present work has proposed to adapt the concept of burnout to the informal caregiving context. This adaptation represents a response to criticisms made regarding the measurement of the impact of caregiving and its conceptual heterogeneity. The three-dimensional approach also expands the view of the impact of caregiving to the accomplishment found in the role and to the depersonalization that may occur. Additional studies should confirm the relevance of this concept, but it appears promising in light of the existing literature.

The second goal of the present work was to propose a theoretical model to frame future research on informal caregiver burnout. The review of the Job Demands-Resources Model from the occupation burnout literature and of the Caregiving Stress and Burden Model led to the development of the Informal Caregiving Integrative Model. This model aims to respond to the opportunities for the improvement of existing models, but also to preserve their most

valuable features. The ICIM stresses the importance of taking full account of the actors and elements at stake when considering the determinants of caregiver burnout: the caregiving setting, the caregiver's characteristics, and their sociocultural environment. Key mediators between the determinants and caregiver burnout are the caregiving appraisal (both positive and negative), and also the relationship between the care-recipient and the caregiver, which has often been neglected.

In adapting the burnout concept and providing an integrative model to address caregiver burnout, our purpose was not to provide an exhaustive treatment of this topic, nor to pretend to disprove existing research. Rather, the objective was to respond to critical work pointing to the need to re-explore informal caregiving research (Bastawrous, 2013; Mosquera et al., 2016). In the same way as other promising works (e.g., Revenson et al., 2016), the present article thus proposes new ideas for informal caregiving research, both in terms of impact measures and in terms of a conceptual framework for studying them.

Section 2

Conclusive note

The present section aimed at developing a better theoretical understanding of what is informal caregiver burnout, what are its existing or potential determinants and consequences, and how to address them. Chapter 2 was a literature review of the studies investigating the correlates of informal caregivers, whether they were determinants or consequences. Among the determinants, it appears that one of the main predictors of burnout was the “subjective evaluation” informal caregivers have of their own situation, mainly in terms of *subjective burden*. This evaluation is the perception they have of the resources they have and demands they face. Along with it, the relationship with the care-recipient was at the core of the understanding of how informal care may take a positive or a negative turn. Apart from these two clear determinants, a series of others also appeared but without a clear framework to articulate all of them.

This articulation was one of the aims of chapter 3. By proposing a theoretical model, it framed the determinants into three different categories that (may) affect informal caregiver burnout. It also proposed that the appraisal (the “subjective evaluation” from chapter 2) and the relationship between the care-recipient and the caregiver are the two key-mediators between determinants and informal caregiver burnout. Therefore, the determinants are considered affecting informal caregiver burnout directly but also through a modification of the appraisal and relationship with the care-recipient. In this framework, informal caregiver burnout is seen a key predictor of potentially deleterious outcomes such as caregiver poor mental and physical health, or violence toward the care-recipient.

Section 3

Empirical investigations of informal caregiver burnout

Empirical investigations of informal caregiver burnout

After the theoretical framework proposed in section 2, section 3 presents empirical investigations of informal caregiver burnout, based on this model. In this section, three different studies will be presented. The first two are based on a common database and investigate, respectively, determinants and consequences of informal caregiver burnout. The third is based on a study focusing on parental burnout.

The first two studies are based on the same dataset. The data were collected through an online questionnaire available between November 2018 and October 2019. The aim was to investigate different determinants and consequences of informal caregiver burnout. Informal caregiver burnout itself was measured with the Maslach Burnout Inventory, adapted to the context of informal care (Appendix 2.). Intentionally, there was no restriction regarding the health issue of the care-recipient, every person being an informal caregiver could answer the survey. This choice had some consequences and implications, which are developed in the two studies and will be discussed in the general discussion.

The first study (chapter 4), entitled “*Caregiving appraisal and relationship quality: Key mediators in the understanding of informal caregiving burnout?*” aimed to put at test the theoretical model presented in chapter 2. To do so, it focused on the caregivers of adult care-recipients, which constituted a subsample of 446 informal caregivers. This restriction was due to the measure of the care-recipient’s dependency, which is developed for people over 16 years of age. Along with the recipient’s dependency, the caregiver’s emotional intelligence and feelings of loneliness were investigated. Measures of appraisal – assessed by subjective burden – and relationship quality were included to explore the theorized mediations through structural equation modeling.

The second study (chapter 5) entitled “*Caring until it hurts: informal caregiver burnout as a determinant of caregiver depression, subjective health, and violence*” investigated the association of informal caregiver burnout with potentially deleterious consequences for the caregivers themselves (depression and reduced subjective health) and the care-recipients (violence perpetrated by the caregiver). With linear and logistic regressions, the role of each burnout dimensions on each consequence was explored, while controlling for potential confounding variables. An additional and exploratory aim was to investigate if a particular kinship was more at risk than the others, since it does not have the same implications to take care of a parent, a child, or a spouse.

The third study (chapter 6), entitled “*Burnout in the context of parents providing informal care to their children: a comparative study*” was an investigation of the determinants of parental burnout in a sample of general parents ($n = 900$). Among them, it appeared that 175 (more than 19%) reported having one or more children with special needs (i.e., having (1) a

chronic or serious disease, (2) a disability, or (3) a behavioural, emotional, or learning disorder). While it does not directly address the informal caregiver burnout is not based on the model in chapter 3, this chapter provides interesting keys for understanding how parents who provide informal care to their child may differ from parents who have typical children. Therefore, the study focused on comparing parents with and without children who have special needs in order to understand where the potential risk of being a parent-caregiver may lie. Determinants such as neuroticism, co-parenting (dis)agreement, and appraisal – measured through statements on the perceived impact of having a child with a special need – were also investigated to explain parental burnout.

Chapter 4

Caregiving appraisal and relationship quality: Key mediators in the understanding of informal caregiving burnout

Informal caregiver burnout appears to be a promising concept to capture the deleterious impact informal caregiving can have. Yet, its understanding remains limited. Recent theoretical developments have suggested that determinants of informal caregiver burnout are mediated by the caregiving appraisal and the relationship quality with the care-recipient (Gérain & Zech, 2019). To date, no study has investigated this issue empirically. The present study therefore investigates the impact of the care-recipient's dependency, the caregiver's emotional intelligence and loneliness on informal caregiver burnout, both directly and through a mediation of caregiving appraisal (measured by subjective burden) and relationship quality. A sample of 444 French-speaking informal caregivers completed online questionnaires in 2018 and 2019. Structural equation modeling were performed, using Stata. Results highlighted that the mediation through both appraisal and relationship quality better fit the data. In more details, the appraisal appears to be a key mediator of the determinant's impact on informal caregiver burnout. Relationship quality was also a mediator for the determinants, but to a lower extent. Emotional intelligence appears to be a protective factor for every investigated dimensions of burnout, as well as for relationship quality and the appraisal. Overall, the results of this study show the relevance of the double mediation, while providing a better understanding of the determinants at play in informal caregiver burnout.

Reference

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Caregiving appraisal and relationship quality: Key mediators in the understanding of informal caregiving burnout

1. Introduction

An increasing number of studies are focusing on caregiver burnout as a measure of the individual consequences of caregiving (e.g., G rain & Zech, 2019; Onwumere et al., 2018). This approach addresses three complementary outcomes: the exhaustion they experience, how they treat the care-recipient, and their feeling of accomplishment in the caregiving role. Each of these dimensions offers promising ways for explaining potentially detrimental consequences of caregiving such as caregivers' poorer mental health or the risk of abuse and neglect of the care-recipient. Yet, little is known about the determinants influencing informal caregiver burnout. To answer this gap, recent theoretical developments have tried to frame this research and highlighted the need to investigate two mediators between informal caregiver burnout and its determinants to better capture by which it occurs (G rain & Zech, 2019).

The first mediator is the appraisal of the caregiving experience, which is a core element in the understanding of how caregiving may lead to deleterious outcomes (Revenson et al., 2016). This appraisal is the global evaluation of how caregiving affects the caregivers' life. To date, it has been mostly investigated negatively, in terms of subjective burden: the global evaluation of how caregiving represents a burden for the caregiver (Bastawrous, 2013; Revenson et al., 2016). The appraisal is therefore seen as a key mediator between the caregiving determinants (such as the dependency of the care-recipient) and informal caregiver burnout (G rain & Zech, 2019). It is the perception of the stress rather than the objective stress itself (e.g., the number of hours caregiving) that seems to affect the caregiver. Several studies have found a highly positive association between the negative appraisal of the caregiving situation and informal caregiver burnout (e.g., Akinci & Pinar, 2014; Truzzi et al., 2008). However, only a few of them have investigated how the appraisal could mediate the impact of determinants on informal caregiver burnout. It also remains unclear if determinants have an impact on burnout through a full mediation of the appraisal, or if they still have a direct impact on it.

The second mediator is the quality of the relationship with the care-recipient, which is as at the heart of the caregiving experience (G rain & Zech, 2019; Revenson et al., 2016). Over the course of caregiving, the relationship with the care-recipient is challenged by the onset of the health issue, but is also maintained through relational and individual resources the dyad possesses and develops (Hagedoorn, Kreicbergs, & Appel, 2011). On the one hand, factors related to the caregiver, the care-recipient, and the context they both evolve in influence the

relationship they experience. For example, the recipient's symptomatology has been shown to be a barrier to communication, leading to lower relationship quality (Watson, 2017). The environment of caregiving therefore seems to influence the relationship. But on the other hand, the relationship quality with the care-recipient also affects the caregiver and the care-recipient in turn (Fauth et al., 2012; Rottmann et al., 2015). Relationship quality is therefore viewed as a key mediator between determinants (the elements affecting the caregiver in some way) and caregiving outcomes (positive and negative).

Several determinants could be considered to influence informal caregiver burnout through the appraisal and the relationship quality. Some of the most investigated are the objective stressors informal caregiver face, i.e., what is usually referred to as their objective burden. One of the proxy of this objective burden is the dependency of the care-recipient (i.e., his/her lack of autonomy). It has been shown to be related to caregiver's lower well-being (Sörensen, Duberstein, Gill, & Pinquart, 2006), but little research has been conducted on the impact of objective burden on the relationship quality with the care-recipient, and its subsequent impact on informal caregiver burnout.

In the investigation of the determinants influencing informal caregiver burnout, a growing interest focuses on emotional and psychological factors. Studies suggest that trait emotional capacities could play an important role in the caregiving experience (Katsifaraki & Wood, 2014), but trait emotional intelligence (EI) has been little investigated in informal caregiving. Yet, in the general population, emotional intelligence has been shown to be related to resistance to stress (Mikolajczak, Luminet, & Menil, 2006), better health (Mikolajczak et al., 2015) and to more satisfying relationships (Petrides et al., 2016). Emotional intelligence is therefore expected to be a strong protective factor for informal caregivers. A study of caregivers of people with dementia noted that EI may indeed be a protective factor against caregiver-related stress and anxiety (Weaving, Orgeta, Orrell, & Petrides, 2014). Yet, its role in informal caregiving burnout remains to be investigated.

Beside the objective burden and the emotional intelligence – which are respectively centered on the care-recipient and on the caregiver psychological resources – the social network of informal caregivers can also contribute to their well-being. Although it does not always depend on objective social networks (“Alone in the crowd”, see Cacioppo, Fowler, & Christakis, 2009), the feeling of being alone in dealing with stressors can be critical to people's well-being, and particularly when it comes to informal caregivers (Vasileiou et al., 2017). Previous research has shown that feeling of loneliness has been related to higher subjective burden (Iecovich, 2016), and has a deleterious impact on informal caregiver burnout (Bachner, Morad, Sroussi, & O'Rourke, 2019). Yet, it remains unclear how feeling lonely could affect informal caregiver burnout. One hypothesis is that feeling of loneliness could affect informal caregiver burnout not directly, but through a worsening of the appraisal of the caregiving situation: feeling lonely can lead to a more negative appraisal of the caregiving role, which can be an additional stress and lead to informal caregiver burnout.

2. Purpose of the study

The purpose of the present study is twofold:

- (1) Investigate the role of determinants in the caregiving setting (i.e., the care-recipient's dependency), the caregiver (i.e., his/her emotional intelligence), and social environment (i.e., loneliness) on caregiving burnout.
- (2) The second objective is to investigate the impact of these determinants through a mediation of the appraisal (i.e., subjective burden) and the relationship with the recipient (i.e., the perceived quality of their relationship).

To summarize these two objectives, a theoretical model can be drawn. In this model, the determinants are expected to influence informal caregiver both directly and indirectly through the appraisal and the relationship quality with the care-recipient (see Figure 7). The present study will therefore investigate if this model offers a better fit in comparison to models where there are only direct effects and no mediation through appraisal and relationship quality.

Model 1: No mediation (only direct effects)

Model 2: Mediation only through the appraisal

Model 3: Mediation only through the relationship

Model 4: Double mediation (independent pathways)

Model 5: Double mediation (dependent pathways)

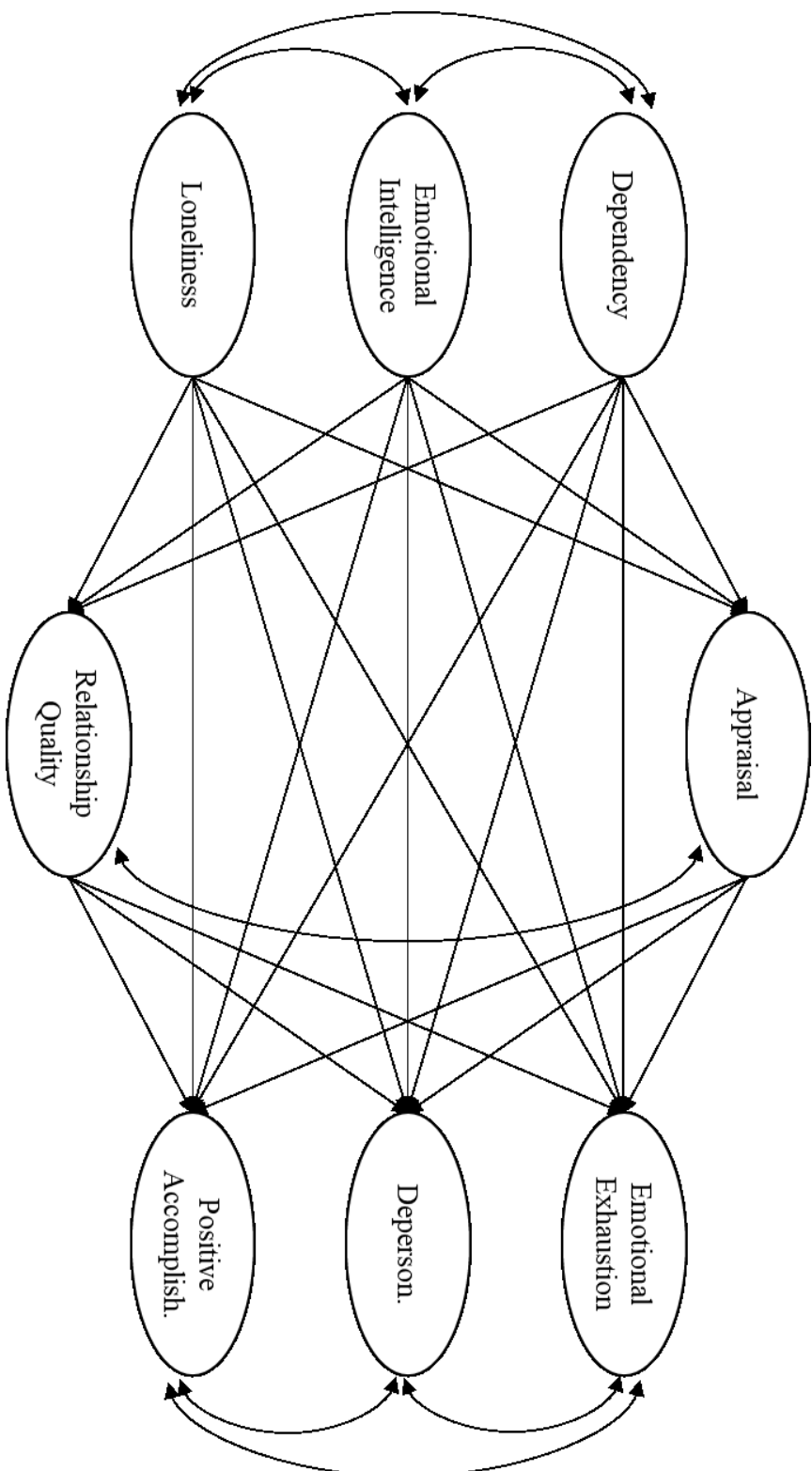


Fig. 7. Theoretical model.

3. Methods

3.1 Sample

An online survey was created on the Qualtrics® survey platform. It was then sent to different informal caregiving associations, websites, and forums for dissemination. The only inclusion criterion was to currently provide informal care to someone they know. A total of 505 people completed the questionnaire. Six of them were removed from the sample as they were identified as being no longer caregivers or professional caregivers. The final sample was constituted of 499 informal caregivers. The present study will focus on the 444 of them who take care of an individual aged more than 16 years old. As presented in Table 3, the sample was mainly constituted of women (86,9%), has a mean age of 54.57 (SD = 13.25). They are mostly taking care of a spouse (25.7%), a child (33.6%), or a parent (21.8%). These three groups account for 81.1% of the total sample. The health issues of the care-recipients were diverse, mostly dementia, mental health disorder, and physical disability.

Table 3. Description of the sample.

	Mean (SD)	N (%)
Age	54.57 (13.25)	
Women		386 (86.9)
Nationality		
Belgian		205 (46.2)
French		224 (50.5)
Other		15 (3.4)
Education		
Primary		7 (1.6)
Secondary		118 (26.6)
Superior		257 (57.8)
Third Cycle		62 (14.0)
Occupation status		
Fulltime		123 (27.7)
Part time		70 (15.8)
Retired		141 (31.8)
Jobless or home		48 (10.9)
Other		63 (14.0)
Care-recipients' age	54.18 (23.13)	
Care-recipient women		184 (41.4)
Care-recipient's issue ^a		
Mental health disorder		146 (32.9)
Dementia		141 (31.8)
Physical disability		118 (26.6)
Chronic illness		47 (10.6)
Loss of autonomy		33 (7.4)
Substance abuse		32 (7.2)
Cognitive disability and autism		31 (7.0)
Cancer		29 (6.5)
Caring for a		
Child (> than 16 y. old)		149 (33.6)
Spouse		114 (25.7)
Parent		97 (21.8)
Brother/Sister		18 (4.1)
Friend		16 (3.6)
Other		50 (11.2)

Note: N = 444.

^a Due to comorbidities, the amount health issues exceeds the number of care-recipients.

3.2 Measures

Informal caregiving burnout was assessed with an adapted version of the Maslach Burnout Inventory – Human Services Survey (Maslach, Jackson, & Leiter, 1996). The scale was designed first for measuring professional burnout, but it is increasingly used in its adapted version to informal caregiving settings. In 22 items, the scale measures three facets of informal caregiving burnout: emotional exhaustion (EE, e.g., “I feel emotionally drained from providing care to my relative”), depersonalization (DP, e.g., “I don’t really care what happens to my relative”), and personal accomplishment (PA, e.g., “I have accomplished many worthwhile things in providing care to my relative”). Higher scores on EE and DP and lower scores on PA represents higher burnout. Individuals rate how often they experience the statements on seven levels Likert scales, from *Never* (0), to *Every day* (6). The adaptation was based on the French validated scale (Dion & Tessier, 1994; Lheureux et al., 2017). Internal consistency was excellent for EE, moderate for DP, and good for PA (respectively Cronbach’s $\alpha = .94, .70, .81$), which is in line with previous studies in caregiving and professional burnout (Aguayo, Pecino, de la Fuente Solana, & Fernández, 2011; Akinci & Pinar, 2014).

Appraisal was evaluated with the Zarit Burden Interview – Short Form (ZBI-SF, Hébert, Bravo, & Prévile, 2000), a shortened version of the 22- items ZBI (Zarit, Reever, & Bach-Peterson, 1980). With 12 items, the scale evaluates the subjective burden, i.e., the perception of the burden caregiving represents (e.g., “Overall, how burdened do you feel in caring for your relative?”). Individuals have to score statements about how they currently feel on 5-point Likert scales, from *Never* (0) to *Nearly always* (4). A higher score represents a higher burden. In the present study, we used the French validated version of the scale (O’Rourke & Cappeliez, 2004). The internal consistency was good in the present study ($\alpha = .91$), comparable with scores in validation studies (Hébert et al., 2000; O’Rourke & Cappeliez, 2004).

Quality of the caregiver-care-recipient relationship was evaluated with three items used in existing studies (Lawrence, Tennstedt, & Assmann, 1998). These three items assess the closeness, similar views, and global evaluation of the relationship with four-point Likert scales, from “*Not at all close/well/similar*” (1) to “*Very close/well/similar*” (4). In the present study, internal consistency was good (Cronbach’s $\alpha = .76$).

Loneliness was evaluated with the three-item UCLA Loneliness Scale (Hughes, Waite, Hawkey, & Cacioppo, 2004). It is based on the Revised UCLA Loneliness Scale (Russel, Peplau, & Cutrona, 1980). This short scale presents good psychometric properties and comparable associations with longer loneliness scales (Elphinstone, 2017). It evaluates the feeling of loneliness in the last few days. Individuals answer the items with four-level Likert scales ranging from *Never* (1) to *Often* (4). In the present study, internal consistency was high (Cronbach’s $\alpha = .91$).

The dependency of the care-recipients was evaluated with the WHO Disability Assessment Schedule (WHODAS) 2.0 (Üstün, Kostanjsek, Chatterji, & Rehm, 2010). It is recommended by the DSM-5 as a measure of the disability and global functioning of adults

(aged 16+) and can be completed by the caregiver (Gold, 2014). It consists of 12 items evaluating the difficulties of the individual to perform various daily life tasks, using 5-level Likert scales, from *No difficulties* (0) to *Extreme difficulties/unable to perform it* (4). A total mean score is computed unidimensionnaly, a higher score representing higher dependency (Andrews, Kemp, Sunderland, Korff, & Üstün, 2009). In the present study, the internal consistency was high (Cronbach's $\alpha = .88$).

Emotional intelligence was measure with the Trait Emotional Intelligence Questionnaire Short Form (TEIQue-SF, Cooper & Petrides, 2010). This scale measures unidimensionnaly the emotional intelligence of the individual with 30 items (e.g., "*On the whole, I'm able to deal with stress.*"). Individuals score the items using 7-level Likert scales, ranging from *Completely disagree* (1) to *Completely agree* (7). Some items are reversed and the total score represents high emotional intelligence. The validated French version was used for the present study (Mikolajczak, Luminet, Leroy, & Roy, 2007). In the validation study, the internal consistency ranged from .87 to .89 and was comparable in the present study ($\alpha = .89$).

3.3 Statistical analyses

Bivariate analyses were first performed on the dataset using IBM SPSS Statistics version 25. Structural equation modeling (SEM) were then used to assess the fit of different theoretical models with Stata version 15.1, using the maximum likelihood method. SEM is a statistical technique that is used to gain information with latent factors by examining the covariation of observed variables. This technique allows to take more error into account and to test the relationship between these latent factors in complex models with multiple relationships involved (see Schreiber, Nora, Stage, Barlow, & King, 2006). The fit indexes used were the CFI, RMSEA, and SRMR (Kline, 2016). A model is considered as having a good fit when $CFI \geq .95$, $SRMR \leq .08$, and $RMSEA \leq .06$ (Schreiber et al., 2006). In order to compare the fit of the different models, both the AIC and BIC were used. A model having the lowest AIC and BIC is preferred.

In SEM when using scales with multiple items, the use of composite indicators (e.g., the mean score of multiple items) is considered as limitative, mostly because it neglects the inter-item variability (Kline, 2016). Therefore, the use of latent variables (i.e., the construction of indicators taking into account the weight of each observed variable and its error) is seen as a better solution. Several methods exist to build the latent variables, the two main methods being the item-based (i.e., using all the items of each (sub)scale as observed variables to build a latent variable) and the parceling method. In the present study, the parceling method was preferred. Parceling refers to the aggregation of multiple item scores on one or more parcels. These parcels are then used to define the latent variables in the SEM. An important prerequisite for parceling is therefore the unidimensionality of the items regrouped (Kline, 2016), all the items in parcels should measure the same construct. This method was preferred over the item-based because it provides a higher reliability than the use of composite indicators while keeping enough statistical power, with the trade-off of a small loss of precision due to the grouping of items (Little, Rhemtulla, Gibson, & Schoemann, 2013).

Based on existing recommendations, the three parcels balancing approach was used in the present study (Little et al., 2013; Yang, Nay, & Hoyle, 2010). This approach is based on the correlation between the scale and its items to build three parcels per scale. The three parcels are based first on the three strongest and three weakest item-scale correlations combined. The first parcel is the combination of the weakest and the stronger item-scale correlation items. The second is the combination of the second weakest and second strongest. And the third with the thirds. Additional items are then added successively to the existing parcels, beginning with the fourth weakest added to the first parcel, the fifth weakest to the second parcel, and so on.

Most parcels presented a normal distribution, with the exception of the third depersonalization parcels (Kurtosis = 2.84). Decision was made not to transform the data, as this was the only problematic element and did not compromise the global fit of the models. Multicollinearity was tested through linear regressions preceding the other analyses. All predictors presented a VIF lower than 5, with the exception of the second and third parcel of MBI-EE which presented a VIF of around 5.5, which remains below common threshold of concern (Kline, 2016).

There was no missing data. With the 444 caregivers and a maximum of 81 estimates, the ratio of subject per parameter was 5.5:1 which is low but remains acceptable (Kline, 2016).

4. Results

4.1 Bivariate analyses

The correlation matrix between the key variables is displayed in Table 4.

Table 5. Fit indexes of the tested models.

	Chi ²	df	CFI	RMSEA	[95% CI]	SRMR	AIC	BIC
Model 1	717.96	231	.934	.069	.063-.075	.149	26765.57	27146.48
Model 2	607.78	228	.949	.061	.055-.067	.095	26661.39	27054.59
Model 3	691.42	228	.937	.068	.062-.073	.141	26745.03	27138.23
Model 4	579.46	225	.952	.060	.054-.066	.068	26639.01	27044.56
Model 5	535.16	224	.958	.056	.050-.062	.046	26596.77	27006.36

Note: CFI $\geq .95$, RMSEA < 0.08 , TLI $\geq .95$, SRMR < 0.08 , AIC and BIC as low as possible.

Table 4. Correlation matrix of investigated variables.

	MBI EE	MBI DP	MBI PA	ZBI	QuaRel	WHODAS	TEIQue	UCLALS
MBI EE	1							
MBI DP	.52**	1						
MBI PA	-.15**	-.26**	1					
ZBI	.81**	.52**	-.18**	1				
QuaRel	-.30**	-.37**	.55**	-.35**	1			
WHODAS	.29**	.13*	.03	.23**	-.07	1		
TEIQue	-.37**	-.34**	.35**	-.33**	.21**	-.18**	1	
UCLALS	.41**	.22**	-.05	.41**	-.11*	.22**	-.40**	1
Mean	3.67	2.40	5.01	3.13	3.02	3.36	4.79	2.47
SD	1.69	1.36	1.22	0.90	0.71	0.94	0.84	1.07
Cronbach α	.94	.70	.81	.91	.76	.88	.89	.91

Notes: N = 444. * $p < .05$ ** $p < .001$. MBI = Maslach Burnout Inventory. EE = Emotional Exhaustion. DP = Depersonalization. PA = Personal Accomplishment. ZBI = Zarit Burden Interview – Short Form. QuaRel = Quality of the relationship with the care-recipient. WHODAS = WHO Disability Assessment Schedule. TEIQue = Trait Emotional Intelligence Questionnaire – Short Form. UCLALS = UCLA Loneliness Scale.

4.2 Structural Equation Modeling (SEM)

The five theoretical models were assessed in structural equation modeling (SEM). Their fit indexes are displayed in Table 5. Models 1, 2 and 3 do not present good fit, regarding either CFI or RMSEA. Models 4 and 5 meet all the criteria of the fit indexes. When comparing the two, model 5 shows slightly lower AIC and BIC than model 4. Model 5 was therefore further investigated.

Figure 8 presents Model 5 with the standardized coefficients and Table 6 develops the direct and indirect effects of the independent variables on informal caregiver burnout. In this model, the appraisal appears as a key element to explain the variance of informal caregiver burnout. Subjective burden was significantly associated to higher emotional exhaustion ($\beta = .83, p < .001$) and higher depersonalization ($\beta = .49, p < .001$). Surprisingly, it was also associated with *higher* personal accomplishment: the more negative the appraisal, the more positive the accomplishment ($\beta = .19, p = .002$). The appraisal was also negatively associated with the relationship quality, which means that higher subjective burden is related to lower levels of relationship quality. Unexpectedly, relationship quality had only an impact on depersonalization ($\beta = -.26, p < .001$) and on personal accomplishment ($\beta = .65, p < .001$), but not on emotional exhaustion ($\beta = .02, p = .636$).

When looking at the determinants, the care-recipient dependency appeared to have an impact on the three informal caregiver burnout dimensions. The dependency increased emotional exhaustion (EE) both directly ($\beta = .09, p = .005$) and indirectly ($\beta = .12, p = .004$). For depersonalization, there was no direct impact of dependency, but an indirect one through an increase of the negative appraisal ($\beta = .14, p = .003$). The impact of dependency on personal accomplishment was direct and comparable to the impact of appraisal: more care-recipient's dependency was associated to *more* personal accomplishment ($\beta = .12, p = .010$). Finally, there was no impact of the care-recipient's dependency on the relationship quality with the care-recipient, suggesting, contrary to what could be expected, that the dependency does not directly impair the relationship quality ($\beta = -.03, p = .590$).

Regarding emotional intelligence, it appears that it plays an important role as a protective factor for every facet of the model. First, it lowers the levels of subjective burden ($\beta = -.16, p = .003$) and increases the relationship quality with the care-recipient ($\beta = .27, p < .001$). Subsequently, emotional intelligence has an indirect effect on every burnout dimension through the appraisal (for EE, $\beta = -.13, p = .004$, for DP, $\beta = -.15, p < .001$, and for PA, $\beta = .14, p < .001$). Along with the indirect effect, it also has a direct protective effect on emotional exhaustion ($\beta = -.08, p = .037$), depersonalization ($\beta = -.21, p < .001$), and its strongest association in increasing personal accomplishment ($\beta = .36, p < .001$).

Loneliness does not appear to be directly related to emotional exhaustion ($\beta = .02, p = .672$), depersonalization ($\beta = -.07, p = .205$), nor personal accomplishment ($\beta = .10, p = .083$). However, it is related to a more negative appraisal, which means that the more lonely the caregivers feel, the more they report subjective burden ($\beta = .36, p < .001$). This impact on the appraisal lead to an indirect effect of loneliness on emotional exhaustion ($\beta = .30, p < .001$) and depersonalization ($\beta = .18, p < .001$). As such, loneliness worsens the appraisal, which then increases the risk of emotional exhaustion and depersonalization.

Table 6. Direct and indirect effect in Model 5.

Dependent	Independent	Direct effects				Indirect effects			
		Std. Coef.	SE	Z	p	Std. Coef.	SE	Z	p
Appraisal	EI	-.161	.066	-3.01	.003				
	Dependency	.140	.047	2.95	.003				
	Loneliness	.358	.045	6.52	.000				
QuaRel	EI	.271	.052	4.30	.000				
	Dependency	-.030	.036	-0.54	.590				
	Loneliness	-.018	.034	-0.29	.774				
EE	Appraisal	.830	.092	17.90	.000				
	QuaRel	.018	.110	0.47	.636				
	EI	-.074	.086	-2.09	.037	-.128	.109	-2.87	.004
DP	Dependency	.086	.059	2.83	.005	.116	.076	2.94	.004
	Loneliness	.016	.060	0.42	.672	.297	.076	6.29	.000
	Appraisal	.493	.093	7.50	.000				
PA	QuaRel	-.263	.127	-4.34	.000				
	EI	-.205	.099	-3.59	.000	-.150	.067	-3.93	.000
	Dependency	-.010	.067	-0.20	.841	.077	.045	2.38	.017
PA	Loneliness	-.074	.067	-1.27	.205	.181	.049	4.29	.000
	Appraisal	.194	.079	3.16	.002				
	QuaRel	.647	.129	9.57	.000				
PA	EI	.357	.093	6.07	.000	.144	.064	3.56	.000
	Dependency	.124	.060	2.57	.010	.008	.044	0.23	.819
	Loneliness	.100	.060	1.73	.083	.058	.046	1.33	.183

Note: QuaRel = Relationship Quality with the care-recipient. EE = Emotional exhaustion. DP = Depersonalization. PA = Personal Accomplishment. EI = Emotional Intelligence

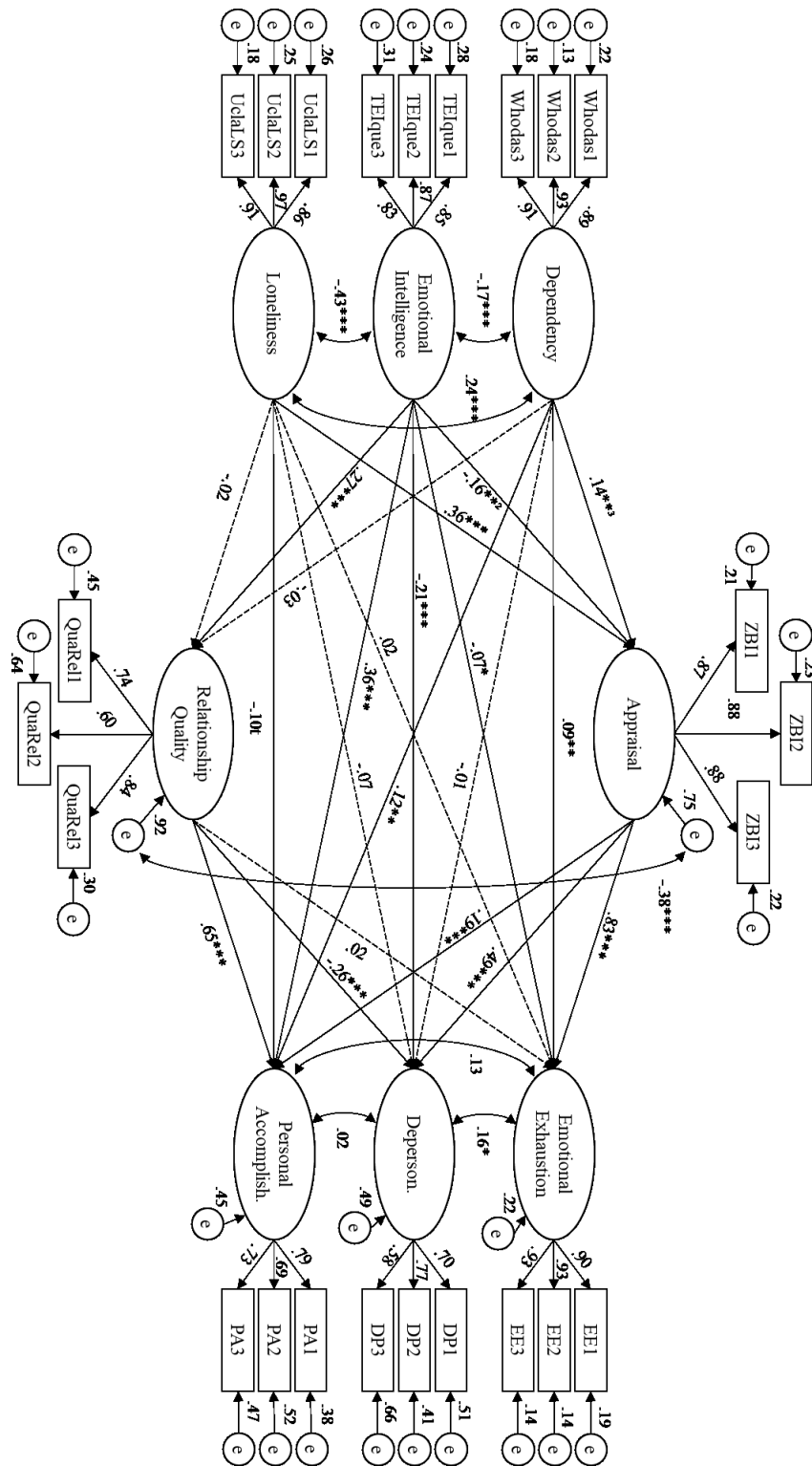


Fig. 8. Structural equation model of dependency, emotional intelligence, and loneliness on the three dimensions of informal caregiver burnout, through appraisal and relationship quality. *Note:* * $p < .05$. *** $p < .001$.

5. Discussion

The present study aimed at investigating the factors influencing caregiving burnout and the mediator role of relationship quality and appraisal. To do so, structural equation modeling were used in order to find the model having the better fit to the data and explaining more variance. After a selection process, the hypothesized model was preferred, including a full mediation of the determinants through the appraisal and the relationship quality, while keeping the direct effects from the determinants to informal caregiver burnout.

Two striking results clearly appeared: (1) appraisal was as a key element in understanding informal caregiver burnout and (2) emotional intelligence appeared to be an important protective factor. The appraisal, here assessed by subjective burden, appears as a fundamental mediator in understanding of how determinants might influence informal caregiver burnout. Every investigated factor in the present study had an indirect impact on informal caregiver burnout through the appraisal. This is in accordance with previous theoretical works pointing that the caregiving appraisal is the main variable to predict deleterious outcomes in caregiving contexts by building a global perception of all the determinants at stake (Gérain & Zech, 2019; Revenson et al., 2016). The perception or evaluation that individuals have on their caregiving situation is therefore a good predictor of the impact they might experience. In the present study, the Zarit Burden Interview (ZBI) was used to assess the appraisal in terms of subjective burden. It provides a good overview of the negative appraisal individuals may have of their caregiving role because it investigates several domains that could be affected by informal caregiving, such as loss of leisure time, in social life, an increased fear of the future, and an overall feeling of being burdened by the role (O'Rourke & Tuokko, 2003). But this diversity may be a double-edged sword since the ZBI merges different components of appraisal in one index, while mainly focusing on the negative valence and low control components. Future research should therefore investigate more precisely which components of appraisal are involved, based on appraisal theories of emotion (Moors, Ellsworth, Scherer, & Frijda, 2013). This refined investigation could lead to a shift from a perspective of "burden" or "negative valence - low control" to something more open and less oriented towards the unpleasant *only*, by including areas of high control and positive valence. It would open to positive evaluations of the caregiver's situation (Carbonneau, Caron, & Desrosiers, 2010) or even low-intensity evaluations, when informal caregivers are not significantly affected by their role.

The second key-result is the protective role emotional intelligence has on the three burnout dimensions and its contribution in reducing negative appraisal and improving relationships with the care-recipient. This echoes studies showing a better mental and social health for individuals with higher emotional intelligence (Baudry, Grynberg, Dassonneville, Lelorain, & Christophe, 2018; Petrides et al., 2016), but also calls for a more detailed understanding of the mechanisms involved in this protective role. Individuals with higher emotional intelligence might be more aware of their needs and limits, therefore being more able to express and act in accordance with them, but also to ask for help when the situation becomes too difficult to handle alone. An additional mechanism could be the increased use of emotion regulation strategies, such as cognitive reappraisal (i.e., the modification of the

appraisal in order to better cope with a distressing situation), which has been shown to be helpful for informal caregivers (Palacio, Krikorian, & Limonero, 2018). Intensive longitudinal designs or experimental studies could investigate when and how such reappraisal can really change the caregiving appraisal in a certain timeframe.

Emotional intelligence is also the only determinant affecting relationship quality, while dependency and loneliness had no significant association with it. Such finding might suggest that, when taking emotional intelligence into account, the onset of the symptoms might not affect the relationship quality with the care-recipient. But this lack of association could more certainly be seen as an addition of positive and negative changes in the relationship (Traa, De Vries, Bodenmann, & Den Ouden, 2015). Indeed, on the one hand, some relationships might be worsened due to difficulties to communicate with the caregiver or symptoms interfering with the relationship, such as alteration of consciousness or decline of cognitive abilities. But on the other hand, the diminution of autonomy might be an opportunity for some caregivers to get closer with their care-recipient and discover new aspects of their bond, as it is reported in palliative care (Drabe et al., 2016). In both cases, relationship quality prior to the onset of symptoms plays a pivotal role and may be the most influential determinant of the current relationship (Lea Steadman, Tremont, & Duncan Davis, 2007).

In return, relationship quality appears to have a protective role for depersonalization and personal accomplishment, while this was not the case for emotional exhaustion. Better relationship quality leads to lower depersonalization and a better sense of accomplishment in the role. This association was expected since more satisfactory relationships are related to better outcomes in illness contexts (Hagedoorn et al., 2011). But, as highlighted in previous works, good relationship quality in the case of informal caregiving might lead to both positive and negative mental and physical outcomes over the course of the care-recipient's disease (Fauth et al., 2012). These mixed observations might be the reason why there was no association in the present study between relationship quality and emotional exhaustion. Some individuals might feel less exhausted because they feel closer to their care-recipient, but some others might feel more exhausted because the relationship is too demanding and they cannot disengage from it. In both cases, the negative association between relationship quality and subjective burden suggests that the higher the relationship quality is, the more positive the appraisal is. The protective role of relationship quality on emotional exhaustion might therefore be indirect, through a more positive perception of the caregiving role (Ybema, Kuijer, Hagedoorn, & Buunk, 2002). Future research should use different evaluations of relationship quality (e.g., relationship satisfaction, closeness, or equity) to determine where the difference lies.

6. Limitations and perspectives

In the present study, the sampling was purposively open to any case of caregiving, regardless of the issue of the care-recipient. This choice was made with the broader objective of identifying the determinants and mediators involved in informal caregiver burnout. In seeking to establish a general pattern, some might argue that a certain specificity has been

lost. Two perspectives emerge from this opinion. The first is to ask for replications of this study and its associations in every possible case of informal caregiving. Such additional research would probably provide a better understanding of each situation, but given the diversity of caregiving environments, this seems an unrealistic goal given the immensity of the task. The effort would not be proportional to the potential benefits. Consequently, a second perspective is emerging, that of identifying and controlling as many factors as possible at the core of this diversity. Being able to take into account what makes the difference between two caregiving situations will allow these factors to be considered together, while taking into account their impact in different analyses. In this study, the dependency of the care recipient was one of many factors of diversity. Including it was a first step towards understanding and fully taking into account this diversity.

Statistically, the use of parceling in SEM is subject to vigorous discussions (Hayduk & Littvay, 2012). Nevertheless, this technique has several advantages that outweighs its shortcomings, as it was stated in the method section. In the present study, the three-parcel balancing approach was used, which led to some parcels being defined by only one item, due to short scales (< 6 items). Again, this was a trade-off, but the use of three parcels prevailed, as it recommended in the literature (Yang et al., 2010). The fact that some parcels were only defined by one item has not been shown to be problematic in the literature, the main risk being that it may cause a poorer global fit of the model (Rogers & Schmitt, 2004).

7. Conclusions

The present study aimed at contributing to a better understanding of the informal caregiver burnout. Among the investigated determinants, emotional intelligence appears as protective factor for the appraisal, the relationship quality with the care-recipient, and informal caregiver burnout. Focusing on emotional intelligence might therefore be a priority for future interventions willing to help informal caregivers at the individual level. Researchers have shown that emotional intelligence could be increased (Kotsou, Mikolajczak, Heeren, Grégoire, & Leys, 2019; Nelis, Quoidbach, Mikolajczak, & Hansenne, 2009), but little evidence of such intervention has been shown in the context of informal care. For this reason, a combination of in person and online programs aiming at increasing informal caregivers' emotional intelligence could be a way to prevent deleterious outcomes.

The second key contribution is to have highlighted the central role of the caregivers' perception, their appraisal, in understanding of how informal caregiving might lead to deleterious outcomes such as informal caregiver burnout. This appraisal represents a key mediator between determinants and positive as well as negative outcomes such as informal caregiver burnout. Because of this centrality, future studies should investigate how this appraisal may vary, both conceptually and in terms of its evolution throughout the caregiving journey. Overall, this mediator role also suggests that while some objective factors cannot be modified (such as the care-recipient's dependency), other modifiable factors such as emotional intelligence can affect the caregiver's appraisal, leading to new opportunities to improve their well-being.

Regarding the different dimensions of burnout, it appears that emotional exhaustion was related to almost every determinant and mediator, with the notable exception of relationship quality. Similarly, depersonalization was associated with every investigated determinant or mediator, either directly or indirectly. These two dimensions therefore seem to share a common risk and protective factor pattern. On the contrary, the surprising role of the dependency and the subjective burden in the increase of personal accomplishment suggests a more complex interaction between care-related and personal or relational determinants.

Finally, this work requires further investigations into several questions that it has raised. What are other determinants involved in informal caregiver burnout? How could be the measurement of appraisal be improved? Why was relationship quality only indirectly associated to emotional exhaustion? What is at the core of the differences between the caregiving settings? The answers to some of these interrogations will lead to a better understanding of the processes involved in informal caregiver burnout, and, on the long run, a better support for informal caregivers in their role.

Chapter 5

Caring until it hurts: informal caregiver burnout as a determinant of caregiver depression, subjective health, and violence

Informal caregiver burnout is expected to lead to deleterious consequences, but this issue remains underinvestigated. Among these consequences, informal caregiver burnout could help understand the causes of violence perpetrated against the care-recipient, the caregiver's risk of depression and low subjective health. An additional need is to investigate the impact of the different kinship relationship with the care-recipient, in order to unveil the potential consequences of such difference. To do so, a sample of 499 informal caregivers was recruited online and completed a questionnaire addressing informal caregiver burnout, depression, subjective health, and violence. A distinction was made between physical and psychological violence, as well as between perpetrated by the caregiver and received from the care-recipient. Hierarchical regression models were used to investigate the stability of the potential predictive role of burnout when controlling for confounding variables. Results show that burnout, and especially emotional exhaustion, is a risk factor for depression, low subjective health, and perpetrated physical violence, but not for perpetrated psychological violence. It appears that received violence is the best predictor of perpetrated violence and kinship relationship accounted for little variability. Overall, these results confirm the role of informal caregiver burnout as a predictor of deleterious consequences, even if this observation must be pondered. Additionally, the central role of received violence in predicting perpetrated violence suggests the risk of violence escalation, one triggering the other.

Reference

Gérain, P., & Zech, E. (2020). Caring until it hurts: Informal caregiver burnout as a determinant of caregiver depression, subjective health, and violence. *Manuscript in Preparation*.

Caring until it hurts: informal caregiver burnout as a determinant of caregiver depression, subjective health, and violence

1. Introduction

Negative consequences of informal care have long been investigated, but research regarding mechanisms by which they occur remain scarce. Yet, recent studies investigating informal caregiver burnout show that it could be a key variable in the understanding of how informal care might take a negative turn (Bastawrous, 2013; Gérain & Zech, 2019). In this emerging field, the investigation of the consequences of informal caregiver burnout needs to be strengthened and further explored. One promising area for the exploration of the role of informal caregiver burnout is the risk of violence toward the care-recipient. Only one study in the specific context of dementia has investigated the role of informal caregiver burnout to understand how violence might occur toward the care-recipient (Yan, 2014). In this study, informal caregiver burnout appeared as one of the risk factors of violence. But a better understanding of how burnout is involved in violence is necessary for the development of better interventions. Along with that, the role of informal caregiver burnout in the higher rates of depression and lower subjective health among informal caregivers remains to be strengthened, especially regarding the specific role of each of the three burnout dimensions.

Informal caregiver burnout has been defined as a tridimensional syndrome in response to the perceived stress that the caregiving context may represent (Gérain & Zech, 2019). It was proposed as a measure of caregiving impact (Bastawrous, 2013) to answer the limitations of existing measures of caregiving impact, and in particular, subjective burden (Mosquera et al., 2016). The first dimension of informal caregiver burnout is the emotional exhaustion, the feeling of not being able to continue to provide the care. It reflects the decrease of the caregivers' resources, and the feeling of no longer being able to assume this role. The second is depersonalization, which describes the detached response to the care-recipient. This dimension echoes the works pointing that caregivers might change the way they treat and consider their care-recipient, with more distance (Cross, Garip, & Sheffield, 2018). The third is the personal accomplishment, which is the positive dimension of the caregiving experience. It reflects the feeling of self-fulfillment and meaning found through the caregiving role. With these three dimensions, it is essential to mention that, while these dimensions are intercorrelated, they are distinct dimensions and may not always co-occur (e.g., high exhaustion does not necessarily mean low personal accomplishment).

The investigation of these three dimensions provide promising keys to understand harmful attitudes and behaviors informal caregivers may have, as theorized in previous works (Gérain & Zech, 2019). Among these behaviors are the psychological and physical violence

that may occur¹. Despite the fact that violence is and often remains a taboo, the risk of psychological and physical violence towards the care-recipient remains real in the caregiving context. Psychological violence can be defined as the “infliction of anguish, pain, or distress through verbal or non-verbal acts” and physical violence covers the “infliction of physical pain, injury, or physical coercion, and involving at least one act of violence [...]” (Ananias & Strydom, 2014, p. 270). Evidence originating from the elderly informal care context shows that the occurrence of violence is annually ranging from 4% to 36%, depending on the type of violence and ways to measure it (Acierno et al., 2010; Lafferty, Fealy, Downes, & Drennan, 2016). If little data has been gathered outside of the context of providing care to the elderly, there is no reason to believe that violence is limited to that sole relation. Caregiving stress, mainly evaluated through the concept of subjective burden, has been found to be one of the caregiver-related risk factors of violence (Boye & Yan, 2016; Johannesen & LoGiudice, 2013). Yet, little research has been performed on the association between informal caregiver burnout and violence in this context. One study conducted among informal caregivers of elderly with dementia highlighted a bivariate association between informal caregiver burnout (mainly emotional exhaustion and depersonalization) and verbal and physical violence by the caregiver toward the care-recipient (Yan, 2014). This is in line with research conducted in professional and parental settings, showing that burnout is a significant risk factor of violence (Borteyrou & Paillard, 2014; Mikolajczak, Brianda, Avalosse, & Roskam, 2018). Yet, with only one study conducted among informal caregivers of elderly persons, evidence is lacking how the informal caregiver burnout, and especially each of its dimension, could affect the risk of violence when providing informal care.

Apart from its potential impact on the care-recipient in terms of violence, informal caregiver burnout has been shown to be related to the caregiver’s depression (e.g., Truzzi et al., 2008, 2012). The more informal caregivers report burnout, the more they are at risk of depression. Previous theoretical and empirical works have highlighted that informal caregiver burnout is a mediator in the association between positive and negative caregiving appraisal (how caregivers perceive their role) and depression (Gérain & Zech, 2019; Lee & Singh, 2010). But the evidence remains unclear regarding how the three dimensions of burnout affect depression. To date, emotional exhaustion appears to be the most investigated dimensions in association to depression, and appears highly correlated to it (Bachner, 2016; Katsifaraki & Wood, 2014; Sugihara, Sugisawa, Nakatani, & Hougham, 2004) but more research needs to be conducted for the role of the other dimensions, especially personal accomplishment. Existing studies have found inconclusive associations between personal accomplishment and depression (Katsifaraki & Wood, 2014; Truzzi et al., 2012; Yilmaz, Turan, & Gundogar, 2009). It might represent a protective factor on the long run as it reflects the reward caregiving might bring, which could counterbalance other risk factors.

In addition to mental health consequences, informal caregivers often report lower physical health than non-caregivers, in terms of lower subjective health, higher reporting of diverse physical symptoms, and higher consumption of medications (Bom, Bakx, Schut, &

¹ The term violence rather than abuse was preferred because the term abuse implies chronic dominance, whereas we aim to understand how any form of violence may occur, even if it does not come with dominance.

van Doorslaer, 2018; Pinquart & Sörensen, 2003). However, mechanisms by which caregivers' physical health is impacted remain unclear (Robaye, Mormont, Lassaux, Janne, & Gourdin, 2018). In the line with works suggesting that stress processes could be mechanisms by which informal caregiving influences physical health, previous research has found an association between informal caregiver burnout and subjective physical health (Choi & Sok, 2012; Goetzmann et al., 2012). Other works have shown that informal caregiver burnout could also be a mediator between informal caregiving and subjective physical health (Lee & Singh, 2010). Such association is expected to occur mainly through emotional exhaustion and not with the two other dimensions, as the emotional exhaustion is intertwined with physical exhaustion and reflects a poorer well-being, while the two others are mostly relational (depersonalization) and cognitive (personal accomplishment). However, some studies have found a negative association with personal accomplishment, in addition to emotional exhaustion (Weiss, 2002), while others did not find such association (Valente et al., 2011). Because there is no clear reason why such association should be found, there is a need for additional information regarding this potential association with higher statistical power.

Finally, research on informal caregivers was often focusing on one specific illness or health issue such as dementia or frailty (Revenson et al., 2016). But with recent calls to move beyond these barriers (Revenson et al., 2016), the need arises to compare how different caregiving situations might differ. An aspect of this differentiation is the investigation of whether kinship would make a difference in the health consequences of caregiving. The question arises as to whether it has different consequences to take care of a parent, a child, or a spouse. Some existing works have highlighted that spouses might be more at risk of emotional exhaustion than others, which suggests that informal caregiver burnout might differ according to kinship (Sugihara et al., 2004). Therefore, and in an exploratory fashion, we investigated how informal caregivers' impact differed based on their kinship relationship to the care-recipient.

2. Purpose of the Study

The present study aims at investigating the role of informal caregiver burnout with its three dimensions in the understanding of two sets of potential deleterious consequences. The first set covers the caregiver depression and subjective health. Higher burnout levels are expected to increase depression levels and lower subjective health. The second set of consequences are the risks of violence toward the care-recipient, an increase in burnout potentially increasing the occurrence of violence. A complementary aim is to investigate whether these deleterious consequences vary depending on the kinship with the care-recipient.

3. Method

To investigate these issues, the present study is based on a dataset also used to investigate determinants of informal care (see other paper).

3.1 Sample

An online survey was created on the Qualtrics® survey platform. It was then sent to different informal caregiving associations, websites and forums for dissemination. The only inclusion criterion was to currently provide informal care to someone they know. A total of 505 people completed the questionnaire. Six of them were removed from the sample as they were identified as no longer being caregivers or being professional caregivers. The final sample was constituted of 499 informal caregivers. The sample is described in Table 7.

Table 7. Description of the sample.

	Mean (SD)	N (%)
Age	53.08 (13.33)	
Women		438 (87.8)
Nationality		
Belgian		233 (46.7)
French		249 (49.9)
Other		17 (3.4)
Education		
Primary		7 (1.4)
Secondary		128 (25.6)
Superior		294 (58.9)
Third Cycle		70 (14.0)
Occupation status		
Full-time		136 (27.3)
Part-time		95 (19.0)
Retired		141 (28.3)
Jobless		57 (11.4)
Other		70 (14.0)
Care-recipients' age	49.17 (26.10)	
Care-recipient women		210 (42.1)
Caring for a		
Spouse		114 (22.8)
Child		195 (39.1)
Parent		97 (19.4)
Other		93 (18.6)

Note: N = 499.

3.2 Measures

Informal caregiver burnout was measured with an adaptation to informal caregiving of the Maslach Burnout Inventory Human Services Survey (MBI-HSS, in Maslach, Jackson, & Leiter, 1996). This scale investigates burnout in 22 items with 7-levels Likert scales from 0 (*Never*) to 6 (*Every day*). The 22 items are distributed in three dimensions: emotional exhaustion (EE, e.g., “*I feel emotionally drained from providing care to my relative*”), depersonalization (DP, e.g., “*I don’t really care what happens to my relative*”) and personal accomplishment (PA, e.g., “*I have accomplished many worthwhile things in providing care to my relative*”). A higher score in emotional exhaustion and in depersonalization, along with a lower score in personal accomplishment reflects higher informal caregiver burnout. In the present study, the internal consistency was good to excellent for each subscale (EE $\alpha = .94$, DP $\alpha = .70$, PA $\alpha = .81$).

Subjective health was measured through the Global Health subscale of the Short Form 36 Health Survey (SF-36, Jenkinson, Coulter, & Wright, 1993; Leplège, Ecosse, Verdier, & Perneger, 1998). Respondents have to rate their perceived health on a first question regarding their global health (1 = *Excellent*, 5 = *Bad*), and four additional statements such as “*My health is excellent*” (1 = *Totally true*, 5 = *Totally False*). In the present study, the coding was made so that higher score represents better perceived health. The scale had good internal consistency ($\alpha = .84$).

Depression was measured by the French version of the short form of the Beck Depression Inventory (BDI, Beck, Ward, Mendelson, Mock, & Erbaugh, 1961; Collet & Cottraux, 1986). The 13-item scales measure depression, based on four different statements for each item (e.g., (0) “*I do not feel sad*” to (3) “*I am so sad that I can’t stand it*”). For each item, respondents must choose the statement better describing their current state. The scale had good internal consistency in the present study ($\alpha = .88$).

Violence was measured through an adapted version of the Conflict Tactic Scale version 2 short form (CTS2sf, Straus & Douglas, 2004), which is based on the full-length CTS2 (Straus, Hamby, Boney-McCoy, & Sugarman, 1996). The scale investigates the violence perpetrated against and received from the partner in two joint sets of items. In the present study, the items were rephrased to be adapted to the caregiver – care-recipient relationship. Only the 2x2 items regarding psychological aggression (e.g., “*I insulted or swore or shouted or yelled at my care-recipient*”) and the 2x2 items regarding physical assault (e.g., “*I pushed, shoved, or slapped my care-recipient*”) were used. Respondents are requested to state if they perpetrated or received each form of violence (e.g., “*I/my care-recipient pushed, shoved, or slapped my care-recipient/me*”) on a non-linear Likert scale from 0 to 7, where 0 is “*It never happened*”, 1 is “*It happened before but not anymore*”, and 2 to 7 are frequencies, from 2 “*Once in the last year*” to 7 “*More than 20 times in the last year*”. Participants were coded as perpetrating (or receiving) violent behaviors when they reported that they had been violent (or subject of violence) at least once in the past year. This coding was made both for psychological and physical violence.

Kinship with the care-recipient was based on the information provided by the caregivers regarding their relationship with the care-recipient. Individuals were therefore categorized as providing care for 1) a parent, 2) a child, 3) a spouse, or 4) any other person (e.g., aunt, neighbor).

3.3 Statistical analyses

Statistical analyses were performed with the IBM SPSS Statistics version 25. To assess bivariate associations, Pearson correlation coefficients were used for continuous variables, chi-squared tests were used for categorical variables, and ANOVA were used to compare continuous variables based on categorical ones. To investigate the predictive role of the three burnout dimensions together on continuous variables (depression and subjective health), linear regression models were used. For the investigation of the predictive role of the three burnout dimensions together on categorical variables, logistic regression models were used.

4. Results

4.1 Descriptive statistics

Means and standard deviations of the investigated variables are displayed in Table 8.

Up to 221 participants (44.3%) reported perpetrating psychological violence against the care-recipient and 49 (9.8%) reported having been physically violent with their care-recipient during the last year (see Table 9). Among the latter group, only two individuals reported having been physically violent without having been psychologically violent with their care-recipient, but the vast majority ($n = 47$, 9.4%) reported having been both physically and psychologically violent.

4.2 Bivariate associations

Bivariate associations are reported in Table 8. The three dimensions of burnout appear to be related to every investigated outcome, with the exception of perpetrated physical violence that was associated only with emotional exhaustion and not depersonalization nor personal accomplishment. Received physical violence was also related to emotional exhaustion and depersonalization, but not with personal accomplishment.

Table 10 presents the association of kinship on the three dimensions of burnout, depression and subjective health. Personal accomplishment, depression, and subjective health did not vary according to the kinship with the care-recipient (respectively, $F(3, 495) = 1.87, p = .134, \eta = .01$; $F(3, 495) = 2.03, p = .110, \eta = .01$; $F(3, 495) = 0.77, p = .512, \eta = .01$). Emotional exhaustion and depersonalization significantly differed depending on the kinship (respectively, $F(3, 495) = 5.60, p < .001, \eta = .03$; $F(3, 495) = 2.76, p = .042, \eta = .02$). Bonferroni post-hoc analyses highlighted that taking care of a spouse was associated to higher emotional exhaustion and depersonalization. For emotional exhaustion, this difference was only significant in comparison to providing care to the group taking care of “others”

(e.g., siblings or friends) ($t(205) = 3.64, p < .001$). For depersonalization, taking care of a spouse is associated with higher depersonalization, only significantly when compared to taking care of a child ($t(307) = 2.37, p = .046$).

Table 8. Correlation matrix of investigated variables.

	MBI EE	MBI DP	MBI PA	SF36-GH	BDI-13	Perpetrated PsyV	Perpetrated PhyV	Received PsyV	Received PhyV
MBI EE	1								
MBI DP	.51***	1							
MBI PA	-.17***	-.29***	1						
SF36-GH	.37***	.21***	-.11**	1					
BDI-13	.61***	.41***	-.31***	.47***	1				
Perpetrated PsyV	.24**	.23***	-.10*	.07	.17***	1			
Perpetrated PhyV	.18***	.08	.03	.05	.15***	.34***	1		
Received PsyV	.26***	.26***	-.15***	.16***	.18***	.51***	.19***	1	
Received PhyV	.15**	.12**	.00	.09†	.09*	.30***	.43***	.41***	1
Mean	3.66	2.36	5.08	2.80	1.60	.44	.10	.51	.17
SD	1.68	1.35	1.22	.86	.47	.50	.30	.50	.38
Cronbach α	.94	.70	.81	.84	.88				

Notes: N = 499. * $p < .05$. ** $p < .01$. *** $p < .001$. MBI = Maslach Burnout Inventory. EE = Emotional Exhaustion. DP = Depersonalization. PA = Personal Accomplishment. SF36-GH = Short Form 36 items Health Survey – Global Health. BDI-13 = Beck Depression Inventory – Short Form. PsyV = Psychological violence. PhyV = Physical violence.

Table 9. Perpetrated physical and psychological violence.

		Physical violence		Total	$\chi^2(1)$
		Yes	No		
Psychological Violence	Yes	47 (21.3%)	174 (78.7%)	221 (44.3%)	58.70***
	No	2 (0.7%)	276 (99.3%)	278 (55.7%)	
Total		49 (9.8%)	450 (90.2%)	499 (100%)	

Note: *** $p < .001$.

Table 10. Comparison of means of burnout, depression, and subjective health by kinship.

	Caring for				$F(3, 495)$
	Spouse n = 114	Child n = 195	Parent n = 97	Others n = 93	
Emotional Exhaustion	4.03 ^a	3.56 ^{abc}	3.89 ^{ab}	3.16 ^c	5.60***
Depersonalization	2.60 ^a	2.18 ^b	2.48 ^{ab}	2.30 ^{ab}	2.76*
Personal Accomplishment	5.09 ^a	5.19 ^a	4.83 ^a	5.11 ^a	1.87
Depression	1.65 ^a	1.55 ^a	1.67 ^a	1.55 ^a	2.03
Subjective Health	2.87 ^a	2.73 ^a	2.86 ^a	2.77 ^a	0.77

Notes: $N = 499$. * $p < .05$. *** $p < .001$. Superscripts represents the significant differences between the means, based on Bonferroni Post-Hoc tests.

Table 11 presents the interplay between perpetrated and received forms of violence. Regarding received violence, 256 (51.3%) reported having received psychological violence, and 87 (17.4%) physical violence. Again, most of those receiving physical violence also received psychological violence ($n = 83$, 16.6%). The rates of received violence are approximatively 7% higher than those of perpetrated violence (respectively 51.3% vs 44.3% for physical and 17.4% vs 9.8% for physical violence). Bivariate analyses highlighted that, for both psychological and physical violence, perpetrated and received violence were significantly associated (for psychological violence, $\chi^2(1, N = 499) = 131.59, p < .001$ and for physical violence, $\chi^2(1, N = 499) = 94.03, p < .001$). These associations reflect that when there is received violence, there is more perpetrated violence. For instance, informal caregivers receiving psychological violence are more prone to perpetrate themselves psychological violence (69.1% of the caregivers receiving psychological violence perpetrate psychological violence versus 30.9% not perpetrating such violence).

Table 12 presents the compared occurrence of the violence by kinship. For both perpetrated and received psychological violence, there was no significant difference based on the kinship with the care-recipient (respectively, $\chi^2(3, N = 499) = 5.76, p = .124$, $\chi^2(3, N = 499) = 5.28, p = .152$). But for physical violence, there was a significant difference based on kinship for both perpetrated, $\chi^2(3, N = 499) = 8.73, p = .033$, and received physical violence $\chi^2(3, N = 499) = 10.73, p = .013$. It appears that caregivers reported being more

frequently physically violent when taking care of a child (13.85%) compared to caregivers taking care of a spouse (3.5%) ($\chi^2 (1, N = 309) = 8.52, p = .004$). The frequency of reported physical violence toward a parent or other care-recipients lied in between (respectively, 9.3% and 9.7%) but was not statistically different from taking care of a spouse ($\chi^2 (1, N = 211) = 3.02, p = .082$, and $\chi^2 (1, N = 207) = 3.31, p = .069$) nor a child ($\chi^2 (1, N = 288) = 1.00, p = .317$, and $\chi^2 (1, N = 190) = 0.01, p = .925$). The same pattern appears for receiving physical violence, where caregivers of their child reported receiving more violence (24.1%) in comparison to their spouse or parent (respectively, 14.0%, $\chi^2 (1, N = 309) = 4.49, p = .034$; 10.3%, $\chi^2 (1, N = 292) = 7.85, p = .005$) with no difference than taking care of others (15.1%, $\chi^2 (1, N = 288) = 3.10, p = .079$).

Table 11. Perpetrated and received forms of violence.

Perpetrated violence	Total	Violence received by the caregiver			
		Psychological		Physical	
		Yes	No	Yes	No
Total	499	256 (51.3%)	243 (48.7%)	87 (17.4%)	412 (82.6%)
Psychological	Yes	221 (80.1%)	44 (19.9%)	131.59***	154 (69.7%)
	No	79 (28.4%)	199 (71.6%)	20 (7.2%)	258 (92.8%)
Physical	Yes	39 (79.6%)	10 (20.4%)	17.41***	16 (32.7%)
	No	217 (48.2%)	233 (51.8%)	54 (12.0%)	396 (88.0%)

Notes: *** $p < .001$.

Table 12. Bivariate association between kinship with the care-recipient and violence (perpetrated by the caregiver and received from the care-recipient).

		Caring for				
		Spouse	Child	Parent	Others	Total
		n = 114	n = 195	n = 97	n = 93	n = 499
Perpetrated	Physical	Yes 4 (3.5%)	27 (13.8%)	9 (9.3%)	9 (9.7%)	49 (9.8%)
	No	110 (96.5%)	168 (86.2%)	88 (90.7%)	84 (90.3%)	450 (90.2%)
Psychological	Yes	61 (53.5%)	85 (43.6%)	38 (39.2%)	37 (39.8%)	221 (44.3%)
	No	53 (46.5%)	110 (56.4%)	59 (60.8%)	56 (60.2%)	278 (55.7%)
Received	Physical	Yes 16 (14.0%)	47 (24.1%)	10 (10.3%)	14 (15.1%)	87 (17.4%)
	No	98 (86.0%)	148 (75.9%)	87 (89.7%)	79 (84.9%)	412 (82.6%)
Psychological	Yes	64 (56.1%)	106 (54.4%)	41 (42.3%)	45 (48.4%)	256 (51.3%)
	No	50 (43.9%)	89 (45.6%)	56 (57.7%)	48 (51.6%)	243 (48.7%)

Notes: * $p < .05$, ** $p < .01$, *** $p < .001$.

4.3 Regression models

In previous analyses, providing care to a child and to a spouse appeared to be significantly different from providing care to a parent or to other close ones. Therefore, in the following regression models, (1) caring for a child and (2) caring for a spouse were integrated in the regression models as two dummy variables (Field, 2013). As such, (1) taking care of a child and (2) a spouse were compared simultaneously to the rest of the sample, which is used as a control group constituted of caregivers taking care of a parent or to others.

For the present analyses, four-level hierarchical regression models were used. The objective was to identify the predictive role of informal caregiver burnout on deleterious outcomes (model 1) and then to investigate if this effect is maintained when adding sociodemographic variables (model 2), kinship with dummy variables (model 3), and received psychological and physical violence (model 4).

The first regression investigated the impact of informal caregiver burnout on depression (in Table 13). Model 1 highlighted that the three dimensions of informal caregiver burnout were significantly associated with depression ($F(3, 495) = 119.94, p < .001, R^2 = .42$). Emotional exhaustion and depersonalization were significant risk factors (respectively, $\beta = .53, p < .001, \beta = .09, p = .034$), and personal accomplishment was a protective factor ($\beta = -.19, p < .001$). The addition of sociodemographic variables (Model 2) led to a small but significant increase of explained variance ($\Delta R^2 = .02, F(4, 491) = 3.77, p = .005$), older caregivers being less prone to depression ($\beta = -.12, p = .001$). The inclusion of kinship (Model 3) and received violence (Model 4) did not lead to additional explained variance (respectively, $\Delta R^2 = .00, F(2, 489) = 0.49, p = .615$ for Model 3 and $\Delta R^2 = .00, F(2, 487) = 0.13, p = .874$ for Model 4). The three burnout dimensions remained significant predictors of depression, even when including sociodemographic, kinship, and received violence variables.

The second regression focused on subjective health (Table 13). The inclusion of the three burnout dimensions (model 1) was a significant predictor of subjective health ($F(3,495) = 26.88, p < .001, R^2 = .14$), with emotional exhaustion being the only significant risk factor of low subjective health ($\beta = .36, p < .001$). The addition of sociodemographic (model 2), kinship (model 3), and received violence (model 4) did not modify the role of emotional exhaustion nor led to additional explained variance (respectively, $\Delta R^2 = .01, F(4, 491) = 1.27, p = .281$ for Model 2, $\Delta R^2 = .00, F(2, 489) = 0.10, p = .908$ for Model 3, and $\Delta R^2 = .00, F(2, 487) = 1.19, p = .305$ for Model 4). Of all the included variables, emotional exhaustion was therefore the sole predictor of subjective health. The higher was the emotional exhaustion, the lower was the subjective health.

Table 13. Linear regression models of caregiver depression and subjective health (n = 499).

Variable	Depression				Subjective Health			
	Model 1		Model 2		Model 3		Model 4	
	β		β		β		β	
Model 1: Burnout dimensions								
MBI EE	.53***		.54***		.54***		.36***	
MBI DP	.09*		.09*		.09*		.01	
MBI PA	-.19***		-.20***		-.20***		-.05	
Model 2: Sociodemographic variables								
CG Female		.04		.04		.03		.06
CG Age		-.12***		-.10*		-.10*		-.07
CR Female		.00		.00		.00		.04
CR Age		-.03		-.08		-.08		.01
Model 3: Kinship								
Caring for spouse		.01		.01		.01		.02
Caring for child		.06		.06		.06		.04
Model 4: Received violence from the care-recipient								
Psy. violence						-.02		.06
Phy. violence						-.00		.01
Total <i>F</i>	119.94***	54.70***	42.57***	34.73***	26.88***	12.27***	9.53***	8.02***
<i>F</i> change	119.94***	3.77**	0.49	0.13	26.88***	1.27	0.10	1.19
ΔR^2	.42	.02	.00	.00	.14	.01	.00	.00

Notes: $p < .05$, ** $p < .01$, *** $p < .001$. MBI = Maslach Burnout Inventory, EE = Emotional Exhaustion, DP = Depersonalization, PA = Personal Accomplishment, CG = Caregiver, CR = Care-recipient, Psy. Violence = Psychological violence, Phy. Violence = Physical violence.

The impact of burnout on perpetrated violence was then investigated with logistic regressions. The previous χ^2 analyses highlighted an overlap of physical and psychological violence (i.e., a vast majority of physically violence caregivers also reported psychological violence, with only two physically violent caregivers not reporting psychological violence). The regression analyses on perpetrated violence were therefore performed in three complementary ways. The first regression looked at the predictors of the occurrence of any form of violence, regardless of its kind in the entire sample (n violent caregivers = 223 on a total of $N = 499$). The second regression investigated the predictors of the occurrence of psychological violence *only*, therefore excluding caregivers perpetrating physical violence (n only psychologically violent caregivers = 174 on a total of $N = 450$). The third regression investigated the predictors of the occurrence of physical violence, therefore excluding the caregivers perpetrating only psychological violence (n only physically violent = 49 on a total of $N = 325$).

The first regression on the occurrence of violence is displayed in Table 14. The inclusion of the three dimensions of burnout (Model 1) contributes to predict the occurrence of violence ($\chi^2 (3, N = 499) = 36.01, p < .001$), where emotional exhaustion and depersonalization appear as risk factors for violence (respectively, $OR = 1.23, p = .001$ for EE and $OR = 1.23, p = .013$ for DP). The inclusion of sociodemographic variables (Model 2) added a significant amount of explained variability ($\chi^2 (4, N = 499) = 15.01, p = .005$), the caregiver's and care-recipient's older age appearing as protective factors ($OR = 0.99, p = .045$ and $OR = 0.99, p = .018$), while maintaining the role of emotional exhaustion and depersonalization. This role was also maintained with the significant inclusion of kinship (Model 3), which also added some explained variance ($\chi^2 (2, N = 499) = 7.70, p = .021$). Caring for a spouse *tended* to represent a risk factor for violence ($OR = 1.66, p = .094$) but not caring for a child ($OR = 0.68, p = .330$). The inclusion of received violence (Model 4) also added a significant explained variance ($\chi^2 (2, N = 499) = 106.43, p < .001$). Received psychological and physical violence were significant risk factors for perpetrating violence ($OR = 7.11, p < .001$ and $OR = 1.93, p = .034$), overshadowing the role of emotional exhaustion and depersonalization, which became nonsignificant ($OR = 1.13, p = .099$ and $OR = 1.13, p = .200$), as well as taking care of a spouse ($OR = 1.60, p = .162$). Emotional exhaustion and depersonalization were therefore significant predictors of the occurrence of violence until the inclusion of received violence.

The second regression focused on perpetrating only psychological violence (Table 14). Overall, the same pattern as for the first logistic regression appears. The inclusion of the burnout dimensions in Model 1 significantly predicts the occurrence of psychological violence ($\chi^2 (3, N = 450) = 27.63, p < .001$), with emotional exhaustion and depersonalization as risk factors ($OR = 1.16, p = .031$ and $OR = 1.26, p = .009$). This effect was maintained until the significant addition of model 4 ($\chi^2 (2, N = 450) = 88.91, p < .001$), while received psychological violence appeared as a significant risk factor of perpetrated psychological violence ($OR = 8.42, p < .001$), overshadowing the role of emotional exhaustion and depersonalization ($OR = 1.07, p = .366$ and $OR = 1.15, p = .164$). When looking at kinship, caring for a spouse *tended* to increase the risk of psychological violence ($OR = 1.91, p = .067$), even when controlling for received violence.

The third regression focused on the occurrence of perpetrated physical violence (Table 14). Informal caregiver burnout (model 1) significantly contributed to explaining perpetrated physical violence ($\chi^2 (3, N = 325) = 24.55, p < .001$) but only through emotional exhaustion ($OR = 1.54, p < .001$). The inclusion of sociodemographic variables (Model 2) significantly increased the explained variance ($\chi^2 (4, N = 325) = 16.61, p = .002$), the care-recipient's age being a protective factor against physical violence ($OR = 0.98, p = .003$). Including kinship (model 3) did not add any explanatory power ($\chi^2 (2, N = 325) = 1.46, p = .482$) but the inclusion of received violence (model 4) significantly increased it ($\chi^2 (2, N = 325) = 67.73, p < .001$). Informal caregivers receiving physical violence were almost 17 times more likely to perpetrate physical violence themselves ($OR = 16.70, p < .001$). Receiving psychological violence only tended to increase the risk of perpetrating physical violence ($OR = 2.55, p = .090$). Contrary to the analyses on global and psychological violence, emotional exhaustion remained a significant risk factor of physical violence ($OR = 1.62, p = .002$) when controlling for received violence.

Table 14. Logistic regressions of prediction of the perpetrated psychological and physical violence toward the care-recipient.

Variable	Perpetrated violence ^a (n = 499)				Perpetrated only psychological violence ^b (n = 450)				Perpetrated physical violence ^c (n = 325)			
	Model 1	Model 2	Model 3	Model 4	Model 1	Model 2	Model 3	Model 4	Model 1	Model 2	Model 3	Model 4
Model 1: Burnout dimensions												
MBI EE	1.23***	1.24***	1.22**	1.13 [†]	1.16*	1.18*	1.15*	1.07	1.54***	1.53***	1.55***	1.62**
MBI DP	1.23*	1.27**	1.26**	1.13	1.26**	1.28**	1.27**	1.15	1.11	1.17	1.17	0.95
MBI PA	0.96	0.94	0.92	0.99	0.91	0.90	0.87	0.95	1.18	1.10	1.11	1.19
Model 2: Sociodemographic variables												
CG Female	0.97	0.97	1.19	1.10	0.93	0.93	1.25	1.08	0.87	0.73	0.71	0.71
CG Age	0.99*	0.99*	0.99	0.99	0.99 [†]	0.99 [†]	0.99	0.99	0.98 [†]	0.98	0.98	0.97
CR Female	0.78	0.89	0.89	1.10	0.67 [†]	0.67 [†]	0.81	0.96	1.32	1.22	1.22	2.23 [†]
CR Age	0.99*	0.98**	0.98**	0.98*	1.00	1.00	0.98*	0.98*	0.98**	0.98*	0.98*	0.99
Model 3: Kinship												
Caring for spouse			1.66 [†]	1.60			1.99*	1.91 [†]		0.47	0.38	
Caring for child			0.68	0.55			0.61	0.50		0.86	0.50	
Model 4: Received violence from the care-recipient												
Psy. violence				7.11***				8.42***				2.55 [†]
Phy. violence				1.93*				1.08				16.70***
Model 5: Control variables												
Model χ^2	36.01***	51.02***	58.72***	165.15***	27.63***	37.66***	50.27***	139.18***	24.55***	41.15***	42.61***	110.34***
Step χ^2	36.01***	15.01**	7.70*	106.43***	27.63***	10.03*	12.61**	88.91***	24.55***	16.61**	1.46	67.73***
Nagelkerke R ²	.09	.13	.15	.38	.08	.11	.14	.36	.13	.21	.22	.50

Note: p < .05. ** p < .01. *** p < .001. MBI = Maslach Burnout Inventory. EE = Emotional Exhaustion. DP = Depersonalization. PA = Personal Accomplishment. CG = Caregiver. CR = Care-recipient. Psy. Violence = Psychological violence. Phy. Violence = Physical violence.

^a Focus on all the caregivers, whether they reported being violent or not (n = 499).

^b Focus on the caregivers perpetrating only psychological violence and non-violent caregivers (n = 450).

^c Focus on the caregivers perpetrating physical violence and non-violent caregivers (n = 325).

5. Discussion

The present study aimed at investigating the association of informal caregiver burnout with potential deleterious consequences, but also to identify if one kinship with the care-recipient was more at risk than others. To do so, a sample of 499 informal caregivers answered an online questionnaire investigating informal caregiver burnout, depression, subjective health, and violence in the caregiving context.

Three main results can be drawn from these analyses. First, it appears that the rates of perpetrated violence by the caregiver are quite high. More than 44% of the 499 informal caregivers reported having perpetrated psychological violence in the past year. Perpetrated physical violence was also present, close to 10% reported having had physically violent behaviors. There was also an important overlap between physical and psychological violence, with almost every physically violent caregiver reporting perpetrating psychological violence. Violence perpetrated by the caregiver and received from the care-recipient were also significantly associated, suggesting a risk of escalation of violence where receiving violence triggers perpetrating violence, and vice-versa.

The second main result is the significant role of informal caregiver burnout in the risk of deleterious outcomes. Five different hierarchical regression analyses were perpetrated in order to have a closer look at the association of informal caregiver burnout with these deleterious outcomes, while controlling for sociodemographic variables, kinship, and received violence. Emotional exhaustion appears as a risk factor for every investigated outcome, with the exception of psychological violence when controlling for received violence. An increased emotional exhaustion therefore appears to lead to depression, low subjective health, and a risk of perpetrating physical violence. Depersonalization and personal accomplishment share a common pattern. They were related to depression, but did not appear as significantly explaining additional variance for the other investigated variables when controlling for the aforementioned variables.

The third result was on the quite limited role of kinship. When using bivariate analyses, kinship was significantly associated with received and perpetrated physical violence: when providing care to their child, caregivers reported significantly more received and perpetrated violence. It was also associated with emotional exhaustion, while taking care of a spouse or a parent led to higher emotional exhaustion scores, in comparison to others. For the other investigated variables, there was no significant association with kinship. When included in regression models, the role of kinship only appeared in one tendency: taking care of a spouse may lead to an increased risk of being psychologically violent. For the other investigated variables, kinship did not appear to significantly contribute to explaining variance.

Therefore, and to answer to the first question of this paper, informal caregiver burnout appears to be a predictor of deleterious consequences, but with a few nuances. The first set of analyses highlighted that burnout in its three dimensions was a significant predictor of depression. This is in line with previous studies showing the close ties between burnout and depression in informal caregiving contexts (Bachner, 2016; Katsifaraki & Wood, 2014; Sugihara et al., 2004). If the significant association between emotional exhaustion and

depression was quite homogeneous in the literature, the same did not hold for personal accomplishment. This association is found inconsistently in the literature, with studies showing no association (D'Aloisio, 1996; Truzzi et al., 2008, 2012; Yılmaz et al., 2009) or, on the contrary, moderate to high ones (Katsifaraki & Wood, 2014; Weiss, 2002). The present results suggest that personal accomplishment may have a protective role to play. Combining exhaustion with accomplishment in the role may therefore be a more balanced risk profile. Since the two are intercorrelated but remain distinct (Gérain & Zech, 2019), there is a possibility that the two might co-occur. Studies on professional burnout suggest that different profiles of burnout might exist (Leiter & Maslach, 2016). Some exhausted caregivers might therefore be more at risk of depression than others who are at the same time exhausted and accomplished. A balanced burnout profile with high exhaustion and high accomplishment may be less at risk on the long run, even if low emotional exhaustion appears to be the best predictor of low depression.

For subjective health, only emotional exhaustion appeared as a risk factor. This result meets our hypothesis, as emotional exhaustion was the sole dimension of informal caregiver burnout expected to be related to subjective health. This expectation is due to the fact that emotional exhaustion is closely tied to physical fatigue and has been shown to be related to adverse physical outcomes (Choi & Sok, 2012; Goetzmann et al., 2012). The general scale assessing subjective health used in the present study has been shown to be a good proxy of the physical state individuals face (McDowell, 2006). But it calls for further research on whether this subjective feeling may truly reflect a future health problem and by which mechanisms. Such mechanisms are currently investigated in terms of biomarkers, both in burnout and informal care literature (Allen et al., 2017; Danhof-Pont, van Veen, & Zitman, 2011). A complementary way would be also to investigate how informal caregiver burnout (and particularly emotional exhaustion) may cause a modification of the health behavior (substance consumption, physician appointment, diet, and physical exercise) (Hoffman, Lee, & Mendez-Luck, 2012; Sisk, 2000). The potential worsening of physical health would therefore be through psychoneuroimmunology processes, but also through harmful behaviors.

Informal caregiver burnout appeared as a risk factor for violence in the caregiving context, but only to some extent. For perpetrated physical violence, emotional exhaustion remained a risk factor, even when controlling for received violence. In regard of the important effect size of received violence, it suggests a moderate but strong effect of emotional exhaustion on physical violence. As previous research has shown, emotions, and particularly anger regulation, could play a key role in violence (MacNeil et al., 2010). Emotional exhaustion could facilitate the onset of anger due to more important irritability (Maslach & Leiter, 2016), and therefore lead to unwanted violent behaviors. In the same idea, research on professional burnout has shown that high levels of emotional exhaustion lead to lower cognitive inhibition abilities (Deligkaris, Panagopoulou, Montgomery, & Masoura, 2014). Emotional exhaustion could therefore lead to lower self-control that would otherwise have blocked violent behaviors.

For perpetrated psychological violence, the effect of informal caregiver burnout disappeared when controlling for received violence. This is in line with the result of the previous study on the impact of informal caregiver burnout on violence in the context of dementia (Yan, 2014). In this study, authors found a significant bivariate association between burnout and violence, but this association became non-significant when controlling for the care-recipient agitated behaviors, which covers various dementia-related behaviors, including violence. This result can be read in light of the high occurrence of psychological violence. Because an important proportion of informal caregivers reported having psychological violent behaviors, this violence might be so common that informal caregiver burnout has little impact. As it was highlighted in previous studies, psychological violence is relatively frequent in the context of informal care, with rates ranging up to 60% (44% in the present study) (Boye & Yan, 2016; Lafferty et al., 2016). Psychological violence may therefore be caused, not by a particular and extreme emotional state, but rather through an unspectacular combination of individual and contextual factors slowly leading a banalization of psychological violence (Ananias & Strydom, 2014).

When taking aside the role of informal caregiver burnout, it appears that received violence is the best predictor of perpetrated violence. In other words, violence seems to breed violence. The present study does not allow drawing some temporal causality but still highlights that received and perpetrated violence are intertwined. This is particularly striking since, in some case, violence is not voluntary. In several contexts of caregiving, it is more likely that the care-recipient is violent due to involuntary violent behaviors (e.g., Sampson et al., 2015) or uncontrolled aggressiveness (e.g., Hounscome, Whittington, Brown, Greenhill, & McGuire, 2018). The escalation of violence may therefore be triggered by the condition of the care-recipient, opening the spiral of violence.

One of the objectives was also to disentangle the role of each of the burnout dimensions on deleterious consequences. It appears that emotional exhaustion and personal accomplishment play an expected role, where depersonalization did not. Depersonalization was hypothesized to play a particular role in perpetrating violence, but it was neither significant (for physical violence), nor acted in addition to emotional exhaustion (for psychological violence). These results are quite surprising regarding the relevance of depersonalization in the informal caregiving context. Several hypotheses could be drawn from this absence of effect, but one stands out particularly clearly. This hypothesis relates to the idea that depersonalization might not make sense for informal caregivers, or may be too skewed. Indeed – and even if it had no impact on the assumptions for the regression models used in the present study – participants seem to rarely endorse the items. This concept might therefore be too extreme to be meaningful for the participants and therefore for research in this field. This observation echoes to the concept of emotional distancing in Parental Burnout, which replaced depersonalization and would probably allow a more nuanced understanding of the continuum of relational attitudes (Roskam, Raes, & Mikolajczak, 2017). In emotional distancing, the items are less extreme (e.g., considering the recipient in automatic mode instead of considering him or her as an object) and may reflect a more nuanced continuum of feelings toward one's children. Applied to the context of informal care, such distancing might

be more like a technical of healthcare professional attitude toward the care-recipient. The caregiver enacts not like a relative but more like a professional, with some distance. One way to test this hypothesis is to use a mixed-method validation of the MBI to the informal care context to investigate the conceptual validity of the concept (does it make sense) and its statistical validity (how do the existing items work together). Qualitative interviews could also look at experiential ways of being with the care-recipient to explore this complex interaction and better understand what is at stake.

Finally, kinship appears to be related to some of the investigated variables, but none of these associations appeared clearly significant when included in regression models with other variables. This relative lack of impact could be due to the fact that the other variables were too strong predictors of adverse outcomes to leave room for descriptive variables such as kinship. For example, a study highlighted that informal caregivers were more prone to perpetrate violence when providing care to their spouse (Beach et al., 2005). But they did not control for other variables included in the present study, such as the received violence. The influence of kinship may therefore be small and overshadowed by stronger predictors, as suggested by the small η^2 highlighted in the ANOVAs. Consequently, an area of further exploration could be to investigate whether it is not the kinship label that has an impact, but rather its role in interaction with other variables (i.e., in modifying their influence). For example, emotionally exhausted caregivers might be more likely to perpetrate psychological violence only if they take care of their spouse. At first, the present study aimed at perpetrating such interaction analyses but it requires considerably more statistical power to ensure that the lack of results is really an outcome in itself and not due to an overly complex model (Field, 2013).

6. Limitations

The present study is cross-sectional and its results would benefit from being investigated longitudinally. One of the aspects that could bring new insights in the literature would be to investigate if the association between informal caregiver burnout and its deleterious consequences fluctuates over the course of caregiving. Therefore, beyond clarifying the causality, such investigation would bring a better understanding of if and how it changes over time.

The measurement and analysis of violence may also be challenged. In the present study, a binomial “presence/absence over the last year” coding was preferred because it was easier and more intuitive to analyses in comparison to a non-linear continuous scale. However, an important proportion of caregivers categorized here as non-violent reported having had such behavior “in the past but not anymore”. Even if we do not have any indicator of the authenticity of this statement, it may be possible that some of them were actually violent and preferred to state that it has stopped. Overall, measuring violence remains a difficult task (Pisani & Walsh, 2012). A dyadic perspective on violence could be a better proxy to have a proper assessment of what is currently happening, but is not always possible since some care-recipient could not be interviewed due to their condition. It also questions the caregiver's (and

care recipient's) perception of the underlying nature of violent behavior. Even if the questions asked here tried to be objective, the threshold where violence starts is different for every caregiver and may depend on their norms (Stones & Bédard, 2002), and this consideration will be even stronger if we consider neglect, which is already less clear from the outset. The challenge of being able to make an assessment of violence that is adequate and free of social desirability therefore remains.

7. Conclusion

Overall, these results suggest that emotional exhaustion is a key caregiver-centered variable when considering possible deleterious consequences of informal caregiving. Of the three burnout dimensions, it remains the most stable predictor for the majority of the investigated consequences, even when controlling for other relevant variables. This finding supports the investigation of informal caregiver burnout, but also calls for a redesign of the depersonalization dimension to better fit with the caregiver's experience.

When looking at violence, it appeared that the occurrence rates were high, and particularly for psychological violence. This important rate interrogates the potential banalization of psychological violence in the caregiving context, and calls for further investigation. If the boundary is clearer for physical violence, where is the limit where a harsh conversation stops and true psychological violence begins? Future research should also focus on more discreet forms of violence, such as neglect, whether it is intentional or unintentional (e.g., not bathing the care-recipient for longer than expected, skip a meal, or not responding to a request for assistance).

Considering the role of kinship in the understanding of the consequences of caregiving, the present study does not contribute to advocating its investigation *per se*. The sole label of taking care of a spouse or a parent is not sufficient to capture what lies behind it. The aim should therefore be to try to decompose what makes a caregiving situation different from another, particularly regarding the element at stake in the relationship, whether in terms of sense of duty to the care recipient, quality of their relationship, their social norms, or the caregiver's appraisal.

Chapter 6

Burnout in the context of parents providing informal care to their children: a comparative study

Introduction: Parenting a child with special needs (CSN) may be an important challenge. Previous research has highlighted an increased risk of parental burnout among parents caring for their CSN. Yet, these studies only focused on children with specific issues and did not consider the wide variety of CSN. There is thus a need to take a more global approach to assessing the impact of caring for a CSN on parental burnout. In addition, the impact on parental burnout of personality and parenting (dis)agreement needs to be measured to have a better understanding of parent-caregivers' (PCgs) burnout. Method: An online survey was completed by a large sample of parents from which a subsample of PCgs was identified. Results: T-tests highlighted significantly more parental burnout among parents of CSN. However, further analyses showed that parents with only one child with one special need did not experience significantly more burnout than parents with typical children. The significant difference lay in the presence of comorbidity or the presence of multiple CSN in the family. Hierarchical regressions showed an important impact of Neuroticism for every burnout facet, along with co-parenting (dis)agreement. Subjective consequences of having to care for a CSN were also related to the burnout facets of both emotional exhaustion and emotional distancing. Discussion: The presence of comorbidity and of multiple CSN in the family were related to more PCg burnout, emphasizing the need to consider these situations in further research. The role of neuroticism in PCg burnout confirms previous research both in parental and professional contexts. Parenting (dis)agreement also highlights the importance of dyadic support among parents. Finally, the importance of subjective aspects suggests that parental perception of their situation remains a central element in understanding the consequences of caregiving.

Reference

Gérain, P., & Zech, E. (2018). Does informal caregiving lead to parental burnout? Comparing parents having (or not) children with mental and physical issues. *Frontiers in Psychology*, 9(884). <https://doi.org/10.3389/fpsyg.2018.00884>

Burnout in the context of parents providing informal care to their children: a comparative study

1. Introduction

Although one of the most positive experiences reported by parents, parenting might also be hazardous. Recent research has shown that some factors might lead to a form of burnout among parents (Mikolajczak et al., 2017). Parental burnout could be defined as a syndrome in reaction to parental stress. It is composed of emotional exhaustion (EE) (its core component), depersonalization/emotional distancing (ED), and lack of personal accomplishment (LPA). A growing literature investigates parental burnout but a particular situation is the experience of parents caring for a child with a chronic illness (Norberg and Green, 2007) or a disability (Basaran et al., 2013). This situation appears to put parents caring for a child with physical or mental issues at greater risk of burnout. These studies converge with a wide literature on taking care of relatives – children or not – exploring the risk of burnout among informal or family caregivers. However, most research on informal caregivers recruit participants based on the specific illness of the child or the relative concerned (e.g., diabetes mellitus, autism, cancer). This approach fails to give a transversal understanding of PCgs burnout. To this end, a more global approach is needed to consider and assess the impact of having a child with specific needs on parental burnout.

Informal caregivers are individuals, voluntarily and mostly free of charge, caring for a relative or a friend (i.e., the care-recipient) facing disease, disability, or any condition requiring particular attention (Schulz and Tompkins, 2010). By definition, all parents are therefore informal caregivers because they all take care of dependent relatives, namely, their child(ren). However, a distinction is made due to the extra care needed by children with special needs (CSNs). Those children present special health needs, defined in terms of use of services, therapies, counseling, medication, or functional limitations that last for at least a year (Schulz and Tompkins, 2010). These needs include a wide range of issues causing activity limitations, from emotional or learning disabilities, to physical illnesses or disabilities. Parents taking care of a CSN could therefore be defined as PCgs – as opposed to parents of “typical” children.

To date, several studies have investigated whether PCg are more prone to experiencing feelings of burnout than parents with typical children. A recent meta-analysis on informal caregivers’ burnout collected every study comparing caregivers with a control group on burnout (Gérain and Zech, unpublished). The vast majority of these studies focused on PCg of children with various special needs – from brain cancer survivors (Lindahl Norberg, 2007) to children with autism (Weiss, 2002). A summary effect size was computed and yielded a medium difference of burnout between PCg and parents of typical children ($d = 0.46$). Thus, parents caring for a CSN experience more burnout than other parents.

However, all the studies on PCg burnout have proceeded in a similar way, that is, they selected a sample of CSN and then compared it with a convenient control sample. This approach may impact studies' outcomes because of recruitment bias for both the control and the PCg group. For the control group, the selection might be biased by the convenient nature of the sample. Often, little is known about how (i.e., on which criteria) the group was selected, suggesting that the control sample may not have been selected as rigorously as the PCg sample. For the PCg group, the risk might be to select parents in specific contexts, thus inflating (or deflating) the occurrence of burnout symptoms among the sample. Selecting children with a particularly acute illness is more likely to result in parents with higher burnout scores. A complementary approach would be to use a sample of parents from which parents with a CSN would be selected. This approach – which is closer to the population-based approach (though still economical) – would make it possible to select the parents of CSN who would not otherwise be reached by a PCg-centered study. This approach would perfectly complement previous research on PCg by providing a different perspective of data on parental burnout symptoms. By shifting the focus from the child to the parents, new kinds of PCg could appear, such as parents taking care of more than one CSN. This would also allow to investigate the impact on PCg burnout of having to care for one or several children and having not only one but multiple issues.

Beyond these questions there is still a need to understand the risk factors of burnout for PCgs. To date, no specific personality trait variable has been investigated among informal caregivers, except for alexithymia (Katsifaraki and Wood, 2014) and Performance Based Self-Esteem (Lindström et al., 2011). The potential role of Big-Five personality traits in the onset of burnout symptoms still needs to be examined. Neuroticism (the reverse of emotional stability) appears as a stable risk factor of burnout both in professional and parental contexts (Alarcon et al., 2009; Mikolajczak et al., 2017). This tendency to experience more emotional instability toward negative feelings might also play a role in PCg burnout. However, there is still a lack of studies supporting such a hypothesis and little is understood about how personality traits might impact burnout in such a context.

Parenting a child often takes place in a dyadic parenting context. Direct indicators of the importance of a good relationship with the other parent have already been shown as protective factors of parental burnout (Lindström et al., 2011). One study showed that feeling the spouse's lack of interest regarding the care of the common CSN also represented a risk of burnout for the PCg (Demirhan et al., 2011). In addition to the quality of the inter-parental relationship, the importance of having a common view about the future of the child could play a role in the development of burnout symptoms. Such an indicator has been described as co-parenting (dis)agreement (Feinberg et al., 2012), i.e., the degree to which parents agree on issues related to raising their child (Mendez et al., 2015). Disagreement in this area could represent a supplementary challenge when having a CSN in as much as one PCg does not feel supported by the other parent, and thus feels the lack of a common vision about important decisions regarding their child's special needs (Mendez et al., 2015).

Being a PCg can also be associated with several perceived detrimental consequences. Previous studies have documented some of these, such as the perception that the illness

affects everyday life and induces sleep disruptions (Lindström et al., 2011). Additional consequences could also be explored such as the perception of having been obliged to give up important things due to having a CSN, or a perceived disruption of the family organization.

In sum, the present research sets three different investigation goals to be explored in a large sample of parents: (1) to compare parents having a CSN with parents with no-CSN; (2) to understand which caregiving setting is more at risk of burnout between having one CSN, multiple CSN or a CSN with comorbidities; and (3) to assess the impact of descriptive variables, neuroticism, co-parenting disagreement and the perceived impacts of having a CSN.

2. Materials and methods

The present database has also been used in an article on the validation of the Parental Burnout Assessment (Roskam et al., 2018). This study was carried out in accordance with the recommendations of APA ethical standards, Ethics Commission of the Psychological Sciences Research Institute (Université catholique de Louvain). The protocol was approved by the Ethic Commission of the Psychological Sciences Research Institute (Université catholique de Louvain). All subjects provided informed consent in accordance with the Declaration of Helsinki.

2.1 Sample and recruitment

A total of 900 parents was recruited for the present study, plus one parent excluded because he did not report having a child. Among the sample, 647 (71.9%) were English-speaking and 253 (28.1%) were French-speaking. A majority of participants were from England (53.3%), Belgium (26.3%), and the United States (9.6%). Other participants were from Canada and several European countries. Descriptive information about the entire sample is presented in Table 15.

The study was labeled as “Being a parent in the 21st century” (Eng) or “*Être parent aujourd’hui*” (Fr). English-speaking parents were recruited through Prolific, a platform to recruit subjects for scientific online research (Palan and Schitter, 2017). French-speakers were recruited through social networks, websites, forums, and snowball effect. The French speakers also had the opportunity to participate in a lottery to win €200 by providing their email address in a separate questionnaire.

Every respondent was asked if each of their children presented a form of (1) chronic or serious disease, (2) disability, or (3) behavioral, emotional, or learning disorder. For each participant and for each type of issue, participants answered by Yes/No if their child presented one or more of these issues. Therefore, each child of each participant was profiled through these three characteristics. Parents reporting at least one of their children having at least one of the three issues were categorized as parents of a CSN, a PCg. Parents not reporting such issues among any of their children were categorized as parents of typical children. Information about these subsamples is also presented in Table 15.

2.2 Measures

2.2.1 Socio-Demographic Measures

The participants had to provide their age, gender, education level, number of children, and marital status. For each child, they had to provide the age and gender as well as information about whether the child lived at home or away.

2.2.2 Parental Burnout

The Parental Burnout Inventory¹ (PBI; Roskam et al., 2017) is a 22-item self-report measurement of parental burnout. It was adapted from the Maslach Burnout Inventory – Human Services Survey (MBI, Maslach et al., 1996). The PBI distinguishes three parental burnout dimensions: EE, ED, and Personal Accomplishment. The EE subscale is based on 8 items (e.g., “*I feel emotionally drained by my parental role*”) and assesses the feeling of the respondent as being emotionally drained by the parenting role. The ED describes a colder relationship with the children, a progressive lack of attention and emotional expression toward them. This subscale is constituted of 8 items (e.g., “*I am less attentive to my children’s emotions*”). Personal accomplishment refers to a feeling of low competence and achievement in the parental role. It is assessed with 6 items (e.g., “*I accomplish many worthwhile things as parent*”). This latter subscale is reversed in order to obtain a score of LPA with higher scores indicating higher symptoms of parental burnout. Each item is rated on a 7-level Likert scale from 1 (“*Never*”) to 7 (“*Every day*”). In the present study, the PBI had an excellent internal consistency on each subscale ($\alpha = 0.936$ for EE, $\alpha = 0.919$ for ED, $\alpha = 0.837$ for the LPA).

2.2.3 Neuroticism

The Neuroticism subscale of the Big Five Inventory (BFI; John et al., 1991; Plaisant et al., 2010) was used in order to evaluate Neuroticism. This subscale includes 8 items starting with “*I am someone who...*” followed by the statement (e.g., “*is moody, has up and down mood swings,*” or “*worries a lot*”). Respondents were asked to refer not especially to their current state but rather how they are in general (i.e., their nature). They had to answer with 5-level Likert scales ranging from 1 (“*Strongly disagree*”) to 5 (“*Strongly agree*”). Items are both positively and negatively phrased. Positively phrased items were recoded to obtain a homogeneous measure. The Cronbach alpha in the present study was good ($\alpha = 0.824$).

2.2.4 Co-parenting (Dis)Agreement

The Agreement subscale of the Co-Parenting Scale (Feinberg et al., 2012) was used to assess the co-parenting (dis)agreement. It consists of 4 items (e.g., “*My partner and I have the same goals for our child(ren)*”) rated on a 7-point Likert-scale from 1 (“*not at all true for us*”) to 7 (“*absolutely true for us*”). Scores were reversed in order to obtain a composite score of co-parenting disagreement. The Cronbach alpha in the present study was good ($\alpha = 0.828$).

¹ Items EE1 to EE8 and PA1 to PA6 Copyright 1981 Christina Maslach and Susan E. Jackson. All rights reserved in all media. Published by Mind Garden, Inc., www.mindgarden.com Altered with permission of the publisher.

Table 15. Descriptive variables of the sample of parents with and without children with special needs (CSNs).

Variable		Parents without CSN (<i>N</i> = 725)	Parents with CSN (<i>N</i> = 175)	Total (<i>N</i> = 900)
Age	Mean	36.31	38.38	36.71
	SD	6.71	7.12	6.84
	Range	[20–59]	[21–57]	[20–59]
Gender	Male	160 (22.1%)	24 (13.7%)	184 (20.4%)
	Female	565 (77.9%)	151 (86.3%)	716 (79.6%)
Working	Full-time	326 (45.0%)	64 (36.6%)	390 (43.3%)
	Part-time	238 (32.8%)	45 (25.7%)	283 (31.4%)
	Home or jobless	161 (22.2%)	66 (37.7%)	227 (25.2%)
Marital status	Biparental couple	639 (88.1%)	144 (82.3%)	783 (87.0%)
	Solo parent	86 (11.9%)	31 (17.7%)	117 (13.0%)
Education	Secondary school	295 (40.7%)	90 (51.4%)	385 (42.8%)
	Bachelor	247 (34.1%)	56 (32.0%)	303 (33.7%)
	Master	129 (17.8%)	26 (14.9%)	155 (17.2%)
	Post-master	54 (7.5%)	3 (1.7%)	57 (6.3%)
# children	Mean	1.97	2.65	2.1
	SD	0.88	1.20	1.03
	Range	[1–7]	[1–7]	[1–7]
Age children	Mean	8.29	11.38	9.04
	SD	6.67	7.01	6.88
	Range	[0–39]	[0–39]	[0–39]
Children	Male	674 (50%)	201 (46.3%)	875 (49.1%)
	Female	674 (50%)	233 (53.7%)	907 (50.9%)

2.2.5 Perceived Psychosocial Impact of Having a CSN

Parents having a child with CSN were also asked five exploratory Yes/No binary questions regarding the impact of having a child with issues: (1) “My child’s disease/disability/disorder has a strong impact on our daily routine,” (2) “Because of his/her disease/disability/disorder, my child requires constant care or attention,” (3) “I feel constantly preoccupied by my child’s disease/disability/disorder.” (4) “Because of my child’s disease/disability/disorder, I had to give up things that were important to me (work and/or activities, etc.),” (5) “Because of my child’s disease/disability/disorder, I had to give up my life.” The impact of each variable was evaluated separately due to the diversity of the elements.

2.2.6 Non-included Measures

The present study also included other measures that were not used for the present report. A new measure of parental burnout, the PBA, was submitted in order to compare it with the psychometric properties of the PBI. This data is analyzed in the PBA validation paper (Roskam et al., 2018). A measure of family disorganization (CHAOS) was also included. Finally, and only in the English-speaking sample, a measure of Job Burnout (MBI) was also used.

2.3 Data analysis

The IBM SPSS Statistics software was used to analyze the data. Group comparisons were performed through ANOVAs and *post hoc* Hochberg GT2 analyses were added due to large differences in group sizes (Field, 2013). Pearson correlations were performed between all variables of interest. Correlation are presented as supplementary material (see SM1).

Hierarchical linear regression analyses were used to assess the impact on explained variance of the addition of variables sets. The first “descriptive” variable set was constituted of descriptive variables on the parent and the family (i.e., gender, age, education, working status, marital status, number of children). The second set, “parenting,” was constituted by co-parenting disagreement. The third set, “personality,” was constituted by neuroticism. The fourth set, “CSN descriptive,” was constituted by descriptive variables regarding the parent-caregiving context (i.e., presence of multiple CSN in the family, and whether the CSN presented any comorbidity). Finally, the fifth set, “Perceived Impact,” was constituted by variables regarding the perceived psychosocial impact of having a CSN.

3. Results

A total of 901 people completed the questionnaire. One parent did not report having any children and was excluded from the data.

3.1 Comparing parents with typical children and parents with children with special needs

Parents reporting having a least one child with a CSN were compared on burnout measures to parents reporting having no child with special needs. For EE, parents with CSN reported significantly more symptoms ($M = 17.70$, $SD = 12.84$) than parents with no CSN ($M = 12.81$, $SD = 10.88$), $t(889) = 4.63$, $p < 0.001$, Cohen’s $d = 0.43$. For ED, parents with CSN also significantly scored higher ($M = 7.91$, $SD = 9.45$) than parents of no CSN ($M = 5.42$, $SD = 6.82$), $t(889) = 3.28$, $p = 0.001$, Cohen’s $d = 0.34$. For LPA, significance indicators were slightly lower but a comparable pattern remained. Parents with CSN had more symptoms of LPA ($M = 8.35$, $SD = 6.84$) than parents with no CSN ($M = 7.00$, $SD = 6.51$), $t(889) = 2.42$, $p = 0.016$, Cohen’s $d = 0.20$.

3.2 Comparing caregiving settings

Parents reporting having (or not) a CSN were then categorized into four groups regarding the specific characteristic(s) of their children's special needs. The groups were constituted of parents reporting having no children with any of the surveyed issues ($n = 725$), having one child with one issue ($n = 98$), having a child with multiple issues (comorbidity) ($n = 35$), and having multiple children with one or more issues ($n = 42$).

To assess the difference in burnout symptoms between parents with no CSN with PCg, three ANOVAs were computed for each burnout subscale (see Table 16). For the EE subscale, a significant group effect was highlighted, $F(3,887) = 13.70$, $p < 0.001$, $\eta^2 = 0.04$. *Post hoc* analyses are reported in Table 16.

These analyses showed no difference between parents of children with no issues and parents with one child having one issue ($p = 0.158$, Cohen's $d = 0.24$). However, the former group was significantly different from the group of parents with one child with comorbidity ($p < 0.001$, Cohen's $d = 1.01$) and from parents having more than one CSN ($p = 0.038$, Cohen's $d = 0.44$). On ED, a group effect was also found, $F(3,887) = 7.72$, $p < 0.001$, $\eta^2 = 0.03$. A comparable pattern was found, *post hoc* analyses showing that parents of one CSN were not different from parents with no CSN ($p = 0.618$, Cohen's $d = 0.17$). Parents with no CSN reported significantly less ED than parents of a child with comorbidities ($p = 0.005$, Cohen's $d = 0.62$) and parents of multiple CSN ($p = 0.003$, Cohen's $d = 0.57$). Finally, for LPA, a group effect was also highlighted, $F(3,887) = 3.35$, $p = 0.019$, $\eta^2 = 0.01$. However, *post hoc* analyses only showed a significant difference between parents of no CSN and parents of multiple CSN ($p = 0.035$, Cohen's $d = 0.44$), the latter having a greater LPA than the former. Thus, except for this latter burnout subscale, a pattern appears with parents of no CSN not having significantly less EE and ED symptoms than parents of one CSN. However, they reported significantly less burnout symptoms than parents of a child with comorbidity or parents having multiple CSN.

Table 16. Comparison of parental burnout scores of parents with or without children with special needs (CSN).

	Typical (n = 717)		One CSN (n = 97)		CSN with comorbidity (n = 35)		Multiple CSN (n = 42)		F test	Partial η^2
	M	SD	M	SD	M	SD	M	SD		
EE	12.81 ^a	10.88	15.47 ^{ab}	11.87	23.89 ^c	12.61	17.67 ^{bc}	13.75	13.70***	.04
ED	5.42 ^a	6.82	6.58 ^{ab}	7.73	9.74 ^b	10.36	9.48 ^b	11.77	7.72***	.03
LPA	7.00 ^a	6.51	7.48 ^{ab}	6.08	8.89 ^{ab}	7.08	9.88 ^b	8.06	3.35*	.01

Note. EE = Emotional Exhaustion. ED = Emotional Distancing. LPA = Lack of Personal accomplishment. Hochberg GT2 post hoc tests were used.

* $p < 0.05$. ** $p < 0.01$. *** $p < 0.001$.

Table 17. Final regression models for the prediction of burnout subscales

Group	EE		ED		LPA	
	F	Adj R ²	F	Adj R ²	F	Adj R ²
Parents with no CSN F (9, 706)	25.46***	.24	10.71***	.11	15.01***	.15
Parents with CSN F (16, 157)	7.83***	.39	2.38**	.11	2.74***	.14

Note. EE = Emotional Exhaustion. ED = Emotional Distancing. LPA = Lack of Personal accomplishment.

** $p < 0.01$. *** $p < 0.001$.

3.3 Comparison of risk factors for parents with or without CSN

Pearson correlations were performed separately for parents with no CSN and for parents with a CSN (see Supplementary Material, SM1). Comparisons of correlation coefficients between the two groups were performed through the Fisher *r*-to-*z* transformation (Cohen, 1988). Only one correlation coefficient was significantly different between the no-CSN and the CSN groups (i.e., working fulltime is more associated to EE for parents with a CSN than parents with no-CSN, respectively, $r(174) = -0.25$, $p = 0.001$ and $r(717) = -0.08$, $p = 0.034$, $F = 2.03$, $p = 0.021$).

All the variables of interest were also computed for each group in a hierarchical linear regression to identify stronger indicators of burnout symptoms. All regressions yielded significant conclusions, with adjusted R^2 ranging from .11 to .39 (see Table 17). The impact of each variable is presented in Table 18 (for the complete model, see Supplementary Material (SM2) for the successive steps).

3.4 Descriptive variables

The descriptive variables appeared to significantly add explained variance for each burnout subscale (from $\Delta R^2 = 0.02$ to 0.13). For EE, being a male had a detrimental impact only for parents with CSN ($\beta = 0.14$, $p = 0.037$) whereas it had no impact for the no-CSN parents ($\beta = 0.03$, $p = 0.417$). Conversely, age had an impact only for parents without CSN ($\beta = 0.13$, $p < 0.001$), older parents reporting less EE. No other descriptive variables had a significant impact on EE. For ED, higher education appeared as a risk factor only among parents without CSN ($\beta = 0.15$, $p < 0.001$). The more highly educated the parents, the more they reported being distant from their typical children. The descriptive bloc had no impact on ED among parents with CSN. For LPA among parents without CSN, older age, being male, and higher education appeared as risk factors. Among parents with a CSN, being male also tended to be a risk factor ($\beta = 0.15$, $p = 0.067$) but there was no significant impact of age and education. However, it appeared that marital status tended to contribute to a risk of LPA, solo parents reporting more LPA ($\beta = 0.15$, $p = 0.063$).

3.5 Co-parenting disagreement

For every burnout facet and for parents both with or without a CSN, the addition of co-parenting disagreement appeared to explain significantly more variance of burnout facets (from $\Delta R^2 = .02$ to $.06$). For ED, although there was only a tendency among parents with CSN ($\beta = .13$, $p = .092$), the addition of the variable still led to significantly higher explained variance ($\Delta R^2 = .03$, $p = .028$). This thus confirms that parents who disagree about the education and care of their children are more prone to burnout symptoms, regardless of whether they have typical or untypical children.

Table 18. Hierarchical stepwise Linear Regression model for the prediction of Emotional Exhaustion, Emotional Distancing, and Lack of Personal Accomplishment

Variable	EE			ED			LPA		
	β	t	AR ²	β	t	AR ²	β	t	AR ²
Parents with no CSN ^a									
Step 1			.24 ^c			.11 ^c			.15 ^c
Male	.03	0.81	.04***	.07	1.86†	.02*	.13	3.44***	.03***
Age	-.13	-3.92***		.03	0.89		.13	3.50***	
Education	.04	1.05		.15	3.95***		.07	1.92†	
Solo Parent	-.03	-0.73		.04	1.02		.02	0.58	
Full-Time Worker	-.06	-1.26		.02	0.32		-.01	-0.26	
Part-Time Worker	-.07	-1.64†		.03	0.56		-.03	-0.64	
#Children	.06	1.66†		.06	1.68†		.02	0.65	
Step 2			.05***			.02***			.02***
Co-parenting disagreement	.14	3.81***		.08	2.06*		.08	2.21*	
Neuroticism	.42	12.03***	.15***	.30	7.98***	.08***	.34	9.43***	.11***
Parents with CSN ^b									
Step 1			.39 ^c			.11 ^c			.14 ^c
Male	.14	2.11*	.13***	.14	1.74†	.05	.15	1.85†	.08*
Age	-.08	-1.22		-.02	-0.28		.11	1.49	
Education	.06	0.86		.10	1.22		-.02	-0.29	
Solo Parent	-.03	-0.40		-.02	-0.25		.15	1.87†	
Full-Time Worker	-.09	-1.12		.02	0.16		.02	0.17	
Part-Time Worker	.02	0.34		.04	0.47		-.02	-0.23	
#Children	.04	0.54		-.04	-0.40		.13	1.52	
Step 2			.05***			.03*	.23	2.96**	.06*
Co-parenting disagreement	.16	2.42*		.13	1.69†		.28	3.48***	.07***
Neuroticism	.37	5.42***	.12***	.19	2.31*	.04**	.00	-0.03	.00
Step 3			.05***			.02			
CSN has a comorbidity	.10	1.58		.05	0.63		.01	0.13	
Step 4			.10***			.06*			
Multiple CSN	-.09	-1.33		.02	0.26		-.04	-0.56	
Impact on family	.15	2.35*		.02	0.22		.00	-0.03	
Permanent attention	.06	0.87		.03	0.38		.03	0.43	
Preoccupation due to issue	.13	1.98*		.11	1.45		-.02	-0.19	
Give up important things	.17	2.26*		.15	1.69†		.10	1.25	
Step 5			.11						
Give up life	.05	0.75		.11	1.34				

Note: ^a n = 715. ^b n = 173. ^c Adjusted R² of the model. EE = Emotional Exhaustion. ED = Emotional Distancing. LPA = Lack of Personal accomplishment.

† p < 0.10. * p < 0.05. ** p < 0.01. *** p ≤ 0.002.

3.6 Neuroticism

Like co-parenting disagreement, neuroticism appeared as a stable risk factor of each facet of burnout for parents both with or without CSN. Neuroticism was in particular a good predictor of EE for parents without CSN ($\Delta R^2 = 0.15$, $p < 0.001$) and for parents with CSN ($\Delta R^2 = 0.12$, $p < 0.001$).

3.7 CSN descriptive variables

Descriptive variables about the CSN added explained variance only for EE ($\Delta R^2 = 0.05$, $p = 0.002$) but neither for ED, nor for LPA. None of the variables constituting these predictors appeared significant, suggesting that, contrary to previous results, comorbidity or the presence of more than one CSN could partially explain more EE but not more emotional distance or LPA.

3.8 Perceived psychosocial impact

The perceived psychosocial impact explained 10% of additional variance of EE ($\Delta R^2 = 0.10$, $p < 0.001$) and 6% of ED ($\Delta R^2 = 0.06$, $p = 0.037$). No further variance was explained for LPA ($\Delta R^2 = 0.01$, $p = 0.807$). For EE, three variables appeared significant: perceiving that having a CSN changed the daily routine of the family ($\beta = 0.15$, $p = 0.020$), feeling constantly preoccupied by the issue of the child ($\beta = 0.13$, $p = 0.050$), and having to give up important things due to the issue of the child ($\beta = 0.17$, $p = 0.025$). For ED, only the latter tended to have a significant impact ($\beta = 0.15$, $p = 0.093$).

4. Discussion

4.1 Comparing parents with or without CSN

The present study aimed to compare the importance of parental burnout symptoms for parents having (or not) a child with special needs (CSN). The results indicated that the three dimensions of burnout symptoms were related to having a CSN. This concurs with previous literature that highlighted that parents with a CSN experience consistently more burnout than parents with no CSN (Gérain and Zech, unpublished). When examining parents' caregiving situation more specifically, it appeared that this excess in burnout symptoms was due either to having to care for a child with a comorbidity and thus dealing with more than one issue, or when parents had more than one child with one or more special needs.

Interestingly, no significant difference was found between parents having no child with an issue and parents who had to deal with only one child with only one issue. This seems to disconfirm previous studies that focused on one specific issue or illness. This non-significant effect could be explained by the difference in recruitment strategies between the present study and previous ones. Here, the focus on a large unspecified sample of parents could reach parents that may have been overlooked in previous studies. Indeed, in those studies, parents were recruited because they had children with a specific illness or disability (such as diabetes, cancer) so parents at greater risk might be preselected. Here, respondents were not preselected based on the issue of the child nor on the PCg status of the parent. We were thus able to reach a wide variety of situations from light to heavy contexts of care,

allowing to investigate the continuum of special needs and stressors that PCg face. The nature of such issues has yet to be defined, as well as defining what constitutes the difference with more burdensome issues.

This study is the first to show that having several CSNs is especially detrimental for parental burnout symptoms. This result may highlight the cumulative burden of having to care for multiple CSN. Even if having a single child with one issue may be as demanding as caring for a child with no CSN, having to deal with more than one issue may imply a new set of stressors for the parent and may also impact the whole family. Caring for one child is time-and- resources-consuming, but having more than one child to care for or more than one issue to deal with seems to consume even more time and more resources. Subjectively, it could be overburdening to learn to cope with two different issues and this could then lead to burnout symptoms. These hypotheses should further be investigated in the future.

In the present study, the most striking result lies in the impact of comorbidity. It is the first study to show the impact of comorbidity on PCg burnout with effect sizes ranging from very large to small (Cohen's $d = 1.012$ for EE, Cohen's $d = 0.617$ for DP and Cohen's $d = 0.288$ for LPA). Previous studies on PCg burnout focused on one specific mental or physical illness. Yet, among CSNs, comorbidity is often present (e.g., Gabis et al., 2015; Flood et al., 2016). Though only comorbidity between broad categories of issues (i.e., disability, illness, and emotional/learning issues) was considered, these results contribute to the growing consideration of how comorbidity may affect caregivers' life and well-being. For example, caregivers of elderly people were found to experience more difficulties when their relative presented an additional mental or physical health issues (Dauphinot et al., 2016). It seems that parents are no exception to this finding.

4.2 Risk factors of parental burnout

The present study also aimed at delineating the risk factors of parental burnout among PCg. Several variables appeared as stable predictors of parental burnout for all parents. Consistently with the broader literature on burnout, both neuroticism and co-parenting disagreement were found to be significant predictors of PCg burnout. First, neuroticism appeared a risk factor for both parents with or without CSN. In the present results, it was also the strongest predictor for almost every burnout facet (with ΔR^2 ranging from 0.04 to 0.16). This result is the first to highlight the role of one Big-Five personality dimension on PCgs' burnout. It echoes findings in the existing literature, where neuroticism has been found to be a fertile ground for increased prevalence of psychopathology and the occurrence of burnout symptoms (Alarcon et al., 2009; Kotov et al., 2010; Le Vigouroux et al., 2017; Mikolajczak et al., 2017). Second, co-parenting disagreement affected every burnout facet. Not feeling oneself to be on the same page as one's spouse represented a risk factor in every parenting setting. This echoes previous research highlighting that conflicts in the caregiving family system put people at risk of burnout (Almberg et al., 2000). This is especially important when providing care as a parent, where the partner's support is essential. These results also complete previous research highlighting the deleterious impact of poor quality couple relationships on burnout in a caregiving context (Lindström et al., 2011; Riva et al., 2014). Some could also argue a reverse relationship, in other words, that an increase of burnout symptoms has a deleterious impact on the relationship with the spouse, with direct consequences on co-parenting (dis)agreement.

This hypothesis must be assessed in future research but it is more than likely that feedback loops occur between poor quality couple relationships and burnout.

Regarding descriptive variables, the most surprising result lies in the unexpected risk factor of being a father with a CSN. Both for EE and LPA – with a tendency for ED – being a father appeared to increase burnout. This adds confusion to an already disputed literature about the impact of gender on PCg burnout. Where some studies showed increases of burnout symptoms among mothers (Jaramillo et al., 2016), others did not consistently find such a gender difference (e.g., Lindahl Norberg, 2007). Yet, there was no evidence of males experiencing more burnout symptoms than women in a caregiving context. In the present study, those associations did not appear with Pearson correlations but did manifest when computed with other predictors. This might suggest an interaction between the gender and several variables, as previously shown when comparing fathers and mothers (Lindahl Norberg et al., 2014). Further research should investigate why fathers differ from mothers when being PCg.

With regard to other descriptive variables, such as education or age, these were rather small and inconsistent predictors of burnout. Unexpectedly, a positive correlation appeared between education level and ED for parents with no CSN. To our knowledge, previous burnout literature did not report such relationship in the past. Such effect – if appearing in other studies – should further be investigated.

Including consequences specific to the parent-caregiving context allowed us to better understand the EE of PCg. Indeed, three statements were related to more EE: (1) perceiving that the issue of the child has an impact on the family organization, (2) having preoccupations about the issue of the child, and (3) feeling that the issue resulted in giving up important things. Perceiving that the issue of the child has an impact on the family organization represents a risk factor only for EE. This may reflect both the absence of family organizational need – meaning a low disruption of the family – and the perfect integration of the special needs into the family – meaning that they do not represent an additional stress. In both cases, the organization of the family remains stable and demonstrates an absence of problems. If everything is going well in the family and for the parent, EE should diminish. Having constant preoccupations regarding the child's issue also plays a role by the constant tension it puts on the parent. This constant tension represents a chronic stressor and thus facilitates EE. Preoccupation has already been shown as a risk factor among caregivers of psychiatric patients, increasing worry about the care recipient being related to higher burnout (Cuijpers and Stam, 2000). This also calls for further research about the importance of ruminative processes – as it has been studied in professional burnout (Brackett et al., 2010). Having preoccupations also impacts ED. More preoccupations lead to more ED with one's children. The variable of constant care/attention – though significantly correlated with burnout – does not appear in the regression models. This is probably due to a widely shared variance and conceptual relatedness with the present variable of constant preoccupation. Perceiving having given up life yielded low response rates (8%), probably due to the extreme content. On the contrary, the variable assessing giving up important things appeared more common among PCg (30.9%). It could also be a key element in understanding PCg burnout because it emphasizes the aspect of self-sacrifice possibly involved in being a PCg. As for co-parenting disagreement, it could be both an antecedent and a consequence of burnout. As an antecedent, co-parenting disagreement

could be a constant cognitive stressor. Parents would always feel they had abandoned important things in their lives only for the well-being of the child. Paired with ruminations, this might be a risk factor of EE. The feeling that the issue of the child has taken important things away from the parent may cause mixed feelings, including resentment against the child, which could then lead to ED with the child. However, such cognitions and feelings could also be seen as a biased observation of one's life, everything looking darker when experiencing burnout. Altogether, when comparing comorbidity and multiple CSN groups with the no-CSN group, burnout was found to be significantly less important among the latter. Nevertheless, when considered in a regression with subjective variables such as the perceived consequences of being a PCg, these subjective consequences seemed to be more related to burnout than the presence of comorbidity or multiple CSN. The effect seems to move from objective indicators to subjective indicators. This might suggest that the subjective perception of one's situation is a central element in understanding the consequences of caregiving. This is consistent with the literature on informal caregivers' burnout: objective factors (e.g., number of hours per week, presence of comorbidity) play a role in the understanding of burnout (Yan, 2014), but perception remains one of the strongest indicators (Truzzi et al., 2008). Thus, it might not be the objective demands but rather the parent caregiver's perception of his or her well-being that matters. For example, where some people may find it normal - and not very tedious - to carry out certain tasks, others will have a great deal of distress with consequences for their well-being. On the contrary, parents who are more resilient because they find more meaning in their parent-caregiving action, may be able to reduce this subjective hardship and its subsequent impacts. Previous studies have highlighted the importance of subjectivity and idiosyncratic perception in the caregiving context. This subjectivity has widely been studied in the informal caregiving literature in the form of *subjective burden*, the subjective weight of being a caregiver (Chiao et al., 2015). Studies have consistently shown a positive relationship between subjective burden and burnout among informal caregivers (e.g., Truzzi et al., 2008; Cill Akinci and Pinar, 2014). In the professional literature, similar findings exist with related variables: the accumulation of subjective stressors is a better predictor of professional burnout than the quantity or type of objective stressors themselves. Thus, rather than the objective stressors, it is the perception of such stressors that is consistently found to have the greatest impact on burnout reactions. The present study makes no exception because it is through the lenses of the person's frame of reference that stressors may (or not) generate the idiosyncratic experience of feeling burned out.

5. Limitations

The present study also has some limitations. One of the main limitations is its cross-sectional design. Though the sample is relatively large, the studied relationships are all correlational and so no clear conclusions of causality can be drawn. Conceptually, this design does not allow to test the bi-directionality of variables that could be conceived as both antecedents and consequences of burnout. Further qualitative studies should investigate the chronological progression of several of the studied variables, for example, to clarify if the feeling of having to give up important things due to the special issue of the child causes burnout or results from it. A second limitation lies in the broad categories of the issues encountered by the parents and their child(ren). Indeed, one does not really know the specific mental or physical problems that the children were going through. Future

studies should better assess the specific issues encountered since these may represent very different realities for children and parents. In a similar vein, the third limitation of this study deals with the self-reported nature of the questionnaire. Because there is no control of the diagnostics of the children, there is a possibility of false reporting. Respondents could have reported having a child with a behavioral or emotional disorder just because they have the feeling of this without any reliable or clinical assessment of it. Although further research should control this, it should not undermine the reachability of the purposively large spectrum of PCg interrogated. More globally, it is not excluded that the recruitment methods used may have affected the sample representativeness. The use of platforms such as Prolific for research purposes in psychology is growing but might lead to biases associated with the remuneration participants perceive. Conversely, the common social media and snowball recruitment methods used could also lead to biases. Though it does not guarantee a bias-free study, the combination of these recruitment procedures aimed at counterweighting each method's downsides and reducing overall biases in the sample. Finally, a fourth limitation is the relatively small PCg sample size. Although up to 19% of the total sample was categorized as PCg, it represented 175 people. Even if this sample size is sufficient for some analyses, it could also have led to possible false negative results. Indeed, the absence of difference between parents having one CSN and those with no-CSN regarding burnout measures could be due to a lack of statistical power. This difference – although not significant – appeared small for EE (Cohen's $d = 0.24$). A G*Power computation (Faul et al., 2007) indicated that such difference would have needed 280 PCg and 1168 parents with no-CSN to reveal a statistically significant difference – nearly 40% more participants.

6. Generalizability and Implications

The present results on PCgs may give insights to both parental and informal caregiving burnout literature. First, the subjective impact of having a CSN could also be investigated among people becoming parents or parents having an additional child. In the present study, the impact of having a CSN was the main focus of attention but this effect could be investigated for every parenting setting. For example, feelings of having to give up important things due to having a child could further be studied among parents of typical children to check whether this might also affect parental burnout. Even if it is more acceptable to disclose that one has to give up things because one has a child with special needs, this feeling could also be present among parents of typical children. The present results are also consistent with previous studies regarding the importance of co-parenting (dis)agreement and neuroticism in the occurrence of parental burnout. Second, the present study gives insights for the wider informal caregiving literature on burnout. Our results bear similarities with research on the subjective burden experienced by caregivers, showing that this burden is a major predictor of EE. It is also the first study to highlight a relationship between neuroticism and burnout measures among informal caregivers. Finally, the results about the similar impact of variables on both parents with and without CSN also suggest that PCg are still parents, so each of these fields of research could learn from the other.

Section 3

Conclusive note

Section 3 was an empirical investigation of informal caregiver burnout, mostly based on the model presented in chapter 3 (the ICIM). In chapter 4, a structural equation model investigated the mediator role of appraisal and relationship quality between dependency, emotional intelligence, and loneliness with informal caregiver burnout. Two key results emerged from these analyses. First, the appraisal, when measured by subjective burden, appears to have a key role in the understanding of informal caregiver burnout. Every determinant had an impact on one or more dimensions of burnout, through a modification of the appraisal. The second key result was the role of emotional intelligence as a protective factor for every investigated aspect. The impact of emotional intelligence was direct on appraisal, relationship quality with the care-recipient, and every dimension of burnout, but also through the mediation of the appraisal. An additional result was the absence of association between relationship quality and emotional exhaustion, which was unexpected. This chapter therefore suggests possible explanations for this absence.

Chapter 5 investigated the consequences of informal caregiver burnout in terms of depression, subjective health, and risk of violence toward the care-recipient. The results highlighted that emotional exhaustion was a stable predictor of depression and low subjective health, whereas depersonalization and personal accomplishment were only significantly involved in explaining depression. When looking at perpetrated violence toward the care-recipient, only emotional exhaustion appeared to be a significant predictor of perpetrated violence, but only for physical violence, after controlling for received violence. This chapter therefore shows that informal caregiver burnout is significantly related to deleterious outcomes, but this association is mainly due to emotional exhaustion and may be overshadowed by some determinants of the caregiving context (in this case, the received violence from the care-recipient).

The third empirical study developed in chapter 6 is a study investigating how being an informal caregiver of its own child may cause an increase in parental burnout. The key results are that having a child with comorbidity or multiple children with special needs may represent a risk on parental burnout. But the impact of this sole label is overshadowed by the perceptions and cognitions of the parent (their appraisal). Along with that, the roles of

neuroticism and parenting (dis)agreement were also highlighted as risk factors for parental burnout among parent-caregivers. Overall, parent-caregivers were more at risk than non-caregivers, but the analyses also show that relatively small influence of objective factors. Additionally, determinants such as neuroticism and coparenting (dis)agreement may affect both parent-caregivers and parent non-caregivers in the same way, which suggests that parent-caregiver remain parents above all, subjects to the same demands and resources as parents without a child with special needs.

General Discussion

General Discussion

1. A reminder

The present work took its roots in the need to address the difficulties informal caregivers may face in their caregiving role. Because informal caregivers experience affective difficulties without proper conceptualization to capture it and following the development of a literature on parental burnout, the idea that informal caregivers could also experience a form of burnout was considered. In reviewing the existing literature bridging informal caregiving and burnout, we realized that the results lacked homogeneity and there was no framework to investigate it. In addition, and in part due to these heterogeneous results and lack of conceptualization in the literature, several gaps in understanding the causes and consequences of this potential informal caregiving burnout were to be investigated.

The present work therefore aimed at (1) giving an overview of the literature bridging informal caregiving and burnout, (2) investigating the added value to use such concept, (3) providing a framework to study it, (4) based on that framework, giving new keys to understand informal caregiver burnout.

To answer these aims, three sections were developed. The first focused on studies comparing informal caregivers and non-caregivers on different forms of burnout (mainly parental and professional). The second section examined the literature on the research investigating informal caregiver burnout *per se* and provided an overview of the associations found in terms of its determinants and consequences. Based on this literature review and on existing models, an integrative model to investigate informal caregiver burnout was proposed. The third section presents three studies testing the newly-developed model and examining the determinants and consequences of informal caregiver burnout.

2. Overview of the results

2.1 Do informal caregiver experience more burnout?

The first chapter was a meta-analysis on burnout among informal caregivers. It was based on the observation that informal caregivers are often seen as having more emotional problems than the general population. Among these problems was the exhaustion or feeling of being worn down, problems that were reported both quantitatively and qualitatively. When combining these observations with the willingness to consider burnout in the context of informal care, a synthesis of the existing literature of burnout in informal care was needed to investigate if informal caregivers experience more burnout than non-caregivers.

To do so, a systematic literature review was performed. To be included, studies had to compare informal caregivers with non-caregivers in terms of burnout and provide enough quantitative information in order to include the study in the meta-analyses. If the studies did

not mention enough information, authors were contacted to have more detailed statistics. The selection process of the keywords was the first opportunity to observe the diversity of terms used to refer to informal care.

More than eleven thousand references were first found in the literature. When going through the selection process, this important number finally narrowed to 18. In these eighteen studies comparing informal caregivers and non-caregivers on burnout, two distinct sets appeared regarding the context they investigated. The first focused on burnout in the familial context ($k = 11$), mainly in terms of parental burnout ($k = 10$). In this set, studies compared if providing informal care to a spouse or a child led to an increase of burnout in that context. The second set of studies focused on the impact informal care can have on professional burnout ($k = 7$). Most of these studies focused on double-duty caregivers ($k = 6$), healthcare professionals who also provide informal care in their private life.

For both family care and professional burnout, the meta-analyses showed that informal caregivers reported more burnout than non-caregivers. For family care, these results applied to emotional exhaustion, emotional distancing/depersonalization, and for low personal accomplishment. For professional burnout, only emotional exhaustion was investigated, but with comparable results. In terms of effect sizes, the strongest difference was the emotional exhaustion in family care burnout ($d = 0.51$), and the lowest was in professional burnout ($d = 0.18$).

The results in family burnout suggested that providing informal care does represent an additional weight on the parent's or spouse's shoulders. The effect-sizes were small to medium, which suggests that the impact is not critical, but needs to be addressed to understand how this deleterious consequence of caregiving might occur. Separate analyses only on parental burnout studies also allowed to investigate the impact of having children with special needs which showed an additional parental burnout when providing informal care in such context.

The results on professional burnout also showed an increase in burnout, but carried a different message. It highlighted that providing informal care in the caregivers' personal life (outside of work) has an impact on their work-related health, meaning that being an informal caregiver in the private life does have an influence on work. Such impact suggests to further investigate how informal care can interfere with work, but also underlines how porous the boundaries between the different spheres of life may be.

With these results, this meta-analysis highlighted that informal care has an impact in family care and professional burnout. Such finding led to the need for a more in-depth investigation of what could be at the origin of this additional strain. One of the ways to address this was to consider the informal caregiver burnout by itself, as a measure of caregiving strain.

2.2 A theoretical approach of informal caregiver burnout

Informal caregiver burnout was defined as a tridimensional concept encompassing emotional exhaustion, depersonalization, and reduced personal accomplishment. Based on that definition, the second chapter aimed at theoretically laying the foundations of research on informal caregiver burnout. To do so, the first step was to have an overview of the literature already investigating informal caregiver burnout. Chapter 2 involved a narrative review of the correlates of informal caregiver burnout, classified in terms of its determinants and consequences. An important range of determinants has been investigated and can be classified in three domains: the caregiver, the care-recipient, and the context of care. Among these determinants, two particularly stood out. The first is the “subjective evaluation” informal caregivers make of their situation, which was mainly explored in terms of “subjective burden”. Subjective burden has large associations with informal caregiver burnout, suggesting a potential conceptual overlap between the two concepts. The relationship with the care-recipient was the second element that clearly appeared to affect informal caregiver burnout because it was the core of the caregiving role.

Following this overview of the literature, there was a need to give a framework for informal caregiver research, as none was clearly identified in the review. Informal caregiver burnout research takes its roots in both informal caregiving stress and professional burnout theories and benefits from the findings in both fields. Therefore, one of the main models in each field was reviewed to adapt it to the informal caregiving context. For informal caregiving stress theories, the Model of carer stress and burden (from Sörensen et al., 2006) was selected because it already merges different theories in caregiving stress. It proposes a process by which primary stressors (the “objective burden”) cause secondary stressors, themselves influencing the appraisal, itself causing outcomes such as subjective burden. In conceptualizing it, the model clearly distinguishes between primary and secondary stressors (the difficulties and their consequences), and highlights the key role of the appraisal (the perceptions) of caregiving. Nevertheless, this model neglected to include determinants related to the caregiver and the context, and did not consider the interactions within the caregiving dyad. For job burnout theories, the Job Demands-Resources model (JD-R, from Demerouti et al., 2001) was chosen because it frames current research in professional burnout with its idea of balancing the resources and demands in the affective management of work. The main contribution of this model is to propose that burnout is a key mediator between determinants (here, job demands and resources) and outcomes, and to present burnout as the results of an imbalance between perceived demands and resources (recalling the role of the appraisal). In addition to these two models, there was a need originating from the literature review to clearly address the difference between the concept of subjective burden and informal caregiver burnout.

Chapter 3 therefore proposes the Informal Caregiving Integrative Model (ICIM) to benefit from the advantages of these two models, but also addressing their limitations. It had 6 complementary aims: (1) to include stressors and resources from inside and outside of the caregiving context, (2) to reconsider the relationship with the care-recipient as central in the

understanding of informal caregiving, (3) to consider informal caregiver burnout as a key-mediator between stressors/resources and outcomes, (4) to consider the appraisal as one of the main predictors of informal caregiver burnout, (5) to address the association between subjective burden and informal caregiver burnout, and (6) to include feedback loops that were missing from the other models.

Therefore, the ICIM establishes three main domains of determinants: the caregiver, the caregiving setting, and the environment. The caregiver-related determinants relate to all the caregivers' own characteristics that are going to affect their well-being. It encompasses sociodemographic characteristics as well as developmental, personality, cognitive, and emotional traits. These traits define the caregiver but also, to some extent, the way he or she is going to deal with his or her caregiving role. The physical state of the caregiver also defines his or her capacity to face the demands.

The caregiving context is the second set of determinants affecting the caregivers' well-being. It covers the "objective burden", the objective stress they face when providing care, such as the tasks that must be performed, or the intensity of the care-recipient's symptomatology or difficulties. The caregiving context also includes the secondary stressors (the consequences of the objective burden) such as having financial issues due to caregiving or having less free time. Even if the literature mostly investigated distressing determinants in the caregiving context, potential resources must also be considered.

The third set of determinants are related to the social context the care-recipient and the caregiver evolve in. This social context can roughly be divided in three complementary spheres: the social support, the professional support, and the sociocultural environment. Social support covers all forms of informal support the caregiver and the care-recipient might receive, and the professional support relates to the interactions and assistance received from healthcare professionals. The sociocultural environment is the global sphere that shapes the norms of the group and the society, defining what is informal caregiving and what are its implications in that environment.

These three categories of determinants are theorized to affect the informal caregiver burnout directly, but also through two key mediators. The first mediator is the appraisal. This is the overall subjective evaluation of the caregiving experience by the caregiver. It is the evaluation of the (im)balance between demands and resources, the weighting of the determinants. The concept of subjective burden is here considered as an evaluation of the negative appraisal of the caregiving experience.

The second key mediator is the relationship quality with the care-recipient. Determinants may modify the relationship with the care-recipient (both positively and negatively) by modifying the conditions in which the caregiver and the care-recipient interact. But the relationship quality is also expected to influence informal caregiver burnout, as this relationship is at the heart of the caregiving role.

Finally, informal caregiver burnout is the main determinant of positive and negative outcomes. These outcomes are mainly assessed on caregivers themselves (in terms of physical and mental health) and on the care-recipient (risk of violence toward the care-

recipient, impact on his or her own physical and mental health, or placement in nursing homes). Informal caregiver burnout and the outcomes have feedback loops to the determinants, the relationship quality, and the appraisal, suggesting that consequences at one point in time may become determinants afterwards.

2.3 Empirical investigations of informal caregiver burnout

2.3.1 *Caregiving appraisal and relationship quality: Key mediators in the understanding of informal caregiving burnout?*

The third part of the thesis aimed at empirically investigating the Informal Caregiving Integrative Model proposed in chapter 3, with three complementary studies. The first study aimed at investigating the determinants of informal caregiver burnout. Three determinants were investigated in this study: the care-recipients' dependency in their daily tasks (the objective burden), the caregivers' emotional intelligence (personal resource), and the caregivers' feelings of loneliness (the caregivers in their context). The two mediators of the ICIM were also included. Relationship quality was therefore measured by the caregiver, and the caregiving appraisal was investigated through caregivers' subjective burden. To test this mediation, data from a sample of 444 informal caregivers were analyzed with structural equation modeling.

The results indicated that the inclusion of the two mediators led to larger explained variance of informal caregiver burnout. When looking closer at the detailed analyses, two main results appeared. First, the appraisal was a key to understanding informal caregiver burnout. It had a significant association to the three dimensions of informal caregiver burnout: the higher was the negative appraisal (the subjective burden), the higher were the burnout scores (high emotional exhaustion, high depersonalization, and *high* personal accomplishment). It showed that the appraisal in the form of subjective burden had a predictive role in burnout, with the exception of personal accomplishment, where it predicted its decrease. The appraisal also mediated every association between the determinants and informal caregiver burnout and was also associated with lower relationship quality with the care-recipient.

The second main result related to the protective role of emotional intelligence. Emotional intelligence appeared to be negatively related to subjective burden and informal caregiver burnout in its three dimensions, and was also associated with better relationship quality with the care-recipient. Emotional intelligence was therefore associated with every investigated element in the model, suggesting its important role when facing the potential difficulties related to informal care.

Apart from that, results were more mixed for the relationship quality, which was expected to be a protective factor for every dimension of informal caregiver burnout. Contrary to expectations, relationship quality was only associated with lower depersonalization and higher personal accomplishment, but not with emotional exhaustion. The absence of

association contradicts the existing literature and the ICIM. Two potential causes of this absence were discussed. The first was the measurement of relationship quality, which may have been too heterogeneous to capture the quality of the relationship. The second questioned the impact of relationship quality on emotional exhaustion, as too close relationships with the care-recipient could also lead to an increase of burnout because it could become too demanding on the caregiver's balance.

Care-recipient's dependency was associated with higher emotional exhaustion, but mostly through a more negative appraisal. It was also unexpectedly *positively* associated with personal accomplishment, which means that the more the care-recipient was dependent, the more informal caregivers felt accomplished in their role. This surprising association could be seen in light of a potential interaction with relationship quality, where the dependency leads to personal accomplishment if there is a good relationship quality beforehand.

Unpublished results from this study were also presented at the 33rd European Health Psychology Society Conference (Appendix 1). These results showed that trait perfectionism was a determinant of informal caregiver burnout. In trait perfectionism, the distinct role of personal and perceived social standards was investigated. It appeared that the more caregivers had social perfectionism, the more they reported emotional exhaustion and depersonalization, whereas more personal perfectionism was associated with higher personal accomplishment.

2.3.2 *Caring until it hurts: informal caregiver burnout as a determinant of caregiver depression, subjective health, and violence*

Chapter 5 aimed at exploring the consequences of informal caregiver burnout. This study investigated the association between informal caregiver burnout and its potentially deleterious consequences for the caregivers themselves (depression and reduced subjective health) and the care-recipients (violence perpetrated by the caregiver). The goal was to investigate the impact of the three dimensions of informal caregiver burnout on each of these consequences, while controlling for potential confounding variables such as age and gender of both the caregivers and the care-recipients. An additional objective was to determine whether a certain kinship relationship was more at risk than others.

To do so, the study is based on the same sample as for chapter 4, but with the addition of caregivers of children under the age of 16 years old, with a total sample of 499 informal caregivers¹. Depression, subjective health, and burnout were assessed through questionnaires. To capture violence, a questionnaire assessing both perpetrated and received psychological and physical violence was used. Based on that questionnaire, caregiver could be categorized as having been psychologically or physically violent in the past year. Bivariate analyses and hierarchical linear and logistic regression models were used to investigate the associations between the variables.

¹ The restriction of this sample in Chapter 4 is due to the measure of dependency, which applies only to adults (individuals over 16 years of age).

Informal caregiver burnout appeared to be a strong and stable predictor of depression and (low) subjective health. For depression, the three dimensions of burnout were significantly explaining variance of depression, even when controlling for sociodemographics, kinship, and received violence. For subjective health, this association was only present with emotional exhaustion, and not the two other dimensions.

When looking at perpetrated violence, it appeared that it was rather common across the sample to have perpetrated psychological (close to 45%) or physical violent behaviors (close to 10%) toward the care-recipient in the past year. Informal caregiver burnout was associated with both psychological and physical perpetrated violence, mostly due to emotional exhaustion. When considered along with received violence, the role of informal caregiver burnout was overshadowed. Only emotional exhaustion remained a significant predictor of perpetrated physical violence. In fact, the main predictor of perpetrated violence was received violence, which suggested that violence breeds violence.

Kinship was associated with emotional exhaustion, depersonalization, and perpetrated physical violence. Individuals taking care of their spouse appeared particularly at risk of being emotionally exhausted and experiencing depersonalization, whereas those taking care of their child were more likely to be physically violent. However, the multivariate investigation showed that, when considered along with informal caregiver burnout and received violence, kinship did not account anymore for additional variance in explaining physical violence.

Overall, informal caregiver burnout appears to be related to caregiver-centered outcomes in terms of depression and subjective health, which is mostly due to emotional exhaustion. To some extent, informal caregiver burnout can affect the care-recipient through an increase of (physical) violence, which is also mostly due to emotional exhaustion. Additionally, received violence was the strongest predictor of perpetrated violence and kinship accounted for very little variability.

2.3.3 Burnout in the context of parents providing informal care to their children: a comparative study

Chapter 6 investigated a particular subsample of informal caregivers: parent-caregivers. This study is based on a comparative investigation of the determinants of parental burnout in a sample of parents with and without children with special needs (i.e., having (1) a chronic or serious disease, (2) a disability, or (3) a behavioral, emotional, or learning disorder). The goal was first to identify if, as reviewed in chapter 1, parents providing informal care were more likely to report more burnout than parents of typical children. The second goal was to investigate if parent-caregivers had the same determinants of parental burnout than other parents.

To do so, neuroticism (caregiver) and co-parenting (dis)agreement were investigated, as well as the negative appraisal of parents having children with special needs through different statements. Mean comparisons were therefore performed to explore the differences in parental burnout between parents having or not children with special needs. Linear regression

models were then used to investigate the determinants of parental burnout, for each dimension.

Consistently with chapter 1's results, parent-caregivers of children with special needs did experience more burnout than parents of typical children. On closer look, however, it appeared that this difference had to be nuanced. In the sample of parent-caregivers, three different groups were identified: the parents having one child with one issue, those with multiple children with one issue, and those of children with comorbidities (more than one issue per child). The difference between parent-caregivers and the other parents became less clear-cut. Parents having only one child with one issue did not significantly differ from the parents of typical children, and only the parents of children with comorbidities or having multiple children with issues were more at risk of burnout.

When looking at the different determinants, it appeared that every investigated determinant accounted for additional parental burnout variability. Neuroticism and co-parenting disagreement were significant risk factors for every parent, which suggests that parent-caregivers face the same set of demands as parents of typical children, in addition to the special needs of their children. In the regression models for parent-caregivers, the role of comorbidity and having multiple children with special needs remained limited and was overshadowed by the appraisal, which was one of the strongest predictors of parental burnout in that context. This result meant that the amount of variability explained by the "objective" difficulties of being a parent-caregiver appears to be limited in comparison to their subjective perception, thereby confirming the ICIM.

3. What does this thesis add to the existing literature?

The different chapters in the present work add to the literature in different ways. The first and main output is to propose and support the use of informal caregiver burnout as a measure of caregiving strain. As it has been underlined, the use of this concept answers to a reality in the experience of the informal caregivers by addressing three different dimensions: the feeling of exhaustion, the altered way to interact with the care-recipient, and the sense of accomplishment that might be affected. It also provides promising keys to capture the complexity of the impact of informal caregiving (rather than looking at it through the lenses of a burden).

Results from chapter one also highlighted the need to consider that being an informal caregiver has an impact not only inside the caregiving setting, but that it also appears in other contexts such as working or parenting. As it was evidenced, being an informal caregiver puts at risk of experiencing family care/parental and professional burnout. The meta-analyses allowed having a clearer picture of this observation by gathering all the existing evidence investigating this question. In the field of professional burnout, these studies mostly revolved around the "double-duty" caregivers (i.e., healthcare professionals providing informal care), even if different terms are used, such as "sandwich generation", "double-caregivers", or "working caregivers" to address these types of caregivers. For parental burnout, some individual studies concluded that there was no impact of informal caregiving on parental

burnout. But the diversity of the situations and the medium effect size found through the meta-analysis nuances this observation by highlighting a consistent risk of family/parental burnout when being an informal caregiver.

Because there was a gap in the literature, the Informal Caregiving Integrative Model (ICIM) was proposed in order to frame current and future research on informal caregiver burnout. Because it is based on both caregiving stress and professional burnout works, the ICIM build bridges between these two fields so that each can benefit from the other. The results in each of these fields can therefore contribute to the understanding of the burnout phenomenon among caregivers. By clearly organizing the different categories of determinants and identifying two key mediators involved, the ICIM proposes a path on which future studies and theories can continue to grow.

In this model, the difference between the appraisal and informal caregiver burnout was clearly identified, where the appraisal is a determinant of burnout. This distinction helped to articulate the concepts of subjective burden and informal caregiver burnout, which were often used indiscriminately in the literature. As it was shown in chapter 2, the two concepts are importantly related. However, they also have conceptual distinctiveness, as pointed in chapter 3 and discussed in chapter 4. Subjective burden is a measure of appraisal characterized by high importance, low control, and negative valence components. As such, it captures some aspects of the appraisal of caregiving. Our results showed that the appraisal individuals have of their caregiving experience is one of the main determinants of informal caregiver burnout which justifies their close ties. By stating that subjective burden is seen as a determinant of informal caregiver burnout, the present work brings a clarification to a vagueness that was left unaddressed.

Beyond the ICIM, the empirical work conducted on the role of the appraisal of caregiving on informal caregiver burnout – through chapters 2, 3, 4 and 6 – has shown that the perception of the situation accounts often more than the “objective burden”. Poor objective conditions can often lead to a poor appraisal, but this is not always the case. A substantial number of other determinants are at play. Several of these determinants of informal caregiver burnout and appraisal have been identified. Regarding the determinants specifically related to the caregiver, chapter 4 highlighted the key role of emotional intelligence as a protective factor informal caregiver burnout, as well as for negative appraisal. In terms of personality factors, neuroticism was shown as a risk factor (in chapter 6), as well as alexithymia (chapter 2). Perfectionism in providing good care was also shown as a risk factor for informal caregiver burnout (through chapter 2 and the unpublished results from study 4 presented in Appendix 1). With regard to the determinants related to the caregiving context, the dependency of the care-recipients (i.e., their lack of autonomy in daily tasks) is another direct risk factor of informal caregiver burnout, but its association to caregiving burnout remains modest, as shown in chapter 4 ($r = .29$). Having a child with comorbidity or multiple children with special needs were shown to be a risk factor, in comparison to having one child with one issue (chapter 6). As discussed in Chapter 2, the intensity of the care recipient's symptomatology appears to be a more important risk factor, as is the need for constant monitoring, which places the caregiver in a state of constant vigilance. Received violence

from the care-recipient was also shown to be associated with higher burnout levels, as shown in chapter 5. Finally, regarding the determinants of the social context in which the caregiver is placed, loneliness was also found to contribute to informal caregiver burnout, but mainly through a worsening of the appraisal (as shown in chapter 4). As shown in chapter 6 and in chapter 2, feeling supported by other caregivers and family members was found to be protective against informal caregiver burnout.

Empirically and theoretically, the present work has also integrated the relationship quality in the ICIM to understand its role in informal caregiver burnout. This proposition integrates the abundant literature on relational and dyadic components in a global framework on informal caregiver burnout, in relation to the determinants and the appraisal. In chapters 2 and 3, relational aspects appear to be strongly associated with informal caregiver burnout. However, in chapter 4, the association between relationship quality and informal caregiver burnout was more nuanced. Relationship quality was associated to lower depersonalization and higher personal accomplishment, but was not significantly associated with emotional exhaustion. This nuance calls for a more in-depth study on how relational aspects might evolve over time over the course of caregiving.

The deleterious consequences of informal caregiver burnout were investigated in chapter 6. Informal caregiver was highlighted as an important risk factor for depression, accounting for 42% of depression's variability. To a lower extent, the dimension of emotional exhaustion has also been shown to be a risk factor of low subjective health, and physical violence toward the care-recipient. The literature review in chapter 2 also pointed out the risk of informal caregiver burnout to trigger the intention to leave the caregiving role and to increase both the caregiver and care-recipient's physical health problems.

In addition to determining the risk factors and consequences of ICB, the present work also aimed at addressing how some informal caregiving contexts may differ. There is an important variability between the caregiving contexts, whether it is due to kinship relationship with the care-recipient, their age, gender, cause of the loss of autonomy, or the intensity of the care-recipient's symptoms. It appears that the impact of labels like kinship relationship between the caregiver and the care-recipient or presence of comorbidity have a limited impact on informal caregivers' outcomes (as shown in chapters 2, 4, and 6). Better indicators of variability across caregiving settings appear to be related to the challenges informal caregivers face when providing informal care, in terms of dependency (chapter 4), intensity of the care-recipient's symptoms (chapter 2), or received violence (chapter 5).

4. Perspectives and issues raised

While this work makes several additions to the literature, it raises other questions and perspectives for future work. A first point relates to the need to find ways to improve the Informal Caregiving Integrative Model (ICIM). The studies included in section 3 were the first to be based on this model. They already give interesting insights regarding how the ICIM could better capture how caregiving can take a deleterious turn.

A second point relates to the adaptation of burnout to informal care, which is at the heart of the present work. Bridging informal care and burnout was made because it answered a gap in the literature. It, however, has several implications, whether in terms of research, potential interventions, and views of caregiving. The empirical studies also put at test the adaptation of the Maslach Burnout Inventory to informal care, interrogating the tridimensional nature of burnout in the context of informal care.

The last point addresses the diversity of informal care. This work has sought to gain a better understanding of the diversity of the caregiving situations. Such diversity may impede the possibility of establishing a comprehensive framework for each caregiver, but could also be an opportunity to better understand what caregiving is all about.

4.1 The Informal Caregiving Integrative Model

Chapter 3 presented the Informal Caregiving Integrative Model (ICIM). Its aim is to frame the research on informal caregiver burnout. It articulates the different categories of determinants, and well as key mediators in terms of appraisal and relationship quality. Studies in section 3 were based on this theoretical model and supported its use. In support of the ICIM, the mediator role of appraisal, and relationship quality to a lower extent, were shown to be very predictive (see chapter 4). As hypothesized, the determinants had an impact both directly on informal caregiver burnout, and indirectly through one of both mediators. The key role of informal caregiver burnout to capture the risk of deleterious consequences of informal care, in particular depression, subjective health, and perpetrated physical violence was also confirmed (see Chapter 5). Finally, the role of the appraisal as a more important predictor of burnout than objective stressors was also confirmed (see chapter 6).

There were also results that challenged the ICIM and call for further investigations of this framework. First, the relationship quality with the care-recipient was not a protective factor of emotional exhaustion. This lack of association contradicts the model, which predicted the relationship quality to be a key factor against informal caregiver burnout as a whole. But such absence of effect needs to further be explored in regard of the existing literature pointing that there is a strong association between relationship quality and exhaustion (as highlighted in the qualitative and meta-analytic reviews of the literature chapters 2 and 3). One of the possible improvement relates to the measurement of the relationship quality, as it was not ideal and could be improved. In our study, we only used three items from a previous study to assess relationship quality (Lawrence, Tennstedt, & Assmann, 1998). These three items were focusing on affective closeness, similarity of views about life, and degree of getting along. Even if there was a good internal consistency, this measure might miss the fine-grained reality of what is at stake when looking at the complexity of the caregiver-care-recipient relationship in the caregiving context. Other measures focusing only on affective closeness or affective support may give better information of what is at stake between the caregiver and the care-recipient. Pushing this vision further, the investigation of dyadic adjustment (i.e., how the dyad faces challenges together) may also help understanding how the relationship could protect or put at risk of deleterious consequences. A second way of improvement would also be to clarify the interplay between relationship satisfaction and appraisal. As theorized

(chapter 3), highlighted in previous studies (chapter 2) and shown empirically (chapter 4), relationship quality and appraisal are steadily correlated. Therefore, the appraisal may mediate, in part, the impact of relationship quality on informal caregiver burnout. Therefore, a bad relationship quality could lead to a more negative appraisal of caregiving, and then to more informal caregiver burnout.

In the ICIM, most of the associations are presented as linear and direct. Even if it is only a theoretical framework, which is not intended to be exhaustive or fixed, the main conveyed idea was on linear associations. However, there are more than likely interactions between the variables involved. In chapter 4 for example, the *positive* association between subjective burden (negative appraisal) and personal accomplishment within the structural equation model was proposed to be due to an interaction with other variables, and particularly with the quality of the relationship. And it is more than likely that the actual (and previous) relationship quality will interact with some determinants, the most obvious being with the dependency and the tasks to perform. For example, too close relationship may impair the willingness to perform some tasks or put a constraint in providing tasks that the caregiver does not want to do. Conversely, carrying out tedious tasks in a context of close emotional relationships could bring the caregiver and care-recipient even closer to each other and create deeper bonds. Another key interaction could be with cultural norms. As for relationship quality (although not in the same way), cultural norms of care might influence how informal caregivers perceive their role. In some cultures, being an informal caregiver is part of life and seen as an opportunity to “repay the debt” to their relative, whereas in others providing informal care is seen as a brave decision that takes courage. This perception can therefore shape the perceived impact of the caregiving duty, causing potentially distinct outcomes.

The investigation of feedback loops in the ICIM model could be done through longitudinal studies, but this would only provide a limited range of information. The goal is to identify if informal caregiver burnout has an impact on its own determinants. Distinct but complementary methodologies could be used to investigate these loops, most of them revolving around the intervention on reducing informal caregiver burnout. The rationale of focusing on the intervention is to clearly isolate the impact of the change in informal caregiver burnout on its determinants. In the first, once informal caregiver burnout (or any general outcome) diminishes due to an intervention, the variation of key determinants could be monitored and see if they change following the intervention. Regression analyses could complete this picture by investigating if the presence or intensity of the determinants is related to the change in burnout score. A second way could be through a retrospective qualitative investigation. After a diminution of informal caregiver burnout, the informal caregivers would be asked to see what has changed in their determinants since they feel less burned-out. The third way would focus on hetero reporting. Relatives of the informal caregiver would report if there was any change since the diminution of informal caregiver burnout (whether quantitatively or qualitatively). Additionally, actor-partner models and analyses could highlight if modifying the caregiver’s mental health has an impact on the care-recipient’s mental and physical state.

Informal caregiver burnout is not the sole mediator of the determinants when looking at the consequences. In chapter 5, the investigation was on depression and subjective health. Several determinants were included in the model and only informal caregiver burnout dimensions appeared to affect the levels of depression and subjective health, mainly due to emotional exhaustion. But when looking at violence, it appears that informal caregiver burnout was not the sole predictor of violence and that there were also direct influences of existing determinants in the risk of violence (received violence, kinship, and age to some extent). Of course, the idea of the model was not to say that everything was supposed to be mediated through informal caregiver burnout, but it might have put aside other paths by which determinants could affect different outcomes.

Another point of interest that appeared afterwards was the absence of a clear reference to emotions (and, consequently, emotion regulation) in the model. Indeed, the model was mostly based on two stress models (whether it was caregiving stress or professional burnout). Therefore, its construction did not focus on emotion regulation and only incorporated a brief mention to coping strategies. This approach makes sense since it postulates how determinants influence informal caregiver burnout, which is seen as a state. On the contrary, the flow of emotions is immediate, with a constant dialog between emotion generation and emotion regulation (Gross, 2015). It would therefore hardly “fit” into a theoretical framework regarding the determinants and consequences of informal caregiver burnout, developed on the long run. It may, however, be interesting to investigate how emotion regulation strategies are used on a regular basis and how they influence the course of caregiving. Such approach could broaden the “coping” component of the model, with the emotion regulation strategies. It would be more tied to the appraisal since *reappraisal* is a commonly used regulation strategy (Gross, 2015). Combining emotion regulation with coping would also have the symbolic consequence of not focusing on stress only, opening to the broad range of emotions involved in caregiving, whether they are “unpleasant” or “pleasant”.

4.2 The concept of burnout in informal care

The present thesis aimed at adapting the concept of burnout to the informal caregiving context. Such adaptation was (*is*) not self-evident for many reasons and has different implications that must be discussed.

4.2.1 Tridimensional concept

In the present work, the concept of informal caregiver burnout was directly transposed from professional settings to informal care. This transposition without conceptual modification was made based on the most common conceptualization of professional burnout based on the work of Christina Maslach and colleagues (Maslach, Jackson, & Leiter, 1996). In this conceptualization, burnout is seen as a tridimensional state consisting of emotional exhaustion, depersonalization, and personal accomplishment (as developed in chapter 1, 2, and 3).

Emotional exhaustion appears as a central variable to understand how informal caregiving can take a negative turn. In parental and professional burnout, it is the most investigated dimension (chapter 1); it is conceptually the core of informal caregiver burnout as it relates to the caregivers' lived experience of exhaustion (chapter 3); and it has been the dimension correlating with the larger scope of determinants (chapter 2, 4, and 6) and consequences (chapters 2 and 5). These findings suggest to further investigate emotional exhaustion and consider it as the key metric of the deleterious consequences of caregiving. It is a homogeneous concept (although it is sometimes extended to physical or mental fatigue, Shirom, 2011), which is easily understandable and relatable for the caregivers themselves.

The clarity of emotional exhaustion is not so simple for the other two dimensions of informal caregiver burnout, especially when it comes to depersonalization. In chapter 2, it appears that this dimension remains underinvestigated in the literature and presents mixed associations with several determinants and consequences. Empirically, chapter 5 highlighted that its (expected) explanatory role in the violence was insignificant. The inclusion of depersonalization did not lead to additional explained variance in comparison to emotional exhaustion. As it is discussed in chapter 5, the distribution of the depersonalization scores were positively skewed, meaning that average scores remained low, possibly due to a too extreme phrasing of the concept.

Parallel to the completion of this thesis, some qualitative inquiries have been performed. Among them, one was Laura Danloy's master's thesis investigating informal caregiver burnout in the context of neurodegenerative disease. In her work, she highlighted that emotional exhaustion was found in every interviewed caregiver, the exhaustion being either actual or past. For personal accomplishment, the definition was found to be a bit broader than simply feeling "accomplished" in the role. Indeed, participants also reported that it also involved the sense of self-fulfillment in the role, of acting in accordance to their values, or of having the opportunity to give back what the care-recipient had done for them.

For depersonalization, the results were more mixed. Even if some interviewees had some distant attitudes (like talking as if the person was not in the same room), most of them did not *feel* that they might, have or had depersonalization attitudes. Therefore, there was no clear evidence of depersonalization among informal caregivers. This observation opens two non-exclusive paths. First, depersonalization could not be investigated by self-reported methods unless it is extreme and noticeable or that caregivers need to be self-reflexive to be aware of it. Such attitude would only be observed through the ways they treat their care-recipient, because they might not be aware of it. One method of addressing this would be to diversify the source of information by interviewing the care-recipient – if he or she is conscious or able to discern it – or the professional caregivers involved in the care (whether at home or in outpatient consultations). Second, if depersonalization was observed and developed in professional settings, the concept may not be entirely appropriate for caregivers as such. Some participants reported having attitudes comparable to formal caregivers (i.e., feeling as a nurse) by interacting with more emotional distance as usual or before. To them, the problem was not that they had these attitudes, because it helped them to perform certain tasks (such as accompanying their care-recipient to the toilet, or providing assistance in personal

hygiene), but rather that they *only* had this attitude. Therefore, it may be the lack of flexibility in leaving such attitude when they are not performing such tasks that could be deleterious to both the caregiver and the care recipient. The problematic attitude would therefore be not in the attitude itself, because it might be necessary to face a specific situation. The problem would arise with its chronic nature, the caregiver's inability to oscillate between affective and professional relational attitude. This echoes the research reviewed in chapter 3, where caregivers under stress pointed the need to take their distance with the care-recipient to be able to keep up doing their caregiving tasks.

In professional burnout, depersonalization leaves more and more room to "cynicism" toward the job, rather than reification of the service's recipient (Maslach & Leiter, 2016a, 2016b). In the parental burnout literature (Roskam, Brianda, & Mikolajczak, 2018; Roskam, Raes, & Mikolajczak, 2017), the concept of emotional distancing was preferred to depersonalization because it was less extreme and people could more easily relate to it and be open to talking about it.

With these elements in mind, it appears difficult to conclude that depersonalization should be kept in its current form in informal care. Two possibilities therefore appear:

- (1) There is an emotional distancing, which is a *protective coping*, and not a dimension of burnout. The emotional distancing or having a professional relationship would therefore be a mechanism by which caregivers maintain their involvement in their relationship and their caregiving role because they can take their distance. This coping would become *in theory* problematic if this attitude becomes rigid. Even if it might appear as a problematic attitude, it should not be excluded that rigid relation professionalization could be beneficial to both the caregiver and the care-recipient.
- (2) There is an emotional distancing, which remains one of the dimensions of burnout. It is the adapted version of depersonalization, but more representative of the continuum of affective distance that could arise in the context of informal care. As such, it is expected to have deleterious consequences for both the caregiver and the care-recipient.

This dichotomization is not new and is present in the context of professional burnout where some consider depersonalization as a coping strategy while others as a symptom of burning out (Schaufeli & Taris, 2005). In addition to these two paths, future studies should also examine other associated relational concepts, such as unconditional positive regard toward the care-recipient (Schoenfelder, Swanson, Specht, Maas, & Johnson, 2000) or dehumanization (Carmack, 1997; Taverner, Baumbusch, & Taipale, 2016). The goal would be to explore their applicability to informal care and to be able to articulate these various concepts in relation to each other and to informal caregiver burnout.

Personal accomplishment appears less problematic since it globally reflects the personal benefit and feeling of competence in the caregiving role. Its inclusion in the broad concept of burnout is already discussed as some see it more as a consequence of emotional exhaustion and depersonalization, rather than their parallel dimension (Schaufeli & Taris, 2005; Taris, Le Blanc, Schaufeli, & Schreurs, 2005). Conceptually, it is probably too heterogeneous (since covering accomplishment, competence, feeling of control, effective emotion regulation) to be useful. But it has the benefit of addressing positive dimensions of caregiving. In fact, the

positive aspects of care should be much more developed based not only on the elements covered by personal accomplishment, but also in relation to other positive dimensions such as acting in accordance to their own values or eudemonia (personal growth, Marino, Haley, & Roth, 2017).

4.2.2 Scale

The present project used an adaptation of the Maslach Burnout Inventory to the context of informal care. This simple adaptation was based on previous studies already using this scale in this context, and showing interesting associations/correlations, as well as good internal properties (as highlighted in chapter 3). Its use is also rooted in Maslach's burnout theory that drove the present project (since the questionnaire defined the theory itself). But because of the conceptual issues of adapting without changing burnout to informal care, and because of the tool itself, several points could be improved.

First, the use of an unpublished adaptation and the absence of statistical validation make the measurement of burnout in informal caregiving too discreet and without rigorous foundations. When taking aside the conceptual issues that were pointed out, using an adapted scale puts at risk of not knowing what it investigates. This was particularly striking for chapters 1 and 2, where some studies did not mention if they adapted the MBI (or any other burnout measure) to the context they were focusing on. The use of the scale without validation also implies that all the items or scoring are relevant to that new context, which may not always be the case (e.g., informal caregivers do not always provide daily care but the scoring is based on frequency in terms of days).

Regarding the tool itself and because it is widely used in the professional burnout literature, it is also widely criticized (Bianchi, Schonfeld, & Laurent, 2015). The problems with the MBI are not new but remain valid. It was developed more than forty years ago and might not meet the actual challenges faced by contemporary workers. The items included were also from a set of factorial analyses that were never performed again since. It is also a fee-based instrument under copyright, which goes against the idea of providing tools to help a maximum of individuals. Nevertheless, it remains the most widely used scale to investigate burnout (Wheeler, Vassar, Worley, & Barnes, 2011).

One answer could be to develop one new scale directly based on the experience of informal caregivers. But this approach appears as a double-edged sword because the benefit of having a new tool would probably lead into the pitfall that has guided the present thesis. On one edge, we would contribute to increasing the conceptual (over)complexity of research in informal care. The multiplication of concepts on top of others has already led to an enormous number of tools assessing the negative impact of providing informal care (Mosquera et al., 2016; Van Durme, Macq, Jeanmart, & Gobert, 2012). The addition of new tools measuring burnout in informal caregiving would therefore take the same path by adding one tool to a mountain of others. But on the other edge lies the observation that there is a need for a proper measurement of the exhaustion of informal caregivers. A recent (submitted) review highlighted that there is no clear tool (nor definition) of informal caregivers' exhaustion (Dubech, Gérain, Rouquette, & Lefranc, 2019). Chapter 3 offers a theoretical

framework and definition of informal caregiver burnout, but there is still no tool to assess it properly.

A midway solution would be to keep one of the professional emotional exhaustion measures (such as in the MBI) and adapt it to the context of informal care (because they are easily available and can easily be applied to informal care). At the same time, it would require to investigate in more depth what is the nature of depersonalization and personal accomplishment (whether they are truly part of the informal caregiver burnout or not). This approach would provide a tool for measuring caregivers' emotional distress, while encouraging the development of what could be conceptually related to it, but in the context of informal care.

4.2.3 Threshold and psychopathology

Whether using existing or developing new tools, the setting of thresholds in such scales may appear as a necessity. The objective of having such cut-offs is to differentiate a particular state where the individual is clearly different from others from another state considered less extreme or "normal". The (hoped) benefit of the threshold is to clearly identify the individuals experiencing burnout (i.e., having the label of "informal caregiver in burnout").

We can only acknowledge how comforting it would be of having a threshold beyond which a caregiver could be categorized as "in burnout" and receive more help. It would also have a role in the self-identification of the current emotional status, helping caregivers to ask for help. For example, on a website of a Belgian association of informal caregivers, the Zarit Burden Interview is displayed for the visitors to answer it (Aidant Proche Bruxelles, 2017). When they have completed it, they receive their score and a small advice telling them how they feel in comparison to the norms. The idea is that this score may be a trigger to ask for professional support. But these cut-off scores are not recent and were not based on a representative sample (Hébert, Bravo, & Prévile, 2000; Schreiner, Morimoto, Arai, & Zarit, 2006).

The relevance of developing a threshold can only be considered if there is a true benefit in this differentiated identification. Such benefit would be either medical or a trigger for public policies. On the medical side, it would mean the identification of above-threshold burnout as a psychiatric disorder needing (and receiving) specific attention. Even if burnout is studied for many years, the two key registry of (mental) health issues (DSM and CIM) do not acknowledge it as a psychopathological disorder per se (Korczak, Huber, & Kister, 2010) and the path will be long before it could, since the debate remains open on its nature (Kaschka, Korczak, & Broich, 2011). Additionally, existing studies on professional burnout (and in particular the MBI) have shown that the use of a threshold for burnout is not a good indicator of DSM criteria for psychopathological disorders and advocate not to use it as a diagnostic tool (Kleijweg, Verbraak, & Van Dijk, 2013). The situation is not likely to be different in the context of informal care.

On the public policy side, the above threshold would mean to be able to provide access to specific forms of support services addressed at exhausted caregivers. Beyond the enormous

financial implications of such a measure, the main problem lies in the rarity of public policies based on self-report questionnaires. The acceptability of such measure would be low to impossible as decision makers would think (or could consider) that the rates would be exaggerated in order to have access to some services.

Therefore, the effort of building norms should cautiously be considered since it would also require a sample of informal caregivers covering the widest possible range of experiences in the population of informal caregivers. As an opening, we also want to mention the necessary hindsight that we must have on the implications that the creation of such thresholds may have. Creating categories within the population – and, therefore, labels – comes with a potential cost, stigma (Bianchi, Verkuilen, Brisson, Schonfeld, & Laurent, 2016; Link, 1982). Burnout research should not avoid such debate.

The goals of establishing norms should not overshadow the initial goal of focusing on the individual. Therefore, the effort and invested resources may be too big for a quite limited expected benefit (Sheldrick et al., 2015). Such resources could better be invested in keeping building up the understanding of informal caregiver burnout, and how it can lead to adverse (or beneficial) psychological consequences.

4.2.4 The necessary interrogation: burnoutS or Burnout?

The present work shows that adapting the concept of burnout to the context of informal care, although needing some adjustments, seems to be fruitful and echoes the experiences and problems informal caregiver face. This is in direct line with works pointing that burnout is not only work-related, but can occur in context where there is a valued involvement (Bianchi, Truchot, Laurent, Brisson, & Schonfeld, 2014; Schaufeli, Taris, & van Rhenen, 2008).

Chapter 1 and chapter 6, however, raise several questions. In chapter 1, we saw that being an informal caregiver represents a risk for family/parental and professional burnout. This suggests that there is some permeability between the spheres of life (e.g., professional burnout is not solely related to job stressors or resources). If it later guided the need to investigate informal caregiver burnout *per se*, it also points that the stressors (or demands) of some spheres of life influence outcomes from other spheres. In chapter 6, the results pointed that parents providing informal care were more at risk parental burnout than the others, when facing comorbidity or multiple children with special need. But it also implies that parents providing informal care are first and foremost parents like others, only facing a different situation. They experience the same determinants of parental burnout as the others.

In parallel to this, the multiplication of domains where burnout is adapted is striking: workers, athletes, students, parents, and now informal caregivers. This is only the tip of the iceberg because the spouses, friends, and volunteers may also be shown to be at risk of burnout, as long as others. So burnout appears to be adapted to every role the person is involved in and exposed to demands.

This adaptation to every context raises an evident question: if there is a burnout for every role or involvement, could it only be the same state with different perceived causes? There

would not be an addition of different “burnouts”, but rather one state that whose roots (and most of its consequences) are in one particular sphere of life. This question regarding the nature of burnout also relates to its measurement. In the empirical studies mentioned or included in the present work, most measures of burnout were “specific”, meaning that they addressed a specific target or role (parent, work, informal caregiver). Such specificity makes sense since the objective is to measure the difficulties faced in one of these contexts. But what do we measure when using such scales? The true context-exclusive exhaustion state or the perception that the exhaustion is caused by a certain context?

There is no clear answer to that question and some might argue that it relates to the debate between the overlap between burnout and depression (Bianchi et al., 2015). The point here is not to give a clear answer to the question of whether we should consider burnout as a unique state or a multiplicity of context-specific difficulties. The goal is to raise the awareness that the evolution of the burnout research will have to address such questions in the future. We provided evidence of the influence of informal caregiving on other roles (chapter 1) and highlighted that same determinants are playing in parental burnout for parents of both “typical” children and children with special issues. This evidence suggests that there may be an overlap between the different forms of burnout. But at the other end of this debate lies the observed distress that seems to originate only in one specific context and having a limited impact in other contexts. For example, in chapter 2, working at the same time as providing informal care can also be a protective factor for informal caregiver burnout because it appears to be more of a refuge than a source of additional stress. In burnout research, the association between parental and professional burnout has been shown to remain limited, suggesting that they are related, but only to a limited extent (Van Bakel, Van Engen, & Peters, 2018). Therefore, one sphere of life may not always affect another.

4.2.5 Implications of talking about “burnout” in informal care

If the adaptation of the concept of burnout to the context of informal care appears to be beneficial, using the term “burnout” has several implications beyond the concept itself. Calling what we observed in the different studies “burnout” appears to be a double-edged sword. Two key benefits and two important risks appear more clearly.

First, using the word burnout helps to raise the awareness on the issue we are currently facing. Burnout is a strong word that is also easily understandable, meaning that public powers can receive a clear message of what the “problem” is. The term of burnout for informal caregivers is already used in the vocabulary of some associations (mostly in the USA) but without a clear echo in the scientific literature. For now, the concept of burden is investigated but it is hardly relatable for people not familiar with the literature on the topic. Moving from the concept of burden, which is too heterogeneous and not easily understandable, to the concept of burnout would make it easier to raise awareness of this issue.

The second benefit relates to the normalization of burnout in the context of informal care. For now and despite a growing interest on informal caregiver burnout, it remains quite a taboo to be exhausted as a caregiver. Therefore, putting a clear word on their exhaustion,

telling them it is possible to be exhausted *due to caregiving* may help a recognition of people's difficulties and suffering and ease the use of existing support services. If caregivers are exhausted, they will recognize it more easily (or see it as a possibility). And even if they feel well, the possibility of burnout will make them aware of the need to use appropriate support services or to take care of themselves.

A third benefit of this would be to legitimize the risk of burnout in any life sphere. In the continuation of work, parental, athlete, and student burnout, considering informal caregiver burnout is only an additional support of the awareness on burnout as a whole. Both individuals and policy makers could therefore acknowledge that such issue could happen in almost every sphere where individuals have time and affective commitment.

One of the risks with the use of informal caregiver burnout is the risk to present the caregiving role as a "problem in the making" and that becoming a caregiver is likely to lead to problems, whether they are financial, social, physical, or psychological. Even if there are problems that caregiving might bring – and the present work contributes to building a better understanding of them – this is not solely what should be addressed when talking about informal care. The focus should be to understand how we could help informal caregivers if they need it, but also what are the determinants and consequences of their well-being and positive aspects of caregiving (Marino, Haley, & Roth, 2017).

The second and most important risk is that the term of burnout may focus the attention on the word itself and not on the problem and the issues at stake. There is such a strong debate storming for more than 30 years regarding burnout in occupational research and there is still no consensus regarding the psychopathological status of burnout (whether it should be acknowledged as a DSM or CIM disorder and whether it is different from depression). We do not wish a 30-year debate for the informal caregivers. There is an exhaustion of the caregivers, and research – whether it is on the subjective burden, burnout, or depression – needs to push toward new ways of helping them. Therefore, the present work will not be a manifesto aggressively promoting the use of the term "informal caregiver burnout", even if our evidence points in that it can exist. Rather, this work – and in particular Chapter 3 – was intended to provide a framework within which all the variables studied could be considered in relation to each other. Providing this framework allows the different approaches in the literature on caregiving to be combined and used together.

4.3 A diverse homogeneity: caregiving in all its shapes

4.3.1 A global focus

In the present work, there was no a priori focus on a particular group of caregivers. Every caregiver could be included in the investigation, regardless of the care-recipient's health or dependency issue. To date, most studies investigating (adverse) consequences of informal care are conducted in groups of individuals taking care of a relative with a specific health issue, and particularly in dementia/old age. The common idea that informal caregivers experience more health issues is therefore mostly based on this literature. For instance, the widely cited meta-analyses of Pinquart & Sörensen (Pinquart & Sörensen, 2003b, 2003a,

2005, 2006, 2007) focused on caregivers of frail elderly people, despite their titles stating “(informal) caregivers” with no specifications. Afterwards, research in this trend took the fruitful turn of expanding research to different possible cases of informal caregiving (Revenson et al., 2016). It opened to the investigation in cancer, chronic pain, cardiovascular disease, diabetes, and different kinds of acute and chronic diseases. However, in most cases, these studies still focused on one particular issue, or a group of them.

In the present project, the choice was made to consider informal caregivers as a group of people, without restrictions, in their “diverse homogeneity”. This approach is not completely new, since it has already been used in some previous studies (especially in population-based studies, e.g., Roth, Brown, Rhodes, & Haley, 2018), but it remains less common. This choice was made because it matched the objective of building up a global framework to address the common risk of informal caregivers to burn out. The context of caregiving is not seen as a barrier to this global framework, but rather as a determinant to consider.

This approach seems to oppose the willingness to consider the informal caregivers in their diversity and the subsequent specificity of each situation. Such willingness can be summed up by the “apples and oranges” idiom, giving the idea that there is no comparability between the different caregiving settings. However, there will always be diversity when investigating informal care. Even when taking the most homogeneous sample, diversity and heterogeneity will remain. This sample will be considered homogeneous, but only to a certain extent, as the caregiving settings will always be different, even if only slightly. In addition, controlling for this diversity by selecting a homogeneous group prior to conducting the study would lead to take into account potentially biased samples. Such samples would not provide a clear picture of what is at stake in the caregiving role since most of the determinants would be the same across the entire sample. Therefore, studies aiming at homogeneous sampling already do some diversity trade-off, even if the balance appears more toward homogeneity. When looking at the bigger picture, always conducting studies on a specific sample would impair the construction of a global framework applied to most of caregivers.

A counterargument to that would be to hypothesize the pointlessness of building a global framework since every situation is different. The problem is that there is no clear evidence of such an assumption. No study has ever been able to define the point where we can conclude that the presence (or absence) of differences is so great that they would make it impossible to compare caregivers in different settings. On the other end of this assumption is the idea that all situations are the same, which means that informal caregivers are considered blindly as a homogeneous group. Of course, there are many differences between caregiving situations, in several domains such as the kinship with the care-recipient, cause of caregiving, care-recipient’s symptomatology, or tasks to perform².

Therefore, a balance must be found between ignoring differences and viewing them as a too significant obstacle to designing a comprehensive framework for informal caregiver burnout. This work has taken small steps towards a more detailed consideration of the

² It should be noted that the diversity of work environments has not precluded the development of unified theories on professional burnout.

diversity of caregiving by highlighting significant differences. In Chapter 4, the inclusion of a measure of the dependency of the care-recipient was associated with emotional exhaustion and provided some indirect indicators of the caregiver's responsibility. In chapter 5, the received violence was also associated with higher emotional exhaustion and perpetrated violence. It also gave some information of what informal caregiver face when they provide informal care. Chapter 5 also addressed the differences between kinship relationships by showing that it had a limited impact on depression, subjective health, and perpetrated violence. Finally, in Chapter 6, caring for a child with comorbidity of having multiple children with special needs appeared to put at risk of parental burnout, but only to a limited extent. Overall, it appears that finer indicators of what caregivers actually experience in their role provide more information than mere labels.

The final objective is to be able to take into account (and control for) a maximum of elements contributing to this diversity. For example, one might argue that taking care of a child with diabetes is different from taking care to a spouse with Alzheimer's disease. Using the framework of "diverse homogeneity" does not mean that it is about the same situations, but rather that they have common features. The role of research is therefore to highlight and measure what makes the difference. It is necessary to focus on what is different in order to be able to focus on what is the same.

4.3.2 The "*within diversity*"

An additional element to this issue of diversity is also that there is a *within* diversity in caregivers: diversity or change over time. Unlike formal caregivers, informal caregivers are closely tied to the health status of one care-recipient. As it was shown (e.g., in chapters 4 and 6), objective factors such as the health issue is not the main predictor of deleterious outcomes, but it shapes what caregiving is by impacting the tasks that must be performed, the relationship with the care-recipient, the emotions at stake, and the appraisal of what caregiving represents for the caregiver. By considering all the informal caregivers together, the objective of the present work was also to have a global view of their experiences. But looking in details might also bring more information. It has been done in research on neurodegenerative diseases, where the evolution of the disease over time is critical and every step in informal caregiving brings its own implications. A future goal is to identify what makes situations different to see what aspect of that difference actually has an impact on the caregiver (e.g., the progression of the disease, the increase in tasks or symptoms, the caregiver's difficulties in adapting emotionally to that progression).

4.3.3 In the end, who are informal caregivers?

More broadly, the overall question remains as to who are the informal caregivers. As it was shown, the literature does not provide a homogeneous definition of informal caregiving. Some define it based on the tasks performed, others on the level of the care-recipient's dependency or on the time spent per week. This causes population-based studies to find different proportions of the population as providing informal care. Such inability to have a clear picture impairs the message sent to policy makers and is a barrier for a proper

consideration (and recognition) of informal caregivers. The need is therefore to provide a unified definition of what is informal care and who can be considered as such. In the present work, individuals only had to provide informal care to some extent, with no restriction on the dependency or the time spent in that activity. This led us to the observation that in the population, there is a lack of *self*-awareness of the caregiving role. Individuals providing informal care are often unaware that they are informal caregivers, even if they know what informal care means. Providing a clearer definition of informal caregiving would most likely help in raising that self-awareness and help individuals understand that they deserve particular attention.

5. Limitations of the present work

The present work is composed of different chapters, which all have their own limitations. These have individually been discussed. However, the combination of their specific limits also bears additional thinking.

First, the empirical part (chapters 4, 5, and 6) is only based on two different datasets. Chapters 4 and 5 used the same sample and the sixth used a different one. This is a limitation since the generalizability of the results may be affected, as there is little overlap between the investigations in the two samples and therefore no cross-validation. The choice to include only two different samples was made because of the willingness to use a non-specific sample of caregivers and the subsequent need to spend a significant amount of resources in order to have a sufficiently diversified sample. This trade-off may therefore lead to an absence of replication of the results, but to a more interesting sample.

Besides that, all of the included empirical works – whether in the meta-analysis or individual empirical studies – are cross-sectional and based on self-report questionnaires. For empirical studies, this choice was made because of the exploratory nature of this work. Its aim was to give solid first steps in order to continue to build knowledge based on them. Nevertheless, it has several implications that could be addressed in different ways in the future.

To tackle the cross-sectional nature of this work, several complementary investigations can be done. The best method would obviously be to conduct longitudinal studies during the course of caregiving, starting with the entry into it and ending only at the end of the caregiving process (e.g., due to better state, full-time institutionalization, or death). This would allow understanding the evolution and predictors of informal caregiver burnout over time. The main problem with this method is the starting point. In the vast majority of the caregiving situations, there is a clear diagnostic of the care-recipient's health problem at some point and it is assumed to be the starting point of informal caregiving by itself. In many cases, however, the caregiving role often starts earlier with a small set of tasks that will probably grow over time due to the progression of the health issue. Therefore, a first challenge would be to identify a common starting point where individuals can be considered informal caregivers. This would be easier on homogeneous groups of caregivers, taking care of individuals with comparable diseases.

To investigate the processes involved in the daily life in response to the emotion and stress regulation, intensive longitudinal design can be used, such as Ecological Momentary Assessments (EMA). When looking at the model presented in chapter 3, there are several feedback loops and coping strategies involved. If cross-sectional (or even regular longitudinal design) would provide interesting insights regarding these loops and moderation effects, the EMA would give a closer look at what is going on in smaller time frames and how it evolved at the moment.

Regarding the self-reported nature of the data, the need is to diversify the source of knowledge and this could be done in several ways, both quantitative and qualitative. For quantitative data, the investigation of the consequences of informal caregiver burnout could be done through medical records and health expenditure. Being able to correlate such results would allow understanding how informal caregiver burnout influences the objective health and health behaviors. The study of the determinants of caregiver burnout could also benefit from objective measures of the health problem of the care recipient, in order to ensure that the effective weight given to it is well-founded.

Regarding the concept of burnout, two different ways could extend the understanding of the phenomenon itself. The first is through biological correlates. In burnout research, biological measures often appear as a way to legitimize the concept of burnout (Danhof-Pont, van Veen, & Zitman, 2011). The possibility of matching subjective measures with objective biological markers would not only legitimize the concept, but the validity of the subjective evaluation. However, this would only address the physical side and not the experiential one. On this side, more in depth qualitative inquiries are necessary to get closer to the experience of informal caregivers experiencing burnout, and identify new factors involved in such distress. As it was discussed for the concept of burnout, qualitative interviews would also allow interrogating and challenging the tridimensional structure currently used.

On the side of the care-recipient, subjective and objective information could be useful to perform dyadic analyses such as those used with the actor partner interdependence model (APIM). Such data and analyses would allow to look at the interaction between informal caregiver's and care-recipient's variables, both in terms of determinants/predictors and of consequences.

A last limitation (or observation) is the important rate of females in the samplings. Whether it was in chapter 1 or chapter 4, 5, or 6, the samples were mainly made up of women (up to 87%). If there is indeed a gender imbalance in the caregiving population (Verbakel, Tamlaagronning, Winstone, Fjær, & Eikemo, 2017), this high percentage might have led to different results if the gender balance was different.

6. Implications

Although the present manuscript's scope is more in psychology, the implications of the present work extend beyond this field. These implications are diverse and provide additional information for different fields, and therefore different professionals. Two distinct sets of implications can be considered. The first relates to research and what needs to be further

investigated. The second is aimed at providing recommendations to professionals whose work is related to caregivers.

6.1 Implications for research

With respect to caregiver research, it is clear that focusing on burnout, and particularly emotional exhaustion, as a negative outcome of caregiving, is a good alternative to existing concepts. The informal caregiver burnout has yet to be defined in its dimensions, but it already seems clearer than the variety of definitions and assessments of subjective burden. Further studies should continue to examine the different issues and methods discussed in this manuscript in order to better understand how informal care can take a negative turn.

More specific to informal care psychology, the emotion regulation strategies at stake should be investigated in more depth. A deeper understanding of how informal caregiver cope with their role when it is experienced as a difficulty is a key feature to build individual interventions. In the same vein, understanding how and why informal caregivers use support and respite services could further be investigated. Such services are often presented as key-solutions in helping informal caregivers in need, but the evidence remains unclear regarding their benefit.

Along with research on the negative turn of caregiving, future studies should also investigate the positive aspects of caregiving. Such positive aspects are increasingly investigated but mainly remain confidential (Marino et al., 2017). In fact, considering the positive aspects does not neglect the negative aspects and would be an opportunity to explore how these positive and negative aspects interact one with the other one.

Public health research should aim at understanding the impact of public policies on the caregiver's well-being and its impact on maintaining favorable conditions for caregiving. For example, the legal recognition of informal caregiving will probably bring support to them, but also additional duties with a risk of doing worse than expected. Such investigation on the implications of policy making would allow to provide feedback on these policies and to nuance their effects in order to provide recommendations for future good practice and changes.

Research in medical studies should also investigate how the physician – patient – informal caregiver triad works. The impact of the physician – patient relationship is increasingly investigated, but the perspective of the informal caregiver often remains neglected or even deliberately excluded. Beyond the sole impact on the caregiver's well-being, a good quality in these interactions is probably a key to handling chronic disease through treatment compliance. In nursing and social care works, understanding how informal caregivers interact with these professionals on a regular basis would provide guidelines on how one can be a resource rather than a barrier to the other.

6.2 Recommendations

For public health systems, the presents work advocates for a better consideration of the informal caregivers and to find ways to support them. But this should not be done blindly and without sound information. A first observation is the relative limited role of objective stressors, at least in comparison to subjective ones. Both in chapter 2 and chapter 3, studies highlighted that objective stressors such as the dependency of the care-recipient or the accumulation of health issues do play a role, but are overshadowed by the perception individuals have of their own situation. Currently, most healthcare systems, *if* they provide some forms of support to caregivers in terms of psychological, financial, or respite support, condition these aids through the care-recipient's health status. Even if it gives a proxy of what the caregiver faces, it does not take into account what is the situation informal caregivers experience in their daily life. We are perfectly aware that the system is built around the patient for a reason, but introducing the caregiver's perspective (and difficulties) will enrich the evaluation of the care-recipient's health. Currently, promising progress is being made in that direction, such as the progressive integration of the Zarit Burden Interview in the new assessment of dependency in Belgium (BelRai).

For public policies, the highlight is on the risk of the system to collapse. The healthcare system enormously (and increasingly) relies on informal caregivers. A balance must therefore be found between these increasing demands and the resources available for them. The burning out of informal caregivers has consequences on caregivers themselves, but also on the care-recipients. Neglecting to support them properly would therefore lead to a vicious circle where informal caregivers are exhausted and have an increased risk of mental and physical health problems, therefore becoming unable (or unwilling) to take care of the care-recipients. The burden would therefore have to be borne by the health system, and this would be impossible in terms of financial, human and material resources.

For medical doctors and healthcare professionals in general, the present work advocates to be more aware of the strain informal caregivers may face. Several signs could appear, the main being the reported (emotional) exhaustion. It appears too limitative to intervene only on the patient's problem, as it is not the sole determinant of caregiver burnout. Other elements are at stake, such as the lack of financial and social resources, relational problems with the healthcare professionals, and the difficulties to have access to adequate support. A better awareness of the difficulties by professionals will help identify problematic situations and target the intervention on caregivers who are in need of help. More generally, the role of healthcare professionals is also to increase the self-awareness of the caregivers regarding their status. Because informal caregivers are often unaware that they are informal caregivers, they will less likely acknowledge that providing care can lead to personal problems, and therefore to ask for help.

Social workers, nurses, and home aids are at the frontlines of the caregiving system and therefore key observers of what is happening. They already have an important workload and it is not their duty to provide additional assistance to the informal caregivers. However, they

can act as sentinels and identify problematic situations in order to refer them to other health professionals or to provide information about existing support opportunities.

For patients and caregivers' associations, the present work advocates to keep building an awareness on informal care, as it is one of the ways to increase the funding for research and support for informal caregivers. As it was shown, tackling loneliness and increasing social support would probably help informal caregivers in difficult situations (chapters 2 and 4). The potential role of the associations in bringing individuals together therefore appears beneficial.

For clinical psychologists, the probability of encountering informal caregivers is high. The problem is that the recognition of the informal caregiver burnout (and more broadly, the exhaustion from caregiving) remains low. Informal caregivers experiencing burnout will most likely have difficulties acknowledging that their exhaustion may come from caregiving and giving time for themselves, even though they are the ones who need it most.

General conclusion

General conclusion

The present work aimed at bridging burnout and informal care, as burnout seemed to reflect the experience reported by caregivers. In that process, the summary of existing studies pointed that informal caregivers are more likely to experience burnout than non-caregivers, whether at work or in family care contexts. Considering informal caregiver burnout by itself then appeared as a promising way to capture the difficulties faced by informal caregivers, as well as being an alternative to existing concepts (such as subjective burden). The three dimensions of informal caregiver burnout provide encouraging keys to explore how caregiving can take a negative turn. Although they need to be further explored, they have the advantage of framing future thinking around three poles: caregiver exhaustion, the way the care-recipient is viewed and treated, and the positive aspects of being a caregiver. To frame the investigation of informal caregiver burnout, the Informal Caregiving Integrative Model was proposed. It synthesizes existing models in caregiver stress and professional burnout literature, and provides the first theorization of how informal caregiver should be investigated. This model highlights two main mediators between the determinants and informal caregiver burnout itself: the relationship with the care-recipient and the caregiver's appraisal of caregiving. Empirical studies of this model conducted in the present work have confirmed its relevance in capturing caregiver burnout. The appraisal of caregiving is a key predictor of informal caregiver burnout, as well as relationship quality with the care-recipient, to some extent. Different determinants were investigated such as emotional intelligence, allowing understanding why some caregivers experience less informal caregiver burnout than others. In terms of consequences, informal caregiver burnout appears to be associated with deleterious outcomes for both the caregiver and the care-recipient, due to an increased risk of perpetrating physical violence among the exhausted caregivers.

Overall, this work advocates for a better awareness of the difficulties informal caregivers may experience. Fortunately, informal caregiving does not necessarily mean caregiver burnout, but the risk is real and there is a need to address it as well. This work has put one rung on the ladder of a better understanding of this phenomenon, while trying to keep this approach in perspective. The implications and perspectives of this work are numerous and support the idea that informal caregiver burnout is not only a concern of research in psychology but could be of interest in every domain related to informal care. To conclude, informal caregiver burnout is a work in progress but already seems to be promising and contributes to a better understanding of the negative consequences of informal care.

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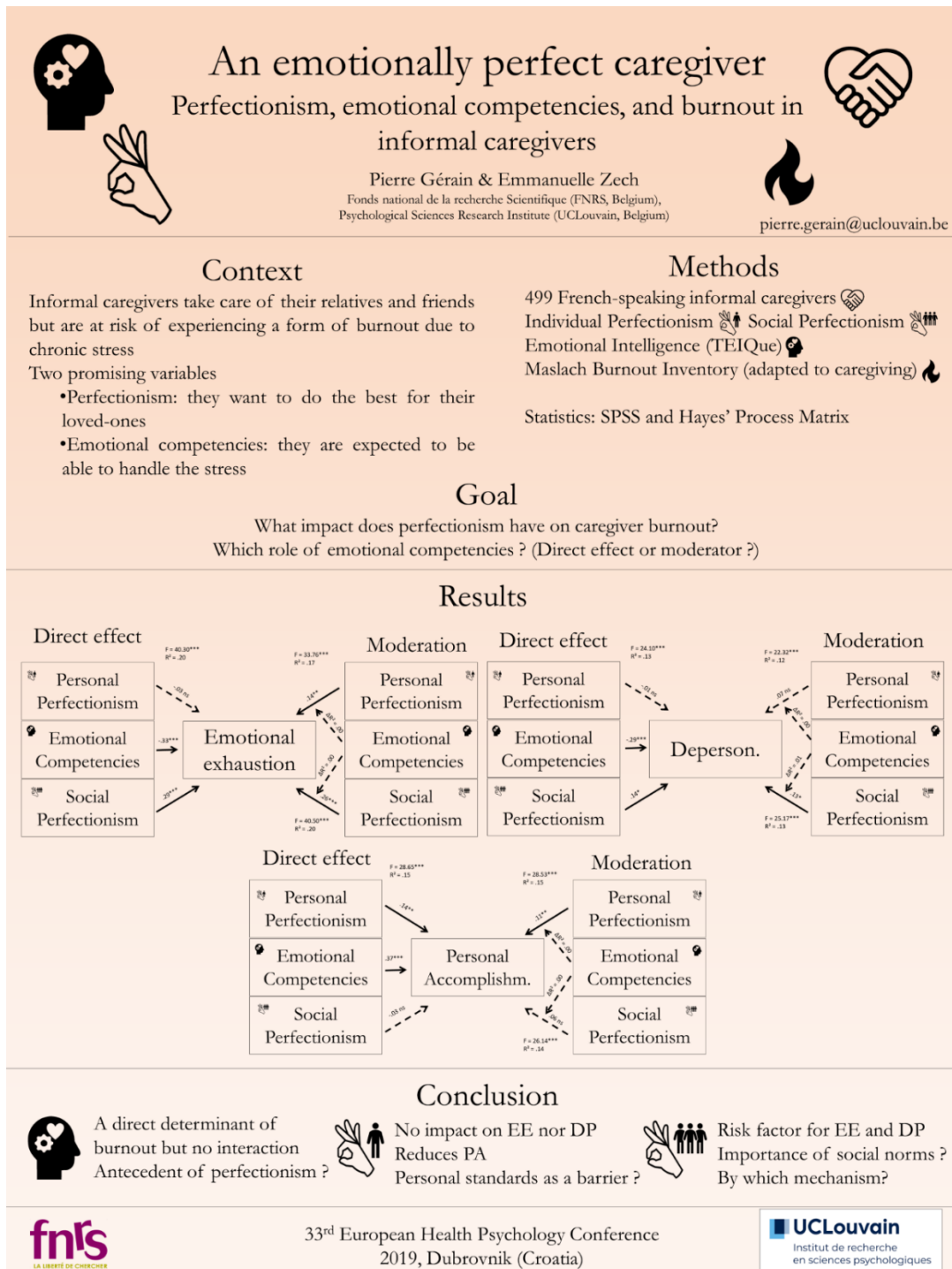
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Appendixes

Appendix 1 - Poster presented at the 33rd EHPS (2019)



Appendix 2 – The Maslach Burnout Intentory adapted to informal care

Dimension	Les questions qui suivent portent sur la personne que vous aidez. Cette personne sera référencée par le signe "(...)" dans les questions qui la concernent. Ces questions portent sur votre ressenti d'être un(e) aidant(e): Veuillez indiquer la fréquence à laquelle vous ressentez ce qui est décrit dans chacune des phrases ci-dessous.	Jamais	Quelquefois par année au moins	Une fois par mois au moins	Quelques fois par mois	Une fois par semaine	Quelques fois par semaine	Chaque jour
EE	1. Je me sens émotionnellement vidé(e) par l'aide que je fournis à (...).	0	1	2	3	4	5	6
EE	2. Je me sens à bout à la fin de ma journée quand j'ai aidé (...).	0	1	2	3	4	5	6
EE	3. Je me sens fatigué(e) lorsque je me lève le matin et que j'ai à faire face à une autre journée où je vais aider (...).	0	1	2	3	4	5	6
PA	4. Je peux facilement comprendre ce que (...) ressent.	0	1	2	3	4	5	6
DP	5. Je sens que je m'occupe de (...) de façon impersonnelle comme s'il/elle était un objet.	0	1	2	3	4	5	6
EE	6. Aider (...) tout au long de la journée me demande beaucoup d'efforts.	0	1	2	3	4	5	6
PA	7. Je m'occupe très efficacement des problèmes de (...).	0	1	2	3	4	5	6
EE	8. Je sens que je craque à cause de l'aide que je fournis à (...).	0	1	2	3	4	5	6
PA	9. J'ai l'impression, à travers l'aide que je lui fournis, d'avoir une influence positive sur (...).	0	1	2	3	4	5	6
DP	10. Je suis devenu(e) plus insensible à (...) depuis que je l'aide.	0	1	2	3	4	5	6
DP	11. Je crains que cette aide que je fournis ne m'endurcisse émotionnellement.	0	1	2	3	4	5	6
PA	12. Je me sens plein(e) d'énergie.	0	1	2	3	4	5	6
EE	13. Je me sens frustré(e) par l'aide que je fournis.	0	1	2	3	4	5	6
EE	14. Je sens que fournir cette aide est « trop dur ».	0	1	2	3	4	5	6
DP	15. Je ne me soucie pas vraiment de ce qui arrive à (...).	0	1	2	3	4	5	6
EE	16. Fournir de l'aide en contact direct avec (...) me stresse trop.	0	1	2	3	4	5	6
PA	17. J'arrive facilement à créer une atmosphère détendue avec (...).	0	1	2	3	4	5	6
PA	18. Je me sens plein(e) d'énergie positive lorsque j'ai été proche de (...).	0	1	2	3	4	5	6
PA	19. J'ai accompli beaucoup de choses qui en valent la peine en aidant (...).	0	1	2	3	4	5	6
EE	20. Je me sens au bout du rouleau.	0	1	2	3	4	5	6
PA	21. Dans l'aide que je fournis, je traite les problèmes émotionnels très calmement.	0	1	2	3	4	5	6
DP	22. J'ai l'impression que (...) me rend responsable de certains de ses problèmes.	0	1	2	3	4	5	6

Remerciements

Remerciements

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Ces quelques années Place cardinal Mercier ont aussi été pour moi une aventure humaine sans commune mesure dans ma courte vie. Il est difficile de résumer combien cette expérience m'a transformé et fait la personne que je suis aujourd'hui, mais il est certain qu'une grande partie de celle-ci a été définie par toi, Marie. Je sais être arrivé comme une tornade dans tes deux dernières années de thèse, construisant malgré nous un lien que nous savions si particulier dans un contexte et une temporalité qui l'étaient eux-mêmes. Il est impossible de résumer en quoi nos échanges, qu'ils soient verbaux ou non-verbaux, m'ont donné une force insoupçonnée. Grâce à toi, j'ai appris de moi-même et des rapports humains, même si a priori nous n'étions pas les mieux équipés pour un tel apprentissage. Ta confiance inconditionnelle et ta détermination à me faire aller toujours plus loin m'ont énormément apporté. A tes côtés, j'ai pu m'épanouir personnellement grâce à cette aventure, trouver mes marques, discuter, se poser au soleil, rire. Grandir, tout simplement. C'est un cadeau que je chérirai toute ma vie, même si tu n'en mesures probablement pas l'ampleur.

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Informal caregivers are people who provide (unpaid) assistance to a parent or relative because they cannot perform certain tasks themselves. Such care has been shown to be a rewarding role in many ways, but it also carries potential negative consequences. The investigation of these consequences remains, however, limited and conceptually unclear. In the present work, the concept of burnout is adapted to the context of informal care, in order to understand how these deleterious consequences can occur. This adaptation is made through syntheses of existing evidence, but also through theoretical and empirical research. By doing so, new insights are provided for the field of informal caregiver burnout research as well as a new framework for studying its determinants and consequences, which contributes to a better understanding of how informal care can take a deleterious turn and providing keys to intervene when necessary.

Les aidants sont des personnes qui apportent une aide informelle (non rémunérée) à un parent ou à un proche ne pouvant pas accomplir certaines tâches par eux-mêmes. Fournir ce type d'aide est gratifiant à bien des égards, mais cela peut aussi avoir des conséquences négatives. L'étude de ces conséquences reste toutefois limitée et peu claire sur le plan conceptuel. Ici, le concept de burnout est adapté au contexte d'aide informelle, afin de comprendre comment ces conséquences néfastes peuvent survenir. Cette adaptation se fait par le biais de synthèses des recherches existantes, mais aussi par de nouvelles recherches théoriques et empiriques. Ce faisant, de nouvelles perspectives sont amenées dans la recherche sur l'épuisement des aidants ainsi qu'un nouveau cadre pour étudier ses déterminants et ses conséquences, ce qui contribue à mieux comprendre pourquoi les soins informels peuvent prendre une tournure délétère et fournit des clés pour intervenir si cela s'avère nécessaire.



Pierre Gérard obtained a Master in Psychological Sciences at UCLouvain in 2016. Right after, he started as a teaching assistant and then received a fellowship from the National Funds for Scientific Research (FRESH, F.R.S – FNRS). Under the supervision of Emmanuelle Zech, he investigates the potential impact of providing informal care on well-being. By adapting burnout to informal care, they explored some of the psychological processes involved in such impact, as well as their determinants and consequences.