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Informal caregivers' health: a literature review

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Summary

Switzerland is facing a shortage of healthcare professionals that, according to experts, will worsen in the coming years due to the ageing of the population and the rise in chronic diseases. In this context, informal caregiving is more important than ever for assuring the well-being of loved ones. However, informal caregivers may themselves face health issues that are often ignored. The aim of this literature review is to highlight the determinants that are associated with informal caregivers' well-being, quality of life, and burden to elaborate a baseline questionnaire for a prospective national cohort of informal caregivers.

The literature review focused on informal caregivers' quality of life, well-being, and burden as outcomes and was conducted between October 2021 and May 2022 using online databases (PubMed and CINAHL) targeting reviews and meta-analyses published between 2010 and 2021 in English or French that have an available abstract. A total of 847 references were selected. After removing duplicates and references published before 2010, 777 documents were assessed based on the abstract. References that reported results of a review of any type about informal caregivers' well-being or quality of life or burden or any dimensions related to those constructs (e.g., depression) and that included an abstract with a method section were selected. After the removal of 502 references, the remaining 275 items were assessed based on the full text and only reviews about the appropriated outcomes that had an abstract and a method section conducted in Europe and/or North America and/or Australia and/or New Zealand were selected. At the end of the selection process, a total of 47 references were chosen in this literature review. References specific to COVID-19 were excluded because we believe that the pandemic likely aggravated some issues experienced by informal caregivers and induced some issues specific to the crisis. Thus, such references would not be representative of the overall experience of informal caregivers.

The literature review's results showed that psychosocial factors regarding informal caregivers' health as identified by the considered outcomes have been widely investigated between 2010 and 2021. Among the aspects considered, social support, coping strategies, psychological health, valued activities, and employment were the most cited as factors affecting informal caregivers' health as identified by the considered outcomes. However, cognitive, functional, behavioural, and neuro-(psychiatric) symptoms of the loved one also affected informal caregivers' health considerably. Contextual factors, such as receiving information, formal support from healthcare professionals, financial difficulties, respite, also seemed to be of great importance regarding these outcomes.

1 Introduction

1.1 Swiss COhort of Healthcare Professionals and Informal CAregivers (SCOHPICA)

This literature review is part of the Swiss COhort of Healthcare Professionals and Informal CAregivers (SCOHPICA), a project conducted in collaboration by Unisanté and La Source School of Nursing, HES-SO.

The objectives of SCOHPICA are: (1) to better understand the trajectories of healthcare professionals, identify the conditions and situations that impact their intention to stay in/leave the profession, and well-being, as well as explore the links between the latter and the trajectories of healthcare professionals; and (2) to identify determinants of informal caregivers' well-being, to better understand the factors influencing their trajectories, monitor the evolution of their trajectories and link them to well-being.

To achieve this objective and to overcome the lack of longitudinal data on Swiss subjects, SCOHPICA comprises two national prospective Swiss cohorts of two of the important stakeholders of the healthcare system: one cohort of healthcare professionals of any professional domain that have direct contact with the patient population and one of informal caregivers.

Quantitative data will be collected for both cohorts through two independent series of questionnaires, and a selection of participants will be invited to an interview to collect qualitative data. Thus, this literature review on the well-being, quality of life, and burden of informal caregivers constitutes the basis upon which the baseline questionnaire will be defined.

1.2 Context

1.2.1 Who are the informal caregivers?

A crucial first step was to define the term *informal caregivers*. There are different elements to consider when investigating the reality of informal caregivers. We must address these aspects explicitly to define this population, as some people, although they do provide care to a relative or a friend, do not self-identify as informal caregivers.

Thus, in the SCOHPICA project, we use the definition of Promotion Santé Suisse in 2019(1):

> "Informal caregivers are persons of all ages who take care or support someone with whom they have a relationship (e.g., family, spouse, friends). They aid with activities of daily living (ADLs) when their relative or friend is no longer able to perform them. This dependence can be caused by a physical or psychological

> disease, disability, or fragility. Informal caregivers provide this support on a long-term basis and are involved to a large extent. [our translation]" (1) (p.6)

This definition was applied because it is the most comprehensive and inclusive one. First, this definition takes into consideration the (sometimes) involuntary nature of informal caregiving; although some individuals may provide this support voluntarily to their loved one, others may feel obliged to do so out of moral conviction or family pressure. Second, this definition allows for a precise identification of the frequency of support (i.e., "daily")(2). Moreover, we intend to be inclusive regarding the health conditions that lead to the dependence of the care recipient by including both physical and psychological illnesses and disabilities. Finally, this definition specifies that informal caregivers are widely involved, which is crucial when investigating their health[a].

Informal caregivers provide various types of assistance to their loved one. They most often take responsibility for financial and administrative tasks (38%), followed by planning activities (23%), and daily help and housework (23%). Informal caregivers also provide moral and social support (21%) to their loved ones(3).

1.2.2 Informal caregivers in Switzerland

According to the Swiss Federal Statistical Office, 13% of the population (mostly 75 years and older) received informal help in 2017. Most Swiss informal caregivers are between 45 and 64 years old(4). It is also essential to mention that 54% of informal caregivers are women(5).

Informal caregiving for adults represents one-third of unpaid care work, which is the "(...) act of caring - whether paid or unpaid - for one or more people to meet their physical, psychological, emotional and personal development needs [our translation]"(6) (p.34). When done in private areas, care work is unpaid and invisible to society (6, 7). For the most part, women take on this responsibility(6). This gender repartition of unpaid care work is explained in part by the traditional societal model of men working and earning money and women taking care of the household(8). Moreover, the qualities needed for this work (i.e., caring for others) are considered naturally feminine, which contributes to its social devaluation(9).

Taking on the role of informal caregiver has financial consequences. Indeed, people who provide informal help often reduce or even stop their professional activity; thus, this represents a loss of earnings(10). However, two out of three informal caregivers maintain a professional activity(11) which entails other challenges in reconciling this activity with informal caregiving(10). A gender perspective is thus relevant here as the majority of informal caregivers are women and the responsibility of caregiving leads to equality issues in the world of work.

Moreover, 8% of adolescents (mostly girls) also take on the role of caregiver in case of illness in the family. Being confronted with adult responsibilities in this manner affects adolescents' schooling as well as their well-being(12). However, despite the importance of this issue, the SCOHPICA project focuses on adult informal caregivers due to ethical and logistical considerations. Indeed,

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[a] Outcomes considered for this literature review were well-being, quality of life and burden and will be summarised as "health" throughout this Raisons de Santé

participants under the age of 18 would need parents' or legal representatives' consent, which makes recruitment rather laborious.

1.2.3 The crucial role of informal caregivers in the Swiss health system

The Swiss health system has been facing a shortage of health professionals. This phenomenon will be further aggravated by the increasing prevalence of chronic diseases and the ageing of the population. Indeed, both of these factors result in a rise in the number of people in need of regular, even daily, formal and informal care(2).

According to experts, by 2029, more care and support staff will be needed(13). In 2016, one-third of physicians of all ages, one-third of care staff under 35 years of age, and 55% of care staff aged over 50 were no longer working in health services(14). Indeed, the arduousness of the work and the difficulty of reconciling private and professional life leads to early retirement from nursing(15). A vicious circle then persists: retirements, early exits from the profession, and the lack of trained personnel to ensure continuity(13) result in significant physical and psychological exhaustion among the remaining healthcare professionals who, in turn, are at higher risk of leaving their profession.

In response to the shortage of healthcare professionals, Switzerland has been recruiting healthcare professionals from abroad. However, this reliance on other countries has shown its limits; not only does the international recruitment of healthcare professionals deprive other countries of valuable human resources, but it also does not encourage the Swiss health system to improve the working conditions of healthcare professions(2). Furthermore, as a member of the World Health Organization, Switzerland has adopted a global code of practice that aims to reduce international dependency on the recruitment of healthcare professionals(16).

In such a context, informal caregivers are an important source of support for their loved ones. Indeed, the lack of formal resources leads to an increased need for informal resources, and informal caregivers play a key role in keeping people in need of daily care and support at home. As observed during the COVID-19 pandemic, informal caregivers act as "shock absorbers [our translation]"(2) (p.36) when the Swiss health system is no longer able to care for the sick(2). Thus, even if data on the health status of informal caregivers are still lacking, the implementation of effective health and social policies seems fundamental to preserving the health of informal caregivers(17).

Despite the importance of informal help and the presence of various recognition initiatives from the Swiss Confederation, informal caregivers struggle to find recognition in either the eyes of healthcare professionals or in their surroundings(2).

1.2.4 Informal caregivers' health

In Europe and Switzerland, informal caregiving is associated with worse perceived health(3, 17). Informal caregivers report suffering from problems affecting both their somatic and psychological health(3). Moreover, caring for a loved one can have significant consequences on their working activity; informal caregivers often have to reduce or stop their paid work to devote themselves to caring for a loved one, resulting in economic hardship. Informal caregivers often also experience family tensions(7).

According to salutogenic approaches, if it is necessary to assess the deleterious factors of caregiving on individuals' health, one should not overlook the positive consequences of this activity to promote their health. Indeed, the assistance provided to the dependent person allows them to acquire useful knowledge and provides a sense of pride to the informal caregiver(3).

As the health of informal caregivers influences the quality of informal care provided to care recipients(2), it is fundamental to better understand the protective and deleterious factors to their well-being and quality of life.

1.3 Aims

This literature review aims to highlight the factors positively and negatively associated with informal caregivers' well-being, quality of life, and subjective and objective burden "a multidimensional response to the negative appraisal and perceived stress resulting from taking care of an ill individual"(18) (p.846) experienced by informal caregivers.

Based on this literature review, a baseline questionnaire will be developed for the informal caregiver cohort included in the SCOHPICA project.

The objective of this cohort of informal caregivers included in the SCOHPICA project aims to: (1) monitor the evolution of informal caregivers' well-being as well as identify and understand its important determinants; (2) better understand the factors influencing their trajectories; and (3) link their trajectories and their well-being. The communication of the results from this cohort to decision-makers of health policies in the health system is a key strength of the SCOHPICA approach.

2 Methods

2.1 Search strategy

The aim of the literature review was to answer the following question: What are the positive and negative determinants of well-being, quality of life, and subjective and objective burden of informal caregivers?

Online databases (PubMed and CINAHL) were searched between October 2021 and December 2021. This search targeted reviews and meta-analyses published between 2010 and 2021 in English or French with an available abstract. Commentaries, letters, posters, reports, and theses were excluded from this search, as they do not contain enough details about the methodology. In addition, articles specifically related to the COVID-19 pandemic were also excluded, as they focus on issues specific to this exceptional situation and are thus not representative of the experience of informal caregivers.

2.2 Selection of references

The eligibility criteria for reviews, systematic reviews, and meta-analyses were as follows:

- The outcome should be discussed/analysed in relation to the well-being, quality of life, or subjective or objective burden of informal caregivers.
- Articles must report the results of a review of any type (e.g., systematic review, meta-analysis, overview or review of reviews, scoping review, mixed reviews) and include an abstract and a methods section (even if these sections are not identified by a title).
- Literature reviews should include studies conducted in Europe and/or North America and/or Australia and/or New Zealand, as health system issues are comparable across developed societies.
- Qualitative data must be collected via interviews, focus groups, and commentary analysis only.
- References about the COVID-19 pandemic specifically were excluded, as we thought it would depict their experience during the pandemic rather than their general experience.

References selected according to the eligibility criteria mentioned above were then screened on title and abstract and then assessed on full texts (see Figure 1). References that satisfied all criteria above and discussed the determinants of the outcome were selected.

For the sake of conciseness, references containing determinants already extracted were removed.

2.3 Data extraction

Relevant terms and expressions for the identification of the main determinants of well-being, quality of life, and the subjective and objective burden of informal caregivers were extracted following an extraction grid developed by the SCOHPICA team.

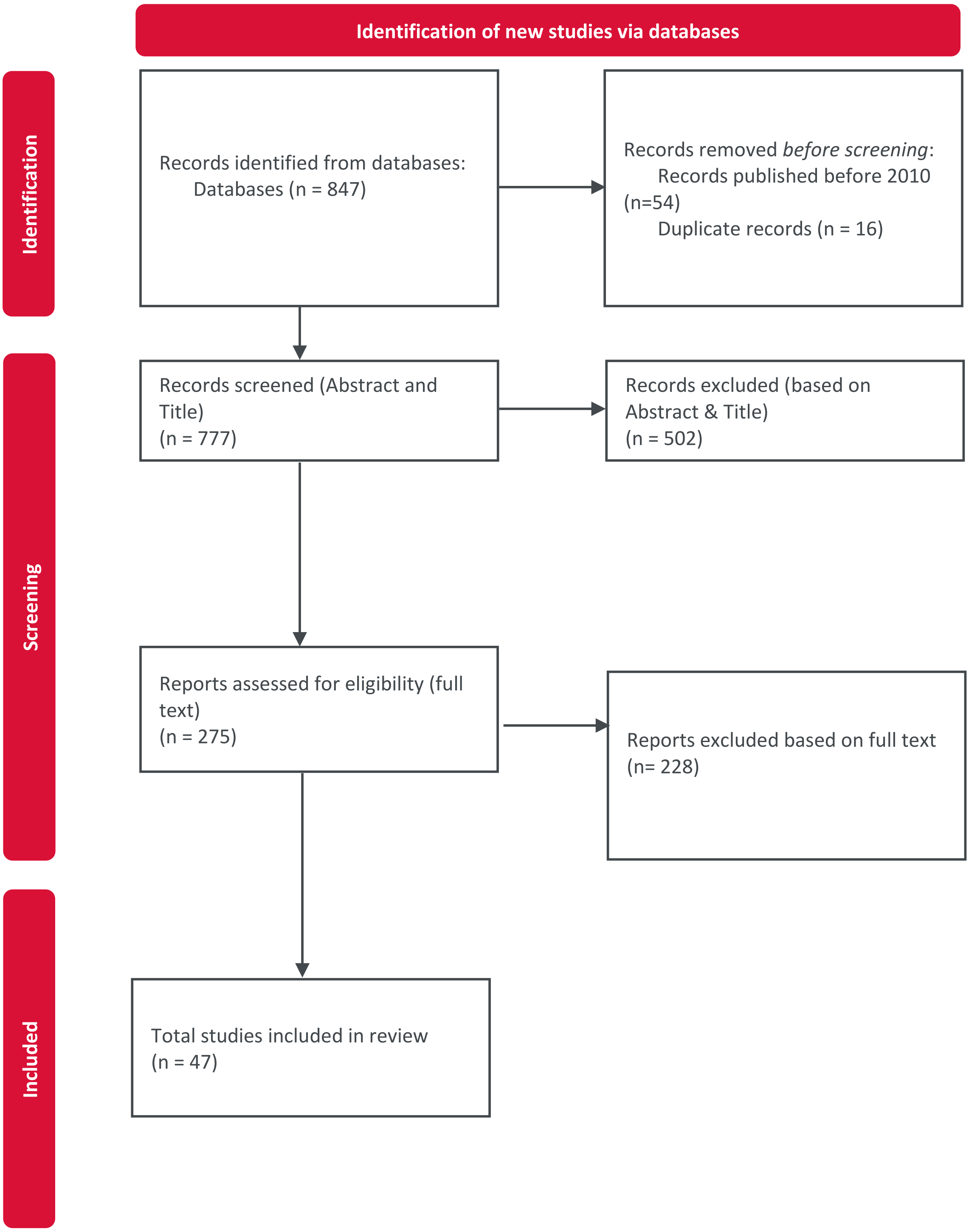
The extraction grid contained the following sections:

- General information: type of publication (systematic review or original article), number of references included (for literature reviews), and objectives.
- Methods: methodology used (qualitative, quantitative, mixed), country, type of help provided, medical conditions or pathology of the person helped, existence of a measure of quality (e.g., Critical Appraisal Skills Programme(19), etc.) of the articles included in systematic reviews.
- Results: The presence or absence of determinants of well-being/quality of life/objective or subjective burden were extracted by category (e.g., sociodemographic determinants of informal caregivers and loved ones, determinants related to the disease, informal caregivers’ and loved ones’ psychosocial determinants, contextual determinants, determinants categorised as “other”) and were classified depending on the direction of their relations (statistically significantly positive or negative or no association) with the outcome. For systematic reviews with narrative summaries, only the presence or absence of the association was noted, without noting the strength of the association, which is most often not mentioned.
- Information on the authors' conclusions or proposals: suggestions for improvement or interventions were noted.
- The direction of the associations was determined by the majority of the selected references.

3 Results

3.1 Selected references

Figure 1 **Flow diagram of studies included in the review**



3.2 Overview of included references

Table 1 Overview of included reviews

First author (year)	Type of review	Aim(s)	Period	Number of reviews included	Countries/ Regions included	Disease	Relationship	Outcome	Quality appraisal
Cochrane (2021)	Systematic review	“Objective: Informal caregivers of people with lung cancer often experience a substantial care burden and associated negative consequences due to the often-contracted course of the disease. The objective of this review was to systematically examine the evidence on the factors associated with lung cancer caregiver distress.” (P.1246)	Up to 2020	30	USA (21); Asia (4); South America (1); Europe (1)	Cancer	Multiple	Distress	Yes
Gonçalves (2021)	Systematic review	“This systematic review aimed to evaluate the representativeness of depression, anxiety, and burden in these caregivers and assess their quality of life.” (p.1)	2017-2020	6	Europe (5); Canada, Australia, USA (1)	Dravet Syndrome	Mothers (Majority)	Frequency of depression, anxiety, and burden	Yes
Hajek (2021)	Systematic review	“Several empirical studies have shown an association between informal care-giving for adults and loneliness or social isolation. Nevertheless, a systematic review is lacking synthesizing studies which have investigated these aforementioned associations. Therefore, our purpose was to give an overview of the existing evidence from observational studies.” (p.1)	Unspecified	12	North America (5); Europe (7)	Multiple	Multiple	Loneliness; social isolation	Yes

First author (year)	Type of review	Aim(s)	Period	Number of reviews included	Countries/ Regions included	Disease	Relationship	Outcome	Quality appraisal
McKenna (2021)	Systematic review	"Aim: In this systematic review we aimed to: (1) examine the origins and conceptualizations of resilience; (2) summarize current resilience measurement tools; and (3) synthesize correlates, predictors and outcomes of resilience in family care- givers of persons with CNCs." (p.1)	Up to 2020	50	Europe; North America; Asia; South America; Australia	Chronic neurological conditions	Multiple	Resilience	No
Sabo (2021)	Integrative review	"(…) to explore the self-care needs and practices of older adult caregivers." (p.570)	2010-2020	15	Brazil; Canada; Spain; UK; USA	Ageing	Multiple	Self-care needs and practices	Yes
Wiegelmann (2021)	Systematic review	"(…) to conduct a systematic review of intervention content, effectiveness and subgroup differentiation of mental health interventions for informal caregivers of persons with dementia living at home." (p.1)	2009-2018	48	USA; UK; Germany; China	Dementia	Unspecified	Burden, depression, QOL (Quality of life), well-being, anxiety, stress, grief, mood	Yes
Zygouri (2021)	Systematic review	"(…) to identify how gender relates to informal carers' experiences of providing care for people aged 60 years and over with mental and physical health needs by synthesising the available empirical data published between 2000 to 2020." (p.1)	2000-2020	16	USA (10); Australia (1); Sweden (1); Canada (2); Japan (2); China (1); Poland (1); Mexico (1); Israel (1); Portugal (1)	Ageing	Family	Impact of gender on caregiving	Yes

First author (year)	Type of review	Aim(s)	Period	Number of reviews included	Countries/ Regions included	Disease	Relationship	Outcome	Quality appraisal
Bressan (2020)	Systematic review	“The aim of this mixed-method systematic review was to identify and synthetize the existing literature on the needs of family caregivers of people with dementia at home.” (p.1942)	2009-2019	16	USA (12); Canada (4); Australia (3); The Netherlands (3); UK (3); Ireland (2); Italy (2); Japan (2); Brazil (1); Singapore (1); Thailand (1)	Alzheimer (majority)	Majority of spouses	Needs	Yes
Dombestein (2020)	Integrative review	“To describe and explore empirical studies of care- givers’ motivation from the perspective of self-determination theory.” (p.267)	2001-2017	10	Singapore (1); USA (4); Canada (2); Belgium (3)	Long-term illness	Multiple	Motivation	Yes
Kim (2020)	Meta-ethnographic review	“Aims: This study aimed to integrate and synthesize the findings of qualitative studies on family members’ experiences of caring for patients with heart failure.” (p.473)	2009-2019	12	USA; Sweden; Italy; UK; England; Australia; Iran (1)	Heart failure	Multiple	Experiences of caring	Yes
Kokorelias (2020)	Meta-synthesis	“This review aimed to characterise stroke caregivers’ experiences and the impact of these experiences on their health and well-being.” (p.325)	Until November 2018	39	USA & UK (majority)	Stroke	Multiple	Health and well-being	Yes

First author (year)	Type of review	Aim(s)	Period	Number of reviews included	Countries/ Regions included	Disease	Relationship	Outcome	Quality appraisal
Lindt (2020)	Systematic review	“This literature review aims to synthesize the literature on the common determinants of caregiver burden in Western countries, to help ensure future continuation of informal care in the home context, and to improve or sustain the quality of life of caregivers and patients alike.” (p.1)	2013-2019	17	Western countries	Multiple	Multiple	Burden	Yes
Mohsenizadeh (2020)	Integrative review	“This integrative review aims to identify, describe, and synthesize the results of current available research focused on the burdens of IBDs on family caregiver.” (p.1)	2000-2019	16	Europe; USA; China (1); Australia; Switzerland	Inflammatory bowel disease	Family	Burden	Yes
Ochoa (2020)	Systematic review	“Informal caregiving may likely increase as the number of cancer survivors grows. Caregiving responsibilities can impact caregivers’ quality of life (QOL). Understanding the current state of the science regarding caregiving QOL could help inform future research and intervention development.” (p.220)	2007-2017	60	USA	Cancer	Multiple	Quality of life	Yes

First author (year)	Type of review	Aim(s)	Period	Number of reviews included	Countries/ Regions included	Disease	Relationship	Outcome	Quality appraisal
Thompson (2020)	Systematic review	"This review addressed 4 central questions: 1) What social support do SMW [sexual minority women] with cancer receive from partners/caregivers? 2) What effect does cancer have on intimate partnerships or caregiving relationships of SMW with cancer? 3) What effects does cancer have on partners/caregivers of SMW with cancer? 4) What interventions exist to support partners/caregivers of SMW or to strengthen the patient-caregiver relationship?" (p.1)	Unspecified	18	USA (12); Canada (1); UK (2)	Cancer	Multiple	Quality of life; social support	No
Xiong (2020)	Systematic review	"We synthesized the evidence on sex and gender distinctions in: (1) the caregiving burden and (2) the impact of caregiving on the physical and mental health of family caregivers of PWD." (p.1)	2007-2019	22	Turkey (1); Canada (2); Spain (2); USA (3); Cyprus (1); Finland (2); Norway (1); Switzerland (1); UK (1); Japan (1); India (1)	Dementia	Family	Burden	Yes

First author (year)	Type of review	Aim(s)	Period	Number of reviews included	Countries/ Regions included	Disease	Relationship	Outcome	Quality appraisal
Amer Nordin (2019)	Systematic review	“Caregiving outcomes have often been reported in terms of care recipients of single disease, rather than multiple health conditions. A systematic review was conducted to outline caregiving health outcomes and its association with care recipient multimorbidity for informal caregivers of older adults.” (p.611)	2000-2017 (except one from 1989)	19	USA (6); France; Canada (4); The Netherlands; China (2); Australia; Japan (2); Unknown (2)	Multimorbidity	Multiple	Physical, psychological, or mental health	Yes
Bjørnnes (2019)	Systematic review	“To provide a comprehensive synthesis of informal caregivers’ experiences of caring for a significant other following discharge from cardiac surgery.” (p.1)	1990-2018	43	North Europe (29); Western Europe (9)	After cardiac surgery	Majority of spouses	Experiences of caring	Yes
Del-Pino-Casado (2019)	Systematic review and meta-analysis	“The main aim of this study was to systematically review current evidence on the association between SOC, burden and mental health outcomes in informal carers.” (p.14)	1994-2017	35	Sweden (4); USA (9); Belgium (1); Germany (1); Finland (2); Poland (2); UK (2); Greece (1); Norway (1); Latin America (3); Asia (7); Unknown (2)	Multiple	Unspecified	Sense of coherence; burden; mental health	Yes
Fauziah (2019)	Literature review	“The study aimed to identify the contradictions, similarity, and uncovered factors related to depressive symptoms scores among family caregivers through comparison of examined variables.” (p.1380)	December 1988 to March 2016	16	USA (4); Iran (1); Hong-Kong (2); China (1); Korea (1); Canada (2); Israel (1); The Netherlands (2); Australia (1); Finland (1)	Stroke	Family	Depressive symptoms	No

First author (year)	Type of review	Aim(s)	Period	Number of reviews included	Countries/ Regions included	Disease	Relationship	Outcome	Quality appraisal
Gumber (2019)	Systematic review	“The study aimed to undertake a literature review of studies conducted in the UK that quantify the direct or indirect impact of Parkinson’s on people with the condition, their families, and society in terms of out-of-pocket payments and financial consequences.” (p.321)	Unspecified	38	UK	Parkinson	Spouses (majority)	Quality of life	Yes
Hodson (2019)	Integrative review	“The unique needs of caregivers of those with advanced heart failure (HF) are not effectively being met, and reports of physical and mental health challenges are common. The objective is to identify the current state of the literature related to family caregivers of persons with advanced HF, ascertain gaps that require further exploration, and provide preliminary practice recommendations based on the results.” (p.720)	2000-2017	24	USA; UK; Sweden; The Netherlands; Canada; Australia	Heart failure	Multiple	Experience	Yes

First author (year)	Type of review	Aim(s)	Period	Number of reviews included	Countries/ Regions included	Disease	Relationship	Outcome	Quality appraisal
Jellema (2019)	Scoping review	“Purpose: Map the literature about valued activities and informal caregiving post stroke and determine the nature, extent, and consequences of caregivers’ activity changes.” (p.2223)	2005-2016	30	High-income western countries (except 3 from India, Brazil, South Africa)	Stroke	Multiple	Activities changes	Yes
Lacerda (2019)	Integrative review	“Identify the occurrence of depressive symptoms in family caregivers of patients with heart failure and the correlation of other variables with depressive symptoms.” (p.1)	2004-2016	26	USA (14); Canada (2); Europe (10)	Heart failure	Multiple	Depressive symptoms	Yes
Quinn (2019)	Systematic review	“The aim of this systematic review was to explore how positive aspects of caregiving (PAC) affects the well-being of caregivers of people with dementia.” (p.584)	1989-2017	53	Mostly from America and Canada	Dementia	Spouses	Well-being	Yes
Waligora (2019)	Systematic review	“To synthesize evidence on the self-care needs and behaviors of Alzheimer’s and dementia ICGs and its research implications.” (p.565)	Since 2000	29	USA (15); Taiwan (1); Canada (5); Spain (3); Australia (2); Sweden (1); Brazil (1); The Netherlands (1)	Dementia	Multiple	Self-care needs	Yes

First author (year)	Type of review	Aim(s)	Period	Number of reviews included	Countries/ Regions included	Disease	Relationship	Outcome	Quality appraisal
Watson (2019)	Systematic review	"The purpose of this review was to identify factors that are associated with depression and anxiety in family carers of PWD." (p.597)	Since 2000	26	USA (18); Canada (1); Switzerland (1); Taiwan (1); Finland (1); Spain (1); Norway (1); Poland (1); The Netherlands (1)	Cancer	Immediate family	Depression; anxiety	No
Grant (2018)	Integrative review	"The purpose of this review was to examine and synthesize recent literature regarding problems experienced by informal caregivers when providing care for individuals with heart failure in the home." (p.41)	2000-2016	37	Canada (2); USA (8); Europe (8); Iran (3); Australia (1)	Heart failure	Spouses (majority)	Problems	Yes
Moral-Fernández (2018)	Meta-synthesis	"The aim of this study is to explore the initial experiences, during the first year of care, of persons who suddenly become caregivers for elderly dependent relatives." (p.1)	Unspecified	19	USA; Canada; South America; Europe; Asia; Australia	Ageing	Wives or daughters (majority)	Initial experiences	Yes
Starks (2018)	Literature review	"To identify factors affecting the quality of life (QOL) of African American women (AAW) family caregivers of individuals with kidney failure." (p.467)	2008-2018	14	USA	Kidney failure	Family	Quality of life	No

First author (year)	Type of review	Aim(s)	Period	Number of reviews included	Countries/ Regions included	Disease	Relationship	Outcome	Quality appraisal
Yu (2018)	Integrative review	"To conduct a systematic critical review of research on the nature of positive aspects of caregiving, and the factors predicting this phenomenon among family caregivers of dementia patients, with the ultimate purpose of gaining insights to explain how and why it emerges." (p.1)	1989-2015	41	USA (19); Europe (7); UK (3); Canada (3); Taiwan (1); Hong Kong (3); Singapore (3); Nigeria (1)	Dementia	Multiple	Positive aspects of caregiving	Yes
Nicholas Dionne-Odom (2017)	Literature review	"(…) the aims of this review were to summarize (1) how caregivers influence patients, (2) the consequences of HF for caregivers, and (3) interventions directed at HF caregivers." (p.543)	1994-2015	120	USA (67); Europe (except UK) (21); UK (16); Iran (6); Canada (6); Australia (2); Turkey (1); Taiwan (1)	Heart failure	Multiple	Experiences	No
Applebaum (2016)	Systematic review	"The purpose of this systematic review was to synthesize the literature on existential distress experienced by these informal caregivers to inform the development of psychotherapeutic interventions for this population." (p.232)	Unspecified	35	Sweden (7); UK (3); Canada (4); Australia (3); USA (10); England (2); Germany (2); Europe (1); Austria (1); Denmark (1); Belgium (1)	Brain tumours	Multiple	Existential distress	No

First author (year)	Type of review	Aim(s)	Period	Number of reviews included	Countries/ Regions included	Disease	Relationship	Outcome	Quality appraisal
Bergin (2016)	Systematic review	“This systematic review seeks to provide evidence-based recommendations to enable healthcare professionals to support carers appropriately to maintain their wellbeing and to continue providing care at home.” (p.518)	2004-2014	23	Australia (5); Canada (2); Holland (1); Italy (4); Sweden (2); UK (4); USA (3); Multiple (2)	Motor neurone disease	Multiple	Well-being	Yes
Caceres (2016)	Integrative review	“The purpose of this integrative review is to: (1) identify the characteristics of family caregivers of patients with frontotemporal dementia, (2) explore the impact of providing care on family caregivers’ health and well-being, and (3) identify coping strategies used by family caregivers.” (p.71)	1984-2015	11	UK (2); Italy; Germany; USA (3); USA and Canada (4)	Dementia	Family	Health and well-being	Yes
Cicolini (2016)	Integrative review	“Objective: The purpose of this review is to understand the experience of caregivers of patients with left ventricular assist device (LVAD) and to evaluate how health professionals can support them properly.” (p.135)	Unspecified	15	Europe (6); North America (9)	Left Ventricular Assist Device	NR	Experiences	Yes
Topcu (2016)	Meta-synthesis	“(…) to improve the conceptual understanding of the experiences of MS carers and to identify factors that affect carers’ QoL.” (p.693)	Unspecified	17	15 of the included studies were undertaken in the UK, the USA and Australia	Multiscerose	Multiple	Experiences; quality of life	Yes

First author (year)	Type of review	Aim(s)	Period	Number of reviews included	Countries/ Regions included	Disease	Relationship	Outcome	Quality appraisal
Van Beusekom (2016)	Literature review	“We aimed to provide a complete overview of the types of burdens reported in informal caregivers of adult ICU survivors, to make recommendations on which burdens should be assessed in this population, and which tools should be used to assess them.” (p.1)	Until June 2014	23	Denmark (1); USA (13); UK (3); France (5); Spain (2); Canada (1); Norway (1); Botswana (1); Australia (1); Sweden (1)	ICU	Spouse (majority)	Psychosocial burden	Yes
Cabote (2015)	Systematic review	“This article presents findings of a qualitative systematic review exploring the experiences of family caregivers of persons with younger onset dementia.” (p.443)	Unspecified	5	UK (2); Sweden (1); The Netherlands (1); USA and UK (1)	Dementia	Multiple	Experiences	No

First author (year)	Type of review	Aim(s)	Period	Number of reviews included	Countries/ Regions included	Disease	Relationship	Outcome	Quality appraisal
Hooker (2015)	Integrative review	"Objective: The aim of this study is to synthesize the literature to date on the associations between HF patient-caregiver relationship quality and communication and patient and caregiver health outcomes. (p.52)"	Unspecified	13	USA; The Netherlands	Heart failure	Multiple	Health-related outcomes	Yes
Huis in Het Veld (2015)	Systematic review	"The objective of this meta-review was to synthesize evidence from previous systematic reviews about professional self-management support interventions for this group." (p.1)	Until March 2014	10 systematic reviews	The Netherlands (3); Australia (1); Brazil (1); Canada (1); Germany (2); Taiwan (1); UK (1)	Dementia	Unspecified	Burden, Depression, Wellbeing, Ability/knowledge, coping skills, Self-efficacy, Decision-Making confidence, Anxiety, Stress or distress, Revised Memory and Behaviour Problem Checklist, Quality of life, Social outcomes, Mood, Health, Sense of competence	Yes

First author (year)	Type of review	Aim(s)	Period	Number of reviews included	Countries/ Regions included	Disease	Relationship	Outcome	Quality appraisal
Cheng (2014)	Systematic review and meta-analysis	“Objective: To evaluate the effectiveness of psychosocial interventions for family caregivers on their psychosocial and physical wellbeing, quality of life, and the use of healthcare resources by stroke survivors.” (p.30)	1988-2010	18	North America (7); Europe (7); Australia (3); Asia (1)	Stroke	Majority of spouses	Psychosocial well-being; physical well-being; QOL of caregivers	Yes
Peacock (2013)	Integrative literature review	“This article presents what is known and highlights the gaps in the literature relevant to the experiences of family caregivers of persons with dementia at the end of life.” (p.155)	1960-2011	10	USA (8); Australia (1); UK (1)	Dementia	Family	Experiences	No
Whittingham (2013)	Literature review	“This review explores the dimensions that impact caregiver burden and quality of life in carers of patients with heart failure and highlights both the negative and positive aspects of being an informal carer for heart failure patients.” (p.596)	Until January 2012	16	USA/Canada (12); UK (2); Sweden (1); The Netherlands (1)	Heart failure	Multiple	Burden; quality of life	Yes

First author (year)	Type of review	Aim(s)	Period	Number of reviews included	Countries/ Regions included	Disease	Relationship	Outcome	Quality appraisal
Del-Pino-Casado (2011)	Systematic review	"This article is a report on a review of the effect of coping strategies on subjective burden in informal caregivers of older adults." (p.2311)	1990-2010	10	Spain (1); England (1); Taiwan (1); USA (5); Japan (1); Canada (1)	Disability	Family	Subjective burden	Yes
Zegwaard (2011)	Systematic review	"This literature review aims to delineate the determinants of perceived burden by informal caregivers and provide insight into the interrelatedness between these determinants." (p.2233)	January 1985-2008	51	Western countries	older persons with a severe functional psychiatric syndrome and concomitant problematic behaviour	Multiple	Perceived burden	No
Northfield (2010)	Literature review	"(…) this literature review investigates how family caregivers endure and cope with the challenges of caring for an adult relative with cancer." (p.567)	2000-2009	70	Developed countries	Cancer	Multiple	Coping strategies	No

3.3 Presentation of results

3.3.1 Determinants associated with the outcomes

Table 2 Determinants associated with outcomes

Determinants of health	Frequency /47	Direction of the association with informal caregivers' health
Sociodemographic determinants of informal caregivers		
Gender/sex	15	/
Age	15	/
Ethnicity/culture	6	/
Education level	3	/
Sociodemographic of loved ones		
Gender/sex	4	/
Age	3	/
Determinants related to the disease		
Cognitive and behavioural changes and symptoms	11	-
Functional status, impairment, dependency	10	-
(Neuro)psychiatric symptoms	8	-
Uncertainty about the disease and the role	6	-
Multi- and comorbidities	4	-
Progress of disease	4	-
Severity of disease	3	-
Informal caregivers' psychosocial determinants		
Social support	30	+
Psychological health problems (e.g., depression, anxiety)	16	-
Coping strategies	16	+
Valued activities and employment	16	+
Adjusting to the new role	11	+
Perceived control and self-efficacy	10	+
Physical health	7	+
Anger and overwhelm	6	-
Growth and meaning	6	+
Guilt	5	-
Self-esteem	4	+
Fear	4	-

Grief	4	-
Resilience	3	+
Sense of identity	3	+
Feeling unprepared and uncertain about the future	3	-
Motivation	2	+
Psychosocial determinants related to the relationship with the loved one		
Type of relationship	7	/
Quality of the relationship and satisfaction	5	+
Contextual determinants		
Information and health literacy	14	+
Formal support	14	+
Financial difficulties	13	+
Respite	12	+
Tasks and demands	7	-
Hours of caregiving	4	-
Duration of caregiving	2	-

Positive association (+); negative association (-); no association (/)

3.3.2 Direction of the associations between determinants of well-being, quality of life, and subjective or objective burden of informal caregivers

Determinants related to disease

Overall, the health condition of the loved one influences the well-being and quality of life of the caregiver. However, some aspects of the disease of the former seem to have greater impact on informal caregivers' health across pathologies.

Cognitive and behavioural changes and symptoms. Cognitive changes (i.e., cognitive decline or changes in personality due to certain diseases such as dementia) and symptoms are challenging for informal caregivers(20), who often feel overwhelmed by these conditions(21). Consequently, cognitive changes (impairment or behavioural problems) and symptoms are positively correlated with greater burden on informal caregivers(22, 23), psychological distress(23), and lower quality of life(24). Behavioural symptoms are also challenging(25-28) and are positively correlated with informal caregivers' burden(22, 29-31) and depression(32). Therefore, informal caregivers confronted with behavioural symptoms or changes in their loved one report an acute need for formal support(20).

Functional status, impairment, and dependency. Functional status of the loved one, which includes functional capacity, performance, reserve, and capacity utilization(33) is a very strong predictor of informal caregivers' burden(34) and is associated with higher levels of depressive symptoms(35). More specifically, this status also negatively influences the well-being of youth (11 to 24 years old) caregivers(36). Some studies show that severe impairments and/or high levels of disability are associated with greater burden on informal caregivers(37) and higher levels of depressive symptoms at discharge(38). Moreover, the dependency of the loved one on informal caregivers negatively affects the well-being of the latter(21, 32, 39) increases the burden(34).

Psychiatric and neuropsychiatric symptoms. Psychiatric and neuropsychiatric symptoms (including anxiety and depression) of the loved one negatively affect informal caregivers' health(30, 35, 40). Those symptoms are associated with informal caregivers' greater burden(22). More precisely, psychological difficulties associated with the disease of their loved ones can trigger distress in informal caregivers(41) and lower their quality of life(24). Additionally, neuropsychiatric symptoms have a negative impact on informal caregivers' sleep quality(27), and psychological changes negatively impact youth (11 to 24 years old) caregivers' well-being to a higher degree compared to adult caregivers(36). Similarly, exhibiting low levels of self-care also puts caregivers' health at risk(30, 35).

Uncertainty about disease and role. Being uncertain about their role(25) and their future(29) and about the symptoms as well as the disease and its progress has negative consequences on informal caregivers' psychological health(26, 35, 42, 43).

Multi- and comorbidities. The presence of comorbidities or multi-morbidities in the loved one also represents a risk factor for burden(44, 45) and mental health of informal caregivers(22).

Progression of disease. Informal caregivers' experience varies across the process of the loved one's disease. In addition, the severity of disease progression seems to be associated with a higher burden(23). More specifically, an advanced stage of disease is associated with lower caregivers' mental health(40, 42), and the experience of grief depends on the stage of dementia(46).

Severity of disease. While the specific disease from which the loved one suffers has a small influence on the well-being of informal caregivers, the severity of the disease and symptoms are correlated with informal caregivers' depression(35, 47) but not with informal caregivers' resilience(48).

Informal caregivers' psychosocial determinants

Psychosocial determinants are very frequent in the references selected for this literature review and seem to be of great importance for the well-being, quality of life and burden of informal caregivers.

Social support. Social isolation(21, 24, 29, 30, 41, 44, 49) is associated with the diminished health of informal caregivers. Conversely, social support (from friends and family) is a self-care need(27) and the main protective factor regarding informal caregivers' burden(28, 34, 40, 47, 50, 51), quality of life(30, 35), well-being(23, 25, 30, 37, 52), and depressive symptoms(32). Social support is associated with a decrease in stress(31, 35, 40, 47). It is also essential for coping(21, 26) and delivering care(29). Social support represents an important element for informal caregivers(39, 53), as it is a "(…) vital resource (…)"(25) (p.63), and it is linked to higher resilience(48). Therefore, it is important to preserve one's social life, despite caregiving obligations(24, 25, 45), as informal caregivers are prone to social isolation(54). Certain types of support are particularly helpful, including emotional (person-centred) and instrumental (task-centred) support(31). In addition, good family functioning(30, 36, 40, 41, 47, 51, 55) is a real resource for informal caregivers. However, it is preferable to measure perceived social support rather than received social support as a predictor of informal caregivers; indeed, whether informal caregivers feel socially supported is more important than the number of people or structures who theoretically support them(40, 47, 52, 56). Furthermore, the quality of social support influences the experience lived by informal caregivers(42) and reduces their negative feelings(49).

Psychological health. Informal caregivers' psychological health is crucial for their well-being(24), quality of life(28, 30, 47), and burden(57). As informal caregivers often report symptoms of depression(20, 24, 25, 28, 30, 32, 44, 45, 47, 49, 51, 58), anxiety(24, 25, 28, 30, 32, 44, 45, 47, 49, 51, 58), distress(21, 25, 30, 40, 47, 58, 59) and stress(20, 24, 25, 30, 35, 44, 47, 56), it is necessary to assess these dimensions when investigating their health. However, it is also necessary to take cultural differences regarding mental health into account when measuring those constructs since some populations may not report mental health symptoms for cultural reasons(56).

Coping strategies. To protect their health, informal caregivers tend to use coping mechanisms. As informal caregivers develop coping strategies based on their knowledge and experience(60), they should be trained to use effective coping mechanisms(20). Indeed, coping strategies play an important role in protecting informal caregivers' mental health only when they are proven to be effective(22, 30, 32, 40, 41, 44, 47, 55, 61, 62), such as problem-focused coping combined with emotional-focused coping(62) and meaning-based coping(55)**.** In contrast, the use of emotional repression(23) and avoidance(32, 61) seem to have a deleterious effect on informal caregivers' health and increase burden. Gender also influences the coping strategy used by the informal caregiver: while women tend to use more coping strategies(29), gender roles influence the choice of strategies used. In fact, men tend to use more problem-focused coping, and women tend to use emotional-focused coping(62). Consequently, not to assume gender roles allows the use of a combination of problem-focused coping and emotional-focused coping reduce informal caregivers' burden(62). Age is also positively associated with dysfunctional coping strategies(29). Furthermore, having religious convictions or a spiritual life act as protective factors of the health of informal caregivers(23, 31, 37, 40, 47, 55, 56). Although having religious convictions or a spiritual life can represent effective coping strategies, they can also increase the meaninglessness felt regarding a loved one's condition (i.e., by raising questions such as "Why did this happen to them?")(21).

Valued activities and employment. Informal caregivers often must limit their leisure activities either because of their caregiving role(31, 42, 44, 45, 53) or due to financial difficulties(51, 53). This limitation is associated with higher depression and depressive symptoms(27, 32, 40, 53, 63), as well as reduced well-being(25, 39) and quality of life(24). Maintaining important activities represents an important way to cope with the caregiving role(36). Thus, although many caregivers have to reduce or leave their employment(24, 39, 44, 45, 58), it may be beneficial to remain employed as employment represents an important part of one's identity(21, 39), is decisive for one's financial situation(21, 24, 39, 45), and is part of perceived social support(41). Informal caregivers who maintain their professional activity experience less distress than those who lose it(31).

Adjusting to the new role. Since becoming an informal caregiver is rarely planned, the adjustment to this new role is not easy(20, 26, 30, 43). However, adapting to the role helps to accept the diagnosis(29), and caregivers who do not accept this role experience negative outcomes regarding their health(23). Nevertheless, dealing with multiple roles and shifting roles can represent a risk factor for informal caregivers' health(21, 25, 34, 39, 60).

Perceived control and self-efficacy. Informal caregivers need to feel some control over their situation and their lives(20, 28-30, 35, 40). Maintaining a sense of self-efficacy is also essential and is associated with lower depression and depressive symptoms(22, 32, 40), better physical health(47), and positive aspects of caregiving(55).

Physical health. The caregiving role causes negative consequences on informal caregivers' physical health(25, 34, 36, 42, 45, 51), and is associated with burden(30).

Anger and overwhelm. Feelings of anger are quite common among informal caregivers(29) and negatively affect their quality of life(24). Informal caregivers often feel overwhelmed by this role(20, 39, 42, 56).

Growth and meaning. It is relevant to highlight that informal caregiving also gives rise to positive consequences on their lives(64), such as the feeling of growth(21, 42, 55, 60) and of having found meaning in their lives(21). Those positive consequences are important not only to avoid because they are associated with better mental health and quality of life(64) but also to identify factors that make this experience positive(55).

Guilt. A very common feeling among informal caregivers is guilt(21, 27, 29, 31, 32). Informal caregivers feel guilty regarding different aspects of caregiving, such as not doing enough(21) or not taking care of the loved one adequately(32). Consequently, informal caregivers tend to take the full responsibility of the loved one(21) and reduce engaging in leisure activities, which, in turn, results in an increase in depressive symptoms (but only for husbands, wives, and sons)(32). Feelings of guilt can appear at diagnosis(29), during the caregiving period, and at the time of death of the loved one(21).

Self-esteem. Lower levels of caregiving and individual self-esteem are associated with higher distress(29, 40, 47), lower quality of life, and physical health problems(30).

Fear. Informal caregivers frequently feel fear. Fear often stems from the loved one's health condition(24). More specifically, fear is a common reaction to a diagnosis(29), especially for adult and spousal caregivers(36). Informal caregivers are also afraid of the loved one's death in the case of brain tumours(21).

Grief. Informal caregivers experience grief(47) and sometimes prolonged grief(23). In the context of dementia, grief experienced by caregivers differs depending on the stage of the disease and their relationship to the loved one(46). Hiding grief following societal discourse increases informal caregivers' burden(41).

Resilience. Being emotionally resilient reduces informal caregivers' burden and is positively associated with well-being and quality of life and negatively associated with psychological distress(48). Moreover, resilience training protects informal caregivers from the stress and fatigue associated with their role(53).

Sense of identity. The sense of identity continuation across situations is associated with higher well-being among informal caregivers(62). Informal caregivers who maintain a sense of identity experience positive outcomes from their role. In contrast, experiencing loss of self (or loss of one's identity) represents a source of stress(31). Informal caregivers experiencing unstable identity are more prone to feeling existential distress(21). Therefore, they try to restore it by making sense of what is happening to them(31).

Feeling unprepared and uncertain about the future. Some informal caregivers also report feeling unprepared for this role(20) and its associated responsibilities, resulting in increased stress(30). Informal caregivers also feel uncertain about their future, which puts their health at risk(29, 30).

Motivation. Informal caregivers who have an intrinsic motivation report more satisfaction, as endorsing this role represents a choice that is associated with higher well-being(52). Intrinsic motivation also contributes to making the caregiving experience more meaningful(55).

Psychosocial determinants related to the relationship with the loved one

Type of relationship. It is difficult to draw conclusions on the influence of the type of relationship between loved ones and informal caregivers on their health(27, 36). Several studies show that spouses experience more negative consequences on their mental health(22, 29, 40), but others report more contrasting results; in fact, other family members are also affected by the caregiving role. For example, adult children caregivers experience more distress than spouses(47), and mother caregivers report a higher level of burden(45).

Quality of the relationship and satisfaction. High-quality relationships and/or satisfaction with the relationship with the loved one are highly associated with fewer depressive symptoms(32, 35, 40, 65), less negative burden(65), and higher well-being(30).

Contextual determinants

Information and health literacy. Informal caregivers who lack information about their loved one's disease and/or the appropriate care(25) feel overwhelmed(49), and experience a reduced quality of life(24). As a result, giving informal caregivers more information about the disease(s) and appropriate care can promote effective coping(29, 31). Healthcare professionals need to provide more information to informal caregivers(20, 26, 37, 41) and doing so could prevent the negative experience of caregiving(42). However, it is important to be conscious of the manner in which information is given, as certain interventions targeting information did not show any positive effects on informal caregivers' well-being(66). Some reviews also address the need for education about disease for the same reasons(37, 40-42). For example, psychoeducation has a positive impact on informal caregivers' well-being(50).

Formal support. Informal caregivers need formal support from healthcare professionals(20, 25, 30, 36), as it helps them cope better(26), reduces perceived burden(23, 34) and depressive feelings(32, 49), and helps them have a more positive experience(42). However, formal support is sometimes inappropriate and difficult to access(36). It is also crucial to offer non-discriminatory services to everyone, including those who are sexual minorities(59). Unmet needs of informal caregivers are quite frequently cited in the literature about their health. Indeed, unmet needs are associated with higher caregiver burden(30, 34), reduced mental health(21, 30), and reduced quality of life(30, 47). Caregivers often feel unseen by health services and need more information and education about the disease and their caregiving role, as well as effective interventions targeting their burdens and quality of life(30). Frequent barriers to accessing formal care are the lack of awareness of those services, caregivers not wanting to receive help, financial constraints, and limitations caused by geographic location(37). In fact, informal caregivers can be reluctant to seek formal care because of loyalty and a sense of obligation(20).

Financial difficulties. Informal caregivers often experience financial difficulties(24, 25, 42, 45, 51), as most are forced to reduce their working hours or even stop their professional activities(41). These financial concerns are linked to higher distress(21, 40), burden(30), decreased quality of life(23, 47), and well-being(26). Moreover, financial difficulties limit their ability to benefit from self-care activities(53).

Respite. Respite, even for a few hours, is important for caregivers(44), as it enables them to maintain relationships(23) and focus on valued and important activities(20, 27, 34, 37, 39, 41, 53). In addition, respite relieves caregivers from stress(36). Although the results on informal caregivers' quality of life are contradictory, respite is essential to maintain the caregiving role in the long term and thus has a positive effect on informal caregivers' quality of life(36). However, there are some barriers to accessing respite. First, placing the loved one in respite care may trigger negative emotions in informal caregivers(36). Second, loved ones who have trouble adjusting to the disease will be more reluctant to receive care from another person than their caregivers(26). Last, informal caregivers living in rural regions may find it more difficult to access respite services(27).

Tasks and demands. The perceived difficulty of tasks is associated with higher level of burden, but the type of tasks perceived as difficult vary depending on informal caregivers' age and gender(28). A greater number of tasks perceived as difficult negatively impact caregivers' health(30). Some caregiving tasks are more burdensome than others. For example, providing emotional support for the loved one is more time-consuming than providing physical care(22) and is associated with higher distress(23, 40), as emotional support is a challenging task(25, 30). However, the physical demands of the caregiving role are also associated with higher distress(23, 30, 40).

Hours of caregiving. The number of hours (per week or per month) that informal caregivers allocate to provide help to their relative negatively influences their psychological well-being(27, 30, 47). However, the association between hours of caregiving and burden disappears when tasks are taken into account, meaning that the number of tasks may have a more direct influence than hours on burden(34).

Duration of caregiving. The duration of caregiving is associated with greater informal caregivers' burden(34) and negatively influences quality of life(24).

3.3.3 Factors not significantly related to the well-being, quality of life and burden of informal caregivers

Sociodemographic determinants of informal caregivers

Gender. Many reviews mention informal caregivers' gender as an important factor affecting health. However, while some posit that being a woman is positively correlated with depression(23, 30, 32, 40, 47), burden(23, 30, 34), and quality of life(24), others find the opposite effects(38, 48, 67). As samples are often mostly composed of women, conclusions on the effect of gender on informal caregivers are difficult to draw(48). Nonetheless, not to assume gender stereotypes (i.e., for women to become more task-focused and for men to allow themselves to have more feelings) can have a positive effect on informal caregivers' health(27, 62), as they represent a barrier to self-care and put women in a position prone to stress(41).

Age. It is quite complicated to draw conclusions on the influence of informal caregivers' age on their health. Some reviews show that younger informal caregivers' health is more at risk than that of older caregivers(23, 25, 28, 30, 32, 39, 40, 47), while others demonstrate the opposite effect(24, 27, 29, 37, 48). Therefore, age is an insignificant determinant(34, 62). However, managing multiple roles (e.g., professional demands, being a parent) is challenging for younger caregivers(25) and may be more relevant to understanding informal caregivers' health.

Ethnicity/culture. Although some reviews show no influence of informal caregivers' ethnicity on their health(32, 48), others show that certain cultural beliefs may prevent informal caregivers from seeking formal support(41). In contrast, African Americans experience lower levels of depression than White Americans, possibly due to their spirituality(56). However, one should be cautious when generalizing those results, as ethnic minorities are not well represented in most samples(27).

Education level. While some reviews show no influence of informal caregivers' education level on their health(56), others demonstrate that a lower education level is associated with an adverse impact of caregiving on health(30, 47).

Sociodemographic determinants of loved ones

Gender. One article reported that caring for a man with dementia increased informal caregivers' risk of experiencing depression symptoms(29). However, most articles state inconclusive results on the influence of loved ones' gender on informal caregivers' health(34, 47).

Age. Conclusions cannot be drawn on the influence of loved ones' age on informal caregivers' health, as some report that age is positively associated with well-being(30, 47), and others report that caring for an older loved one is associated with more depressive symptoms(35).

4 Discussion

4.1 Summary of results and recommendations for the questionnaire

This literature review highlighted the different determinants of the health of informal caregivers (mostly family members) who play an essential role in the current and future health care system.

Sociodemographic determinants. It is difficult to draw conclusions on the effect of sociodemographic determinants on informal caregivers' health, as the samples are mostly composed of middle-aged women.

Determinants related to the disease. Cognitive and behavioural changes/symptoms, functional status, impairment, and dependency are the most influential determinants caused by the disease on informal caregivers' health.

Informal caregivers' psychosocial determinants. First, perceived social support is a crucial protective factor for the health of informal caregivers. Then, the use of effective coping strategies also protects their health. Moreover, we concluded that we should measure some aspects of their psychological health, such as depressive symptoms and anxiety, when investigating their health. Although dealing with multiple roles represents a risk factor, maintaining valued activities (leisure and employment) can prevent negative consequences of the caregiving role and caregivers' health. It is also important to adjust to this caregiving role and to perceive a sense of control and self-efficacy in one's life.

Psychosocial determinants related to the relationship with the loved one. Spouses and other family members experience negative consequences of the caregiving role on their health, which makes it difficult to conclude any specific effects solely based on this literature review. Nonetheless, the quality of the relationship is an important factor regarding informal caregivers' health.

Contextual determinants. Informal caregivers experience financial difficulties, which reinforces gender inequality in society, as most informal caregivers are women. Some of them need more information and education about their caregiving role and the disease. While respite allows informal caregivers to rest and engage in valued (and/or social) activities, it can also trigger negative emotions. Formal support is also very important for informal caregivers.

In summary, we believe that these determinants are important to measure. Moreover, according to salutogenic approaches, it seems important not only to measure the risk factors for informal caregivers' health but also to assess the protective factors of their health and the potential positive consequences of the activity of informal caregivers.

4.2 Perspectives

Although it is important to investigate the positive consequences of informal caregiving (e.g., sense of personal accomplishment, sense of personal growth and purpose)(55) to identify the elements that promote the health of caregivers, one should also bear in mind the negative consequences of this activity on health.

In this literature review and for SCOHPICA as a project, we decided not to include informal caregivers under the age of 18 because they would need their parents' or legal representative's consent, which would make the recruitment rather laborious. However, informal caregivers under the age of 18 face significant challenges throughout their childhood and adolescence that influence their life course (e.g., they likely have a significantly lower level of education than their peers and are more prone to isolation)(68). Moreover, caregivers under the age of 18 have poorer mental physical and psychological health than their peers who do not have caregiving responsibilities(69). As caring is culturally defined as an activity that should be kept private, young caregivers are often invisible and are not supported by services(70). Consequently, it would be necessary to investigate their experience to implement adequate health and social policies.

References about informal caregiving during the COVID-19 pandemic were not included in this literature review, as we thought their results would be too specific to this context and thus not depict the general experience of informal caregiving. Nevertheless, the pandemic had an important influence on informal caregivers; for example, 25.5 to 39.7% of German informal caregivers reported more difficulty during COVID-19(71). Thus, in the future, it would be interesting to take this period into consideration when investigating informal caregivers' well-being, quality of life, and burden.

When investigating informal caregiving, it is crucial to adopt a gender perspective. As informal caregiving negatively affects caregivers' professional activities because they are often obliged to reduce their employment rate or even quit their jobs(7), the overrepresentation of women in informal caregivers(6) contributes to gender inequalities. Relying mostly on women is thus not a suitable solution because: (1) the availability of potential informal carers decreases as more women are encouraged to be part of the labour market; and (2) informal caregiving hinders paid work and career, among other things, and thus contributes to gender inequality(72). Moreover, it reinforces gender roles as a domestic sphere, and informal caregiving work as a traditionally women's responsibility(72).

Consequently, social policies allowing informal caregivers to maintain their professional activities while caring for their relative may: (1) limit the financial burdens and obstacles to women caregivers' careers; and (2) allow more men to take on the responsibility of informal caregiving.

Finally, this literature review included reviews from high-income countries. The experiences of informal caregivers may differ in low-income countries.

4.3 Strengths and limits

This literature review is part of the Swiss COhort of Healthcare Professionals and Informal CAregivers (SCOHPICA): a collaborative and interdisciplinary prospective cohort, which will continue to publish results regularly. Informal caregivers are completely included in this cohort as they are essential contributors to the Swiss health system. This literature review participates in real research and represents a basis for future questionnaires.

This literature review is very broad. We decided to consider reviews assessing the well-being, quality of life, and burden of informal caregivers to investigate the influence of this activity in the most complete way. As we wanted to be inclusive, we considered every configuration of informal caregiving. For example, adult children informal caregivers were included as well as spouse and parent caregivers. However, we did not include child caregivers, as their experience is different because of their young age.

Because of the scope of the review and the limited resources available, reviews included in this literature review, which is not a systematic review per se, were searched, selected, and assessed by the first author (LE), and data were extracted by LE and OKP. In addition, the broad scope of this literature review does not allow us to draw conclusions on the effect of specific diseases or types of relationships between informal caregivers and their loved ones.

4.4 Conclusion

This literature review presented important determinants of informal caregivers’ health (burden, quality of life, and well-being). Therefore, it represents a good starting point to develop the cohort of informal caregivers of the SCOHPICA project.

This review highlighted the need to assess informal caregivers’ health in a comprehensive manner, as there are several different types of determinants. According to salutogenic approaches, we think that it is crucial to investigate not only risk factors but also the protectors of their health.

5 References

1. Kessler C, Boss V. Promotion de la santé psychique des proches aidant·e·s de personnes âgées: Un guide pour la promotion de la santé des personnes âgées. Berne: Promotion Santé Suisse; 2019.
2. Oulevey Bachmann A, Ludwig C, Tétreault S. Proches aidant.e.s: Des alliés indispensables aux professionnels de la santé. Genève: Georg; 2021.
3. Otto U, Leu A, Bischofberger I, Gelrich R, Riguzzi M, Jans C et al. Besoins des proches aidants en matière de soutien et de décharge – enquête auprès de la population. Berne: Office fédéral de la santé publique OFSP; 2019.
4. Office fédéral de la statistique. Aides informelles [cited 2023 Apr 25]. Available from: https://www.bfs.admin.ch/bfs/fr/home/statistiques/sante/systeme-sante/aides-informelles.html
5. Rička R, von Wartburg L, Gamez FM, von Greyerz S. Rapport de synthèse du programme de promotion «Offres visant à décharger les proches aidants 2017-2020 ». Berne: Office fédéral de la santé publique OFSP; 2020.
6. Belser K. Reconnaissance et revalorisation du travail de care : Agir pour l'égalité. Berne: Bureau fédéral de l'égalité entre femmes et hommes BFEG; 2010.
7. Cès S, Hlebec V, Yghemonos S. Valuing informal care in Europe: analytical review of existing valuation methods. Brussels: Eurocarers; 2019.
8. Eurocarers. The gender dimension of informal care. Brussels: Eurocarers; 2021.
9. Benelli N, Modak M. Analyser un objet invisible: le travail du care. Revue française de sociologie. 2010;51:39-60.
10. Kaplan C. Protection financière des proches aidants: Prestations reposant sur un financement à la personne aux niveaux fédéral, cantonal et communal. Berne: Office fédéral de la santé publique OFSP; 2020.
11. Département de la santé et de l'action sociale. Pour une reconnaissance des proches aidant.e.s: Rapport explicatif et questions soumises. Lausanne: Département de la santé et de l'action sociale; 2020.
12. Kalaidos Haute Ecole Spécialisée Suisse. Les Young Carers en Suisse [cited 2023 Apr 25]. Available from: https://www.kalaidos-fh.ch/fr-CH/Forschung/Fachbereich-Gesundheit/Young-Carers/Forschungsfokus
13. Merçay C, Grünig A, Dolder P. Personnel de santé en Suisse – Rapport national 2021: Effectifs, besoins, offre et mesures pour assurer la relève. Obsan Rapport 03/2021. Neuchâtel: Observatoire suisse de la santé; 2021.
14. Lobsiger M, Kägi W, Burla L. Les professionnels de la santé: sorties de leur profession. Obsan Bulletin 07/2016. Neuchâtel: Observatoire suisse de la santé; 2016.
15. Schaffert R, Trede I, Gronning M, Hänni M, Bänziger A, Helfenstein E. Résumé exécutif du rapport: Parcours professionnels dans les soins infirmiers. Zurich: Zürcher Hochschule für Angewandte Wissenschaften; 2021.
16. Merçay C, Burla L, Widmer M. Personnel de santé en Suisse: Etat des lieux et projections à l'horizon 2030. Obsan Rapport 71. Neuchâtel: Observatoire suisse de la santé; 2016.
17. Estrada Fernández ME, Gil Lacruz AI, Gil Lacruz M, Viñas López A. Informal care. European situation and approximation of a reality. Health Policy. 2019;123(12):1163-72.
18. Kim H, Chang M, Rose K, Kim S. Predictors of caregiver burden in caregivers of individuals with dementia. J Adv Nurs. 2011;68(4):846-55.
19. CASP Critical Appraisal Skills Programme Oxford: CASP UK [cited 2023 Apr 25]. Available from: https://casp-uk.net/casp-tools-checklists/
20. Bressan V, Visintini C, Palese A. What do family caregivers of people with dementia need? A mixed-method systematic review. Health Soc Care Community. 2020;28(6):1942-60.
21. Applebaum AJ, Kryza-Lacombe M, Buthorn, J, DeRosa A, Corner G, Diamond EL. Existential distress among caregivers of patients with brain tumors: A review of the literature. Neurooncol Pract. 2016;3(4):232-44.
22. Amer Nordin A, Hairi FM, Choo, WY, Hairi NN. Care Recipient Multimorbidity and Health Impacts on Informal Caregivers: A Systematic Review. Gerontologist. 2019;59(5):e611-e28.
23. Bergin S, Mockford C. Recommendations to support informal carers of people living with motor neurone disease. Br J Community Nurs. 2016;21(10):518-24.

24. Gumber A, Ramaswamy B, Thongchundee O. Effects of Parkinson's on employment, cost of care, and quality of life of people with condition and family caregivers in the UK: A systematic literature review. Patient Relat Outcome Meas. 2019;10:321-33.

25. Grant JS, Graven LJ. Problems experienced by informal caregivers of individuals with heart failure: An integrative review. Int J Nurs Stud. 2018;80:41-66.

26. Topcu G, Buchanan H, Aubeeluck A, Garip G. Caregiving in multiple sclerosis and quality of life: A meta-synthesis of qualitative research. Psychol Health. 2016;31(6):693-710.

27. Waligora KJ, Bahouth MN, Han HR. The self-care needs and behaviors of dementia informal caregivers: a systematic review. Gerontologist. 2019;59(5):e565-e83.

28. Whittingham K, Barnes S, Gardiner C. Tools to measure quality of life and carer burden in informal carers of heart failure patients: a narrative review. Palliat Med. 2013;27(7):596-607.

29. Caceres BA, Frank MO, Jun J, Martelly MT, Sadarangani T, de Sales PC. Family caregivers of patients with frontotemporal dementia: An integrative review. Int J Nurs Stud. 2016;55:71-84.

30. Nicholas Dionne-Odom J, Hooker SA, Bekelman D, Ejem D, McGhan G, Kitko L, et al. Family caregiving for persons with heart failure at the intersection of heart failure and palliative care: a state-of-the-science review. Heart Fail Rev. 2017;22(5):543-57.

31. Zegwaard MI, Aartsen MJ, Cuijpers P, Grypdonck MH. Review: a conceptual model of perceived burden of informal caregivers for older persons with a severe functional psychiatric syndrome and concomitant problematic behaviour. J Clin Nurs. 2011;20(15-16):2233-58.

32. Watson B, Tatangelo G, McCabe M. Depression and anxiety among partner and offspring carers of people with dementia: a systematic review. Gerontologist. 2019;59(5):e597-e610.

33. Leidy NK. Functional status and the forward progress of merry-go-rounds: toward a coherent analytical framework. Nurs Res. 1994;43(4):196-202.

34. Lindt N, van Berkel J, Mulder BC. Determinants of overburdening among informal carers: a systematic review. BMC Ger. 2020;20(1):304.

35. Lacerda MS, do Prado PR, de Barros ALBL, de Lima Lopes J. Sintomas depressivos em cuidadores familiares de pacientes com insuficiência cardíaca: revisão integrativa. Rev Gaúcha de Enferm. 2019;40.

36. Cabote CJ, Bramble M, McCann D. Family Caregivers' Experiences of Caring for a Relative With Younger Onset Dementia: A Qualitative Systematic Review. J Fam Nurs. 2015;21(3):443-68.

37. Kokorelias KM, Lu FK, Santos JR, Xu Y, Leung R, Cameron JI. “Caregiving is a full-time job” impacting stroke caregivers' health and well-being: A qualitative meta-synthesis. Health Soc Care Community. 2020;28(2):325-40.

38. Fauziah W, Kato M, Irwan AM. Contradiction, Similarity, and Uncovered Factors of Depression among Post-Stroke Patients Family-Caregivers. International Journal of Caring Science. 2019;12(3):1380-401.

39. Jellema S, Wijnen MAM, Steultjens EMJ, Nijhuis-van der Sanden MWG, van der Sande R. Valued activities and informal caregiving in stroke: a scoping review. Disabil Rehabil. 2019;41(18):2223-34.

40. Cochrane A, Reid O, Woods S, Gallagher P, Dunne S. Variables associated with distress amongst informal caregivers of people with lung cancer: A systematic review of the literature. Psychooncology. 2021;30(8):1246-61.

41. Northfield S, Nebauer M. The caregiving journey for family members of relatives with cancer: how do they cope? Clin J Oncol Nurs. 2010;14(5):567-77.

42. Hodson AR, Peacock S, Holtslander L. Family caregiving for persons with advanced heart failure: an integrative review. Palliat Support Care. 2019;17(6):720-34.

43. Moral-Fernández L, Frías-Osuna A, Moreno-Cámara S, Palomino-Moral PA, Del-Pino-Casado R. The start of caring for an elderly dependent family member: a qualitative metasynthesis. BMC Geriatr. 2018;18(1):228.

44. Cicolini G, Cerratti F, Della Pelle C, Simonetti V. The Experience of Family Caregivers of Patients With a Left Ventricular Assist Device: An Integrative Review. Prog Transplant. 2016;26(2):135-48.

45. Gonçalves C, Martins S, Fernandes L. Dravet syndrome: Effects on informal caregivers' mental health and quality of life – A systematic review. Epilepsy Behav. 2021;122:108206.

46. Peacock SC. The experience of providing end-of-life care to a relative with advanced dementia: an integrative literature review. Palliat Support Care. 2013;11(2):155-68.

47. Ochoa CY, Lunsford NB, Smith JL. Impact of informal cancer caregiving across the cancer experience: A systematic literature review of quality of life. Palliat Support Care. 2020;18(2):220-40.

48. McKenna O, Fakolade A, Cardwell K, Langlois N, Jiang K, Pilutti LA. Towards conceptual convergence: a systematic review of psychological resilience in family caregivers of persons living with chronic neurological conditions. Health Expect. 2021;25(1):4-37.

49. Bjørnnes AK, Moons P, Parry M, Halvorsen S, Tønnessen T, Lie I. Experiences of informal caregivers after cardiac surgery: A systematic integrated review of qualitative and quantitative studies. BMJ Open. 2019;9(11):1-10.

50. Cheng HY, Chair SY, Chau JP. The effectiveness of psychosocial interventions for stroke family caregivers and stroke survivors: A systematic review and meta-analysis. Patient Educ Couns. 2014;95(1):30-44.

51. Mohsenizadeh SM, Manzari ZS, Vosoghinia H, Ebrahimipour H. Family caregivers' burden in inflammatory bowel diseases: An integrative review. J Educ Health Promot. 2020;9:289.

52. Dombestein H, Norheim A, Lunde Husebø AM. Understanding informal caregivers' motivation from the perspective of self-determination theory: An integrative review. Scand J Caring Sci. 2020;34(2):267-79.

53. Sabo K, Chin E. Self-care needs and practices for the older adult caregiver: An integrative review. Geriatr Nurs. 2021;42(2):570-81.

54. Hajek A, Kretzler B, König HH. Informal caregiving, loneliness and social isolation: A systematic review. Int Environ Res Public Health. 2021;18(22):12101.

55. Yu DSF, Cheng ST, Wang J. Unravelling positive aspects of caregiving in dementia: An integrative review of research literature. Int J Nurs Stud. 2018;79:1-26.

56. Starks SA, Outlaw F, Graff JC, Likes W, White-Means S, Melaro L, et al. Quality of life and african american women who are family caregivers: a literature review with implications for psychiatric mental health advanced practice registered nurses. Issues Ment Health Nurs. 2018;39(6):467-81.

57. Del-Pino-Casado R, Espinosa-Medina A, López-Martínez C, Orgeta V. Sense of coherence, burden and mental health in caregiving: A systematic review and meta-analysis. J Affect Disord. 2019;242:14-21.

58. van Beusekom I, Bakhshi-Raiez F, de Keizer NF, Dongelmans DA, van der Schaaf M. Reported burden on informal caregivers of ICU survivors: a literature review. Crit Care. 2016;20:1-8.

59. Thompson T, Heiden-Rootes K, Joseph M, Gilmore LA, Johnson L, Proulx CM, et al. The support that partners or caregivers provide sexual minority women who have cancer: A systematic review. Soc Sci Med. 2020;261:113214.

60. Kim EY, Oh S, Son YJ. Caring experiences of family caregivers of patients with heart failure: a meta-ethnographic review of the past 10 years. Eur J Cardiovasc Nurs. 2020;19(6):473-85.

61. Del-Pino-Casado R, Frías-Osuna A, Palomino-Moral, PA., Pancorbo-Hidalgo PL. Coping and subjective burden in caregivers of older relatives: A quantitative systematic review. J Adv Nurs. 2011;67(11):2311-22.

62. Zygouri I, Cowdell F, Ploumis A, Gouva M, Mantzoukas S. Gendered experiences of providing informal care for older people: a systematic review and thematic synthesis. BMC Health Serv Res. 2021;21:1-15.

63. Wiegelmann H, Speller S, Verhaert LM, Schirra-Weirich L, Wolf-Ostermann K. Psychosocial interventions to support the mental health of informal caregivers of persons living with dementia: a systematic literature review. BMC Geriatr. 2021;21(1):1-17.

64. Quinn C, Toms G. Influence of positive aspects of dementia caregiving on caregivers' well-being: A systematic review. Gerontologist. 2019;59(5):e584-e96.

65. Hooker SA, Grigsby ME, Riegel B, Bekelman DB. The impact of relationship quality on health-related outcomes in heart failure patients and informal family caregivers: an integrative review. J Cardiovasc Nurs. 2015;30(4S):S52-S63.

66. Huis in Het Veld JG, Verkaik R, Mistiaen P, van Meijel B, Francke AL. The effectiveness of interventions in supporting self-management of informal caregivers of people with dementia; a systematic meta review. BMC Geriatr. 2015;15(1):1-10.

67. Xiong C, Biscardi M, Astell A, Nalder E, Cameron JI, Mihailidis A, et al. Sex and gender differences in caregiving burden experienced by family caregivers of persons with dementia: A systematic review. PLoS ONE. 2020;15(4):e0231848.

68. Carers Trust. About Young Carers [cited 2023 Apr 25]. Available from: https://carers.org/about-caring/about-young-carers

69. Lacey RE, Xue B, McMunn A. The mental and physical health of young carers: a systematic review. Lancet Public Health. 2022;7(9):e787-e96.

70. Leu A, Berger FMP, Heino M, Nap HH, Untas A, Boccaletti L, et al. The 2021 cross-national and comparative classification of in-country awareness and policy responses to 'young carers'. J Youth Stud. 2022:1-18.

71. Budnick A, Hering C, Eggert S, Teubner C, Suhr R, Kuhlmey A, et al. Informal caregivers during the COVID-19 pandemic perceive additional burden: findings from an ad-hoc survey in Germany. BMC Health Serv Res. 2021;21(353):1-11.

72. Cascella Carbó GF, García-Orellán R. Burden and Gender inequalities around Informal Care. Invest Educ Enferm. 2020;38(1):e10.

6 Appendices

6.1 Algorithm of research in Pubmed

Meta-analysis OR systematic review OR review with available abstract:

informal caregiver

"informal caregiver*"

"informal caregiver*" trajectory

"informal caregiver*" work

"informal caregiver*" disability

"informal caregiver*" motivation

"informal caregiver*" professional activity

"informal caregiver*" employment

"informal caregiver*" work efficiency

"Family caregiver*"

"informal caregiver*" career

"informal caregiver*" work performance

"informal caregiver*" "quality of life"

"informal caregiver*" well-being

"informal carer" burden

"informal carer*" burden

burden perception informal carers

6.2 Algorithm of research in CINAHL

Meta-analysis OR systematic review OR review with available abstract:

informal caregiver "professional activity" / "informal caregiver" "professional activity" / "informal caregiver*" "professional activity" informal caregiver

informal caregiver

informal caregivers or family caregivers or informal carers or family carers

informal caregivers or family caregivers or informal carers or family carers

informal caregivers professional activity

informal caregivers work

informal caregiver incentive

"informal caregiver*" motivation