

## Mapping the domains and influencing factors of quality of life in informal carers of community-dwelling older adults

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Discussion Paper Series

# Mapping the domains and influencing factors of quality of life in informal carers of community-dwelling older adults

Judith Kieninger  
Birgit Trukeschitz  
Paulina Wosko  
Sabine Pleschberger

Discussion Paper 1/2019



## The Older People Living Alone (OPLA) project

This discussion paper contributes to the results of the Older People Living Alone (OPLA) project.

The OPLA project is a qualitative longitudinal study that aims to better understand how older people living alone manage to stay at home in spite of an increase in care needs as they reach the end of their lives. The role of non-kin carers in these arrangements are of specific interest as they form an important but rather neglected group in research. Serial interviews with older people living alone as well as non-kin carers form the database and different strategies of qualitative analysis will be applied. Dr. Sabine Pleschberger and a multiprofessional team at the Austrian Public Health Institute in Vienna (Gesundheit Österreich GmbH) are conducting this study together with national research partners at the University of Vienna (Department of Nursing Science) and the Vienna University of Economics and Business (Research Institute for Economics of Aging). The study is funded by the Austrian Science Fund (FWF); grant number: P 30607-G29 (study duration March 2018 to February 2022). [https://goeg.at/OPLA\\_Projekt](https://goeg.at/OPLA_Projekt)

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## Abstract

**Background:** Over the past decades, research interest has increased in exploring quality of life (QoL) and well-being of informal caregivers who provide support for home-dwelling older people. However, as the concepts are very broad and all encompassing, a wide range of interpretations exist, resulting in differences in understanding of QoL and influencing factors.

**Aim:** By following the scientific discussion over the last 20 years, this literature review maps differences in the understanding of QoL of informal carers and explores the benefits, losses, and wide-ranging impact of caregiving on the living situation of the informal carers. In detail, it aims to (i) identify the relevant domains and aspects associated with QoL and well-being of informal caregivers providing care for older people living at home and (ii) to map the variety of influencing factors affecting the QoL and well-being of informal carers.

**Method:** This study follows a scoping review that allows for integrating a diversity of relevant literature and studies using different methodologies. In total, 42 qualitative and quantitative studies were included in the review. The literature search was conducted during the months of November 2018 and March 2019.

**Results:** Three core domains related to caregiving could be identified as most relevant in empirical studies focusing on overall QoL or well-being: the *physical, psychological, and social dimensions* of life. Additional domains highlighted in the literature related to *work/daily routine, spirituality/religion, or financial security*. Major influencing factors that were discussed included gender, education, and financial status of the carer, personal resources, informal and formal support, health condition of the care recipient, relationship between carer and care recipient and socio-cultural factors. Study designs were not particularly sensitive to certain subgroups of informal carers and only one study explicitly focused on caregiving experiences of non-relatives.

**Conclusions:** The caregiving process needs to be understood as a complex and individual experience, which has to be considered in evaluations of QoL and well-being of informal carers. Researchers need to be aware that the conceptualization of QoL and the selection of domains to be involved has a substantial impact on shaping results and policy implications. Further, future research should consider to what extent public or family support translates into benefits for informal carers' QoL, and which areas of life are affected by such support. Due to the lack of literature on informal non-kin carers, more studies are needed to understand how informal care impacts lives and how this differs from family care.

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# 1 Introduction

Provision of informal care is still one of the main pillars of caring for older people in many countries, enabling older frail people to remain in their own home. With a continued political priority on enabling 'aging in place', informal caregivers, i.e. relatives, friends, or neighbors who provide unpaid care to a dependent older person, remain important players. Thus, the support provided by informal caregivers largely determines the well-being of care receivers but can also significantly affect the living situation of the caregiver. Caregiving can have a variety of effects on caregivers' lives, in negative ways (e.g. financial burden, stress and depressive symptoms) and positive ways (e.g. rewarding experience). The attention given to the consequences and effects of caregiving have therefore been growing in public discourse and scientific research over the last few decades.

Since the 1980s, increasing research has focused on experiences of informal caregivers and a variety of different instruments were developed and used to measure caregiver outcomes using quantitative methods (Eddy et al., 1995, Van Durme et al., 2012). Among the studies, there was a strong emphasis on negative aspects of caregiving, such as burden, depression, and stress or other physical and emotional strain. In fact, caregiver burden is still one of the most common examined outcome measures using quantitative study designs (Chou, 2000, Van Durme et al., 2012, Bastawrous, 2013). The identification of 105 tools to measure the impact of caregiving showed that 30 tools assessed burden as main dimension (Van Durme et al., 2012). On the other hand, scholars explored positive consequences of caregiving associated with the process of caregiving. These comprised, among others, personal satisfaction, joy, rewards, and feelings of being needed (Turner and Findlay, 2012). To counterbalance the overly negative portrayal of informal caregiving several studies have been carried out in the last few years to additionally capture the positive experiences and benefits of caregiving and authors called for a more comprehensive view on informal caregiving (van Groenou et al., 2013, Roth et al., 2015).

However, since the early years of informal caregiving research, few scholars have already made efforts to show the dual nature of caregiving in order to obtain a fuller understanding of informal care outcomes (Lawton et al., 1989, George and Gwyther, 1986, Orbell et al., 1993). Lawton and colleagues (1989) confirmed the existence of both positive and negative effects of caregiving analyzing caregiver burden besides satisfaction and feelings of caregiving mastery. Orbell and colleagues (1993) supported the findings of Lawton et al. (1989) proving a multidimensional impact of care investigating the strain experienced by informal carers but also the self-worth benefits derived from caregiving. Miller (1989) proved the simultaneous existence of positive and negative effects of caregiving by demonstrating that caregiving burden and stress are not negatively related but rather had

a positive zero-order correlation. Building on previous studies, Chappell and Reid (2002) showed that quality of life (QoL) of caregivers may improve even in the presence of caregiver burden.

Thus, in addition to the assessment of burden, QoL has gained prominence in caregiving research within the last three decades. QoL was discovered as a key outcome of health-related interventions capturing the subjective perception of the caregiving experience and assessing the impact on the caregiver's life (Deeken et al., 2003). Numerous studies followed in evaluating the QoL and well-being of informal caregivers, measuring a variety of different dimensions and factors. As quality of life is often used as an umbrella term, the concept is understood and applied in different ways and may encompass various aspects of life. Understood in its widest sense, it captures a range of different dimensions such as health, autonomy, social support, resources, occupation and activity levels, or it may only refer to a specific aspect, e.g. health. Due to its multiple definitions, the evaluation of QoL offers the possibility to gain a broad spectrum of effects related to caregiving covering positive and negative components (Ratcliffe et al., 2013). The QoL concepts allow for a multidimensional view of informal caregiving, both the assessment of selected aspects or the entirety of a life-situation (Gasper, 2010).

This discussion paper aims to capture the variety of responses to and effects of informal caregiving on quality of life or well-being that have been investigated in the caregiving literature in the past 20 years. We aim to explore (i) the relevant dimensions and aspects associated with quality of life and well-being of informal caregivers providing care for community-dwelling older people, and to investigate (ii) influencing and moderating factors that have been discussed when assessing informal carers' QoL outcomes.

## **2 Conceptualization of QoL and well-being**

As the concept of QoL relates to a variety of different interpretations and is not clearly delimited from other multidimensional concepts to evaluate a life situation (Vanleerberghe et al., 2017, Gasper, 2010), the main ideas associated with the notion of QoL and well-being are discussed briefly for further clarity.

### **2.1 Quality of life**

QoL is an elusive concept and substantial differences exist in its definition and relationships with corresponding concepts. Despite a lack of consensus on the definition, most authors (of gerontological studies) agree that "quality of life" is a multidimensional and dynamic concept that encompasses objective and subjective aspects and goes beyond the health status or functional ability of a person (Karimi and Brazier, 2016, Vanleerberghe et al.,

2017). Further, many scholars underline the possibility to include positive and negative aspects of caregiving on the life of caregivers when using the concept of quality of life (Van Durme et al., 2012, Ratcliffe et al., 2013, Glzman, 2004). A common definition cited in articles is provided by the Quality of Life Group of the World Health Organization defining quality of life as *an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns*.<sup>1</sup> The definition stresses the subjective perception of one's life embedded in a cultural, social, and environmental context and refers to an integrative approach understanding quality of life as multidimensional phenomenon.

To evaluate quality of life, qualitative and quantitative measures may be applied; however, the majority of research on QoL uses quantitative measures. A quantitative measurement of QoL is usually based on QoL domains and domain-specific indicators, defined as certain conditions and behaviors that express a person's well-being (Gasper, 2010). Objective elements (housing, finances, education level, work) are usually measured but considered rather as influencing factors. Qualitative methods have been used particularly in the development of QoL measurements or to evaluate content adequacy of QoL instruments (Galloway et al., 2006).

A useful typology of QoL that attempts to secure conceptual clarity is provided by Farquhar (1995). In her taxonomy, she distinguishes between the following four types of QoL:

- *Global definition*: the most general definition of QoL that seeks an overall evaluation of life experiences. It usually involves a one-dimensional understanding of QoL (e.g. degree of satisfaction with life/happiness)
- *Component definitions*: QoL is broken down into several components or dimensions that are considered important in evaluating QoL (e.g. physical domain, social domain, mental domain). This definition can be further subdivided into a research-specific definition including only the components of QoL that are most relevant to the research focus or a non-research specific definition.
- *Focused definitions*: the definition either *explicitly* or *implicitly* refers to one or a smaller number of components of QoL (e.g. health-related QoL that only refers to health and functional ability).
- *Combination definition*: includes QoL concepts that overlap the global and component definition and as such comprise specific components and overall QoL.

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<sup>1</sup> <https://www.who.int/healthinfo/survey/whoqol-qualityoflife/en/>

## **2.2 Well-being and its relationship to QoL**

Similar to QoL, the concept of well-being is a vast and multi-faceted construct that provides a broad spectrum of different definitions and is closely intertwined with QoL. As there is no conceptual agreement on well-being and quality of life, there is also no consensus on their relationship to each other. Some authors use the term synonymously with QoL, referring to different domains of well-being, whereas others consider it a component of the overarching concept of QoL (Makai et al., 2014, Camfield and Skevington, 2008).

## **3 Method**

A comprehensive scoping review was conducted based on the methodological framework outlined by Arksey and O'Malley (2005) and the guidelines recommended by Peters et al. (2015). Scoping reviews aim to provide an overview of the extent and range of a diverse body of literature on a particular topic by mapping the key concepts and relevant aspects pertaining to a research question (Levac et al., 2010, Peters et al., 2015). Unlike systematic reviews, which attempt to synthesize empirical evidence within a relatively small set of parameters, scoping reviews are used to achieve in-depth and broad results incorporating a variety of study designs. This method is useful for disciplines with emerging evidence to clarify working definitions and key concepts of an extensive topic or field (Peters et al., 2015, Levac et al., 2010, Arksey and O'Malley, 2005). Scoping reviews focus on content rather than on the methodological quality of studies (Peters et al., 2015, Levac et al., 2010).

The scoping review process is iterative, requires reflection at each step and, if necessary, a revision of search terms or identified literature to ensure comprehensive results. This review of QoL of informal carers was conducted following the five key stages of (1) identifying the research question, (2) identifying relevant studies, (3) study selection, (4) charting the data, and (5) collecting, summarizing and reporting the results (Arksey and O'Malley, 2005). After having formulated a research question (1), the identification of relevant studies (2) involved a comprehensive literature search that went beyond electronic databases and included reference lists and searching for key journals by hand. Different from systematic reviews, the process of study selection (3) included post-hoc exclusion and inclusion criteria that were applied after a first round of searching and reading to specify the search strategy and eliminate irrelevant studies. To extract data and illustrate the key characteristics of all included studies with respect to the research question, we used a (4) data-charting form. For the final stage of the scoping review (5), an analytical framework, or thematic construction, was applied to provide an overview of the range of evidence. Tables and charts were used to graphically represent the results,

the descriptive account to report the findings in terms of extent, nature and characteristics of the studies.

### **3.1 Data sources and search strategy**

In autumn 2018, the initial search was implemented on two electronic databases: MEDLINE/Pubmed (biomedical sciences) and CINAHL/EBSCO (nursing and allied health) databases were searched for relevant articles. Limits were placed on the publishing dates ranging from 1998 and 2019 to capture the expansion of studies on quality of life and well-being in the informal caregiving literature. The following keywords were used for the search: informal care OR informal caregiver AND quality of life OR well-being OR satisfaction OR outcome OR effect OR long-term care OR care at home AND older people OR elderly. In addition, a web search was conducted in Google Scholar to identify further articles and potential grey literature. Considering the plethora of literature in Google Scholar, we limited the search to the first 200 hints (sorted by relevance by Google Scholar). A follow-up search of the two databases involving a modification of key words was performed in spring 2019 to maximize the findings of relevant articles and to include studies published after the initial search. The reference lists of several key articles were also screened at this time to identify further articles that were not found on the databases.

### **3.2 Eligibility Criteria**

The decision on the articles deemed relevant for inclusion was based on several eligibility criteria with respect to the phenomenon of interest. Studies were included if they analyzed outcomes of caregiving or experiences of caregivers with respect to quality of life, well-being, or life satisfaction of the informal carers. As for the study participants, informal carers who provided home-based care for older people with functional disabilities or medical diagnosis were eligible for inclusion. Studies exclusively addressing dementia care were excluded. Studies in the context of institutionalized care (e.g. nursing homes, hospitals) were excluded as the research interest lies in the provision of informal care in the individual's home or residence. Due to translation constraints, articles published in languages other than English or German were excluded.

### **3.3 Study selection: screening**

This step involved an iterative process of data screening, refining the search strategy, and reviewing full-text articles. In the first screening process, the titles and abstracts were reviewed according to inclusion criteria. Studies that did not meet the eligibility criteria were eliminated. Based on the abstract review process, the search strategy was refined and key words were modified to ensure all relevant studies were captured. When the abstract was not available or not sufficient to determine relevance, the article was included

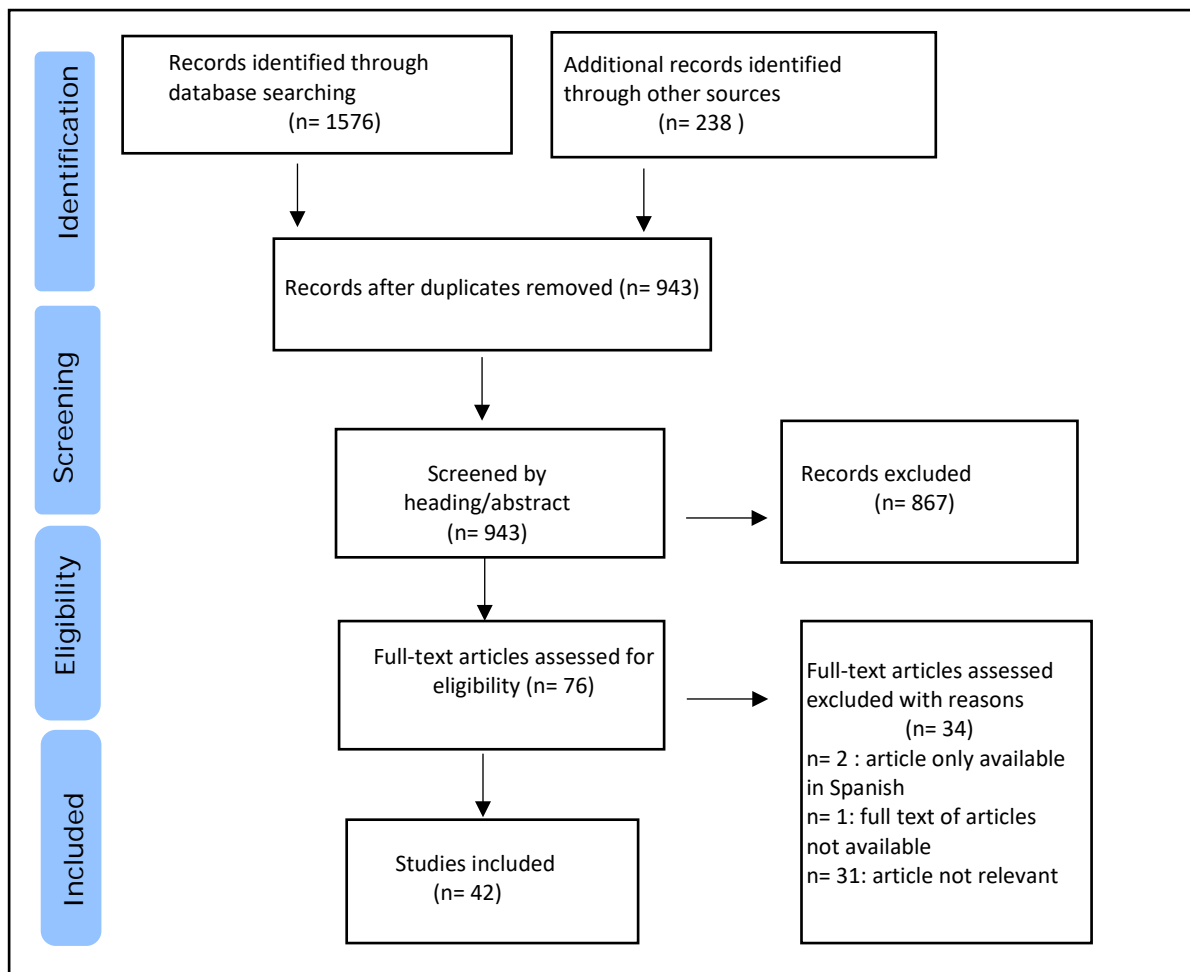
for subsequent screening of the full text. As for the full-text review, each study was reviewed and assessed to determine inclusion with respect to the aim and objective of the research question. Any uncertainties or difficulties related to the selection of articles were discussed with the second co-author.

### **3.4 Data extraction and synthesis**

For organizing, analyzing and synthesizing data, the Microsoft Excel spreadsheet program was used. First, data from the included studies was extracted with respect to certain characteristics and key information that help to answer the research question. Data items included: author, country and date of publication, research question, study design, study population, dimensions/ themes of QoL, influencing QoL factors, limitations, and uniqueness of the study. This data extraction framework allowed for comparison of key components and enabled synthesis of data across various categories. In a second step, the extracted data was synthesized using manual coding to identify the relevant data items that emerged regarding domains and themes of caregiving outcomes and the factors influencing caregiving effects.

### **3.5 Number of studies and their characteristics**

The initial database search conducted in October 2018 and the follow-up search conducted in February 2019 yielded 851 potentially relevant articles. Including additional sources and removing duplicates, all together 943 records were identified. On the basis of title and abstract screening, 76 articles were selected for the full-text review. Three articles were not included in the review due to unavailability or language barrier (Berg-Weger and Tebb, 2015, Orueta-Sanchez et al., 2011, Ferreira et al., 2011). After the full-text screening, a final sample of 42 articles was included in the analysis. The flow chart below in Figure 1 shows the scoping review process in detail.

**Figure 1 PRISMA flowchart of study selection process**

## 4 Results

### 4.1 Included studies and their characteristics (search results)

The main characteristics extracted from each study are provided in Table 1. All included articles were published between 1998 and 2019, with the majority (60%) published after 2008. The scoping review comprised 31 quantitative studies and 11 qualitative studies (including one case study). Among the quantitative studies included, six longitudinal designs were identified, with a follow-up period ranging from 7 days to 9 years.

The most frequently used data collection method among the quantitative studies was a self-administered questionnaire (17), followed by face-to-face or telephone interviews (13). Two studies additionally used a palm pilot or time diaries to collect data. The qualitative studies mainly used semi-structured interviews for data collection (9) and one study combined semi-structured questions with the technique of cognitive interviewing.

The effects of caregiving were evaluated either in the context of quality of life, well-being, or life satisfaction. With respect to the conceptual framework applied in the QoL context, 7 studies used a generic concept of QoL, 5 studies applied a psychological or emotional



concept of QoL, 7 studies used a health-related concept of QoL, 4 studies adopted a concept of care-related QoL and 2 studies focused on disease-specific QoL. Half of the qualitative studies referred to a subjective definition of QoL or well-being and the other half explored outcomes of caregiving in a general context of positive and negative caregiving experiences. A construct of well-being was applied in 7 studies, among which 2 studies used a concept of experienced well-being.

The study population either involved informal carers as a general group of relatives, neighbors or friends or referred to specific subgroups of informal carers. A number of studies included a mix of family carers (15), spouse carers (4), female caregivers (4) or adult children (2). 5 studies included a mix of family carers, neighbors and friends or "others". One study defined informal carers as family or non-kin carers and a different study distinguished between spouses, adult children and non-immediate carers (including siblings, in-laws and friends). 11 other studies did not report on the relationship between carer and care receiver.

Several studies were related to informal carers supporting a specific diagnosis group such as patients suffering from cancer, rheumatoid arthritis, Parkinson's disease, incontinence, pressure ulcer or general chronic diseases.

**Table 1 Main characteristics of the included studies**

Author, Year and Country	Aim/Research Question	Study Design	Study Population	Domains of Carers' QoL/Well-being
<b>QoL and its domains</b>				
Iecovich 2008 Israel	To examine the extent to which various types of formal services help to reduce burden and increase QoL and to find the factors that best explain the QoL of primary caregivers	Quantitative cross-sectional study, random selection; face-to-face interviews	Family primary caregivers (spouses, adult children, sons/daughters-in-law) (n=114)	<b>QoL:</b> <ul style="list-style-type: none"> <li>▪ Physical health</li> <li>▪ Mental health</li> <li>▪ Social relationships</li> <li>▪ Environment</li> </ul>
Rodriguet-Pérez et al. 2017 Spain	To analyze the relationship between coping strategies and QoL dimensions in primary caregivers of dependent elderly relatives	Quantitative cross-sectional study; face-to-face interviews	Primary family caregivers of dependent relatives (n=86)	<b>QoL:</b> <ul style="list-style-type: none"> <li>▪ Psychological</li> <li>▪ Physical</li> <li>▪ Social relations</li> <li>▪ Environment</li> </ul>
Reis et al. 2013 Brazil	To evaluate the QoL and associated factors for caregivers of functionally impaired elderly people	Quantitative cross-sectional study; self-administered questionnaire	Family caregivers of functionally impaired elderly people (n=40)	<b>QoL:</b> <ul style="list-style-type: none"> <li>▪ Physical</li> <li>▪ Psychological</li> <li>▪ Social Relations</li> <li>▪ Environment</li> </ul>
Naef et al. 2017 Switzerland	To determine subgroups of family carers based on relationship and caregiving indicators and to explore group differences in carer outcomes.	Quantitative secondary analysis, mailed questionnaire	Family caregivers (identified as the closest confident of the care recipient) (n=277) High-intensity carers (n=120) and low-intensity carers (n=157)	<b>QoL:</b> <ul style="list-style-type: none"> <li>▪ Physical well-being</li> <li>▪ Psychological well-being</li> <li>▪ Social relationships</li> <li>▪ Environmental QoL</li> </ul>
Irfan et al. 2017 Pakistan	To assess the impact of caregiving on the lives of caregivers	Quantitative cross-sectional study; self-administered questionnaire	Caregivers including relatives and friends (mainly adult-children)	<b>QoL:</b> <ul style="list-style-type: none"> <li>▪ Physical</li> <li>▪ Psychological</li> <li>▪ Family</li> <li>▪ Work</li> <li>▪ Financial status</li> <li>▪ Daily routine</li> <li>▪ Recreational life</li> <li>▪ Health</li> </ul>
Di Rosa and Lamura 2016 Italy	To assess whether urinary and or fecal incontinence in people aged 60 or over affects caregivers' QoL.	Quantitative experimental study; self-administered questionnaire	Family or non-kin carer supporting an older person who suffers from any kind of incontinence	<b>QoL:</b> <ul style="list-style-type: none"> <li>▪ Psychological</li> <li>▪ Emotional</li> </ul>
Chappell and Dujela 2008 Canada	To identify the risk of lower quality of life among the caregivers providing heavy care and	Quantitative longitudinal study (T1 and T2 after a year), face-to-face interviews with structured questionnaire	Informal caregivers (sample divided in spouses, daughters, sons and others) (n= 92)	<b>QoL:</b> <ul style="list-style-type: none"> <li>▪ Life satisfaction (health, finances, family relations,</li> <li>▪ Overall perceived stress</li> </ul>

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Author, Year and Country	Aim/Research Question	Study Design	Study Population	Domains of Carers' QoL/Well-being
	distinguishing between role-specific and overall outcomes.		Caregivers with heavy demands (Eligible caregivers had to provide at least 4h of direct care for at least 3 days/week)	friendships, housing, partner, recreation activity, religion, self-esteem, transportation, life as a whole)
Hubley et al. 2003 Canada	To compare QoL, health and social support of caregivers and non-caregivers living in non-metropolitan areas	Quantitative cross-sectional survey; self-administered questionnaire	Family caregivers (85% of the sample were spouses) (n=239)	<b>QoL:</b> <ul style="list-style-type: none"> <li>▪ Happiness</li> <li>▪ Life satisfaction</li> <li>▪ Satisfaction with QoL</li> <li>▪ Satisfaction with current/past accomplishment in life</li> </ul>
Ratcliffe et al. 2013 Australia	To measure and evaluate the quality of life of a sample of the older Australian population according to carer status (comparing caregivers to non-caregivers).	Quantitative survey study; face-to-face interviews	Informal caregivers (Relative, friend or neighbor) (n=115) Non-caregivers (n=671)	<b>QoL:</b> <ul style="list-style-type: none"> <li>▪ Attachment (love and friendship)</li> <li>▪ Security (Future concern)</li> <li>▪ Role (doing things that make you feel valued)</li> <li>▪ Enjoyment</li> <li>▪ Control</li> </ul>
Di Novi et al. 2015 Italy/UK	To analyze the impact of provision of care on the health and QoL of female informal caregivers and to compare the relationship across European regions.	Quantitative analysis of secondary data drawn from two waves (2004 and 2006) from a European database and compared to non-caregivers.	Female family caregivers between 50 and 65 caring for a parent (in-law) comparing Northern Europe, Southern Europe and the Mediterranean countries (n=1825)	<b>QoL</b> <ul style="list-style-type: none"> <li>▪ Control</li> <li>▪ Autonomy</li> <li>▪ Self-realization</li> <li>▪ Pleasure</li> </ul>
Van den Broek and Grundy 2018 UK	To measure the impact of LTC on QoL of informal caregivers regarding different LTC coverage in Sweden and Denmark	Quantitative secondary data analysis of longitudinal data (6 waves) of European study on health, aging and retirement	Adult children providing care to one or both parent(s) (n=5450)	<b>QoL:</b> <ul style="list-style-type: none"> <li>▪ Control</li> <li>▪ Autonomy</li> <li>▪ Self-realization</li> <li>▪ Pleasure</li> </ul>
<b>Health-related QoL (HrQoL) and its domains</b>				
Brouwer et al. 2004 USA	To examine the burden of informal caregivers supporting patients with rheumatoid arthritis at home and to discuss the relationship between objective burden, subjective burden and QoL	Quantitative study; postal questionnaire	Spouse caregivers providing care for a long time (n=153)	<b>HrQoL:</b> <ul style="list-style-type: none"> <li>▪ Mobility</li> <li>▪ Self-care</li> <li>▪ Daily activities, Pain/complaints, Mood/anxiety</li> </ul>

Author, Year and Country	Aim/Research Question	Study Design	Study Population	Domains of Carers' QoL/Well-being
Kenny et al. 2007 Australia	To understand the health impacts of caregiving on informal carers in the palliative context	Cross-sectional quantitative study; observational design; face-to-face interview	Informal carers of patients receiving formal palliative care at home	<b>HrQoL domains</b> <ul style="list-style-type: none"> <li>▪ Physical functioning</li> <li>▪ Role physical</li> <li>▪ Bodily pain</li> <li>▪ General health</li> <li>▪ Vitality</li> <li>▪ Social functioning</li> <li>▪ Role emotional</li> <li>▪ Mental Health</li> </ul>
Ho et al. 2009 Hong Kong	To investigate the impact of caregiving on the health status and QoL of primary informal caregivers of elderly care recipients comparing caregivers and non-caregivers	Cross-sectional quantitative study; random telephone dialing	Primary informal caregivers aged 65 or older: family member, relative or friend (n=246)	<b>HrQoL:</b> <ul style="list-style-type: none"> <li>▪ Physical functioning</li> <li>▪ Role physical</li> <li>▪ Bodily pain</li> <li>▪ General health</li> <li>▪ Vitality</li> <li>▪ Social functioning</li> <li>▪ Role emotional</li> <li>▪ Mental Health</li> </ul>
Yikilkan et al. 2014 Turkey	To assess depression, anxiety and the QoL of caregivers for LTC home patients	Quantitative cross-sectional data; self-administered questionnaire	Informal caregiver of LTC home patients (63)	<b>HrQoL</b> <ul style="list-style-type: none"> <li>▪ Physical functioning</li> <li>▪ Role physical</li> <li>▪ Bodily pain</li> <li>▪ General health</li> <li>▪ Vitality</li> <li>▪ Social functioning</li> <li>▪ Role emotional</li> <li>▪ Mental Health</li> </ul>
Tooth et al. 2008 Australia	To investigate the effect of type of impairment of care recipients on the level of burden and QoL of elderly Australian carers	Quantitative cross-sectional sub-study nested in a longitudinal Study on women's health; postal survey	Female caregivers providing care to a person they live with having either a physical or cognitive impairment	<b>HrQoL:</b> <ul style="list-style-type: none"> <li>▪ Physical functioning</li> <li>▪ Role physical</li> <li>▪ Bodily pain</li> <li>▪ General health</li> <li>▪ Vitality</li> <li>▪ Social functioning</li> <li>▪ Role emotional</li> <li>▪ Mental Health</li> </ul>
Rodrigues et al. 2016 Portugal	To evaluate the quality of life of informal caregivers of patients with pressure ulcer; assess their levels of burden; to analyze the variables influencing both their quality of life and burden.	Quantitative cross-sectional study; self-administered questionnaire	Primary caregivers of patients with pressure ulcer (n=145)	<b>HrQoL:</b> <ul style="list-style-type: none"> <li>▪ Physical functioning</li> <li>▪ Role physical</li> <li>▪ Bodily pain</li> <li>▪ General health</li> <li>▪ Vitality</li> <li>▪ Social functioning</li> <li>▪ Role emotional</li> <li>▪ Mental Health</li> </ul>
Roth et al. 2009 USA	To examine the QoL correlates of family caregiving and caregiving strain	Quantitative cross-sectional study (part of a bigger study on geographic and racial differences in stroke); structured telephone interviews	Family caregivers (n=43,099)	<b>HrQoL:</b> <ul style="list-style-type: none"> <li>▪ Physical functioning</li> <li>▪ Role physical</li> <li>▪ Bodily pain</li> <li>▪ General health</li> <li>▪ Vitality</li> <li>▪ Social functioning</li> <li>▪ Role emotional</li> <li>▪ Mental Health</li> </ul>
<b>Care-related QoL and its domains</b>				
Metzelthin et al. 2017	To study positive and negative caregiver outcomes at home and in	Quantitative secondary analysis of a longitudinal study; face-to-	Primary informal caregivers delivering unpaid care in family,	<b>Care-related QoL</b>

Author, Year and Country	Aim/Research Question	Study Design	Study Population	Domains of Carers' QoL/Well-being
Netherlands	LTC and the association with characteristics of informal caregivers and receivers.	face interviews or self-administered questionnaire	household or social network (n=5197)	<ul style="list-style-type: none"> <li>▪ Care-related fulfilment</li> <li>▪ Relational problems with care-recipient</li> <li>▪ Mental health problems</li> <li>▪ Physical health problems</li> <li>▪ Problems completing daily activities</li> <li>▪ Financial security</li> <li>▪ Social support</li> </ul>
Van de Ree et al. 2017 Netherlands	To determine the care-related quality of life (CarerQoL) of informal caregivers of elderly patients in the first 6 month after a hip fracture.	Quantitative cross-sectional study; random sample; telephone interviews	Primary informal caregivers: Family member or unpaid helper of a person following a hip fracture at one, three or six month (n=123)	<b>Carer related QoL:</b> <ul style="list-style-type: none"> <li>▪ Satisfaction</li> <li>▪ Support</li> <li>▪ Problems with daily activities</li> <li>▪ Financial problems</li> <li>▪ Relational problems</li> <li>▪ Mental health</li> <li>▪ Physical health</li> </ul>
Rand and Malley 2014 UK	To explore carers' experiences and perceptions of QoL in the context of adult social care services	Qualitative study; cognitive interviewing and open-end questions	Informal carers of people with physical disability, mental disability or intellectual disability (n=31) being in contact with social care services	<b>Care related QoL:</b> <ul style="list-style-type: none"> <li>▪ Occupation</li> <li>▪ Control</li> <li>▪ Social participation</li> <li>▪ Feeling encouraged and supported</li> <li>▪ Self-care</li> <li>▪ Time and space to be yourself</li> <li>▪ Safety</li> </ul>
Rand et al. 2019 UK	To explore the relationship between reasons for caring and care-related QoL and subjective strain	Quantitative cross-sectional study; face-to-face or telephone interviews	Informal carers of adults with care needs using LTC services (n=387)	<b>Care related QoL:</b> <ul style="list-style-type: none"> <li>▪ Occupation</li> <li>▪ Control</li> <li>▪ Social participation</li> <li>▪ Time and space to be yourself</li> <li>▪ Self-care</li> <li>▪ Safety</li> <li>▪ Feeling encouraged and supported</li> </ul>
<b>Disease-specific QoL and its domains</b>				
Cubukcu 2018 Turkey	To evaluate the QoL and influencing factors affecting the caregivers of cancer patients	Quantitative cross-sectional descriptive study; questionnaire	Caregivers of cancer patients (77% family members, 23% nurses) (n=48)	<b>Cancer-specific QoL:</b> <ul style="list-style-type: none"> <li>▪ Physical burden</li> <li>▪ Disruptiveness</li> <li>▪ Positive adaption</li> <li>▪ Financial concerns</li> <li>▪ Additional factors (disruption of sleep, pain management, protection of patient, sexual functioning, etc.)</li> </ul>
Borneman 1998 USA	To illustrate the impact of care on QoL of family caregivers	Case study from a study in progress	Family caregivers of cancer patient s(person who plays a significant role in the care recipient's life, not necessarily legally related	<b>Cancer-specific QoL:</b> <ul style="list-style-type: none"> <li>▪ Psychological well-being</li> <li>▪ Social well-being</li> <li>▪ Spiritual well-being</li> </ul>

Author, Year and Country	Aim/Research Question	Study Design	Study Population	Domains of Carers' QoL/Well-being
				<ul style="list-style-type: none"> <li>Physical well-being</li> </ul>
Morley et al. 2012 UK	To determine the main influences of informal caregiving on carer's QoL supporting people with Parkinson's disease at home	Quantitative cross-sectional study; self-reported questionnaire	Informal carers supporting a patient with Parkinson's disease (92% spouses and partners) (n=238)	<b>Parkinson's disease carer QoL:</b> <ul style="list-style-type: none"> <li>Social and Personal Activities</li> <li>Self-Care</li> <li>Anxiety and Depression</li> <li>Stress</li> </ul>
<b>Well-being and its domains</b>				
Gitlin et al. 2006 USA	To examine the short- and long-term effects of Adult day services on carers' well-being	Longitudinal quantitative study (T1, T2, T3 within a year); Quasi-experimental design; Face-to-face or telephone interviews	Primary caregivers of a family member who used adult day services (n=129)	<b>Well-being:</b> <ul style="list-style-type: none"> <li>Overall well-being (self-perceived change of psychological and emotional aspects)</li> </ul>
Arai et al. 2002 Japan	To investigate the experiences among caregivers providing informal care at home	Quantitative longitudinal study (T1 and T2 after one year); Self-reported questionnaire	Family caregivers (spouses, daughters (in-law)) (n=47)	<b>Well-being</b> <ul style="list-style-type: none"> <li>Subjective burden (= personal strain and role strain)</li> </ul>
Wagner and Brandt 2017 Germany	To determine whether regional formal LTC provision affects the well-being of spousal caregivers	Quantitative secondary data analysis of data from 138 European regions; Face-to-face interviews	Spousal caregivers (n=1 807)	<b>Well-being</b> <ul style="list-style-type: none"> <li>Life satisfaction</li> <li>Loneliness</li> <li>Depression</li> </ul>
Eom et al. 2017 Singapore	To understand the effect of informal caregiving on caregivers' well-being with respect to different types of patient- caregiver relationships	Quantitative analysis of secondary data of a longitudinal survey (T1 and T2 after 6 month)	Primary carers grouped in: Spouses Adult-children Non-immediate family members (siblings, in-laws, friends)	<b>Well-being:</b> <ul style="list-style-type: none"> <li>Self-rated general health</li> <li>Stress level</li> <li>Quality of life (mobility, self-care, daily life, pain, anxiety)</li> </ul>
Trivedi et al. 2014 USA	To characterize the socio-demographics, health and well-being of informal carers	Quantitative secondary analysis using data of a large US telephone survey	Informal carers providing help to friends or relatives with a health problem or long-term illness (n=111 156)	<b>Well-being:</b> <ul style="list-style-type: none"> <li>Mental health</li> <li>General health</li> <li>Sleep hygiene</li> <li>Perceived social and emotional support</li> </ul>
Freedman et al. 2019 USA	To explore whether there are signature care patterns throughout the day and whether these care patterns have implications for caregivers' experienced well-being	Quantitative study using secondary panel data; telephone interviews and time diary data	Spouse caregivers (n= 511) Sample divided in 4 caregiver types: marginal (1h/day) sporadic helping with mixed activities (2h/day)	<b>Experienced well-being:</b> <ul style="list-style-type: none"> <li>Calm</li> <li>Happy</li> <li>Sad</li> <li>Frustrated/ worried</li> </ul>

Mapping the domains and influencing factors of quality of life in informal carers of community-dwelling older adults

Author, Year and Country	Aim/Research Question	Study Design	Study Population	Domains of Carers' QoL/Well-being
			persistent, transportation and visiting persistent, household work (7h/day)	
Poulin et al. 2010 USA	To measure active helping behavior among spouse caregivers and its positive and negative effects for caregivers	Quantitative study survey; use of palm pilot data over 7 days	Spouse caregivers providing full-time home care(n=73)	<b>Experienced well-being:</b> <ul style="list-style-type: none"> <li>▪ Happy/Joy</li> <li>▪ Pleased</li> <li>▪ Enjoyment/Fun</li> <li>▪ Depressed</li> <li>▪ Unhappy/Frustrated</li> <li>▪ Angry/hostile</li> <li>▪ Worried/anxious</li> <li>▪ Guilty/stressed</li> </ul>
<b>Experiences of caregiving in the context of QoL or well-being (qualitative studies)</b>				
Puig et al. 2015 Spain	To assess the objective and subjective elements related to QoL of the primary caregivers of dependent elderly	Qualitative descriptive study; semi- structured interviews	Primary caregivers providing daily care (about 7h/day) (n=22)	<b>Subjective definition of QoL:</b> <ul style="list-style-type: none"> <li>▪ Health</li> <li>▪ Having money and resources</li> <li>▪ Good relationships</li> <li>▪ Having love</li> <li>▪ Autonomy</li> <li>▪ Job</li> <li>▪ Time for yourself</li> </ul>
Lee et al. 2015 Singapore	To identify domains of QoL that are relevant to Chinese caregivers of advanced cancer patients in Singapore	Qualitative study; exploratory phenomenological design; semi-structured interviews	Primary family caregivers (direct care of the patient's day-to-day needs) and secondary caregivers (main decision maker) of advanced cancer patients (n=26)	<b>Affected domains</b> <ul style="list-style-type: none"> <li>▪ Physical health</li> <li>▪ Mental health</li> <li>▪ Social health</li> <li>▪ Spiritual health</li> <li>▪ Financial health</li> <li>▪ Daily life</li> </ul>
Thai et al. 2016 USA	To explore factors affecting QoL of informal caregivers supporting older adults with late-life disabilities	Qualitative interview study; semi-structured telephone interviews	Caregivers of older adult relatives of 65 or older (n =42)	<b>Affected domains:</b> <ul style="list-style-type: none"> <li>▪ Emotional</li> <li>▪ Social</li> <li>▪ Financial</li> <li>▪ Physical</li> </ul>
Gallardo-Flores et al. 2018 Spain	To analyze the perceptions of health, well-being , support networks and quality of life of informal caregivers after completing an intervention program	Qualitative interventional study; semi-structured interviews	Female caregivers between 45 and 73 providing support to a family member with high care needs (also involving some dementia patients)	<b>Affected domains:</b> <ul style="list-style-type: none"> <li>▪ Leisure-time</li> <li>▪ Social relations</li> <li>▪ Self-care</li> <li>▪ Body pain</li> <li>▪ Worry</li> <li>▪ Anxiety</li> <li>▪ Stress</li> <li>▪ Depression</li> <li>▪ Self-efficacy</li> </ul>
Hawranik and Strain 2007	To explore the experiences of caring and whether employment, use of home care-services, or other factors influence the health of	Qualitative exploratory descriptive study; focus groups and semi-structured interviews	Informal carers (sample included family member or friends) (n=26)	<b>Affected Domains</b> <ul style="list-style-type: none"> <li>▪ Psychological</li> <li>▪ Emotional</li> </ul>

Author, Year and Country	Aim/Research Question	Study Design	Study Population	Domains of Carers' QoL/Well-being
Canada	caregivers and their ability to manage their caregiving.			<ul style="list-style-type: none"> <li>▪ Physical health</li> </ul>
Metha and Leng 2017 Singapore	To explore the impact of caregiving on the lives of caregivers focusing on the experiences of informal and formal live-in caregivers	Secondary analysis of qualitative data; exploratory design;	Adult children (n=28), formal carers (n=15)	<b>Affected domains</b> <ul style="list-style-type: none"> <li>▪ Financial stress</li> <li>▪ Physical stress</li> <li>▪ Emotional stress</li> <li>▪ Psychological stress</li> <li>▪ Work life</li> </ul>
Mthembu et al. 2014 South Africa	To explore the perceptions and experiences of family caregivers regarding caring for older adults with chronic diseases in the Western Cape	Qualitative study; exploratory descriptive design; semi-structured interviews	Family caregivers of older people with chronic diseases (n=6)	<b>Affected domains:</b> <ul style="list-style-type: none"> <li>▪ Mental domain</li> <li>▪ Emotional domain</li> <li>▪ Physical domain</li> <li>▪ Work life</li> <li>▪ Social life</li> <li>▪ Family support</li> <li>▪ Spiritual life</li> </ul>
Nocon and Pearson 2000 UK	To explore the experiences of non-kin carers providing support to frail older people living at home.	Qualitative exploratory study; in-depth interviews	Non-relative main caregivers (friend or neighbor) (n=29)	<b>Affected domains:</b> <ul style="list-style-type: none"> <li>▪ Emotional domain (satisfaction, pleasure, feeling privileged)</li> <li>▪ Adjustments</li> <li>▪ Relational domain (developing friendships with care recipient) Daily/weekly life</li> </ul>
Sawatzky et al. 2003 Canada	To examine the effects of caregiving on the health and well-being of urban female caregivers	Qualitative study; descriptive design; two in-depth semi-structured interviews	Female caregivers being primary caregivers of a family member (they all suffered from a chronic disease) (n=11)	<b>Affected domains:</b> <ul style="list-style-type: none"> <li>▪ Physical domain</li> <li>▪ Social domain</li> <li>▪ Mental domain</li> <li>▪ Emotional domain</li> <li>▪ Financial domain</li> <li>▪ Personal goals and life expectations</li> <li>▪ Spirituality</li> </ul>
Brewer 2008 USA	To explore if there is a relationship between the caregiving approach utilized and the subjective well-being of the caregivers	Qualitative study; semi-structured interviews; Exploratory descriptive study	Family caregivers divided into 3 subgroups: primary caregivers; spouse caregivers; caregiving teams (23% spouses, 45% children, 14% sons/daughters (in-law), friends (n=22)	<b>Affected domains:</b> <ul style="list-style-type: none"> <li>▪ Overall well-being,</li> <li>▪ Physical health</li> <li>▪ emotional impact</li> <li>▪ Social support</li> <li>▪ Adaption to caregiving function</li> <li>▪ Family conflict</li> </ul>



## 4.2 Dimensions and subdimensions of QoL and well-being

Studies on QoL of informal carers applied quantitative and/or qualitative methods. Quantitative studies used pre-defined concepts involving domains and subdomains of different levels, ranging from an exclusive focus on a small number of QoL domains to an overall QoL broken down into a series of dimensions and subordinate components. In contrast, only a minority of qualitative studies were conducted within a conceptual framework of QoL or well-being and explicitly measured perceptions concerning these concepts. Instead, most qualitative studies identified themes related to informal carers' experiences and embedded their findings in the context of QoL or well-being.

As the concepts of QoL and well-being were used interchangeably or reflected comparable domains of life, the following results present the domains and subcomponents without distinguishing between the two concepts.

Figure 2 illustrates the various domains, subdomains, and aspects that were identified in the articles according to different levels of abstraction. The bigger circles refer to the three broadest dimensions that subsume most aspects of carers' QoL and well-being. Depending on the approach and the concepts of QoL or well-being, the measurements in the studies involved several broad dimensions including a variety of subcomponents or solely referred to certain subdomains considered relevant.

### 4.2.1 Three core domains of informal carers' QoL and well-being

In the majority of studies, three core domains of life were discussed: the physical, psychological, and social domains. The *physical domain* typically comprised several components, such as energy/fatigue, mobility, pain/discomfort, work capacity, activities of daily living and dependency on medical aids (Rodríguez-Pérez et al., 2017, Iecovich, 2008, Reis et al., 2013, Naef et al., 2017, Irfan et al., 2017, Chappell and Dujela, 2008). The *psychological domain* was predominantly measured in terms of positive and negative emotions (anxiety, guilt, worries, depression, despair, satisfaction, etc.), mental health, self-esteem and/ or general life satisfaction. Qualitative studies added components such as loss of privacy, control, spontaneity, and grieving as well as diverse positive emotions of feeling competent, appreciated, hopeful (Lee et al 2014), joyful and blessed (Thai et al., 2016), and feeling pleased and privileged (Nocon and Pearson, 2000). The reported emotional effects also referred to the psychological processing of the caregiving experience in terms of change, acceptance and adaption. The *social domain* typically captured social relationships, friendships, and support but also sexual activity and family relations or familial support (Rodríguez-Pérez et al., 2017, Iecovich, 2008, Naef et al., 2017, Reis et al., 2013, Chappell and Dujela, 2008, Cubukcu, 2018). In qualitative studies, identified aspects concerned social isolation (Gallardo-Flores et al., 2018), change of social roles (not

feeling as a couple anymore) (Sawatzky et al., 2003), social support (Lee et al., 2015, Brewer, 2003) or sacrificing own time (Mthembu et al., 2016).

#### **4.2.2 Additional domains of informal carers' QoL**

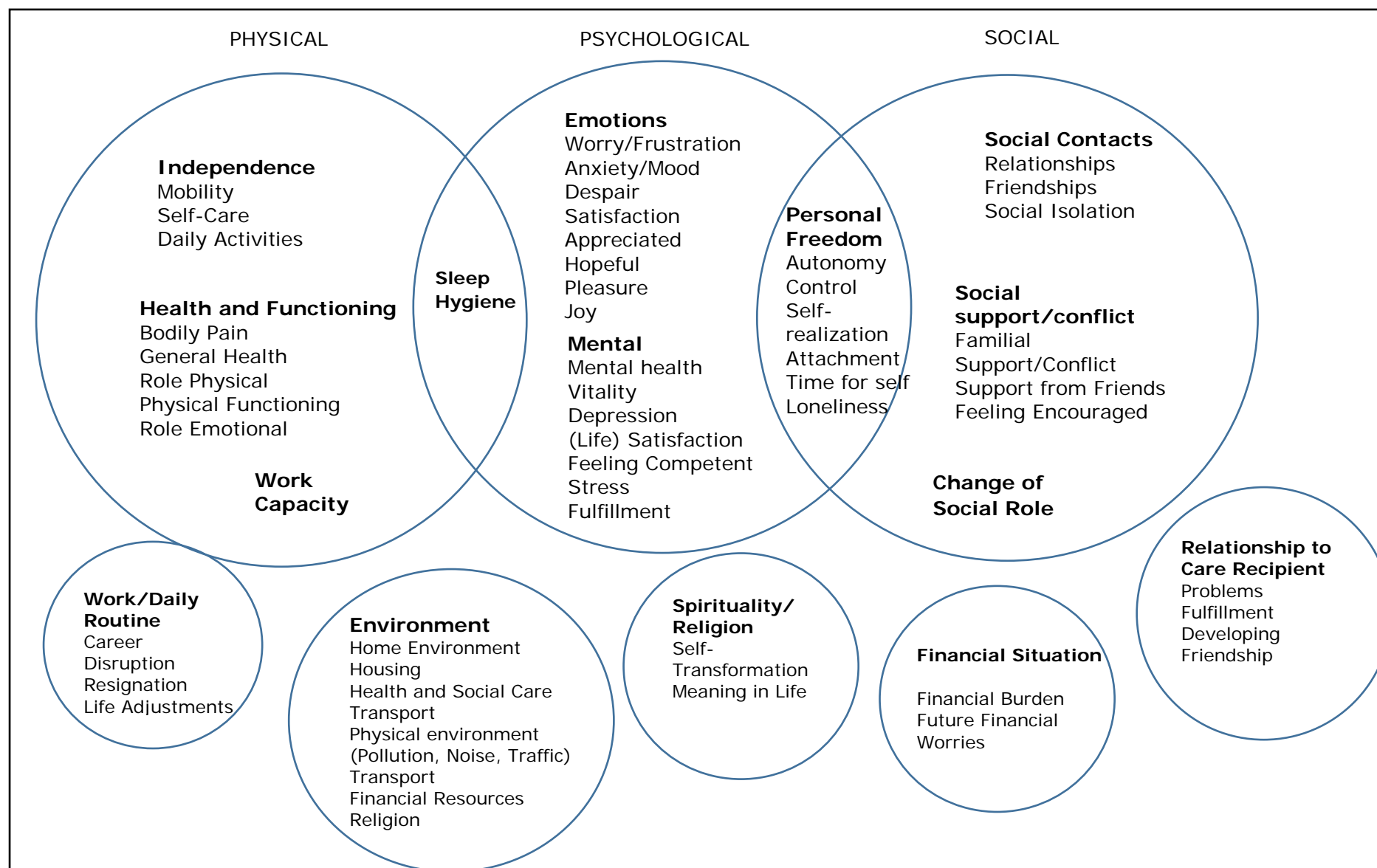
In addition to the three dominant domains of QoL of informal carers mentioned above, other domains that could be identified in the literature were, for example, *Spirituality/Religion*, *Financial Security*, *Environment* and *Work/Daily Routine*. The domain of *Spirituality or Religion* resulted from a more specific context of care provision and was assessed in studies related to caregivers supporting (palliative) cancer patients or providing high intensity care (Borneman, 1998, Chappell and Dujela, 2008, Cubukcu, 2018). The theme of spirituality was also reported in several qualitative studies focusing on caregivers of patients with cancer or a different chronic disease and was mainly associated with meaning in life, coping strategies, and self-transformation (Lee et al., 2015, Mthembu et al., 2016, Sawatzky and Fowler-Kerry, 2003). The environmental domain was broader [in nature] covering aspects such as physical environment (pollution, noise,...), transport, home environment, health and social care, opportunities for recreation or financial aspects (Rodríguez-Pérez et al., 2017, Iecovich, 2008, Reis et al., 2013, Naef et al., 2017). The latter two were also considered as a single QoL domain (Cubukcu, 2018, Irfan et al., 2017). In qualitative studies, financial issues were reported in the context of current financial burden due to medical expenses or loss in income and future financial worries (Mehta and Leng, 2017, Sawatzky and Fowler-Kerry, 2003, Lee et al., 2015). *Work or daily routine* was mainly captured as a component of the physical domain in terms of functional limitation (Rodríguez-Pérez et al., 2017, Iecovich, 2008, Reis et al., 2003, Naef et al., 2017) or in terms of role conflict (Metzelthin et al., 2017, Van de Ree et al., 2017). In several qualitative studies, *Work/Daily routine* was reported in the context of work and career disruptions, adjustments, or resignation (Lee et al., 2015, Mehta and Leng, 2017, Nocon and Pearson, 2000, Mthembu et al., 2016).

#### **4.2.3 Specific concepts of QoL and well-being of informal carers**

Several studies applied a specific concept of QoL or well-being focusing only on certain aspects of QoL. These concepts comprised health-related QoL and care-related QoL, as well as psychological and emotional constructs of QoL or well-being. Several authors focusing on specific concepts still used the overall term 'QoL' or well-being but only covered a selection of components considered most relevant. Health-related QoL focused on physical and mental health of informal carers and its interference with social and physical activities. The key characteristics included physical functioning, physical role, bodily pain, general health, vitality, social functioning, emotional role (referring to role limitations due to emotional problems) and mental health (Kenny et al., 2010, Ho et al., 2009, Yıkılkan et al., 2014, Tooth et al., 2008, Rodrigues et al., 2016, Roth et al., 2009). Concepts of care-

related QoL that were applied in the context of LTC only covered domains that directly corresponded to the use of formal care services. This included aspects such as *Feeling encouraged and supported*, *Personal Safety* (related to the caregiving role) or *Time and space to be yourself* (Rand et al., 2019, Rand and Malley, 2014). Other constructs of care-related QoL were more interested in feelings arising from caregiving measured in terms of *Care-related Fulfillment*, *Satisfaction* and *Relational problems with the care recipient* (Metzelthin et al., 2017, Van de Ree et al., 2017). Similarly, psychological constructs of QoL and well-being referred to an individual's personality at the interface of mental and social domains. QoL was conceptualized in terms of *Control*, *Autonomy*, *Self-realization* and *Pleasure* (van den Broek and Grundy, 2018, Di Novi et al., 2015) or *Attachment* (love and friendship), *Role* (doing things that make you feel valued), *Enjoyment* and *Security* (future concerns) (Ratcliffe et al., 2013). Further psychosocial aspects involved *Overall life satisfaction*, *Loneliness* and *Depression* (Wagner and Brandt, 2017) or *Mental and general health*, *Sleep hygiene* and *Emotional and social support* (Trivedi et al., 2014). The spectrum of emotional well-being was measured by two studies focused on experienced well-being during a day or week. A range of positive and negative emotions such as calm, happy, joyful, pleased, sad, depressed, unhappy, etc. were assessed together with the momentary caregiving activities and helping behavior (Freedman et al., 2019, Poulin et al., 2010). In a broader sense, emotional QoL also covered *Happiness*, *Life Satisfaction*, *Satisfaction with QoL*, and *Satisfaction with current and past accomplishment in life* (Hubley et al., 2003).

**Figure 2 Identified domains and subcomponents of informal carers' QoL and well-being**



### **4.3 Factors influencing the impact of caregiving on QoL of informal carers**

The consequences of caregiving on QoL of informal carers are shaped by a number of different influencing and moderating factors. In the selected articles, socio-economic characteristics of the informal carers, objective and subjective care burden, coping strategies, the characteristics of the care recipients, characteristics of the care relationship, social informal support of the informal carer, the care arrangement and the socio-cultural context were related to carers' QoL and well-being (see Table 2). The heterogeneity of characteristics sheds light on the complexity of caregiving outcomes as a result of numerous interacting factors.

#### **4.3.1 Caregiver characteristics**

A number of studies indicated that informal carers' QoL and well-being were influenced by certain **caregiver characteristics**, including age, gender, income, education and the health status of the informal carers. Amongst these socio-economic factors, gender was one of the most cited factors associated with QoL, with mixed results. A stream of studies demonstrated a higher risk of lower general QoL, mental QoL and more relational problems with the care recipient among female carers (Brouwer et al., 2004, Freedman et al., 2019, Ho et al., 2009, Morley et al., 2012, Van de Ree et al., 2017, Rand et al., 2019). However, there are also studies that did not find any gender differences with respect to informal carers' overall QoL (Chappell and Dujela, 2008, Di Rosa and Lamura, 2015, Yikilkan et al., 2014, Gültas and Yilmaz, 2017).

The majority of the studies observed a negative association between age and QoL of informal carers, revealing higher psychological, physical, and general QoL within the younger age group (Morley et al., 2012; Metzelthin et al., 2017; Ratcliffe et al 2013; Rodriguez-Perez et al 2017; Van den Ree et al., 2018; Van den Broek and Grundy, 2018). Several other studies, however, did not discover an influence of caregiver's age on QoL (Metzelthin et al., 2017; Chappell and Dujela, 2008; Di Rosa and Lamura 2016; Yikilkan et al., 2014).

Financial instability and lower education of the informal carers may aggravate the negative impact of caring, contributing to less happiness and lower mental or general QoL as several studies showed (Yıkılkan et al., 2014, Reis et al., 2013, Iecovich, 2008, Ekwall, 2004, Cubukcu, 2018, Gültas and Yilmaz, 2017).

With respect to the health status of informal carers, a clearly positive association between health status of the carer and physical and overall QoL was documented (Ekwall, 2004, Morley et al., 2012, Puig et al., 2015, Iecovich, 2008, Rand et al., 2019).

#### **4.3.2 Caregiver burden**

Another important relationship captured in several studies referred to the influence of **objective and subjective burden** on carers' quality of life. Objective burden, predominantly measured in terms of time spent on caregiving (comparing high-intensity vs. low-intensity care) was negatively associated with several aspects of QoL (Ho et al., 2009, Metzelthin et al., 2017, Naef et al., 2017, Van de Ree et al., 2017, Iecovich, 2008, Rand et al., 2019). Other studies considered the duration of the caregiving role revealing both negative and positive effects of longer duration of caregiving on the QoL of informal carers (Rodrigues et al., 2016; Morley et al., 2012, Ratcliffe et al., 2013, Di Rosa and Lamura, 2016, Trivedi et al., 2014; Rand et al., 2019). However, apart from the detrimental effects of high intensity and long duration of care, distinct helping behaviors may affect caregivers' experienced well-being in different ways. Using more precise measures, Poulin and colleagues (2010) found that a caregiver's active helping behavior predicted greater levels of positive emotional well-being whereas time spent on call was associated with negative feelings among spouse caregivers. Similarly, Freedman and colleagues (2019) observed different care patterns over a 24-hour period with respect to experienced well-being. Providing sporadic assistance (2 hours a day) with mixed activities was associated with higher emotional well-being compared to providing marginal (1 hour a day) or persistent (more than 7 hours a day) care.

The relationship between QoL and subjective burden, including the carer's emotional and mental perception of the caregiving experience was also ambiguous. Several studies discovered a negative association between subjective burden and psychological, social or health-related QoL of informal carers (Iecovich, 2008, Ho et al 2009, Roth et al., 2009) whereas others found a high level of carer QoL despite the existence of subjective burden (Metzelthin et al., 2017; Chappell and Dujela, 2008). This was explained by the fact that personal resources and positive experiences included in the overall QoL measures may buffer the negative consequences of caregiving on carers' QoL.

### **4.3.3 Coping strategies**

The literature review shows that informal carers rely on different **coping strategies and personal resources** that may buffer the negative impact of caregiving on the quality of life of informal carers. Coping resources, including resilience (e.g. Chapell and Dujela, 2008), inner strength and personal mastery (e.g. Cameron et al., 2006) or spiritual practices (e.g. Sawatzky et al., 2003; Mehta and Leng, 2017; Mthembu et al., 2016) were observed as moderating factors associated with higher psychological well-being or better general QoL of carers. Rodriguez and colleagues (2017) focused on different types of coping strategies and observed both positive and negative impacts on QoL. Thus, behavioral and emotional disengagement were associated with lower emotional QoL, whereas acceptance and reappraisal of the caregiving situation were associated with higher emotional QoL. An important strategy identified among non-kin carers was related to self-determination, such as the possibility to set limits in order to protect their own health and general well-being (Nocon and Pearson, 2000). Another factor that may contribute positively to caregiving outcomes related to skills training and preparedness for the role of an informal carer (Mehta and Leng, 2017; Mthembu et al., 2016; Naef et al., 2017, Rand et al., 2019).

### **4.3.4 Characteristics of the care recipient**

Among the **characteristics of the care recipients**, usually comprising age, gender and health conditions, the latter seemed to be the most important explanatory factor for informal carers' QoL. A negative association was found between the QoL of informal carers and their health conditions in terms of level of disability, number of morbidities, level of mobility and self-perceived health (Brouwer et al., 2004, Reis et al., 2013, Metzelthin et al., 2017, Morley et al., 2012, Naef et al 2017, Rodrigues et al., 2016, Rand et al., 2019). Age and gender of the care recipient, however, appeared to be less relevant in explaining QoL of informal carers although Metzelthin and colleagues (2017) found evidence of a positive relationship between age of the care recipient and the quality of life of informal carers.

### **4.3.5 Relationship between informal carer and care recipient**

In several studies, the **relationship between informal carer and care recipient** has been discussed as a factor affecting QoL of informal carers. Type (Eom et al., 2017, Van de Ree et al., 2017, Arai et al., 2002) and quality of relationship (Naef et al., 2017, Poulin et al., 2010, Mehta and Leng, 2017) was reported as a predictor of QoL outcomes for carers. However, only a small number of studies referred to the subgroups of caregiver-care recipient relationships (e.g. spouses, adult-children, friends, neighbors). Eom and colleagues (2017) examined the effects of the caregiving relationship on carers' well-being, making a distinction between spouses, adult children and "non-immediate" carers (siblings,

in-law, friends). Better QoL outcomes and lower levels of stress for the latter were explained by higher emotional detachment and typically less help provided among siblings, relatives-in-law and friends. However, Van den Ree and colleagues (2018) did not find lower care-related QoL among spouses despite them providing significantly more hours of care compared to children, siblings, or others. Likewise, in a longitudinal study by Arai and colleagues (2002) higher evidence of adaption and better well-being were observed among spouses compared to adult children (in-law).

With respect to the quality of relationship, a sense of mutuality (e.g. Naef et al., 2017, Poulin et al., 2010), closeness in the relationship or high interdependence (e.g. Poulin et al., 2010) mostly observed in family relationships, was associated with positive consequences of caregiving. In contrast, a difficult caregiver-care-recipient relationship was examined to have a negative influence on the emotional and psychological QoL domains of informal carers (Mehta and Leng, 2017). A study on non-kin carers found a good relationship between informal carers and care recipients to be a crucial factor for providing care in the first place (Nocon and Pearson, 2000). Furthermore, co-residence was associated with poorer QoL in mental and social domains and a lower overall care-related QoL (e.g. Roth et al., 2009, Metzeltin et al., 2017, Di Rosa and Lamura 2016, Rand et al., 2019).

#### **4.3.6 Informal support**

Various studies also examined the role of **informal support**, provided by family, friends, or neighbors on the QoL and well-being of carers. Several studies discovered support from the family as a moderating factor, showing a positive influence on the QoL of informal carers. Family support was detected to buffer the negative effects of emotions, such as anger, anxiety, and guilt experienced by informal carers (Brewer, 2008) and was associated with positive feelings of reward, attachment, and stress relief or in general with better mental and physical health (Mthembu et al., 2016, Sawatzky et al., 2003, Nocon and Pearson 2000, Reis et al., 2013). On the other hand, tensions with other family members regarding the caregiving situation or lack of assistance from other family members was found to have a negative effect on the emotional and psychological well-being of the informal carers (Mehta and Leng, 2017, Hawranik and Strain, 2007).

#### **4.3.7 LTC provision and formal care arrangements**

In a broader perspective, the LTC policy of a country and the availability of formal care services may be essential to the well-being of an informal carer. A cross-cultural study by Di Novi and colleagues (2015) traced the different well-being outcomes of female informal carers across the European North-South gradient partially to the formal care structures. A higher degree of formal care services in Northern Europe was thus likely to explain better results regarding autonomy and control experienced by informal carers than in Continental



Europe. Similarly, a cross-European study by Wagner and Brandt (2017) found a positive link between the perceived control over one's life and the regional availability of LTC services. Likewise, a positive effect between LTC coverage and QoL of informal carers was observed in a longitudinal study comparing QoL outcomes in Denmark and Sweden during a time of cutbacks in LTC services (Van den Broek and Grundy, 2018).

With respect to formal care arrangements, several studies pointed to positive and negative influences of home care workers or other professionals on the QoL of informal carers. The use of home-based care services or stays in adult day care centers was associated with higher social and mental or overall QoL (Iecovich 2008, Mehta and Leng, 2017, Gitlin et al., 2006, Di Rosa and Lamura, 2016). A study by Rand and Malley (2014) revealed positive effects of support services distinguishing between direct support for the carers themselves (e.g. support groups) and indirect support meeting the care recipient's needs (e.g. home care). By contrast, negative impact of home care services on the informal carers' QoL was expressed in terms of stress and frustration due to frequent change of staff and lack of skills or due to a mismatch between the support provided and the care recipient's needs (Hawranik and Strain, 2007, Mehta and Leng, 2017, Eom et al., 2017).

#### **4.3.8 Socio-cultural factors**

In line with different geographical locations and different LTC policies, **socio-cultural factors** may also explain different QoL outcomes across countries. In Southern European countries, as the aforementioned study by Di Novi and colleagues showed (2015), female carers had a better QoL in terms of self-realization and pleasure compared to Northern and Continental Europe. This difference was partially explained by the stronger social bonds prevailing in Southern countries and the positive effects deriving from the fulfillment of social norms and expectations. Several other studies observed positive effects on carers' well-being associated with a strong sense of obligation due to filial responsibility in eastern cultures, religious promises, and marital commitment or a strong personal bond with the care recipient (Metha and Leng, 2017, Mthembu et al., 2016, Van Groenou et al., 2013). However, regarding caregiving as a duty or obligation may also lead to negative caregiving outcomes such as lower mental well-being (Arai et al., 2002, Rand et al., 2019).

**Table 2 Influencing factors for QoL and well-being of informal carers**

Influencing Factors	Positive/Negative Association with QoL of Informal Carers	Studies
<b>Caregiver Characteristics</b>		
<b>Age</b>	Negative association with care-related QoL, physical and psychological QoL  No age-based effects found	Metzelthin et al. (2017); Ratcliffe et al. (2013); Rodriguez-Perez et al. (2017); Van den Ree et al. (2018); Morley et al. (2012); Van den Broek and Grundy (2018)  Chappell and Dujela (2008); Di Rosa and Lamura (2016); Yikilkan et al. (2014)
<b>Gender</b>	Lower general QoL, mental QoL and more relational problems for female carers  No gender-based effects found with respect to QoL	Brouwer et al.(2004); Freedman et al. (2019); Ho et al. (2009); Morley et al. (2012); Van de Ree et al. (2017); Rand et al. (2019)  Chappell and Dujela (2008); Di Rosa and Lamura (2016); Yikilkan et al. (2014)
<b>Education</b>	Negative association with mental and general QoL	Yikilkan et al. (2014); Reis et al. (2013); Iekovich (2008); Ekwall and colleagues (2004); Cubukcu (2018)
<b>Financial Status</b>	Positive influence on mental and general QoL	Yikilkan et al. (2014); Reis et al. (2013); Iekovich (2008); Ekwall and colleagues (2004); Cubukcu (2018); Ratcliffe et al. (2013)
<b>Health Status</b>	Positive association with general and physical QoL	Ekwall et al. (2004); Morely et al. (2012); Puig et al. (2015); Iekovich (2008); Rand et al. (2019)
<b>Care recipient characteristics</b>		
<b>Age</b>	Positive effect on QoL	Metzelthin et al. (2017)
<b>Gender</b>	-	-
<b>Health Condition</b> (level of disability/mobility, number of morbidities, self-perceived health)	Negative effect on QoL	Brouwer et al. (2004); Reis et al. (2013); Metzelthin et al. (2017); Morley et al. (2012); Naef et al. (2017); Rodrigues et al. (2016); Rand et al. (2019)
<b>Relationship between informal carer and care recipient</b>		
<b>Type of Relationship</b>	Better QoL outcomes for siblings, in-law-relatives, and friends compared to spouses and adult children	Eom et a.l (2017)

	Better QoL outcomes for spouses compared to adult children	Ree et al. (2018); Arai et al (2002)
<b>Quality of Relationship</b>	Relationship of mutuality, closeness and high interdependence had a positive effect on QoL  A difficult relationship was negatively associated with mental and psychological QoL	Naef et al. (2017); Poulin et al. (2010)  Metha and Leng (2017)
<b>Co-residence</b>	Negative effect on mental and social QoL and overall care-related QoL	Brouwer et al 2004; Reis et al 2013; Metzelthin et al 2017; Morley et al 2012; Naef et al 2017; Rodrigues et al 2016; Rand et al 2019
<b>Coping strategies</b>		
<b>Resilience &amp; Personal Resources</b>	Positively associated with psychological well-being and general QoL	Chapell and Dujela (2008); Cameron et al. (2006); Sawatzky et al. (2003); Metha and Leng (2017); Mthembu et al. (2016)
<b>Type of Coping Strategies</b> ▪ Avoidance coping  ▪ Emotion-focused coping  ▪ Problem-focused coping	Behavioral and emotional disengagement  Was negatively associated with emotional QoL  Acceptance and reappraisal was positively associated with emotional QoL  No association found	Rodriguez-Pérez et al. (2017)
<b>Skills Training &amp; Preparedness</b>	Positive effect on QoL	Metha and Leng (2017); Mthembu et al. (2016); Naef et al. (2017); Rand et al. (2019)
<b>Burden of Caregiving</b>		
<b>Objective Burden</b> ▪ Time spent on caregiving  ▪ Duration of caregiving	Negatively associated with QoL  Positive and negative effect on QoL	Ho et al. (2009); Metzelthin et al. (2017); Naef et al. (2017); Van de Ree et al. (2017), Iekovich (2008); Rand et al. (2019)  Rodrigues et al. (2016); Morley et al. (2012); Ratcliffe et al. (2013); Di Rosa and Lamura (2016); Trivedi et al. (2014)
<b>Subjective Burden</b> (Emotional and mental perspective of the caregiving experience)	Negative association with psychological, social or HrQoL  Co-existence of QoL and burden	Iekovich (2008); Ho et al. (2009); Roth et al. (2009)  Metzelthin et al. (2017); Chappell and Dujela (2008)

<b>Social Informal Support</b>		
<b>Family</b>	<p>Positive moderating factor on emotional, mental and physical QoL</p> <p>Familiar tensions had a negative effect on emotional and psychological well-being</p>	<p>Brewer (2008); Mthembu et al. (2016); Sawatzky et al. (2003); Nocon and Pearson (2000); Reis et al. (2013);</p> <p>Mehta and Leng (2017); Hawranik and Strain (2007)</p>
<b>Care Arrangement</b>		
<b>Home-Based Care Services</b>	<p>Positive association with social, mental and overall QoL</p> <p>Negative effect on emotional and psychological QoL</p>	<p>Iekovich (2008); Metha and Leng (2017); Gitlin et al. (2007); Rand and Malley (2014); Di Rosa and Lamura (2016)</p> <p>Hawranik and Strain (2007); Metha and Leng (2017); Eom et al. (2017)</p>
<b>LTC Policy</b>		
<b>Availability of LTC Services</b>	<p>Positive association with perceived control and general QoL</p>	<p>Di Novi et al. (2015); Wagner and Brandt (2017); Van den Broek and Grundy (2018)</p>
<b>Socio-Cultural factors</b>		
<b>Social Norms and Obligation</b>	<p>Fulfillment of social norms had a positive effect on emotional QoL</p> <p>Regarding caregiving as a duty was associated with lower mental well-being</p>	<p>Di Novi (2015); Metha and Leng (2017)</p> <p>Arai et al. (2002); Rand et al. (2019)</p>
<b>Marital Commitment</b>	<p>Positive effect on well-being</p>	<p>Mthembu et al. (2016)</p>

## 5 Discussion

The goal of this paper was to deepen the understanding of informal carers' QoL, its definitions, and determinants. Building on a scoping review, we mapped and displayed a variety of QoL concepts and their domains, aspects and influencing factors published in scientific literature on QoL and well-being of informal carers. By doing so, we combined the concepts of QoL and well-being for a comprehensive picture of the aspects of caregiving on the living situation of caregivers in the context of home care. The present scoping review included 42 studies, following eligibility criteria.

Measuring the impact of caregiving on informal carers' QoL and well-being turned out to be a complex and multilayered field of research that involves a variety of concepts, domains, themes, and experiences. In the studies included in this scoping review, QoL components were heterogeneous, ranging from mental and physical health variables to social aspects (e.g. social relations and support) and personal freedom (e.g. control, autonomy and independence) to emotional, financial, and spiritual well-being. Three core domains (psychological, social, and physical) seemed to underlie most of the measured components, however, as no issue is solely a physical, psychological, or social problem, the dynamic interrelationship of the domains needs to be considered (Schalock et al., 2002).

This scoping review found that the phenomenon of QoL and well-being can be approached in a variety of ways producing results on different aspects of a carer's life. Two approaches could be identified: the first, those seeking to capture overall life experience of informal carers within a broad theoretical framework, and the second, studies using specific constructs of QoL and well-being. Specific concepts focused on particular domains that are relevant in the context of serious illness or end-of-life care, on domains sensitive to LTC services or on aspects mainly influenced by the health of the informal carer. Depending on the chosen construct, QoL may serve as an indicator of psychosocial well-being, of satisfaction with LTC services, or rather as an index of mental and physical health in the context of caregiving. Hence, the conceptualization of QoL and well-being applied in a study needs to be well considered, as the definition and understanding of the concepts has important implications for the way we think about informal carers and their needs and shape the caregiving policy lens (Schalock et al., 2002).

The understanding of informal carers' QoL also depended on the methods used. While in quantitative studies the evaluation of predefined domains and key indicators implies what aspects of life matter in a carer's life, qualitative studies seemed to be more capable of capturing QoL of informal carers as an individual phenomenon in the personal context of the informal carer. As good QoL has a different meaning for different people (Schalock

2002), qualitative studies were more sensitive to exploring those aspects of life that were relevant to the individual in their unique environment. Despite the important contribution of qualitative research, quantitative studies still seem to predominate in the literature on QoL and well-being of informal carers, offering insights in the determinants of QoL. Mixed method approaches could build upon the strength of each method and would allow both QoL and well-being to be understood as sensitizing concepts rather than concrete entities (Gasper, 2010).

Although informal carers comprise of a diverse group of people including spouses, adult children, relatives, friends, and neighbors, QoL research has not been sensitive to certain subgroups of informal carers. Most studies focused on family carers and particular subgroups of family relatives (spouses, adult children) whereas only one study was explicitly interested in caregiving experiences of non-relatives (Nocon and Pearson, 2000). In the remaining studies, neighbors and friends were not excluded but treated as a rather neglected category defined as "others". Family members indeed play a major role and seem to be the most valuable and vulnerable group of caregivers (Glozman, 2004). However, recent research suggests that non-kin carers are an important resource for older people aging at home (Wosko and Pleschberger, 2016, Pleschberger and Wosko, 2015) and thus need to be considered as an independent subgroup of informal carers. As there is increasing agreement that we need to know more about the variation in QoL between different groups of older adults (e.g. age, gender) (Vaarama, 2009), there should also be more awareness about the differences of QoL indicators between subgroups of carers including non-kin carers.

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