

## REVIEW ARTICLE

# Supporting family caregiver engagement in the care of old persons living in hard to reach communities: A scoping review

Niccolò Morelli<sup>1</sup>  | Serena Barello<sup>2</sup> | Maria Mayan<sup>3</sup> | Guendalina Graffigna<sup>2</sup>

<sup>1</sup>Department of Sociology and Business Law, Engage Minds Hub Consumer & Health Research Center, Università di Bologna, Bologna, Italy

<sup>2</sup>Department of Psychology, EngageMinds Hub Consumer & Health Research Center, Università Cattolica del Sacro Cuore (Milano), Milano, Italy

<sup>3</sup>Faculty of Extension, University of Alberta, Edmonton, AB, Canada

**Correspondence**

Serena Barello, Engage Minds HUB – Consumer & Health Research Center, Università Cattolica del Sacro Cuore, Milano, Italy.

Email: serena.barello@unicatt.it

**Funding information**

Fondazione Cariplo

**Abstract**

Today, 8.5% of the world's population is 65 and over, and this statistic will reach 17% by 2050 (He et al., *U.S. Census Bureau, international population reports, P95/16-1, An ageing world: 2015, U.S., 2016*). They are the people who, with increasing age, will find themselves more closely interfacing with the national health system, which in many countries shows strong imbalances between rural and urban areas. In this context, a fundamental role is played by the relatives who find themselves becoming informal caregivers to compensate for lack of services. To date, however, little has been done to help these people. In this article, we want to identify the nature and extent of research evidence that had its objective to help informal caregivers in rural, hard to reach areas (Grant & Booth, *Health Information & Libraries Journal*, 2009, 26, 91). Following the approach set out by Arksey and O'Malley (*International Journal of Social Research Methodology*, 2005, 8, 19), we conducted a scoping review in May 2018 and closed the review with an update in September 2018. We identified 14 studies published from 2012, the European Year of Active Ageing, promoted by the European Commission, which had three domains of implementation: emotional support to decrease the emotional burden of caregivers, educational support to increase their skills, and organisational support to improve the mobility of caregivers and care-receivers. Although informal caregivers play a fundamental role in many countries, the studies that have been involved in alleviating their caring burden are few; nevertheless, they provide interesting indications. This lack of attention confirms how this portion of the population is still neglected by scientific research and risks having unequal access to health and social care. Future research is needed, not only to create and improve services to caregivers in rural, hard to reach areas, but also to evaluate and focus on the participation and the engagement of caregivers in the co-design of these services.

**KEYWORDS**

caregiver engagement, family engagement, hard to reach contexts, health, informal caregiving, rural areas, scoping review

## 1 | INTRODUCTION

The proportion of the population aged 65 or over is increasing worldwide. Today, 8.5% of the worldwide population is already 65 or over, and this statistic will reach 17% by 2050 (He, Goodkind, & Kowal, 2016). In Europe, this statistic is already at 19.2%, with a 3% point increase from 2006 to 2016 (Eurostat, 2016). Literature suggests that there is an inequity in the health of the elderly population living in rural and remote areas with higher levels of disease risk factors, frailty and social exclusion (Burholt & Dobbs, 2012; Phillipson & Scharf, 2005) compared with their urban counterparts (Bacsu et al., 2014; Jakovljevic & Laaser, 2015; Johansson, 2014).

The ageing population presents a range of challenges for the health and social services system, particularly in hard to reach areas where the workforce shortage and lack of access to specialist services are complicating factors. It is interesting to note that, ironically, "ageing in rural areas has received less attention in the literature than the proportions of older people living in rural areas might suggest" (Wenger, 2001, p. 117). Given that much of the research on the ageing population to date has had an urban bias, it is time to begin considering data on the ageing process occurring in rural and remote areas. The needs of the older population in rural and remote communities are expected to be different from those in urban areas. In this regard, many authors have stated that the specific needs of rural and remote areas in terms of health and social services have not been met by service provision derived from criteria developed in urban contexts. (Burholt & Dobbs, 2012; Havens, Hall, Sylvestre, & Jivan, 2004; Kinsella, 2001; Lau & Morse, 2008; Marcellini, Giuli, Gagliardi, & Papa, 2007; Phillipson & Scharf, 2005). Furthermore, ageing in rural and remote areas might present huge challenges to families, and society as a whole, not least because many of rural contexts, especially in Southern European Countries, are highly family-based with respect to their support for older people (Davey, 2006; Howden-Chapman, Signal, & Crane, 1999; Sixsmith & Sixsmith, 2008; Sixsmith et al., 2014). In these contexts, family is shrinking dramatically, and the role of the family is changing. As an example, across the OECD (Organisation for Economic Co-operation and Development), more than one in ten adults is involved in informal, typically unpaid, caregiving for family and friends, defined as providing help with personal care or basic activities of daily living to people with functional limitations (Schorch, Wan, Randall, & Wulf, 2016) due to old age. There are significant variations in the percentage of the population involved in this type of caregiving across OECD countries. There is no clear geographic distribution in the rate of caregiving, but certain southern European countries have among the highest percentages (Italy, Spain). In 2008, around 35% of the adult population of the Netherlands provided informal care, and 23% of this for more than 3 months (Oudijk, Boer, Woittiez, Timmermans, & Klerk, 2010). In 2009, about four million of the 65 million people in France provided informal care compared to 4.3 million people providing formal care, and in Italy around two-thirds of the care needed by older people was provided by their relatives (Triantafyllou, Mestheneos, Troisi, & Kondratowitz, 2013). In other words, family caregivers of elderly

### What is known about this topic

- Across the OECD, more than one in ten adults is involved in informal caregiving.
- Family caregivers in rural communities are at risk of unequal access to the healthcare system.
- Family caregivers who are more engaged in the care journey have more capability to deal with the stressful situations associated with caregiving.

### What this paper adds

- A comprehensive overview of interventions for engaging family caregivers of elderly people living in rural contexts.
- Three areas of support and intervention: emotional, educational and organisational.
- Engagement is a fundamental strategy to build highly effective services.
- Studies do not focus clearly on a place's definition.

people are a segment of the population at risk of unequal access to the healthcare system, particularly in rural communities, due to the lack of support provided to them.

According to the statistics, it is a fact that informal caregivers do a significant amount of work, and research has shown that in remote communities, caregivers report a daunting burden. In discussing the concept of remote communities in this article, we will refer to both rural and hard to reach communities in order to grasp the differences between them and urban, easily accessible contexts. In assisting the elderly, caregivers indeed experience several hardships, particularly in remote rural areas. In fact, caregivers attest to a critical decrease on their quality of life (Wolff, Spillman, Freedman, & Kasper, 2016) and health issues such as tiredness, insomnia, depression, weight loss or gain, drug use and the need for psychological support; these issues are frequently reported by women, especially if older. This is especially the case for the caregivers of elderly people and for those who are required to dedicate a significant amount of time and intensity to care. In fact, the caregivers of elderly people often become the primary interlocutors for health and social services to make decisions about the patients' therapies and long-term treatments (Hasselkus, 1992). Moreover, caregivers support compliance with treatments and therapies, and they support the elderly in managing follow-ups and clinical exams (Quam, Smith, & Yach, 2006). Last, caregivers are often the primary sources of psychological support and empathy for the care receiver.

Several studies have shown that caregivers are the invisible backbone of the social and health care system, as they facilitate its integration especially in those areas and communities with limited access to services (Bookman & Harrington, 2007; Levine, 2016). For this reason, a stronger partnership and engagement between informal and professional caregivers through more integrated and

person-centred aged care services is needed (Banks, 2004; Barelo & Graffigna 2015; Kröger, 2003; Leichsenring, 2004), particularly in geographically hard to reach communities. Informal caregiver engagement is, similar to patient engagement, an active involvement of the caregiver in the health care system to become more autonomous and effective in taking care of patients' physical and mental health (Coluter, 2012; Graffigna & Barelo, 2018b).

In this scoping review, we will refer to informal caregivers, in particular familial or friend caregivers, using the term caregiver, because their engagement is indeed regarded as a key factor to improve the quality and sustainability of care services for the elderly (Blumenthal, Chernof, Fulmer, Lumpkin, & Selberg, 2016; Boehmer et al., 2014; Graffigna & Barelo, 2015; Noel, Kaluzynski, & Templeton, 2017). Research shows that caregivers who are more taken into account in the decisions related to the care journey of their loved one have more capability to deal with stressful situations associated with caregiving and thus have less anxiety and depression and better perceived health (Barelo, Graffigna, et al., 2015). By feeling more empowered and engaged in caregiving tasks, caregivers might also reach a better work-family balance. Appropriate engagement of and tailored support to caregivers have the potential to improve their experiences and quality of life and to facilitate shared decision-making, while enhancing the quality of care provided to older people and reducing the use of unnecessary health and social services (Lee et al., 2015), as well as increasing the effectiveness of health and social care interventions. Furthermore, supporting the role of caregivers is an important part of providing an adequate continuum of care between informal and formal caregiving.

However, this type of research is not unaffected by serious methodological problems. In fact, rural areas are hard to reach due to the lack of services (Flanagan & Hancock, 2010) caused by a remote geographical, social and economic situation (Shaghghi, Bhopal, & Sheikh, 2011) that isolates these communities.

Caregivers in rural areas can be defined as doubly hard to reach (Brackertz, 2007): they have little time to devote to research, because they are caught up between care tasks and work commitments, and often are not convinced of the utility of doing such research, especially when there are few economic resources. Moreover, there are several problems in defining rural contexts. Definitions of rural are widespread and usually taken as intuitively associated with a small population, sparse settlement and remoteness (Hewitt, 1989), but there is no agreement within the academic community whether these characteristics have to be present together in order to define a settlement as rural or if it is sufficient to present only one of these items (Ratcliffe, Burd, Holder, & Fields, 2016). In this review, we consider studies that have different perspectives on defining "rural", including demographic, remoteness, availability and service accessibility characteristics.

## 1.1 | Objectives

Our aim is to "identify the nature and extent of research evidence" (Grant & Booth, 2009, p. 92) on the interventions in the engagement

of caregivers to the elderly in rural communities, so we conducted a scoping review to analyse, describe and systematise published interventions, supports and programs concerning instruments and tools devoted to improve caregivers' engagement in rural settings. We opted for a scoping review because we wanted to deeply explore the conceptualisation of ageing and of intervention mechanisms adopted to promote caregiver's engagement which oriented such interventions.

## 2 | METHODS

Following the scoping review approach set out by Arksey and O'Malley (2005), we aimed to identify all peer-reviewed, English-language academic articles that investigate interventions for informal caregivers of the elderly living in a rural setting.

The following sections explain the process of identifying search terms, criteria for inclusion and exclusion, and the identification of additional material.

### 2.1 | Search terms

A search string was developed; thanks to several discussions with international multidisciplinary experts in the disciplines of psychology, sociology and managerial engineering. The initial search string was the following:

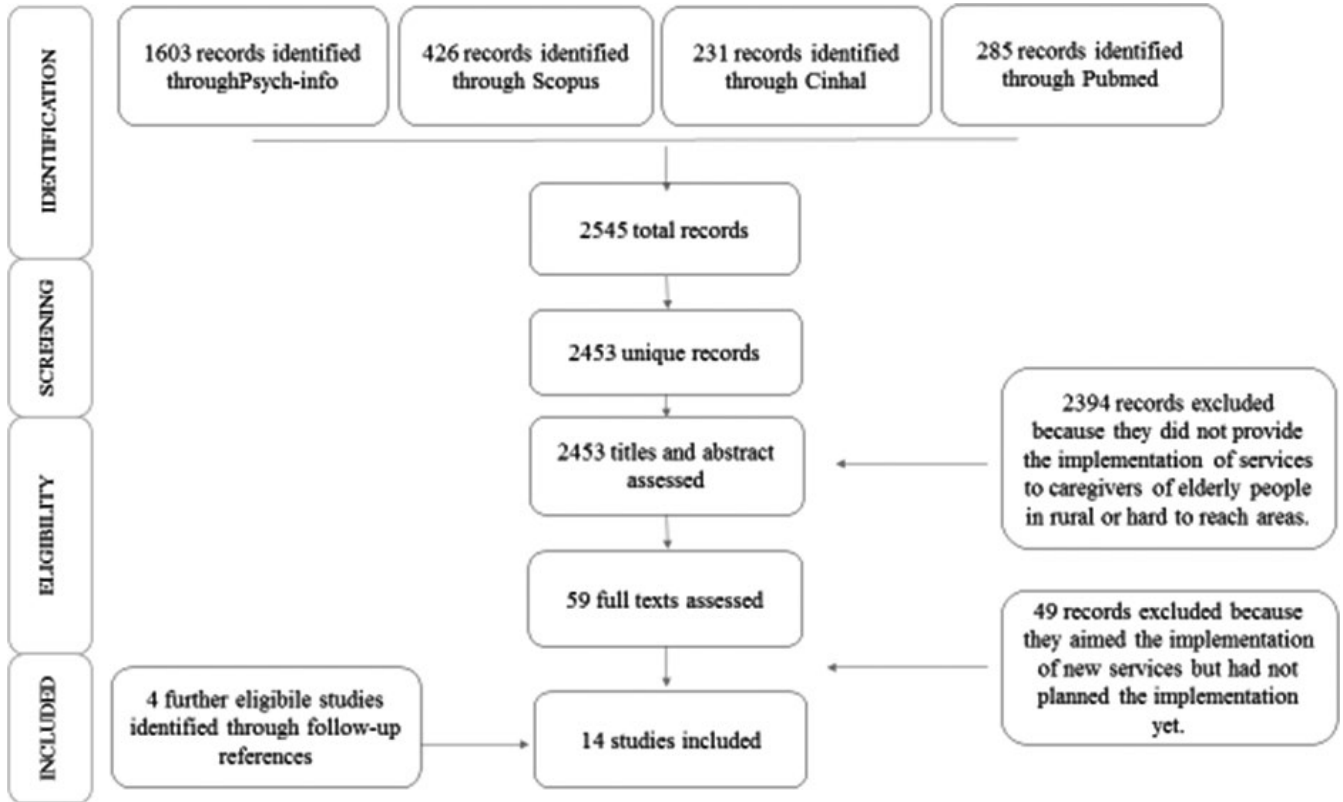
[(caregivers OR family member\*) AND (ageing OR elderly\* OR old\*) OR (patient\*) AND (support OR intervention OR program OR education OR counselling) AND (rural\* OR mountain\* OR "hard to reach")].

The first two terms, "caregivers" and "family member", helped us identify parental caregivers, different from professional caregivers. In order to improve the sensitivity of the search, we added a term linked to the health condition of the care receiver with the term "patient". As we are interested in ageing people, we provided several alternatives in order to catch all the possibilities that refer to old people, including "ageing", "elderly" and "old". Since the types of activity provided to caregivers vary, we included alternative terms to capture all of the possibilities, including "support", "intervention", "program", "education" and "counselling". Moreover, having found difficulties in defining the rural context due to different conceptualisations in several nations, we added to "rural" and "mountain" the phrase "hard to reach", because it is a broader concept and may likely encompass the terms rural and mountain.

### 2.2 | Selection of studies

To be included, scientific articles had to meet these criteria:

1. Publication: articles must have been published in English (as the recognised language of international academic debate), accessible as a full text manuscript in a peer-reviewed journal, and published from 2012 on, which was declared the European Year for Active ageing.



**FIGURE 1** Flowchart of the scoping review

2. Interventions: articles needed to focus on interventions (e.g. psychosocial, educational/training support, organisational help) during the planning, implementation, or analysis of results. This criterion was added in order to remove articles that focused on the necessity of improving services for informal caregivers, but which were not yet implemented. With this criterion, we were able to exclude letters, opinions and comments that did not relate to the effective provision and testing of services for informal caregivers.
3. Receivers: the receivers of the interventions needed to be informal caregivers or family members of old people. It was necessary, in this phase, to sort out from the titles and abstracts articles that focused on informal caregivers, because many interventions were focused on professional caregivers.
4. Care receivers: the care receivers needed to be people aged 60 or over. Although Eurostat defines older generations as those aged 65 and over, some research on older generations include those aged 60 years and over. In order to include as wide a range of research as possible, we lowered the limit to 60 years.
5. Geographical context: articles needed to target rural, mountain, or hard to reach contexts (remote). This choice was aimed at targeting those geographical areas where efforts are being made to support ageing in places where caregivers are primarily informal rather than professional caregivers.

For each electronic database search, a database with the results obtained was built. The databases were then merged and scanned to remove duplicates and create a single database. Titles and abstracts

were checked against criteria one to four. The full texts of potentially eligible articles were then screened against criterion five. Full texts were also screened in cases where it was not clear from the title and abstract which of the criteria had and had not been met (Figure 1). Table 1 shows the detailed process of selection.

### 2.3 | Identification of additional material

Additional material was identified by following up the reference lists of the articles whose full texts were screened. The same criteria were applied to these newly identified articles. Four studies were assessed in this step.

## 3 | ANALYSIS PROCESS

We conducted a mixed methods approach for the analysis of the articles.

For the qualitative analysis, each article was analysed at two levels and divided into a table as follows:

Level 1) Intervention characteristics: objective of the intervention, characteristics of the receiver (by type of patient), context of intervention, presence or absence of technologies, individual or group setting, tools and duration of the intervention. The retrieved studies were organised according to their main objective. In particular, we identified three categories of objectives: (a) psychosocial interventions, (b) educational interventions, (c) organisational interventions.

**TABLE 1** Description of included studies

References	Countries	N participants	Mean age caregivers	Mean age care receivers	Care receiver illness	RCT	CT	CS	P
Alves et al., 2016	Portugal	60 (90% women)	52	83.35	Not specifically diagnosed, inclusion criteria: >60 years old, having problems in performing activities of daily living		X		
Bakitas et al., 2017	USA	20	58.75 (80% spouse)	64.05	Cancer	X			
Blusi et al., 2013	Sweden	31	75	79	Dementia, Stroke, Parkinson's disease, multiple diseases				X
Blusi et al., 2015	Sweden	31	74	n.a.	Chronic illnesses				X
Danzl et al., 2016	USA	12	55	63	Stroke survivors				X
Fordeucey et al., 2012	USA	11	n.a.	n.a.	Progressive dementia				X
Hicken et al., 2017	USA	231 (90% females)	70	n.a.	Dementia	X			
Kaye et al., 2014	USA	n.a.	n.a.	n.a.	n.a.				X
Lorig et al., 2012	USA	60	57	69	Cognitive impaired adults				X
Lundberg, 2014	Sweden	10	80.2	74.5	Stroke or dementia				X
Scott et al., 2015	Australia	n.a.	n.a.	n.a.	Dementia				X
Srisuk et al., 2017	Thailand	100	41	62	Heart failure	X			
Wakefield and Vaughan-Sarrazin 2017	USA	244	64	69	Chronic illnesses			X	X
Wallack et al., 2018	Canada	22	n.a.	n.a.	Dementia	X			

We identified these categories inspired by the categorisation of Roter et al. (1998). We considered the studies under “educational interventions” if they had a knowledge-based pedagogical focus, “psycho-social intervention” if they concerned emotional and affective support and counselling, and “organisational interventions” if they developed strategies and devices aimed at improving health and social services planning and delivery. The classification was discussed, decided and approved by consensus among the authors.

Level 2) Study characteristics: country, study design (randomised controlled trial “RCT”, controlled trial “CT”, cross-sectional “CS”, pilot “P”), sample and number of participants, outcome measures and results.

We also reported how the interventions focused on family caregiver needs, how studies offered a place definition, and the reported barriers to the interventions’ implementation.

## 4 | RESULTS

We completed the literature search in May 2018, finding 2,453 unique results. Following the review of titles and abstracts, 2,394 articles were excluded because they did not provide the implementation of a service to informal caregivers of those 60 and over (criteria 2, 3 and 4). We conducted a further follow-up in September 2018, but we did not find any new studies.

Fifty-nine articles were read in full text, and 49 were excluded mainly because their interventions were not conducted in rural contexts. As described above, a purposive search was conducted to identify additional relevant publications to be included in the review, primarily by scanning reference lists of shortlisted sources. This process yielded four articles that met the inclusion criteria. In total, our scoping review identified 14 publications that met all inclusion criteria.

### 4.1 | Description of included studies

Six of these studies (43%) were conducted in the USA, three (21%) in Sweden and the rest in Portugal, Canada, Australia or Thailand. Most studies were pilot studies (57%), four were randomised controlled trials (29%), two controlled trials (14%) and one a cross-sectional study (7%). One study did not specify the number of cases. The outcome measures varied considerably, but most reported on quantitative measures (79%), and a few reported on qualitative descriptions (21%).

The analysed articles highlight three main categories of needs addressed by the interventions: (a) to overcome isolation, (b) to acquire skills and knowledge and (c) to increase accessibility to services.

Interventions devoted to helping caregivers in overcoming isolation showed how loneliness can be conceived in terms of

psychological isolation or social/relational isolation and can lead to worsening health of the caregiver. For instance, Alves, Teixeira, Azevedo, Duarte, and Paul (2016) explain how caregiving can be a stressful experience with negative outcomes on caregiver's health and even lead to illness, resulting in two ill people. Blusi, Asplund, and Jong (2013) show how the intensity of caring tasks leads many caregivers to feel social isolation and depression (cf. Ekwall, Sivberg, & Hallberg, 2004). These problems tend to increase in hard to reach contexts where home health, transportation services or caregiver support groups are less likely to exist, as shown by Hicken et al. (2017).

Moreover, caregivers often complain about a lack of information on how to manage the pathology of their loved one. This information is often complex and requires the presence of several specialists who can help the caregiver and is particularly difficult to understand in hard to reach contexts, as explained by Wakefield and Vaughan-Sarrazin (2017). Additionally, as shown by Srisuk, Cameron, Ski, and Thompson (2017) speaking about heart failure patients, caregivers play a fundamental role in the prevention of complications and a good education can prevent the exacerbation of diseases.

As many studies have pointed out, psychological and educational support problems are worsened by organisational problems due to the inaccessibility of services by caregivers in small and remote contexts.

## 4.2 | Outcome measures

For the quantitative measures, five studies (36%) proposed scales on caregiver learning linked with proposed educational interventions. Bakitas et al. (2017) used a questionnaire containing questions about how much of the program subjects had viewed, the length of time they engaged in the program, and the clarity of the language. Kaye, Crittenden, Kelly, and Boylan (2014) used the Geriatric Social Work Competency Scale II with Life-long Leadership Skills in order to understand the assessments of acquired gerontological social work competencies after the implementation of the program. Scott, Mittelman, Beattie, Parker, and Neville (2015), translating the New York University Caregiver Intervention for use in Australia, used a multiple-choice quiz in order to reinforce knowledge acquisition and highlight any knowledge areas requiring further attention. Srisuk et al. (2017) assessed outcome measures at baseline, 3 months and 6 months. The outcome measures evaluated heart failure knowledge with the Dutch Heart Failure knowledge scale (van der Wal, Jaarsma, Moser, & Veldhuisen, 2005) and carer perceived control over managing patients with heart failure symptoms through the Control Attitudes Scale-Revised (CAS-R) (Moser et al., 2009). Wallack, Harris, Ploughman, and Butler (2018) used the Cohen Mansfield Agitation Inventory (Cohen-Mansfield et al., 1989) which consists of a list of 29 agitated behaviours, each rated on a 7-point scale of frequency (Table 2).

Five studies (36%) provided measures in order to assess the quality of life in caregivers. Alves, et al. (2016) used the COPE Index-Carers for Older People in Europe (Mckee et al., 2003) scale in order to understand the caregiving context variables. Moreover, Alves, Lorig and

**TABLE 2** Outcome measures

References	Outcome measures
Alves et al., 2016	COPE Index-Carers for Older People in Europe, Caregiver Strain Index (CSI), Zarit Burden Inventory ZBI, Portuguese version of the General Health Questionnaire-12, Short-Form 12 health survey (SF-12)
Bakitas et al., 2017	Survey for educational attainment
Blusi et al., 2013	Interviews
Blusi et al., 2015	Interviews
Danzl et al., 2016	Interviews
Forducey et al., 2012	Subjective Burden subscale, Assistance Support subscale of the Interpersonal Support Survey Checklist (ISEL), Center for Epidemiological Studies-Depression Scale, Physical Symptoms Subscale of the Caregiver Health and Health Behaviour
Hicken et al., 2017	Zarit Burden Inventory ZBI, Patient Health Questionnaire, questions originally proposed by Scharlach et al., 2006 about family conflict and hardship
Kaye et al., 2014	Geriatric Social Work Competency Scale II with Life-long Leadership Skills
Lorig et al., 2012	Caregiver Strain Index (CSI), The Illness Intrusiveness Index, National Health Interview Survey, Visual numeric scales (VNS), PHQ-8 scale
Lundberg, 2014	Caregiver Strain Index (CSI)
Scott et al., 2015	Multiple-choice survey
Srisuk et al., 2017	Dutch Heart Failure knowledge scale, Control Attitudes Scale-Revised (CAS-R), Short-Form 12 health survey (SF-12)
Wakefield and Vaughan-Sarrazin 2017	Zarit Burden Inventory Short form, Caregiving Satisfaction Scale (CSS), National Alliance for Caregiving survey, baseline interviews
Wallack et al., 2018	Cohen Mansfield Agitation Inventory, Caregiving Hassles Scale, Custom Caregiver Quality of Life Index, Desire to Institutionalize Scale (DIS)

Wakefield in their studies used the Caregiver Strain Index (CSI) which measured the stress the caregivers were under (Thornton & Travis, 2003). Alves et al. (2016) and Hicken et al. (2017) used the Zarit Burden Inventory (ZBI) for the caregiver burden (Parks & Novielli, 2000) while Wakefield & Vaughan-Sarrazin used the short version of the Zarit Burden Inventory (Bedard et al., 2001). Wakefield and Vaughan-Sarrazin (2017) measured also the caregiving satisfaction with the Caregiving Satisfaction Scale (CSS; Lawton, Kleban, Moss, Rovine, & Glicksman, 1989). On the same scale, Forducey, Glueckauf, Bergquist, Maheu, and Yutsis (2012) used the Subjective Burden subscale, and they also used the Assistance Support subscale of the Interpersonal Support Survey Checklist (ISEL; cf. Rogers, Anthony, & Lyass, 2004) which assesses caregivers' access to instrumental support, material aid and physical assistance. Lorig et al. (2012) used the

Illness Intrusiveness Index to measure the impact of disease on daily life (cf. Devins et al., 1990). Wallack et al. (2018) used the Caregiving Hassles Scale with a 42-item that assesses the daily burden of caring for a family member with dementia (cf. Kinney & Stephens, 1989). Moreover, they used the Custom Caregiver Quality of Life Index with questions about the impact of caring for a person with dementia, aspects of the caregiver's life, and the caregiver's mental well-being. Finally, they were also interested in understanding the desire of the caregiver to displace the patient to a nursing home through the Desire to Institutionalize Scale (DIS; cf. Morycz, 1985).

Six studies (43%) took measurements concerning the mental and physical health of caregivers. Alves et al. (2016) measured the general health status of caregivers using the Portuguese version of the General Health Questionnaire-12 (Golberg & Hillier, 1979; Laranjeira, 2008) about psychological distress. Both Alves et al. (2016) and Srisuk et al. (2017) used the Short Form-12 health survey (SF-12; Ware, Kosinski, & Keller, 1996) with self-assessment items on health, physical functioning, physical role limitation, mental role limitation, social functioning and mental health. Lorig et al. (2012) used several scales at baseline and three months through self-administered online questionnaires drawn from the National Health Interview Survey (U.S Department of Commerce, 1985). The Visual Numeric Scales (VNS) were used to measure pain, shortness of breath, stress problems, sleeping and fatigue over the past 2 weeks, and they also measured depression with the PHQ-8 scale. Depression was measured likewise by Hicken et al. (2017), who used the Patient Health Questionnaire in order to detect major depressive disorder (Kroenke & Spitzer, 2002), and by Forducey et al. (2012), who used the Center for Epidemiological Studies-Depression Scale (Radloff, 1977) consisting of a 20-item self-report scale measuring depression in non-clinical community populations and the Physical Symptoms Subscale of the Caregiver Health and Health Behaviour (Posner, Jette, Smith, & Miller, 1993). Wakefield and Vaughan-Sarrazin (2017) used the National Alliance for Caregiving survey with 98 questions in eight domains: characteristics of the relationship between the caregiver and care receiver, characteristics of recipient needs, medications, other support, stress on work of the caregiver, physical/emotional/financial stress, information services and demographics.

Six studies (43%) included qualitative outcomes. Blusi et al. (2013), Blusi, Kristiansen, and Jong (2015) used interviews in which they asked to participants to speak freely about their experiences of using internet-based caregiver support. Lundberg (2014) asked questions related to the caregivers' appreciation of life. Danzl et al. (2016) used semi-structured and open-ended interviews to describe the participants' experiences of receiving education. Hicken et al. (2017) assessed family conflict and hardship through some questions originally proposed by Scharlach, Li, and Dalvi (2006). Wallack et al. (2018) also used baseline interviews.

### 4.3 | Target of the intervention

Most of the studies (64%) reported on a sample of female spouse caregivers, two studies (14%) had a more balanced sample, and

three studies did not include the sex of caregivers. The mean age of caregivers was 54.7; four studies (28.6%) did not included the age of caregivers. The mean age of care receivers was 80.6; half of the studies (50%) did not specify the age of the care receivers, but stated they were "older people". Sample sizes varied widely from 12 caregivers in the study of Danzl et al. (2016) to 244 caregivers in the study of Wakefield and Vaughan-Sarrazin (2017). Within the studies, the care receivers suffered from dementia (in six studies, 42.9%), stroke (in three studies, 21.4%), chronic diseases (in two studies, 14.3%), or suffered from cancer, heart failure, Parkinson's, or cognitive impairment (7.1% each). Several symptoms were present in two studies (14.3%).

## 4.4 | Characteristics of the interventions

Overall, half of the interventions had a psychosocial dimension. Eleven consisted of educational interventions (78%) and only one was an organisational intervention (7%). Five interventions had a multicomponent program, but only one study had all three characteristics (Kaye et al., 2014). In the following paragraphs we shall describe in detail the main strategies, tools, settings and results of such different intervention characteristics.

In addition to these three categories, a fourth includes multi-componential interventions, studies that do not focus on a single intervention. Thirty-six percentage of interventions had more than a single objective. Here, for each category of intervention, the main characteristics will be presented (Table 3).

### 4.4.1 | Psychosocial intervention

Psychosocial interventions are understood to be interventions for support caregivers in order to reduce their psychological and social burden. Providing psychosocial services helps the mental health of caregivers in a twofold way: on the one hand, in the management of their own lives, and on the other, in improving the care of their beloved. In fact, caregivers often complain that they do not have the necessary skills to be able to prevent or understand any deterioration in the health of their family member, but this has consequences also on the mental health of caregivers, as he/she feels usually unsuitable for his/her duties. In Alves et al. (2016), the intervention explored the effectiveness of a psychoeducational program for informal caregivers of older adults called "Caring at Home" including 60 informal caregivers of elderly people. The intervention was structured in a 7-week psychoeducational intervention programme in defined sessions, with psychological group support; thanks to the presence of a psychologist in each group session and dedicated emotional support. In the intervention provided by Blusi et al. (2013), Blusi et al. (2015), older family caregivers received ICT-based support from their local authorities for a 3-year period, having access to a secure social community with other family caregivers. The possibility to meet with peers was evaluated by caregivers as an important feature. Kaye et al. (2014)'s intervention shows different support services

**TABLE 3** Characteristics of interventions

References	Psychological support	Educational intervention	Organisational intervention	Multicomponent
Alves et al., 2016	X	X		X
Bakitas et al., 2017		X		
Blusi et al., 2013	X	X		X
Blusi et al., 2015	X	X		X
Danzl et al., 2016		X		
Forducey et al., 2012	X			
Hicken et al., 2017				
Kaye et al., 2014	X	X	X	X
Lorig et al., 2012		X		
Lundberg, 2014	X			
Scott et al., 2015	X	X		X
Srisuk et al. (2017)		X		
Wakefield and Vaughan-Sarrazin 2017		X		
Wallack et al., 2018		X		

for caregivers: by telephone, in person, with familiars, or in support groups, and designed also to enhance caring for themselves. From the studies that have used group settings, it emerges that sharing one's experiences and emotions with people who live with the same conditions can be a very positive tool to reduce stress and exchange good practices (Lundberg, 2014). In the intervention of Lundberg, households containing a family caregiver and a spouse diagnosed with dementia or stroke were followed and observed in a 2-year case study. Caregivers had regular meetings in groups empowering informal caregivers. In the study of Forducey et al. (2012), the Telephone-Based Cognitive-Behavioral Therapy (CBT) for African American Family Caregivers of Older Adults with Progressive Dementia programme and in-person CBT was provided in order to lower the caregiver's stress and depression and to ameliorate their health status. The CBT intervention consisted of a total of 12 1-hr weekly sessions in both group and individual settings. Scott et al. (2015) translated the New York University Caregiver Intervention for use in Australia. This intervention is a 10-week multicomponent intervention which aims to maintain well-being by increasing social support and decreasing family discord, delaying or avoiding nursing home placement of the person with dementia. A learning site was established as well as a learner's manual containing a self-directed training program with information, counselling, assessment and sessions.

#### 4.4.2 | Educational interventions

Educational interventions include those actions aimed at training and improving the skills of caregivers for more effective care of the relative in order to reduce caregiving burden and stress. Alves et al. (2016) in their intervention provided information in their sessions; thanks to a professional expert on the theme of each session. Blusi et al. (2013), Blusi et al. (2015) in their intervention

provided information and educational software in order to ameliorate caregivers' skills. The intervention of Danzl et al. (2016), with the Kentucky Appalachian Rural Rehabilitation Network, aimed to disseminate information to caregivers of stroke survivors through verbal, visual and written methods. Hicken et al. (2017) developed an internet-based multisite support intervention for caregivers of veterans with dementia. The intervention lasted 6 months and included a program of assessments, educational content and skill training. All caregivers were assigned a care manager in the form of a licensed clinical social worker or psychologist who provided telephone support. The electronic intervention allowed participants to access intervention content 3 days per week for 10 to 15 min and consult video vignettes about dementia progression and caregiving skills, information about health topics and assessments of caregiver health and well-being. Likewise, the study of Lorig et al. (2012) used an internet intervention called "Building Better Caregivers" (BBC), which is a 6-week internet-based workshop for caregivers aimed at enhancing caregiving skills. Training included participation in the workshop, four webinars and following a detailed protocol. The intervention of Kaye et al. (2014) provided education, training and support program opportunities in order for the caregivers to learn new skills in both individual and group settings. The intervention provided by Scott et al. (2015) also had an educational component, providing lessons and educational software for caregivers. Srisuk et al. (2017) describe the development of a 6-month heart failure education program for caregivers in Thailand, providing face-to-face counselling, a heart failure manual and DVD and telephone support. Wakefield and Vaughan-Sarrazin (2017) examined the efficacy of home telehealth and caregiving appraisals in chronic illness between caregivers of enrolled and non-enrolled veterans in the home telehealth program which focus on health education, behaviour management and symptom recognition and control. Finally, Wallack et al. (2018) demonstrate



tele-gerontology as an approach, using videoconferencing for caregivers of a person with dementia. This study consisted of a 6-month intervention with a weekly Skype-based video conferencing call with tele-gerontology physicians, other therapists and control participants that received the usual study team.

#### 4.4.3 | Organisational interventions

Organisational interventions include those services which assist the caregiver in caring for their loved one and in managing daily life. The only example in this scoping review is the intervention promoted by Kaye et al. (2014), in which the project provided a caregiver navigator.

#### 4.4.4 | The adoption of digital health technologies

As mentioned in the tools section, many interventions included technology. Actually, 85.7% of studies included in this scoping review provided at least one technological support, and four studies (33.3%) included more than one. Among the programs that covered this component, most provided website support (58.3%), half telephone support and three (25%), Skype. Only the study of Srisuk et al. (2017) provided a DVD support. Studies that used technology supports were more likely to report evidence about less isolation of the caregiver and less difficulties in accessing rural settings. It has been argued that the digital divide, so the difference in accessing Internet based services, especially in the rural context, could be a major issue, but interventions were respectful of the digital knowledge of the caregivers.

Most of the studies have used technological tools to reach areas of physical isolation. These studies have shown how the use of technology helps to improve the skills of caregivers and at the same time to decrease the sense of social isolation. Online support can even reduce caregiver burden, depression, pain and stress (Lorig et al., 2012). Nonetheless, Danzl et al. (2016) show that between caregivers that received support with technology interventions and those who accessed telephone-delivered support, there was no difference. This means that for people suffering from the digital divide, even a telephone-based support could be effective in order to ameliorate their skills and mental health. Technological interventions have the advantage of cutting the cost of providing the service, both because the lessons can be made available to caregivers once and remain available forever on a website, but at the same time there are no other reasons to prefer them to physical support or face-to-face contact.

## 5 | DISCUSSION

From our scoping review, some elements of particular interest emerge. First of all, it should be pointed out that there are few interventions in favour of caregivers of the elderly in hard to reach rural areas. This confirms how this segment of the population (i.e. caregivers of the elderly in rural areas) is still neglected by scientific research and risks unequal access to health and social care.

Furthermore, the great variety of available definitions and conceptualisations of “rural” areas is a further signal of how the scientific debate about this matter is still in its infancy and needs further study to reach a consensus across scientific and clinical communities around the world. In this scoping review, defining the concept of rural was one of the greatest difficulties. Within the articles, different definitions of the rural context emerged, in some cases also supported by regulatory definitions (Blusi et al., 2015), in others defined as a location with few services and away from major urban areas (Danzl et al., 2016). It is possible to identify some dimensions which allow us to speak about the rural context: distance from major urban centres, dispersion or scarcity of services and physical barriers (mountains or inaccessible regions). The concept of “hard to reach” helped us to capture all the above-mentioned dimensions because it is more inclusive than the meaning of the term “rural”.

Moreover, a culturally savvy reflection about anthropological and psychosocial characteristics of different rural communities is urgently needed to improve the access to care and social services of elderly people and their caregivers in these communities. The ongoing scientific debate, still nascent, risks a tokenistic approach to the challenges and opportunities for interventions that each country or cultural community may present to improve the engagement of those caring for the elderly in rural communities.

With respect to the needs highlighted by the articles included in the scoping review, it is necessary to pay attention to the need for information, training and psychological support for caregivers. Nevertheless, this review did not reveal an in-depth focus on organisational support. With respect to the creation of services, the peer-to-peer or mutual support dimension will have to be evaluated as a priority, as the studies that have included it have evaluated very positively the impact on caregivers.

The adoption of technologies can certainly be a way to overcome the problems of accessibility and dissemination of services, especially in the field of training and information, but we cannot forget that in many countries, the phenomenon of the digital divide is still relevant, especially in the elderly population.

As a consequence, if we want family caregivers in these places to be resilient, collaborative, engaged in the ageing process and allied with us, then we need to build a robust environment to succeed and make it happen. However, we cannot expect family caregivers to effectively engage with the welfare system if we do not provide a comprehensive understanding of their needs and priorities in services aimed to support them according to the specificities of the places where their caring tasks occur.

Thus, interventions and supports aiming to diminish unequal access to care in rural communities need to overcome a hyper-simplistic and tokenistic vision of the ageing process. They, on the contrary, need to move forward with a deep psychosocial understanding of the rural community's characteristics, to support processes of citizen involvement and to co-design services with all stakeholders, including caregivers, elderly citizens, social and health professionals, researchers and policy makers. In other words, the process to develop a sustainable framework for successful ageing in rural remote

communities needs first an environment that fosters active and long-term family caregiver engagement.

Finally, although all the interventions had as their objective the engagement of caregivers, it was not measured on any appropriate scale, delegating the concept of engagement to the dimensions of the emotional burden of the informal caregiver. This is a dimension that we believe to be fundamental to building better services more focused on the needs of the caregivers, but at the same time to improving the health of the relative him or herself (Barello, Graffigna, et al., 2015; Barello, Savarese, & Graffigna, 2015; Graffigna & Barello, 2018a; Lamiani, Barello, Browning, Vegni, & Meyer, 2012; Provenzi et al., 2016).

This scoping review aimed to highlight the existing interventions focused on helping caregivers in remote areas and the need of more empirical studies. It is the first scoping review that assessed the state of interventions on this subject. In the future, we hope that several interventions will be established, as we are convinced that helping caregivers is a crucial factor for the future of rural areas in ageing societies.

Nonetheless, this study has several limitations. First, we used the term “ageing” with the US spelling and not the UK spelling. This could have excluded some articles. Moreover, we only included articles from after 2012, the European Year of Active Ageing. This could be a limitation of our scoping review, however, in order to limit this potential source of exclusion, additional material was identified following up the reference lists of articles included, without founding any previous intervention. Finally we struggled in defining hard to reach communities: this could have had an influence on the results of this review. However, this study is a first contribution to systematize literature related to interventions for supporting the engagement of caregivers in hard to reach contexts, also by pointing out the current gaps that need further considerations in future research.

## ACKNOWLEDGMENTS

This study is part of the Place4Carers project funded by Fondazione Cariplo.

## CONFLICTS OF INTEREST

All the authors declare that there is no conflict of interest.

## ORCID

Niccolò Morelli  <https://orcid.org/0000-0001-8916-8640>

## REFERENCES

- Alves, S., Teixeira, L., Azevedo, M. J., Duarte, M., & Paúl, C. (2016). Effectiveness of a psychoeducational programme for informal caregivers of older adults. *Scandinavian Journal of Caring Sciences*, 30(1), 65–73. <https://doi.org/10.1111/scs.12222>
- Arksey, H., & O'Malley, L. (2005). Scoping studies: Toward a methodological framework. *International Journal of Social Research Methodology*, 8(1), 19–32.
- Bacsu, J., Jeffery, B., Abonyi, S., Johnson, S., Novik, N., Martz, D., & Oosman, S. (2014). Healthy aging in place: Perceptions of rural older adults. *Educational Gerontology*, 40(5), 327–337. <https://doi.org/10.1080/03601277.2013.802191>
- Bakitas, M., Dionne-Odom, J. N., Jackson, L., Frost, J., Bishop, M. F., & Li, Z. (2017). There were more decisions and more options than just yes or no: Evaluating a decision aid for advanced cancer patients and their family caregivers. *Palliative and Supportive Care*, 15, 44–56. <https://doi.org/10.1017/S1478951516000596>
- Banks, P. (2004). *Policy framework for integrated care for older people*. London, UK/Dublin, Ireland: King's Fund/EHMA.
- Barello, S., & Graffigna, G. (2015). Engaging patients to recover life projectuality: An Italian cross-disease framework. *Quality of Life Research*, 24(5), 1087–1096. <https://doi.org/10.1007/s11136-014-0846-x>
- Barello, S., Graffigna, G., Vegni, E., Savarese, M., Lombardi, F., & Bosio, A. C. (2015). 'Engage me in taking care of my heart': A grounded theory study on patient–cardiologist relationship in the hospital management of heart failure. *British Medical Journal Open*, 5(3), e005582. <https://doi.org/10.1136/bmjopen-2014-005582>
- Barello, S., Savarese, M., & Graffigna, G. (2015). The role of caregivers in the elderly healthcare journey: Insights for sustaining elderly patient engagement. *Patient Engagement: A consumer centered model to innovate healthcare*, 108–119.
- Bedard, M., Molloy, D. W., Squire, L., Dubois, S., Lever, J. A., & O'Donnell, M. (2001). The Zarit Burden interview: A new short version and screening version. *The Gerontologist*, 41(5), 652–657. <https://doi.org/10.1093/geront/41.5.652>
- Blumenthal, D., Chernof, B., Fulmer, T., Lumpkin, J., & Selberg, J. (2016). Caring for high-need, high-cost patients—An urgent priority. *New England Journal of Medicine*, 375(10), 909–911. <https://doi.org/10.1056/NEJMp1608511>
- Blusi, M., Asplund, K., & Jong, M. (2013). Older family carers in rural areas: Experiences from using caregiver support services based on Information and Communication Technology (ICT). *European Journal of Ageing*, 10, 191–199.
- Blusi, M., Kristiansen, L., & Jong, M. (2015). Exploring the influence of Internet-based caregiver support on experiences of isolation for older spouse caregivers in rural areas: A qualitative interview study. *International Journal of Older People Nursing*, 10, 211–220. <https://doi.org/10.1111/opn.12074>
- Boehmer, K. R., Egginton, J. S., Branda, M. E., Kryworuchko, J., Bodde, A., Montori, V. M., & LeBlanc, A. (2014). Missed opportunity? Caregiver participation in the clinical encounter. A video graphic analysis. *Patient Education and Counseling*, 96(3), 302–307. <https://doi.org/10.1016/j.pec.2014.05.016>
- Bookman, A., & Harrington, M. (2007). Family caregivers: A shadow workforce in the geriatric health care system? *Journal of Health Politics, Policy and Law*, 32(6), 1005–1041. <https://doi.org/10.1215/03616878-2007-040>
- Brackertz, N. (2007). Who is hard to reach and why? Working paper No. SISRQ/EL 06.07, pp. 1–7.
- Burholt, V., & Dobbs, C. (2012). Research on rural ageing: Where have we got to and where are we going in Europe? *Journal of Rural Studies*, 28(4), 432–446.
- Cohen-Mansfield, J., Marx, M., & Rosenthal, A. (1989). A description of agitation in a nursing home. *The Journal of Gerontology*, 44(3), M77–M84. <https://doi.org/10.1093/geronj/44.3.M77>
- Coulter, A. (2012). Patient engagement—What works? *The Journal of Ambulatory Care Management*, 35(2), 80–89. <https://doi.org/10.1097/JAC.0b013e318249e0fd>
- Danzl, M. M., Harrison, A., Hunter, E. G., Kuperstein, J., Sylvia, V., Maddy, K., & Campbell, S. (2016). “A lot of things passed me by”: Rural stroke survivors' and caregivers' experience of receiving education from health care providers. *Journal of Rural Health*, 32, 13–24.

- Davey, J. (2006). "Ageing in place": The views of older homeowners on maintenance, renovation and adaptation. *Social Policy Journal of New Zealand*, 27, 128.
- Devins, G. M., Mandin, H., Hons, R. B., Burgess, E. D., Klassen, J., Taub, K., ... Buckle, S. (1990). Illness intrusiveness and quality of life in end-stage renal disease: Comparison and stability across treatment modalities. *Health Psychology*, 9, 117-142. <https://doi.org/10.1037/0278-6133.9.2.117>
- Ekwall, A., Sivberg, B., & Hallberg, I. R. (2004). Dimensions of informal care and quality of life among elderly family caregivers. *Scandinavian Journal of Caring Sciences*, 18(3), 239-248. <https://doi.org/10.1111/j.1471-6712.2004.00283.x>
- Eurostat. (2016). Population structure and ageing. Retrieved from [http://ec.europa.eu/eurostat/statistics-explained/index.php?title=Population\\_structure\\_and\\_ageing/en](http://ec.europa.eu/eurostat/statistics-explained/index.php?title=Population_structure_and_ageing/en)
- Flanagan, S. M., & Hancock, B. (2010). Reaching the hard to reach - Lessons learned from the VCS (voluntary and community Sector): A qualitative study. *BMC Health Services Research*, 10(1), <https://doi.org/10.1186/1472-6963-10-92>
- Fordeucey, P. G., Glueckauf, R. L., Bergquist, T. F., Maheu, M. M., & Yutsis, M. (2012). Telehealth for persons with severe functional disabilities and their caregivers: Facilitating self-care management in the home setting. *Psychological Services*, 9(2), 144-162. <https://doi.org/10.1037/a0028112>
- Goldberg, D., & Hillier, V. (1979). A scaled version of the general health questionnaire. *Psychological Medicine*, 9, 139-145. <https://doi.org/10.1017/S0033291700021644>
- Graffigna, G., & Barelo, S. (2015). Innovating healthcare in the era of patient engagement: Challenges, opportunities, & new trends. Patient engagement: A consumer-centered model to innovate healthcare. In G. G., S. B., & S. T. (Eds.), *Patient engagement: A consumer-centered model to innovate healthcare* (Vol. 10). Berlin, Germany: De Gruyter Open, 9783110452440-002
- Graffigna, G., & Barelo, S. (2018a). Spotlight on the Patient Health Engagement model (PHE model): A psychosocial theory to understand people's meaningful engagement in their own health care. *Patient Preference and Adherence*, <https://doi.org/10.2147/PPA.S145646>
- Graffigna, G., & Barelo, S. (2018b). Patient Health Engagement (PHE) model in enhanced recovery after surgery (ERAS): Monitoring patients' engagement and psychological resilience in minimally invasive thoracic surgery. *Journal of Thoracic Disease*, 10, S517-S528. <https://doi.org/10.21037/jtd.2017.12.84>
- Grant, M. J., & Booth, A. (2009). A typology of reviews: An analysis of 14 review types and associated methodologies. *Health Information & Libraries Journal*, 26, 91-108. <https://doi.org/10.1111/j.1471-1842.2009.00848.x>
- Hasselkus, B. R. (1992). The meanings of activity: Day care for persons with Alzheimer Disease. *The American Journal of Occupational Therapy*, 46(3), 199-206.
- Havens, B., Hall, M., Sylvestre, G., & Jivan, T. (2004). Social isolation and loneliness: Differences between older rural and urban Manitobans. *Canadian Journal on Aging/la Revue Canadienne Du Vieillessement*, 23(2), 129-140. <https://doi.org/10.1353/cja.2004.0022>
- He, W., Goodkind, D., & Kowal, P. (2016). *U.S. Census Bureau, international population reports, P95/16-1, An aging world: 2015*. U.S. Washington, DC: Government Publishing Office.
- Hewitt, M. E. (1989). *Defining "rural" areas: Impact on health care policy and research*. Washington, DC: DIANE Publishing.
- Hicken, B. L., Daniel, C., Luptak, M., Grant, M., Kilian, S., & Rupper, R. W. (2017). Supporting Caregivers of Rural Veterans Electronically (SCORE). *Journal of Rural Health*, 33, 305-313. <https://doi.org/10.1111/jrh.12195>
- Howden-Chapman, P., Signal, L., & Crane, J. (1999). Housing and health in older people: Ageing in place. *Social Policy Journal of New Zealand*, 14-30.
- Jakovljevic, M. M., & Laaser, U. (2015). Population aging from 1950 to 2010 in seventeen transitional countries in the wider region of South Eastern Europe.
- Johansson, M. (2014). Demographic trends in rural Europe. Territorial cohesion in rural Europe: The relational turn in rural development, 99-125.
- Kaye, L. W., Crittenden, J. A., Kelly, N., & Boylan, D. (2014). Brief report #3: Building a rural community caregiver network: Student learning in small town America. *Gerontology and Geriatrics Education*, 35(3), 240-245. <https://doi.org/10.1080/02701960.2014.921106>
- Kinney, J., & Stephens, M. (1989). Caregiving hassles scale: Assessing the daily hassles of caring for a family member with dementia. *The Gerontologist*, 29(3), 328-332. <https://doi.org/10.1093/geront/29.3.328>
- Kinsella, K. (2001). Urban and rural dimensions of global population aging: An overview. *The Journal of Rural Health*, 17(4), 314-322. <https://doi.org/10.1111/j.1748-0361.2001.tb00280.x>
- Kroenke, K., & Spitzer, R. L. (2002). The phq-9: A new depression diagnostic and severity measure. *Psychiatric Annals*, 32, 509-521. <https://doi.org/10.3928/0048-5713-20020901-06>
- Kröger, T. (Ed.). (2003). *Families, work and social care in Europe*. Brussels, Belgium: European Commission.
- Lamiani, G., Barelo, S., Browning, D. M., Vegni, E., & Meyer, E. C. (2012). Uncovering and validating clinicians' experiential knowledge when facing difficult conversations: A cross-cultural perspective. *Patient Education and Counseling*, 87(3), 307-312. <https://doi.org/10.1016/j.pec.2011.11.012>
- Laranjeira, C. A. (2008). General health questionnaire-12 items: Adaptation study to the Portuguese population. *Epidemiologia E Psichiatria Sociale*, 17(2), 148-151. <https://doi.org/10.1017/S1121189X00002840>
- Lau, R., & Morse, C. A. (2008). Health and wellbeing of older people in Anglo-Australian and Italian-Australian communities: A rural-urban comparison. *Australian Journal of Rural Health*, 16(1), 5-11. <https://doi.org/10.1111/j.1440-1584.2007.00933.x>
- Lawton, M. P., Kleban, M. H., Moss, M., Rovine, M., & Glicksman, A. (1989). Measuring caregiving appraisal. *The Journal of Gerontology*, 44, P61-P71. <https://doi.org/10.1093/geronj/44.3.P61>
- Lee, C. S., Vellone, E., Lyons, K. S., Cocchieri, A., Bidwell, J. T., D'Agostino, F., ... Riegel, B. (2015). Patterns and predictors of patient and caregiver engagement in heart failure care: A multi-level dyadic study. *International Journal of Nursing Studies*, 52(2), 588-597. <https://doi.org/10.1016/j.ijnurstu.2014.11.005>
- Leichsenring, K. (2004). Developing integrated health and social services for older persons in Europe. *International Journal of Integrated Care*, 4, e10.
- Levine, C. (2016). Putting the spotlight on invisible family caregivers. *JAMA Internal Medicine*, 176(3), 380-381. <https://doi.org/10.1001/jamainternmed.2015.8002>
- Lorig, K., Thompson-Gallagher, D., Traylor, L., Ritter, P. L., Laurent, D. D., Plant, K., ... Hahn, T. J. (2012). Building better caregivers: A pilot online support workshop for family caregivers of cognitively impaired adults. *Journal of Applied Gerontology*, 31(3), 423-437. <https://doi.org/10.1177/0733464810389806>
- Lundberg, S. (2014). The results from a two-year case study of an information and communication technology support system for family caregivers. *Disability and Rehabilitation: Assistive Technology*, 9(4), 353-358. <https://doi.org/10.3109/17483107.2013.814170>
- Marcellini, F., Giuli, C., Gagliardi, C., & Papa, R. (2007). Aging in Italy: Urban-rural differences. *Archives of Gerontology and Geriatrics*, 44(3), 243-260. <https://doi.org/10.1016/j.archger.2006.05.004>
- McKee, K. J., Philp, I., Lamura, G., Prouskas, C., Öberg, B., Krevers, B., ... Szczerbinska, K. (2003). The COPE index—a first stage assessment of negative impact, positive value and quality of support of caregiving

- in informal carers of older people. *Aging & Mental Health*, 7, 39–52. <https://doi.org/10.1080/1360786021000006956>
- Morycz, R. K. (1985). Caregiving strain and the desire to institutionalize family members with Alzheimer's disease. Possible predictors and model development. *Research on Aging*, 7(3), 329–361. <https://doi.org/10.1177/0164027585007003002>
- Moser, D. K., Riegel, B., McKinley, S., Doering, L. V., Meischke, H., Heo, S., ... Dracup, K. (2009). The control attitudes scale-revised: Psychometric evaluation in three groups of patients with cardiac illness. *Nursing Research*, 58(1), 42–51. <https://doi.org/10.1097/NNR.0b013e3181900ca0>
- Noel, M. A., Kaluzynski, T. S., & Templeton, V. H. (2017). Quality dementia care: Integrating caregivers into a chronic disease management model. *Journal of Applied Gerontology*, 36(2), 195–212. <https://doi.org/10.1177/0733464815589986>
- Oudijk, D., de Boer, A., Woittiez, I., Timmermans, J., & de Klerk, M. (2010). Mantelzorg uit de doeken[Informal care explained]. Den Haag: Sociaal en Cultureel Planbureau.
- Parks, S. M., & Novielli, K. D. (2000). A practical guide to caring for caregivers. *American Family Physician*, 62, 2613–2622.
- Phillipson, C., & Scharf, T. (2005). Rural and urban perspectives on growing old: Developing a new research agenda. *European Journal of Ageing*, 2(2), 67–75. <https://doi.org/10.1007/s10433-005-0024-7>
- Posner, B. M., Jette, A. M., Smith, K. W., & Miller, D. R. (1993). Nutrition and health risks in the elderly: The nutrition screening initiative. *American Journal of Public Health*, 83, 972–978. <https://doi.org/10.2105/AJPH.83.7.972>
- Provenzi, L., Barello, S., Fumagalli, M., Graffigna, G., Sirgiovanni, I., Savarese, M., & Montirosso, R. (2016). A comparison of maternal and paternal experiences of becoming parents of a very preterm infant. *Journal of Obstetric, Gynecologic & Neonatal Nursing*, 45(4), 528–541. <https://doi.org/10.1016/j.jogn.2016.04.004>
- Quam, L., Smith, R., & Yach, D. (2006). Rising to the global challenge of the chronic disease epidemic. *The Lancet*, 368(9543), 1221–1223. [https://doi.org/10.1016/S0140-6736\(06\)69422-1](https://doi.org/10.1016/S0140-6736(06)69422-1)
- Radloff, L. S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*, 1, 385–401. <https://doi.org/10.1177/014662167700100306>
- Ratcliffe, M., Burd, C., Holder, K., & Fields, A. (2016). Defining rural at the U.S. census bureau. ACSGEO-1, U.S. Census Bureau, Washington.
- Rogers, S. A., Anthony, W., & Lyass, A. (2004). The nature and dimensions of social support among persons with severe mental illnesses. *Community Mental Health Journal*, 40, 437–450. <https://doi.org/10.1023/B:COMH.0000040657.48759.0e>
- Roter, D. L., Hall, J. A., Merisca, R., Nordstrom, B., Cretin, D., & Svarstad, B. (1998). Effectiveness of interventions to improve patient compliance: A meta-analysis. *Medical Care*, 36, 1138–1161. <https://doi.org/10.1097/00005650-199808000-00004>
- Scharlach, A., Li, W., & Dalvi, T. B. (2006). Family conflict as a mediator of caregiver strain. *Family Relations*, 55(5), 625–635. <https://doi.org/10.1111/j.1741-3729.2006.00431.x>
- Schorch, M., Wan, L., Randall, D. W., & Wulf, V. (2016). Designing for those who are overlooked: Insider perspectives on care practices and cooperative work of elderly informal caregivers. In Association for Computing Machinery (ACM)(Ed.), *Proceedings of the 19th ACM conference on computer-supported cooperative work & social computing* (pp. 787–799). New York, NY: ACM.
- Scott, T. L., Mittelman, M. S., Beattie, E., Parker, D., & Neville, C. (2015). Translating training in the NYU caregiver intervention in Australia: Maintaining fidelity and meeting graduate standards in an online continuing professional education setting. *Educational Gerontology*, 41(10), 710–722. <https://doi.org/10.1080/03601277.2015.1048171>
- Shaghghi, A., Bhopal, R. S., & Sheikh, A. (2011). Approaches to recruiting 'hard-to-reach' populations into research: A review of the literature. *Health Promotion Perspectives*, 1(2), 86–94.
- Sixsmith, A., & Sixsmith, J. (2008). Ageing in place in the United Kingdom. *Ageing International*, 32(3), 219–235. <https://doi.org/10.1007/s12126-008-9019-y>
- Sixsmith, J., Sixsmith, A., Fänge, A. M., Naumann, D., Kucsera, C., Tomsone, S., ... Woolrych, R. (2014). Healthy ageing and home: The perspectives of very old people in five European countries. *Social Science & Medicine*, 106, 1–9. <https://doi.org/10.1016/j.socscimed.2014.01.006>
- Srisuk, N., Cameron, J., Ski, C. F., & Thompson, D. R. (2017). Randomized controlled trial of family-based education for patients with heart failure and their carers. *Journal of Advanced Nursing*, 73(4), 857–870. <https://doi.org/10.1111/jan.13192>
- Thornton, M., & Travis, S. S. (2003). Analysis of the reliability of the modified care-giver strain index. *Journals of Gerontology: Social Sciences*, 58B, S127–S132.
- Triantafyllou, J., Mestheneos, E., Troisi, J., & von Kondratowitz, H. J. (2013). The present and future health status of older people in the Mediterranean region. *Ageing in the Mediterranean*, 123–149.
- U.S. Department of Commerce. (1985). *National health interview survey*. Washington, DC: Bureau of the Census.
- van der Wal, M. H., Jaarsma, T., Moser, D. K., & van Veldhuisen, D. J. (2005). Development and testing of the Dutch heart failure knowledge scale. *European Journal of Cardiovascular Nursing*, 4(4), 273–277. <https://doi.org/10.1016/j.ejcnurse.2005.07.003>
- Wakefield, B. J., & Vaughan-Sarrazin, M. (2017). Home telehealth and caregiving appraisal in chronic illness. *Telemedicine and E-Health*, 23(4), 282–289. <https://doi.org/10.1089/tmj.2016.0105>
- Wallack, E. M., Harris, C., Ploughman, M., & Butler, R. (2018). Telegerontology as a Novel approach to address health and safety by supporting community-based rural dementia care triads: Randomized controlled trial protocol. *JMIR Research Protocols*, 7(2), e56. <https://doi.org/10.2196/resprot.8744>
- Ware, J. Jr, Kosinski, M., & Keller, S. D. (1996). A 12-item short-form health survey: Construction of scales and preliminary tests of reliability and validity. *Medical Care*, 34(3), 220–233. <https://doi.org/10.1097/00005650-199603000-00003>
- Wenger, G. C. (2001). Myths and realities of ageing in rural Britain. *Ageing and Society*, 21(01), 117–130. <https://doi.org/10.1017/S0144686X01008042>
- Wolff, J. L., Spillman, B. C., Freedman, V. A., & Kasper, J. D. (2016). A national profile of family and unpaid caregivers who assist older adults with health care activities. *JAMA Internal Medicine*, 176(3), 372–379. <https://doi.org/10.1001/jamainternmed.2015.7664>

**How to cite this article:** Morelli N, Barello S, Mayan M, Graffigna G. Supporting family caregiver engagement in the care of old persons living in hard to reach communities: A scoping review. *Health Soc Care Community*. 2019;00:1–12. <https://doi.org/10.1111/hsc.12826>