ORIGINAL PAPER

# Action Research as a Method to Find Solutions for the Burden of Caregiving at Hospital Discharge

Flaminia Reale[1] · Federica Segato[1] · Daniela Tartaglini[2] · Cristina Masella[1]

## Abstract

The role played by family caregivers in delivering long-term care is crucial: they enhance the quality of care perceived by the patients and support the shift to out-of-hospital care. However, taking care of a relative entails a huge burden that usually begins with the patient's hospital discharge and may mean that caregivers become patients in need of care as well. Owing to socio-demographic trends, informal caregiving is the most important source of care in community settings; hence targeting the caregivers' burden properly is crucial. This study explores how action research (AR) can be used to develop new hospital practices to manage the burden borne by family caregivers when patients are discharged from hospital. The 7-month-long action research reported in this paper consisted of three stages (burden identification, burden sharing, and burden management) and it was conducted in a teaching hospital in Rome (Italy). Both quantitative (surveys) and qualitative (focus groups and simulation sessions) techniques were used to engage participants. The AR demonstrates that there is a feasible way in which hospital managers can address proactively the caregivers' needs in the hospital discharge process, to the advantage of the patients and the entire community.

**Keywords** Family caregiver · Caregiver burden · Action research · Discharge process · Hospital management

## Introduction

Family caregivers are unpaid relatives or friends of a patient who assist him/her throughout the care pathway, generally without specific training or professional knowledge (Giovannetti et al. 2013; Lang 2010; Glajchen 2004). Although family caregivers have long been overlooked as

✉ Flaminia Reale
   flaminia.reale@polimi.it

1   Department of Management, Economics and Industrial Engineering, Politecnico di Milano, Via R. Lambruschini 4/B, 20156 Milan, Italy

2   Campus Bio-Medico University Hospital of Rome, Via Alvaro del Portillo 200, 00128 Rome, Italy

health and care partners (Gibson et al. 2012), evidence is growing about their role (Boltz et al. 2018; Cramm and Nieboer 2016; Ament et al. 2015; Caswell et al. 2015; Hazzan et al. 2015).

Caregiving has in fact received increasing attention because the number of people that are managed in community settings instead of hospital is increasing worldwide, particularly because the population is ageing and larger numbers of people live longer also with long-term conditions (OECD 2017; Kinsella and He 2009). Moreover, when possible, most patients prefer to receive care in the domestic environment, surrounded by their family, since it brings psychological and emotional comfort (Landers et al. 2016).

Although the extent of recourse to informal care may vary across countries due to socio-demographic factors and differences in long-term care systems (Pickard 2011), in the OECD countries more than one in ten adults are involved in informal caregiving, which proves to be the most important source of care in community settings (OECD 2017).

Informal care is often seen as cost-effective with respect to formal care, since it is a means whereby patients can remain at home, preventing recourse to acute care and allowing rapid discharge from hospitals (Landers et al. 2016; Courtin et al. 2014; Varney et al. 2014; Kehusmaa et al. 2013). However, from a public expenditure perspective, informal care may result in significant costs in the long run. Indeed, informal care has a negative impact on health and employment and entails adverse consequences for both society and families (Brimblecombe et al. 2018; Brimblecombe et al. 2017; Rodrigues et al. 2013). Given the role that family caregivers perform in providing out-of-hospital care, caregiver support strategies have become necessary (Batiashvili and Gerzmava 2013; Hagedoorn et al. 2017; Gervès et al. 2014; Brunton et al. 2008). Evidence for this is provided, for example, by Dujardin et al. (2011) who show in a cross-country comparison that caregiving is more prevalent in Britain than in Belgium, but the burden associated with caregiving is lower in Britain because of better support provided through home care policies.

Despite the unique nature of any given caregiver's role over time, caregivers from any country and culture share common features and face common challenges worldwide (OECD 2017; Batiashvili and Gerzmava 2013).

Broad domains of activity characterize family caregiving, which ranges from daily assistance to the patient to navigating healthcare and social services systems. Traditionally, women were more likely to be involved in informal care than men (King and Pickard 2013), but recently, due to trends such as increasing women's employment and smaller families, men are more involved in care than they used to be (Kramer and Thompson 2004).

Often, caregivers need support, but do not ask for it (Van Exel et al. 2008) and they experience a multidimensional suffering related to both physical and psychological aspects and to the costs of providing care; this is what the literature calls the "burden of caregiving" (Watanabe et al. 2015; Zarit et al. 1986;). The burden of caregiving usually begins with the discharge of the caregiver's relative from hospital: because the caregiver perceives the latter as now his/her responsibility, s/he experiences severe psychological distress. Therefore, this kind of burden needs to be identified and addressed promptly (Ranieri et al. 2017).

The aim of this study is to use AR to develop new hospital practices to manage the burden borne by family caregivers when patients are discharged from hospital.

The article starts with an overview of the literature on the caregiver burden and its implications; it proceeds with a description of the action research project with details on the study design. Then, the results of the action research in the specific research setting (i.e. a teaching hospital in Rome, Italy) are reported and discussed. Finally, we share lessons learned from this approach.

## The Caregiver Burden

### What it Is

Becoming a family caregiver has a huge impact on daily life (Bremer et al. 2015): caregivers change their working habits and sacrifice their leisure activities to acquire more time to devote to the patient (Van Exel et al. 2007). Family caregivers are deeply involved, both emotionally and operationally, in a duty that generally comes unexpectedly and persists for a long time, and for which they receive scant preparation and support from the healthcare system (Bartolo et al. 2010). Problems that may arise with caregiving range from anxiety and depression to financial difficulties, restrictions of social activities and reduction of working time (Miravitlles et al. 2015). The overall difficulties experienced by caregivers are termed the 'caregiver burden' (Bartolo et al. 2010; Zarit et al. 1986). This burden may have severe consequences on the caregiver's health, to the point that caregivers are often considered the potential second victims of a disease (Dal Pra Ponticelli 2004). Recent studies have shown that the burden may expose caregivers to higher risks of contracting chronic diseases, depression and premature death (Bové et al. 2016; Hazzan et al. 2015; Bremer et al. 2015).

### State of the Art of Targeting the Caregiver Burden

The caregiver burden has received attention from researchers, whose contributions fall into two major streams of research. The first has analyzed the burden and its dimensions, often adopting validated scales, such as the Caregiver Burden Inventory or the Caregiver Needs Assessment (Novak and Guest 1989; Moroni et al. 2007). In these studies, caregivers are asked to rate their agreement with specific statements that pertain mainly to the social, psychological and economic spheres of their everyday lives (Llanque et al. 2016). By analyzing the caregivers' responses, researchers identify the dimensions of the burden that most affect the caregivers' lives.

A second stream of studies on the caregivers' burden focuses on actions undertaken to respond to the caregivers' burden, such as counselling and respite services (Van Exel et al. 2008). These analyses mostly involve caregivers already subject to a burden (Corry et al. 2015; Alvira et al. 2015) but they are seldom applied to prevent the burden or to prepare caregivers for it.

Navanandan et al. (2017) and Al-Harthy et al. (2016) are among the few authors who provide examples of a "preventive" endeavor against burden occurrence. They report actions intended to increase caregiver preparedness at patient discharge and highlight that generally caregivers do not receive comprehensive instructions during the discharge process, with the consequence of unscheduled returns to the hospital.

Although awareness about the caregiver burden is now widespread, the diversity of actions implemented and the fragmentation of support interventions jeopardize the taking of effective decisions to support caregivers in coping with or preventing the burden (Bastawrous 2013). Yet it seems that a "one-fits-all" solution is hard to find: solutions need to be designed according to caregivers' needs and may differ from case to case.

According to Bauer et al. (2009), hospital discharge planning could be improved through specific actions (e.g. inclusion, communication between staff and users) that address caregivers' needs. However, there is a paucity of research on how to involve caregivers directly in improving the hospital discharge process. (Navanandan et al. 2017; Sexson et al. 2017; Bauer et al. 2009).

## How Action Research Could Help in Finding Solutions

The need to investigate the experiences of family caregivers, and the intent to devise a practical solution for the burden of caregiving at discharge, prompted us to conduct an action research (AR) project.

Action research is a fertile source of new solutions in a variety of sectors, including healthcare (Sonğur et al. 2018). In fact, AR is an approach to problem solving that enacts participative values, and it promotes the collaboration of the action researchers and members of the organizational system (Ottmann et al. 2011; Bradbury-Huang 2010; Crawford et al. 2002). As such, it is a methodology suited to implementing successful innovations in hospital settings (Loewenson et al. 2014; Torlak and Müceldili 2014), also in order to improve relationships among healthcare professionals, patients and families (Avcı et al. 2017; Top and Tekingündüz 2015; Meyer 2000).

## Methods

Action research is commonly used to improve practices in healthcare (MacFarlane et al. 2009; Meyer 2001). This AR approach was based on a process of planning, acting, observing and reflecting, in order to generate mutual understanding and positive changes in practice (Reason and Bradbury 2001; Kemmis and McTaggart 2000). It is expected that people involved in the mutual collaboration gain a new understanding of their practice, perceive the need to change and are willing to apply what they have learned (Meyer 2000). Consequently, the research outcomes are relevant to all stakeholders by rooting them in the reality of everyday practice (Reason and Bradbury 2001; Meyer 2000).

This AR is characterised by the active involvement of different stakeholders in a combination of quantitative (e.g. validated scales) and qualitative (e.g. focus group) tools, enabling the investigation of problems through diverse lenses (Gelo et al. 2008; Onwuegbuzie and Johnson 2004).

An action research project begins with the identification of a problem (Collatto et al. 2018; O'Sullivan et al. 2014). In this case, the problem is the burden that caregivers experience in giving care, which is analyzed to evaluate potential solutions for its prevention or reduction.

A stakeholder analysis was conducted to identify which actors take part, both directly and indirectly, in the caregivers' experience during hospitalization and at discharge.

The stakeholder analysis was performed by adapting the established "Guidelines for Conducting a Stakeholder Analysis" (Schmeer 1999). It comprised: (i) a group brainstorming session among the researchers; (ii) list of all potential stakeholders; (iii) identification of stakeholders' interests and roles in the project; (iv) stakeholders' prioritization and selection based on their ability to affect the identification of a solution for the burden of caregiving.

The stakeholders identified in this case were family caregivers, hospital managers, nurses and psychologists.

By means of the AR study, our purpose was to capture stakeholders' experience, understand the relationships among various actors, and mediate relationships between actors that generally stand at different organizational levels (e.g. caregivers and nurses, nurses and managers).

Therefore, this AR was based on data collection and meaningful interactions with participants and stakeholders (Davison et al. 2012; Meyer 2000).

## Setting and Participants

The study was conducted at Campus Bio-Medico University Hospital, a teaching hospital in Rome (Italy). It was carried out through the commitment of the Counselling Center, i.e. a hospital unit that provides information and psychological support to patients and caregivers.

Family caregivers and hospital nurses were involved as research participants. The researchers invited: (i) all the experienced family caregivers - i.e. with one year or more of experience in giving care to a relative with a chronic disease - enrolled on a training course (for the purpose of burden identification and burden sharing) and (ii) family caregivers of hospital inpatients attending a Day Hospital (for the purpose of burden management). Overall, a total of 33 caregivers enrolled on the course and 22 caregivers from the Day Hospital participated in the project on a voluntary basis. Patients undergoing a day hospital procedure generally undergo uncomplicated procedures and go home after a few hours; but the days following the discharge are often critical for both the patients and their caregivers. The choice of focusing on caregivers dealing with patients of this type was motivated by the intent to maximize the short-term measurable impact of final solutions on the caregivers' burden.

Seven hospital nurses were selected within the Department of Geriatrics, Neurology and Internal Medicine on a voluntary basis, after a meeting with the head nurse of each Department.

Each participant was informed about the aim of the study. He/she gave formal consent to participate and was told that he/she could withdraw from it at any time.

## Role of Researchers

The Board Directors of the hospital provided the stimulus to start an AR study in their setting because they needed to investigate the discharge planning system and family caregiver role and burden, and they asked the Head of the Nursing Department to study the topic. For this purpose, she created a multidisciplinary team (Huzzard et al. 2010) with colleagues also from other disciplines (henceforth: research group).

The research group comprised the authors of this paper (Head of the Nursing Department and three engineers with academic qualifications) and the staff of the Counselling Center (one nurse and two psychologists).

In order to discuss emerging issues, the research group conducted reflection meetings throughout the project's lifecycle, and in particular at the start and end of each step. According to the principles of action research, people should reflect on results as they are generated, and these reflections should be used to inform further action and data collection (Reason and Bradbury 2001). During reflection meetings, reflection is performed as a collective activity rather than being approached as a purely introspective one, thus enhancing deeper and more critical understanding (Péraire and Sedano 2014). All members are encouraged to think, be engaged and express their views, and this is useful for translating ideas into concrete alternatives and plans for practice (Söderhamn et al. 2015; Boerboom et al. 2011).

This strategy helped to create and feed discussion channels, and thus to facilitate the design of feasible solutions in each stage of the research.

The research group guided the interactions with participants, and it was also helpful to ensure engagement and consistent relationships among all the people involved in the action research and to give momentum to the project.

In particular, the staff of the Counselling Center ensured deep understanding of caregivers' experience and furnished adequate expertise about the hospital environment.

Figure 1 shows the research group and participants in the AR study.

## Data Gathering and Analysis

The AR consisted of three stages (burden identification, burden sharing, and burden management). For each of them, data were collected from multiple sources. Overall, the AR lasted from January to July 2015.

**Stage 1: Burden Identification** The aim of stage 1 was to identify the burden borne by caregivers in their everyday lives, and to assess their needs through a survey. At this stage, the researchers intended to understand the burden of caregivers with experience in the role.

To this end, the researchers submitted to the sample of 33 experienced family caregivers the following three validated scales in a paper-based version:

– The Caregiver Burden Inventory (CBI, Novak and Guest 1989): a tool used to determine the level of psychological distress and perceived feeling of burden of caregivers. The CBI is a self-rated multidimensional questionnaire that considers 5 dimensions of caregivers' burden (i.e. time dependent; developmental; physical; social; emotional).
– The Activities of Daily Living (ADL, Johnson et al. 2004): an index used to measure the level of independence in the everyday functions of the care receiver (i.e. dressing; eating; ambulating; toileting; continence).
– The Caregiver Needs Assessment (CNA; Moroni et al. 2007): a questionnaire constructed to reveal those assistance-related needs that caregivers have and to which the healthcare system should give satisfactory responses. CNA is related to different types of needs (i.e. emotional; psycho-functional; cognitive-behavioral; relational; organizational; spiritual).

Moreover, to select caregivers for stage 2, the researchers added two yes/no questions: one related to caregivers' experience with hospitalization ("Is your sick family member hospitalized in this Hospital now? Has he/she been hospitalized here in the past?"); the other to their willingness to take part in a focus group. The results were recorded in a Microsoft Excel file and processed with the Statistical Package for Social Sciences (SPSS 22.0). A regression
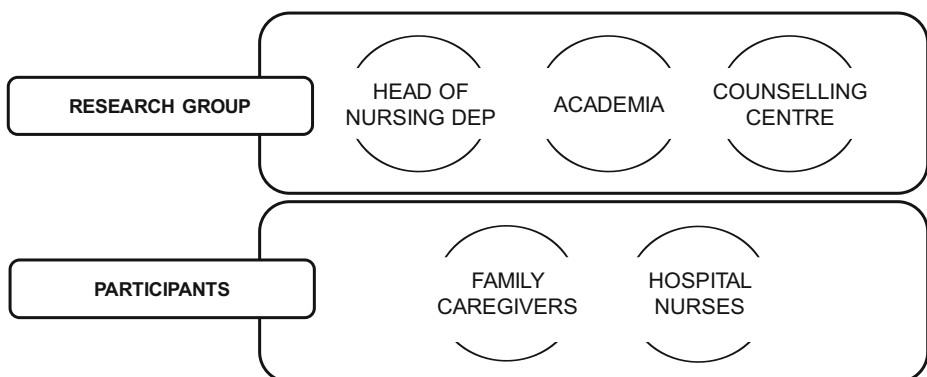


**Fig. 1** Research group and participants in the AR study

analysis was performed in order to identify the relationships among different items of the questionnaires. The research group met to discuss the output of stage 1; the results yielded by the scales, as well as the records and notes of the reflection meeting, provided the basis for the following stage.

**Stage 2: Burden Sharing** The aim of stage 2 was to deepen understanding of the caregivers' experience and emotions, and to induce the various participants involved in the AR to share their viewpoints and feelings. Operationally, the stage consisted in one focus group with ten caregivers and one with seven hospital nurses organized and conducted by the research group.

Both the focus groups were focused on the discharge process, albeit from different points of view (that of the users in the first, and that of the providers in the second). Integrating diverse perspectives of family caregivers and nurses was necessary to situate the problem in real life, and thereby consider needs and constraints experienced by the stakeholders involved in the process of patients' discharge from the hospital.

The research group decided to run separate sessions with caregivers and nurses in order to avoid face-to-face interaction, which carries different risks (Bélanger et al. 2017). First, since caregivers were selected among relatives of former inpatients of the hospital, they could have been influenced by potentially negative past relationships or even conflicts due to nurses' lack of willingness to meet their demands. In turn, nurses could have been affected by their perception of caregivers and become defensive.

The caregivers in the first focus group were selected among those that had answered the previous survey at stage 1. Specifically, the researchers selected caregivers that had past experience with hospitalization and were willing to join a focus group (i.e. affirmative response to the yes/no questions).

The invitation to join the focus group was delivered to selected participants two weeks before the date set for the meeting. The invitation stated that, during the focus group, some issues on their needs would be discussed.

The researchers participated in both focus groups as mediators and collectors of ideas. Specific tools were applied to further the discussion and the sharing of experiences. To let emotions emerge, instigate a reflection on feelings, and give value to them consistently with the search for actions to manage the burden, the researchers invited the participants to use the 'wheel of emotions' (Boyd et al. 2010) and build emotional maps using questions like "How did you feel in that situation?". The emotional map is a co-design tool useful for identifying the participants' emotional touchpoints in experience of a service (Bowen et al. 2013). It helps to involve all the participants directly and to facilitate the sharing of opinions, thereby enabling the representation of the different touchpoints and the related emotions on a paper map (Donetto et al. 2014). Posters, post-its, sheets of paper, markers and pens were available during both focus groups so that the participants could take notes, share their emotions and let the other participants visualize them (Perrott 2013).

The focus groups were recorded and transcribed for analysis, and short reports were produced for each of them.

During the reflection meetings that followed each focus group, the researchers analyzed the transcripts, identified the quotations made by participants and fixed the relevant themes that had emerged during discussions. Data were analysed one focus group at a time; thus, researchers could use the output of discussion among caregivers as inputs for finalising effective questions for nurses. Topics of discussion are explained in the findings section (Stage 2: Burden Sharing).

**Stage 3: Burden Management** The aim of stage 3 was to develop solutions and implement practices for managing the burden and improving the discharge planning. This arrangement would have an impact on the hospital's practice and, as such, it would require the Hospital Board's approval and commitment. Thus, the research group met the Board. Directors asked to test a new service idea, in order to collect information on how it could be operationalized within the hospital and gather the caregivers' opinions.

Starting from the outcomes of stage 2 and the meeting with the Board, the research group met in order to: (i) design a survey on a new sample of family caregivers (stage 3 – part I); (ii) devise the practical solution and decide how to evaluate it (stage 3 – part II).

**Stage 3: Part I - the Survey** A survey was designed to define the features of the new hospital service better. The survey was distributed in the Day Hospital to the sample of 22 caregivers and included: (i) the Caregiver Needs Assessment scale (CNA) to verify if the needs which had emerged at stage 1 and 2 were also common in the new sample of caregivers; (ii) a question to ask if the respondents were willing to take part in testing a newly designed practice; (iii) multiple choice questions related to specific service requirements to collect expectations in regard to the service idea (i.e. when, where, how respondents would like to access the service and how much they would be willing to pay for it); (iv) a sign-up sheet that respondents could fill in if they were willing to take part in a service simulation to give their references in order to be invited back to the session.

**Stage 3: Part II - Simulation Session and Follow-Up Interview** As requested by the Board, the researchers decided to simulate the service and to test how and if it could be helpful for caregivers to manage their burden (Exner et al. 2014). The research group supported the idea of a "simulation session", this being a tool frequently used in the service literature as a means to collect useful representations of what the future service could be (Dieckmann et al. 2017). On the one hand, a simulation session could support caregivers in providing substantial feedbacks for service design improvement; on the other hand, hospital managers could make sense of the potential outcomes of the newly designed practice and proceed toward more informed approval and financing. The simulation sessions were conducted by the nurse of the research group; the remaining members of the group observed and took notes.

After collection of the caregivers' feedbacks and conduct of the simulation sessions, a preliminary assessment of the service was performed through follow-up interviews. The research group drew up an outline for an interview, which the nurse of the Counselling Center conducted by telephone in order to limit interference with the patients' and caregivers' daily lives. The aim of the follow-up interview was to assess how participating in the simulation sessions had affected the caregiver's experience after the patient's discharge. Table 1 provides an overview of the methodology.

## Findings

### Stage 1: Burden Identification

The research group analyzed the results of the scales that were returned by 33 experienced family caregivers (27 women and 6 men; mean age 51.5 years).

**Table 1** Overview of the methodology

| Stages | Participants | Activities and Tools |
|---|---|---|
| Stage 1: burden identification (i.e. identification of the burden and needs experienced by caregivers). | 33 experienced family caregivers enrolled on a training course. | - Users were surveyed by means of validated scales.<br>- Researchers arranged reflection meetings at the start and end of the stage. |
| Stage 2: burden sharing (i.e. in-depth analysis of the burden emerged at stage 1 with both users and professionals). Focus on the discharge process. | 10 experienced family caregivers enrolled on a training course; 7 hospital nurses from the Department of Geriatrics, Neurology, internal Medicine. | - Users and professionals took part in participatory focus groups.<br>- Researchers conducted focus groups and arranged reflection meetings at the start and end of the stage and between-focus group. |
| Stage 3: burden management, part I – the survey (i.e. definition of actions to manage the burden at discharge). | 22 family caregivers of hospital inpatients attending a Day Hospital. | - Users were surveyed by means of validated scales and questions related to specific service requirements.<br>- Researchers arranged reflection meetings at the start and end of the sub-stage. |
| Stage 3: burden management, part II – simulation session and follow-up interview (i.e. Implementation of actions to manage the burden at discharge). | 2 family caregivers of hospital inpatients attending a Day Hospital. | - Users were involved in service simulations to design a feasible solution better.<br>- Researchers conducted/observed the simulation sessions and arranged reflection meetings at the start and end of the sub-stage and in between activities. |

The results of the CBI questionnaire showed that the respondents' average burden was low to medium (mean score of $29.78 \pm 16.54$; possible score 0–96). Almost all values observed had the same frequency, meaning that all the respondents experienced different values of burden.

Overall, caregivers take care of patients with a medium level of care dependency (mean score of ADL $2.94 \pm 2.28$; possible score 0–6). The correlation of the CBI with the ADL questionnaire, through which the caregivers rated the perceived patients' dependence on them, suggested that a higher perceived dependence of the patients on the caregivers for everyday activities - i.e. lower ADL score - was associated with a higher level of caregivers' distress and negative emotions - i.e. higher CBI score -. The value of the Pearson correlation coefficient ($r = -0,589$) indicates a moderate linear relationship.

Finally, the correlation of the third questionnaire (CNA scale) showed that cognitive-behavioral needs (i.e. need to be informed and trained about the disease and how to manage patient care) were predominant and very common among all respondents. The summary of CNA values is shown in Table 2.

### Stage 2: Burden Sharing

At stage 2, the research group organized two focus groups with ten family caregivers and seven hospital nurses. Table 3 provides details about ages, occupations, education level and other information about the participating caregivers and nurses.

As shown in Table 3, the majority of the respondent caregivers were women of working age. They provided a few hours of care a week (average: 3.12 h), and 1 in 2 of them had some spare time thanks to the help of a formal or private caregiver. However, during the meetings, they clarified that if they were working full-time, if they needed to combine caring for a relative with looking after their own family, or if they had to travel long distances to provide care, caregiving had a severe impact on their lives.

The objective of both focus groups was to gather more details on the cause of the burden that emerged at stage 1, and to understand if and how the services currently offered by the hospital before discharge met the needs of caregivers in regard to being trained and informed.

During the reflection meeting arranged before the focus group with caregivers, researchers stated that the aim of the focus group was to understand aspects associated with the following questions: (i) "given what is important in terms of patient care according to your experience, what kind of information was given to you and by whom in the hospital? (e.g. physicians, nurses, others)"; (ii) "how would you have preferred the information to be provided?"

**Table 2** Findings from stage 1 – CNA values

| CNA – Types of need | Saturation level ($\alpha$)[a] |
|---|---|
| emotional | 55% |
| psycho-functional | 70.2% |
| cognitive-behavioral | 87.3% |
| relational | 69.5% |
| organizational | 74.7% |
| spiritual | 35.3% |

[a] The saturation level ($\alpha$) is calculated as the percentage of the score related to the specific need, when compared to the total score of the questionnaire

**Table 3** Description of participants (caregivers and nurses)

| Family caregivers | Value |
|---|---|
| Number of participants | (10) |
| Male | (2) |
| Female | (8) |
| Average age (y.o.) | 49.78 |
| Middle school | (1) |
| High school | (7) |
| Bachelor degree | (2) |
| Numbers of hours of care provided (hours/week) | 3.12 |
| Average duration of caregiving (years) | 3 |
| Work and manage caregiving activities at the same time | (8) |
| Changed type of work (switching to a part-time job or taking early retirement) | (2) |
| No spare time | (5) |
| Helped by private carers | (5) |
| Hospital nurses | |
|   Average age | 31 |
|   First level degree | (7) |
|   First level master | (4) |
|   Average years of experience as hospital nurse | 5 |

Overall, discussion highlighted critical issues and the predominant themes were: a) that some key issues were not explained to caregivers and b) their desire to be given information about patient care by nurses.

Specifically, the caregivers made it clear that the most critical part of their task was when variations, such as hospitalizations, occurred in the patients' pathways: in those cases, the patients' conditions changed, and so did the therapies and needs, and the caregivers might not be prepared to address them properly. While caregivers recalled their experience with a sick relative during hospitalization and soon thereafter, a great amount of emotions and feelings were expressed. They ranged from relief to anxiety, from happiness to sorrow. Co-design tools were helpful in facilitating the discussion and focusing the attention of the caregivers on their specific experience.

The use of the emotional map evidenced two main drawbacks in the caregivers' experience:

– Very often nurses provide information on demand, and it is not easy to find nurses that give advice spontaneously (this was rated as a very critical problem);
– It is rare for nurses to give advice during their working hours, and it sometimes happens that nurses and caregivers talk to each other outside working time (this was rated as a critical problem).

In many instances, caregivers reported that they had never received guidance and advice on how to take care of patients. In their words:

*"I decided to take care of my loved one, but nobody takes care of me. My duty is to provide help, but I'm not a physician, and I'm not even a nurse. When he [the patient] came home from hospital, I wasn't ready for this new duty…and I didn't receive any help. But I need help as well!"* (A., 46 y.o., female).

*"This focus group…well, this is the first time that someone has recognized that I exist, as a caregiver. My responsibility is huge, but I can't cope with the patient's needs, I don't feel that I can do it"* (N., 75 y.o., male).

Thus, in the reflection meeting, the research group decided to explore the following topics and questions during the second focus group with the nurses: (i) "what kind of information was asked/not asked to you by caregivers when the patients are hospitalized?"; (ii) "what kind of information have/have you not been willing and able to provide to caregivers before the patients' discharge?"

Nurses highlighted two predominant themes: a) while the patient was hospitalized, caregivers did not generally ask questions about how to manage the patient in the future; and b) nurses did not provide information in that regard.

Moreover, when building the emotional map, negative emotions were connected by the nurses to the relationship with the caregiver after the patient's discharge. In their words:

> "*The focus of our daily work is on patients, their medications and emergencies. We don't have time to inform the caregivers in the ward corridors. And when their relative is hospitalized they usually don't ask for information…*" (M., 37 y.o., female).

> "*When patients are hospitalized, caregivers are unaware that, in many cases, they should be able to perform many activities by themselves in the future. So it often happens that they come back to us, or they call us on the phone, once the patient has been discharged, to get advice. But this is not manageable, it doesn't work. I can't interrupt my work to answer the phone or have them walk through the ward again, once the patient has been discharged!*" (G., 33 y.o., female).

The researchers agreed that the interactions in the focus groups highlighted the need for caregivers' training during patients' hospitalization. However, caregivers are not proactive in asking for advice, since they become aware of the need for specific training only when they go home with the patient and the burden of care comes under their responsibility. On the other hand, nurses rarely provide information to caregivers spontaneously, and they usually give advice in their overtime, because caregiver training is not a duty of nurses during patients' hospitalization.

## Stage 3: Burden Management

In light of the results of stage 1 and 2, the research group proposed that, in order to prevent the burden after discharge, caregivers should receive support when the patient is hospitalized, without causing interruptions in the everyday work of hospital nurses. Thus, the solution that emerged in the reflection meeting was to arrange a consultation with the caregiver at the hospital before the patient's discharge. This consultation could be a training session so that the caregiver is able to take care of the patient once discharged.

The research group discussed the activities that caregivers generally perform after patients' discharge (e.g. taking vital signs, wound management) and agreed that nurses could have the appropriate professional background to run a service that teaches caregivers how to perform those actions.

Before proceeding, the research group met with the Hospital Board. At the beginning, some skepticism was expressed by the members of the Board of Directors about the utility and cost-effectiveness of the solution proposed: caregivers have been traditionally seen as acting beyond organizational boundaries, outside the control of healthcare professionals, and their actions have had scant impact on the hospital's performance.

Once aware of the problem, the Board authorized the third stage of the AR project and discussed how the hospital could design a proactive system to provide guidance on how to treat patients when they left the hospital, whether or not the caregiver was aware of the need for such training.

## Stage 3: Part I - the Survey

The research group analyzed the results of the survey, which was returned by 22 caregivers. The results of the CNA on the new population confirmed that cognitive-behavioral needs were dominant also in this sample (saturation level equal to 82.8%). Moreover, 16 respondents showed interest in educational support; 3 specified that they were not interested because they were competent in health care and had already received enough information; 3 were not interested because they were assisted by experts in providing care. Among those who expressed interest in the service idea, most would prefer to access the service during patients' hospitalization, in a dedicated place, by appointment, and they were willing to pay a fee for the service, if necessary. A total of nine respondents signed up to the simulations.

## Stage 3: Part II - Simulation Session and Follow-Up Interview

The service was tested by means of a simulation session performed by the nurse of the Counselling Centre. The staff of the Counselling Centre selected people according to their availability to be engaged during the week following the invitation. In that period, two caregivers were readily available and the research group was able to organize two simulations of the service process; both sessions lasted about an hour.

For the service simulation, the entire research group cooperated and supported the nurses in personalizing the training on specific caregiver needs. The simulation foresaw that the nurse should meet the caregiver to gather information about his/her life and the patients' clinical status, and about the specific training that he/she would need. The first simulation was arranged with a caregiver in need of individual training on lifestyle, correct diet, and wound management, so that she could provide better care for her mother. In the second service simulation, the caregiver needed to learn how to monitor blood pressure and give medication to her husband. Guided by the nurse, during the session she learned how to monitor pulse rate and blood pressure and how to give an injection.

Finally, in order to assess the impact of the service simulations on the caregivers' burden, the nurse conducted a follow-up interview. During interviews, caregivers confirmed that they perceived a relief from their burden after participating in the simulation, since obtaining specific skills made them feel more confident and more secure. In their words:

> "*The training enabled me to help my loved one get a better quality of life.*" (G., 59 y.o., female).

> "*The training session was useful; it was a positive experience. Now that I've met the nurse I feel much more secure. I am following her suggestions and I am more confident.*" (L., 63 y.o., female).

> "*Now I feel confident and better able to communicate with the doctor, to understand my responsibilities, and put the care team's suggestions into practice.*" (G., 59 y.o., female).

## Discussion

The aim of the research reported in this study was to use AR to develop new hospital practices to manage the burden borne by family caregivers when patients are discharged from hospital.

In compliance with the democratic principles of action research (Bradbury-Huang 2010), the researchers pursued meaningful interactions and collaboration with all the stakeholders involved. Participants were involved by means of various strategies. Validated scales were used at stage 1, to identify the burden. Focus groups were conducted at stage 2, so that caregivers and professionals could share their experiences. Finally, at stage 3, simulation sessions were run to test the service idea. The tools used at different stages in the research (e.g. emotional map, wheel of emotions, simulation) enhanced the participation of caregivers and professionals and complemented each other: while surveys were useful for example to test the level of burden, they are not able to understand causes and find solutions. Hence organizations need to adopt also in-depth techniques to detect dynamics and interactions which could enable the sharing of experiences and of the related emotions and feelings.

Helping participants speak for themselves was instrumental to designing an action and generating understanding among stakeholders (Coghlan and Brannick 2014). Within this setting, the research group acted as the intermediary (Huzzard et al. 2010) among diverse stakeholders' perspectives, collecting relative interests and trying to get them involved. Specifically, the main duty of the research group was to propose different strategies to maintain the commitment of caregivers throughout the project and to raise the awareness of hospital professionals and Board concerning users that they did not perceive as their own.

This study has some implications for decision makers in healthcare, especially for hospital managers.

First, the AR project was useful to detect and share the caregivers' burden: throughout the research, caregivers expressed their needs, discussed improvements, and declared that they were willing to test possible solutions. As such, the project shows that, if properly involved, caregivers are keen to reflect on their experience. Through the use of AR, important issues, which may not have surfaced otherwise, are identified. Some of them are the low awareness of family caregivers about the importance of being trained before discharge and nurses' difficulties in managing family caregivers' demands even after discharge. This AR study provided the opportunity for the opinions of caregivers and professionals to be voiced, resulting in the improvement of hospital discharge planning in a way aligned with their needs and preferences. This prevents burden, potentially risky behaviors for patient safety and ineffective use of the hospital resources (Ranieri et al. 2017).

Second, AR helped to develop and implement agreed and feasible interventions to bridge the gap between what is required and what is delivered by the organization (Groen van de Ven et al. 2017). Although some members of the hospital Board were initially skeptical about the scheme, the AR highlighted that caregivers are actors crucial in managing patients' health effectively. Thus, even without providing evidence on the cost-effectiveness of the solution proposed, the AR project improved knowledge sharing within the organization and raised awareness of the caregiver's role in the interest of both the patients and the better use of hospital resources (e.g. limited patient readmissions).

Therefore, this study contributes to the growing body of evidence regarding family caregivers and describes the phenomenon of providing effective information and training as a fundamental step toward appropriate initiatives that policymakers should implement regarding better quality of care (Roter et al. 2018).

Third, taking the perspective of the Head of the Nursing Department, it was valuable to study the roles that nurses could play in regard to caregivers and acknowledge that communication between nurses and caregivers of hospitalized patients is not systematic. This is mainly due to a lack of time and skills on the nurses' side: more encouragement from hospital managers is needed to consider caregivers as part of the care process and nurses as key members in caregiver training (Hagedoorn et al. 2017). To this end, the project made it possible to collect information so that personnel could be trained in skills for communicating with families in the hospital.

Finally, the case showed that AR can be applied as an approach to address issues that relate to caregivers or to service users in general. For example, hospital managers could be willing to apply AR if they note an unexpected increase in patient readmission rates, which could denote an inefficient management of the patients at home, or if physicians report recurrent negative situations detected during follow-up visits.

The case made it clear that hospital managers need to move proactively towards caregivers, and the method proposed here is a feasible way for them to do so.

## Limitations

Our AR has some limitations. One of them is that the project had to respect a strict timeline; as such, we could run only two simulation sessions and one focus group for each category of participants (caregivers and nurses), which limited generalization of the results and prevented us from controlling for specific group dynamics. Second, the simulation assessment was conducted a few days after the session; a consistent assessment of the outcomes in the long term is still lacking.

Third, the members of the Hospital Board, in a form of defensive response, did not consider it appropriate to involve caregivers in the reflection meetings, in order not to raise expectations that could not be supported for organizational and economic reasons. To resolve these issues (i.e. limited number of caregivers and exclusion of caregivers from the reflection meetings), we involved a group of 22 caregivers through a second survey.

Moreover, the setting of the research was a teaching hospital; consequently, the professionals and the Board might have been keener to experiment with innovative solutions than managers and professionals in other contexts.

Furthermore, the needs of caregivers and families typically vary in the course of a disease as well as in response to life changes. Information and services useful at one point may not be helpful at another; this further suggests that periodic or ongoing training may be necessary besides that provided at discharge.

Lastly, this is a case study from Italy, and this intervention strategy works in our country. Although informal caregivers exist worldwide, replication of our approach in other countries that differ in terms of long-term care systems and culture should be studied further.

## Conclusions

We conducted an AR study in order to develop a solution for managing the caregivers' burden from the moment when patients are discharged from hospital.

The project was carried out in a teaching hospital in Rome. It involved more than 50 caregivers and several professionals, and it consisted of 3 stages: burden identification,

burden sharing, and burden management. For each stage, specific techniques and tools were applied, with an especial focus on tools that support the users' emotional involvement and experience sharing.

In a scenario in which family caregivers' experiences are seldom considered in participatory research projects, we involved family caregivers that experience hospital discharge in an AR project. The results provide insights into the importance of caregiver engagement and knowledge about how to manage the tremendous need for caregivers' training in the care transition from hospital to home. Hospital managers should design and implement discharge policies more effectively and consider how to re-organize hospital activities to let nurses invest time in caregiver training.

## Compliance with Ethical Standards

**Conflict of Interest**  The authors declare that they have no conflict of interest.

## References

Al-Harthy N, Sudersanadas KM, Al-Mutairi M, Vasudevan S, Bin Saleh G, Al-Mutairi M, Hussain LW (2016) Efficacy of patient discharge instructions: a pointer toward caregiver friendly communication methods from pediatric emergency personnel. J Family Community Med 23(3):155–160. https://doi.org/10.4103/2230-8229.189128

Alvira MC, Risco E, Cabrera E, Farré M, Rahm Hallberg I, Bleijlevens MH, Meyer G, Koslcenniemi J, Soto ME, Zabalegui A, RightTimePlaceCare Consortium (2015) The association between positive–negative reactions of informal caregivers of people with dementia and health outcomes in eight European countries: a cross-sectional study. J Adv Nurs 71(6):1417–1434. https://doi.org/10.1111/jan.12528

Ament BH, Wolfs CA, Kempen GI, Ambergen T, Verhey FR, De Vugt ME (2015) The benefit of a geriatric nurse practitioner in a multidisciplinary diagnostic service for people with cognitive disorders. BMC Res Notes 8:217. https://doi.org/10.1186/s13104-015-1189-6

Avcı K, Çınaroğlu S, Top M (2017) Perceptions of pediatric nurses on ethical decision making processes. Syst Pract Action Res 30:67. https://doi.org/10.1007/s11213-016-9386-3

Bartolo M, De Luca D, Serrao M, Sinforiani E, Zucchella C, Sandrini G (2010) Caregiver burden and needs in community neurorehabilitation. J Rehabil Med 42(9):818–822. https://doi.org/10.2340/16501977-0612

Bastawrous M (2013) Caregiver burden - a critical discussion. Int J Nurs Stud 50(3):431–441. https://doi.org/10.1016/j.ijnurstu.2012.10.005

Batiashvili G, Gerzmava O (2013) Administration on aging. Global comparison of formal and informal caregiving. Eur Sci J 9(10). https://doi.org/10.19044/esj.2013.v9n10p%25p

Bauer M, Fitzgerald L, Haesler E, Manfrin M (2009) Hospital discharge planning for frail older people and their family. Are we delivering best practice? A review of the evidence. J Clin Nurs 18(18):2539–2546. https://doi.org/10.1111/j.1365-2702.2008.02685.x

Bélanger L, Bourbonnais A, Bernier R, Benoit M (2017) Communication between nurses and family caregivers of hospitalised older persons: a literature review. J Clin Nurs 26(5–6):609–619. https://doi.org/10.1111/jocn.13516

Boerboom TB, Jaarsma D, Dolmans DH, Scherpbier AJ, Mastenbroek NJ, Van Beukelen P (2011) Peer group reflection helps clinical teachers to critically reflect on their teaching. Med Teach 33(11):615–623. https://doi.org/10.3109/0142159X.2011.610840

Boltz M, Lee KH, Chippendale T, Trotta RL (2018) Pre-admission functional decline in hospitalized persons with dementia: the influence of family caregiver factors. Arch Gerontol Geriatr 74:49–54. https://doi.org/10.1016/j.archger.2017.09.006

Bové DG, Zakrisson AB, Midtgaard J, Lomborg K, Overgaard D (2016) Undefined and unpredictable responsibility: a focus group study of the experiences of informal caregiver spouses of patients with severe COPD. J Clin Nurs 25(3–4):483–493. https://doi.org/10.1111/jocn.13076

Bowen S, McSeveny K, Lockley E, Wolstenholme D, Cobb M, Dearden A (2013) How was it for you? Experiences of participatory design in the UK health service. CoDesign 9(4):230–246. https://doi.org/10.1080/15710882.2013.846384

Boyd H, McKernon S, Old A (2010) Health service co-design: working with patients to improve healthcare services: guide and toolkit. Waitemata District Health Board

Bradbury-Huang H (2010) What is good action research? Why the resurgent interest? Action Res 8(1):93–109. https://doi.org/10.1177/1476750310362435

Bremer P, Cabrera E, Leino-Kilpi H, Lethin C, Saks K, Sutcliffe C, Soto M, Zwakhalen SM, Wübker A, RightTimePlaceCare Consortium (2015) Informal dementia care: consequences for caregivers' health and health care use in 8 European countries. Health Policy 119(11):1459–1471. https://doi.org/10.1016/j.healthpol.2015.09.014

Brimblecombe N, Pickard L, King D, Knapp M (2017) Perceptions of unmet needs for community social care services in England. A comparison of working carers and the people they care for. Health Soc Care Community 25(2):435–446. https://doi.org/10.1111/hsc.12323

Brimblecombe N, Fernandez JL, Knapp M, Rehill A, Wittenberg R (2018) Review of the international evidence on support for unpaid carers. Journal of Long-Term Care 25–40. https://doi.org/10.21953/lse.ffq4txr2nftf

Brunton M, Jordan C, Fouche C (2008) Managing public health care policy: Who's being forgotten? Health Policy 88(2):348–358. https://doi.org/10.1016/j.healthpol.2008.04.007

Caswell G, Pollock K, Harwood R, Porock D (2015) Communication between family carers and health professionals about end-of-life care for older people in the acute hospital setting: a qualitative study. BMC Palliat Care 14:35. https://doi.org/10.1186/s12904-015-0032-0

Coghlan D, Brannick T (2014) Doing action research in your own organization, 4th edn. Sage, London. https://doi.org/10.1080/14767333.2015.1049453

Collatto DC, Dresch A, Lacerda DP, Bentz IG (2018) Is action design research indeed necessary? Analysis and synergies between action research and design science research. Syst Pract Action Res 31:239. https://doi.org/10.1007/s11213-017-9424-9

Corry M, While A, Neenan K, Smith V (2015) A systematic review of systematic reviews on interventions for caregivers of people with chronic conditions. J Adv Nurs 71(4):718–734. https://doi.org/10.1111/jan.12523

Courtin E, Jemiai N, Mossialos E (2014) Mapping support policies for informal carers across the European Union. Health Policy 118(1):84–94. https://doi.org/10.1016/j.healthpol.2014.07.013

Cramm JM, Nieboer AP (2016) The changing nature of chronic care and coproduction of care between primary care professionals and patients with COPD and their informal caregivers. Int J Chron Obstruct Pulmon Dis 11:175–182. https://doi.org/10.2147/COPD.S94409

Crawford MJ, Rutter D, Manley C, Weaver T, Bhui K, Fulop N, Tyrer P (2002) Systematic review of involving patients in the planning and development of health care. BMJ 325(7375):1263. https://doi.org/10.1136/bmj.325.7375.1263

Dal Pra Ponticelli M (2004) Prendersi cura e lavoro di cura (Taking care and care work). E. Zancan Foundation, Padova

Davison RM, Martinsons MG, Ou CXJ (2012) The roles of theory in canonical action research. MIS Q 36(3):763–778. https://doi.org/10.2307/41703480

Dieckmann P, Patterson M, Lahlou S, Mesman J, Nyström P, Krage R (2017) Variation and adaptation: learning from success in patient safety-oriented simulation training. Adv Simul 2:21. https://doi.org/10.1186/s41077-017-0054-1

Donetto S, Tsinakas V, Robert G (2014) Using experience-based co-design (EBCD) to improve the quality of healthcare: mapping where we are now and establishing future directions. King's College, London

Dujardin C, Farfan-Portet MI, Mitchell R, Popham F, Thomas I, Lorant V (2011) Does country influence the health burden of informal care? An international comparison between Belgium and Great Britain. Soc Sci Med 73(8):1123–1132. https://doi.org/10.1016/j.socscimed.2011.07.016

Exner K, Lindow K, Buchholz C, Stark R (2014) Validation of product-service systems–a prototyping approach. Procedia CIRP 16:68–73. https://doi.org/10.1016/j.procir.2014.03.004

Gelo O, Braakman D, Benetka G (2008) Quantitative and qualitative research: beyond the debate. Integr Psychol Behav Sci 42(3):266–290. https://doi.org/10.1007/s12124-008-9078-3

Gervès C, Chauvin P, Bellanger MM (2014) Evaluation of full costs of care for patients with Alzheimer's disease in France: the predominant role of informal care. Health Policy 116(1):114–122. https://doi.org/10.1016/j.healthpol.2014.01.001

Gibson MJ, Kelly K, Kaplan AK (2012) Family caregiving and transitional care: a critical review. Family Caregiver Alliance, San Francisco. https://www.caregiver.org/family-caregiving-and-transitional-care-critical-review-2012. Accessed 5 Sep 2016

Giovannetti ER, Reider L, Wolff JL, Frick KD, Boult C, Steinwachs D, Boyd CM (2013) Do older patients and their family caregivers agree about the quality of chronic illness care? Int J Qual Health Care 25(5):515–524. https://doi.org/10.1093/intqhc/mzt052

Glajchen M (2004) The emerging role and needs of family caregivers in cancer care. J Support Oncol 2(2):145–155

Groen van de Ven L, Smits C, Elwyn G, Span M, Jukema J, Eefsting J, Vernooij-Dassen M (2017) Recognizing decision needs: first step for collaborative deliberation in dementia care networks. Patient Educ Couns 100(7):1329–1337. https://doi.org/10.1016/j.pec.2017.01.024

Hagedoorn E, Paans W, Jaarsma T, Keers J, Van Der Schans C, Luttik ML (2017) Aspects of family caregiving as addressed in planned discussions between nurses, patients with chronic diseases and family caregivers: a qualitative content analysis. BMC Nurs 16(37). https://doi.org/10.1186/s12912-017-0231-5

Hazzan AA, Ploeg J, Shannon H, Raina P, Oremus M (2015) Caregiver perceptions regarding the measurement of level and quality of care in Alzheimer's disease. BMC Nurs 14:54. https://doi.org/10.1186/s12912-015-0104-8

Huzzard T, Ahlberg BM, Ekman M (2010) Constructing interorganizational collaboration. Action Res 8(3):293–314. https://doi.org/10.1177/1476750309335206

Johnson N, Barion A, Rademaker A, Rehkemper G, Weintraub S (2004) The activities of daily living questionnaire: a validation study in patients with dementia. Alzheimer Dis Assoc Disord 18(4):223–230

Kehusmaa S, Autti-Rämö I, Helenius H, Rissanen P (2013) Does informal care reduce public care expenditure on elderly care? Estimates based on Finland's age study. BMC Health Serv Res 13:317. https://doi.org/10.1186/1472-6963-13-317

Kemmis S, McTaggart R (2000) Participatory action research: communicative action and the public sphere. In: Denzin NK, Lincoln YS (eds) The sage handbook of qualitative research. Sage, Thousand Oaks, pp 559–603

King D, Pickard L (2013) When is a carer's employment at risk? Longitudinal analysis of unpaid care and employment in midlife in England. Health Soc Care Community 21(3):303–314. https://doi.org/10.1111/hsc.12018

Kinsella K, He W (2009) An aging world: 2008. International Population Reports, P95/09–1. U.S. Census Bureau, Washington, DC

Kramer BJ, Thompson EH (2004) Men as caregivers. Prometheus Books

Landers S, Madigan E, Leff B, Rosati RJ, McCann BA, Hornbake R, MacMillan R, Jones K, Bowles K, Dowding D, Lee T, Moorhead T, Rodriguez S, Breese E (2016) The future of home health care: a strategic framework for optimizing value. Home Health Care Manag Pract 28(4):262–278. https://doi.org/10.1177/1084822316666368

Lang A (2010) There's no place like home: research, practice and policy perspectives regarding safety in homecare. Int J Qual Health Care 22(1):75–77. https://doi.org/10.1093/intqhc/mzq007

Llanque S, Savage L, Rosenburg N, Caserta M (2016) Concept analysis: Alzheimer's caregiver stress. Nurs Forum 51(1):21–31. https://doi.org/10.1111/nuf.12090

Loewenson R, Laurell AC, Hogstedt C, D'Ambruoso L, Shroff Z (2014) Participatory action research in health systems: a methods reader. TARSC, AHPSR, WHO, IDRC Canada, Equinet, Harare. http://equinetafrica.org/sites/default/files/uploads/documents/PAR_Methods_Reader2014_for_web.pdf. Accessed 5 Apr 2018

MacFarlane A, Singleton C, Green E (2009) Language barriers in health and social care consultations in the community: a comparative study of responses in Ireland and England. Health Policy 92(2–3):203–210. https://doi.org/10.1016/j.healthpol.2009.03.014

Meyer J (2000) Qualitative research in healthcare. Using qualitative methods in health related action research. BMJ 320(7228):178–181. https://doi.org/10.1136/bmj.320.7228.178

Meyer J (2001) Action research. In: Fulop N et al (eds) Studying the organization and delivery of health services: research methods. Routledge, London, pp 172–187

Miravitlles M, Peña-Longobardo LM, Oliva-Moreno J, Hidalgo-Vega Á (2015) Caregivers' burden in patients with COPD. Int J Chron Obstruct Pulmon Dis 10:347–356. https://doi.org/10.2147/COPD.S76091

Moroni L, Sguazzin C, Filipponi L, Bruletti G, Callegari S, Galante E, Giorgi I, Majani G, Bertolotti G (2007) Caregiver need assessment: a questionnaire for caregiver demand. G Ital Med Lav Ergon 30(3 Suppl B):B84–B90

Navanandan N, Schmidt SK, Cabrera N, DiStefano MC, Mistry RD (2017) The caregiver perspective on unscheduled 72-hour return visits to pediatric acute care sites: a focus on discharge processes. Acad Pediatr 17(7):755–761. https://doi.org/10.1016/j.acap.2017.02.003

Novak M, Guest C (1989) Application of a multidimensional caregiver burden inventory. The Gerontologist 29(6):798–803. https://doi.org/10.1093/geront/29.6.798

O'Sullivan J, Hocking C, Spence D (2014) Action research: changing history for people living with dementia in New Zealand. Action Res 12(1):19–35. https://doi.org/10.1177/1476750313509417

OECD (2017) Health at a glance 2017: OECD indicators. OECD Publishing, Paris

Onwuegbuzie AJ, Johnson RB (2004) Validity issues in mixed methods research. American Educational Research Association, annual meeting San Diego, CA

Ottmann G, Laragy C, Allen J, Feldman P (2011) Coproduction in practice: participatory action research to develop a model of community aged care. Syst Pract Action Res 24:413. https://doi.org/10.1007/s11213-011-9192-x

Péraire, C, Sedano T (2014) Essence Reflection Meetings: Field Study. EASE '14 Proceedings of the 18th International Conference on Evaluation and Assessment in Software Engineering, Article no. 25. https://doi.org/10.1145/2601248.2601296

Perrott BE (2013) Including customers in health service design. Health Mark Q 30(2):114–127. https://doi.org/10.1080/07359683.2013.787882

Pickard L (2011) The supply of informal care in Europe. ENEPRI Research Report no 94. http://aei.pitt.edu/id/eprint/32514. Accessed 8 Oct 2018

Ranieri V, Madigan K, Roche E, McGuinness D, Bainbridge E, Feeney L (2017) Caregiver burden and distress following the patient's discharge from psychiatric hospital. BJPsych Bull 41(2):87–91. https://doi.org/10.1192/pb.bp.115.053074

Reason P, Bradbury H (2001) Handbook of action research: participative inquiry and practice. Sage Publications, London

Rodrigues R, Schulmann K, Schmidt A, Kalavrezou N, Matsaganis M (2013) The indirect costs of long-term care. Research note 8/2013, European Commission. http://ec.europa.eu/social/BlobServlet?docId=11780&langId=en. Accessed 7 Oct 2018

Roter DL, Narayanan S, Smith K, Bullman R, Rausch P, Wolff JL, Alexander GC (2018) Family caregivers' facilitation of daily adult prescription medication use. Patient Educ Couns 101(908–916). https://doi.org/10.1016/j.pec.2017.12.018

Schmeer K (1999) Guidelines for conducting a stakeholder analysis. Partnerships for Health Reform, Abt Associates Inc., Bethesda

Sexson K, Lindauer A, Harvath TA (2017) Discharge planning and teaching. Am J Nurs 117(5):S22–S24. https://doi.org/10.1097/01.NAJ.0000516390.43257.c8

Söderhamn U, Kjøstvedt HT, Slettebø Å (2015) Evaluation of ethical reflections in community healthcare: a mixed-methods study. Nurs Ethics 22(2):194–204. https://doi.org/10.1177/0969733014524762

Songur C, Özer Ö, Gün Ç, Top M (2018) Patient safety culture, evidence-based practice and performance in nursing. Syst Pract Action Res 31:359. https://doi.org/10.1007/s11213-017-9430-y

Top M, Tekingündüz S (2015) Patient safety culture in a Turkish public hospital: a study of nurses' perceptions about patient safety. Syst Pract Action Res 28:87. https://doi.org/10.1007/s11213-014-9320-5

Torlak NG, Müceldili B (2014) Soft systems methodology in action: the example of a private hospital. Syst Pract Action Res 27(4):325–361. https://doi.org/10.1007/s11213-013-9290-z

Van Exel J, De Graaf G, Brouwer W (2007) Care for a break? An investigation of informal caregivers' attitudes toward respite care using Q-methodology. Health Policy 83(2):332–342. https://doi.org/10.1016/j.healthpol.2007.02.002

Van Exel J, De Graaf G, Brouwer W (2008) Give me a break!: informal caregiver attitudes towards respite care. Health Policy 88(1):73–87. https://doi.org/10.1016/j.healthpol.2008.03.001

Varney J, Weiland TJ, Jelinek G (2014) Efficacy of hospital in the home services providing care for patients admitted from emergency departments: an integrative review. Int J Evid Based Healthc 12(2):128–141. https://doi.org/10.1097/XEB.0000000000000011

Watanabe A, Fukuda M, Suzuki M, Kawaguchi T, Habata T, Akutsu T, Kanda T (2015) Factors decreasing caregiver burden to allow patients with cerebrovascular disease to continue in long-term home care. J Stroke Cerebrovasc Dis 24(2):424–430. https://doi.org/10.1016/j.jstrokecerebrovasdis.2014.09.013

Zarit SH, Todd PA, Zarit JM (1986) Subjective burden of husbands and wives as caregivers: a longitudinal study. Gerontologist 26(3):260–266. https://doi.org/10.1093/geront/26.3.260