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Moving beyond the first response phenomenon

Exploring carers' views and experiences of being involved in research and development work

Exploring
carers' views
and
experiences

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Abstract

Purpose – In Sweden, the care of older people and people with disabilities is increasingly carried out by informal carers, often family members, who are unpaid and outside a professional or formal framework. While there is an increasing awareness of the role of carers within service systems and their own needs for support, their involvement in research is underexplored. The purpose of this paper is to explore carers' views and experiences of involvement in research and development (R&D) work.

Design/methodology/approach – A qualitative study was conducted, consisting of 12 individual interviews with carers from different local Swedish carer organizations.

Findings – Core findings included carers' discussions of the perceived challenges and benefits of their involvement in research, both generally and more specifically, in the context of their involvement in the development of a national carer strategy.

Research limitations/implications – Limitations included the relative lack of male carer participants and the convenience sample.

Practical implications – Authentic carer involvement in research demands a high level of engagement from researchers during the entire research process. The provided CRAC framework, with reference to the themes community, reciprocity, advocacy and circumstantiality, may help researchers to understand and interpret carer involvement in research and provide the prerequisites for their involvement.

Originality/value – There is a dearth of studies that systematically examine carer involvement in research. This paper attempts to redress this gap by providing a nuanced analysis of carer involvement in R&D work from the perspective of carers themselves.

Keywords Identity, Heterogeneity, Research and development, Social policy, Carer involvement, Carer strategy

Paper type Research paper

Introduction

Should carers be invited as partners in research and development (R&D) work concerning informal carers, care and caring? The first response to this question is usually positive, and in many cases, unproblematized – user involvement appears to be a “win–win” situation

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(Kylberg *et al.*, 2018). However, there is currently a lack of research which specifically explores the significance of carers' involvement in research. This paper, based on a qualitative study involving a sample of Swedish informal carers, is an attempt to address this knowledge gap. More specifically, it aims to move current knowledge beyond the initial positive response by outlining a framework (the CRAC framework, based on the following themes: a sense of Community, feelings of Reciprocity, a sense of Advocacy and reflecting on Circumstantiality) for interpreting and evaluating the experiences of carers with regard to their involvement in R&D work.

The caring experience

As the world's population ages, it has been recognized that informal carers will increasingly play a critical role in every society (IACO, 2018). Indeed, this global trend is also reflected within a Nordic context, which once boasted a generous welfare-state system in which citizens were predominantly cared for by the state from "the cradle to the grave." More and more, however, the care of frail older people is being "handed over" to the family (Szebehely and Meagher, 2018). Informal carers are hence a key, yet often unacknowledged, part of the Swedish health and care systems (Eurocarers, 2015; SFCCC, 2016). Currently, approximately one in five adults in Sweden provide regular help, support and/or care for a family member or significant other, and one-third of these 1.3m individuals do this on a daily basis. Carers are predominantly female and are typically spouses, middle-aged daughters or daughters-in-law and between the ages of 45 and 75 years (Eurocarers, 2018). Recent data from a major population survey indicated that carers are performing more caring activities compared with a similar survey conducted in 2011 (SNAO, 2014; Magnusson and Hanson, 2019). Since being a carer is known to affect one's health, well-being, finances, work and social inclusion, it is essential that the voices of carers are listened to and respected in different societal arenas (Erlingsson *et al.*, 2012; NBHWS, 2012; Buckner and Yeandle, 2015; Eurofound, 2015).

Taking on a caring role is a significant undertaking that brings with it both challenges and rewards. Within the Nordic countries, informal caring is considered to be voluntary and complementary to the interventions of the formal sector (Zigante, 2018), but in reality it is common for carers to feel that they have no choice (Healey, 2012; Takter, 2017; Ulmanen, 2017). Most people find the overall experience of being a carer positive and personally rewarding, providing them with a sense of well-being through the knowledge that their loved one is receiving proper care (Ulmanen, 2017), and possibly even strengthening their relationship (Nolan *et al.*, 1996; Erlingsson *et al.*, 2012; Healey, 2012; NBHWS, 2012). However, there are challenges associated with informal caring, which may differ depending on the nature of the caring role (Erlingsson *et al.*, 2012; Healey, 2012) and also in relation to gender, since research has highlighted the fact that women are more negatively affected by their caring roles than men (Szebehely *et al.*, 2014; Ulmanen, 2017).

Carers are a heterogeneous group, or as Healey (2012) describes it:

Carers come from all walks of life, all cultures and all religions. Some are only 10 years old while others are nearing 90. They may be spouses, parents, sons or daughters, siblings, friends, nieces or nephews or neighbors. (p. 1).

Hence, being a carer is a complex experience that develops over time (Nolan *et al.*, 1996; Montgomery and Kosloski, 2009), affecting both everyday life and the understanding of self (Andréasson *et al.*, 2018). The process of becoming a carer often involves a life change and is, for this reason, identity-constructing (Montgomery and Kosloski, 2009). An identity shared with others, like "being a carer," can therefore have a significant influence on how we perceive ourselves. Often, this perceived fellowship has a bonding and emotional significance (Hammarén and Johansson, 2009). Collective identities, unified by mutual

interests, ambitions and experiences build on images of fellowship and homogeneity, which may lead to heterogeneity within the group being underappreciated (Hammarén and Johansson, 2009). However, in reality, the collective carer identity is truly heterogeneous, in addition to being created in relation to another person (Montgomery and Kosloski, 2009). Some carers fully embrace this identity, while others do not even define themselves as carers, but merely consider themselves as someone who “is around,” giving support to someone with whom they have a relationship or other ties (Healey, 2012; Andréasson *et al.*, 2018). Iliffe *et al.* (2010) refer to the latter group as “invisible carers” and emphasize that they are at significant risk of not being offered nor receiving appropriate support measures from the formal sector.

The demanding and sometimes all-consuming role of being a carer requires sufficient support, from the formal sector as well as from family and friends, to prevent carers from developing health issues of their own (NBHWS, 2016). In recent years, demographic trends combined with fiscal constraints have led to continued cutbacks in services, leading to a renewed focus on community-care services (Spasova *et al.*, 2018). These changes have led to a growing awareness among policymakers and researchers, together with the raised voices of civil society, of the urgent need to provide more timely and effective support for carers (SNAO, 2014; Hanson *et al.*, 2019).

User and carer involvement in R&D work

There is, currently, a dearth of empirical literature concerning carers' involvement in R&D work (Eurocarers, 2015, 2016). For this reason, the literature regarding user, consumer and patient involvement in R&D in health and social care settings has acted as the broader context for this study.

User involvement in R&D work is widely recommended, enabling the benefits of theoretical developments in research and services to be grounded in relevant perspectives as well as being beneficial for users themselves (Heikkilä and Julkunen, 2003; Smith *et al.*, 2008). User involvement has been found to operate at different levels (national, group and individual) as well as being collective/individual, indirect/direct and varying in extent (Arnstein, 1969; Tritter and McCallum, 2006). However, it is a vague concept and not universally accepted definition exists, hence it must always be placed in context (Healy, 2000; Smith *et al.*, 2008). When viewed hierarchically, user involvement encompasses user consultation through to user-led research (Arnstein, 1969; Hewlett *et al.*, 2006). However, according to Heikkilä and Julkunen (2003), user involvement always implies the precondition that the users' activity has an impact on the process in some way. User involvement in research, service design, implementation and evaluation is suggested to have the potential to enhance a study's design, practicality and recruitment, as well as the interpretation, dissemination and assessment of data (Hanson *et al.*, 2006; Minogue and Girdlestone, 2010; Brett *et al.*, 2012). User involvement is also increasingly becoming a more natural part of social policy discourses, emphasized by concepts such as empowerment, participation and partnership (Hewlett *et al.*, 2006; Hanson *et al.*, 2006; Nolan *et al.*, 2007; Kylberg *et al.*, 2018).

There is no “set” optimal level for the involvement of users in R&D work; rather, this level should be reflected upon in relation to the aims and circumstances of the specific research project (Smith *et al.*, 2008), as well as considering the expectations of outcome and desired degree of participation from the individual user (Beresford, 2013). When choosing participants for involvement in R&D work, an established way is to use representatives from organizations (Tritter and McCallum, 2006; Smith *et al.*, 2008; Morrow *et al.*, 2012). Although established, this way of working may negatively affect heterogeneity and result in non-organized carers being under-represented, possibly reinforcing existing patterns of inequality; this could lead to service provision that meets the needs of some people more

than others (Tritter and McCallum, 2006; Beresford, 2007). More women than men are active within user organizations, as well as being more involved in R&D work (Hanson *et al.*, 2011), which is a further aspect that could potentially affect the heterogeneity of user participants.

It is argued that user involvement in R&D work aims to bring together the perspectives of all those involved in a particular study to promote a shared understanding of complex issues (Tritter and McCallum, 2006), with a desired focus on generating both “knowledge for action” and “knowledge for understanding” (Hanson *et al.*, 2006). According to earlier studies, involving users with distinct personal experiences has shown itself to be especially fruitful in research that aimed to identify shared solutions to common problems, such as clinical interventions or public policy development (Hanson *et al.*, 2006; Hewlett *et al.*, 2006; Boote *et al.*, 2012). From the point of view of the user, benefits such as being able to contribute valuable information and experiences are expressed, as well as increased self-confidence, empowerment and a sense of equal partnership (Minogue *et al.*, 2005; Hitchen and Williamson, 2015). However, there is a need for a more systematic approach, since outcomes in practice have been mixed and not exclusively positive (Tritter and McCallum, 2006; Smith *et al.*, 2008; Beresford, 2013). It has even been suggested that the existing literature tends to overlook adverse outcomes and regressive consequences of user involvement (Beresford, 2003), with negative experiences generally described and hidden as “challenges” (Smith *et al.*, 2008). Thus, it is of great importance for researchers to reflect upon and specify their reasons for involving users and the extent of their involvement, as well as considering other aspects such as heterogeneity, ethics, working relationships, finances, methods, education and training (Tritter and McCallum, 2006; Smith *et al.*, 2008), to create the necessary prerequisites for genuine user involvement.

Rationale and aims of the study

Municipalities in Sweden are obliged under the Social Services Act to offer support to carers but, in reality, relatively few receive such support (SNAO, 2014). One potential reason may be that the support provided is not seen as meaningful from the carers’ point of view. During the last decade or more, user- and patient-involvement in R&D work has been viewed as a feasible way to succeed in the development of more appropriate policies and to provide more responsive and innovative support services for users (Beresford, 2013), with researchers and practitioners alike being encouraged to work in a participatory manner (Tetley and Hanson, 2000; Hewlett *et al.*, 2006; Smith *et al.*, 2008).

Since the subject of carer involvement in R&D work remains a relatively new phenomenon, there is an associated lack of systematic research in this area that also actively considers possible negative experiences, barriers and other issues. As a result, the significance or meaningfulness of carer involvement in R&D work remains inconclusive. This study aimed to explore how carers perceived and reflected on carer involvement in R&D work, with specific reference to their personal experiences of being involved in the development of a Swedish carer strategy (SCS). The purpose of this paper is to raise awareness among policymakers, decision makers, practitioners and researchers of a hitherto neglected area that merits due attention given the trend toward integrated, people-centered health and care systems, with a focus on self-care and care at home, which in reality translates to care provided by family members.

Methods

Context for the research

The context of this paper is formed from the consultation phase with carers in the development of a SCS, conducted by the Swedish Family Care Competence Centre (SFCCC). The SFCCC is a center of excellence in the field of informal care; it was established in 2008 and is commissioned by the National Board of Health and Welfare Sweden via the Ministry

of Health and Social Affairs (MHSA). The SFCCC made contact with the MHSA during the Spring of 2016, with a proposal for a national carer strategy. The proposal was based on prior discussions with carers, their organizations and other stakeholders at both the national and the European Union levels (Eurocarers, 2014, 2015). The MHSA expressed interest in the initiative but requested to see more concrete actions proposed within the draft document. This feedback led to the consultation phase during the development of the SCS, consisting of six focus-group interviews (FGIs) and several individual interviews during 2017–2018 with representatives from carer and patient organizations, together with a range of practitioners working directly with carers and decision makers from across Sweden. Carers participated in a total of four out of the six FGIs.

The consultation phase during the development of the SCS forms the context of this paper.

Setting, sample and data collection

To explore carers' experiences and reflections, the study adopted a descriptive and explorative qualitative design (Kvale, 2007). The inclusion criteria for enrollment in the study were being a carer and having participated in an FGI during the SCS consultation phase. A convenience sample (Bryman, 2002) was established by the first author (CM) contacting coordinators from the different carer organizations where FGIs had taken place and then getting in touch with potential participants. These individuals were contacted via e-mail or phone and subsequently provided with written information about the study. All those who were approached and who, after the initial contact, expressed interest in being interviewed were selected to participate and thereafter given additional information. Attempts to recruit more participants were made, however, these attempts were unsuccessful. The final sample of 12 participants ranged in age from 35 to 77 years (mean age 60 years). Some participants were retired or unemployed/on sick leave, while 50 percent remained in paid work. Their level of education varied from vocational training to several years of university studies. The number of years spent caring varied from 2 to 35 years, with a mean value of 16 years. Reported relationships to the cared-for persons were five spouses, five parents, one adult child and one sibling. Three participants (spouses) lived together with the person they cared for. Some participants experienced a double caring role for different family members at the time of the interviews, while others had performed a caring role more than once over their lifetime. All participants were of Swedish origin. The majority of participants were female (75 percent). No participants withdrew from the study.

Data collection consisted of individual interviews via the "Zoom" videoconference system, over the telephone or face-to-face, depending on the preference of the participant. Face-to-face interviews were conducted at the Linnaeus University or a café. CM conducted the interviews during the Spring of 2018. A conversational interview guide based on the study's core aims was used. This included: reflections about R&D work generally and with reference to the SCS; the experience of being involved in R&D work in general and in the SCS FGIs; and reflections about carer involvement in R&D. Probing questions were asked to gain richer descriptions of participants' experiences (Kvale, 2007; Creswell, 2016). Interviews lasted between 40 and 90 minutes, were recorded with participants' permission and subsequently transcribed verbatim (Lincoln and Guba, 1985; Kvale, 2007). Participants were given both oral and written information about the study, including how the results would be published and their own role as participants, as well as having the opportunity to ask questions. They were informed that they could withdraw from the study at any time without any repercussions with regard to the support that they and/or their relative received and without having to offer any explanation. Full and informed written consent was secured from all participants (WMA, 2013). It was recognized that participating in an interview could be viewed as potentially therapeutic, yet it could also involve the risk of possible recall of personally emotive and/or challenging caring situations (Andréasson *et al.*, 2019).

The first author (CM) is an experienced social worker with extensive experience of working with families, so she was able to offer support in the event this was deemed appropriate. Formal ethical approval for the study was granted by the Regional Ethical Review Board of Linköping University (Dnr: 2018/37-31, 2018-02-13).

Data analysis

A qualitative content analysis was conducted (Graneheim and Lundman, 2004; Graneheim *et al.*, 2017) by CM to identify themes related to the aims of the study. Transcripts were carefully read by CM and co-authors SA and EH, and meaning units were subsequently identified, condensed, abstracted and assigned a code by CM using the computer software NVivo (QSR, 2018); these were subsequently checked by SA and EH. Table I provides illustrative examples of the qualitative coding and condensation process. Co-authors had regular supervision sessions with CM during the analysis process to ensure transparency. Participants were given the opportunity to read and comment on the draft findings and analysis work and approximately half of them responded.

A large number of subthemes were created from inductive analysis of the data. These were abstracted into four core themes: a sense of Community, feelings of Reciprocity, a sense of Advocacy and reflecting on Circumstantiality; each described different aspects of carer involvement. During the process an overarching or umbrella theme (Graneheim and Lundman, 2004), Mediating lived experience, was identified (see Table II).

Findings

In this section, the themes will be described, starting with the overarching theme Mediating lived experience, illustrating the intimacy and relevance between the participants and the research topic, namely, themselves, their carer identities and their circumstances, exposing a certain vulnerability. This overarching theme also described the mediations and accommodations needed to be able to discuss both personal views and experiences in addition to reflecting carers' views and experiences in a broader context, as well as between carers and researchers.

A sense of Community

This theme was described as being part of a context, of experiencing a sense of commonality when meeting other carers, grounded in their mutual yet still widely varying carer experiences.

Meaning unit	Condensed meaning unit	Code	Theme
But I do believe ... // ... that it is therapeutical for many. And, as I said before, that it may ease the sense of loneliness too	Therapeutical for many, and may ease the sense of loneliness	Therapeutical involvement	A sense of Community
One should choose carers with the ability to, of course express their own opinions, but they must be able to put it in a broader context as well	Involved carers should be able to express both own opinions and to put it in a broader context	Different perspectives	Feelings of Reciprocity
At least I have seen it as an opportunity, to participate and influence in some way	An opportunity to participate and influence	Opportunity to influence	A sense of Advocacy
It is probably difficult for some carers, I have on occasions heard people saying that "I can't engage, I'm not allowed"... so it exists, right?	It is difficult for some carers to engage, they are not allowed	Hindrance of engagement	Reflecting on Circumstantiality

Table I.
Illustrative examples of the condensation and coding process of the qualitative content analysis

Table II.
The CRAC framework
overview of the
overarching theme,
themes and
subthemes

Subthemes	Themes	Overarching theme
Feeling involved Emotional impact Being in a heterogeneous context Knowing the others Being invited Being important Being taken for granted The complexities of involvement Experiencing a freedom of choice Expecting action Expecting feedback Expecting to recognize oneself Attitudes toward R&D A possibility to influence Contributing with knowledge and commitment Being in the hands of the interpreter Hoping for change but fearing false hopes Illuminating complexity but risking generalizations Jeopardizing voluntarism and freedom of choice Speaking for other carers The heterogeneity of carers	A sense of Community (C) Feelings of Reciprocity (R) A sense of Advocacy (A) Reflecting on Circumstantiality (C)	Mediating lived experience
Hindering aspects in a family context Hindering aspects from a practical view Hindering aspects within the individual Challenges from an R&D perspective Experiencing personal change The need for a leading light		

Several participants expressed that meeting other carers in an R&D context was positive and rewarding. For some, it was the main reason for wanting to be involved. A sense of similar circumstances, having the potential of creating a mutual understanding and decreasing the often-experienced feelings of loneliness was expressed. Spending time and being able to recognize oneself in others' stories was described as providing relief and even being therapeutic:

At least I felt comfortable [...] even at those times when I couldn't keep the tears away I felt comfortable, since I knew that nobody [...] well, would react or think "Why is she crying"? (6)

Being involved in R&D was also described as a way of helping to reduce carers' sense of frustration and/or deflation. One carer described how being involved in R&D helped to control worry and to channel it into engagement, and hence positively protecting the cared-for person from being over-cared-for:

If I hadn't engaged [...] // [...] then I'd worried to death and it would've been bad for him right [...] I would've tried to baby him in another way. So really he has escaped from me over-caring, you can say [...]. (11)

However, meeting other carers in an R&D context as well as being involved in R&D work, where a certain amount of sharing of personal experiences is common, was also described as potentially emotionally demanding, due to the parallels drawn with their own personal caring situation. According to participants, this vulnerability could be experienced just by being in a situation where many often burdensome life stories are presented, which could be experienced as both stressful and exhausting. When reflecting upon other carers, participants believed that the emotional strain could cause them to avoid being part of R&D work altogether.

Both positive and negative reflections about the sense of involvement in the SCS FGIs emerged. Some participants described a sense of not feeling involved at all, while others described the FGIs as bringing a sense of comfort and of being understood. Some participants described their FGI experience as energizing and bringing a sense of acquiring new angles and ideas. Feeling comfortable in a research context alongside other carers was described as being dependent on a variety of different aspects. When reflecting upon themselves and others, two important features noted were the length of time in a carer role and the extent to which someone had reflected about and accepted being a carer. Participants described how the FGI dialogue had a positive effect by bringing together participants with varying experiences of both caring and involvement in R&D work. They meant that by mixing individuals who were more mature and experienced in their caring role with carers who had only recently taken on a caring role offered many advantages. They also acknowledged that realizing what being a carer is indeed about needs to be viewed as a lifelong process. Having an already established relationship with the other FGI members was also mentioned as a positive, as it resulted in views and reflections being firmly established and achieving a consensus within the group. However, a concern mentioned was the potential difficulty, in an FGI context, to dare to express opinions that were different from those of the majority.

Feelings of Reciprocity

This theme was described as feelings of being regarded as a partner, the relationship between carers and researchers, as well as explaining the mutual responsibilities when being partners in research.

A consensus emerged about the importance of involving carers in R&D work focused on carers as a target group, both from the perspective of strengthening the self-confidence of individual carers, but also mainly to increase the validity of the R&D. Participants explained that if researchers or policymakers disregard carers, there is a significant risk of research outputs or policies not hitting their intended target. The need for carer involvement should, according to participants, be viewed as self-evident, since carers and professionals bring different kinds of knowledge to the table. Several participants acknowledged that when these two types of expertise meet, real knowledge is created. Participants emphasized that when carers are given the chance to contribute, a voice is given to reality, to things which are often invisible to researchers and other people:

When carers are given the possibility, then you also give a voice to reality. Because it is us carers who know the inside of [...] of the whole thing. Both what's really positive, which others might not really see, but also the parts that are very sensitive and hard. (12)

Participants argued that involving carers in research is often a complex matter, with a researcher's honesty, curiosity and respect described as a prerequisite. Participants explained that sufficient time and effort must be dedicated to clarifying and discussing the reasons why a carer should prioritize involvement in any specific R&D work, as well as describing the extent and demands involved. Furthermore, they stressed the importance of the researcher, from the perspective of power, being aware of the unequal situation. When reflecting upon the challenges for the involvement of carers in general, the unfamiliarity with R&D was mentioned, where the language and jargon of researchers could easily be experienced as both foreign and intimidating. Not being able to keep up or understand was described as running the risk of the carer feeling alienated or stupid.

Discussing R&D in general, participants described researchers as often having an attitude that suggested they were letting the carers participate as some sort of favor. As confirmation of this statement, several participants expressed their gratitude for having been given the opportunity to have their say in the consultation phase of the SCS.

Participants also emphasized that carers involved in R&D must have both the capacity to express personal views and opinions and an ability to view things in a broader context:

When choosing carers to participate in these contexts [...] one should choose carers with the ability to, of course express their own opinions, but they must be able to put it in a broader context as well. (12)

One important prerequisite highlighted by participants for creating reciprocal relationships among carers and researcher(s) was the need for a working structure, including a proper invitation, clear aims and structured leadership. The circumstances regarding the purpose as well as the invitation process of the SCS FGIs were unclear to most participants. For some, the SCS FGI formed part of a committee meeting or a conference, while some had not understood that they were being invited to take part in an FGI. Few participants received a formal invitation. This lack of clarity created a sense of confusion, with some participants experiencing the FGI as a failure due to these uncertainties. Other aspects mentioned were a preference for feedback and the need to receive information about the results of their involvement.

A sense of Advocacy

This theme was concerned with the incentive for carers to be involved in R&D work, where giving carers a voice was mentioned as being crucial. This theme also included expectations and concerns around the outcomes of the research.

Personal attitudes toward R&D were viewed as crucial in deciding whether or not to become involved in R&D. Attitudes were said to include different aspects, for example, a person's level of education or previous experiences of R&D. However, the most important factors put forward by participants were personal traits and experiences and having the ambition to be involved in changing the living conditions of carers:

I believe that the most important thing is who you are as a person, and your life experiences. Some are keen on the future, they want to participate and to make changes [...] if you have that attitude, if you have that ambition, then it's much easier to engage in a thing like this. (12)

Even if some participants mostly enjoyed the opportunity to get away from home and meet others in similar situations to their own, the main reason given to be involved was a desire to positively impact the everyday lives of carers. Motivational factors were described as a sense of contributing to change, development and improvement. Involvement in R&D was viewed as a way to accept and make use of the sometimes exhausting experiences of caring. Telling their stories was described as a way of reducing the ignorance around the circumstances of carers and showing how being a carer affects every aspect of life, often for the rest of one's life:

Well, being a carer affects life a lot, and it usually lasts for the rest of your life and in some way you need to find out what [...] well now it's like this and what can I do [...] what can help me to accept my situation? (11)

Discussing both R&D results in general and the SCS, the potential to strengthen and give weight to carers' voices in different arenas was emphasized. When referring to the SCS, participants were generally satisfied, which means that this document describing carer circumstances and needs has the necessary prerequisites for converting their involvement into practice. However, concerns about the SCS were also expressed, which related to the risk of it being interpreted by the formal sector as a way of providing the least possible support to carers, instead of, as intended, a way of creating guidance to make meaningful interventions for carers. Participant carers noted that if any action was to be realized, then serious implementation efforts of the SCS would be necessary. Participants' previous

experiences suggested that such strategies often simply become “shelf warmers.” Having invested time and effort in R&D work which is then never realized in practice was described as a major reason for feeling exhausted and worn out, and not the activity of being involved in the R&D itself:

It can become tiresome if you, as you understand, I have been doing this since -95 and been talking about the same things in one group after another, where the same questions are discussed again and again [...] So, there might be a certain resignation. (9)

There was great accord among participants with regard to their views and reflections of carer involvement in R&D being relevant not only for themselves but also for other carers. They acknowledged that due to their long experiences as carers and involvement within organizations, their contribution was beyond personal opinion; they had the words and experiences of many carers to lean on. However, participants stressed that many carers are never even asked about their views or experiences, and also that some carers may not have the strength to have their voices heard.

Reflecting on Circumstantiality

This theme was described as reflecting on and taking into account the often diverse circumstances of carers on a personal, relational and practical level and how these may be handled to facilitate their involvement in R&D.

When involving carers in R&D, participants emphasized the importance of viewing carers as a heterogeneous group, due to variations in family status, socioeconomic conditions, level of education and the time and extent of caring. The condition of the cared-for person was also included as an influencing aspect, where the concepts of stigma and shame concerning certain mental illnesses were mentioned. As one participant said: “Being a carer doesn’t show on the outside” (2), meaning that the only common denominator could be that of being a carer. When reflecting upon themselves and other carers, these widely varying circumstances of carers were viewed as a significant challenge that could possibly prevent individuals from being involved in R&D work. A need for facilitation with practical considerations was recommended, for instance with practical planning, financial remuneration, how to find the time to participate, or how to handle challenges related to the needs of the cared-for person. For some, staying away from home overnight was regarded as unmanageable, but a general sense of anxiety and worry from just not being home and close to the cared-for person was described. This anxiety was often phrased as being related to a lack of societal or family support. Other potential problems identified were a lack of energy, a lack of self-confidence and experiencing emotional strain. However, the sense that emotional tension decreased the more times a carer had been involved in R&D work was also expressed. A further challenging aspect that was described occurred when the cared-for person objected to or even forbade the carer to be involved in R&D work, creating considerable difficulty for the carer to put him/herself and personal wishes first, especially when living together with the cared-for person:

It is probably difficult for some carers, I have on occasions heard people saying that “I can’t engage, I’m not allowed” [...] so it exists, right. (9)

Hence, the need for external support for carers was described as significant. “She’s a leading light, taking care of a lot... //... it is necessary that someone is engaged, else nothing will happen” (5). Participants described the concept of “a leading light,” defined as someone charged with the specific task of supporting and motivating carers throughout the entire R&D process, as well as providing carers with the spirit to dare to become involved in the first place.

Discussion

This study aimed to explore carers' views and experiences of involvement in R&D, with the point of departure being their recent participation in the development of the SCS. This discussion will address the aims of the study, including carers' rationales for being involved and the benefits and challenges they experienced through their involvement in R&D work. It will also highlight how the CRAC framework was developed and how it may meaningfully be used by policymakers, decision makers, practitioners, researchers and not least by carers and their organizations themselves.

To some extent, this study confirmed the findings of previous research, as participants emphasized the significance of lived experience and practical knowledge (Glasby and Beresford, 2006; Tritter and McCallum, 2006; Boote *et al.*, 2012), as well as acknowledging that only those who are part of a particular collective are capable of understanding the circumstances and having insight about possible needs. The first, or immediate, response from participants when asked about the importance of carer involvement in R&D, suggested that a positive experience of R&D could be regarded as standing against the absence of involvement. However, on further examination, it became apparent that meaningful involvement was viewed as complex, comprising benefits but also various challenges, and placing demands on everyone involved, in keeping with the views of Kylberg *et al.* (2018). Hence, to reach a deeper understanding of the complexities of user and carer involvement, it is necessary to move beyond the first response phenomenon. Only when exploring and seriously considering carers' views, including the challenges and obstacles they face, is it feasible to reach a deeper understanding of carer involvement.

Although the main reason given by carers for participating in R&D was a desire to contribute to the improvement of carer situations, personal benefits emanating from being in a context together with other carers were also described, for example, a sense of well-being and of being understood. Hence, carer involvement in R&D could be explained as both altruistic and personally rewarding, along with (through its supportive structures) having the conditions to instill hope and help to imbue the lives of carers with greater meaning (Smith *et al.*, 2008). The statement "finding new angles and ideas" in the theme a sense of Community implies that involvement in R&D can indeed contribute to an extended epistemology, providing participants with renewed insights (Bradbury and Reason, 2003). However, considering user involvement in R&D *per se* as bringing about more adequate results (Kylberg *et al.*, 2018) or individuals automatically being empowered through their involvement is an over-simplification of the processes involved (Smith *et al.*, 2008). Several practical, emotional and relational challenges regarding involvement were found within the themes, illustrating the heterogeneous circumstances, attitudes, needs and preferences of carers.

As described in the theme a sense of Community, emotional reactions were experienced when carers participated in the SCS FGIs, despite the research topic neither being viewed as nor expected to be emotionally straining by the participants. The experienced emotional strain could be argued to emanate from the research topic being close to the carers' own life situations, as seen in the overarching theme Mediating lived experience, and through the exposure to burdensome stories of other carers. Emotions such as anxiety, worry, guilt and fatigue were seen to be common. Likewise, a lack of self-confidence in the context of involvement in R&D work was noted, possibly because of the primarily practical role of caring for another person (Hewlett *et al.*, 2006; Morrison and Dearden, 2013). In accordance with a life-course perspective, the family constellation, the caring role and the often mutual dependency between carer and the cared-for person all have the potential to affect opportunities for carers to actually be involved in R&D. In addition, the needs and preferences of carers vary not only from

individual to individual, but also over time due to changes in the caring situation (Nolan *et al.*, 1996).

The extensive variations in carer situations, therefore, as seen in the theme reflecting on Circumstantiality, suggest a heterogeneity within the carer collective (Montgomery and Kosloski, 2009). However, these differences are often overlooked (Smith *et al.*, 2008) both by researchers and by carers themselves (Hammarén and Johansson, 2009), pointing toward the insidious and implicit role of informal caring. The only common denominator may be the role of caring itself, which challenges the capability of mediating both personal views and the views of others, in an R&D context. Consequently, to acquire as complete a perspective as possible (Morrow *et al.*, 2012), attention must be paid to reach and engage the entire spectrum of carers, from those who are affiliated to an organization and/or recognize themselves as a carer, to those who are not even aware of being a carer (Iliffe *et al.*, 2010; Healey, 2012).

The theme feelings of Reciprocity highlights the responsibility of the researcher to ensure the safety and well-being of carers during the R&D process, for example, by recognizing the asymmetrical relationship and providing adequate support. This could, for example, be done by utilizing a leading light, as described in the theme reflecting on Circumstantiality, who could provide optimal guidance and support throughout the research process (Smith *et al.*, 2008), as well as reassuring participants as to the value of their unique contributions (Hewlett *et al.*, 2006).

Our findings revealed that, due to both a lack of preparation opportunities for participants and with meeting on just one occasion, their actual involvement in the development of the SCS was technically minimal. Despite this, a strong sense of involvement was expressed, likely mirroring the closeness of the research topic to the participants' personal lives, as described in the overarching theme Mediating lived experience. This indicates carer involvement is far more complex than simply being concerned with the extent of the participation, and is more of a reciprocal process involving and making demands on both researchers and carers. The concept of the mosaic (Tritter and McCallum, 2006) could be a useful way to describe the process, with no one aspect of involvement valued as more important or better than any other, but with every "tile" having its significant place in the overall picture. Concerning the mosaic of the SCS, it could be argued that its construction began in an international context with the carers and carer organizations involved in developing the Eurocarers EU-wide carer strategy (Eurocarers, 2014), which, in turn, the SCS is built on.

Nevertheless, the development process of the SCS had several weaknesses that endangered genuine carer involvement, for example, the unclear organization and the lack of feedback to some of the participants. A lack of evidence of their involvement in being linked to practical change and improvements for carers, as shown in the theme a sense of Advocacy, was expressed as being frustrating and acted as a possible barrier to engaging in R&D in the future (Heikkilä and Julkunen, 2003; Tritter and McCallum, 2006; Kylberg *et al.*, 2018). In addition to working systematically during the research process, this highlights the need for having a praxis of evaluating carer involvement in each specific R&D project; preferably examining both participant carers' satisfaction with the process and the effect of their involvement and activities on actual results (Tritter and McCallum, 2006).

Several of the challenges mentioned could be seen as specifically applicable to carers; mainly those linked to a family context and consequently the issues of the carer identity (Montgomery and Kosloski, 2009) and the temporal perspective of caring (Nolan *et al.*, 1996). Other challenges mentioned, for example, emotional strain and a lack of confidence, may arguably be applicable to both carers and other user groups. However, it could also be argued that these challenges might significantly affect carer involvement and, if not taken

into consideration, could possibly discourage many carers from becoming involved in R&D, whereupon researchers and policymakers would be at risk of ignoring important voices and experiences. Researchers therefore need to have both a readiness and an ambition to handle various challenges. If carers' often unpredictable lives go unrecognized, there is a risk of carers being considered as troublesome or non-productive partners (Barnes, 2011; Barnes and Cotterell, 2012).

When analyzing and thematizing the qualitative data described here, the idea that the themes could actually be used as an analytical tool crystallized during discussions among the authors. In effect, a framework that illustrates different aspects of carer involvement in R&D, and which with reference to the themes of a sense of Community, feelings of Reciprocity, a sense of Advocacy and reflecting on Circumstantiality could help researchers, policymakers, decision makers and practitioners to better understand and interpret carers' views and experiences of involvement in R&D. Further, it could be used as a tool to enable carers, when participating in R&D work, to develop a more in-depth understanding and greater awareness of their own situation, as well as that of other participant carers and other participant groups (Magnusson *et al.*, 2001). Clearly, this initial study presents a tentative framework which requires further testing and validation. Nevertheless, it acts as a useful starting point to help ensure that policymakers and decision makers remember to actively consider carers' voices and involve them as partners in developing policies and practices that affect them and the person they care for. The CRAC framework helps to shed light on the complexity of carer involvement and outlines core considerations that should be taken into account to ensure more authentic carer engagement in policies, practice and research. In addition, the framework can be used as an evaluation tool to not only help interpret but also to evaluate carers' experiences of involvement in R&D and policy making.

Methodological considerations

The trustworthiness of any findings should be considered in relation to their strengths and limitations (Lincoln and Guba, 1985). The research process described here was transparent, with co-authors involved in reading the transcribed interviews, and in discussing and reflecting upon pre-understandings, ethics, findings and interpretation. The sample involved could be seen as the main limitation of the study, not least the small sample size which makes a certain caution necessary with regard to the wider implications of the study. It would have been beneficial to have recruited a larger sample of carer participants, including carers that were not part of a carers' organization. Nevertheless, the challenges of recruiting carers to participate in research have been previously documented; these challenges are principally due to carers' caring situations, such that they are often unable to prioritize their limited "own" or "free time" to devote it to participating in research (Andréasson *et al.*, 2019). However, referring to the strained situation of carers could on some occasions be argued as being an excuse on the part of researchers to refrain from involving carers directly. It would also have been desirable to have had a more equal number of women and men, but due to the nature of the convenience study sample, this was not feasible. Likewise, the lack of participation from participants from different cultural and ethnic backgrounds was a drawback. Furthermore, all participants were representatives of various carer organizations (Smith *et al.*, 2008; Morrow *et al.*, 2012) and as such were more likely to have had experience of being engaged in an R&D context than the average carer. Hence, it may be argued that the sample used for this particular study is not representative of carers in general (Tritter and McCallum, 2006) and therefore attention must be paid to Beresford's (2007) cautionary words about the reinforcement of existing patterns of inequality. However, as the process of developing the SCS formed the context for this paper, the sample was drawn from a

specific carer population. Despite these limitations, the thick description of context and detailed participant characteristics help to increase the transferability (Lincoln and Guba, 1985) of the findings to other R&D settings.

Conclusion and implications for practice and policy

In conclusion, this study highlights the fact that involving carers in R&D work is complex and possesses several more unique aspects than user involvement in general, arising from carers' basis in a family context and the carer identity. Due to varying prerequisites for involvement and differing needs for support, it is not feasible to have a general recipe describing how carer involvement can be realized in practice. Genuine carer involvement in research and policymaking demands a high level of engagement from all involved, otherwise there is a risk of carer involvement becoming tokenistic. Here, the CRAC framework presented may act as inspiration for researchers, policymakers, decision makers and practitioners who are considering involving carers in R&D projects, policymaking and policy development, or other initiatives. Future research should seek the voices of carers who are not organized or who may be hard to reach, as well as explore the reasons why more female than male carers participate in R&D work, and/or further develop the CRAC framework.

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