



Including People with Dementia and Their Caregivers as Co-Researchers in Studies of Dementia Care and Services

Background Paper

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Additional information can be found at the Summit website (<https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers>) or the National Alzheimer's Project Act website (<https://aspe.hhs.gov/national-alzheimers-project-act>). The opinions and views expressed in this report are those of the authors. They do not necessarily reflect the views of HHS, the contractor or any other funding organization.

Introduction

Traditionally, people with dementia and their caregivers are the subjects of research but do not participate in devising the research. More recently, new models give people with dementia and their caregivers important roles in the research enterprise. As “co-researchers” or “partners in research” with professional researchers, people with dementia and their caregivers may be engaged in all aspects of research on dementia care and services, jointly developing research questions and study designs, collecting and analyzing data, and disseminating results (Hickam et al., 2013). Conducting research in collaboration with the population that is being studied has been shown to enhance the quality and appropriateness of research (Brett et al., 2014) and has been identified as an essential component of studies examining the effectiveness of different approaches to care and services (Hickam et al., 2013). This approach also allows people with dementia to generate opportunities to exercise their communication skills (Tanner, 2012).

This paper addresses several key challenges that researchers face in working with people with dementia and their caregivers as co-researchers in studies of dementia care and services, including setting the level of involvement that people with dementia and their caregivers will have in the research, determining how to identify and recruit people with dementia and their caregivers to serve as co-researchers, and establishing how to effectively engage people with dementia and their caregivers as co-researchers.

Consultation, Control, and Collaboration

Three types of patient involvement in research have been distinguished: consultation, control, and collaboration (Abma, Nierse, Widdershoven, 2009). Consultation is a common form of research engagement, wherein the role of patients, or of people with dementia or caregivers, is advisory. In consultative models of engagement, people with dementia and caregivers provide input to the research through their inclusion on research advisory committees. Specific tasks may include evaluating scientific articles and research proposals from the perspective of people with dementia and caregivers.

Control, in contrast, is a less common form of research engagement, wherein people with dementia or caregivers serve as the principal researcher and have decision-making power over all strategic choices in the research. In this form of research engagement, specific tasks of people with dementia and caregivers may include initiating the research, collecting and analyzing data, and writing publications and presenting findings at scientific conferences.

Collaboration falls in between control and consultation in terms of the control exercised by patients, people with dementia, or caregivers. In collaborative models of engagement, people with dementia and caregivers serve as research partners or co-researchers and are involved at every stage of the research process, sharing control and working alongside professional researchers.

Connecting People with Dementia, Caregivers, and Researchers

Some research funders, such as the Patient-Centered Outcomes Research Institute, emphasize studies that engage individual representatives of the study populations to serve as research partners, including people with dementia and caregivers. Supporting engagement of people with

dementia and caregivers in research, the Patient-Centered Outcomes Research Institute funded the National Alzheimer's and Dementia Patient/Caregiver-Powered Research Network, which includes participants who have, are at risk for having, or care for someone who has Alzheimer's disease and related dementias. This national network will connect patients, caregivers, and researchers focused on developing, conducting, and disseminating patient-centered dementia research (Petersen, 2016). The National Alzheimer's and Dementia Patient/Caregiver-Powered Research Network will enroll individuals through existing web-based registries and will screen and refer individuals for clinical trials. The National Alzheimer's and Dementia Patient/Caregiver-Powered Research Network will be led by the Network Governance Board, composed of key stakeholders, including patients, caregivers, leaders of patient groups, and directors of existing patient registries. The Network Governance Board will serve as a checkpoint for accountability for the project leadership and will be asked to engage in outreach to expand the network's reach and impact. The network also includes several advisory councils, including a Patients and Caregivers Sub-Council that includes people with dementia, caregivers, and advocates. Although focused on biomedical research, this project may be a helpful resource and model for studies of care and services for people with dementia.

Other advisory groups of people with dementia and caregivers that are interested in collaborating in research also exist and can be a resource for researchers seeking people with dementia and caregivers as research partners. For example, in Canada, the Ontario Dementia Advisory Group is a group of people with dementia and caregivers that aims to become involved in all decisions that will affect their lives (Holroyd-Leduc et al., 2016). Members also serve on the Canadian Dementia Priority-Setting Partnership, helping to identify the "top ten" dementia research priorities from Canadians affected by dementia.

Study Examples That Engage People with Dementia and Caregivers in Research

Although scant literature depicts the engagement of people with dementia and caregivers as co-researchers, studies conducted in the United Kingdom and Canada provide useful examples.

Co-research with Older People with Mild to Moderate Dementia

In a United Kingdom study of older people's experiences of care transitions, people with mild or moderate dementia served as co-researchers; they participated in planning the research methods, conducting interviews, and interpreting the findings (Littlefield, Tanner & Hall, 2015; Tanner, 2012). People with dementia who served as co-researchers had a *collaborative* role in this study; notably, other people with dementia served as study participants.

- *Recruitment*--People with dementia were recruited from voluntary agencies that specialized in working with people with dementia to serve as co-researchers in this study. To facilitate recruitment, a request for co-researcher involvement and information about the research was publicized through the agencies.
- *Preparation*--Orientation sessions about the study were held to prepare the people with dementia to serve as co-researchers (i.e., to participate in planning the research methods, conducting interviews, and interpreting the findings). The sessions were conducted in a setting that was familiar to the people with dementia to help them feel comfortable. During these sessions, the people with dementia discussed their views

about the study interview content and structure and practiced their interviewing skills (Tanner, 2012).

- *Interview Protocol Development*--During preparation sessions, professional researchers facilitated discussion among the co-researchers about their experiences with receiving a dementia diagnosis and accessing services. The perspectives of people with dementia guided development of an interview framework addressing stages of experience. These stages were typed on laminated cards and each co-researcher was provided a set of these cards to cue memory and use as a guide during the interviews.
- *Conducting Interviews*--Interviews with people with dementia were conducted collaboratively by the co-researchers and the professional researcher. The professional researcher's role in the interviews was to explain the research to participants, obtain informed consent, and operate the digital recorder. Beyond those tasks, the professional researcher's role was flexible, adapting to what each co-researcher could contribute in the interview. Before each interview the professional researcher met with the co-researcher who was co-conducting the interview and provided the co-researcher with reminders about the purpose and process of the interview.

At the outset of the interviews, co-researchers acknowledged their dementia identity. According to the professional researcher, involving people with dementia as co-researchers was beneficial in establishing trust and credibility with the interview respondents, helping the participant to be open about his or her experiences and difficulties:

People with dementia are aware of the threat to selfhood presented by a dementia diagnosis, cautious about sharing their diagnosis and highly sensitive to the reactions of others... The presence of an interviewer who shared the stigmatized identity seemed to encourage openness and trust in the participants (Tanner, 2012, p. 302).

Professional researchers reported that the interviews conducted with co-researchers resulted in more information about managing life with dementia than about accessing and using services and depicted the data as "different" but neither better nor worse than if they had performed the interviews alone (Littlefield, Tanner, & Hall, 2015).

- *Analysis*--The co-researcher and the professional interviewer discussed the interview process and content immediately after each interview. A meeting with the co-researchers was held to discuss key themes and issues after each round of interviews.

Co-research with Caregivers

For 20 years, a multidisciplinary research team in Canada has been using community-based participatory research approaches to improve services for people with dementia and caregivers in rural settings (Morgan et al., 2014). Three of these projects, which include rural family caregivers, spouses of people with atypical dementias, and aboriginal grandmothers as co-researchers, are described below. Each of these studies may be categorized as involving caregivers in a consultative role, with some features of a collaborative role.

- *Rural caregivers*--One study involved developing and evaluating a rural and remote memory clinic. The research team established a decision-maker advisory council that

included family caregivers, care professionals, advocates, and researchers to provide direction in “all phases of the research-to-action cycle, from identifying research priorities to developing policy implications” (Morgan et al., 2014, p. 340). This advisory council role reflects the *consultative* type of engagement with aspects of *collaborative* engagement (Abma, Nierse, & Widdershoven, 2009). The council meets in an annual summit, which helps to build and sustain partnerships, and is designed for a diverse mix of caregivers and professionals. The summit includes a scientific poster session followed by a 1-day meeting in which participants discuss key issues regarding rural dementia care, research priorities, and specific research projects (Morgan et al., 2014).

The team reported numerous benefits of their approach: it informed the research focus, the interventions implemented, and the research design. The approach also enhanced the team’s understanding of the community’s needs and priorities and improved the quality, relevance, and application of study findings. For example, whereas the professional researchers originally proposed a between-group (telehealth vs. in-person) randomized study design, participants reported that telehealth is perceived desirably and cautioned that providing only in-person services for one group could limit stakeholder buy-in (Morgan et al., 2014).

- *Spouses of people with atypical dementias*--A related study involved developing and evaluating a telehealth support group for spouses of rural and remote memory clinic patients diagnosed with atypical, early-onset dementias such as frontotemporal dementias (O’Connell et al., 2013). Led by rural and remote memory clinic psychologists, 10 spouses of patients with atypical dementias served as co-researchers and collaborated on the support group’s development and evaluation, including decisions about the frequency, format, membership, and aims (e.g., emotion processing vs. psychoeducational). Co-researchers were active partners in the research design, data collection, interpretation, and dissemination. The group functioned as follows:

An initial consultation meeting was held over telehealth videoconferencing to identify goals for the group based on caregivers’ expressed needs. All caregivers were balancing multiple demands on their time, many maintaining employment in addition to caregiving, so attending frequent meetings was not deemed feasible. Instead, a monthly meeting for 90 minutes was decided upon. In addition, group members agreed to commit to the group and to attend most sessions. The group decided to maintain an open group (i.e. members could join as needed and leave when ready). The structure of each session was decided as flexible rather than agenda-based. For example, rather than allotting a specific amount of time for each member, each session began with a brief ‘check in’ with all members to determine group priorities based on evident immediate needs (O’Connell et al., 2013, p. 386).

Multiple data sources were used to assess effectiveness of the co-researcher group, including a face-to-face workshop held 18 months after the beginning of the group and audio recordings of discussion sessions that addressed group members’ perceptions of the telehealth program’s effectiveness and of the core components of the intervention. Professional researchers identified empirical themes from these data and presented these themes to group members via videoconferencing for feedback and clarification. Engaging the spouses in creating and evaluating the telehealth support group is reported to have improved the research quality and validity (Morgan et al., 2015).

Additionally, three videos--additional outputs of the collaborative study--were created in which support group collaborators described their caregiving experiences. These videos were identified as helping to support dissemination of resources to others (O'Connell et al., 2013).

- *Aboriginal grandmothers*--Finally, researchers in Saskatchewan partnered with an Aboriginal grandmothers group--whose members provided care to Aboriginal seniors--in a study of the Aboriginal population's perceptions of normal aging and dementia. The study informed development of culturally appropriate assessment tools. A series of six 3-hour group interview sessions were conducted with the Aboriginal grandmothers group over 6 months. The grandmothers reviewed all transcripts of the interview sessions and participated in an iterative process of qualitative data analysis to identify common themes (Morgan et al., 2014).

Based on the grandmothers' recommendations, modifications were made to existing screening instruments and neuropsychological testing protocols to enhance their cultural appropriateness for Aboriginal older adults (Lanting et al., 2011), and a new screening tool was developed for use by frontline care providers (Morgan et al., 2014). The Aboriginal grandmothers group's coordinator also traveled with the professional researchers on some home visits to pilot test the assessment protocols with Aboriginal seniors; these visits were conducted in partnership with a family physician and Aboriginal homecare staff and managers (Morgan et al., 2014).

Conclusion

People with dementia and their caregivers can serve as research partners in a variety of ways, such as providing consultation at key junctures of a study, actively collaborating on all major study activities, and controlling the direction of the study. In the United States and internationally, research groups of people with dementia and caregivers exist, and some major research funders emphasize studies that include people with dementia and caregivers as research partners. Researchers who have included people with dementia and caregivers as research partners suggest beneficial outcomes of their involvement, such as enhanced research quality.

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