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Article

When Actions Speak Louder Than Words: Extending the Reach of Qualitative Data Collecting

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Justine McGovern[1]

Abstract

Through the lens of a study exploring dementia care partnering, the purpose of this methods article is to focus on the role of artifacts and embodied data in data collection. In addition, it illustrates how to use a range of data collecting methods. The article identifies benefits of additional data collecting methods to research and care. These include the need to expand data collecting methods beyond spoken word, integrate a range of data collecting approaches into research courses across disciplines, increase support of qualitative research, and advocate for greater inclusivity in research. Data collecting approaches can also have implications for quality of life among persons often excluded from research-building endeavors. They can contribute to the unfolding of new findings, which can influence care practices.

Keywords

older people, aging, caregivers, caretaking, dementia, methodology

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Introduction

Building on a study of dementia care partnering, this methods article focuses on the role of artifacts and embodied data in data collecting approaches. Moving beyond verbal narration of experience can increase inclusivity in knowledge-building processes and influence quality of life for persons who might benefit from the translation of research into care practices. Persons affected by dementia suffer varying degrees of cognitive impairment. The illness can affect verbal communication, critical thinking, and interpretive capacity (Alzheimer's Association, 2015) and puts potential participants at risk for exclusion from research based on interviews.

Through the lens of an exploratory qualitative study with persons affected by dementia and their partners in care, the article illustrates how complementing the interview with observed and tangible data stands to enhance knowledge building, increase inclusivity in research, and better address diversity of experience and capacity. The implications of study findings for dementia care practices are expanded on in other articles (i.e., McGovern, 2010, 2011, 2016). They are referred to briefly here. This methods article focuses on the inclusion of artifacts and embodied data in data collection.

Dementia in Context

The World Health Organization (WHO; 2016) estimates that 47.5 million people currently have dementia and that there are 7.7 million new cases diagnosed each year globally. The number of cases is expected to reach 75.6 million by 2030, and to almost triple by 2050, directly affecting upward of 135 million people (WHO, 2016). A chronic and terminal illness defined by progressive deterioration of cognitive ability that ultimately affects memory, language, judgment, and physical capacity, as well as emotional control and social interaction, dementia is a major cause of disability and dependency worldwide (WHO, 2016). It is a terminal condition for which there is currently no cure or durable treatment.

Lasting on average 10 years, it can take a great toll on individuals experiencing it first hand, as well as on families and friends who report emotional, physical, social, and economic distress at higher rates than peers who are not caregiving for loved ones with dementia (Alzheimer's Association, 2015). Informal caregiving partnerships, the most common dementia care model worldwide, typically involve at least three people, usually a spouse, an adult child, and a close friend or other relative (Alzheimer's Association, 2015). As a result, the number of affected persons is greater than the number of people diagnosed with

[1]Lehman College, Bronx, New York, USA

Corresponding Author:
Justine McGovern, Assistant Professor, Department of Social Work, Lehman College, City University of New York, 250 Bedford Park Boulevard West, Bronx, NY 10468, USA.
Email: Justine.McGovern@Lehman.CUNY.edu

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the illness. Consequently, statistics on progressive cognitive impairment in later life may be low as compared with actual occurrences. In addition, a lack of awareness and workforce preparedness for the epidemic can result in stigmatization, bias, and poor treatment of affected persons who are often restrained, isolated, and overmedicated (Alzheimer's Association, 2015).

The cost of dementia reaches beyond individuals. The illness can strain national economies struggling to meet the medical needs of a growing population, which experiences increasing needs over time. When direct medical, social, and informal care costs were calculated in 2010, the global societal cost of dementia was estimated to be US$604 billion (WHO, 2016). As a result, the WHO has identified dementia as a global public health priority since 2012.

Dementia in Research

Dementia research tends to focus on caregivers, rather than on the person with dementia. When it does include the person with dementia, it usually includes only persons in early stages of the illness who can still be reached through verbal means (Hellstrom, Nolan, Nordenfeldt, & Lundh, 2007). As a result, perspectives of persons more greatly affected are excluded, and valuable insight into the illness is lost. Although not a new approach, complementing spoken word with non-verbal data collecting is underutilized with this population. Non-verbal data collecting runs the risk of becoming unwieldy if documents and artifacts are being collected, and idiosyncratic if body language is being interpreted. However, benefits include providing a "voice" to those often excluded from research endeavors, developing new knowledge, and extending the reach of research (i.e., Buse & Twigg, 2014; Elliot, 1997; Hubbard, Cook, Tester, & Downs, 2002; Kontos, 2004; Tangenberg & Kemp, 2002; Twigg, 2010).

To include the contributions of verbally impaired participants, data collecting needs to extend beyond the interview and incorporate a range of data, such as artifacts, which can be imbued with meaning and create meaning (Plummer, 2001; Prior, 2008), and embodied data, such as interactions, touch, visual cues, and more (Phinney & Chesla, 2003). Making use of embodied data shrinks the false dichotomy between the mind and the body where knowledge building is concerned. The emphasis of the mind over the body not only restricts the development of new knowledge but also suggests a Western bias to the detriment of other ways of knowing (Sandelowski, 2002). Moreover, focusing on embodiment addresses loss of self in dementia. Embedding the sense of self in more than the mind and memory to include lived experience in the present moment allows for persons experiencing cognitive impairment to claim a sense of self, albeit defined through new means (McGovern, 2011; Millett, 2011).

Methodology: Making Use of Additional Data Collecting Methods in a Qualitative Study

Study Design

The study adopted a qualitative exploratory design to capture the experience of dementia care partnering. Combining core elements of qualitative research to move beyond spoken-word data, such as prolonged engagement, participant observation, and thick description, is particularly well suited to the study of dementia where meaning becomes manifest not just through verbal reporting but also through non-verbal expressivity (Buse & Twigg, 2014; Hellstrom, Nolan, & Lundh, 2005; Kontos, 2004; O'Connor et al., 2007; Phinney, 2002; Twigg, 2010).

The study adhered to protocols protecting human research participants. Informed consent was established following guidelines for persons with cognitive impairment, as defined by the American Geriatrics Society (AGS; 1998). These guidelines recognize that requiring cognitive capacity to communicate consent can exclude those in various stages of cognitive impairment. As a result, the guidelines approve a variety of ways of communicating consent, including a range of written and verbal means, and the absence of agitation (AGS, 1998). All participants met the American Geriatrics Association guidelines for providing consent, which do not require a cognitive status assessment if consent can be secured within the guidelines. The study received institutional research ethics board approval.

Sample

Adopting a purposive sampling approach, participants were recruited with the help of the Alzheimer's Association New York City Chapter. The sample was consistent with expectations for qualitative research, which do not necessarily require a large sample to focus on depth rather than breadth. Study participants consisted of 14 persons in dementia care partnerships (Lincoln & Guba, 1985; Padgett, 2008). Inclusion criteria included that potential participants be actively engaged in an intimate dementia care partnership, that those with dementia were diagnosed at age 65 or older, and that all were eligible for Alzheimer's Association support groups. These support groups maintain their own standards, such as absence of serious mental illness, willingness to engage voluntarily in group processes, and ability to attend on a regular basis. Inclusion criteria were selected to avoid mixing adult child caregivers with intimate partner caregivers, as the two groups are known to experience caregiving differently (Alzheimer's Association, 2015); to avoid early-onset dementias, which present and progress differently than other types of dementia (Alzheimer's Association, 2015); and to avoid conditions that might interfere with participation in a study over time.

There were no restrictions in regard to legal status or gender orientation where the definition of "couple" was concerned. Participants defined "couple" as they saw fit.

Recruitment

Participants were recruited with the help of the Alzheimer's Association New York City Chapter. The researcher has volunteered for the Chapter since 2005 but had no previous relationship with any of the study participants.

Recruitment consisted of four steps, following established dementia research guidelines (Hellstrom et al., 2005). These consisted of securing support from the Alzheimer's Association New York City Chapter, meeting with gatekeepers, introducing the project to potential participants, and securing informed consent.

Participant Retention

Retaining participants has not proven to be difficult in qualitative research on dementia. It has been suggested that this is because elders living at home in difficult circumstances enjoy the attention and social interaction of the research process itself. A US$30 stipend was given to each couple that completed a minimum requirement consisting of two interviews and one participant observation.

Nature of the Data

Beyond digital recordings of interviews and interview transcripts, data consisted of artifacts such as artwork, photographs, and various written documents provided by participants. Data also included embodied data consisting of meaningful actions and interactions, which were captured through prolonged engagement and recorded in field notes. Embodied data were gathered through observation that occurred over time. Here, "embodied data" refers to the layers of meaning embedded in actions and interactions as distinct from observations of interactions that provide descriptive information. Finally, the researcher kept a journal to track thoughts and logistical processes, as well as her feelings, reactions, and impressions. The journal was included as data, following Denzin and Lincoln (2005). Data collection continued until saturation was achieved (Padgett, 2008).

Interviews. On average, interviewing with each partnership occurred over the course of 4 weeks. With the exception of one interview in an assisted living residence common room, one in a coffee shop, and one in church space, all interviews occurred in the participants' homes, as recommended by Benner (1985). The length and number of interviews were commensurate with guidelines for research on the dementia experience (Hellstrom et al., 2005). In total, the researcher conducted 19 interviews. On average, interviews with the couple together lasted one and a half hours, as did interviews with the partner in care. Interviews with the partner with dementia were shorter, lasting a half hour on average. In total, 27 hours was spent on interviews.

Twenty-seven hours of interviews generated 541 pages of transcripts. Interviews included open-ended questions that were embedded in conversation, following naturalistic inquiry guidelines (Lincoln & Guba, 1985). Since the study sought to capture subjective experience, participants were not necessarily asked all the same questions. However, all were asked to describe core aspects of the experience, including the quotidian activities related and unrelated to care practices; the emotions attached to the experience; the changes in their relationship and ways of relating; and what they thought could be helpful going forward.

Interviewing occurred with members of care partnerships together and separately. Sample interview questions included the following: Can you describe a typical day? What makes for a good/bad day? How do you spend your time together? How do you spend your time apart? Have you experienced anything unexpected, good or bad, during this experience? How do you explain what is going on? How have things changed? What do you expect going forward? What kind of help do you wish was available to you?

Artifacts. The study made use of a range of artifacts. Artwork, diaries, journals, letters, and photographs have long held a place as data in qualitative research adopting an ethnographic approach (Denzin & Lincoln, 2005; Padgett, 2008). Artifacts can be used in different ways in knowledge building. They tend to be analyzed from two perspectives for the purposes of research: in terms of content and form. Here, the artifacts provided evidence of perceptions, feelings, and emotions that elucidate existential meanings (Plummer, 2001; Prior, 2008). Eleven separate artifacts were offered to the researcher: four works of art, one photograph, and six pieces of writing, including a letter, published documents, and journal selection.

Artwork was interpreted as data communicating unspoken feelings and thoughts not only through content but also through the act of creation. As such, artwork and art making, interpreted as embodied data, were included in the study. In addition, the study included photographs as data. While participants were not asked to document their lives photographically during the study, if they chose to share photographs from their past, these were included as data. This was a common occurrence. Often, the photographs provided a frame for conversation during the interview with the person with dementia.

Written documents were also collected as data. These included emails, journal entries, writing samples from a professional writer, post-it note reminders for persons with dementia, and a letter to family members describing how to integrate the relative with dementia into group activities

during family holidays. Following Plummer (2001), all documents were included to support and generate findings. The researcher's field notes were also included as data.

During the course of interviews and observations, participants spontaneously shared personal items, such as artwork, letters, and journal entries. These were included in the study as artifacts. The researcher did not solicit these donations. Rather, participants went out of their way to provide examples of what they were discussing to clarify meaning for the researcher. When multiple artifacts were available, such as many drawings or emails, those to be included in the study were selected in a collaborative process between the researcher and the participants. Selection was made according to the items' interpretive value rather than their artistic or literary merit.

Embodied data. Embodied data were collected through prolonged engagement and participant observation. This enabled dementia-affected participants to feel at ease with the researcher and behave as they usually do. Embodied data consisted of actions and interactions that occurred between partners in care and demonstrated relatedness beyond words. For example, when a care partner repeatedly turned to the person with dementia and posed a rhetorical question, such as, "Isn't that so, hon?" the question served less as a verbal means of extracting information than as an act of inclusion. Likewise, the constant staring of a person with dementia at his spousal care partner, something she described as his "Velcro eyes," became a physical rendering of relatedness. Joint activities beyond activities of daily living, such as making art or singing, also became embodied data, as these demonstrated ongoing relatedness between care partners. Examples of embodied data include laughing (24 instances of individual and couple laughter during one interview), rubbing the head and shoulder (4 times in one observation session), making music (4 times in one observation session, includes singing, humming, and drumming on the table), and sharing photographs (4 times over the course of data collection with one couple).

Embodied data collection consisted of participant observation during prolonged engagement and extended over the course of 7 months, consistent with qualitative research data collection expectations (Lincoln & Guba, 1985; Padgett, 2008). Participant observation is defined as the researcher's active engagement with participants in their activities (Lincoln & Guba, 1985; Padgett, 2008). Participant observation in this study consisted of time that the researcher spent observing care partners in action, supplemented by observation that occurred concurrently with interview sessions. Attempts were made to observe participants at different times of day and days of the week to capture a range of interactions.

Consisting of more than observing, participant observation in this study ranged from the researcher's sharing a meal or quiet time with participants at their home, taking a walk with participants, attending church with participants, and bowling with participants and their friends. During participant observations, verbal data collecting consisted of naturally occurring conversation. Participant observation data were rendered through thick description, the multidimensional rendering of experiences and events (Geertz, 1973). Making use of detailed field notes, thick description aims to capture visual, emotional, psychological, and physical dimensions of experience, contextualizing behavior in a cultural setting and making it accessible to an etic audience (Geertz, 1973).

Data Analysis

Consistent with qualitative research, data analysis consisted of an ongoing, iterative process that moved from the particular to the more general in a series of steps that were revisited in response to emergent findings (Denzin & Lincoln, 2005; Lincoln & Guba, 1985; Padgett, 2008). Analysis began as soon as data collecting was underway, continued during the transcription process, and was considered complete only when saturation was achieved. Saturation became evident with no new data, and when codes and themes were fleshed out fully. The analysis process consisted of four steps, which, while distinct, were constantly returned to in an iterative fashion. In addition, memoing occurred in every stage of the research, starting with data collection, and extending through the write-up. Memoing consisted of noting the ideas, connections, expanded lines of inquiry, and so forth, that were stimulated by the researcher's process and the data (Padgett, 2008). Analysis was ongoing to capture emerging findings. Moreover, analysis bridged genres of data, following qualitative methodologies that aim to capture more than spoken word, such as ethnography and other naturalistic inquiry approaches (Denzin & Lincoln, 2005; Geertz, 1973; Lincoln & Guba, 1985; Padgett, 2008). For example, documents were not interpreted separately from the words participants used to describe and explain them. Furthermore, a care partner most often translated embodied data, clarifying what was being communicated.

Analysis occurred with a co-coder with whom the primary investigator compared notes. An iterative process, the coding process consisted of identifying and labeling recurring terms, utterances, actions, interactions, and artifacts within cases. Cases consisted of the data pertaining to each care partnership. Codes consisted of short quotes, descriptive terms, and brief descriptions of repetitive and significant sounds, gestures, interactions, and artifacts. Examples of interview codes include, "I wanna be me" (six repetitions in one interview); "I like her, I respect her, and I love her" (six repetitions in one interview); "She's the boss" (four repetitions in one interview); and "It's hard" (four repetitions in one interview). Examples of embodied data codes included "laughing" (24 instances of individual and couple laughter during one interview); "affection," evident in, for example, rubbing the head and shoulder (4 times in one observation session); "making music" (4 times in one observation session, including singing, humming, and drumming on the table); and "sharing . . . , that is, a photograph" (4 times over the course of data collection with one couple, and multiple

times across couples). Coding of artifacts consisted of naming the artifact, such as "artwork," "photograph," and "note."

Thematic analysis consisted of three steps. First, codes were compared and contrasted across cases to establish commonalties and differences across cases. Second, codes that were found across cases were identified as themes. Finally, themes were labeled. Theme names sought to capture the relationship between codes. Examples include "focusing on the good things" and "living with loss."

The third analytical step consisted of contextualizing themes in existing literature by reviewing existing literature to synthesize data and then identify knowledge and service gaps. Contextualized themes were used as starting points for challenging and confirming what was already known about the dementia experience. In a final step, findings were used to develop suggestions for care. Once service gaps were identified, suggestions to better meet needs of dementia care partnerships were articulated.

Study Limitations

Study limitations primarily reflect sample restrictions, in terms of recruitment strategies, and participant demographics. Recruitment occurred through service providers. As a result, findings only capture the experiences of a help-seeking population. In addition, diversifying participants, specifically where sexual orientation is concerned, could contribute to developing new knowledge significant to quality of life for all persons affected by dementia. Moreover, findings do not address the experience of people affected by dementia who are being cared for by professional caregivers, do not have intimate caregivers, and do not live at home.

Strategies for Rigor

The researcher adopted four strategies to increase rigor, in addition to prolonged engagement, following Lincoln and Guba (1985). These included member checking, triangulation, audit trail, and peer debriefing. Member checking consisted of phone calls and emails to complete data collection. Triangulation was twofold. One consisted of drawing on several types of data, interviews, embodied data, and artifacts. The other reflected multiple methods of data collection, interviewing, observing, and compiling documents. In addition, the researcher maintained an audit trail, following Padgett (2008). The audit trail tracked not only the research procedures but also the researcher's thinking process.

Discussion: The Benefits of Additional Data Collecting Methods

Implications for Research: Extending the Reach of Qualitative Inquiry

Until recently, dementia research has tended to separate the caregiver from the care receiver, emphasizing either the caregiver's burden and burnout or the biomedical characteristics of the disease (O'Connor et al., 2007). Moreover, it has focused on decline and loss: loss of self, including memories, abilities, expectations and roles, and loss of a meaningful relationship (O'Connor et al., 2007). However, a growing body of work, exploring the perspective of the person with dementia, positive aspects of caregiving, relationship-centered dementia care, and capacity versus loss, is beginning to challenge perceptions of the illness and traditional approaches to knowledge building (i.e., Basting, 2003) When dementia research explores how the illness is experienced in the context of care partnerships, rather than as a diagnosis, findings suggest additional outcomes, for all members of care partnerships, at least in the early- to mid-stages of the disease. Specifically, partners in care have identified the perception of an enduring sense of relatedness as a locus for well-being (Hellstrom et al., 2005).

This is significant because while relatedness can be described in words, it is also possible to observe it in embodied communications, including actions and interactions, and in material representations, such as artifacts imbued with meaning. Observable relatedness might be demonstrated through touch, visual focus, anticipating needs and desires, and other forms of embodied communication that compensate and complement truncated verbal exchanges (Hellstrom et al., 2005). Similarly, artifacts can be perceived as stand-ins for feeling and relationship. Relying on interviews alone to describe the dementia experience runs the risk of overlooking nuances best captured through other means, with significant consequences for persons facing tremendous challenges. Embodied communication and artifacts can provide pathways to new findings. When translated into practice, new findings can support new outcomes for persons facing the great challenges of progressive cognitive impairment.

Implications for Care Practices: New Content, New Outcomes

Study findings have been expanded on in previous publications (i.e., McGovern, 2010, 2011, 2016). However, they are not unrelated to the focus of this methods article, which describes the process of using additional data collecting methods more fully. When applied to persons affected by cognitive impairment, which may affect speech and interpretative abilities, the benefits of additional data collecting extend beyond the research process. Complementing spoken word with embodied data and artifacts sheds light on new content.

There are implications for dementia care practices, which can build on strengths previously underexplored in the literature and service provision. These include the need for supporting embodied care partnering as both a sustaining dynamic and an attempt to manage symptoms and burden, in addition to supporting care partners. Care practices that promote interaction and recognize the meaning of "things" are

to be encouraged. Significantly, occupational, recreational, and supportive therapies that bring members of care partners together in various ways, often to create things—art, plays, scrapbooks—are beginning to gain traction. They demonstrate success in terms of increasing well-being, mood, and overall health for both care partners but are still few and far between (Basting, 2009; Epstein, Auclair, & Mittelman, 2006; Gordon, 2013; Graff et al., 2007).

Data collecting needs to move beyond interviews to broaden the reach of knowledge building, capture a range of experiences, and better contribute to evidence-based care provision for neediest cases. Specifically, the benefits of additional data collecting argue for expanding definitions of data, and including non-verbal data, such as interactions and artifacts, to increase inclusivity in research processes. In this study, embodied, material and verbal data were taken into account, allowing not only for new knowledge to emerge but also to broaden the reach of the research process. When those who can no longer express themselves through words can still be included in research, chances are greater that their needs will be met.

Conclusion

This methods article highlights the need for additional data and illustrates how to use additional data collecting methods in qualitative research. Extending the reach of data collecting can contribute to increasing equitable knowledge building and service provision. As a result, it can enhance social justice for vulnerable persons often excluded from knowledge-building endeavors.

In the study, research participants with dementia possessing few or no words forced the researcher to supplement the most common form of qualitative data collecting, the interview (Englander, 2012). By including artifacts and embodied communication as data, this study was able not only to access nuances of the experience but also to include persons with dementia in the research process more consistently than have studies adopting a more traditional approach to data collection focused on spoken word and interviews.

A review of other qualitative dementia studies revealed that most researchers manage the data collecting challenge by either addressing the experience of the caregiver instead of the person with dementia, or limiting research to persons in the early stages of the illness who remain able to speak and interpret experience (O'Connor et al., 2007). Findings from interview-based research highlight burden, burnout, decline, and despair (O'Connor et al., 2007). In contrast, studies that include embodied data and artifacts indicate that there is more to dementia than negative outcomes, which has implications for care practices (i.e., Buse & Twigg, 2014; Kontos, 2004).

Specifically, care that supports relatedness through supportive, recreational, and occupational therapies can extend quality of life (Basting, 2009; Epstein et al., 2006; Gordon, 2013; Graff et al., 2007). By excluding those in further stages of the illness whose cognitive abilities have failed them, traditional approaches to data collecting limit the potential of research where applying findings to best practices for care for the widest range of patients is concerned.

The article submits that qualitative research that moves beyond spoken word may better reach participants with diverse capacities, experiences, and priorities. It suggests that building on observable and tangible data can make a difference in knowledge-building endeavors by promoting ethical research and revealing new findings. Furthermore, the study argues that increasing inclusivity can improve the lives of vulnerable participants who might be excluded from interview-based health research and its translation into care practices, for a variety of reasons.

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Author Biography

Justine McGovern, PhD, LMSW, is an Assistant Professor in the Lehman College (CUNY) Department of Social Work. Her research examines diversity in late-life experiences, taking social justice issues into account. She has practice experience in parental care, community mental health, and child welfare.