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Barriers to qualitative dementia research: the elephant in the room

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Abstract

As our population is aging, the global prevalence of dementia is rising. Recent extensive reviews of the dementia literature highlight a clear need for additional qualitative research to address the experiences of people with dementia and their carers. To date, the vast majority of published dementia research is quantitative in nature and, perhaps not surprisingly, attracts the bulk of government funding. In contrast, qualitative dementia research is poorly resourced and less frequently published. Although a myriad of factors are responsible for this dichotomy, we propose that inadequate funding represents the "elephant in the room" of dementia research. In this article, we describe and emphasize the need for qualitative dementia research, highlight existing barriers, and outline potential solutions. Examples of barriers are provided and theoretical underpinnings are proposed.

Keywords

dementia, geriatrics, health care, economics of, research, qualitative, resource allocation

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Barriers to Qualitative Dementia Research: The Elephant in the Room

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Abstract

As our population is ageing, the global prevalence of dementia is rising. Recent extensive reviews of the dementia literature highlight a clear need for additional qualitative research to address the experiences of people with dementia and their carers. To date, the vast majority of published dementia research is quantitative in nature and, perhaps not surprisingly, attracts the bulk of government funding. In contrast, qualitative dementia research is poorly resourced and less frequently published. Although a myriad of factors are responsible for this dichotomy, we propose that inadequate funding represents the elephant in the room of dementia research. In this article, we describe and emphasize the need for qualitative dementia research, highlight existing barriers and outline potential solutions. Examples of barriers are provided and theoretical underpinnings are proposed.

Keywords

Dementia; geriatrics; health care, economics of; research, qualitative; resource allocation.

Qualitative research has, thus far, played a crucial role in improving our understanding of dementia and its impact on individuals, carers, families and the broader community (Gibson et al., 2004; Prorok, Horgan, & Seitz, 2013). As our population is aging, the impetus for improved dementia care is increasing (Burns & Iliffe, 2009; Larson et al., 2013). Qualitative research is well suited to meet this call (Beuscher & Grando, 2009; Gibson et al., 2004; Morse, 2012). Unfortunately, qualitative (and quantitative) dementia research is fraught with challenges. We propose that a major barrier, inadequate government funding, is the elephant in the room of dementia research. The purpose of this article is to: (a) describe the increasing need for qualitative dementia research; (b) highlight barriers faced by researchers; and (c) outline steps required of key stakeholders to promote dementia research. An initial description of dementia is proffered to enhance readers' understanding of the current clinical context. Priority topics for future qualitative dementia research are explored.

Background

Dementia refers to a neurocognitive disorder characterized by a disturbance of multiple higher cortical functions (e.g. memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgment) (APA, 2013). Cognitive deficits are often accompanied by deterioration in emotional control, social behavior, or motivation (WHO, 2010). Six and a half percent of those over the age of 65 years were found to have dementia in a large English study (Matthews et al., 2013). The World Health Organisation (WHO) recently established that 35.6 million people have dementia; 58% of whom live in low or middle-income countries. In addition, WHO anticipates that the number of people with dementia will double every 20 years, to 65.7 million in 2030 and 115.4 million in 2050 (WHO, 2012).

The most common forms of dementia include Alzheimer's disease, vascular dementia, dementia with Lewy bodies, frontotemporal dementia and alcohol-related dementia (Samuels, 2009). People with dementia have a high level of medical comorbidity and are often prescribed complex medication regimens: those attending primary care have, on average, 2.4 chronic conditions and receive 5.1 medications (Schubert et al., 2006). Epilepsy, delirium, falls, oral disease, malnutrition, frailty, incontinence, sleep disorders and visual dysfunction occur more frequently in people with dementia and lead to excess disability and reduced quality of life for the affected person and their family (Kurrle, Brodaty, & Hogarth, 2012). A large prospective observational study of community-dwelling older Americans with dementia established that the median survival from initial diagnosis was 4.2 years for men and 5.7 years for women (Larson et al., 2004).

A diagnosis of dementia is based on the history provided by an individual, a collateral history taken from an informant and a physical examination. A formal neuropsychological assessment can provide valuable additional information (APA, 2013). The clinical features of dementia vary but can include difficulty with: (a) learning and memory; (b) handling complex tasks; (c) reasoning; (d) spatial ability and orientation; and (e) language (US HHS, 1996). Up to 90% of people with dementia will experience behavioral and psychological symptoms ranging from agitation and pacing to wandering and getting lost (Burns & Iliffe, 2009). Depending on the form of dementia, there is wide variability in rates of decline between individuals and in the rapidity with which the condition develops. Of concern is that dementia is usually degenerative and progressive (Grand, Caspar, & MacDonald, 2011).

Pearls: the need for dementia-related research

Alzheimer's Disease International (ADI), in its 2010 World Alzheimer Report, predicted a near doubling in global societal costs incurred by dementia from \$604 billion in 2010 to

\$1,117 billion by 2030 (Wimo & Prince, 2010). More recently, ADI called on governments and research funders worldwide to rearrange existing priorities and provide a tenfold increase in current levels of research funding in line with other conditions, such as cancer (Prince, Prina, & Guerchet, 2013). Of the research areas identified by ADI as important, several are well suited to a qualitative approach: (a) the values and preferences of people with dementia and their carers; (b) the impact of long-term care delivery on quality of life and service satisfaction; (c) how best to implement person-centred care in community care and care home settings; and (d) the impact of care delivery on professional care workers (e.g. mood, burn out and retention).

In 2010, the Australian Government commissioned a review of existing dementia research (Seeher, Withall, & Brodaty, 2010). The authors, charged with the task of identifying gaps in the available literature, determined that there remained a large number of unanswered questions relating to dementia which are worthy of research. Specifically, they highlighted the need for a greater understanding of the experiences and needs of people with dementia and their carers. Furthermore, they argued that research using qualitative as well as quantitative methods is required (Seeher, Withall, & Brodaty, 2010). Three years later in the United Kingdom, these findings were echoed by the James Lind Alliance priorities for dementia research review (Alzheimer's Society, 2013).

Notwithstanding the clear necessity for additional research, the Australian National Health and Medical Research Council (NHMRC), which allocates more than \$720 million of research funding annually, only awarded \$25.5 million for dementia research in the 2012-2013 financial year. This figure is small when compared to other NHMRC funding recipients: \$158.4 million for cancer research; \$97.9 million for cardiovascular disease research; \$60.3 million for mental health research; and \$56.8 million for diabetes research (NHMRC, 2013).

In the United States (US), the prevalence of dementia among persons aged 70 and older is 14.7% (Hurd et al., 2013). Hurd et al. (2013) estimated that the annual US monetary cost of dementia is between \$157 and \$215 billion. The authors concluded that dementia represents a substantial financial burden on society, similar to that of heart disease and cancer. Despite such compelling findings, the National Institutes of Health (NIH), which allocate over \$30 billion of research funding annually, only awarded \$0.65 billion for dementia research in 2013. This figure represents a small fraction of the NIH funding awarded to other recipients: \$5.27 billion for cancer research; \$2.17 billion for mental health research; \$1.96 billion for cardiovascular disease research; and \$1.01 billion for diabetes research (NIH, 2013a).

It would appear then that funding for dementia research lags far behind that allocated to other important medical conditions. Most funding is channeled into quantitative rather than qualitative research projects (NHMRC, 2013; NIH, 2013b; Padgett & Henwood, 2009). Although qualitative research projects are often small in scale, some can be resource-intensive and expensive to conduct (Padgett & Henwood, 2009). In the absence of adequate financial support, qualitative researchers defer or abandon valuable projects. This is an unfortunate dilemma as, in contrast to a quantitative approach, qualitative research has the potential to capture the meaningful experiences and life values of people with dementia and their carers (Beuscher & Grando, 2009; Gibson et al., 2004; Morse, 2012; Prorok, Horgan, & Seitz, 2013).

Qualitative health research serves as an important tool in our understanding of health care (Morse, 2012). This form of inquiry is well suited for “why”, “how” and “what” questions about human behavior, motives, views and barriers (Neergaard et al., 2009, p. 2). Accordingly, with its mainly inductive approach qualitative research is ideal for problem identification, hypothesis generation, theory formation and concept development (Neergaard

et al., 2009). A large international body of qualitative dementia-related literature with several strands now exists (Beard, 2012; Dalby, Sperlinger, & Boddington, 2012; Dewing, 2007; Evans & Lee, 2014; McDonnell & Ryan, 2013; Prorok, Horgan, & Seitz, 2013). The existing body of high-quality qualitative dementia research, incorporating varied methodologies (e.g. grounded theory, meta-ethnography, immersion crystallization, participatory approach, phenomenology), strengthens the argument in favour of this mode of inquiry.

To date, qualitative researchers have already addressed a series of important issues including: (a) individuals' perception of their illness; (b) exploration of carers' experiences; (c) impact of dementia on friends and family (Prorok, Horgan, & Seitz, 2013); among others. However, several gaps in our knowledge remain (e.g. optimal psychosocial interventions for carers, achieving social integration, evaluation of training and education in dementia care) (Moniz-Cook et al., 2011). Careful prioritization of the gaps which warrant further qualitative research is needed (Prorok, Horgan, & Seitz, 2013).

Pith: barriers and the elephant in the room

An indirect measure of qualitative research is publication in peer-review medical journals. Shuval et al. (2011) conducted a retrospective review of the publishing patterns of 67 general internal medicine journals (e.g. British Medical Journal, Lancet, New England Journal of Medicine). The authors established that the proportion of qualitative studies published in medical journals, although low, rose over a ten year period from 1.2% (1998) to 4.1% (2007). They argued that the overt dominance of quantitative research in medical journals may obstruct our (a) learning how to improve health care services/delivery, and (b) understanding of the impact of interventions as experienced by patients/health care providers (Shuval et al., 2011). What, then, are the barriers to successful qualitative research?

Beuscher and Grando (2009) described three key obstacles to qualitative dementia research: (a) determining capacity to provide informed consent; (b) engaging in effective communication; and (c) ensuring credibility of data. However, additional hurdles do exist. First, unpredictable ethical challenges can arise in the conduct of qualitative research with people with dementia (Heggestad, Nortvedt, & Slettebø, 2012). For example, interviewees may divulge sensitive or inappropriate personal or financial details to researchers in the course of an interview. Furthermore, researchers may become aware of inappropriate carer/partner behavior which warrants notification of a treating physician or the police. Accordingly, ethics review boards may be reticent to grant approval of dementia research. An in depth appraisal of the ethics relating to qualitative dementia research is beyond the scope of this article and is available elsewhere (Beuscher & Grando, 2009; Carmody et al., 2013; Dewing, 2007; Heggestad, Nortvedt, & Slettebø, 2012; Hellström et al., 2007).

Second, recruitment of participants for dementia research can prove challenging in culturally and linguistically diverse (CALD) populations (Shanley et al., 2013) for a number of complex reasons, such as: past abuse of CALD groups in research; social stigma associated with dementia; cost of participation; lack of access to research; language barriers; and a belief that memory loss is a normal part of aging (Chao et al., 2011; Hinton, 2000). Third, a structured review of 434 original research articles published over a two year period in an international geriatric medicine journal found that 29% of researchers explicitly exclude individuals with cognitive impairment from participation (Taylor et al., 2012). Moreover, this often occurs without explanation or mention of exclusion as a limitation (Taylor et al., 2012). Last, a major impediment to the conduct of qualitative dementia research is the clear inadequacy of government funding. Sadly, the dearth of dementia research funding represents an elephant in the room as it is rarely mentioned, and instead, usually neglected or ignored as

a topic of discussion by the media and in contemporary medical literature (Kmietowicz, 2012).

An array of theoretical explanations are required to address the wide range of barriers that arise in qualitative dementia research: (a) ageism; (b) apathy; (c) cultural context; (d) denial; (e) lack of political impetus; (f) nihilism; (g) social stigma; and (h) taboo. Unfortunately, people with dementia have been largely excluded from research in the past (Dewing, 2002; McKeown et al., 2010). Furthermore, until the 1990s researchers tended to overlook their perspectives (Hubbard, Downs, & Tester, 2003; McKeown et al., 2010). An overly medical model has dominated past research endeavours (Downs, 1997; McKeown et al., 2010; Shuval et al., 2011). Thus, a person with dementia was viewed as a ‘disease entity’, unable to contribute directly to an understanding of their condition (Cottrell & Schultz, 1993; McKeown et al., 2010). This approach hampered a holistic understanding of the needs of individuals with dementia and their carers.

Regardless of the barriers (or their theoretical underpinnings) faced by qualitative dementia researchers, people with dementia and their carers are keen to avail of excellent health care. Members of the community have a reasonable expectation of health care researchers, clinicians and policy makers: a passionate and clear focus upon person-centered care. Qualitative researchers are well placed to address the key components of person-centered care: (a) respect for individuals’ needs and preferences; (b) emotional support; (c) physical comfort; (d) information, communication and education; (e) continuity and transition; (f) co-ordination of care; (g) involvement of family and friends; and (h) access to care (Luxford, Safran, & Delbanco, 2011). In order to achieve or maintain high-quality person-centered care, qualitative dementia researchers will require support to address a series of hurdles.

Provocation: a call for change

The conduct of qualitative dementia research is beset with barriers. Overcoming such obstacles is increasingly important as our population ages and the prevalence of dementia rises (Larson, Yaffe, & Langa, 2013). Changes to policy and practice are required of four key stakeholders to facilitate meaningful qualitative dementia research: (a) health professionals; (b) researchers; (c) media; and (d) government. Acknowledgement of insufficient funding as the elephant in the room is an important first step on the path to improved research output and better patient care. *Sine qua non* is the careful prioritisation of relevant topics worthy of qualitative research.

Health professionals play a crucial role in the development of qualitative research. At times, physicians (and, perhaps, other clinicians) require reminding that a quantitative approach is not always the most important or relevant methodology when dealing with people (Malterud, 2001). Malterud (2001) and Shuval et al. (2013) propose that quantitative and qualitative forms of inquiry should be viewed by physicians as complementary. Harrington et al. (2009) suggest that the traditional view of clinical research (led by physicians relying heavily on statisticians) is no longer viable or appropriate. They argue that conducting clinical research without dedicated training and experience in the field is unacceptable. Although leading academic research hospitals offer clinical research training programs to their employees (Harrington et al., 2009), a large proportion of hospitals do not. The introduction of a formalised research training module for interested health professionals in hospitals has the potential to result in an improved understanding of and appreciation for qualitative research methods.

Researchers are largely responsible for the direction and design of their studies. Important gaps exist within the dementia literature which would be well suited to qualitative studies (Prorok, Horgan, & Seitz, 2013; Seeher, Withall, & Brodaty, 2010). It would appear

that researchers should consider three pressing issues. First, in view of the numerous challenges which accompany dementia research, researchers would be wise to adopt pragmatic study designs. The application of overly restrictive exclusion criteria (e.g. poor English language skills, living in residential care, cognitive impairment) should be avoided as it limits the relevance (e.g. credibility, dependability) of one's findings.

Second, experienced qualitative researchers are in a position to promote the use of alternative forms of consent. Bartlett (2012) provides a detailed account of adopting a form of process consent in her qualitative study of people with dementia. Process consent, as originally described by Dewing (2002), involves asking participants for verbal consent at each stage of data collection and reminding them that they may withdraw at any stage. This method is appropriate for people with limited capacity for informed consent who, on observation, can communicate and express their wishes (Dewing, 2007). Unfortunately, a consensus does not yet exist regarding the application of concepts such as assent and dissent in dementia research or which procedures researchers should use in practice (Black et al., 2010). This has the potential drawback of delaying or preventing research to understand and manage important issues relevant to dementia care (e.g. agitation). (Black et al., 2010).

Third, a key ingredient in attracting funding is a researcher's ability to craft compelling research questions which address major gaps in the literature (see below). A careful focus upon pertinent deficiencies in the literature can lead to macro-level solutions (e.g. enhancement of qualitative research training, interdisciplinary research groups, lobbying of funding agencies, and media engagement).

The media can serve a wide range of positive roles with regard to dementia (e.g. awareness, education, research funding, and study recruitment). National consumer organizations (e.g. Alzheimer's Australia, Alzheimer's Foundation of America, and Alzheimer's Society) rely heavily on media to reach members and the broader community.

This valuable relationship results in greater awareness, reduces social stigma, informs debate and encourages fundraising. Thus, the conduct of dementia research (i.e. qualitative and quantitative) is expedited. Advocacy efforts that portray the need for increased research funding with videos and stories of individuals with dementia are a helpful strategy often adopted by national consumer bodies. Positive portrayals of people with dementia in magazines (Kessler & Schwender, 2012) are an example of the constructive approach adopted by some journalists. However, negative portrayals of individuals with dementia also exist.

A comprehensive United Kingdom report on dementia, commissioned by the Alzheimer's Society, criticized the media for their tendency to portray dementia in its most severe form thereby perpetuating negative perceptions of the condition (Williamson, 2008). Furthermore, contributors to the report argued that there was inadequate coverage of dementia in the media and that this had contributed to ignorance, fear, misunderstanding and consequently social stigma (Williamson, 2008). Of concern, is that the media often focus on new cures for dementia and unfairly raise people's expectations and hopes (Williamson, 2008). In an attempt to curtail sensational journalism, dementia consumer groups now offer online guides to media regarding appropriate language and content for reports (Alzheimer's Australia, 2013a; Alzheimer's Foundation of America, 2013). Such measures may successfully counteract the influence of ageism and social stigma which, all too frequently, accompany dementia.

Adequate government funding of dementia research is long overdue (Alzheimer's Australia, 2013b; Kmietowicz, 2012). Leading researchers, national consumer organizations and prominent community members are prevailing on governments to recognize the far-reaching impact of dementia and the clear need for additional research funding (Prince, Prina, & Guerchet, 2013). Specific clinical and research priorities relating to dementia have been

identified by both clinicians and researchers (Alzheimer's Society, 2013; Burns & Iliffe, 2009; Moniz-Cook et al., 2011; Prince, Prina, & Guerchet, 2013; Seeher, Withall, & Brodaty, 2010). These include: (a) raising awareness of dementia; (b) highlighting the need for early diagnosis and investigation; (c) improving the care for people with dementia in general hospitals and institutional settings; (d) focusing on the benefits of non-drug interventions; and (e) increasing dementia research funding.

Prioritisation of gaps in the literature is a crucial prerequisite when planning qualitative dementia research. Cogent reviews of major deficiencies and directions for future dementia research are available. Notable among these reviews are: (a) the James Lind Alliance dementia priority setting partnership (Alzheimer's Society, 2013); (b) the INTERDEM manifesto (Moniz-Cook et al., 2011); and (c) the Australian dementia research mapping project (Seeher, Withall, & Brodaty, 2010). Many of these priority areas could be addressed/evaluated using qualitative methods. However, it behoves our public representatives in government to acknowledge these calls and act appropriately. Meeting the therapeutic challenge of dementia (using quantitative research methods) is of paramount importance since the rising prevalence of dementia poses serious challenges for health care systems (Yates, 2013). Enhanced government funding and support of qualitative research will be required to realise these goals.

Conclusion

Dementia is becoming increasingly prevalent as our population is aging (Larson et al., 2013). Accordingly, the social and economic impact of dementia is expected to soar, unless a novel therapy is discovered that can prevent or treat this condition (Yates, 2013). Globally, dementia is a major cause of disability in later life: it contributes 11.2% of all years lived with

disability. This is in contrast to stroke (9.5%), musculoskeletal disease (8.9%), heart disease (5%), and cancer (2.4%) (Burns & Iliffe, 2009).

Current attempts to engage in qualitative dementia research are hampered by numerous obstacles. Inadequate funding, the elephant in the room, hinders progress and condemns many worthwhile qualitative studies to failure. In spite of a pressing need to promote dementia research, many qualitative researchers persevere and conduct their studies with meagre government funding. Although funding agencies claim to support worthwhile and feasible projects (Carey & Swanson, 2003), qualitative dementia researchers are often relegated to sifting through the flotsam and jetsam of government funding. Promising government policy developments are now emerging in several countries (Benson, 2013; Hurd et al., 2013; Kmietowicz, 2012) (e.g. modification of existing research funding models, strengthening of national dementia strategies). However, it remains to be seen if such developments result in much-needed qualitative dementia research.

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