Abstract (274 words)

Background Low participation in research is one of the key challenges to advancing understanding of dementia, and improving the care and treatment of those who live with this condition. Nurses and nurse researchers play a vital role in recruiting people with dementia to studies, as several countries including the United States and the United Kingdom set national targets and develop initiatives to encourage more people with dementia to take part in research.

Aim To highlight the challenges to recruiting people with dementia to studies, and to identify strategies that nurses, and in particular, nurse researchers can use for overcoming them. Our focus is primarily on the role of nurses in recruiting people with dementia to dementia studies, but much of the discussion will apply to other health professionals involved in the recruitment of people with dementia to research more generally.

Discussion Challenges discussed include a lack of awareness about research participation opportunities and a suitable study partner. We discuss how the nurses' role is to ensure that recruitment practices are personalised and responsive to participants' needs and situation, rather than target-driven. The notion of responsible research is used to anchor the discussion.

Conclusion

Increasing the participation of people with dementia in research is a global priority. Nurses and nurse researchers play an important role in ensuring that people who take part in research have an optimal research experience.

Implications for practice

Recruiting people with dementia to research studies is a national priority in many countries. With a greater understanding of the challenges involved and strategies that can be used to overcome them, nurses can have an effective role in the recruitment process and research experience.

Key words

Cohort Studies, dementia, recruitment, nursing research, qualitative research

Background

Even though there are millions of people living with dementia worldwide, only a fraction of these individuals take part in research (Alzheimer's Disease International, 2013). This is a problem for studies of the incidence and prevalence of dementia in the population, for observational and qualitative studies and for research into treatments and interventions for people with dementia, which may not work if research does not accurately include those with the condition in the trialling or piloting of them.

Recruiting people with dementia to studies is becoming an international priority, with several countries including the United States and the United Kingdom setting national targets and creating initiatives to encourage more people with dementia to take part in research. In England, for example, the government is committed to increasing numbers of people with dementia participating in research to 10 per cent, up from the current baseline of 4.5 per cent (Prime Minister's Office, 2015). Dementia research registries have been established in an effort to improve recruitment (Iliffe et al., 2011), and initiatives such as the UK's Join Dementia Research and the US Alzheimer Prevention Registry aim to use the internet and social media to encourage research participation. The topic of recruitment in dementia research is thus becoming increasingly urgent.

Recruitment is a challenging and an often disregarded aspect of research (Riedel-Heller, Busse, & Angermeyer, 2001). This is particularly the case in dementia-related research, as ethical issues and seeking ethical approval often take precedence over recruitment problems (Holland and Kydd, 2015). In this article, we discuss the challenges involved in recruiting people with dementia to studies, including clinical trials, cohort studies and qualitative or exploratory research studies, and identify the strategies nurses and nurse researchers can use for overcoming them. Although the focus is on nurses and dementia-related studies, much of the discussion will apply to other health professionals and recruiting people with dementia to research more generally.

Recruitment in dementia research

Dementia research has traditionally involved small numbers of people, and recruitment is a longstanding problem. Writing over a decade ago, Cohen-Mansfield suggested that recruitment rates to dementia drug trials varied from 80% to 1%, but that there was little systematic reporting of recruitment (Cohen-Mansfield 2002). The overall difficulty with recruitment for dementia research is compounded by an imbalance within recruitment. Those with mobility or health problems and persons with moderate to severe dementia can be difficult to recruit, while certain groups are often underrepresented. Women are underrepresented in clinical trials (Baron, Ulstein, & Werheid, 2015), while the age of participants in clinical research is significantly lower than that of the population with dementia (Schoenmaker and Van Gool, 2005). Recruitment problems create concerns about a lack of a generalizability of dementia research, and also the applicability of results to different social groups, including women, black and ethnic minorities and older populations. While the extent of difficulties with recruitment varies between research areas, the fundamental problem of a lack of participation persists.

Motivations and barriers to participation

Before considering strategies to improve recruitment, it is essential to understand why people choose to take part in research, and what barriers are associated with recruitment. A growing body of research exists around the motivations for participation in research in general, and in dementia research in particular (Grill and Galvin 2014; Mein et al. 2012). This work suggests that people choose to participate in research for a number of reasons, and that these reasons may overlap or change over time. This is reflected in the context of dementia and memory impairment research, including altruistic motives (Grill and Karlawish*,* 2010), increased access to healthcare professionals and social contact (Keyserlingk, 1995), obtaining an unambiguous diagnosis and the perceived potential benefits of taking a new investigational product (ADI, 2013).

However, there are a number of barriers which prevent people with dementia from participating in studies, perhaps the most significant of which is a lack of awareness about research opportunities (ADI, 2013, Grill and Galvin 2014). People with dementia simply do not know about the opportunities to participate in research that are available to them. This might be, for example, because those around them, including practioners and ethics committees, are being overprotective (McKeown, et al, 2010a). Or because recruitment processes are so inadequate that general physicians and caregivers are not aware of the research opportunities themselves; this is certainly what the IMPACT study found, in relation to local clinical trials being conducted across Europe (Jones et al. 2010). Clearly, all health and social care professionals have a role to play in finding out about and raising awareness of research opportunities.

In addition, there are a number of cited logistical and practical difficulties preventing participation. For instance, caregivers may live some distance away from the person with dementia (Kolanowski, 2013, Grill and Galvin 2014), participants may be unable to travel to research sites (Lawrence, et al. 2013), or report being too busy (Tsai, 2009), and there may also be linguistic barriers (ADI, 2013). At an individual level, potential participants may be diagnosed in the advanced stages of dementia (Cowdell, 2008) and consequently not be able to provide consent or understand study procedures (Lawrence, et al. 2013). Moreover, in the case of clinical trials, it is possible that people with dementia will meet exclusion criteria, such as comorbidities or polypharmacy, or due to the requirement for a study partner (ADI, 2013).

Indeed, an added complexity with dementia research is the frequent requirement of a study partner, who is typically a spouse or adult child. The commitment of study partner can be perceived as time consuming (Connell, 2012) especially for adult children who are more likely to be working and have additional obligations (Grill and Karlawish, 2013). Others note that people with dementia themselves, may be concerned about burdening their relatives with the role of study partner (Lawrence, et al, 2013). Interestingly, evidence shows those with dementia are less likely to participate in research if they have a non-spouse caregiver, suggesting different recruitment approaches are needed (Grill et al, 2013). It is clear that research requiring a study partner relies on the willingness of both the person with dementia and the study partner (Cole, 2009); thus consideration of relationship status may be important when seeking to recruit a person with dementia to any study. Furthermore, it is thought that caregivers may act as gatekeepers assisting the person with dementia to avoid potentially distressing circumstances and unnecessary burden (Bull, Boaz and Sjostedt, 2013). The latter point reflects the importance of gatekeepers in negotiating research access to people with dementia (McKeown, Clarke, Ingleton, & Repper, 2010b).

Finally, social and cultural differences related to dementia between populations have been shown to influence the success rates of recruitment. While there is limited evidence, cultural barriers may prevent participation in dementia research (Kwon and Kim, 2011). A small number of primarily qualitative studies highlight the importance of culturally specific meanings attached to dementia and its relation with ageing (Hinton et al. 2000). Despite the continuing efforts of patients' organisations, a significant stigma remains associated with Alzheimer's dementia, particularly in early disease stages (Burgener et al. 2015; Johnson et al. 2015). This may be particularly the case in some ethnic minority and older populations potentially making research participation less likely(Feldman et al. 2008; Hinton et al. 2000). Other possible barriers include cultural suspicions about research and a view that research may not be of benefit to the target community (Connel, 2001, Faison, 2007).

Strategies for improving the recruitment process

Barriers to recruitment and retention can compromise the integrity of research and undermine findings. It is therefore essential to deploy a range of strategies to recruit an adequate number and diversity of appropriate research participants to produce valid results (ADI, 2013). The nurse researcher's role in particular is to ensure that whatever approaches are used, the overall strategy is one of 'responsible research'.

Responsible research, and in particular responsible recruitment practices, is about ensuring that research not only meets the and the needs of society in terms of dementia prevention, and requirements of research ethics, in terms of consent and conduct, but that it also responds to the needs of people with dementia and contributes to the delivery of improved care. The notion reflects a broader movement towards the development of 'responsible research and innovation' (Owen et al 2013) and is increasingly used in the context of Alzheimer's disease (Boenink et al. 2016).

A focus on responsibility is intended to enable nurse researchers and others to consider a broader range of issues that come together within the planning and conduct of dementia research. This includes the extent to which recruitment to dementia research can be responsive to the needs and situations of people with dementia, carers and the wider population, and can adapt to reflect these. It includes processes for engaging and working with people with dementia and their carers in research planning and design. It also emphasises the fact that interpersonal and caring relationships – whether formal or informal – are formed during research (cf Latimer and Puig de la Bellacasa 2013; Milne and Badger 2016) and that it is often nurse researchers who are responsible for balancing the needs of the study and research participants (Fisher 2006). These relationships are important in recruitment as well as supporting a rewarding research experience for participants, and consequently participant retention.

The potential relevance of this work is highlighted by the growing use of the internet and social media by researchers and research organisations to inform and try and attract people to their studies. For example, the Alzheimer's Prevention Registry in the USA and the Join Dementia Research registry in the UK both aim to establish populations of research-interested individuals, and match them with studies. Both organisations have short films on YouTube that explain how people can sign up for research studies.

While these initiatives represent powerful and valuable new ways of attracting ever-larger numbers of people in dementia research, it is important for nurse researchers to reflect on them in terms of a model of ‘responsible’ recruitment practices. First, in assessing the success of these initiatives, one should consider not just the weight of numbers recruited, but also the questions of inclusiveness. For example, internet-based recruitment strategies are perhaps more likely to attract younger people into dementia research, than older individuals with more severe dementia. Furthermore, there is value to considering whether and how these nonpersonal approaches to recruitment might benefit from complementation with more personal face-to-face strategies with both gatekeepers and potential participants.

Relationships are key to helping the recruitment process to run smoothly. Getting to know gatekeepers, and finding out what strategies they have used successfully in the past, is a helpful way to approach recruitment. For example, through informal conversations with research governance officers, we have learnt that the more complicated the study, the less willing people are to take part. Elsewhere, one of Bartlett's PhD students who is planning to recruit patients with dementia from an acute medical unit to take part in a visual ethnography on mobility (which is will be quite demanding of participants) has spoken to the medical photography team at the hospital to find out what they think of the idea. Making contact with this team and gaining their support has certainly helped the student to develop a responsible plan for consenting and recruiting participants.

Of course, it is important to develop rapport with potential participants as well as gatekeepers. Someone with a dementia, particularly a person with severe dementia, will need to feel comfortable in your company if you wish to elicit information from them. One helpful strategy for engaging a person with dementia in research is to begin every encounter with an act of kindness. This might be as simple as giving the person a warm smile and compliment, anything to help establish rapport. For example, in one study on spouse's experiences of dementia over time, the researchers presented a small flower to the couple at each visit (Hellstrom, Nolan, Nordenfelt and Lundh, 2007). Another idea is to share something about yourself that you think the person might relate to, maybe a shared interest in music or photography. Thoughtful gestures like these can make all the difference during the recruitment process, as they help to preserve the person's dignity, which in turn can create more equitable research relationships.

During the recruitment process, people with dementia will often make insightful comments, revealing that they are well aware of their situation (Nygard, 2006). Nurse researchers need to be attuned to these and respond accordingly. For example, during the recruitment stage of Bartlett's PhD fieldwork she recalls talking to a woman with Alzheimer's disease in a nursing home. The woman was extremely unhappy about where she was living and cried a lot during the encounter, the purpose of which was to establish whether she was well enough to take part in the study. To help her understand why she was there and what she was doing, Bartlett informed the woman that she was doing her PhD. To which the woman immediately replied, 'so you are here to help yourself, not me'. Honesty about what you are doing and why is obviously vital when seeking to recruit people with dementia to research. Even though it may mean the person does not then participate (as was the case here).

Tailor your approach to the study setting

The study setting, whether it is community-based or a clinical setting, will make a difference to the recruitment process. Not least because of the potential myriad of people who might need to be involved in the process. For example, in a study conducted across six care homes, staff members were found to hold varied perceptions of research and their role as gatekeeper, which could either promote or hinder the resident's participation in research (Goodman, 2011). In another community-based study, teams of nurses, therapist and psychologists were invited to recruit participants with dementia to a study about the quality of community care. Unfortunately, recruitment was 'alarmingly low', partly because the research was not a priority for the clinicians, but also because they were not sure about the benefits of the study to participants (Lowery, D., Warner, J., Cerga-Pashoja, A and Thune-Boyle, I (2011: 765). We would refer the reader to this paper for a more detailed discussion of how to deal with staff pressures. One approach a team of American researchers are using in their clinical trial of a home care intervention, is to 'embed recruitment' within daily practices, thus avoiding it seeming like an extra burden on staff (Fortinsky, et, al, 2016: 159). Arguably, this is easier to achieve in a community setting where a participant's situation is more likely to be stable, and practices less restrictive.

In specialised in-patient facilities, recruitment issues may be different again, as more is often required of nurses and nurse researchers during the process. For instance, in a study assessing people with dementia and delirium, admitted to skilled nursing facilities, participant's families were typically experiencing crisis circumstances. This setting thus required nurse researchers to be sensitive and ideally hold a mental health background (Kolanowski, 2013). Others obstacles included an unstable environment due to high nursing staff turnover and the time pressure within such services contributing to research being considered an added burden (Kolanowski, 2013). Therefore, to aid recruitment this authors suggests keeping eligibility criteria as flexible as possible, meeting with key personnel prior to study commencement to coordinate procedures, highlighting the potential benefits of participation, and employing researchers who understand the work and culture of the service (Kolanowski, 2013). Likewise, it has been deemed helpful to work alongside hospice staff prior to study commencement to better understand the research environment (Lawton, 2000). Overall, it is clear from this small selection of studies that recruitment needs to include consideration of the setting and recognition of the pressures that staff members, family carers, and clinicians may be under.

Create a patient or public-led culture of research

The current literature provides substantial encouragement to incorporate sufficient planning and realistic resources to enable effective recruitment. This can be facilitated by the involvement of stakeholders, including the public, potential participants and people with dementia and their carers, in the research design and planning process. There has been a gathering move within health research in the UK towards 'Patient and Public Involvement' (PPI) in a more-or-less standardised fashion. Such activities, properly conceived and implemented, have the potential to contribute to the development of research that meets some of the criteria of 'responsible' research and recruitment set out above. In particular, involvement work allows for the identification of recruitment practices that are responsive to the changing needs of all stakeholders. In turn, research suggests that the involvement of patient and public representatives contributes to a significant increase in recruitment success (Brett et al. 2012; Ennis and Wykes 2013)

Factor in costs

The financial requirements for recruitment are often under estimated. A feasibility study investigating people with mild to moderate dementia determined 13.3 hours of staff time was spent recruiting each participant costing $49.47 (Cole, 2009). Other research conducted in care homes estimated the cost of recruitment over a five month period totalled to £27,300 which mainly covered the cost of staff time (Goodman, 2011). Elsewhere, general recommended recruitment strategies include receiving referrals from nurses and other healthcare professionals, raising public awareness by presenting at applicable community events, and distributing study specific flyers to relevant groups. Of interest, the most costly recruitment strategy of newspaper advertising has been deemed least effective (Yu, 2013), suggesting a more individualised approach is favourable. Indeed, personalised communication with potential participants, including face-to-face contact, has been consistently considered successful (Norton, 1994; Riedel-Heller, Busse and Angermeyer, 2000). Moreover, researchers report arranging visits at a time that is convenient for the potential participant when they will be most receptive to study procedures is beneficial (Mody, 2008), as is providing sufficient time to enable discussion (Norton, 1994; ADI, 2014). Therefore, staff time emerges from the literature as a key element of recruitment strategy that requires incorporation into research costs.

In conclusion, to assist with recruitment, nurse researchers need to keep the requirements of the study under continuous review taking into account factors specific to the target population and research environment. The importance of these factors should be illustrated by incorporating them into the study design stage, formation of eligibility criteria, and forecasted costs. Reflected throughout this review is the emphasis on adopting a personalised approach to overcome recruitment challenges. In essence, one size does not fit all when it comes to recruiting people with dementia to research.

Conclusions

Recruiting people with dementia to research is a growing global priority. In this article, we have focused on the topic from the perspective of nurses, particularly nurse researchers, as well as people with dementia and family carers and argued for greater consideration to be paid to recruitment practices.

Recruiting people with dementia to a research study is a challenge for junior and experienced researchers alike. One of the authors (Croucher, R) is a Research Manager and doctoral student conducting a large-scale clinical trial supervised by a senior neuroscientist. Regardless of level or scale, the fundamental challenges around recruitment are shared by all researchers and across all studies. These include, concerns about recruiting enough people (i.e. the target sample) to the study, and ensuring the sample is sufficiently diverse or representative. Enabling black and minority ethnic nurses to take a strategic role in recruitment could help with this, as might paying bicultural researchers to perform a 'bridging role' (Rugkasa and Canvin, 2011: 136). The point is that nurse researchers need to be flexible throughout the recruitment process, and conscious of how their persona might influence a person's decision to participate.

Finally, it is increasingly important that researchers get the balance right between the needs of the study and participants. The creation of national targets and initiatives to encourage participation in dementia research, whilst laudable, can mean that the needs and circumstances of individual participants are at risk of being overlooked, as researchers strive to reach targets. In our view, a conscious focus on personalised and responsible recruitment practices is one way of mitigating this potential risk, and of ensuring that participation in research is a desirable outcome for participants, as well as researchers. Codes of conduct to help guide researchers through the recruitment process, and indeed other aspects of the research process (e.g. Department of Health, 2005) are a useful starting point in developing recruitment strategies In addition, we suggest that the research process should also emphasise the importance of the context of recruitment, the relationship between researcher and participant and a sensitivity to individual needs and expectations on the part of all researchers, regardless of research domain and level.

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