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SHORT COMMUNICATION

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ABSTRACT

Dementia is the leading chronic disease which causes disability and dependence among older people. While dementia research is a priority, there are many barriers to engagement and participation in research for people with dementia. Stigma may cause an unwillingness for people to seek evaluation or participate in clinical trials. People with dementia tend to be excluded from research, affecting generalizability of findings. There is an emphasis on the medical model, reducing the person with dementia to neurobiology and neuropsychology with a need to explore the experiences and psychosocial context of individuals. Researchers may also need to negotiate multiple layers, including 'gate-keepers', family members or carers. Culturally and linguistically diverse (CALD) people with dementia also tend to be excluded from research participation. It is hoped that an understanding of these barriers will lead to active consideration by researchers to improve involvement of people with dementia in planning and execution of research.

Keywords: Dementia, Gatekeepers, Participation, Research

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INTRODUCTION

Dementia is a progressive condition, leading to impairment in memory, behaviour and cognition. Dementia has widespread implications, including psychological and economic costs, affecting the individual, family and caregivers and is the leading chronic disease contributing to disability and dependence among older people [1]. A Global action plan on the public health response to dementia 2017-2025 was launched to guide countries on the urgent action that should be taken to manage this crisis [2]. However, it is important to ensure that these steps are evidence-based, which requires quality research.

A global research prioritisation exercise was performed, where 863 research questions from 201 participants were consolidated into 59 themes, and prioritised through anonymous scoring by 162 researchers and stakeholders from 39 countries [3]. The top research priorities relate to prevention, identification, and reduction of dementia risk; and on delivery and quality of care for people with dementia and their caregivers. Other priorities include diagnosis, biomarkers, treatment development, basic research into disease mechanisms, and public awareness and understanding of dementia.

Although there is a demand for more dementia research internationally, there are multiple barriers to participation and engagement of

people with dementia in research. In this review, these barriers are outlined so that researchers in dementia may proactively consider them and implement measures to ameliorate them.

Stigma in dementia and participation rights

Stigma is defined as “an attribute, behavior, or reputation which is socially discrediting in a particular way. It causes an individual to be mentally classified by others in an undesirable, rejected stereotype rather than in an accepted, normal one” [4]. It promotes social exclusion, causing reluctance to participate in community activities or seek help. A worldwide survey of people with dementia and caregivers found that a quarter conceal their diagnosis, while 40% received negative treatment including loss of friends after diagnosis due to stigma [5]. Stigma impacts dementia research in multiple ways. Identifying research participants will be difficult if people are unwilling to seek evaluation of stigmatising symptoms or learn about opportunities to participate in clinical studies. It also causes unwillingness to enroll in clinical trials or persevere after assignment to treatment groups, affecting participant retention [6].

People with dementia also tend to be excluded from research, which may affect utility of study findings or generalisability of outcomes to the evidence-base for older people. A structured review of 434 original research articles

published over a 2-year period in an international geriatric medicine journal found that 29% of researchers explicitly exclude individuals with cognitive impairment from participation, with very few (6%) providing justification for exclusion criteria [7]. A review of people with dementia eligible for and willing to participate in dementia intervention studies found that 26% of people with Alzheimer's disease attending memory clinics or receiving medications for dementia were eligible for the drug trials, while 43% of eligible people agreed to participate [8]. This suggests that only 11% of people with dementia would take part in drug trials if approached. There was also a bias towards including younger people (5 year difference between recruited participants and not recruited), men and those with more education for eligibility into drug trials.

If this data is extrapolated to the United Kingdom (UK) with a national target of recruiting 10% with a dementia diagnosis to research; if only one in 10 people with Alzheimer's disease or taking donepezil would take part in drug trials if approached, this target would only be achieved through a nationwide policy of asking all people with dementia and their carers to participate in research [8].

Recruitment rates are also variable, depending on perceptions of risk, benefits and exclusion criteria. A research team which conducted five studies on drug treatment for dementia analysed their recruitment rates, which varied widely from

1% to 80% [9]. Pharmacological studies tend to have lower recruitment rates, which may be due in part to their exclusion criteria. When older people from the longitudinal study on Aging and Dementia in Stockholm were surveyed regarding their participation in the study, majority (80%) had a positive attitude [10]. However, those with cognitive impairment had the least positive attitude, reporting the first contact and cognitive testing as the most stressful situations. They also often refused parts of the clinical examination. The authors of the review recommended more attention is necessary to the initial contact; reducing stressful or tiring examinations; and providing complete information about the research protocol, including the right to refuse individual parts of the study.

Nature of Dementia as a Disease

From a researcher's perspective, dementia has several inherent characteristics that challenge traditional validated, analytic approaches. Dementia can be caused by distinct underlying brain pathology, which lead to similar clinical manifestations. The disease process may precede signs and symptoms, occurring insidiously over years or decades. Causes and determinants of dementia and severity of disease are usually multifactorial [11].

In terms of the research protocol, participant selection issues may occur due to differential enrolment and survival rates of dementia

subtypes. It is also difficult to identify reliable measurements to link pathophysiology and clinical or research measures. For example, neuropsychological tests do not accurately reflect brain capacity and function, while measures of severity and progression utilises crude measures such as functional dependence and neuropsychiatric symptoms. As pathological changes begin at least two decades before clinical dementia can be diagnosed, assessing the impact of exposures or protective factors is difficult [12].

There is also development of high dimensional data, such as new brain imaging modalities and biomarkers, which researchers need to acquaint with in order to take advantage of these tools.

Dementia research tends to emphasise the medical model, reducing the person with dementia to neurobiology and neuropsychology. The experience and manifestation of dementia was focused on the disease process, ignoring the psychosocial context surrounding the individual. The majority of published and government funded dementia research are quantitative in nature, while research on psychosocial aspects of dementia also concentrated on family carers [13].

There needs to be renewed focus on the person with dementia, particularly the individual's sense of self; the person's rights; and the value gained from perspectives of people with dementia [14].

Ethical Considerations

Recruitment may be problematic due to stigma, participation costs, limited access to research and language barriers [13]. After participants register their interest, it may be difficult to determine capacity for informed consent, engage participants in effective communication, and ensure credibility of data from people with dementia [15]. Details regarding consent for research in dementia are discussed in another paper [16].

When research goes through ethics committees, the principles of respect, autonomy, non-maleficence, beneficence and justice are emphasised.

Researchers are required to pay attention to moral values in a conflict-laden situation, acknowledge ethical principles involved and be aware of their role in the situation. This moral sensitivity is required when assessing a person's capacity to give consent and when informing participants about the dementia focus in research.

When researchers are involved in daily cares, these are intimate situations, which may be viewed as an invasion of privacy. Participants may also divulge sensitive or inappropriate personal or financial details during interviews. In this example, it is important to take care of how and what results are reported to respect participants [17].

'Gatekeepers'

'Gate-keepers' are usually involved to ensure that benefits of participation outweigh the risks in dementia research. Researchers already have to negotiate multiple layers, such as ethics committees, practitioners and family members or carers. Gatekeepers, such as family members or carers may be actively involved in the research to contribute insights into the experiences of people with dementia. However, they may have vested interest in convincing a person with dementia to participate, especially when there are possible benefits for themselves. For example, when interviewing people with dementia in the presence of spouses, the spouses often acted as spokespersons [18]. Although they usually support the person with dementia to make their own decision, occasionally they tried to convince hesitant spouses to continue in the study. While such discussions may be common between couples, this raises questions regarding the voluntary nature of participation by the person with dementia.

However, researchers' perspectives on the role of study partners in dementia research were generally positive, as they helped facilitate research enrolment and post-enrolment decisions, served as knowledgeable informants for participants, managed logistics enabling participants to comply with study protocols, and

provided comfort and encouragement for a person to engage in and complete a study [19]. For people in residential care, recruitment may be supported or hindered by staff managing the facility. This is affected by the residential home culture, staff understanding of how people with dementia can be involved in research, and how they interpret their roles as mediators, protectors and gatekeepers [20]. Generally, there is a basis to the supporting protocols, which enable access to personal information in certain circumstances without the consent of the individual for research. However, due to ambiguity in legislation and conditions relating to disclosure, professional guidance and formal protocols are required across the whole range of social care providers [21].

In a study which attempted a survey of residents in nursing homes, 46 (31.0%) out of 148 homes refused access to researchers [22]. The most common reason given was that 'residents would not be interested', leading authors to question whether over-protective gatekeeping was denying residents their right to participate in research. Similar challenges were encountered in the CASCADE (Choices, Attitudes, and Strategies for Care of Advanced Dementia at the End-of-Life) study, which was a prospective cohort study of nursing residents with advanced dementia and their health care proxies [23]. Barriers that arose in the study included perceptions that the study would occupy too

much staff time, instabilities in nursing home management, screening large nursing homes for residents with advanced dementia, engaging busy nurses for interviews and keeping track of follow-up assessments. Strategies employed by the CASCADE researchers to circumvent challenges include selecting nursing homes with prior track records of conducting research with computerised minimum data set assessments, seeking support and endorsement from nursing home staff and administrators, as well as minimising nursing home staff involvement in data collection.

Culturally and linguistically diverse (CALD) people with dementia

It is appropriate to provide special mention to minority groups that tends to be excluded from research participation: culturally and linguistically diverse (CALD) people with dementia. Barriers affecting participation of racial and ethnic minorities in dementia-related research can be classified into several groups [24]. At the individual level, a person may underestimate their ability to effect change through research participation. This may be due to low levels of awareness or self-efficacy, embarrassment regarding their current circumstances or fear of stigmatisation. Socio-cultural factors refer to the differences in disease-treatment-rehabilitation paradigms due to language, culture, socio-historical and minority group status factors. Economic barriers

include financial and transaction costs due to participation, including fears of having benefits or entitlements discontinued. Scientific processes may also result in exclusion of certain subpopulations, which compromises social justice or redistributive goals. Administrative issues may also result in overly cautious practices leading to delays in inclusion of CALD people, such as limited pools of ethnically and culturally competent investigators or staff.

A study of Chinese people living in Boston looked at how culturally shaped conceptions of health, aging and dementia impacted research recruitment [25]. Dementia changes were assumed to be the normal part of aging rather than a disease, making it difficult to identify people affected by dementia. Research participation was also viewed as potentially harmful as it can lead to excessive worry. Stigma caused families to avoid formal diagnosis and research participation. Practitioners also viewed dementia research as an intrusion, without offering direct benefits to participants. In another study, a variety of approaches were used to recruit Chinese participants from memory clinics. The researchers had to give lectures to local healthcare providers and community members, participated in community events and distributed publications via mass media to achieve an 88% annual follow-up rate [26].

Another study compared the effectiveness of three recruitment modalities (media, non-

professional referrals or professional referrals) to enroll Chinese-American and white family caregivers into dementia research [27]. Response rate was lower for Chinese Americans than whites, (39% vs 50%) and were less likely to be recruited through non-professional sources compared to media or professional referrals. A consumer-oriented approach, which included direct face-to-face contact with key community leaders, generated the highest number of Chinese-American participants. Culture-specific factors such as trust-building with social service agencies, demonstrating genuine commitment to the well-being of the target community, and linguistic and ethnic matching between research staff and potential participants were also useful to improve recruitment [28].

There are several differences between caregiver attitudes towards family members' participation in dementia research between white and African-American people. Among white caregivers, primary barriers to participation included: potential for no direct benefit, problems with procedures and tests involved, lack of time and resources, and difficulty accepting diagnosis of dementia. Among African-American caregivers, primary barriers included: general skepticism about the research process and firmly established attitudes about medical treatment and help seeking that serve as disincentives to research

participation. In order to improve participation, caregivers required access to regular staff contact, information about health status changes in the care recipient, and short-term and long-term results of the research they participated in. The main obstacles cited by older African-Americans were expenses, transportation difficulties and lack of rapport with clinic staff. By setting up a good community referral network, offering community education about dementia as well as professional staff sensitive to cultural needs, a group of researchers managed to double the proportion of African-American subjects enrolled in their study [29].

For the Latin-American population, there is heterogeneity with significant intra-group diversity. Generally, stigma regarding mental illness and help-seeking resulted in low utilisation of mental health services, such as dementia diagnostic centres, adult day care programmes and community support groups. Misconceptions of dementia as a mental rather than physical illness, language barriers and time constraints also limit their participation in research [30]. For Latin-Americans, it was essential to hire bilingual or bicultural staff in key positions, ensuring outreach and advertising materials were culturally appropriate and using conceptual rather than literal translations of assessment, recruitment and intervention instruments. In a dementia intervention trial,

Caucasians were more likely to be successfully retained across all recruitment strategies compared to Latin-Americans (52% vs 31% respectively) [31]. Partnerships with community agencies and spending time building rapport in a culturally sensitive manner were essential recruitment.

Another minority group that tends to be marginalised are immigrants and refugees. A study was designed to explore how family members of immigrants and refugees caring for relatives with dementia receive information from Swedish health care services. When established organisations were contacted to enroll eight ethnic groups from different countries, a very low recruitment rate was identified. Participants responded that after consulting family members, they were advised not to participate for safety or security reasons. Reported fears include deportation of family

members back to their home country or being forced into nursing homes, which would isolate their family members. For those who have fled from other countries, suspicion and insecurity may limit participation. Further research is required to assess how best to include them in research [32].

CONCLUSION

It is the right of people with dementia to participate in opportunities available in the community, including research. There are many barriers limiting participation and engagement of people with dementia in research which should be actively considered to improve involvement of people with dementia in planning and execution of research.

Conflict of Interest

The author has no conflicts of interests to declare.

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