

Perceptions of people living with dementia regarding patient-centred aspects of their care and caregiver support

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Abstract

Objective: This study examined the perceptions of a sample of Australian people living with dementia regarding the person-centred care and support they received from health professionals and family.

Methods: Community-dwelling people living with dementia were invited to complete a cross-sectional survey.

Results: Seventy-one people participated in the study. More than 90% agreed that health professionals explain who they are, why they are seeing them and listen to what they have to say; 63% agreed that health professionals ask how they would like to be involved in decisions about treatment; 78% agreed health professionals mainly speak to them rather than anyone accompanying them; 76% reported their family 'support you to do tasks by yourself', and 36% indicated that family caregivers 'get frustrated with you'.

Conclusions: Results suggest that people living with dementia have a positive perception of the care and support they receive. Improvements may be needed in how health professionals speak directly to the person living with dementia when exploring how they would like to be involved in treatment decisions. Family caregivers may benefit from education and support on how they can manage frustrations and assist the person they support to maintain their independence.

KEYWORDS

Alzheimer's disease, caregivers, dementia, patient-centred care, quality of healthcare

1 | INTRODUCTION

Most people living with dementia live in the community and are supported by family caregivers.¹ People living with dementia also frequently access health care services to meet their complex health needs.^{2,3} Therefore, the support needed to meet the needs of people living with dementia may come from both healthcare professionals as well as family caregivers.

It is important, where possible, to seek the views of those living with dementia in order to gain an understanding of how person-centred care and support is experienced.⁴ Qualitative studies indicate that interpersonal aspects of person-centred care are valued by people living with dementia.^{5,6} One study revealed that people living with dementia value the following from community aged care services: feeling as though they were collaborating in determining what services they would receive; having

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their needs understood; being encouraged to interact with their service providers; being listened to and the verbal and non-verbal communication of service providers.⁵ Another study found that aged care facility residents with cognitive impairment equated quality of care with connection with family and being given choice and freedom, feeling valued and useful, engaging in meaningful activities, and being shown respect for possessions and personal space.⁶

Family members often provide direct hands-on care as well as liaising with services that provide care needed by the person living with dementia.⁷ To our knowledge there has been no quantitative examination of the views of people living with dementia in the community regarding the person-centred care and support received from family members and health professionals.

1.1 | Aims

To explore, among a sample of community dwelling people living with dementia their perceptions of quality of person-centred care and support from: (a) health professionals, and (b) family.

2 | METHODS

2.1 | Design

A cross-sectional survey of people living with dementia. Research ethics approvals were obtained from the Hunter New England Health (16/05/18/4.05; 17/07/19/4.06; 180,718/4.06) and the University of Newcastle (H-2018-0308) Human Research Ethics Committees. Data collection took place between July 2018 and June 2020.

2.2 | Participants

Eligible participants were aged 18 or older, able to read and write in English, living in the community and diagnosed with any type of dementia by a medical professional. Those who did not have capacity to provide independent consent were excluded.

2.3 | Recruitment and data collection

Participants were identified from geriatrician clinics, respite centres, community aged care service providers and support groups and mailed a survey pack consisting of a survey, study information and reply-paid envelope to

Practice Impact

Many people living with dementia report not being involved in their own healthcare or supported to do things for themselves. There is a need for education of health professionals and carers about how to support people with dementia to be actively involved in day-to-day activities and health care decisions.

return surveys to the research team. Completion of the survey was taken as implied consent. Four questions, adapted from the University of California, San Diego Brief Assessment of Capacity to Consent (UBACC), were presented at the start of the survey.⁸ The questions were used to assess the participants' understanding of the purpose of the research and its risks and benefits. Those who answered fewer than three out of four questions correctly were excluded from the research. Where available, carers were asked to complete questions on the type of dementia and time since diagnosis.

2.4 | Measures

Survey questions were developed based on the literature on support preferences and experiences of people living with dementia reported through semi-structured phone interviews (eight people) and focus groups (two people). Items were refined by a working group consisting of behavioural scientists, clinicians working in aged care, a statistician, carers and a person living with dementia. Survey questions had a Grade 4–6 reading age and were pilot tested by 31 people living with dementia.

2.4.1 | Sociodemographic characteristics

Participants self-reported their age, gender, living arrangements and whether they had any of the following health conditions: heart disease, lung disease, back pain, cancer, diabetes, arthritis, mental health condition and/or other.

2.4.2 | Quality of health professional care

Participants were asked eight yes/no questions about the quality of support they received from health professionals. The questions commenced with the stem, 'During your appointments with health care professionals, do they...?'

2.4.3 | Quality of family support

Participants were asked 10 yes/no questions about the quality of support received from family. The questions began with the stem, 'Does your family often...?'

2.5 | Statistical analysis

Counts and percentages for responses were calculated for each variable. Results were presented as in tabular or graph format. Data analysis was completed in Stata v11.⁹

3 | RESULTS

Of the 316 survey packs distributed, 112 (35%) were returned completed. Of those who completed a survey, 71 (63%) were included in the analysis. Four were excluded due to living in a residential aged care facility, 13 due to missing the UBACC questions or scoring less than 3 and 24 because they did not complete the questions on family and professional support. Most participants were aged 75 to 85 years (57%; mean age = 79; SD = 7.9), were male (61%), and lived with their partner or spouse (85% compared with 7% who lived alone and 8% who lived with their child or grandchild). Seventy-five percent reported having other chronic health conditions. Most participants were reported by carers as having Alzheimer's disease (47%) and being diagnosed less than 3 years ago (62%).

More than 90% of respondents agreed with five of the statements (Figure 1). In contrast, only 78% indicated that healthcare professionals mainly spoke to them rather than others accompanying them to the appointment,

while 63% agreed that health professionals asked how they would like to be involved in decisions about their treatment.

More than 90% of respondents agreed that their family members often 'showed affection towards them', 'spoke to them with respect' and 'listened to what they have to say' (Figure 2). Only 76% reported that their family 'supported them to do tasks by themselves', and 36% agreed that family caregivers 'got frustrated with them'.

4 | DISCUSSION

Our study is one of the first to attempt to quantitatively assess the care and support received from family and healthcare professionals from the perspective of people living with dementia. Encouragingly, the single negatively framed item about whether family caregivers 'get frustrated with you' showed a much lower percentage of affirmative responses, suggesting that respondents differentiated between the positively and negatively framed items. In line with other findings,⁴ our results suggest that those who can complete the UBACC satisfactorily are able to provide insights into their care experiences.

Results were positive with most participants reporting that they received each of the indicators of person-centred care and support. The two lowest scoring indicators were still endorsed as being received by the majority of participants: 'mainly speak to you rather than anyone accompanying you' (78%), and 'ask you how involved you would like to be in making decisions about treatment' (67%). Literature on the interactions between doctors and older patients suggests that it is common for healthcare providers to seek information from the

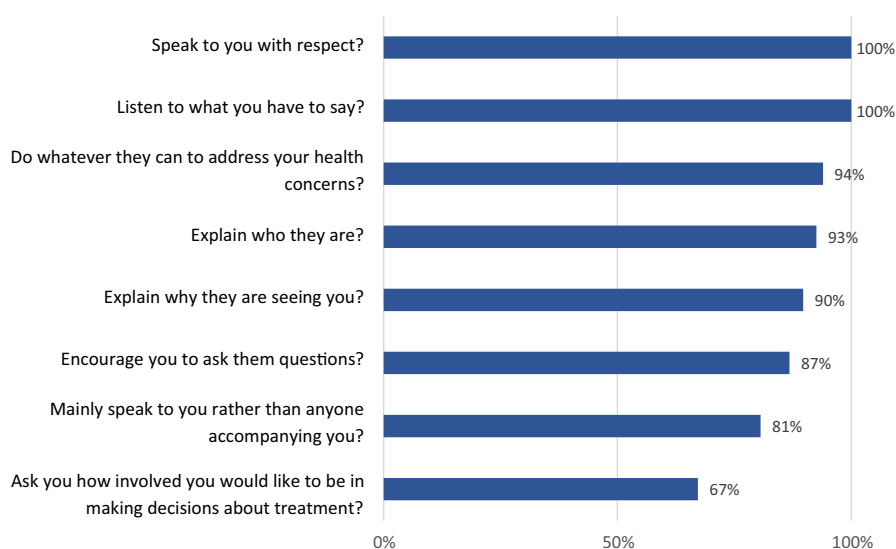


FIGURE 1 Percentage of respondents agreeing with statements about care provided by health professionals.



FIGURE 2 Percentage of respondents agreeing with statements about care provided by family members.

accompanying family member rather than from the patient.¹⁰ Our results suggest that participants in our study value involvement in decisions about their care. Reviews of shared decision-making suggest a range of ways that people living with dementia could be involved in care decisions, ranging from complete involvement, consideration of prior preferences and reliance on caregivers to make decisions.^{11,12}

Just over a third of participants perceived that their family got frustrated with them. These perceived frustrations may reflect a variety of factors including the family members' own difficulty in balancing their needs with those of the care recipient, as well as adjusting to changes in the person living with dementia and their relationship with them.¹³ Caregiver strain can negatively impact family members' quality of life,¹⁴ which in turn may impact on the quality of support that they are able to provide to the person living with dementia.¹⁵ This highlights the importance of providing practical and emotional support to caregivers not only to preserve their quality of life, but to support the caregiver-care recipient relationship.

Only 76% of respondents perceived that their family supported them to do things themselves such as cooking, cleaning or going to the shops. People living with dementia value being able to participate in meaningful activities.^{6,16} Structured training sessions may assist people living with dementia to maintain activities of daily living.^{17,18} People living with dementia should be given access to those types of interventions, and caregivers provided with support and education in how to encourage and support continued participation in such activities.

4.1 | Future research

Future research could establish whether our findings can be replicated with a larger and more representative sample of people living with dementia. It would also be useful to examine the correlates of positive perceptions of person-centred care and carer support. This could include exploration of factors such as training and support received by family caregivers, as well as healthcare provider knowledge related to dementia and confidence in providing care to people living with dementia. The perceptions of people living with dementia could also be compared to caregivers' perceptions of person-centred care and observational measures. This type of research may help elucidate the factors that underlie person-centred care and carer support.

4.2 | Limitation

Our sample size was relatively small and response bias is likely to have affected the generalisability of the results. Further, as our study included only people who were able to complete three out of four of the modified UBACC questions correctly, results are unlikely to be generalisable to those with more severe dementia.

5 | CONCLUSIONS

Our study suggests that community-dwelling people living with dementia perceive that they receive person-centred

care from health professionals and support from their carers. Areas for improvement include health professionals asking questions directly of the person living with dementia and asking how they would like to be involved in decisions about their treatment. The relationship between people living with dementia and their carers may be improved by encouraging and supporting daily living activities in the person living with dementia.

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CONFLICTS OF INTEREST

No conflicts of interest declared.

DATA AVAILABILITY STATEMENT

De-identified data are available upon request from the authors. Any use of the data will need ethics approval from the University of Newcastle Human Research Ethics Committee.

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