

RESEARCH

The experience of paramedics providing care to people living with dementia: Working with uncertainty

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Abstract

Paramedics are key to the provision of emergency care in the community. Those living with dementia use paramedic services at a high rate, due to a range of issues related to comorbid conditions and other acute events which mean care cannot continue in the home. There is a paucity of literature related to care provided in such instances. Anecdotally, a perception exists that providing care to this group of people is challenging for paramedics in situations where high level assessment and emergency care are paramount.

Paramedics in one Australian state were sought to participate in an exploratory study to enhance understanding of how they currently worked with people who lived in the community and had dementia. Sixteen participants were recruited to the study, and they worked in a number of areas, including urban and rural. Experience was broad, ranging from one to 36 years in the paramedic role. Inductive thematic analysis of interviews revealed key themes that framed the paramedic role and permeated interactions, assessment and decision-making.

Paramedics participating in this study recognised people living with dementia who had high level impacts of the condition, suggesting those with less visible symptoms may remain hidden. With the projected increase of people diagnosed with dementia it is imperative that paramedics are aware of, and integrate dementia knowledge, skills and confidence into their practice. Deeper exploration of the area that includes volunteer ambulance personnel and further inquiry of the role of paramedics in relation to those living with dementia is needed. A focus on education and professional development to equip paramedics to work with people living with dementia is recommended. The findings suggest that greater work in this area is required.

Keywords

community; dementia; paramedic

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INTRODUCTION

Dementia is an umbrella term describing a syndrome where a range of diseases affecting the brain lead to cognitive and physical decline. The prevalence of dementia is growing; it is now the second leading cause of death in Australia (1) and estimates suggest the global prevalence of dementia may increase from 57.4 million in 2019 to over 150 million in 2050.(2) People with dementia live with increasing requirements for support from health and social care providers to manage cognitive, physical and social impacts. There is no known cure, and effects are far-reaching for the individual, friends and family, and the community as a whole.(3) Although many people living with dementia face challenges leading to supported living or residential

aged care, current Australian data suggest between 60% and 70% of people living with dementia are community dwelling, and 20% live alone.(4) In this paper we define community dwelling as living in any accommodation outside residential aged care, which may include retirement villages or shared housing. People living with dementia in the community are an important stakeholder group for paramedics, intersecting with paramedic services at higher rates than other groups due to frailty, comorbid conditions and complex care needs.(5) There is a range of reasons for seeking paramedic attendance, including acute illness, falls, delirium or other health impacts of dementia.(5)

Complex presentations, such as those experienced by people living with dementia, are arguably not best

managed by the current model of on-scene treatment followed by transport to medical care. This model has emerged from the military models which historically informed paramedic practice in Australia.(6,7) Although there has been some paramedic research related to people living with dementia in residential aged care (8) and community settings,(9) the orientation of research and practice change have focused on hospital avoidance and the role of paramedics in transfer to acute care. Such focus is based on knowledge that entry to acute care settings for older people, and particularly older people living with dementia is associated with increased risk of distress, falls, pharmaceutical errors, development of pressure injuries and in extreme cases death.(10)

Little is known about paramedic services provided to community dwelling people living with dementia. Transfer of information related to the person is important in aged care settings and is known to impact care provision, decisions to transfer and assessment capacity of paramedics.(11) We would suggest that in the community, provision of information about a diagnosis and the impact of dementia for that person is equally important to assist with decision-making and management,(12) but that this information is often unavailable. Adding to complexity is that unlike aged care where handover to paramedics is provided by other health professionals, in the community the history is provided by the person, or an advocate, with the potential to miss vital information. Little is known about the interface of care, the knowledge or skills utilised by paramedics during such interactions, or any ongoing needs for education or resources, particularly in the Australasian context.(13)

The study objective was to examine these identified gaps in knowledge by answering the following research question:

What are the perspectives and experiences of paramedics providing care to people living with dementia in community settings?

METHODS

An exploratory descriptive study methodology was used to explore the perspectives of paramedics from one Australian state, with a focus on paramedic experience with community dwelling people living with dementia, within the context of paramedic work. Such an approach is an effective method to uncover participant experiences and perceptions of the phenomena under investigation (14) and is particularly pertinent when little is known about the area.

Procedures

Information about the study and an invitation to participate was distributed via Paramedics Australia (now known as the Australasian College of Paramedicine), the peak professional organisation for paramedics. Inclusion criteria included registration with the Australian Health Practitioner Regulation Agency (AHPRA) and current work in the service. Passive

snowball sampling was added to increase participation: three members of the research team were active in the area and distributed information to contacts with an invitation to share with others. People who were interested in participation contacted one of two members of the research team and arranged to participate in a semi-structured interview. Interviews in person, via video link or phone were offered to all to facilitate inclusion. Data were collected to the point where the research team were satisfied there were sufficiently rich data to answer the study's question.

An interview protocol was developed that broadly outlined semi-structured questions with prompts (see examples in Table 1). Interviews were conducted from June to October 2019. Audio recording was followed by verbatim transcription and subsequent analysis.

Table 1. Semi-structured interview guide: sample questions

Topic	Sample questions
Introduction	Tell me about the area you usually work in. Can you tell me what you understand by the term dementia?
Experience working with people living with dementia	Can you tell me about the experiences you have had working with people with dementia living at home, in your role as a paramedic?
Education	What kind of training or education opportunities have you had, relating to working with people living with dementia?

Data analysis

Inductive analysis guided by Braun and Clark's (15) six step process for thematic analysis was used. Initially researchers became familiar with the data, then generated codes. Eight of the interview transcripts were coded independently by two researchers, who each identified and labelled basic segments of raw data that could be considered relevant to the phenomena of interest. The two researchers then discussed and refined codes through comparison. One researcher coded the remaining eight transcripts. Codes were then collapsed into broader themes. Review and further interrogation of themes was via critical conversations by the whole research team. Identified relationships between codes and themes resulted in the final analysis.

Rigour and trustworthiness

We were guided by the consolidated criteria for reporting qualitative research (COREQ) checklist to support the transparency of our reporting,(16) enabling readers to evaluate the rigour and trustworthiness of our work. Reflexivity acknowledges the influence of researchers in analysing and shaping qualitative data, and specifying the backgrounds of the research team promotes quality by strengthening the auditability of a project.(17) In this study, interviews were conducted by a dementia education researcher and a clinician researcher (physiotherapist) from the research team. There are both advantages and disadvantages to utilising peer interviews (18) in studies such as this. In a small state where the paramedic research team members may have known respondents, interviews

were conducted by other team members to protect identity, and to ensure open conversations. It has been recognised that researchers without the same professional background can employ a naivety which may facilitate more detailed conversations about the topic.(19) The wider team who undertook analysis included researchers with experience in a range of methodologies focused on dementia research and included one paramedic. The following practices also supported the rigour and trustworthiness of findings: audio recording and transcription of semi-structured interviews,(20) member checking,(20) thick, rich description of data using direct quotes from participants,(17) and provision of a detailed description of the participants and setting.(17)

Ethics

Ethical approval was provided by the Tasmanian Social Sciences Human Research Ethics Committee in line with NHMRC guidelines in June 2019.

RESULTS

Sixteen paramedics (eight female, eight male) from one Australian state agreed to participate in the study. Paramedic experience varied, with a mean of 15 years, and ranged from less than one year to 36 years. Participants' mean age was 42 years (range 28–61 years). Five paramedics had completed postgraduate education and 11 held a degree or advanced diploma. In presentation of results the participants are identified by a code, as a strategy to preserve confidentiality. Participants were representative of all areas of the state which included urban and rural areas. One interview was undertaken by phone and 15 were conducted face to face. Mean interview time was 52 minutes (23–90 minutes).

Analysis of the interviews generated four key themes: framing the role; interactions and response to people living with dementia; uncertainty in assessment findings; and complexity of clinical decision-making.

Framing the role

The requirement for registration is a recent development for paramedicine in Australia and responses were underpinned by knowledge that the role was changing. Initially several participants identified regulatory change that they perceived as impacting practice:

I think since registration happened this year there's going to be much more push on people to make these better decisions ... So that's a huge change. Before you were an employee, now you're a health professional. (P7)

Participants also directly addressed the impact of changing population needs, and reasons paramedics attend people's homes:

I think the days of big traumas and time critical medical conditions are gone because they're managed so well in the community with

medications and stuff like that, a lot of what we're seeing now is those chronic conditions and in an ageing population, a lot of it is mental health in the elderly, dementia/delirium type presentations, all those sorts of things. (P10)

Interactions and response to people living with dementia

The changing landscape of paramedic practice was evidenced as participants explored their interactions with people living with dementia. When asked to consider how often they might provide care to people living with dementia in the community, paramedic responses varied from reporting frequent engagement:

I would say at least every two days. Normally, at least once a day, if not more. (P5)

to considering such interactions as rare:

It's just highly variable, when was the last time? I don't know – it might have been a year or two but then maybe you get a spate of three people in a month or four people. (P2)

Reasons for paramedic attendance were reported as varied; for some the need for paramedic services was not directly related to the diagnosis of dementia:

We don't necessarily go to a lot of patients because of their dementia, we do go to quite a number of patients with dementia. But they might have a chest infection or something. (P12)

One participant described how consideration of the presence of dementia might emerge:

So we knock on the door, we only know that we're called because they're having trouble breathing or because they're having chest pain or they've fallen and they need help getting up or whatever it is ... that's all we know ... so if you go to an older person who lives at home alone and they've fallen over and they're not making a lot of sense, you just don't know [if they have dementia]. (P3)

It was not unusual for paramedics to be called because of aggression, or increasing distress for the person living with dementia or their family:

just before they are going into a nursing home ... so that's why we get called, which is a shame. So, we often get people who are very confused, more often agitated, sometimes violent. Yes, I'd say that would be the majority. (P15)

As paramedics considered their interactions and understanding of the frequency with which they provided support to people living with dementia, aspects of assessment were considered, and again were impacted by uncertainty.

Uncertainty in assessment findings

If paramedics were uncertain about a diagnosis in the community, they relied on their own assessment, often linking dementia with the differential diagnosis of delirium:

If there is somebody who is presenting as slightly vague or confused as a way of trying to find out – we often ask family members, ‘what is normal for this person?’ (P9)

thinking is it more of a dementia type process or is it that more acute delirium type presentation that’s happening there and then getting the history of the events in the past twelve months or the past week or something to try and differentiate between the two. (P10)

Uncertainty regarding a dementia diagnosis was also noted in the recognition that a dementia diagnosis may not be openly disclosed:

We’re 100% reliant on what people tell us, what information they might have on pages from their doctor, and what medications they’re on ... And people maybe: (a) do not want to tell you; or (b) can’t tell you, they might not understand themselves. But for me dementia really falls into that category of medical conditions that people aren’t as comfortable sharing, whether it’s because of lack of knowledge or because of this shame or whatever it is. (P3)

A further participant reflected on the communication required, and difficulty asking about an existing diagnosis:

Yes. It’s harder though to ask people in the community [about dementia diagnosis] because, as I said, some people don’t know [they have dementia] or don’t want to know or don’t want to talk about it. You just have to do it gently I suppose. (P9)

Paramedics needed to make decisions regarding transport to acute care and often based this on understandings of individual wishes and what was in the person’s interests.

Complexity of clinical decision-making

One participant claimed that

most paramedics are like, ‘Do I need to take you to hospital or not?’ and ‘what am I going to do?’ (P9)

An absence of clear guidelines in relation to those living with dementia complicated all decisions:

Paramedics by nature are quite protocol driven, so we have clear practice guidelines, which theoretically govern everything we do. But

unfortunately ... there is no guideline for dealing with a dementia patient. (P1)

The previously discussed uncertainty regarding disclosure of dementia also impacted on transport decisions. Participants related that it was not up to them to diagnose and there was no process to support that.

in terms of diagnosing dementia and stuff, I don’t think we have any sort of processes or anything like that, although I guess it’s about us assessing regardless of the cause, dementia/delirium ... it’s about assessing their safety at home and assessing how their family are coping and whether they need a follow-up with a GP ... or if we think that they’re not safe at home at that point in time, then they need to be transported to hospital. (P10)

At other times, a sense of hopelessness pervaded responses where one participant describes no option but to transport:

When you’re with a patient with dementia, I mean what do you do? Especially after hours, you’re not confident to leave them at home, because you don’t have the education, the training, there’s no support with your decision-making, there’s no guideline that tells you what to do. So, the tendency will be we’ll just transport them. (P1)

Feelings of uncertainty and hopelessness were framed by concerns about what was best for the person, and knowledge that the acute care sector is not the best place for a person with dementia.

In terms of, I guess acute delirium or advanced dementia, and if they have had a significant decline in a short amount of time is the patients that become quite agitated and aggressive as a result of it. That’s probably where it can get quite complicated. Thinking about if you’re having to go down the pathway of sedating and restraining elderly people ... that can be quite complex as they’re quite reluctant and that’s something I probably don’t feel confident with is that agitated dementia patient or the agitated delirium patient because sedating an elderly patient with a medication that has a lot of side effects is quite a serious thing to do. Restraining them is quite a serious thing to do and something that we try and avoid if we can, so that can be quite complicated. (P10)

Participants also related concern about ethical framing of care and the notion of capacity that also contributed to uncertainty, knowing they should transport but also knowing the person may decline to be transported:

At a certain point, you have got to – especially people with dementia. You have got to assess their capacity. Do they have the capacity to

consent for this stuff? If they don't have the capacity to consent, they also don't have the capacity to decline. So, if it is in their best interest, and there is a family member there, we can use our powers to say, 'We are going to take you to hospital.' We will do it very nicely. And we also have the option of we do have some medications we can give for agitated patients. So, those things, given the right situation, we can always apply. (P5)

DISCUSSION

Paramedic participants in this study shared their experiences of interactions with people living with dementia in the community. The study adds to an emerging body of work considering how paramedics respond to, and work with people living with dementia in the community. Participants acknowledged the changing role of paramedicine and the experiences shared focused mainly on people who have higher-level impacts of dementia. Variation in how paramedics in this study recognise dementia in their practice might indicate some have awareness of providing care to people living with dementia, while for others it remains an invisible aspect. Findings suggest the presence of dementia is only acknowledged in the later stages and hence those living with dementia with fewer symptoms are likely to remain undetected. Stigma or shame may also result in non-disclosure and reduce capacity to deliver care adjustments oriented to those living with dementia. It is an area of study requiring greater exploration.

Paramedic attendance when people have been aggressive or distressed as a symptom of their dementia was described by participants in our study. This phenomenon has been reported previously by Buswell et al.(9) and described as a 'safety net' – calls that occur when the primary carer is exhausted or does not know what else to do. Paramedics in our study framed their responses based on the perceived safety of the person and others, at times negotiating to follow the family's wishes. As such they considered complex care needs, knowing that transport was not always in the person's best interests, particularly when restraint or sedation was required to facilitate transport.

Findings confirm historical influences still permeate current practice with key decisions framed by assessment and decisions to transport or otherwise. Paramedic practice is typically based on a medical emergency model of care with a linear process where assessment is required to decide action. In Australia, specific practice guidelines mandate scope of practice and standards of paramedic assessment and care.(21,22) Yet paramedics in this study reported an absence of practice guidelines specific to dementia to support decision-making. Despite being the second leading cause of death in Australia, dementia is referred to only once in the guidelines of the state where this study took place. A person's safety may be compromised when guidelines to support clinical care are lacking,

which has been found to be particularly evident regarding care of older adults with lower acuity of illness.(22) Unconscious bias among paramedics may also lead to negative discrimination towards people with cognitive impairment such as those living with dementia,(23) which may be mitigated by the use of practice guidelines. Further studies and direct engagement with paramedics should inform how to improve clinical guidelines and embed care of people living with dementia further. This may be through specific clinical practice guidelines such as those that exist for paediatrics or greater integration into existing areas. A study by Harris et al.(24) further highlights the underrepresentation of older adults in existing clinical practice guidelines.

Prior research highlights the need for further dementia education content for paramedics that focuses on medical aspects of presentation, but also includes communication, gaining consent from people with dementia, handover at entry to acute care, and working with carers at crisis point.(9,13,25) Buswell et al.(26) found in their integrated review that there is an urgency for ambulance services to specifically consider the needs of older people living with dementia. Further, it is also claimed that paramedics need to be equipped with person-centred skills, dementia knowledge and ethical frameworks to assist decision-making.(26) There was some evidence that ethical considerations, especially related to consent and capacity, contributed to uncertainty for the paramedics who participated in this study. However, in the interviews few spoke about their direct involvement with people living with dementia when seeking information or in the decision-making processes, deferring to their own assessment and input of others. Choonara and Williams (27) make a similar finding and highlight the opportunities that may exist to enhance communication between paramedics and people living with dementia whom they attend in order to improve care. This is in line with interdisciplinary findings regarding the impact of dementia knowledge and education on patient care and outcomes, in allied health professions, nursing and medicine.(28,29)

Limitations

This study took place in only one Australian state, however through use of qualitative research methods the data obtained are rich and the participants and setting have been described in detail to enhance transferability. The study was not able to include other ambulance personnel including volunteers who may also be responding to the needs of those living with dementia in the community. Different findings may have been reported to an interviewer who was a paramedic, however the research project has delivered some new data suggesting there are areas of further research to undertake. Studies that seek data from a range of respondents, including those living with dementia and their families, volunteer ambulance services, and from other geographical areas will extend knowledge in the area.

CONCLUSION

The purpose of this study was to explore the experiences and perceptions of paramedics as they engage with people who live with dementia in the community. The information presented in this paper provides insights that shed new light on an area that has received little attention. As the number of people living with dementia increases so will the need for all health professionals to have capacity to deliver services that consider cognitive impairment. Consideration should be given to greater inclusion of the impacts of living with dementia in practice guidelines, with a focus on the impact on communication, clinical assessment and decision-making, with additional education to support dementia specific knowledge, communication and ethics.

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COMPETING INTERESTS

The authors declare no competing interests. Each author of this paper has completed the ICMJE conflict of interest statement.

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