Australian Journal of DementiaCare Research Focus

This section aims to provide a channel of two-way communication between researchers and practitioners in the expanding field of social, psychological and nursing research in dementia care, including all aspects of nursing and care practice, communication and the environment.

The Research Focus section of the *Australian Journal of Dementia Care* aims to keep readers up to date with the fast expanding field of social, psychological and nursing research in dementia care. By this we mean every aspect of person-to-person communication, nursing and care practice and organisation, and the influence of all aspects of the environment. The aim is to provide a channel of two-way communication between researchers and practitioners, to ensure that research findings influence practice and that practitioners' concerns are fed into the research agenda. We would like to hear from you, specifically with:

- notice of the publication (recent or imminent) of peer reviewed papers with practical relevance to dementia care;
- research reports available for interested readers;
- requests or offers for sharing information and experience in particular fields of interest.

What's needed to stay at home together?

Claire Morrisby, Marina Ciccarelli, Annette Joosten and **Janet Beilby** discuss research which reveals a gap between what people with dementia and their partners living in the community say they need and what service providers think they need

Love, humour, patience and tolerance were key values identified by spousal carers when it came to providing support to their partners through the disease process. Photo: www.freepik.com/pvproductions

Older adults often identify staying at home as a priority (McGrath *et al* 2021). A diagnosis of dementia rarely changes that, but it does create challenges as the person with dementia requires increasing support to stay at home.

Support is most commonly provided by families, in particular, spouses, with formal care services supplementing this. Reports over the past decade have indicated "a need for services that meet [carer and people with dementia] needs rather than the needs of the service providers" (Alzheimer's Australia 2011 p8) and that most recently, "when they do get access to care, they may receive less care than they need or they may not have access to specific services they need" (Royal Commission into Aged Care Quality and Safety 2021b p65).

Information and access to respite services for people with dementia continue to not meet carers' needs (Phillipson *et al* 2019). Ongoing restrictions in funding and availability of appropriate home-based care, where services are provided, mean that people with dementia and carers still experience unmet needs. In addition, carers experience difficulties in recognising their own needs, and those of the person with dementia they care for which may limit service use (Morrisby *et al* 2018).

This article reports on a study published in 2020, (Morrisby *et al* 2020) which aimed to identify what carers of people with dementia, and the person with dementia themselves, perceive they need. It also sought to identify whether this aligned or differed with what service providers perceive they need.

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Background

Spousal carers often transition from their roles as 'husband and wife' to 'carer and person with dementia', as the carer becomes the primary decision maker (Braun *et al* 2009; Fetherstonhaugh *et al* 2016). Changes occur in intimacy, identity, and perceived role within the relationship. Recognition and understanding of the unique needs of spouses as they interact with community aged care services is important in developing effective services (Braun *et al* 2009).

Consumer-directed aged care potentially provides greater flexibility and person-centeredness in the delivery of care services for people with dementia (Low *et al* 2011). However, a lack of information about available care, poor quality services and carers' sense of obligation to provide care may act as barriers to accessing support (Macleod *et al* 2017).

The views of people with dementia have not often been included in research; however, their inclusion in qualitative research is important in developing personalised and responsive services (Braun *et al* 2009; Carmody *et al* 2015).

Research on dementia-specific services in Australia has considered the experiences of carers who use services, including reasons for this service use (or non-use), evaluating strategies to understand and meet the needs of carers and understanding information-seeking behaviours of carers (Aoun *et al* 2018; Brodaty *et al* 2005; O'Connell *et al* 2012; Phillipson *et al* 2019; Robinson *et al* 2012).

A broader discussion of the needs of people with dementia and their spousal carers is important in developing services and systems that will support couples living in the community. Service providers have a unique perspective when addressing needs because they are positioned to provide support as a priority (Danaher & Gallan 2016) and may understand the barriers to meeting these needs at a broader level.

Method

The study described in this article involved interviews and focus groups. The interview and focus group data were analysed using a two-phased thematic analysis (Braun & Clarke 2012), which is a flexible and inductive approach to data analysis.

Ten qualitative interviews were conducted with people with dementia and their spousal carers living at home in Perth, Western Australia (WA), followed by two focus groups with spousal carers, and interviews with 10 community service providers within the same community of people in Perth.

Results

The interviews with people with dementia and their spousal carers explored the participants' experiences across a range of needs, and as dementia progressed, the changing nature of these needs. Three overarching themes emerged:

- Factors that support care. This theme included three sub-themes: institutional support that is timely, effective, and affordable; a safe home and community; and a social environment that is supportive and well-educated.
- Strong caring relationships.
- Engaging in meaningful activities for people with dementia and carers.

Conversely, service providers identified that:

- Services and supports required by people with dementia and their carers should be flexible, tailored and equitable.
- The skills, attitudes and power of people with dementia and their carers need to be identified and developed.
- Current systems designed to care are fragmented and difficult to navigate.

At a thematic level, the perspectives of both participant groups aligned (see Figure 1, below). However, service providers primarily considered the needs of people with dementia and spousal carers through the lens of the services available to them.

Factors that support care

Factors that support dementia care were described by spousal carers and people with dementia as encompassing three distinct levels: institutional (eg, government-funded support services and systems), social, and physical.

Institutional support that is timely, effective and affordable

This theme was articulated as important for spousal carers living with people in the later stages of dementia and aligned with the needs of people with dementia reported by service providers. In particular, it was highlighted how services should be tailored to meet progressive needs of people with dementia and should provide relationship-based care. Both participant groups identified a lack of consistent and skilled support workers available to provide relationship-based care:

"They [service providers] give them different placings, which I object to because when you get used to somebody, they know exactly what to do".

Access to skills training for community-based support workers and adequate education for health professionals involved in diagnosis and coordination of care was identified as inconsistent by service providers. There was agreement regarding the need for flexible hours of care and support to access services such as short-term respite.

Spousal carers reported that the cost of services restricted them from accessing the amount of services that would help them manage their loved one's needs successfully; in contrast, service providers reported that spousal carers required more education regarding fee waiver options.

Both groups agreed that Government Centrelink support was difficult to access and navigate. Service providers offered insights into the barriers that impacted the support and care available for people with dementia and

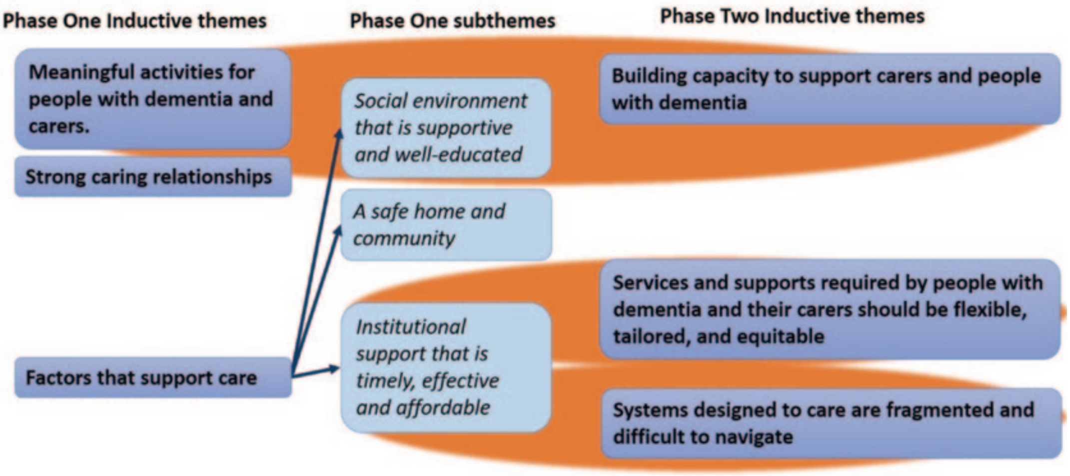

Figure 1: Phase one and phase two themes that emerged from the study described in this article

Key points

What is known about this topic?

- Spousal carers and people with dementia living at home need support to manage with the changes that occur with dementia.
- The available community services are often difficult to access and may not meet the needs.

What does this article add?

- It highlights that there is a gap between what spousal carers and people with dementia describe they need, and what service providers consider most important.
- It highlights that the needs of people with dementia and spousal carers are much broader than the available services.

Points for practice

- Providing education and reducing stigma about dementia for families and the general public is important.
- Finding ways to support people with dementia and their spouses to continue their meaningful activities is critical to enable people with dementia to continue living at home.

spousal carers:

"I think that's part of the challenge, you could have two people who are fairly similar in progression of their dementia and their needs, if you go to one service provider you might get this, if you go to another service provider you might get this. And it's trying to navigate the quality or equity."

Further, they identified how inequities existed in the current assessment and service access pathways, which is an issue corroborated by people with dementia and spousal carers in the navigation between public and private diagnostic services such as memory clinics and private geriatricians.

Fragmentation within the system, such as needing to contact multiple services to access information or support was described by service providers, though less commonly by spousal carers.

A social environment that is supportive and well-educated

Spousal carers and people in the early stages of dementia reported that knowledge and understanding of dementia in their social networks contributed to the amount of support they received. These social supports were outlined as family, friends and acquaintances.

Although supported in general by service provider participants, there was limited recognition of the extent of the impact of stigma, and thereby the buffering support offered by social networks.

Furthermore, the importance of social support from other people with dementia and family carers was almost exclusively described by spousal carers and people with dementia, eg: *"They've [the person with dementia] got people there, the same as what they are or similar to what they are. And we've got people that we can talk to and communicate with. So, to me that's a real asset"*, underlining a lack of recognition of the value of this support from service providers.

People with dementia and spousal carers identified that family who lived close by tended to provide more care and demonstrate greater awareness and understanding of the impacts of dementia.

Service providers recognised the importance of education and knowledge of dementia to improve family-based support in geographically separated families, however, identified that it was difficult to know who could provide this.

A safe home and community

The decisions made by spousal carers and people with dementia (in the early stages) regarding where they would live considered not just the family home (which was well understood by service providers) but also access to local shops, medical care and the overall feeling of safety in the community.

Service providers repeatedly identified the importance of adapting the home environment to maximise safety and function, however, they indicated that they were generally unable to provide comprehensive support in this area themselves, or refer on to another agency for this support, due to a lack of available funding.

Strong caring relationships

Spousal carers, people with dementia (in early to moderate stages) and service providers all recognised the importance of maintaining strong spousal relationships through adapting roles and responsibilities within the relationship and the importance of seeking ongoing support. Love, humour, patience and tolerance were key values identified by spousal carers when it came to providing support through the disease process.

Service providers identified a spectrum of adaptability in spousal relationships of carers with whom they had worked. Carers' knowledge and understanding of dementia was identified as a mediating factor that impacted upon adaptability, and that assessment needed to consider the needs of both:

"We allow them the opportunity to discuss things separately, because often, you know, we see the person with the spouse, but we need to make sure that we can separate at some stage, so they can really talk openly about what's going on."

Coping strategies, both effective and ineffective, were identified by service providers as developing organically with the progression of dementia; however, ineffective coping strategies were linked to early admission to residential care.

Education and collaborative development of coping strategies were identified as important for future community-based services.

Meaningful activities

Most spousal carers and people with dementia identified the importance and value of continuing to perform meaningful tasks and roles, such as being an active grandparent or contributing to home maintenance. People with dementia identified how they often needed help to continue to perform everyday tasks.

In comparison, only two service providers identified that an important part of their role included supporting carers and people with dementia to adapt to changes in functional performance related to the progression of dementia.

Conclusion

People with dementia and spousal carers interviewed for the study presented a dynamic care situation which inevitably poses a challenge for service providers.

Service providers identified a range of needs for their clients, but rarely considered needs that were beyond services and supports already funded, such as supporting spousal carers to develop caring skills.

Both groups of participants offered insights into the challenges and barriers of effective community care, including accessing the right types of information and support at the right time in the dementia journey, and access to well-trained community-based staff.

Although the study discussed in this article was completed during the introduction of Commonwealth Home Support Program and Home Care Packages, the Aged Care Royal Commission findings released this year echo the needs identified here for early and consistent support for informal and family carers, improved access to home modifications, assistive technology and respite support (Royal Commission into Aged Care Quality and Safety 2021a).

Key recommendations from the study include a greater focus on education about dementia for family carers, and the general community, as this may reduce the impact of stigma on availability of social support.

Finally, the importance of supporting people with dementia and spousal carers to adapt within their relationship and support ongoing meaningful roles as dementia progresses was highlighted.

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New resources to guide staff in delivering Behaviour Support Plans

Dementia Support Australia (DSA) has released a substantial toolkit of resources to support delivery of **Behaviour Support Plans** in residential aged care settings – which, as of 1 September 2021, are mandatory for residential aged care providers, whenever a resident is needing behavioural support or when a restrictive practice is imposed or likely to be imposed.

The suite includes a website hub with information and links to a long list of resources, including:

- Behaviour Support Plans: Your Essential Guide
- The When and What of Behaviour Support Plans
- The Behaviour Support Plan Template (when no restrictive practices are used)
- The Behaviour Support Plan Template (where restrictive practices are used)
- DSA Behaviour Frequency Chart
- DSA Behavioural Assessment Form
- Behaviour Support Flowchart
- Behaviour Care Planning Process
- ABCDE Posters
- DSA Lifestyle and social history form
- Brain and Behaviour Factsheet
- DSA Abbey Pain Scale
- The Guide to the Cornell Scale for Depression in Dementia

The key resource – the 36-page 'essential guide' – sets out in detail the three key steps that are required in offering behaviour support to a person living with dementia who is experiencing changes in their behaviour: (i) identify (ii) assess and (iii) plan, implement and evaluate.

The guide is aimed at all staff involved in delivering care to people living in residential care settings. It includes case studies and explains how to use each of the related DSA Behaviour Support Plan resources (eg the DSA Behaviour Frequency Chart). All the resources can be found here: https://dementia.com.au/bsp