

Lack of specialized tools could see dementia patients miss out on care improvements

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Despite more than half of all residents in aged care having dementia, tools designed to improve quality of care across the sector are likely not meeting their needs, new research has found.

Two studies from Flinders University's Caring Futures Institute have highlighted gaps in the current monitoring tools used to measure care quality, with the authors calling for the development of more robust instruments tailored to the needs of people with [dementia](#).

"Quality of care measures, including patient-reported experience measures, are vital tools in ensuring the experiences of those in our health and [aged care](#) sector are heard and understood so improvements to care can be made," says Associate Professor Rachel Milte from the Caring Futures Institute and Flinders' College of Nursing and Health Sciences.

"Previously, little was known about the methods and instruments used to capture these perspectives, but now our work has highlighted there is an urgent need for more inclusive and effective instruments in long-term care settings for older people living with dementia, in order to best capture their feedback."

In one study, the authors conducted a comprehensive review of existing [quality of care](#) instruments used in long-term care facilities. Of the 16 identified instruments, only two were specifically created for older people with dementia, while three were modified to accommodate people with mild to moderate dementia. The work is [published](#) in the journal *Dementia*.

Furthermore, the review found none of the instruments had been fully psychometrically tested—which ensures the tools' accuracy and that the scale is measuring what it is intended to measure—and highlighted their failure to incorporate alternative communication techniques suitable for individuals with dementia.

"Many existing instruments rely heavily on text-based formats, which can be challenging for people with cognitive impairments. There is a

pressing need for tools that use more accessible communication methods such as images, pictographs, and audio-visual materials," says Associate Professor Milte, senior author of the paper.

In the [second](#) *Dementia* study, the researchers looked into the use of patient-reported experience measures (PREMs) for populations likely to have diverse communication needs more broadly.

"There has been growing use of patient-reported experience measures to help evaluate the care experiences of vulnerable populations, including people with [cognitive impairment](#), [mental health concerns](#), and children," says study author Professor Kate Laver from Flinders' Caring Futures Institute.

"We wanted to understand what PREMs have been used previously with people with diverse communication needs, and whether they could be adapted and improved for people living with dementia."

The researchers reviewed the existing PREMs and found similar gaps in the tools available for capturing the lived experiences of dementia patients. The study found most PREMs are not adequately tailored for people with dementia, often lacking sensitivity to the specific aspects of care that matter most to them.

"Current PREMs tend to prioritize organizational and clinical indicators rather than [personal experiences](#), which can lead to an incomplete understanding of care quality from the patient's perspective," says Professor Laver.

"For those with moderate to advanced dementia, we need to develop dementia-specific PREMs that prioritize the voice of patients themselves, rather than relying on proxies like [family members](#) or health care staff who may not fully understand or accurately represent the

patient's needs and preferences."

As Australia's population continues to age and the prevalence of dementia increases, the authors say the need for dementia-specific, validated tools that reflect the voices and experiences of people living with dementia is more critical than ever.

"These tools will be key to understanding and monitoring self-reported health care experiences for people with moderate to advanced dementia, ensuring that consumer voices are elevated and platformed to inform quality improvement throughout the sector," says Associate Professor Milte.

More information: Digisie M Jemere et al, Are quality of care instruments inclusive of older people living with dementia? A scoping review in long-term care settings, *Dementia* (2024). [DOI: 10.1177/14713012241270758](https://doi.org/10.1177/14713012241270758)

Madison Chapman et al, Patient-reported experience measures for people living with dementia: A scoping review, *Dementia* (2024). [DOI: 10.1177/14713012241272823](https://doi.org/10.1177/14713012241272823)

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