Giving a Voice to People with Dementia: A New Way to Participate in Decision-Making

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One of the major challenges in caring for people with dementia (PwD) is ensuring they continue to participate in decision-making as the disease progresses (Zhang et al., 2022). Due to the cognitive changes experienced by PwD, many care-related decisions are often made by family members or informal caregivers on behalf of the PwD. However, numerous studies have shown that caregivers' preferences do not always fully align with those of PwD (Ho et al., 2021).

This situation has led to a search for strategies that allow the perspectives of those living with dementia to be incorporated more directly. In this context, Discrete Choice Experiments (DCEs) have emerged as a widely used methodology for understanding people's preferences when choosing between different alternatives (Regier et al., 2026). In the field of dementia, this methodology has been adapted to enable the participation of people with cognitive impairment and their informal caregivers.

According to Wammes et al. (2023), adapted DCEs exercises enable PwD to express their preferences and participate actively in decisions relating to their care. Rather than being asked direct questions, participants are presented with a series of scenarios that include different options defined by specific characteristics, such as the type of support received, the amount of available care time, or certain service conditions. The choices made can then be analyzed to identify which aspects are most important to each person (Zhang et al., 2024).

How can DCEs be adapted for PwD?

First, the person PwD and their caregiver complete the decision-making tasks individually. Then, they analyze the different options together and make a joint decision. The scenarios are presented using simple attributes and a limited number of options. Visual aids, illustrations, examples and adapted explanations are also used to reduce cognitive load and make the tasks easier to understand (Özdemir et al., 2024).

According to Turner et al. (2025), it is possible to adapt DCEs to enable the participation of PwD. Their studies have shown that many PwD can actively participate in this type of exercise when the tasks are adapted appropriately. While initial comprehension may be limited, using prompts, clear explanations and visual aids can significantly improve performance and help to preserve the autonomy of people with dementia.

Furthermore, joint participation with caregivers fosters communication, makes it easier to identify shared preferences and encourages more consensus-based decision-making. However, studies also emphasize the importance of ensuring that the views of PwD are not overshadowed by those of their caregivers (Leng et al., 2024).

What are the implications of DCEs for professional practice with PwD and their families?

The available scientific evidence enables to make the following practical recommendations for professionals, researchers and service providers (Engelsma et al., 2020; Janssen et al., 2017; Whitty & Oliveira Gonçalves, 2018):

- Design simple, structured tasks.
- Limit the number of attributes that must be assessed simultaneously.
- Incorporate illustrations and visual aids.
- Adapt the complexity of activities to each person's cognitive level.
- Combine individual and group interviews with caregivers.
- Consider both individual and shared preferences when planning care.

A step toward more person-centered care

Participation in decision-making is one of the fundamental principles of person-centered care. Adapted DCEs is a promising tool for achieving this, as it enables PwD to continue expressing their preferences even when cognitive difficulties arise.

Listening to and taking these preferences into account not only promotes respect for the individual's autonomy and dignity, but can also improve family communication, increase satisfaction with the care received, and contribute to the

design of more personalized services and resources tailored to the needs, expectations, and priorities of PwD and their families, thereby improving the quality of life for both them and those who support them in their care journey.

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