

Two Sides Of The Same Experience?

Comparing Perspectives Of People Living With Dementia And Caregivers



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Key message: People living with dementia and caregivers share core priorities but differ in their support needs, highlighting the importance of person-centred, relationship-focused, and adaptable interventions.

INTRODUCTION	METHODS	Preliminary RESULTS	Preliminary CONCLUSIONS	REFERENCES
There is a growing body of research examining factors influencing quality of life for people living with dementia (Górska et al., 2018) and informal caregivers (Ateyobi et al., 2022), alongside increasing advocacy for the inclusion of care recipients in intervention development (Duffner et al., 2025). To inform the development of an intervention as part of our <i>Trialog</i> project, we conducted separate focus groups with people living with dementia and informal caregivers, exploring three themes: (1) impacts on their quality of life (QoL), (2) considerations for therapeutic interventions, and (3) changes in equality and agency following a dementia diagnosis. The aim was to compare the perspectives of both groups, identifying areas of shared experience as well as distinct needs and priorities to inform intervention development.	Questions: Focus group questions were co-developed with people living with dementia from the German Alzheimer Society research group. Groups were facilitated separately to provide a shared-experience setting; both discussing the same questions. Setting: the duration was two hours, with breaks as needed. Most sessions took place at our central research institute; one group took place in a space closer and more familiar to the participants with dementia. Ethics: Written informed consent was obtained before participation and continuously monitored. Participants received a small reimbursement. Visual support (flipchart with questions and responses) was provided throughout. Data: Focus groups were audio- and video-recorded, transcribed, and analysed in MAXQDA using content-structuring qualitative content analysis (Mayring, 2010).	Seven focus groups with $N=7$ people living with dementia and $N=14$ caregivers were conducted, 66% of participants were female. Commonalities • Open communication about the diagnosis improves QoL • Shared activities support QoL and relationship maintenance • Therapeutic offers should be person-centered, adaptive, and clearly described to support decision making. • Dominating sentiments of shame, fear and frustration Differences • People living with dementia highlighted the importance of purpose and meaningfulness of an intervention • Caregivers highlighted organizational burden, the need for roles beyond caregiving, and their responsibility to maintain equality. They also emphasized changing needs across dementia stages.	This study suggests that people living with dementia and care partners share many experiences while also having distinct needs and concerns shaped by their differing perspectives. Therapeutic interventions may benefit from acknowledging both shared and unique experiences, with a focus on supporting the relationship throughout the dementia journey. Participants valued the focus group discussions, reporting that they provided opportunities for reflection on their experiences and connection with others facing similar situations.	Ateyebi, O et al., (2022). A systematic review of systematic reviews of needs of family caregivers of older adults with dementia. <i>European journal of ageing</i>, 19(3), 381-396. Duffner, L., et al. (2025), Pathways to Participation – Understanding Barriers and Enablers to Participation in Dementia Research. <i>Alzheimer's Dement.</i>, 21: e108736. Górska, S., Forsyth, K., & Maciver, D. (2018). Living with dementia: a meta-synthesis of qualitative research on the lived experience. <i>The Gerontologist</i>, 58(3). Mayring, P. (2010). Design. In <i>Handbuch qualitative Forschung in der Psychologie</i> (pp. 225-237). Wiesbaden: VS Verlag für Sozialwissenschaften.
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