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The Subjective Wellbeing and Lived Care Experiences of Family Caregivers of People Living With Dementia: The Case Study of Photovoice Practice Implementation in Lithuania

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Purpose: To examine the subjective wellbeing and lived care experiences of family caregivers of people living with dementia (PLWD) in Lithuania through the implementation of the Photovoice practice.
Methods: Photovoice practice as a participatory research method. Qualitative research methods included focus group discussions with family caregivers of PLWD. Data collected during the process was analysed using a thematic analysis approach. Creative research results – photographs and stories were presented in a public exhibition.
Results: The following themes emerged within the focus group discussions, photographs, and stories: 'interdependency', 'interconnectedness of care', 'mundane', 'the bond in care', 'the role of supportive environment', 'the aspiration to maintain one's inner freedom', and 'who is the bearer of responsibility?'.
These themes uncovered areas of poor caregiver wellbeing (experienced high levels of stress and fatigue, challenges related to health and mental wellbeing, self-care skills, and free time; emotional and physical distress in care relationships); lack of daily dementia care skills; lack of support for caregivers (providing emotional support, assisting with daily tasks, creating opportunities for rest, and fostering healthy family-work life integration); lack of knowledge and stigma related to dementia within society and among formal and informal caregivers; limitations in the support system for people living with dementia (absence of a person-oriented approach, challenges in pre-, during, and post-diagnostic services, worrisome aspects of accessibility and quality); and the need for community support groups and arts-based approaches to support caregivers' health and wellbeing.
Conclusion: There is an urgent need to actively support the wellbeing of family caregivers of PLWD in Lithuania by offering services that focus on care and self-care skills development, physical and mental resilience, and ensuring the accessibility and quality of care systems. The application of the Photovoice practice is an innovative arts-based approach to provide insight into the intimate environments and current quality of care and support received by both family caregivers and PLWD in Lithuania.
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