Tittel: Processes of user participation among formal and family caregivers in home-based care for persons with dementia.

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Sammendrag: Scandinavian health policy supports prolonged home-based care for people with dementia. User participation is expected to reduce family burden. The aim of this study was to explore how formal and family caregivers experience collaboration while providing home-based dementia care, with a focus on user participation. Seventeen qualitative in-depth interviews were conducted among formal and family caregivers in rural municipalities. The theme identified during this process was ‘negotiating participation in decisions’. This theme was analysed using positioning theory. Concepts such as user participation are ambiguous, and caregivers negotiate positions during decision-making processes. Such negotiations are caused by the problematic relationships among patients’ legal consent, undefined spokespersons and pragmatic care practices. These constant negotiations enable or obstruct collaboration in several situations. User participation as a concept might contribute to conflicts during collaborations. Dialogues about user participation that focus on consent and spokespersons could reduce the burden created by negotiations in practice.

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