

Conference abstract

## Key issues in transitional care for people with dementia and their family caregivers facing institutionalisation

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### Abstract

**Purpose:** To gain insight into the experience of family caregivers of demented people with the decision-making regarding institutionalisation, and to develop a guideline for professional caregivers how to ease the transition from home to nursing-home.

**Theory:** The (possible) institutionalisation of a relative with dementia has high impact on both the person with dementia and his relatives. As far as we know, there are no evidence-based guidelines for professionals involved in this difficult time.

**Methods:** Qualitative interviews were held with 15 family caregivers (eight children, six partners and one other relative) of a person with dementia. Interviews focused on their expectations and needs regarding decision-making and institutionalisation. The audio-recorded interview transcripts were analysed using Atlas-ti.

**Results:** Preliminary analyses reveal practical and emotional problems. Before institutionalisation, the decision-making may be hindered by a negative view of nursing-home care, reluctant relatives, or feelings of guilt. Family caregivers often experience mixed feelings and more or less lack support from relatives and friends or from health care professionals throughout the process. Difficulty communicating the institutionalisation to their relative with dementia is another problem. Some relatives totally deny the possibility of institutionalisation. After institutionalisation, family caregivers have to cope with aversive and aggressive behaviours of their relative, loneliness, taking on a new social role, and discussing their concerns about nursing-home care with nursing-home staff.

**Conclusions:** A transition programme for people with dementia and their relatives should include timely discussion of the possibility of moving into a nursing-home or a small-scale living facility. Professionals should discuss the choices and support the decision-making of people with dementia and their relatives. After institutionalisation, the client-relative dyad should be supported to give new meaning to their lives, both as a couple and individually.

### Keywords

**family caregivers, dementia care, transition, institutionalisation**

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Presentation slides