

Qualitative

4 thematic patterns described the experience of placing a relative with Alzheimer's disease in a special care unit

Butcher HK, Holkup PA, Park M, et al. *Thematic analysis of the experience of making a decision to place a family member with Alzheimer's disease in a special care unit. Res Nurs Health* 2001 Dec;24:470–80.

QUESTION: How do caregivers describe their experience of making the decision to place a relative with Alzheimer's disease (AD) in a special care unit (SCU)?

Design

Semistructured interviews.

Setting

3 Midwestern states in the US.

Participants

30 family caregivers (80% women; 70% were children and 30% were spouses) of patients with AD who lived in an SCU.

Methods

Caregivers were interviewed for 1–3 hours by clinical nurse specialists or a gerontology specialist. Semistructured interviews were videotaped and transcribed. Caregivers were asked to describe the type and quantity of care they had provided before the SCU placement; their involvement since placement; the quality of their relationship with the SCU staff; their evaluation of the care their relative was receiving in the SCU; and their feelings about the SCU placement. They were asked to

describe their feelings at the time of making the decision and during the actual relocation of their relative, and what helped or made it difficult to deal with their feelings about the SCU placement. 3 reviewers independently used QSR NUD*IST NVivo® qualitative software and Luborsky's method for thematic analysis to code and analyse the transcripts. The data interpretation involved independent and then consensual interpretation of all aspects of the text.

Main findings

4 patterns emerged. *Moving towards the unavoidable decision:* caregivers gradually realised that something was wrong with their relative, which led to a breaking point at which they realised they could no longer care for their relative at home. Caregivers were worried about their relative's safety, which resulted in a vigilance that was physically and emotionally draining. They described the breaking point with a sense of finality. *Struggling with decision:* caregivers described their anguish at the realisation they would need to place their relative in an SCU, and they used words like "hard," "difficult," "tough," "devastating," and "terrible." Feelings of guilt were often present. The presence or absence of support influenced the decision to place their relative in an SCU. Feelings of anguish and guilt were decreased when the entire family shared the decision. *Seeking reassurance:* caregivers needed to know that they had made the right decision, and the perception that their relative was receiving better care in the SCU gave them the best reassurance. This reassurance depended on their perception of the quality of care and their relative's level of contentment in the SCU. Sometimes the symptoms of AD made it difficult for caregivers to know how their relative was responding to the SCU. Caregivers observed and noticed how the staff interacted with residents in the SCU, and it was important to them that their relative appeared neat and clean. Caregivers experienced relief if they believed that their relative was receiving good care. *Remaining connected:* family ties and connectedness were themes throughout the decision making process. The placement in the SCU marked a turning point and indicated the finality of the progression of AD. Caregivers remained involved in their relative's life by visiting often and taking their relative out.

Conclusions

Family caregivers who placed their relatives with Alzheimer's disease in a special care unit (SCU) described the anguish they felt in making the decision. The knowledge that their relative received good care helped to relieve their anguish, and they maintained involvement in their relative's life in the SCU.

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COMMENTARY

In a book describing a 3 year longitudinal study of 555 carers of people with dementia, Aneshensel *et al* identified 3 stages of the "caregiving career",¹ namely role acquisition, role enactment, and role disengagement. Their stage of role enactment included care provided while people with dementia lived in their own homes, and care provided after admission of the person with dementia to a long term care facility. In this study, Butcher *et al* look in greater detail at the transition between "in-home" and "institutional" caring.

Butcher *et al* drew their participants from a pool of 256 carers in a quasi-experimental trial to assess the effect of a programme for enhancing family involvement with the care of relatives in long term care. For inclusion, carers were expected to be visiting on at least a monthly basis and to agree to participate in assessments throughout the study (baseline and 3 post intervention follow ups), suggesting a degree of commitment to continuing care and involvement that cannot be assumed for all carers. On the other hand, the sample contained a greater proportion of adult offspring than spouses, and the latter are generally found to have a greater commitment to the caregiving relationship than the former.²

Clinically, the study raises areas in which care staff can support family carers in what they find to be a painful and difficult decision. Every participant raised the topic of monitoring the quality of care provided in the unit, and this topic generated more than twice the number of coded themes than any other. Participants found comfort when they were satisfied with the quality of care provided by care staff. This may be more achievable in specialist care units than general residential or nursing facilities.

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- 1 Aneshensel CS, Pearlin LI, Mullan JT, et al. *Profiles in caregiving: the unexpected career*. San Diego: Academic Press; 1995.
- 2 Pot AM, Deeg DJ, Knipscheer CP. Institutionalization of demented elderly: the role of caregiver characteristics. *Int J Geriatr Psychiatry* 2001;16:273–80.