Introduction

When a person with dementia is receiving in-hospital treatment, transitioning through the hospital system and subsequently assessed as requiring residential care, family caregivers may feel overwhelmed and disempowered by the healthcare system. There is a danger that they will feel excluded from decision-making and uncertain about their role as ‘expert’ and key provider of care for their relative.

Aims

The aims of this study were to:

1. Explore the experience of the family caregiver during the transition of a relative with dementia through hospital care to residential care
2. Develop a brochure that assists family caregivers during the transition through hospital into residential care.

Methods

A descriptive exploratory design was used to explore family caregivers’ experiences during this transition phase in a 60 bed Aged Rehabilitation and Geriatric Evaluation and Management Facility in Victoria, Australia.

Potential participants were identified from patient hospital admission data by staff within the facility. After obtaining informed consent, twenty caregivers of people with dementia in the subacute care hospital setting who were waiting for a position in a residential care facility were interviewed. Interviews were conducted between April and November 2013, taped and transcribed prior to thematic analysis using Sandelowski’s method of qualitative description

In-depth interviews included questions such as,

• Can you tell me what your experience has been like with your relative in hospital?
• Can you tell me some of the experiences you have had in relation to your relative’s hospitalisation?

Results

<table>
<thead>
<tr>
<th>Caregiver participants (N=20)</th>
<th>9 Males and 11 Females</th>
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<tr>
<td>Age</td>
<td>The youngest caregiver was 34 years and the oldest 92 years</td>
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<td>Interview length</td>
<td>Average 25.01 minutes ± 7.39 (SD) (The interviews lasted from 14 minutes to 43 minutes)</td>
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Table: Study Participants and Interview details

Many of the caregivers appreciated the opportunity to talk about their experience, likening it to ‘getting things off their chest’, as they had received minimal emotional support during a highly stressful time:

I must admit I’m very strong, which I’m pleased with. But I have my moments when, you know, you get down. You think, “Why me?”

Many of the caregivers were older and of a generation that had relatives in hospital and going into a nursing home and their families.

Relief

Some of the caregivers were older and of a generation that experienced hard times and tried to make the best of a bad situation. One caregiver spoke about how things were easier for her now since her husband had been hospitalised.

And look, I manage at home. You’ve got to be able to do things. I’ve got a girlfriend, I go down there generally Saturday night and we have dinner together and we go watch the footy (Jane, wife)

Discussion

Our findings reinforce the research of Davies and Nolan16 and Elka et al.7 regarding the inevitable need to place a loved one in residential care, although these studies were not specific to dementia. The systematic review of adjustments made by people with dementia moving into care and their families by Sury et al.3 highlights the varied emotions of loss, regret, sadness, guilt, stress and ongoing burden, particularly for women.

Conclusion

One implication from this study is the need to improve the transition process for the caregiver; allow them to be involved in the decision making process, keep them informed and importantly, family caregivers require emotional support to help them adjust to this transition.

Development of the support brochure

The results of this study have been used to develop a support brochure. The brochure highlights the varied emotions and includes direct quotes from the caregivers. It was designed to reassure caregivers that they are not alone; other people are experiencing the same emotions and must also make the same decisions.

References