

Decision-making experiences of family carers of older people with moderate dementia towards community and residential care home services: a grounded theory inquiry (abridged secondary publication)

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KEY MESSAGES

1. The burden of care for family carers of dementia elders can be relieved by formal services.
2. Types of decisions carers made were mainly the day-to-day management of distressing symptoms of moderately severe dementia.
3. Decision-making experiences included options perceived by family to meet the dementia caring needs, decisions about service options, and the degree to which the service decision has met needs.
4. 'Contested provocation' provided an

understanding of the struggles, disputes, and battles carers contended with during the course of caring for elders with dementia while using formal services.

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Introduction

Caring and supporting older people with dementia is a public health priority. The number of family carers to provide dementia care is diminishing in the future.¹ Carers bear considerable psychological, practical, and economic challenges as the disease advances over time. The burden of care can be relieved by formal services.

This study retrospectively examined the decision-making experiences of family carers of elders with dementia towards the use of community care services (CCS) and residential care services (RCS). CCS and RCS play an important role in supporting older adults with dementia and their family members. The objectives were: (1) to explore the decision-making experiences and types of decisions families make for their elders with dementia, (2) to identify the extent to which CCS and/or RCS have helped families to meet their own needs and challenges when serving their elders with dementia, (3) to explore factors influencing the families' decision on CCS and/or RCS for their elders with dementia, (4) to explore the families' perceived needs of elders with dementia and the degree to which CCS and/or RCS have met those needs, (5) to examine specific experiences and circumstances that have influenced the family to make a decision to continue using CCS and/or RCS for elders with dementia, (6) to examine

the roles families play and the influences they have in shaping the elders' lives when they use CCS and/or RCS, and (7) to develop a theoretical framework for the decision-making experiences of family members towards CCS and/or RCS.

Methods

A 2-year constructivist grounded theory design² was used to collect the data. For CCS, we approached one district elderly community centre, two neighbourhood elderly centres, and four day-care centres for the elderly. For RCS, we approached three subsidised care and attention homes and one self-financed care and attention home. We did not approach private aged homes. Purposive sampling was used to select family carers of elders with moderate dementia. Screening for dementia was based on a confirmed diagnosis of dementia and a Mini-Mental State Examination score of 11-20 or an Abbreviated Mental Test score of <7. We interviewed 94 family carers (50 from district elderly community centre / neighbourhood elderly centre and 44 from day-care centre for the elderly) who used CCS and 51 family carers who used RCS (Table 1). An interview guide was used. Data were analysed using constant comparative analysis methods. The quality criteria addressed the credibility, resonance, and usefulness of the findings.

Results

Types of decisions warranting decision making to take care

Types of decisions made by the family carers for the elders was a generic theme identified (Table 2). It was not unusual to hear making decisions associated with managing the distressing symptoms of moderately severe dementia. Trying to engage in any form of discussion and decision making with older people required time and patience.

Options perceived by family carers to meet the caring needs

Making decisions on behalf of the elders was to meet their current needs and to make plans for future needs. When asked about the extent to which services could help the participants to meet their needs and help them take care of their elders, the usual responses were applying for and being put onto the waiting list for CCS and RCS. Approaching these services meant that they could have access to professional advice from the social worker about current situation, plan what to do, and be told about what could happen, and actions that could be needed. Other options to help them relieve the caring needs included giving up one's paid employment and becoming a full-time carer, and exploring other services to temporarily relieve them while still caring for the elders at home.

Making decisions about service options

A lot of emotions were expressed when asked about what would be considered in deciding to use CCS and/or RCS. This highlighted the need to acknowledge the carers own needs and help them overcome the challenges of being a carer. There were well-intended carers who were willing to take care of their elders at home, but caring on a daily basis was more than they had expected and could cope with. Some carers tried the CCS first and then tried RCS when the circumstances at home with the elder and/or family carer changed. Carers were explicit about the reasons for using the services. Once a decision was made to consider CCS and/or RCS,

TABLE 1. Characteristics of family carers in district elderly community centre / neighbourhood elderly centre, day care centre for the elderly, and residential care services

Postoperative day	No. of family carers		
	District elderly community centre / neighbourhood elderly centre	Day care centre for the elderly	Residential care services
Age range, y			
35-59	16	23	27
60-64	10	9	12
≥65	24	12	12
Relationship with older person			
Daughter/son	27	24	38
Wife/husband	20	15	4
In-law (daughter, sister, cousin)	2	5	6
Other close relation (niece)	1		1
Grandchildren			2
Caring experience, y			
1-5	45	28	33
6-15	5	16	16
>20			2

carer emotions moved from one of guilt and a sense of abandonment to one of gradually acknowledging their own needs and challenges of caregiving. Carers provided specific experiences and circumstances that led to the need to consult services. There was a lack of service options for carers, especially when they faced with difficult circumstances at home that required immediate attention.

Degree to which the service decision has met needs

Carers may involve the elders in decision-making for using CCS and/or RCS. When elders were consulted, the decision was a more contented and informed one. For CCS, decision making about the future care and institutionalisation was still far away. Services that enable the elders to be occupied in the

TABLE 2. Types of decisions family carers made for their older relative with dementia

Healthcare and illness decisions	Hospitalisation, seeing family doctor, deteriorating health issues
Medical decisions	Medical follow-up, medical/psychiatric consultations, medications, health, and well-being
Everyday decisions	Activities of daily living relating to what to eat, when to exercise, who bath them, which pastime activities, where to eliminate; personal safety, and home alone
Lifestyle decisions	Personal habits, attitude changes, healthy choices, conduct, and behaviour
Future care decisions	Unknowing how to plan for the future, unsure of what could happen, learning to live for each day, managing residents and staff relations, options other than institutions

day helped ease the carers' mind. Data highlighted expressions of relief and more free time. Carers stated that they continued to make decisions for the elders. Some carers shared that the elders agreed to go into aged homes when they became cognitively unable to make decisions and incapable of caring for themselves. Therefore, the degree to which the selected service met the elders' needs should be accounted for how involved they were in making the decision. Another consideration was whether the carer was involved in the services used by the elders. Some wanted to be more engaged in the service provision and delivery of care. It is unclear what else they could do and contribute however willing. The importance of recognising the potential roles carers can play, and how they can continue to contribute to their care after institutionalisation of elders should be explored further.

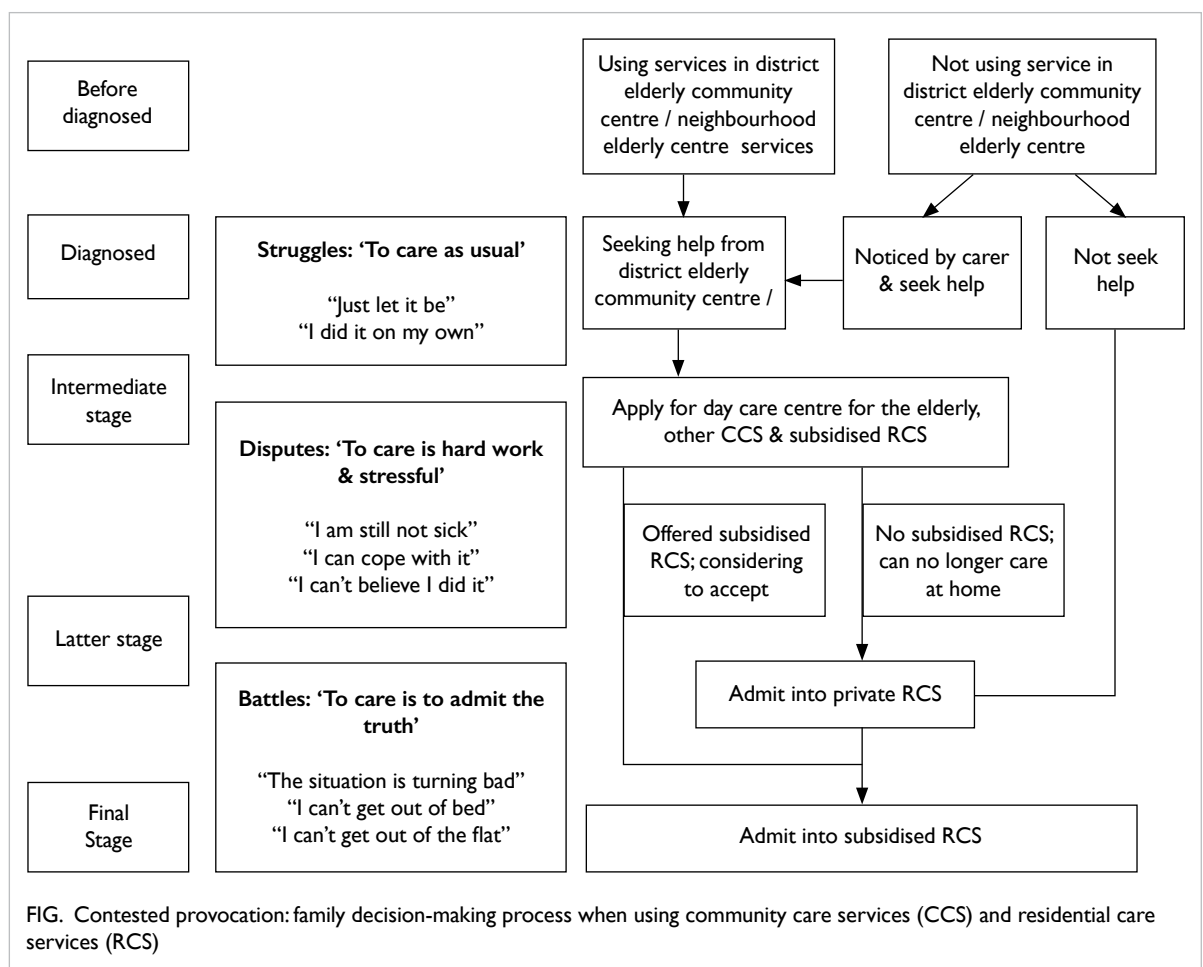
Contested provocation

Contested provocation describes the struggles, disputes, and battles family members contended during the course of caring for the older relatives prior to making the decision to use CCS and

eventually RCS (Fig). Making the decision to use RCS was the final outcome for the older person with dementia. Making the decision to use CCS may delay institutionalisation. Each family's experience was unique; it was not possible to delineate the time-points in which the changes of circumstances could be made. Identifying factors that provoked and irritated family members to lead the older person to use CCS and/or RCS may help ease the difficult caring situation at home.

Discussion

Contested provocation encapsulates the family decision-making process for CCS and/or RCS. It is highly practical and encompasses the stories of carers. However, decision making is an abstract concept, and some older carers have difficulties understanding the term. Deeper understanding of service needs, expectations, and hopes among carers for improving service support to elders with dementia in CCS and/or RCS are needed. Care by spouses is different from care by children, particularly when there is sex difference between the child and parent.



One constraint on sampling was the difficulty in getting a balanced ratio of male-to-female carers. Nonetheless, participants were recruited from multiple sites and thus the transferability of the study was enhanced. The constant comparative analysis method and theoretical sampling facilitated identification of most appropriate participants and thus the study credibility was enhanced. This study reflects different issues carers face, and how such issues were provoked by elders with dementia. Understanding these issues may promote the health and well-being of both parties. If caregivers are better supported, the need for CCS and/or RCS can be deferred. Future studies may use qualitative interviews with family carers in CCS and may consider a strategic measure to recruit participants. Given the struggles and challenges of family caregiving, views of carers using private RCS should be included.

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Disclosure

The results of this research have been previously published in:

1. Le Low LP, Lam LW, Fan KP. Decision-making experiences of family members of older adults with moderate dementia towards community and residential care home services: a grounded theory study protocol. *BMC Geriatr* 2017;17:120.

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