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Contested provocation: Making sense of the plight of family caregiving in dementia care and moving on

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Background

- Caring & supporting older people with dementia have become a major public health priority regionally & globally, & advocate actions to be taken (WHO, 2012).
- World Alzheimer's Report (2013):
 - a rising trend of elders in **great need for dementia care in the long-run**, and a **predicted unsustainable shortage of informal carers**.
 - alarmingly predicts a **3-fold increase in the no. of dependent elders**, with a 101 million in 2010 to 277 million in 2050 (**one half of them living with Alzheimer's Disease or other form of dementia**).
- It is expected that as elders continue to live longer, the prevalence of those suffering from dementia is expected to increase.



Background

- HK Alzheimer's Disease Association Press Release (2013) made **explicit headlines of a diminishing lack of support for family members.**
- Therefore, the focus on the need to plan and address both formal and informal care needs for dementia sufferers is urgently warranted.



Decision-making role, potential and challenges
faced by family members when making
decisions for residential care home residents
with mild to moderate dementia

16th Asia Pacific Regional Conference of
Alzheimer's Disease International (Dec. 2013)



Background

- **Considerable burden** on the family members who acted as **advocates & are decision-makers** for their older relatives with dementia.
- Family members still continue to **play different roles** and are **engaged in making lifestyle decisions** to help the elder to maintain a sense of individuality, identity and respect.
- **Additional support and training** is recommended for informal carers in this endeavor.



Background

- Dearth knowledge about the decision-making experiences of family members, esp. **at what point they reconsider their own roles & responsibilities** of caring for their community-dwelling older relatives with moderate dementia.
- Evidence that burden of care can be relieved by formal services.



Multi-sites

Design Complexity



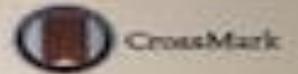
Low et al. BMC Geriatrics (2017) 17:120
DOI 10.1186/s12877-017-0510-8

Design Complexity

BMC Geriatrics

STUDY PROTOCOL

Open Access



Decision-making experiences of family members of older adults with moderate dementia towards community and residential care home services: a grounded theory study protocol

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HMRF 2015-2017

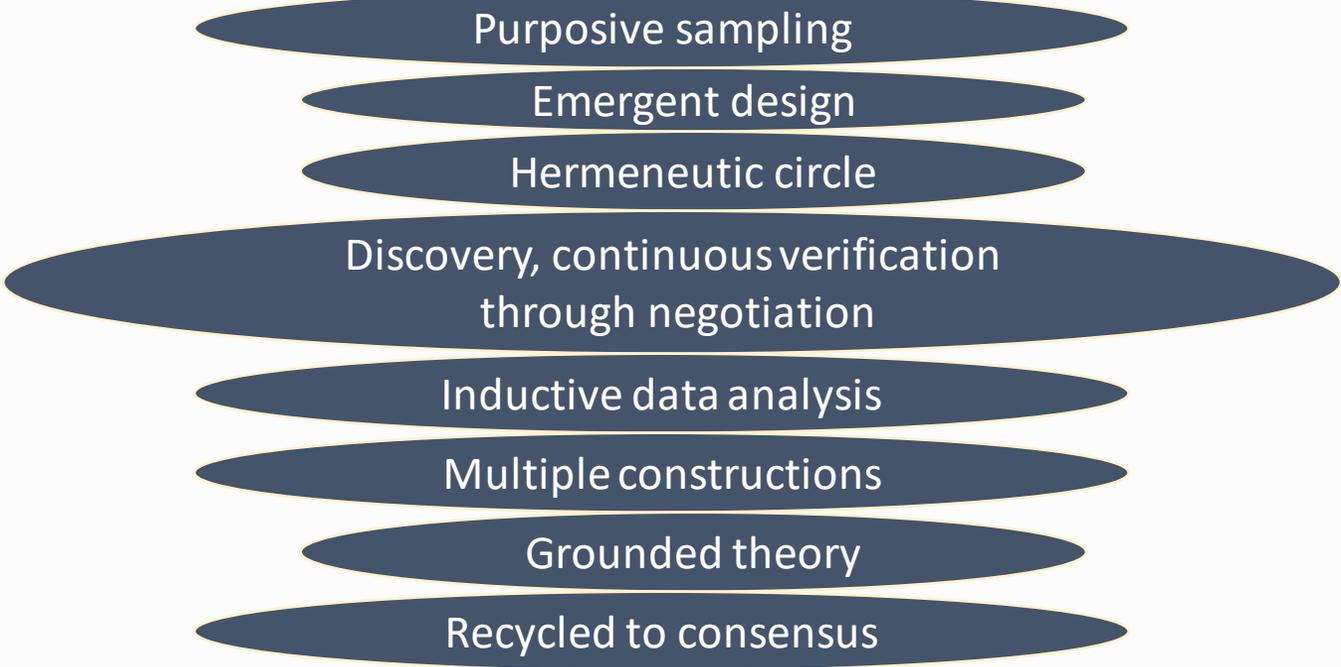
Abstract

Background: Caring and supporting older people with dementia have become a major public health priority. Recent reports have also revealed a diminishing number of family carers to provide dementia care in the future. Carers who

BMC Geriatrics, 17, 120

<http://rdcu.be/tfwQ>

Entry Conditions:
Natural setting
Human instrument
Tacit knowledge
Qualitative methods



Inquiry Product:
Case report
Negotiated joint constructions
Idiographic interpretations
Tentative findings
Vicarious experiences

Modified from
Rodwell (1998, p.53)



Family

- Elder with moderate dementia.
- Involved in managing physical & psychosocial needs of the elder, and/or
- Main decision-maker for the elder.
- Currently using CSS &/or RCS.

Older person

- Diagnosed with dementia.
- MMSE score = 11-20 (moderate cognitive impairment).

Purposive sampling



Theoretical sampling



This presentation

To present decision-making experiences of family members of older people with moderate dementia, and were using CCS and/or RCS.



Contested Provocation



- Described the **struggles, disputes and battles** family members contended with during the course of caring for elders at home before making decision to use CCS & eventually resorting to RCS.
- At the point of making **that decision**:
 - **factors** identified that provoked and irritated family members to become aroused, and
 - **triggered a series of events** that eventually led the elder to receive different types of services to help ease the difficult caring situation at home.
 - **strategies** of how families had dealt with them at the time.



Opting out of own homes for residential care homes:
Decision-making experiences of family members of
older adults with moderate dementia

**7th International Conference on
Geriatrics Gerontology & Palliative Nursing (Sept. 2017)**



Early Stage Later Stage

Struggles

**'To Care
as Usual'**

'Just let it be'
'I did it on my own'

Disputes

**'To Care is Hard Work
& Stressful'**

'I am still not sick'
'I can cope with it'
'I can't believe I did it'

Battles

**'To Care is to
Admit the Truth'**

'The situation is turning bad'
'I can't get out of bed'
'I can't get out of the flat'

Entry to aged home



'To Care as Usual' - Struggles

Arousal Factors

- Illogical speech
- Slight disorientation
- Another person's presence
- Repeating tasks
- Misplacing possessions
- Loosing money

Triggering Events

- Manage by oneself & avoid outside interference
- When to tell or not tell the family
- When to ask for help & burden other
- Consider finances & hired help

Strategies

- Avoid anger & arguments
- Have patience & tolerance.
- Offload occupied housework
- Make time to talk & reminisce
- Get objective advice & outside support
- Get support from children living together



Arousal Factors

- Likes to walk, not walk well
- Wandering behaviours
- Getting lost in streets
- Fall incidents but no injuries
- Occasional sleepless nights
- Forgetting what has been said
- Forgetting how to do daily things

Triggering Events

- Standby supervision needed
- Realize can't do it alone any more
- Contemplate to tell or not tell the family
- What help & how to ask for it
- When best time to get help with what
- Handle anger & frustration released by elder
- Consider outside help & waitlist in aged home

Strategies

- Admit to own physical limitations
- Get support from children living & not living together
- Listen to advice & try strategies from others



Emotional caring is intensified when...

He forgot something that he said. He got into a bad temper. If he wants to do something, but you can't help him to do so, he'll be **angry**. (F4)

I was very **hard**. I was **stressful**. He can't express his needs, I can't understand what he needs. Then he was in a **bad temper**. (F9)



'To Care is to Admit the Truth' - Battles

Arousal Factors

- Blaming & stealing
- Disorientation to place & persons
- Frequent falls & injuries
- Hospitalization
- Unable to recall past events
- Poor hygiene
- Night-time restlessness

Triggering Events

- Occurrence of overheated incidents
- Handling unfamiliarity - 'It's not my home'
- Sustaining falls & injuries
- Constant supervision needed
- Cannot engage in usual daily conversations
- Repetitive & constant reminder of past events
- Feelings of poor health & not owning a life
- Feeling 'all the stress is on me' & loosing patience

Strategies

- Admit the situation is getting worse
- Admit exhaustion & tiredness
- Admit ageing & unforeseen illnesses
- Accept to let go, get advice & consider alternatives
- Know where, how and what help is needed
- Welcome visits & support from others/children



The hardest time was he always fell down at night. He's heavy and it's difficult to lift him up. I need to help him to stand up as he can't stand up on his own. I called the police and he was hospitalized. Luckily, **they helped us apply for an aged home. I really can't take care of him anymore.** When he falls, **I can't support him. I'll fall down with him. It's dangerous.** (F5)

It's **difficult to arrange others to take care of her** if I want to leave her for a while. Her condition was declining. She did not sleep sometimes and walk inside the home, wanting to find something. **I can't sleep either. I need to look after her. It affected me during the day. It's difficult and impossible to take care of her** so I consider the OAH. **All the stress is on me!"** (F6)



Issues

- Family carers of elders with dementia needed to **face different kinds of issues** that were **provoked by the older persons with dementia**.
- Understand the **arousal factors, triggering events & strategies for handling them** are ways forward to promoting health & well-being.
- In-depth range of **memorable circumstances & incidents** that can catalyze the affirmative decision to move into RCHs.
- **Changing roles & responsibilities** before & after entry into RCHs.



Conclusion



- Findings generated **understanding of the preliminary processes** that family members went through as they **begun taking care** of the older relative with dementia at home.
- Based on **various changing circumstances and incidents** described, there is a process of how family members then **consider opting out** of caring at home for RCHs.
- Need to **support** these family caregivers is highlighted.



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Participants

Staff Members

Delegates



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