POSTER PRESENTATION

Title: 'You're at their mercy': Older peoples' experiences of moving from home to a care home: A grounded theory study.

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Introduction

- The population of the world is ageing (WHO, 2018), and internationally, there is an increasing trend for older people with complex care needs to reside in care homes.
- It is recognised that the transition from living at home to living in a care home is a uniquely significant experience for older people that can be an stressful, challenging and an emotional event for individuals and families,(Cheek et al., 2007; Ellis 2010; Brandburg et al., 2013; Sury et al., 2013; Ryan & McKenna, 2015; McCarthy, 2016)
- The transition experience includes the decision-making process, planning process and preparation of the older person and their family (Lee et al., 2013). Numerous factors including health and social issues can influence the

adaption and adjustment process for older people when relocating to a care home (Bradshaw et al., 2012; Brownie et al., 2014; Križaj et al., 2016).

- Residents admitted to care homes 'against their will' and those who felt that they 'had no choice' were more likely to experience sadness, depression and anger compared with those individuals who relocated willingly (Fraher and Coffey, 2011; Ryan & McKenna, 2015; Brownie et al., 2014).
- It is known that good communication can enhance the move for residents and families, allowing them to feel confident in their decisions, able to ask questions and make suggestions without fear of repercussions. On the other hand, poor communication can lead to uncertainty, worry and anxiety (Graneheim et al., 2014; Ryan and McKenna 2015).
- Some studies that have focused on the decision-making processes surrounding the move have highlighted that older adults rarely initiate relocation decisions themselves relying instead on family, professionals or both to determine when relocation is called for (Reed et al.,2003; Keister, 2004; Fraher & Coffey, 2011).
- The processes involved in moving to a care home from home or following acute hospitalisation is still poorly investigated and there is a paucity of research that takes into consideration the relocation experience with a focus on the pre-placement and immediate post-placement phase of the move. This study aims to address the dearth of research in this area.

Design and Method

- A grounded theory approach, consistent with the work of Strauss and Corbin (1990, 1998), was therefore chosen as it facilitated the development of a new perspective on the phenomenon of entry to long-term care.
- Consistent with grounded theory methodology, the overall aim of this study was to explore individuals' experiences of moving into a care home with a specific focus on the pre- placement (7 days) and immediate post-placement (within 3 days) period of the move to the care home.

Data collection

- Semi-structured interviews were utilised to collect data from 23 individuals who were due to move to a care home on a permanent basis between April 2017 and August 2018.
- As outlined in **Table 1**, most of the participants were female (n = 14). Semi-structured interviews were utilised as they provided both focus and flexibility, consistent with Strauss and Corbin's grounded theory method.
- Purposive sampling was adopted in the initial phases of data collection, and thereafter, theoretical sampling was employed. The initial selection criteria stipulated that participation in the study was confined to individuals who 1) were due to move to a care home on a permanent basis; 2) were within one week of moving into the care home and 3) minimal or no cognitive impairment as defined by the Mini Mental State Examination (MMSE >24) (24 or over).

- Participants were recruited through social workers within older people's community teams and by waiting lists held by care home managers within a large Health and Social Care Trust in the U.K.

Ethics

Ethical approval to conduct the study was granted by the University Research Ethical Committee, The Office of Research and Ethics Committee, Northern Ireland and the Health and Social Care Trust where the study was carried out.

The main reasons cited for prompting the relocation to a care home was deterioration in physical health (n=17), recent bereavement (n=3) and no-one to take care of me/changing family circumstances (n=3). Only four of the Individuals had made the decision to move to a care home, and of these four, only two were able to move to the care home of their choice.

Insert Table 1: Characteristics of the Interviewees.

Pseudonym	Age	Living arrangement prior to move	Reason for admission	Location of interview (Time-point)
Jane	84	Lived alone in rented accommodation	"Too old to be on my own and I'm frightened of falling". Jane developed a chest infection was admitted to hospital, and then had poor mobility.	Hospital (Pre-placement)
Ellen	82	Lived alone in rented accommodation	Husband died recently. In Hospital had a stroke. Wanted to move to sheltered housing Nursing Home was only available choice.	Nursing Home (Post-Placement Day1)
David	88	Lived alone in family home.	Chose care home as wife already there a year previously. Health deteriorated after a fall at home "I'm too old to be on my own"	Hospital (Pre-placement)
Bernadette	92	Lived alone in family home.	Had fall at home admitted to hospital. "Family thought it was not right for me being on own. Mobility poor- "Doctor says move in".	Home (Pre-placement)
Sarah	84	Lived alone in Rented accommodation.	Health deterioration- admitted to hospital with chest infection- lost mobility. Domiciliary care support twice each day, was not working out.	Hospital (Pre-placement)
Joseph	86	Lived with wife at home	Change in health-. "Losing balance" Wife unable to meet his care needs.	Nursing Home (Post-placement Day2)
Andrew	82	Lived alone in family home	Wife died. Had recent stroke. Was taken to hospital. Family overseas.	Nursing Home (Post-placement Day2)
Martha	80	Lived alone at home	"Fell at home needed a new hip". Changing family circumstances - no-one now at home.	Home (Pre-placement)
Sean	60	Lived with wife and children in family home	Developed sepsis, progressed to paraplegia with lesion on spine. Total nursing care required. Facilities at home do not support nursing care.	Nursing Home (Post-placement Day2)

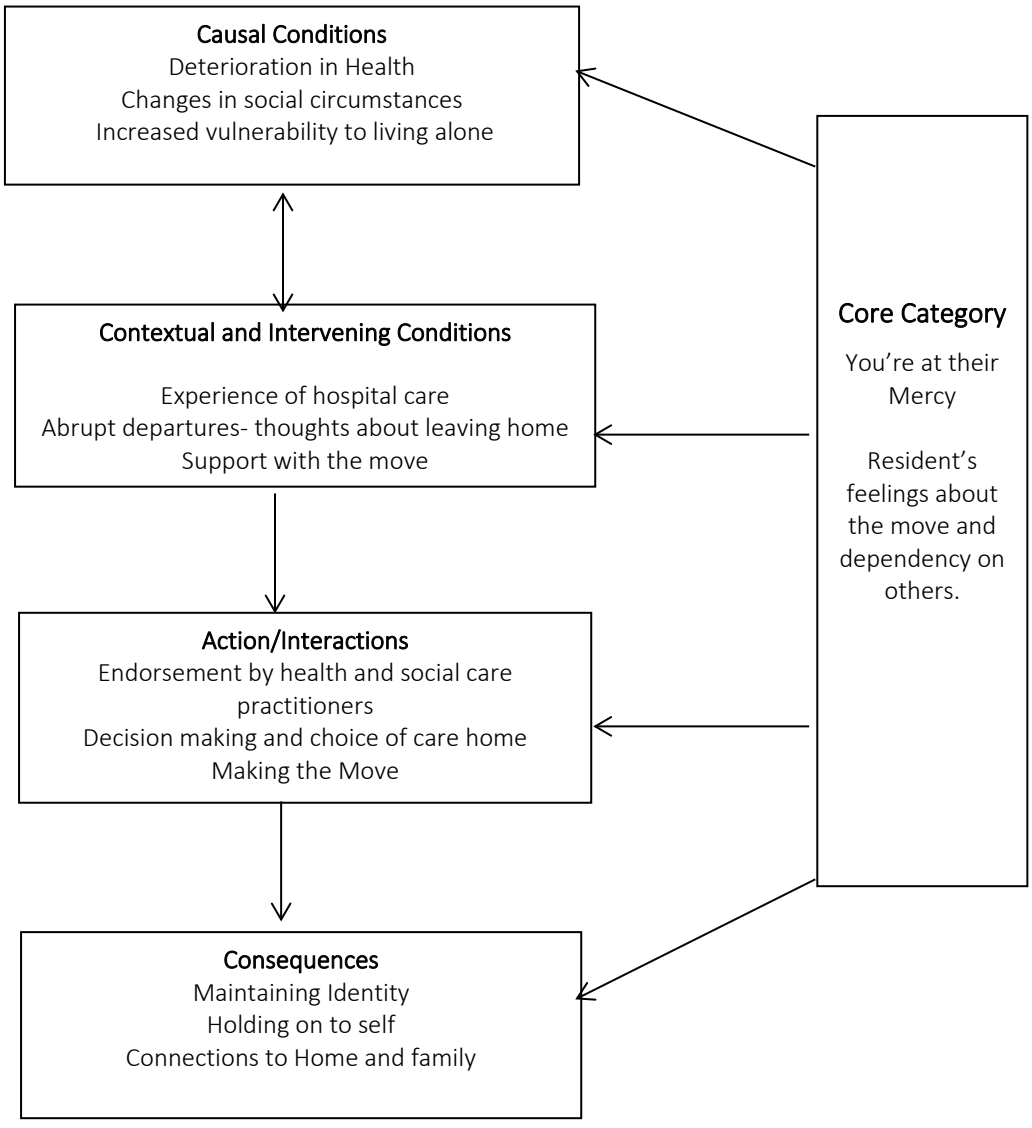
Tracey	88	Lived alone in rented accommodation	Getting worried about deterioration in health or falling, chose residential care admission.	Home (Pre-placement)
Molly	80	Lived alone in rented accommodation	“Developed anxiety”. G.P advised admission “feeling safe now”	Residential Home (Post-placement Day3)
Charles	83	Lived with wife in rented accommodation	Wife died suddenly who was carer. Had been in a wheelchair for many years due to war injury. Admitted to care home on day of wife’s death in a taxi.	Nursing Home (Post-placement Day1)
James	81	Lived with wife at home	Admitted to hospital with stroke and poor mobility. Wife unable to support care at home, due to mental ill health.	Nursing Home (Post-placement Day3)
Ann	90	Lived alone in own home	Admitted to hospital with TIA. Then transferred to nursing Home - “no choice”. Subsequently requested move from Nursing home to residential care - as “not that ill”.	Residential Home (Post-placement Day2)
Isobel	96	Lived alone in rented accommodation	Chest infection admitted to hospital. Reduced mobility in hospital. Son working away.	Home (Pre-placement)
Therese	78	Lived at home with brother and sister.	Recent stroke. Sister and brother were “too old to care for me at home”.	Hospital (Pre-placement)
Francis	87	Lived alone in family home.	Developed pneumonia and was admitted to hospital. G.P advised admission to care home.	Residential Home (Post-placement Day2)
Hugh	83	Lived alone in family home	Accident at home, admitted to hospital. Reduced mobility- niece lives far away and made arrangements for care home admission.	Hospital (Pre-placement)
Mona	81	Lived at home with daughter	Poor mobility for many years. Daughter (carer) fell and injured back requiring hospital admission. Mona was taken to care home the same day. Both mother and daughter will require care home placement.	Hospital (Pre-placement)
Kevin	83	Lived alone in family home	Fell while shopping. Taken to hospital. Staff advised residential care home admission.	Residential Home (Post-placement Day2)
Sophie	74	Lived with niece and nephew	Changing family circumstances following death of brother. Niece and nephew had ownership of house and “I’m no longer welcome”.	Residential Home (Post-placement Day3)
Martina	81	Lived alone in family home	Deterioration in health and general mobility. “family all away and were frightened in case I should fall”	Home (Pre-placement)
Philomena	73	Lived alone in rented accommodation	Getting old now and worried about being on own. Hoping for sheltered housing no places.	Residential Home (Post-placement Day2)

Findings

Key findings pertaining to the experiences of older people at the pre- placement and immediate post-placement phase of the relocation to care home. Identified categories were 1): Inevitability of the Move '*I had to come here'*, 2) Making the Move '*Abrupt Departures'*, 3) Decision Making and Exercising Choice: '*What can I do, I have no choice'* 4) Maintaining Identity, '*Holding on to self'*, and 5) Maintaining Connections. '*I like my family to be near'*. The concept '*You're at their Mercy'* links the identified five categories and encapsulates the experiences of the older people in the study who perceived a sense of disempowerment and being at the mercy of a health and social care system and professionals as well as their family throughout the admission process. Moreover, on arrival to the home they were at the mercy of others to maintain independence and connections to their own identity, sense of self, family and home.

Insert Table 2

Table 2 Residents' experiences of moving from home into a care home- A Grounded Theory Conceptual paradigm model illustrating relationship of major categories to each other and to the core category



From Concepts to Categories:

Inevitability of the Move: 'I had to come here'

The admission to a care home was a unique experience. For a minority, it was a planned process with active participation and for others it was challenging and complex. Health care professionals, especially GPs, social workers, hospital staff and care home managers, were frequently described by individuals as very influential in the decision-making process. Moreover, the data conveyed a sense of the inevitability of the move. Changes in health, social circumstances such as a carer becoming unwell or dying, and an increased vulnerability to living alone were predictors of the move to a care home.

> ***"Well to tell you the truth I wasn't going to do another winter on my own at home. Well I said to Dr X that I wasn't great, and he got me in here. I used to be able to walk anywhere seven days a week do you know how much I can walk now …. about ten minutes then I am done" (Francis)***
>
> ***"I had to come here as I have been on my own a long time since my husband died and I suppose finding things more difficult. My sister would be worried about me you see, her and my daughter. They convinced me that maybe a residential home would be a good place for me as I could come and go as I please" (Philomena)***

The circumstances surrounding an individual's admission to a care home were rarely ideal. The person may have had several previous hospital visits, and perhaps a more recent deterioration in their health that left them unable to care for themselves at home. When combined with little or no family support, a care home was seen as the only choice.

> ***"I have really bad arthritis now and I would have bother getting about you know on my own with no family. You feel as you get older everything starts to fail…it gets worse" (Jane)***
>
> ***"Well I had sicknesses, two operations on my hip, and that's why I can't walk very well, and I had this thing with falling. They came and took me to Hospital and that was it no more going home for me on my own the social worker said, I am here now" (Ellen)***

'Making the Move: 'Abrupt Departures'

Many individuals in the study reported that the move to the care home was often a rushed and a hasty affair regardless if it was from the hospital or their own home.

> ***"Well the same day the nurse in the hospital told me I was not going home the carers from the home came and got me from the hospital and***

took me here" (James)

"I came from home as an emergency the day my wife took sick, she had a stroke and died in hospital. I had to come here. I had no choice about coming here and the social worker said that staying on my own was not an option……. I was put in a taxi with no shoes on my feet and brought here" (Charles)

Many individuals in the study spoke about how care managers/hospital staff are the key people making the decisions about moving to care home, often very quickly once they received confirmation of bed availability.

'When the bed becomes available well that's it, apparently you have to grab it. The sad thing for me about moving to the care home tomorrow is that I'm walking in a dead man's shoes!'(David)

"So really you are at the mercy of other people and the health care system, aren't you?" (Sean)

During the recruitment process the researchers took cognisance of care managers who reported that once financial funding became available for a care home placement, the transfer of older people to a care home very quickly thereafter.

Decision Making and Exercising Choice: '*What can I do, I have no choice'*

The data conveyed that only three individuals had been able to exercise some choice in the care home they moved to:

David explained that *"I chose this nursing home for my wife. She is here, and I liked what I saw".*

Tracey related "*I got a social worker through the G.P. They ask you what you think of all the different ones you know. So, you tell them what you think and that's it. I just looked at two homes that was the choice. I think it's very good here*", and

Therese stated "*Well I wanted to come here as I was here a few years ago for a couple of weeks when I had surgery (pause)…. but it was good then, I liked it, but it is not the same now*".

For some individuals there was no offer or choice to stay at home with increased support. Personal control and level of engagement in decision making processes appear to have been guided by healthcare staff and family.

"I didn't really have a say in where I would go, it was the social worker talking to my family, they arranged it all (Ann)

"The doctor said I needed to come in here. What can I do, I have no choice? I couldn't go home unless I was able to go home, like if I was fit or had proper care at home" (Therese)

The small 'window of opportunity' to obtain a care home 'bed' when one became available, further restricted choice. Individuals conveyed an understanding of having to "*take the next one available*".

"My niece was responsible for me coming here, that's the way it was, the pressure was put on her to get me a home quickly so that is why I am

here. All these places are all filled up you see". (Hugh)

For individuals that were receiving care in acute hospital services, there were additional pressures to 'move on' and 'free up beds'.

> ***"I didn't know about this place at all. In the hospital they were looking to get the bed released and we had to start looking for a care home, but they were all filled up. The pressure was put on us you see so under the circumstances I had to come here and take the first place that came up" (Jane).***

Another factor that appeared to influence the choice of care home was 'age'. After admission to hospital for an extended period following the development of sepsis and paralysis, Sean needed 24-hour care upon transfer to the care home. In Sean's locality, there was only one care home that accommodated residents under the age of 65 years.

> ***"I came here because there was nowhere for me to go. This is the only home that takes people like me under 65 in this area. I had no choice I couldn't comprehend any of this, on me and on my family and it took a while for us to get used to what had happened. (Sean)***

Maintaining identity: 'Holding on to self'

The importance of maintaining continuity between past and present roles and relationships was seen as an important element of future adaptation to life within a care home, encouraging the individual's self-esteem and personal identity. A major challenge associated with the transition into a care home was the perceived loss of the individual's home life, therefore threatening identity, belonging and sense of self.

> ***"I wouldn't feel like myself here. The farm is my life so that is where I want to be every day. You never retire being a farmer you know it is in your blood ……. a way of living" (Joseph)***

Another individual spoke about her feelings of sadness at moving into a care home but worried about expressing this anxiety about the move to others.

> ***"It's a very sad time for me just now you know. But I mean other people are just getting on with it…. people don't talk about their own bothers…. they help everybody else instead. So, I don't know whether I'm right or wrong staying quiet" (Tracey)***

Despite the unsettling nature and anxiety provoking contexts of getting to know residents and staff, efforts were utilised to project self-agency and resilience.

> ***"The future……you don't have much choice being in here but I'm holding on, I'm trying to fit in" (Andrew)***

> ***"Look love I am here now, I've arrived. There is no going back home. I have to put up with it so there is no point in me talking about it anymore. I just need to get on with it now". I don't want to talk about it" (Martina)***

The importance of supporting independence for sense of identity was emphasised. There was frustration expressed that care home staff were preventing them from doing the things they wanted to or were taking their independence away by doing

things for them that they were able to manage themselves.

> ***"I'm trying to get my power assisted wheelchair here, so I can get about myself. This is not a big thing…but once they hoist you into that chair, you're at their mercy for them to take you somewhere" (Sean)***

> ***The hospital told them that I needed to have physio to get me walking more and nothing has happened since I have arrived…. apparently, it all takes time to organise…. Not much good if you have had a stroke and you have to keep moving…… (Andrew).***

On arrival at the care home, some individuals felt that they were incorrectly placed in their particular care home. For these individuals the care home environment and care provided were perceived as not meeting their needs. For one individual, this sense of mismatch, prompted her to discuss other options with the social worker. In her case, this action prompted a rapid move from the nursing home, to a residential home.

> ***"I couldn't sit in a big room with a whole lot of people looking at TV all day and no-one talking. I didn't want to be like that or turn into something that I wasn't. And even in that big room the poor souls would all fall asleep. And I thought you know I'm just not suited to this at all. Restriction, it's a big thing isn't it? When I came around to saying to the social worker that the home wasn't for me, she agreed this residential home was more suitable and here I am" (Ann)***

Maintaining Connections: 'I like my family to be near'

Individuals talked about the positive contribution family visits and old friendships would make towards maintaining a sense of connectedness between their past life at home and life in a care home.

> ***"My family come in and that makes a difference" (Joseph)***

> ***"There's not much to look forward to now I'm here. I mean I look forward to seeing people belonging to me coming in" (Isobel***

It was important for individuals to maintain their role as father, mother, sister and brother. One individual Andrew had a schedule of family visits lined up from children who were living in other countries.

> ***"My children are all away. They have made a pact that one of them will come over every month to see me for a few days. My son is coming this week" (Andrew)***

Getting a care home near to home was important in maintaining a sense of well-being. If participants were able to continue corresponding with friends and families, it gave them a sense of control and enabled them to maintain the relationships. One individual spoke about her "delight" at getting a care home placement which was near to her family and where she felt "at home".

> ***"When I came here, they were all throwing their arms round me here because they all knew me from visiting other residents, so I felt so welcome. (Ann)***

Discussion

- The reasons for moving into a care home were challenging and complex and indeed often fraught with difficulties, not least because of the lack of involvement in decision making about care home placement or location.
- In terms of choice, collaboration, or the actual move itself, there was little or no pre-planning. Neither was there a planned process of admission in which individuals were an active participant.
- For many individuals, there was little opportunity to plan or consider which possessions they could be taking into the home. As a result, personal belongings were brought in by family/ friends /neighbours or indeed from social workers under the instruction of the individual either from a hospital bed or within the first few days of arrival to the care home.
- While there were those who felt that the decision to move to a care home was out of their control or made on their behalf, a few individuals did acknowledge the realisation that perhaps the move was necessary and this is endorsed previously within the literature (Graneheim et al., 2014).
- International research literature (Cooney, 2011, Brownie & Horstmanshof 2012, McKenna & Staniforth, 2017) shows the importance to older people of retaining autonomy in their lives and of feeling valued and purposeful. Older people in this study experienced a lack of autonomy pre- and post-relocating to a care home.
- The world Health Organisation advocate that international health systems should be organized around older people's needs and preferences, designed to enhance older peoples' intrinsic capacity, and integrated across settings and care providers (WHO, 2015).
- By implementing a human rights-based approach, health care professional can empower older people to know and claim their health and social care rights, therefore increasing the accountability of individuals and institutions responsible for respecting, protecting and fulfilling the rights of older people. These core elements of advocacy underpin person-centred approaches to care (McCormack & McCance 2017; Phelan et al., 2017).
- Findings suggest the need for nurse educators to equip future nurses and health care professionals with the knowledge, skills and attitudes to work in partnership with older people, promoting autonomy and choice and challenging systems and approaches that are system focussed, ageist and disempowering to older people..
- It is very disconcerting to find that in the 21st century most older people within this study had such negative experiences of making the move to a care home. These findings indicate a health care system that cannot cope with meeting individual acute health care needs causing disempowerment and depersonalisation of the older person through system pressures.
- This finding may also identify an ageist attitude towards older people who felt 'left out' of the decision-making process thus minimalizing the most significant

move in that persons' life. attitudes, more accessible environments, and changes to health care systems that align with the needs of older people.

Planning for the Future

Considering the implications, recommendations concerning the health and well-being of older people who for whatever reason need to be moved into residential care, include:

- Formulate a policy/model of transfer around decision-making, planning and moving to a care home with emphasis on the rights of individuals to autonomy and choice. Strive to involve prospective residents rather than exclude them.
- Develop a clear care home induction process to be instigated pre-move which should include a visit to proposed care home, moving day plan, welcome orientation to home, planned meeting with residents and staff, information on facilities, services, identified staff member to 'ease transition' by facilitating caring conversations and upholding links to the older person's home and family.
- Support and empower older people to plan for the future when deciding on their own long-term care needs.
- Consider involving advocacy services who may positively facilitate the transition to a care home and help to maximise the quality of life and wellbeing of individuals.
- Future research should include the perspective of health care professionals involved in relocation of older people to care homes.
- Best practice policy directives on moving to a care home should include the development of auditable guidelines to include equal access to health and social care services post transition.

Conclusion

This study offers novel insight from the person's perspective on how they perceive moving into a care home to be at 'the mercy' of others: families, social workers, hospital nursing staff, community care managers and care home staff.

The importance of involving 'the person' in making the decision to move and having a choice of care home is vital and has a hugely significant impact on their experience of transition.

Maintaining continuity between the persons past and present roles, providing opportunities to form new relationships with other residents and staff are also important factors which contribute to the person's adaption process.

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