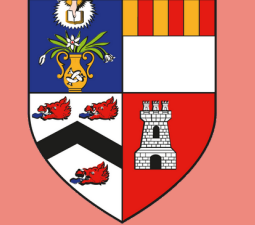


Involvement of older adults in the UK in decision-making related to transitions to care facilities: A narrative review of recent evidence

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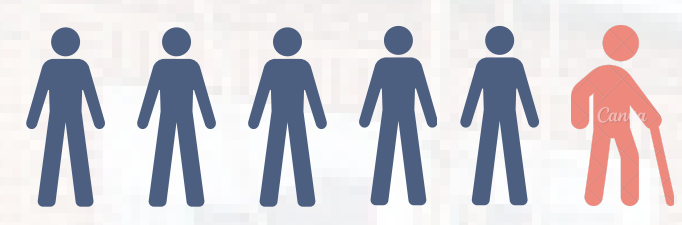
Remarkable research for healthy ageing
THE DUNHILL MEDICAL TRUST

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BACKGROUND

- Trend to increasingly older population (Department of Economic and Social Affairs, 2019)



1 in 6 people aged 65+ by 2050

Increased need for use of care facilities (408,371 older adults in UK care homes; Munson, 2022)



Care homes/facilities: "24-hour residential care settings providing care and support for older adults (aged ≥65 years) both with and without on-site registered nursing staff" (Burton et al., 2022)



- Older adults often only partially or not at all involved in future care decisions (Bynum et al., 2014; High, 1993; Reed, Mikels & Simon 2008, Wetzels et al., 2004)
- Aging research (including reviews) focused on healthcare, medical decisions, overlooking everyday personal care and housing decisions of older adults

Objective of the narrative review:

To explore the involvement of older adults in decision-making processes related to transitioning into care facilities in the United Kingdom.

METHODS

Systematic Search

- Databases searched:
 - Web of Science, Scopus (general)
 - CINAHL (health-focused)
 - ASSIA (social science-focused)
- Inclusion criteria:
 - Studies carried out within the UK in the past 10 years
 - Peer-reviewed studies, not reviews or other non-study reports

Systematic Search Outcomes

- 1,242 screened articles; 9 studies included in narrative analysis
- All qualitative studies (or with quantitative parts not related to the question)
- Studies divided into two groups:

- focus solely on older adults:**
 - Pocock et al. (2021)
 - Stevens, Raphael & Green (2015)
- focus on both older adults and carers:**
 - Kumpunen, Trigg & Holder (2019)
 - Leyland, Scott & Dawson (2016)
 - Lord et al. (2016)
 - O'Neill et al. (2020)
 - Rhynas et al. (2018)
 - Samsi, Cole & Manthorpe (2020)
 - Scheibl et al. (2019)

NARRATIVE ANALYSIS FINDINGS

1. Involvement*

- Least involved: "older old" adults (95+) & older adults with dementia or other frailties, resulting in:

- Frustration & Humiliation

"I feel it's rather humiliating frankly to be treated as incompetent" (Lord et al., 2016, p. 3)

- Pushed resignation:

"And we argued and argued for about four weeks, and in the end they beat me." (Pocock et al., 2021, p. 9)

- Upset & Regret:

"[I]t was a damn silly thing I did to come here from Cambridge. [...] [W]hat with losing these friends." (Scheibl et al., 2019, p. 5)

- Older adults with minimal care needs are often only partially involved despite being fully autonomous:

"My niece was worrying about what was going to happen to me. I think I could have carried on for a while" (Stevens et al., 2015, p. 97)

*most prevalent across analysed studies

- The lack of involvement of older adults found due to carers and professionals working in older adults' perceived best interest:

"It is a shame that it has come to this, but Mum has been in a very confused state which has become much worse recently." (Scheibl et al., 2019, p. 6)

- The positive impact of being involved on transition and the post-transition period:

"It went really well, because I had my own bed and my own big television and it was all done in one day" (Leyland et al., 2016, p. 387)

2. The Necessity of Moving

- Either a gradual accumulation of factors (e.g., worsening of health) or a sudden event (e.g., fall; hospitalisation) (Samsi, Cole & Manthorpe, 2022)

Older adults:

- realising they need more help and wanting to alleviate responsibility for their family carer

"You know you can't do this on your own. You have to have help." (older adult about herself following a fall; O'Neill et al., 2020, p. 7)

"[I]t does take a bit of the pressure off the main carer like [daughter] is to me" (Samsi et al., 2020, p. 1858)

Family carers:

- Often leave transition decisions as a last resort

"I did it when I could cope no more. When I couldn't give her the care she needed and keep her safe." (Samsi et al., 2022, p. 1858)

3. Early Planning

- Early planning is recognised as potentially useful, but generally not discussed and used, despite being recognised as helpful if done
- Avoided to prevent discomfort to older adult or self:

"[T]hey will think the worst...let the patient get used to it a little bit, let it sink in a bit you know and see what progress" (Lord et al., 2016, p. 7).

- How is early planning helpful?

- Emotionally by having time to confront and accept potential future changes:

"You've got to face up to the fact, as one gets older, that you can't do things that you used to do. So you've got to go into a care home and er, be looked after," (Samsi et al., 2022, p. 1858)

- Practically by having contingency plan for potentially sudden change event:

"[I]f you were at the bottom of the waiting list and you are then in a crisis, it's too late" (Samsi et al., 2022, p. 1858)

4. Preferred Information*

*Accounting for location and budget

- Subjective information and information related to personal approach within the homes is preferred
 - e.g.: the feeling and atmosphere of the home, retention of social relations, assurance of continuity (Leyland et al., 2016); friendliness of staff, socialising (Kumpunen et al., 2019)

"[She] would probably have benefited from nursing care but obviously wanted the continuity of friendship." (Leyland et al., 2016, p. 383)

- Objective quality information typically provided by the homes is:

- less important
- difficult to understand
- E.g.: available facilities, building design or medical treatments and health support (Kumpunen et al., 2019)

- Information most trusted from relatives/ friends with experience or own experience

FUTURE DIRECTIONS

- 3 main stages over 3 years:

- Further literature search on:

- alternatives to moving to a care home
- socioeconomic status affecting care decisions
- demographics affecting care decisions

- Qualitative research to understand what older adults and any involved parties find useful and what is difficult when making future care decisions

- line of questioning informed by literature review and by advisors with lived experiences in this topic

- Intervention creation and evaluation

- informed by the analyses of interviews
- different for older adults vs their appointed decision-makers
- evaluation of effectiveness

REFERENCES



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