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Factors affecting dementia care practitioners' decision-making on moves to a care home for persons living with dementia: a factorial survey

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TITLE: Factors affecting dementia care practitioners' decision-making about moving to a care home for persons living with dementia: a factorial survey

ABSTRACT:

Deciding if and when might be the 'optimal' time for a person living with dementia to move to a care home is often difficult for the individual, family and practitioners. In this study we describe the outcome of a factorial survey conducted with 100 dementia care practitioners (a frontline health or social care worker who works with people living with dementia) in England, which investigated factors used in deciding when a person living with dementia moves to a care home. Using findings from qualitative interviews with older people living with dementia, family carers, care home managers and social workers, we identified four factors that appeared to influence the decision to move to a care home: 1) family carers' ability to support the person with daily activities, 2) amount of support provided by homecare workers, 3) level of risk of harm, and 4) the person living with dementia's wishes. These factors were then randomised within skeleton vignettes which told the story of a fictitious woman (Jane) living with dementia at home with her husband. Fifty-four variations of the vignettes were produced and randomly assigned to 100 surveys. 100 volunteer dementia care practitioners (78% female, 54% over 50 years of age) received their own personalised online survey link via email and were asked to read each vignette and decide whether to suggest Jane a) move to a care home or b) continue living at home. Results indicated that Jane's wishes principally drove most dementia care practitioners' decision on whether to suggest a move to a care home or stay living at home (odds ratio = 6.5 to 19.5).

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Findings will inform better understanding of the factors that contribute towards a decision to move to a care home and be of relevance to policy, practice, training and support.

(WORD COUNT: 277/300)

KEYWORDS: long-term care, decision making, dementia, surveys and questionnaires, professional practice, caregivers

WHAT IS KNOWN ABOUT THIS TOPIC:

1. The majority of care home residents have dementia.
2. Deciding if and when to move to a care home is often a difficult decision for people living with dementia, family carers and professionals.
3. Social workers' and care home managers' views on the timing of a move to a care home for people living with dementia are that it is specific to the individual and the context of their care situation.

WHAT THIS PAPER ADDS:

1. The wishes of a person living with dementia predominantly predicted dementia care practitioners' hypothetical decision on whether to suggest a move to a care home.
2. The age and the work setting of the dementia care practitioner influenced their decision-making, with those working in care homes or sheltered housing and younger practitioners being more likely to recommend a move to a care home.
3. Dementia care practitioners reported that in a real-life situation they would have wanted further information, explored the use of supportive interventions (e.g.

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respite, telecare), and increased homecare and support for the person living with dementia and their family, before exploring a care home move.

1. INTRODUCTION

In the United Kingdom (UK) nearly 500,000 (61%) older people live in the community with dementia, while over 300,000 (39%) live in long-term care facilities, known as care homes (Prince et al., 2014). There is substantial evidence that for many people living with dementia and their families, thinking about the possibility and deciding if and when to move to a care home are difficult (Elliott et al., 2007; Elliott et al., 2009) and even distressing (Cole et al., 2018a). It is English government policy that people living with dementia should have a 'choice' about the type of care they receive, depending on their needs (Department of Health, 2014). However, individuals and families often turn to practitioners to provide information, advice and guidance when considering such a move (Cole et al., 2021; Miller et al., 2016), but little is known about how such decisions are made by dementia care practitioners (Cole et al., 2018a).

Dementia care practitioners (such as social workers and care home managers) acknowledge that most people living with dementia want to stay at home for as long as possible (Cole et al., 2021); which is in line with English government policy objectives (Department of Health, 2014). However, when care at home may no longer be feasible, such as the need for 24-hour care or a break-down in the support available, moving to a care home often appears to be the only option. Internationally, care homes are referred to by different terms, such as long-term care facilities or nursing homes (Sanford et al., 2015). In England, care homes are defined as *"a place where personal care and accommodation are provided together"* (Care Quality Commission, 2010, p.26), which can be with or without nursing care.

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Although establishing evidence on the optimal timing of a move to a care home was identified as a major research priority by the James Lind Alliance and Alzheimer's Society UK (2013a), little research has addressed this subject. A systematic review of the literature around timing of a move to a care home for people living with dementia (Cole et al., 2018a) explored evidence on the experiences and opinions of those involved. However, there was limited empirical research on dementia care practitioners' views. Only one United States case study reported the experience of a family carer and her social worker, in which the social worker believed that their role was to take a neutral stance towards a move to a care home and assist the family carer with the emotional side of this decision-making (Mamier & Winslow, 2014). More recently, interviews with social workers and care home managers experienced in care home moves for people living with dementia revealed that these professionals tried to balance the person living with dementia's wish to stay at home for as long as possible with levels of risk. The need for people living with dementia to be involved in the decision-making process (from as early in the condition as possible) was declared paramount (Cole et al., 2021).

Optimally, meaningful shared decision-making requires the involvement of all parties, the person living with dementia, family members (and friends) and professionals (Miller et al., 2016). In this way, people living with dementia and their families play an 'active' part in the decision-making process which involves the incorporation of their views, wishes and feelings about current or future care needs and plans (Coulter & Collins, 2011; Donnelly et al., 2019; Whitlatch et al., 2005). However, some people living with dementia and their families may

be at a loss as to what to do and adopt a 'passive' approach, leaving it for the practitioner to decide on the best course of action (Stevenson et al., 2019).

Decisions made by practitioners are usually based on several factors, sometimes drawn from the outcome of professional assessments (of need and risk of harm), within the guidelines of policy or practice (in England, the Care Act, 2014; Department of Health, 2012, 2014). These can be complex decisions often involving ethical dilemmas based on a series of multifactorial and contextual elements (Cole et al., 2021). However, the precise factors used for deciding whether to recommend a move to a care home for people living with dementia remain unknown (Cole et al., 2021, 2018a).

The aim of this present study was to determine which overriding factors, or combination of factors, influenced dementia care practitioners' decision to recommend that a person living with dementia move to a care home. Our objective was to learn from a hypothetical scenario to develop understanding and knowledge of factors important to practitioners in making this decision, which could inform professional practice, supervision, policy, and support.

2. METHODS

2.1. Study design

The study employed a factorial survey design (Auspurg & Hinz, 2015; Taylor, 2006; Taylor & Zeller, 2007); an experimental method used for descriptive studies which aim to understand factors that influence individuals' decisions. Using real-world scenarios or case-studies (i.e.

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vignettes) individuals are asked questions in response to reading the vignette which require them to make a judgement or decision (Taylor, 2006). This design has been shown to be an effective tool in investigating how health and social care practitioners make decisions, particularly the factors important to them in the decision-making process (Killick & Taylor, 2012). Examples include investigating professionals' decisions on reporting abuse of older people (Killick & Taylor, 2012) and advanced care planning (Donnelly et al., 2019; Sinclair et al., 2016).

2.2. Survey development

For this study, a skeleton vignette (Figure 1) was created to describe a fictitious woman living with dementia called Jane, who lived at home with her husband. The empirical value of this type of study is that each vignette is made up of different 'factors', contextual variables which indicate an important element of the decision-making process, derived from previous related research (e.g. literature review or qualitative findings). From our previous systematic review (Cole et al., 2018b) and qualitative findings, interviewing people living with dementia, family carers, social workers and care home managers (Cole et al., 2021; Samsi et al., submitted), we identified four overriding factors that appeared to influence the decision-making of the timing of a move to a care home. The four discrete factors (translated for the purposes of the skeleton vignette) were: 1) the family carer's ability to support the person with daily activities '*carer support*', 2) amount of support provided by homecare workers '*homecare provided*', 3) level of '*risk of harm*', and 4) the person living with dementia's '*wishes*'. Each factor had different 'levels' (independent variable) which

were variations of the factor defined by the researcher. For example, the factor ‘homecare provided’ had three levels: ‘no’, ‘some’ and ‘a lot’.

‘Carer support’ and ‘risk of harm’ each had three levels, and ‘wishes’ had two levels. Levels for each of the four factors are summarised in Table 1. Factors’ levels (vignette factors) were then randomised within the skeleton vignette which created 54 possible combinations of different vignettes.

[Figure 1: ADD HERE]

[Table 1: ADD HERE]

These vignettes were randomly assigned to surveys, with each participant receiving seven different vignettes, for a total of 700 responses. This sampling frame ensured that each vignette was received multiple times by different participants (at least 5 different participants), allowing for the assessment of variance and internal consistency of the responses (Killick & Taylor, 2012).

The vignettes were presented to dementia care practitioners recruited through an online English survey platform (Jisc.ac.uk). After being presented with a vignette, the volunteer participants were asked to make a judgment in response to the vignette, which is the decision (dependent variable); “Would you suggest that Jane: a) move to a care home or b) continue living at home?” The response of the participant to this question formed the main

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binary outcome measure. This question was repeated after each of the seven vignettes that the participant received in their specific survey.

Each survey included a brief section that asked questions regarding participant demographics: age, ethnicity, gender, profession and work setting. There was also an opportunity for participants to leave a comment at the end of the survey, should participants wish to explain their responses or feedback to the researchers about the survey.

2.3. Sample and procedure

We aimed to recruit 100 dementia care practitioners. Practitioners were eligible if they were working with people living with dementia and their family carers across health and social care settings in England. This was a purposive sample. Practitioners were either professionally known by the researchers as working in dementia services and personally invited to take part by email or responded to adverts distributed by colleagues and peers via various forms of media (e.g. social media, websites). If eligible, practitioners were sent an email with an attached study information sheet. On confirmation that they had read and understood the information, the researcher sent each participant a personalised web address that took them directly to the online survey. The first page summarised the study and gained consent from participants to use their data. Confidentiality and anonymity were maintained, and each participant was assigned a unique ID code. All data were transferred from the survey to SPSS (IBM, 2017) for data management. Ethical approval was obtained from King's College London Research Ethics Committee (MRA-18/19-7106).

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2.4. Statistical analysis

The binary outcome measure ('move to a care home' vs 'continue living at home') was analysed using a generalized linear mixed model with a binomial family specification, which incorporated both fixed-effects parameters and random effects in a linear predictor, via maximum likelihood.

There were three different levels for the fixed predictors: Level 1 included the four discrete vignette factors ('carer support', 'homecare provided', 'risk of harm', 'wishes'). Level 2 included participant characteristics (e.g. age, gender, ethnicity and profession). Level 3 included participant work setting (e.g. hospital, social care, or community health service).

The effects of each level on the outcome were assessed using three models: 1) a model with vignette factors only, 2) a model with vignette factors and participant characteristics and 3) a model with vignette factors, participant characteristics and work settings. This modelling strategy enabled us to assess the effects of the vignette factors after adjusting for participant characteristics.

Random effects were included in the models to allow for the correlation of seven replicates within the same participant's response, and for the random assignment of vignettes to each participant. Auspurg and Hinz (2015) recommend the use of subgroup-specific random intercept models or cross-level interactions to detect differences in the evaluation rules of different participant responses. This method was deemed more "efficient" than using random slope models with randomly varying impacts of the vignette factors. There was

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some uncertainty as to which combination of random effects would lead to the most parsimonious model, therefore we compared intercept only models with different combinations of participant ID and vignette factors (variables) as the random effects, and chose the combination with the smallest Aikake Information Criterion (AIC) and assessing how much of the standard deviation of the outcome was attributable to the random effect component.

A traditional kappa statistic could not be utilised to validate the consistency of the data because a) the number of responses per vignette was not the same and b) each vignette was assessed by different participants. Hence, the intraclass correlation coefficient (ICC) was used to assess the consistency of the response across all vignettes. There were three ways to calculate the ICC for this dataset (ICC (1,k), ICC (2,k), ICC (3,k)) – using the methods described by Koo and Li (2016). R studio (2015) was used to conduct the analysis.

2.5. Qualitative analysis

Participant comments made at the end of the survey were compiled into one document and thematically analysed (Braun & Clarke, 2006). Initial codes were generated by LC and KS independently and grouped into a table or coding framework. These were verified through discussion and consensus and a final coding framework produced. All text was then analysed using the coding framework. All authors discussed and agreed on the final themes.

3. RESULTS

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3.1. Demographics

One hundred dementia care practitioners participated in the factorial survey. Most participants were female (78%), aged over 50 years (54%), and White (81%). Their places of employment ranged from working in a care home (19%) to community, mental health or other social care services settings (39%). There was a broad distribution of practitioners working in health and those working in social care. Table 2 summarises participant characteristics.

[TABLE 2: ADD HERE]

3.2. Model results

The final models included a random intercept for participant ID and a separate intercept for vignette (Table 3). After adjusting for practitioners' characteristics, all four vignette factors were found to be associated with practitioners' decision on a move to a care home for Jane. The strongest association was the factor 'wishes', with the adjusted odds of 'move to a care home' being 11.1 times higher (95% CI = 6.32-19.50) when Jane would 'rather move to a care home' compared to 'wants to stay in her own home'. This was followed by the 'carer support' factor, where a decreasing level of 'carer support' was found to increase the odds of practitioners suggesting a move to a care home by 5.8 (95% CI 3.07-11.04). Higher levels of 'homecare provided' and 'risk of harm' both increased the odds of practitioners deciding to choose the 'move to a care home' option.

[TABLE 3: ADD HERE]

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Factors such as practitioners' gender, ethnicity and profession were not associated with their decision outcome. However, there was an association between practitioners' age and work setting. Compared to those working in shared living settings (i.e. care homes and sheltered housing), practitioners working in hospitals, the community (i.e. health service, primary care), or multiple sites were less likely to recommend a move to a care home. Older age groups were also less likely to recommend a move to a care home, with a reduction of odds by a factor of 0.26 (95% CI = 0.09-0.72) in practitioners aged 50-59 years compared to those less than 40 years of age.

3.2.1. Consistency of the response

Each of the 54 vignettes was assessed by a minimum of five different practitioners (some vignettes being rated by up to 20 practitioners). The ICC values of 0.59 to 0.86 indicated a moderate to good consistency between practitioners' responses for each vignette, which is displayed in Table 4. This was supported by the consistency in the Odds Ratios (OR) and the widths of the confidence intervals across the three models (Table 3) – the fact that the OR values do not vary with the addition of practitioner characteristics suggests that the decision to 'move to a care home' depended more on the vignette factors rather than the differences in practitioner characteristics.

[TABLE 4: ADD HERE]

3.3. Findings from the comments section

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Fifty-seven participants left a comment at the end of the survey. Most appreciated the opportunity offered to give explanations to their responses and reflect on contextual information. Three overarching themes were found: 1) exploring other areas of care and support, 2) wishes of the person living with dementia taking precedence, and 3) requiring more information. These themes are summarised in Table 5 and discussed below.

[TABLE 5: ADD HERE]

3.3.1. Exploring other areas of care and support

Some participants considered a move to a care home to be a last resort, after all options of supporting the person living with dementia at home had been exhausted. Participants, particularly social workers, reported that in real-life they would explore further opportunities to increase the care package at home (e.g. suggest a 'live-in' co-resident care worker), support Jane's husband (e.g. provide respite or a break) and/or reduce levels of risk of harm (e.g. telecare – an alarm system to offer a quick response to a fall), before a care home move was considered. However, there was recognition that additional interventions might not be appropriate for all individuals and that an earlier move to a care home might benefit those in different situations and circumstances to Jane, such as those living alone.

3.3.2. Wishes of the person living with dementia take precedence

Most practitioners maintained that their responses to each vignette were largely determined by Jane's wishes and that this took precedence over other factors. However, many were concerned with the wording of Jane's wish to move to a care home as it included

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the word 'burden' (e.g. '*does not want to be a burden to her family and would rather move to a care home*'). Practitioners queried whether Jane might still 'wish' to move had she not considered herself a burden to her family. Four participants suggested that not wanting to feel like a burden did not mean that Jane would be happy with her choice to move, and perhaps her wish was largely influenced by feelings of guilt. Some participants commented that in a real work situation they would unpick this more, investigating whether better support systems could be put in place, especially for her husband, to determine whether that would mitigate her perception of being a burden, now or in the future. Practitioners also queried Jane's capacity to decide and the timing of when Jane's decision was made, stating that as situations and circumstances change then decisions may also change over time. Others mentioned that even if Jane wanted to move to a care home, unless she was funding the care home fees herself, in some situations she would not be eligible for Local Authority (public) funding, therefore a move to a care home might not be possible unless her needs increased.

3.3.3. More information required

Overall, qualitative analysis of the comments section of the survey indicated that most practitioners felt that the information obtained from the vignettes was not enough to make a decision. They wanted much more contextual information about these four factors as well as other details not included in the vignette, based on a full assessment of needs for Jane and her husband. Participants observed that real life decisions are based on more contextual and nuanced information.

4. DISCUSSION

The findings from 100 factorial surveys completed by dementia care practitioners across England on recommending whether a fictional person living with dementia should move to a care home revealed that all four factors were influential in practitioners' decisions. The wishes of the person living with dementia took precedence over other factors, such as the carer's ability to support the person, amount of homecare received, and risk of harm present. The characteristics of the participants also influenced their decision, with younger practitioners and those working in long-term care facilities, such as care homes, more likely to recommend a move. Interestingly, these factors were independent of each other and differing combination of factors did not increase the odds of the outcome of practitioners' decisions.

Person living with dementia's wishes

While there has been growing interest in the abilities of people living with dementia to express their wishes for their present and future care arrangements (see Whitlatch et al., 2005), and rights-based policy advances in decision-making (Donnelly et al, 2019), practitioners stated they would put the wishes of the person living with dementia above other factors when deciding on recommending a move to a care home. The comments at the end of the survey suggest that some practitioners felt the importance and the appropriateness of including the prior wishes of the person living with dementia in their decision-making. This has been found in other research where the willingness of the person living with dementia to move to a care home is a crucial factor (Cole et al., 2018a; Samsi et

al., submitted), and may even affect the outcome of the move in terms of how well the person settles in the care home (Samsi et al, 2021).

However, the qualitative element of this study also highlighted the complexities of real-world practice in which the practitioners said they would assess the person's decision-making capacity and revisit their wishes over time as a recognition of changing circumstances and therefore perspectives. Assumptions are often made about people living with dementia and their ability to take part in decision-making, such as the person lacks capacity to understand the matters under discussion or is unable to communicate their views and wishes (Donnelly et al., 2019).

Carers' ability to support and amount of homecare

From the survey findings, a decreased ability of the carer to support the person living with dementia and a higher amount of homecare support received were both independent factors that indicated a greater chance of a care home move decision. However, the qualitative text at the end of the survey indicated that, in an ideal situation, professionals would have explored further care and support for Jane and her husband, which might enable Jane to remain at home for longer and not require her needs to be met by a move to a care home.

Risk of harm

The three levels of risk chosen for the vignettes reflected concerns or 'triggers' commonly encountered in dementia care practice (Cole et al., 2018a, 2021; Taylor et al., 2018).

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Stevenson and colleagues (2019) encouraged a ‘problem-solving’ approach to assessing risk and evaluating safety based on actual and not feared risks, as risks for people living with dementia are often ‘emotive’ and not based on probability. They acknowledged that a higher degree of perceived risk of harm indicated a likely decision to move to a care home. It is possible that practitioners’ acknowledgement of their duty of care or professional accountability when it comes to the safety and well-being of people living with dementia might influence their decision-making (Taylor et al., 2018).

Participant Characteristics

While there were many characteristics which did not influence the decision (e.g. gender, ethnicity or profession), dementia care professionals under 40 years of age were more likely to recommend a move to a care home than older professionals. This has been reflected in earlier qualitative research when a social worker said that, when younger, she would have recommended a person living with dementia move to a care home early. However, now being older, she would consider other options before recommending a move (Cole et al., 2018b). The reasons for this difference in decision according to age, however, remain unknown; it may be due to professional or personal experience, or changes in attitudes to housing options and care as people age (e.g. Alzheimer’s Society, 2013b).

Professionals working in long-term care facilities, such as care homes or sheltered housing, were more likely to recommend a move to a care home rather than those working in hospital or community settings. This may have reflected a bias in these professionals to promote their particular perspective of care, or they may be more likely to see under-

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recognised benefits from a care home environment than other community-based professionals who may see it as a 'last resort' (Wagner, 1988). Alternatively, community-based practitioners may be more keen to advocate for the person to remain at home, recognising the wish of many people living with dementia to stay at home for as long as possible (Cole et al., 2021; Cole et al., 2018), and considering a move to a care home as still being a 'last resort' for older people (Campbell-Enns et al., 2020; Alzheimer's Society, 2013b).

4.1. Strengths and limitations

The chosen design for this study was a factorial survey, as this has proven a helpful tool in gauging practitioners' decisions on important health and social care dilemmas that are multifactorial (Auspurg & Hinz, 2015; Taylor, 2006; Taylor & Zeller, 2007). However, the use of factorial surveys has been criticised for being simplistic and lacking external validity, not representing 'real life' scenarios in which practitioners must make a decision (Taylor, 2006). Many participants commented that they would have liked to have further information and not enough was known about Jane and her situation to be able to make a 'proper' judgement, and in the real world more information would be desired. The lack of information is a common complaint when using a factorial survey design (Hughes & Huby, 2004).

One particular concern this study was the use of the wording at a factor level. The use of the word 'burden' in Jane's wish to not be a burden on her family may have been particularly influential. Future studies using this design are recommended to ensure that levels of

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factors avoid such ambiguity. For example, an alternative to “*Jane does not want to be a burden to her family and would rather move to a care home*”, would be simply “*Jane wants to move to a care home*”. This eliminates any doubt as to her intention and wishes about her future care.

Finally, due to the practicalities of randomising vignettes and the limitations of the survey application, each participant received their own individualised link to the survey and was therefore not anonymous to the researcher. This may have caused participants to decide differently than they might in practice and provided what they might consider to be socially desirable responses, or decisions reflecting the priorities of their particular organisation (Taylor & Zeller, 2007, p. 6). We recruited a volunteer convenience sample that are not necessarily representative of dementia care practitioners.

The study’s strengths are found in the multi-randomisation procedures taken in the design of the survey (i.e. randomisation of factor levels within vignettes, and vignettes between and within each survey), eliminating researcher bias (Taylor & Zeller, 2007). It is also argued that the use of vignettes helps to improve awareness of the ways in which practitioners make decisions, especially when given limited information, as it focuses on the essential parts of the vignette, that which is being studied (i.e. factors) (Hughes & Huby, 2004).

4.2. Practice and policy implications

People living with dementia may feel that their views are not heard or considered and that they have limited participation in the decision-making process when it comes to their care

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(Tyrrell et al., 2006). Dementia policy and guidance in England have long advocated person-centred care and the involvement of people living with dementia in discussions of their care (Department of Health, 2014, 2015), giving rise to specific roles when certain decisions are necessary and the person lacks specific decision making capacity (under the provisions of the Mental Capacity Act 2005 (England and Wales)).

While many practitioners seemed to be following policy guidance advocating choice and control, and ageing in place, there are many other factors to consider, not only risks to safety and carer capacity, but other factors such as availability, access, choice and cost of resources (Cole et al., 2021, 2018a; Samsi et al., submitted). The funding of a move to a care home is important as those who are funding their own care may only gain the views of their family or care home managers and not have access to other dementia practitioners from the NHS or social care, thereby receiving a potentially biased perspective and may not consider alternative care options at home.

Future studies should include the legislative context (such as the need for a Best Interests Assessor or Independent Mental Capacity Advocate (for people without family and friends)) and funding entitlements as additional factors as part of the decision-making process. This study has taken a considered approach to the decision on whether a move to a care home should be suggested. However, often such decisions are made in a crisis, and future research could offer a more urgent scenario for practitioners to make their decision on.

Further exploration is required to investigate how these findings could aid practitioners in effectively supporting people living with dementia and their carers. Possible areas of future investigation include: 1) how practitioners assist in planning for future care needs during the early stage of the dementia syndrome, 2) how to incorporate key legislative principles, such as 'taking into account others' experiences, values and perspectives' into their decision-making through multi-disciplinary discussions and professional supervision, and 3) how to support people living with dementia and their families with decision-making when considering care and support options, including a move to a care home.

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CONFLICT OF INTEREST

JM is a Trustee of the Orders of St John Care Trust

(Description of authors' roles)

The research question was initiated by KS and JM. KS, LC, and JM designed the study and LC undertook data collection and drafted the paper. Statistical analyses were conducted and drafted by AB, verified by LC, KS and JM. Qualitative analysis was conducted by LC and verified by KS. All authors contributed to the drafting of the paper and agreed on the final paper for publication.

DISCLAIMER

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REFERENCES

- Alzheimer's Society. (2013a). *Outcomes of the James Lind Alliance Dementia Policy Setting Partnership*. London: Alzheimer's Society.
- Alzheimer's Society. (2013b) *Low Expectations: Attitudes on choice, care and community for people with dementia in care homes*. London: Alzheimer's Society.
- Auspurg, K. & Hinz, T. (2015). *Factorial survey experiments*. SAGE Publications
- Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 32, 77-101.
- Campbell-Enns, H. J., Campbell, M., Rieger, K. L., Thompson, G. N. & Doupe, M. B. (2020). No other safe care option: Nursing home admission as a last resort strategy. *The Gerontologist*, 60(8), 1504-1514.
- (The) Care Act 2014. Available at:
https://www.legislation.gov.uk/ukpga/2014/23/pdfs/ukpga_20140023_en.pdf
- Care Quality Commission. (2010). *Guidance about compliance: Essential standards of quality and safety*. London: Care Quality Commission; 274 p.
- Cole, L., Samsi, K. & Manthorpe, J. (2021). Professionals' views on the 'optimal time' for people living with dementia to move to a care home. *International Journal of Geriatric Psychiatry*, 36(1), 136-142
<http://dx.doi.org/10.1002/gps.5405>
- Cole, L., Samsi, K. & Manthorpe, J. (2018a). Is there an 'optimal time' to move to a care home for a person with dementia? A systematic review of the literature. *International Psychogeriatrics*, 30(1), 1649-1670.
- Authors' copy of accepted manuscript

Cole, L., Samsi, K. & Manthorpe, J. (2018b, July). *Multiple perspectives on when a person with dementia should move to a care home: The 'Optimal Time Study'*. British Society of Gerontology 47th Annual Conference, Manchester, UK.

Coulter A, & Collins A. (2011). *Making shared decision-making a reality. No decision about me, without me*. London: The King's Fund.

Department of Health (2015). *Prime Minister's challenge on dementia 2020*. London: Department of Health.

Department of Health (2014). *Care and Support Statutory Guidance*. London: Department of Health.

Donnelly, S., Begley, E. & O'Brien, M. (2019). How are people with dementia involved in care-planning and decision-making? An Irish social work perspective. *Dementia*, 18(7-8), 2985-3003.

Elliott, B. A., Gessert, C. E. & Peden-McAlpine, C. (2007). Decision-making on behalf of elders with advanced cognitive impairment. *Alzheimer's Disease and Associate Disorders*, 21, 49-54.

Elliott, B. A., Gessert, C. E. & Peden-McAlpine, C. (2009). Family decision-making in advanced dementia: narrative and ethics. *Scandinavian Journal of Caring Sciences*, 23, 251-258.

Hughes, R. & Huby, M. (2004). The construction and interpretation of vignettes in social research. *Social Work & Social Sciences Review*, 11(1), 36-51.

IBM Corp. (2017). *IBM SPSS Statistics for Windows, Version 25.0*. Armonk, NY: IBM Corp.

Authors' copy of accepted manuscript

Killick, C. & Taylor, B. J. (2012). Judgements of Social Care professionals on elder abuse referrals: a factorial survey. *British Journal of Social Work*, 42(5), 814-832.

Koo, T. K. & Li, M. Y. (2016). A guideline of selecting and reporting intraclass correlation coefficients for reliability research. *Journal of Chiropractic Medicine*, 15(2), 155-163.

Mamier, I. & Winslow, B. W. (2014). Divergent views of placement decision-making: a qualitative case study. *Issues in Mental Health Nursing*, 35, 13-20.

Miller, L. M., Whitlatch, C. J., & Lyons, K. S. (2016). Shared decision-making in dementia: A review of patient and family carer involvement. *Dementia*, 15(5), 1141–1157.

<https://doi.org/10.1177/1471301214555542>

(The) Mental Capacity Act 2005. Available at:

<https://www.legislation.gov.uk/ukpga/2005/9/contents>

Prince, M., Knapp, M., Guerchet, M., McCrone, P., Prina, M., Comas-Herrera, A., . . . Salimkumar, D. (2014). *Dementia UK* (2nd ed.). London: Alzheimer's Society.

R Studio Team (2015). *Integrated development for R Studio, Inc.*, Boston, MA,

<http://www.rstudio.com/>

Samsi, K., Cole, L., & Manthorpe, J. (2021). 'The time has come': Reflections on the 'tipping point' in deciding on a care home move. *Aging & Mental Health*, 9, 1–7.

<https://doi.org/10.1080/13607863.2021.1947963>

Sanford, A. M., Orrell, M., Tolson, D., Abbatecola, A. M., Arai, H., Bauer, J. M., . . . Vellas, B. (2015). An international definition for “nursing home”. *Journal of the American Medical Directors Association*, 6, 181-184.

Authors' copy of accepted manuscript

Sinclair, C., Gates, K., Evans, S. & Auret, K. A. (2016). Factors influencing Australian general practitioners' clinical decisions regarding Advance Care Planning: A factorial Survey. *Journal of Pain and Symptom Management*, 51(4), 718-727.

Stevenson, M., Savage, B. & Taylor, B. J. (2019). Perception and communication of risk in decision making by persons with dementia. *Dementia*, 18(3), 1108-1127.

Taylor, B. J. (2006). Factorial surveys: using vignettes to study professional judgement. *British Journal of Social Work*, 36, 1187-1207.

Taylor, B. J., Stevenson, M. & McDowell, M. (2018). Communicating risk in dementia care: survey of health and social care professionals. *Health & Social Care in the Community*, 26; e291-e303.

Taylor, B. J. & Zeller, R.A. (2007). Getting robust and valid data on decision policies: The factorial survey. *The Irish Journal of Psychology*, 28(1-2), 27-42.

Tyrell, J., Genin, N. & Myslinski, M. (2006). Freedom of choice and decision-making in health and social care: views of older people with early-stage dementia and their carers. *Dementia*, 5(4), 479-502.

Wagner, G. (1988). *Residential care: A positive choice, report of the Independent Review of Residential Care, Vol. 1*. London: HMSO.

Whitlatch, C. J., Feinberg, L. F. & Tucke, S. S. (2005). Measuring the values and preferences for everyday care of persons with cognitive impairment and their family caregivers. *The Gerontologist*, 45(3), 370–380.

TABLES

Table 1: Factors and levels within the vignettes

| FACTOR / NUMBER OF LEVELS | LEVELS WITHIN EACH FACTOR | | |
|--|---|--|--|
| Carer support (3) | feels that he is no longer able to support | is finding it increasingly difficult to support | supports |
| Homecare provided (3) | no | some | a lot |
| Risk of harm (3) | went to the shops and got lost on the way home | put the electric kettle on the hob when making a cup of tea | was found by the police out walking at 2am |
| Wishes of person living with dementia (2) | does not want to be a burden to her family and would rather move to a care home | never wants to move to a care home and wants to stay in her own home | |

Table 2: Characteristics of dementia care practitioners

| N=100 | |
|--|------------|
| Age | (%) |
| 18-29 years | 4 |
| 30-39 years | 20 |
| 40-49 years | 22 |
| 50-59 years | 39 |
| 60-69 years | 13 |
| 70-79 years | 2 |
| Gender | |
| Female | 78 |
| Male | 22 |
| Ethnicity | |
| White | 81 |
| Asian / Asian British | 9 |
| Black / African / Caribbean / Black | |
| British | 7 |
| Mixed / Multiple ethnic groups | 2 |
| Other ethnic group | 1 |
| Profession | |
| Admiral nurse / CMHN / CPN | 21 |
| Allied health / care professional | 11 |
| Dementia advisor | 11 |
| General Practitioner (GP) | 4 |
| Manager of homecare/day care/care home | 11 |
| Homecare / care home worker | 5 |
| Nurse | 7 |
| Psychogeriatrician / psychiatrist | 4 |
| Social worker / care manager | 18 |
| Geriatrician | 8 |
| Work setting | |
| Care home | 19 |
| Community mental health service | 17 |
| Homecare | 7 |
| GP surgery | 3 |
| Hospital | 15 |
| Adult social services | 16 |
| Community | 6 |
| Voluntary sector | 6 |
| Multiple sites | 11 |

†CMHN – Community Mental Health Nurse

‡CPN – Community Psychiatric Nurse

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Table 3: The odds of a practitioner suggesting that Jane ‘move to a care home’, according to different factor levels and participant characteristics

| Total responses = 700 out of 100 practitioners (7 replicates per practitioner) | | % response that Jane move to a care home | Factor levels only | | Factor levels and participant characteristics | | Factor levels, participant characteristics and work setting | |
|--|---|--|-----------------------|---------|---|---------|---|---------|
| | | | OR (95% CI) | p-val | OR (95% CI) | p-val | OR (95% CI) | p-val |
| FACTOR LEVELS | | | | | | | | |
| Carer support | no longer able to support n=231 | 30% | 5.62 (2.97,10.64) | < 0.001 | 5.70 (3.01,10.81) | < 0.001 | 5.82 (3.07,11.04) | < 0.001 |
| | is finding it increasingly difficult to support n=238 | 21% | 2.23 (1.18,4.20) | | 2.28 (1.21,4.32) | | 2.34 (1.24,4.43) | |
| Homecare provided | supports n=231 | 14% | ref | | ref | | ref | |
| | no n=241 | 16% | ref | 0.01 | ref | 0.01 | ref | 0.01 |
| | some n=217 | 20% | 1.54 (0.82,2.91) | | 1.49 (0.79,2.80) | | 1.41 (0.75,2.65) | |
| | a lot n=242 | 29% | 2.41 (1.33,4.34) | | 2.35 (1.30,4.23) | | 2.30 (1.28,4.14) | |
| Risk of harm | went to the shops and got lost n=246 | 17% | ref | <0.01 | ref | <0.001 | ref | < 0.001 |
| | put the electric kettle on the hob n=249 | 21% | 1.49 (0.81,2.73) | | 1.54 (0.84,2.82) | | 1.60 (0.88,2.94) | |
| | was found by the police n=205 | 28% | 2.93 (1.58,5.44) | | 3.03 (1.63,5.62) | | 3.32 (1.78,6.20) | |
| Wishes | does not want to be a burden n=353 | 35% | 10.77 (6.17,18.80) | <0.001 | 10.50 (6.03,18.28) | < 0.001 | 11.10 (6.32,19.50) | < 0.001 |
| | Never wants to move n=347 | 8% | ref | | ref | | ref | |

| Total responses = 700 out of 100 participants (7 replicates per practitioner) | | % response that Jane move to a care home | Factor levels only | Factor levels and participant characteristics | Factor levels, participant characteristics and work setting |
|---|-------------------------------|--|--------------------|---|---|
| PARTICIPANT CHARACTERISTICS | | | | | |
| Age | <40 n=168 | 29% | | ref 0.07 | ref 0.03 |
| | 40-49 n=154 | 25% | | 0.59 (0.18,1.95) | 0.71 (0.24,2.11) |
| | 50-59 n=273 | 15% | | 0.28 (0.09,0.85) | 0.26 (0.09,0.72) |
| | 60+ n=105 | 24% | | 0.66 (0.17,2.63) | 0.49 (0.13,1.81) |
| Gender | Female n=546 | 23% | | ref 0.84 | ref 0.68 |
| | Male n=154 | 19% | | 1.09 (0.38,3.16) | 1.21 (0.45,3.23) |
| Ethnicity | White n=567 | 21% | | ref 0.21 | ref 0.76 |
| | Other n=133 | 26% | | 1.84 (0.62,5.42) | 1.15 (0.42,3.17) |
| Profession | Health n= 238 | 22% | | ref 0.83 | ref 0.31 |
| | Community n= 224 | 23% | | 1.15 (0.41,3.21) | 1.40 (0.51,3.82) |
| | Social Care n= 210 | 20% | | 0.77 (0.26,2.23) | 0.69 (0.22,2.19) |
| | Other profession n= 28 | 25% | | 1.42 (0.15,13.46) | 3.01 (0.37,24.31) |
| Work Setting | Hospital n=105 | 28% | | | 3.36 (0.97,11.62) <0.001 |
| | Community n=343 | 17% | | | ref |
| | Shared living n=133 | 35% | | | 7.39 (2.50,21.83) |
| | Other or Multiple sites n=119 | 17% | | | 0.94 (0.30,2.97) |

Table 4: Intra class correlation coefficients assessing the consistency of response across 54 vignettes

| Type | ICC | 95% CI |
|-----------|------|-----------|
| ICC (1,k) | 0.71 | 0.59-0.81 |
| ICC (2,k) | 0.77 | 0.68-0.85 |
| ICC (3,k) | 0.78 | 0.69-0.86 |

†ICC – Intra Class Correlation.

‡(1,k) - One-way random effects, absolute agreement, multiple raters/measurements

§(2,k) - Two-way random effects, absolute agreement, multiple raters/measurements

¶(3,k) - Two-way mixed effects, consistency, multiple raters/measurements

Table 5: Themes from the comments section of the survey (n=57)

| Overarching Theme | Sub theme | Examples |
|---|---|--|
| Exploring other areas of care and support | Interventions to reduce risk of harm | Remove appliances (e.g. kettle), telecare, monitoring, Herbert protocol, Police at Risk Register |
| | Increase package of care | Live-in care, sheltered housing |
| | Support for carer | Residential respite, day care, sitting service, admiral nurse, dementia advisor |
| Wishes of the person living with dementia take precedence | Burden | Wish to move to a care home 'without' burden being a part of the option. |
| | Account for capacity and changes of perspective over time | Fluctuating capacity, capacity to make this decision, is she aware of the risks of harm |
| | Funding options | Self-funding or eligibility of Local Authority funding |
| More information required | | Difficult to make a decision based on presumptions, and without a full assessment of needs and wishes of all involved. |

FIGURES

Figure 1: Skeleton vignette

Jane was diagnosed with dementia two years ago. She is in the moderate stages of dementia and is sometimes able to make decisions. She lives with her husband who [_ _ _ _ _] her with her daily activities. She receives [_ _ _ _ _] support from home care workers, and Jane's dementia is getting worse. Recently she [_ _ _ _ _]. Jane has always said that she [_ _ _ _ _].