Patient and carer preferences for home support services in early stage dementia

Helen Chester[1], Paul Clarkson[1]*, Linda Davies[2], Caroline Sutcliffe[1], Sue Davies[1], Alexandra Feast[3a], Jane Hughes[1] and David Challis[1]

[1] *Personal Social Services Research Unit, University of Manchester, Manchester M13 9PL, UK; (helen.chester@manchester.ac.uk; caroline.sutcliffe@manchester.ac.uk; susan.l.davies@manchester.ac.uk; jane.hughes@manchester.ac.uk; david.j.challis@manchester.ac.uk).*
[2] *Centre for Health Economics, Institute of Population Health, University of Manchester, Manchester M13 9PL, UK; (linda.m.davies@manchester.ac.uk).*
[3] *North East London Foundation Trust, Goodmayes Hospital, Ilford, Essex, UK; [a] now UCL Division of Psychiatry, 6th floor, Wing B, Maple House, 149 Tottenham Court Road, London W1T 7NF; tel: 02076799500, (a.feast@ucl.ac.uk).*

and Members of the HOST-D (Home Support in Dementia) Programme Management Group.

*Address for correspondence: Dr Paul Clarkson, Personal Social Services Research Unit, 2nd Floor Crawford House, University of Manchester, M13 9PL, UK (Email: paul.clarkson@manchester.ac.uk)

4,520 words

Conflict of interest

None.

ABSTRACT

Title: Patient and carer preferences for home support services in early stage dementia

Journal: Aging & Mental Health

Objectives. With population ageing, dementia is a significant public health and care challenge. The immediate priority is to help those with dementia, and their carers, to live well through appropriate interventions. Since around 60 per cent of those with dementia live at home, evidence as to preferences for home-based support are needed as a prelude to effectiveness evidence. The objective was to examine patients' and carers' preferences for different attributes of home support in early stage dementia to build on the paucity of evidence in this area.

Method. Preferences from 44 patients and 103 carers, recruited through memory clinics and an on-line questionnaire, were assessed with a Discrete Choice Experiment survey, with attributes informed by an evidence synthesis and lay consultation. A conditional logit model was used to estimate preference weights for the attributes within a home support 'package'.

Results. The most preferred attributes were support with personal feelings and concerns, provided by a trained counsellor at home (coefficient 0.67, $p=<0.001$) and information on coping with dementia, provided by an experienced worker at home (coefficient 0.59, $p=<0.001$). However, for patients, opportunities for social and recreational activities were considered the most important (coefficient 0.48, $p=<0.001$).

Conclusions. These patient and carer preferences for home support concur with emerging evidence on psychosocial interventions in dementia. Support with personal feelings, information and social engagement are important components. Additionally, knowledge of patients' and carers' preferences can identify other attributes that may be important to effectiveness in 'living well' but for which there remains limited evidence.

Key words: dementia; carer/patient preferences; home-based interventions

Introduction

With population ageing, dementia is a significant public health and care challenge. In 2015, worldwide, 9.9 million new cases of dementia were estimated each year, one case every 3.2 seconds, leading to a figure of 46.8 million people living with dementia. This figure is projected to reach 74.7 million in 2050 (Alzheimer's Disease International, 2015). At current rates of prevalence, there were 850,000 people with dementia in the UK in 2015, which is forecast to increase to over 1 million people by 2025 and be in excess of 2 million by 2051 (Alzheimer's Society, 2014). The total estimated worldwide cost of dementia reached US$ 818 billion in 2015, and it is projected to become a trillion dollar condition by 2018 (Alzheimer's Disease International, 2015). At present, the cost of dementia in the UK is estimated at £26.3 billion per annum (Alzheimer's Society, 2014) and by 2026 the cost will rise to £34.8 billion in the UK (King's Fund, 2008). Currently there is no evidence-based method of preventing or curing dementia as it is a chronic, long-term condition associated with high levels of physical as well as cognitive problems and increased risk of death. However, the immediate priority remains helping people to live well with dementia (Department of Health, 2009), through developing interventions likely to ameliorate difficulties and enhance well-being, so-called tertiary prevention (Cooper, 2002).

As around 60 per cent of people with dementia live at home, helping them to live well requires effective and appropriate forms of home support from a variety of agencies. A range of home support approaches are used in different settings. However, little is known about their effectiveness or acceptability and usefulness (Comas-Herrera, Wittenberg, Pickard, & Knapp, 2007). Reviews have indicated that psychosocial interventions, broad-based approaches describing different ways of supporting people with dementia and their carers to overcome challenges and maintain health, may potentially be effective in supporting people with dementia and their carers at home (Elvish, Lever, Johnstone, Cawley, & Keady, 2013; Olazáran et al., 2010). Yet, evidence of translating these treatment approaches into effective routine home support is scant (NICE-SCIE, 2011). Moreover, whether patients/service users and carers feel these approaches are acceptable, relevant and appropriate for their needs is unclear. Knowledge about how particular components (active ingredients) of these interventions may be combined into different packages of support is relatively limited.

Canvassing the views of patients and carers concerning what care is needed and their priorities for different components of care is seen as increasingly important (Care Quality Commission, 2013; Freeman & Hughes, 2010). Patient and carer preferences can guide treatment and care decisions and recognising and responding to them are part of promoting person-centred care, which is associated with better engagement with, and adherence to, treatment (Wilberforce et al., 2016). Discrete Choice Experiments (DCEs) offer a means of exploring the value patients and carers place on different attributes of home support (Ryan, Bate, Eastmond, & Ludbrook, 2001a). They also provide an opportunity to make more realistic choices between them compared with simple ranking exercises, which ask them to assess features separately rather than as part of a package of care (Wijnen et al., 2015). Separate choices may oversimplify the process of eliciting preferences, compared with options participants face in real-world situations. Moreover, DCEs are also sensitive to changing levels of input rather than just the presence or absence of features and thus enable respondents to prioritise differing degrees of input, allowing trade-offs among choices (Ryan et al., 2001a; Phillips et al., 2002). This is particularly important because packages of support, with multiple inputs, operate in a cost-constrained environment and a recipient cannot have everything they might wish. For example, a care package may be more attractive because it contains a comprehensive counselling element

alongside information and advice at home, but it may be more expensive. This method therefore offers a way of eliciting, systematically, evidence of the patient/carer experience, which can be used to promote changes to health and social care support, better suited to their needs and wishes.

However, there have been limited applications of reports of DCEs in older people's care and particularly in dementia care (Access Economics Pty Limited, 2009; Hall, Kenny, & Hossain, 2007; Nieboer, Koolman, & Stolk, 2010; Ryan, Netten, Skåtun, & Smith, 2006). Nevertheless, a pilot study focussing on home care for older people with dementia used this method to identify carers' preferences amongst several attributes, such as workers' availability, continuity and training, and whether a waiting list operated and concluded that this provided a useful and feasible means of identifying aspects of home care, important to carers of people with dementia (Chester et al., submitted). More widely, home support for dementia is formal support (i.e. not purely through informal and family channels), which may be categorized according to its expressed purpose, and includes: information about dementia and its consequences; supportive emotional and practical help; education, including skills training in managing behaviour; and more structured therapeutic interventions, such as counselling. The current study aims to explore the relative value of attributes of home support in dementia from the perspective of both patients with dementia and their carers in relation to the early stages of dementia using a DCE approach.

Methods

Design of the Discrete Choice Experiment

In this study, we conducted a Discrete Choice Experiment (DCE) to establish the relative value of different attributes of home support from the perspective of both people with early stage dementia and their informal carers (Lancsar & Louviere, 2008). A key stage in the design of the DCE for this study was ensuring that relevant attributes (or components of the intervention) and levels were included and that these were described in a meaningful way (Coast & Horrocks, 2007). Evidence synthesis review methods and consultations with people with dementia and carers were used to achieve this. First, a systematic review of effective home support to people with dementia and their carers was conducted as part of a wider research programme (Clarkson et al., 2016). The review aimed to identify both components and impacts of home support interventions for people with dementia; that is, 'who, did what, where and how'. The components identified in this review were used to generate an initial list of attributes and levels for the DCE.

Second, consultation meetings were held with two patient and public involvement reference groups in May 2015 to identify those attributes (n=13), from this list, particularly salient to people in early stage dementia and their carers. The first group was made up of three carers and one person in the early stage of dementia. The second group included one person in early stage dementia and five carers. Both groups were facilitated by one researcher experienced in this area of research with the assistance of two others. Attendees were asked by this researcher what forms of home support were potentially helpful to them and the person they cared for and invited to comment on the list of components of home support and prioritised and explored a subset of these in more detail. The other researchers took written notes of the discussion. As noted in Table 1, three components emerged as of particular importance.

These consultations were used with the evidence review to identify the range of attributes for the DCE. Owing to limits on the number of attributes that can be included, to avoid the associated large sample sizes required to explore a large number of components and the potential cognitive complexity this would cause (Miller, 1956), seven attributes were selected for the DCE. The description of the attributes and levels were informed by the consultation groups. Six were components of a home support package, which respondents may have to trade-off against each other and are described in Table 1. Additionally, an attribute of cost was included as an indirect method of estimating willingness to pay for each of the other components. Descriptions of each of the attributes were deliberately short and succinct to make them easier to understand and avoid misinterpretation. Details of the different levels of each attribute are described in Table 2.

[Insert Table 1 around here]

The seven attributes were used to describe hypothetical home support packages in a series of choice questions. Each choice question described two hypothetical alternative home support packages – option A or option B – and asked respondents to choose the one they preferred most. To enable us to obtain estimates of the respondents' strength of preference for the different attributes of a service care packages the same attributes were used to describe the services each time with the levels of all attributes varying between each (Ryan et al., 2001a). It was not possible to include all possible combinations of attributes and levels in the questionnaire. With seven attributes, with three levels for each, the total of all possible combinations would be 2,187 (3^7) (Lancsar and Louviere, 2008). Therefore this was reduced to a fractional factorial design, a sample from the full factorial number of possible combinations that, nevertheless, allows all effects of interest to be estimated (Burgess, 2007; Ryan et al., 2001a).

The software from Burgess (2007) was used to calculate an optimal number of choice sets based on the number of attributes and levels, with a choice between two scenarios in each set. The calculation resulted in a design of 18 choice sets with two scenarios in each set. The design of the choice questions met published criteria so that each level appeared with equal frequency (level balance), there was no overlap between attribute levels in each choice set, efficiency and near orthogonality (attributes are statistically independent and uncorrelated) (Burgess, 2007; Sloane, 2010). Figure 1 shows an example of one of the 18 choice questions included in the DCE schedule.

The questionnaire also included questions about participants' demographic characteristics and their health status. These are factors that may influence participants' preferences (Turner et al., 2007). Health status was measured by the three-level EQ-5D (EuroQol) measure (EuroQol Group, 1990) and converted to utility values using published utility tariffs for the UK population (Dolan, Gudex, Kind, & Williams, 1995).

[insert Table 2 around here]

[insert Figure 1 around here]

Participants

Between November 2014 and August 2015, patients with early stage dementia and their carers were recruited through memory clinics and a carers organisation. Respondents recruited through the former participated in a face-to-face interview and those recruited through the latter completed the DCE online. For the face-to-face interviews, patients with early stage dementia were identified by the clinic and them and their carers (if appropriate) were also invited to take part. Potential participants were provided with information sheets. For the face-to-face interviews, written information sheets were distributed to potential participants prior to being asked if they wished to participate. Formal written consent was obtained prior to completion of the schedules. All consent procedures complied with the *Mental Capacity Act* 2005; researchers ensured that any carers or family members were formally consulted on the question of capacity if this arose as an issue. Respondents who took part in the online survey received an invitation and written information about the survey via an email from the carers organisation prior to taking part. The invitation specifically asked people who were carers of people with early dementia to respond to the survey. They consented through submission of their completed online form and their responses were returned anonymously. In both cases, the attributes contained in the survey were described more fully (as in Table 1) before respondents began the survey and they were able to ask any questions they had about the exercise. In the face-to-face interviews, the interviewers were able to answer any queries during completion of the exercise and respondents completing the exercise online were provided with contact details of a named researcher in case of any comments or queries. The NHS Research Ethics Committee, North West, Haydock approved the study (14/NW/1044; 17 July 2014).

It was estimated that with 18 choice sets, a minimum sample of 85 was required for accurate estimation of the relative value of attributes at alpha=0.05 and 90% power (Hensher, Rose, & Greene, 2005).

Statistical analysis

The data were analysed using the statistical package STATA. There were multiple observations for each respondent, reflecting the number of choice questions in the DCE design. First, a model was estimated to ascertain the relative importance of each attribute in the choice of care package. The probability of each respondent choosing A or B for each choice was dependent on the seven attributes included. A multinomial logit model (conditional logit model), an approach widely used in applications of this nature, was used to analyse the data and estimate the weights (Bowen et al*.,* 2012; Ryan, Gerard, & Amaya-Amaya, 2008). This is the statistical technique used to fit McFadden's choice model (Louviere, Hensher, & Swait, 2000). In a sensitivity analysis we also fitted different model forms (conditional logit with robust standard errors and panel probit model as an alternative to conditional logit) to assess whether these influenced the final preference order and marginal willingness to pay values. There was no evidence that the model form had an impact on the relative importance of attributes or marginal willingness to pay. This did indicate some variation in the sub-group analyses, but this was thought to be due to the smaller sample sizes. In the model presented, *p* values $\leq 5\%$ were considered statistically significant. However, the full model with all attributes included was reported, irrespective of statistical significance. This was considered to be an appropriate means of presenting findings from DCEs due to the possibility that non-significant attributes may still have influenced respondents' choices. The model provided information about the direction of influence of each attribute, for example a positive sign for a level of an attribute indicates that it is preferred relative to the base category.

Second, marginal willingness to pay values were calculated to explore what respondents would be willing to pay for a discrete change in a level of a particular attribute, thus giving an indication of attributes they considered most important (Nieboer et al., 2010). Exploratory sub-group analyses were used to explore how preferences varied across individuals (Bowen et al., 2012; Ryan et al., 2001a). The sub-groups considered included whether preferences varied between patients and carers and between the method of administration (face-to-face *vs.* online). This approach has been referred to as segmented or subgroup analysis (Ryan et al., 2001a).

Results

Participant characteristics and health status

A total of 147 respondents participated in this study, with 43 completing an online questionnaire and 104 taking part in a face-to-face interview. Feedback from the interviewers suggested that generally completion took between 35 and 60 minutes. For 37 of the respondents completing the questionnaire online it was possible to determine the length of time they had taken to complete the survey. This suggested that completion times ranged from between 6 and 58 minutes, 15 minutes on average. A small number (N=6) of respondents paused whilst completing the DCE questionnaire and returned to fully complete it on another occasion within the next few days. Table 3 provides socio-demographic details of the participants. There were 44 patients and 103 carers. The majority of respondents were white and female. All patients and most carers completed the survey in a face-to-face interview meaning overall the majority of respondents completed it in this way. The average health status utility score was 0.80 overall, with patients scoring 0.73 and carers 0.80.

[insert Table 3 around here]

Preferences for different components of home support

Table 4 presents findings from the analysis which explores the influence of each attribute on respondent choices between alternative care packages.

[insert Table 4 around here]

All attributes and levels were found to have a statistically significant impact on respondent choices with p-values equal to or smaller than the 5% significance level. Findings demonstrated that 'support with personal feelings and concerns – provided by a trained counsellor at home' was judged by respondents as one of the most important attributes together with 'information on coping with dementia – provided by an experienced worker at home'. The findings also showed respondents preferred a service where there were opportunities for social and recreational activities provided by a dedicated worker at home or available through outside organisations. Cost had a significant effect on choice of care package with lower cost packages taking preference. From the marginal willingness to pay analysis, the most valued attribute was again 'support with personal feelings and concerns – provided by a trained counsellor at home' for which participants would be willing to pay £31 per week. 'Advice on the use of memory aids – available at a clinic appointment' was relatively less valued, with respondents willing to pay £5 per week for this service.

Additional analysis also explored how preferences varied according to whether or not the respondent was a carer or patient and the method of administration. Most important to carers were 'Support with personal feelings and concerns – provided by a trained counsellor at home' and 'Information on coping with dementia – provided by an experienced worker at home.' Most important to patients were 'Opportunities for social and recreational activities – provided by a dedicated worker at home' and 'Support with personal feelings and concerns – provided by a trained counsellor at home.' For both patients and carers there was a trend for preferring attributes being provided at home with the exception of health promotion advice, where for patients, this being provided at a clinic was equally preferred. For carers, there was a greater preference for this being provided at a clinic appointment. With regard to advice on the use of memory aids for patients there was a preference for this being provided by a trained worker at home but no preference between this being available at a clinic appointment as opposed to not being provided. In contrast, carers showed a preference for this being provided at a clinic appointment, though there was little difference in the coefficient for this being provided by a trained worker at home.

In terms of method of administration, irrespective of whether they completed the survey online or face to face 'Support with personal feelings and concerns – provided by a trained counsellor at home' and 'Information on coping with dementia – provided by an experienced worker at home' were the most preferred attributes by carers. Health promotion advice and advice on the use of memory aids were least preferred by both groups. There was again a preference for attributes being provided at home amongst both groups; however, there were two differences. Those interviewed face-to-face appeared to have a preference for advice on the use of memory aids being provided at a clinic whereas those completing the survey online appeared to prefer this being provided at home by a trained worker. Likewise, those being interviewed face-to-face appeared to have a preference for health promotion advice being provided at a clinic, with those completing the survey online expressing a slightly greater preference for this being provided regularly at home as opposed to in a clinic setting.

Feedback was received from a small number of carers and patients about their experience of completing the survey and this was mixed in nature. Some indicated that the survey was challenging to complete, with reports of 'too many choices' within each scenario whilst others were pre-occupied with the cost of the packages rather than focusing on the different attributes of home support, in conjunction with cost. These carers wanted to choose the cheapest option regardless of the attributes listed within each care package. Furthermore, some carers and patients struggled with the hypothetical nature of the questions. Following further discussion and reassurance that they would not be using their own money and would not actually be receiving the services, these concerns however were ameliorated and the questionnaires were completed. Some were very positive about the experience with respondents indicating that they thought the survey was 'a good idea', 'useful' and 'not tiring' with one respondent going on to say that they enjoyed the task, being of the opinion that it was stimulating.

Discussion

The main findings of this study are that, in early stages of dementia, the most preferred attributes for home support were support with personal feelings and concerns – provided by a trained counsellor at home and information on coping with dementia – provided by an experienced worker at home. These two attributes were found to be most preferred by carers but for patients, opportunities for social and recreational activities – provided by a dedicated worker at home was considered the most important, followed by support with personal feelings

and concerns. These findings concur partially with other studies on preferences for dementia care, albeit there are only limited examples of such studies available. The Discrete Choice Survey undertaken by Access Economics Pty Limited (2009), for example, found that counselling, recreational activities, education, and information services provided in the community were particularly valued by carers of those with dementia. From a slightly different perspective, that of the preferences of the general older population for long-term care services (Nieboer et al., 2010), attributes most valued were those of social activities, along with transportation and the availability of a regular care provider. The health status of participants as measured by the EQ-5D was consistent with previous studies of patients in early stages of dementia (Jönsson et al., 2006) and carers of older people with dementia (Knapp et al., 2013).

Generally, both patients and carers tended to prefer attributes to be provided at home. The findings about the two main attributes favoured by carers were largely unaffected by whether the DCE was completed face-to-face or online (viz. support with personal feelings and concerns and information on coping with dementia). However, those carers completing the DCE online preferred all the chosen attributes to be provided at home. This might suggest a preference amongst patients and carers for options where there was more personal contact available. This may have ramifications for those developing home support services in early stage dementia as more personalised approaches, involving face-to-face contact may be more preferred (Bowen et al., 2012; Bowers, Fibich, & Jacobson, 2001). However, in this survey, patients equally preferred health promotion advice to be provided, at a clinic. Carers, on the other hand, tended to prefer this attribute to be delivered at a clinic rather than at home. Therefore, there may be certain attributes, such as information giving, that is just as, if not more, appropriately provided through health or care facilities such as clinics. However, in contrast, other attributes, such as emotional support ('support with personal feelings or concerns') may be more effectively provided at home and there is evidence to support this, particularly that to caregivers (Woods, Wills, Higginson, Hobbins, & Whitby, 2003).

Evidence of patient and carer preferences has implications for clinical practice. First, it is feasible to enquire into the choices of patients in early stage dementia and over the trade-offs that they make, in balancing the mix of support components they may wish to receive. The DCE is one means of doing this and it has the advantage that it can take into account these trade-offs in making choices between alternate packages. However other preference elicitation methods are available (Ryan et al., 2001b) and it would be useful to explore some of these within dementia care, as the cognitive complexity of the DCE may pose difficulties in administration, particularly in later-stage dementia. Eliciting the choices of carers is also feasible using this method and it is noteworthy that many of the attributes examined here are those signalled as particularly important in other carer consultations (Newbronner, Chamberlain, Borthwick, Baxter, & Glendinning, 2013).

Second, knowledge of these patient and carer preferences might also be useful when considering the types of home support package that might best be provided in localities. Commissioners and service planners may be assisted in their decisions as to which care packages might be more appropriate to implement by relying on firstly, which components are shown to be most valued by those to whom they are to be delivered. These preferences can then be linked to the effectiveness evidence for each component, or mix of components that may be identified (Clarkson et al., 2016). Thus, decision making about relative degrees of priority can then be informed by both patient/carer preferences and data concerning effectiveness. Additionally, knowledge of patients' and carers' preferences can identity other attributes that may be important to effectiveness in living well but for which there remains

limited evidence. One such example from this study would be a cognitive training component, implemented through the provision of and advice concerning the use of memory aids in the home, an attribute valued by patients and carers. There remains, however, only limited evidence for the effectiveness of such an intervention (Gillespie, Best, & O'Neill, 2012; Gillespie & O'Neil, 2014). Future studies could test the effectiveness of a package, containing this element as a main component, to further inform decision-making.

There were several limitations but also strengths to this study. A general limitation to designing DCEs is that the researcher is restricted in the number of attributes to include, due to limitations in the amount of information people can process. If too many attributes are included participants can find it tiring, leading them to ignore attributes or address them in random ways (Green & Srinivasan, 1990). Thus, our findings are dependent on the attributes chosen and other potential attributes may have resulted in alternative choices on the part of participants. However, a particular strength of this study is that the attributes chosen were grounded in the evidence synthesis and lay consultation. Such qualitative dimensions to piloting attributes for use in DCEs follows established practice (Coast & Horrocks, 2007). In this way, the consultation meetings held with two patient and public involvement reference groups provided useful validation of attributes for inclusion in the DCE, which helped ensure they had real world validity (Turner et al., 2007). Furthermore, all attributes were found to have statistically significant coefficients, indicating that they strongly influenced choices (Coast & Horrocks, 2007).

A further limitation is that DCEs can be cognitively demanding. As noted above, feedback from a small number of carers and patients was mixed with some suggesting that the survey was challenging to complete and others seeming to enjoy the task. As with all feedback of this nature, it may be that responses depend on the person being consulted. A particular strength, to counter these limitations, was that the study achieved and exceeded the minimum sample size; 147 participants completed the DCE. Of note is that 44 of these were patients with early stage dementia, receiving support from memory clinics. The fact that this group of patients, and their carers could complete the DCE within a 35 to 60 minute interview is testament to the feasibility of this approach in a clinical setting. Carers, on the other hand, were able to complete the survey online, on average, within 15 minutes, which again is evidence that the approach is viable to explore preferences for dementia care, amongst a large group of geographically dispersed carers able to complete the schedule electronically.

This study sought to explore the relative value patients with dementia and their carers placed on different attributes of home support in early stage dementia utilising a DCE approach. People with dementia and their carers were willing and able to participate in the face-to-face interviews. In addition, carers successfully completed the schedule online in a short time period. The findings offer insights into patient and carer preferences which may aid the delivery of effective provision and delivery of home support from the perspective of those receiving these services. However, participants did not form a homogenous group with differences evident between the two groups of respondents. Thus these findings highlight the challenge for policy makers, commissioners and providers inherent in delivering care tailored to the preferences to both patients with dementia and their carers simultaneously.

References

Access Economics Pty Limited. (2009). *Making Choices. Future Dementia Care: Projections, problems and preferences.* Sydney: Alzheimer's Australia/ Access Economics Pty Limited.

Alzheimer's Disease International. (2015). *World Alzheimer's Report: The global impact of dementia*. London: Alzheimer's Disease International.

Alzheimer's Society. (2014). *Dementia UK: 2014 edition*. London: Alzheimer's Society.

Ayalon, L,, Gum, A., Feliciano, L., & Areán, P. (2006). Effectiveness of nonpharmacological interventions for the management of neuropsychiatric symptoms in patients with dementia. *Archives of Internal Medicine, 166*, 20, 2182-2188.

Basu, A., & Brinson, D. (2010). The Effectiveness of non-pharmacological interventions for behavioural and psychological symptom management for people with dementia in residential care settings. *HSAC Report, 3*, 19.

Bowen, A., Hesketh, A., Patchick, E., Young, A., Davies, L., Vail, A., …Tyrrell, P. (2012). Clinical effectiveness, cost-effectiveness and service users' perceptions of early, well-resourced communication therapy following a stroke: a randomised controlled trial (the ACT NoW Study). *Health Technology Assessment, 16***,** 26.

Bowers, B.J., Fibich, B., & Jacobson, N. (2001). Care-as-service, care-as-relating, care-as-comfort: understanding nursing home residents' definitions of quality. *The Gerontologist, 41*, 539-545.

Burgess, L. (2007). *Discrete Choice Experiments* [computer software]. Sydney: Department of Mathematical Sciences, University of Technology. Retrieved from http://crsu.science.uts.edu.au/choice/.

Care Quality Commission. (2013). *Not Just a Number: Home care inspection programme. National overview***.** Newcastle upon Tyne: Care Quality Commission.

Chester, H., Clarkson, P., Davies, L., Sutcliffe, C., Roe, B., Hughes, J., & Challis, D. (in press). A discrete choice experiment to explore carer preferences. *Quality in Ageing and Older Adults*.

Clarkson, P., Giebel, C.M., Larbey, M., Roe, B., Challis, D., Hughes, J., … Members of the HoSt-D (Home Support in Dementia) Programme Management Group (2016). A protocol for a systematic review of effective home support to people with dementia and their carers: components and impacts. *Journal of Advanced Nursing, 72*, 186-196.

Coast, J., & Horrocks, S. (2007). Developing attributes and levels for discrete choice experiments using qualitative methods. *Journal of Health Services Research and Policy, 12*, 25-30.

Comas-Herrera, A., Wittenberg, R., Pickard, L., & Knapp, M. (2007). Cognitive impairment in older people: the implications for future demand for long-term care services and their costs. *International Journal of Geriatric Psychiatry, 22*, 1037-1045.

Cooper, B. (2002). Thinking preventatively about dementia: A review. *International Journal of Geriatric Psychiatry*, *17*, 895-906.

Cooper, C., Mukadam, N., Katona, C., Lyketsos, C.G., Ames, D., Rabins, P., …World Federation of Biological Psychiatry – Old Age Taskforce (2012). Systematic review of the

effectiveness of non-pharmacological interventions to improve quality of life of people with dementia. *International Psychogeriatrics, 24*, 856-870.

Department of Health. (2009). *Living Well with Dementia: A national dementia strategy*. London: Department of Health.

Dolan, P., Gudex, C., Kind, P., & Williams, A. (1995). *A Social Tariff for Euroqol: Results from a UK general population survey* (Discussion Paper No.138). University of York: Centre for Health Economics.

Elvish, R., Lever, S-J., Johnstone, J., Cawley, R., & Keady, J. (2013). Psychological interventions for carers of people with dementia: A systematic review of quantitative and qualitative evidence. *Counselling and Psychotherapy Research, 13,* 106-125.

EuroQol Group. (1990). EuroQol-a new facility for the measurement of health-related quality of life. *Health Policy,* 16, 199-208.

Freeman, G., & Hughes, J. (2010). *Continuity of Care and the Patient Experience*. London: The King's Fund.

Gillespie, A., Best, C., O'Neill, B. (2012). Cognitive function and assistive technology for cognition: a systematic review. *Journal of International Neuropsychological Society,* 18**,** 1–19.

Gillespie, A., & O'Neill, B. (2014). *Assistive Technology for Cognition: A handbook for clinicians and developers*. Hove, East Sussex: Psychology Press.

Green, P., & Srinivasan, V. (1990). Conjoint analysis in marketing: new developments with implications for research and practice. *Journal of Marketing,* 54, 3–19.

Hall, J., Kenny, P., & Hossain, I. (2007). *The Provision of Informal Care in Terminal Illness: An analysis of carers' needs using a discrete choice experiment* (CHERE Working Paper 2007/12). Sydney: Centre for Health Economics Research and Evaluation, Faculty of Business.

Hensher, D., Rose, J., & Greene, W. (2005). *Applied Choice Analysis: A primer*. Cambridge: Cambridge University Press.

Jönsson, L., Andreasen, N., Kilander, L., Soininen, H., Waldemar, G., Nygaard, H., …Wimo, A. (2006). Patient- and proxy-reported utility in Alzheimer Disease using the EuroQoL. *Alzheimer Disease and Associated Disorders,* 20, 49-55.

Kim, S.Y., Yoo, E.Y., Jung, M.Y., Park, S.H., & Park, J.H. (2012). A systematic review of the effects of occupational therapy for persons with dementia: A meta-analysis of randomized controlled trials. *NeuroRehabilitation,* 31, 107-115.

King's Fund. (2008). *Paying the Price: The cost of mental health in England to 2026*. London: King's Fund.

Knapp, M., King, D., Romeo, R., Schehl, B., Barber, J., Griffin, M., …Livingston, G. (2013). Cost effectiveness of a manual based coping strategy programme in promoting the mental

health of family carers of people with dementia (the START (STrAtegies for RelaTives) study): a pragmatic randomised controlled trial. *British Medical Journal,* 347, f6342.

Kong, E.H., Evans, L.K., & Guevara, J.P. (2009). Nonpharmacological intervention for agitation in dementia: A systematic review and meta-analysis. *Aging and Mental Health,* 13, 512-520.

Lancsar, E., & Louviere, J. (2008). Conducting discrete choice experiments to inform healthcare decision making: A user's guide. *PharmacoEconomics,* 26, 661-677.

Lee, H., & Cameron, M.H. (2004). Respite care for people with dementia and their carers. *Cochrane Database of Systematic Reviews, Issue 1*. CD004396.

Li, R., Cooper, C., Austin, A., & Livingston, G. (2013). Do changes in coping style explain the effectiveness of interventions for psychological morbidity in family carers of people with dementia? A systematic review and meta-analysis. *International Psychogeriatrics, 25*, 204–214.

Livingston, G., Johnston, K., Katona, C., Paton, J., & Lyketsos, C.G. (2005). Systematic review of psychological approaches to the management of neuropsychiatric symptoms of dementia. *American Journal of Psychiatry,* 162, 1996–2021.

Louviere, J.J., Hensher, D.A., & Swait, J.D. (2000). *Stated Choice Methods: Analysis and application*. Cambridge: Cambridge University Press.

Miller, G.A. (1956). The magical number seven, plus or minus two: Some limits on our capacity for processing information. *Psychological Review,* 63, 81–97.

Neal, M., & Barton Wright, P. (2003) Validation therapy for dementia. *Cochrane Database of Systematic Reviews*, Issue 3. CD001394.

Newbronner, L., Chamberlain, R., Borthwick, R., Baxter, M., & Glendinning, C. (2013). *A Road Less Rocky: Supporting carers of people with dementia*. London: Carers Trust.

NICE-SCIE. (2011). *Dementia: Supporting Ppeople with dementia and their carers in health and social care.* Care guideline (amended March 2011). London: National Institute for Health and Clinical Excellence (NICE) and Social Care Institute for Excellence.

Nieboer, A., Koolman, X., & Stolk, E. (2010). Preferences for long-term care services: willingness to pay estimates derived from a discrete choice experiment. *Social Science and Medicine, 70*, 1317–1325.

Olazarán, J., Reisberg, B., Clare, L., Cruz, I., Peña-Casanova, J., Del Ser, T., …Muñiz, R. (2010). Non-pharmacological therapies in Alzheimer's disease: a systematic review of efficacy. *Dementia and Geriatric Cognitive Disorders,* 30, 161-178.

Phillips, K., Johnson, F. and Maddala T. (2002) Measuring what people value: a comparison of 'attitude' and 'preference' surveys. *Health Services Research* 37, 6, 1659-79.

Ryan, M., Bate, A., Eastmond, C., & Ludbrook, A. (2001a). Use of discrete choice experiments to elicit preferences. *Quality in Health Care, 10*, Suppl I, i55-i60.

Ryan, M., Scott, D.A., Reeves, C., Bate, A., van Teijlingen, E.R., Russell, E.M., …Robb, C.M. (2001b). Eliciting public preferences for healthcare: a systematic review of techniques. *Health Technology Assessment, 5*, 5.

Ryan, M., Netten, A., Skåtun, D., & Smith, P. (2006). Using discrete choice experiments to estimate a preference-based measure of outcome-an application to social care for older people. *Journal of Health Economics,* 25, 927-944.

Ryan, M., Gerard, K., & Amaya-Amaya, M. (Ed.). (2008). *Using Discrete Choice Experiments to Value Health and Health Care.* New York: Springer.

Sloane, N. (2010). A library of orthogonal arrays [software]. Retrieved from http://neilsloane.com/oadir/.

Spector, A., Davies, S., Woods, B., & Orrell, M. (2000). Reality orientation for dementia: a systematic review of the evidence of effectiveness from randomized controlled trials. *Gerontologist, 40*, 206-212.

Turner, D., Tarrant, C., Windridge, K., Bryan, S., Boulton, M., Freeman, G., & Baker, R. (2007). Do patients value continuity of care in general practice? An investigation using stated preference discrete choice experiments. *Journal of Health Services Research and Policy, 12*, 132-137.

United Kingdom Home Care Association. (UKHCA) (2013). *An Overview of the UK Domiciliary Care Sector*. Sutton: UKHCA.

Wijnen, B., van der Putten, I., Groothuis, S., de Kinderen, R., Noben, C., Paulus, A., Ramaekers, B., Vogel, G. and Hiligsmann, M. (2015) Discrete-choice experiments versus rating scale exercises to evaluate the importance of attributes. *Expert Review of Pharmacoeconomics and Outcomes Research* 15, 4, 721-728.

Wilberforce, M., Challis, D., Davies, L., Kelly, M.P., Roberts, C., & Loynes, N. (2016). Person-centredness in the care of older adults: a systematic review of questionnaire-based scales and their measurement properties. *BMC Geriatrics* 16, 63, DOI 10.1186/s12877-016-0229-y.

Woods, R.T., Wills, W., Higginson, I.J., Hobbins, J., & Whitby, M. (2003). Support in the community for people with dementia and their carers: a comparative outcome study of specialist mental health service interventions. *International Journal of Geriatric Psychiatry, 18***,** 298–307.

Table 1. Discrete Choice Experiment attributes – description and benefits

Component[a]	Description	Attribute for DCE	Benefit/evidence	
			Literature review[a]	Lay consultation
Cognitive training	To provide enhancement and stimulation of cognitive functions for person with dementia, through guided practice on a set of standard tasks, reflecting memory, attention or problem solving.	Advice on the use of memory aids	Olazáran et al. (2010); Basu and Brinson (2010); Cooper et al., (2012)	Identified as an interesting and novel area but many had yet to have experience of it.
Education/advice	Structured presentation of information concerning the condition and carer-related issues (e.g. legal issues), including an active role for carers (e.g. role playing).	Information on coping with dementia[b]	Ayalon, Gum, Feliciano, and Areán (2006); Elvish et al., (2013); Li, Cooper, Austin, and Livingston (2013).	Particularly valued by participants. Information should be timely and include information about services available to them which they may not know about.
Social engagement	To provide access to different forms of social contact to counterbalance the limited contact with others that may be characteristic of the experience of dementia. This social contact may be real or simulated.	Opportunities for social and recreational activities (e.g. walks)	Lee et al. (2004); Livingston, Johnston, Katona, Paton, and Lyketsos (2005); Kong, Evans, and Guevara (2009).	Seen as useful and some carers in particular had experience of it with their relatives.
Sensory enhancement /relaxation	To increase or relax the overall level of sensory stimulation in the environment to counterbalance the negative impact of sensory deprivation/stimulation that is common in dementia.	'Relaxation therapy'	Livingston et al. (2005); Kim, Yoo, Jung, Park, and Park (2012).	Identified, as an interesting area but many had no experience of it.
Emotional support	To address the feelings and emotional needs of people with dementia through prompts, discussion or to stimulate memories and enable people to share their experiences; for carers, to resolve pre-existing personal problems that can complicate caregiving.	Support with personal feelings and concerns[b]	Spector , Davies, Woods, and Orrell (2000); Neal and Barton Wright (2003); Olazáran et al. (2010).	Valued by carers; considered to help them feel more confident in caring, secure and better able to cope with the condition.
Daily living assistance	Assistance with basic care for the person with dementia, e.g. provision of basic nutrition and advice thereof for carers, e.g. promoting physical health.	Health promotion advice[b]	Kong et al. (2009); Olazáran et al. (2010); Kim et al. (2012).	Health advice, covering both mental and physical health and particularly how carers can keep well to continuing caring was considered to be important.

[a]Clarkson et al. (2016). [b]Emerged as particularly important in the lay consultation.

Table 2. Discrete choice experiment – attributes and levels

Attribute	Levels		
1. Advice on the use of memory aids (e.g. calendars, wall clocks) is[a]	Not available	Available at a clinic	Provided by a trained worker at home
2. Information on coping with dementia is[a]	Available in writing only on request	Available over the phone or internet when needed	Provided by an experienced worker at home
3. Opportunities for social and recreational activities (e.g. walks) are[a]	Not provided	Available through outside organisations	Provided by a dedicated worker at home
4. Relaxation therapy is[a]	Not available	Available at a clinic by appointment	Provided when needed at home
5. Support with personal feelings and concerns is[a]	Not provided	Available through a helpline	Provided by a trained counsellor at home
6. Health promotion advice is[a]	Not provided	Available at a clinic by appointment	Provided regularly at home
7. The cost of the service, to you, is [b,c]	£15 per week	£30 per week	£44 per week

[a] Attributes coded as dummy variables
[b] Attributes take numerical value
[c] Values defined from real unit costs of home care in England; average unit cost of a daytime hour of home care from the independent sector (2011/12) applied to different assumed durations of care: 1 hour a week for the first level, 2 hours per week for the second level and 3 hours a week for the third level (United Kingdom Home Care Association, 2013).

Figure 1. Example of a Discrete Choice Experiment choice question (1 of 18)

We ask that you imagine being offered these options for a home support service for you/your relative/person for whom you care today and that you had a budget of £60 per week to pay for care.

Please tick the box for the option you prefer more (A or B)

	Option A	**Option B**
Advice on the use of memory aids (e.g. calendars, wall clocks) is	Available at a clinic appointment	Provided by a trained worker at home
Relaxation therapy is	Available at a clinic by appointment	Provided when needed at home
Opportunities for social and recreational activities (e.g. walks) are	Available through outside organisations	Provided by a dedicated worker at home
Support with personal feelings and concerns is	Available through a 'helpline'	Provided by a trained counsellor at home
Health promotion advice is	Available at a clinic by appointment	Provided regularly at home
Information on coping with dementia is	Available over the phone or internet when needed	Provided by an experienced worker at home
The cost of the service, to you, is	£15 per week	£30 per week

Which service do you prefer?

(*Tick <u>one</u>*)

Table 3. Characteristics of respondents completing the choice experiment

Characteristic	Respondent type[a]		
	Patients (N=44)	Carers (N=103)	Overall (N=47)
	Mean (range)	Mean (range)	Mean (range)
Age	77 (57-94)	60 (20-89)	65 (20-94)
Gender	N (%)	N (%)	N (%)
Male	17 (39)	33 (32)	50 (34)
Female	27 (61)	69 (68)	96 (66)
Ethnic group	N (%)	N (%)	N (%)
White	43 (98)	100 (98)	143 (98)
Black	1 (2)	0 (0)	1 (1)
Asian	0 (0)	2 (2)	2 (1)
Method of administration	N (%)	N (%)	N (%)
Face-to-face interview	44 (100)	60 (58)	104 (71)
Completed online survey[b]	0 (0)	43 (42)	43 (29)
Health status			
Mobility	N (%)	N (%)	N (%)
I have no problems in walking about	26 (59)	80 (80)	106 (74)
I have some problems in walking about	18 (41)	20 (20)	38 (26)
I am confined to bed	0 (0)	0 (0)	0 (0)
Self-care	N (%)	N (%)	N (%)
I have no problems with self-care	40 (93)	93 (93)	133 (93)
I have some problems washing or dressing myself	3 (7)	7 (7)	10 (7)
I am unable to wash or dress myself	0 (0)	0 (0)	0 (0)
Usual activities	N (%)	N (%)	N (%)
I have no problems with performing my usual activities	22 (51)	80 (81)	102 (72)
I have some problems with performing my usual activities	20 (47)	16 (16)	36 (25)
I am unable to perform my usual activities	1 (2)	3 (3)	4 (3)
Pain or discomfort	N (%)	N (%)	N (%)
I have no pain or discomfort	26 (59)	66 (67)	92 (64)
I have moderate pain or discomfort	13 (30)	28 (28)	41 (29)
I have extreme pain or discomfort	5 (11)	5 (5)	10 (7)
	N (%)	N (%)	N (%)
Anxiety or depression			
I am not anxious or depressed	33 (75)	74 (74)	107 (74)
I am moderately anxious or depressed	10 (23)	25 (25)	35 (24)
I am extremely anxious or depressed	1 (2)	1 (1)	2 (1)
	Mean (range)	Mean (range)	Mean (range)
Health status, average utility score[c]	0.73 (0.09-1)	0.83 (-0.02-1)	0.80 (-0.02-1)

[a]The N given is the maximum N for each respondent group. There was a small amount of missing data: N for patients ranged from 42 to 44; carers from 98 to 103; and overall N from 141 to 147. [b]The online survey was distributed to carers. [c] The score quoted is anchored by the points 1 (full health) and 0 (death).

Table 4. Discrete choice experiment – regression analysis

Attribute	Coefficient (SE)	p-value	Marginal willingness to pay (£)
Advice on the use of memory aids is			
(Not available)			
Available at a clinic appointment	0.117 (0.060)	0.052	5
Provided by a trained worker at home	0.179 (0.064)	0.005	8
Information on coping with dementia			
(Available in writing only on request)			
Available over the phone or internet when needed	0.286 (0.060)	0.000	13
Provided by an experienced worker at home	0.592 (0.064)	0.000	27
Opportunities for social and recreational activities are			
(Not provided)			
Available through outside organisations	0.376 (0.062)	0.000	17
Provided by a dedicated worker at home	0.555 (0.064)	0.000	25
Relaxation therapy is			
(Not available)			
Available at a clinic by appointment	0.269 (0.062)	0.000	12
Provided when needed at home	0.385 (0.064)	0.000	18
Support with personal feelings and concerns is			
(Not provided)			
Available through a helpline	0.310 (0.060)	0.000	14
Provided by a trained counsellor at home	0.676 (0.064)	0.000	31
Health promotion advice is			
(Not provided)			
Available at a clinic by appointment	0.274 (0.060)	0.000	12
Provided regularly at home	0.195 (0.064)	0.002	9
Cost of the service	-0.022 (0.002)	0.000	
Pseudo R^2	0.106		
Log-likelihood	-1634.0675		
No. of observations	5274		
No. of individuals	147		