INTRODUCTION

Dementia, health economics and economic evaluation

Dementia is recognised as one of the greatest challenges for health and social care systems in Australia and internationally.\(^1,2\) By 2060, public expenditure on dementia in Australia is projected to be $83 billion, exceeding that of any other health condition, and dementia will represent approximately 11% of all health and residential aged care sector expenditures.\(^3,4\) Given ever-increasing resource and budgetary constraints, the drive to promote efficiency in the delivery of dementia care treatments and services is becoming more acute. Health economics is a sub-discipline of economics principally concerned with these issues. Any decision to introduce new services and/or supports or expand existing services and supports for people with dementia and their family carers will be associated with lost opportunities (or opportunity costs) and such decisions potentially have major implications for well-being and quality of life.\(^5\)

The overall aim of economic evaluation is to provide a mechanism to facilitate efficient and equitable decisions about the allocation of scarce resources by comparing the...
costs and benefits of competing interventions. The most utilised form of economic evaluation is cost-utility analysis which summarises the cost-effectiveness of an intervention in terms of the additional cost per quality-adjusted life years (QALYs) gained. QALYs combine length of life and quality of life into a single measure of outcome so that the value for money of competing interventions can be compared on an equivalent QALY scale. Generic preference-based instruments such as the Assessment of Quality of Life and the EQ-5D (EuroQol) have become popular mechanisms for the estimation of QALYs for cost-utility analyses in the healthcare sector.

1.2 Measuring and valuing quality of life in relation to dementia

Generic preference-based instruments for economic evaluation show a lack of sensitivity to detect change over time in important aspects of specific conditions. Recent acknowledgement of these types of limitations has motivated the development of the DEMQOL-U, a dementia-specific preference-based instrument generated from the DEMQOL. A new dementia-specific quality of life classification system, the Alzheimer’s Disease Five Dimensions (AD-5D), has also recently been developed, based upon the Quality of Life in Alzheimer’s Disease (QOL-AD), a widely used and well-validated condition-specific instrument for assessing health-related quality of life for people living with dementia.

This paper reports upon the valuation element of a larger project, the overall aim of which is to generate a preference-based scoring algorithm for the AD-5D for people with dementia and their carers to facilitate its application in economic evaluation. Conventional approaches to valuation, such as time trade-off (TTO) and standard gamble, have been widely applied in health economics with general population samples to elicit values and generate preference-based scoring algorithms for quality of life instruments. However, the application of valuation approaches with people with dementia and family carers is relatively rare. One previous study used a TTO task to value quality of life states defined by the DEMQOL with people with dementia and family carers. They noted that the complexities associated with completing TTO tasks represent a significant limitation for the elicitation of quality of life state values in this population. In this regard, two relatively new approaches to quality of life state valuation—Discrete Choice Experiment with survival duration (DCE-TTO) and Best Worst Scaling (BWS)—have been proposed as potentially less cognitively challenging and more appropriate approaches to quality of life state valuation for people with dementia and family carers. DCE-TTO involves presenting the participant with a series of choices between two or more hypothetical quality of life states of varying survival duration and asking the participant to indicate which quality of life state they prefer. BWS involves the presentation of a series of single quality of life states presented one at a time and the participant is asked to indicate the best and worst feature associated with each state.

The main aim of this study was to employ a qualitative think aloud approach to assess the decision-making processes applied by people with dementia and family carers as they value dementia-specific quality of life states using DCE-TTO and BWS approaches.

2 METHODS

2.1 Survey design

Full details of the survey design have been published in the study protocol. In brief, a series of DCE-TTO and BWS questions were administered via a face-to-face interview with a trained interviewer to people with dementia and family carers. The DCE-TTO questions guided participants to select a preferred quality of life state from pairs of hypothetical states reflecting differing combinations of dimension (physical health, memory, mood, living situation and ability to do things for fun), level (excellent, good, fair or poor) and survival durations (1, 4, 7 or 10 years). The BWS questions guided participants to identify the best and the worst features of a single life state (utilising the same quality of life dimensions and levels described above, but without the survival duration included). A series of socio-demographic questions was also included. The survey design is represented in Figure 1. This study has ethical approval from Griffith University HREC (number 2016/626) and the HREC of The University of Queensland (number 2017001481/2016/626).

2.2 Sample

Interviews were conducted with people with dementia and family carers in country and metropolitan areas of South Australia between December 2017 and April 2018. Participants for this study gave informed signed consent to adopt a think aloud
protocol whilst completing each choice task and to have their interviews recorded and transcribed. In all instances, the carer volunteered the dyad (person with dementia and a carer) to participate in the interviews and provided information on the diagnosis of the person with dementia (evidence of diagnosis was not required). In all but two instances (where the person with dementia was considered by a trained interviewer as unable to participate), carers were the primary carer for the interviewed person with dementia. The GPCOG test, a brief screening tool for assessing the level of cognitive impairment in an individual recommended for application in community and primary care settings,\(^\text{12}\) was administered initially with people with dementia to assess their level of cognitive impairment. The cognitive test includes nine items: date orientation (one item); numbering and time placement on a clock (two items); awareness of a current news event (one item); and recall of a name and an address (five items). Each correct answer is assigned one point leading to a maximum score of 9 (with fewer points indicating more impairment). Responses are classified into three main groupings: 0-4 cognitive impairment is indicated; 5-8 more information required; 9 no significant cognitive impairment indicated.\(^\text{13}\)

Participants were recruited via our partner aged care organisation Helping Hand, newspaper and radio advertising and local dementia support networks. There was a single general inclusion criterion: the ability to participate in an interview conducted in English of between 30-40 minutes in duration, to be determined by discussion with caregivers and the observations of the interviewer.

### 2.3 Interview

All interviews were conducted by a single interviewer with experience working with people with dementia and trained according to the interview protocol. People with dementia and their caregivers were interviewed separately. The interviewer used observations and their own judgement to determine the suitability of the person with dementia for the interview process. Once this was confirmed, written informed consent (including consent to audio recording) was obtained from both the person with dementia and their carer. Participants were randomly allocated either a set of five DCE\(_{TTQ}\) (from 40 possible blocks) or four BWS tasks (from four possible blocks) to complete first (Figure 1). Participants were encouraged by
the interviewer to think aloud concurrently and retrospectively whilst completing each task. At the completion of each question block, participants were asked whether they found the task difficult.

### 2.4 Analysis

Interviews were audio recorded and transcribed verbatim. Transcripts were reviewed, and any identifying information was removed prior to analysis. Transcripts were analysed using template analysis informed by heuristics and prior studies employing a similar think aloud approach alongside DCEs conducted in general population samples. For each approach, we sought to investigate whether the decision-making strategies adopted concur with the theoretical assumptions underlying the application of DCE TTO and BWS methods in this context. Specifically, it is assumed that participants make choices according to the framework of random utility theory by considering all of the information presented to them and choosing the alternative that maximises their utility. For the DCE TTO task, this would involve the participant choosing their most preferred quality of life state and providing logical reason/s for this choice (e.g., option A involves better quality of life overall and a longer survival duration). For BWS, this would involve the participant choosing the best and least attractive features of a single quality of life state and again providing logical reason/s for these choices.

The analysis template is presented in Table 1. Data analysis and interpretation was guided according to three main elements or themes: challenges of task (such as misunderstanding the task or difficulty in answering as proxy), the context brought to the task (such as anchoring to familiar health states) and assumptions made to assist decision-making (such as inferring additional information beyond that provided in the quality of life state descriptions to assist the participant in making choices and decisions). Any additional information brought to the exercise that was not previously categorised according to the above three themes was noted (see Table 1 for analysis template). Author 2 (CH) conducted template analysis on all transcripts. Author 3 (RM) then independently applied the template to two matched pairs of transcripts (person with dementia and their carer). Authors 2 and 3 then jointly reviewed the second round of coding together to ensure that the template was being consistently applied.

### 3 RESULTS

Interviews were conducted with 13 people with dementia and 15 caregivers. The majority (61.5%) of people with dementia were male, the mean age of people with dementia was 76.7 years, Alzheimer’s disease was the most common diagnosis (77%), and the mean time since diagnosis was 2.3 years. The mean GPCOG score for people with dementia was 3.2 (within the classification range of 0-4, indicating cognitive impairment). The vast majority of carers were female (80%), mean age of carers was 66.8 years, and all but two carers lived with the person with dementia (Table 2).

### 3.1 Task challenges

All participants engaged with the tasks and provided usable data on their preferences. All participants with dementia and all but one carer reported that they understood both the DCE TTO and BWS tasks and what was required of them. However, five (38%) participants with dementia reported that they found the DCE TTO task difficult to complete, and six (46%) indicated that they found the BWS task difficult to complete. For carers, nine (60%) participants found the DCE TTO task difficult to complete, compared to 11 (73%) participants for the BWS task. On some occasions, carers struggled with maintaining their positions as proxy decision-makers throughout each task and needed the interviewer to remind them that they were answering on behalf of the person they cared for:

Just a minute. This is about me? [Interviewer: No, this is you choosing for PWD.] Oh I see. That’s all right then, so far I was okay. (laughs) I thought it was choosing for me, that’s different.

Oh, the best would be a good mood, I suppose. Wouldn’t it? Well, this is, this is him and not me. And I do, I think the, the questions are tricky
3.2 | Familiarising the context of the task

The most common and consistent strategy adopted by participants for simplifying decision-making for both the DCE_TTO and BWS tasks was that of anchoring to familiar quality of life states. Using this strategy, participants identified which aspects of the descriptions were most like them (or like the person they care for). This then provided an anchoring point and context for their decisions, as this pair of participants demonstrate:

I’d choose A, because I think that does fit me. My … obviously my mental health is not as good. My memory’s poor, well not poor, but it’s not as good as it used to be.  PWD007

Given the memory loss experienced by people with dementia, both they and their carers readily anchored to descriptions of fair or poor memory as particularly salient to their own experiences. However, they also anchored to other attributes and levels depending on their assessment of their current health status, quality of life state and living situation, as demonstrated in the following quotes:

You have good physical health. I agree with that one.  PWD017

Good ability to do things for fun. I could do that. Not a lot though. PWD018

There was therefore a propensity for participants to choose scenarios that were familiar and most similar to their lived experiences. However, both carer and person with dementia participants were also able to differentiate between what attributes of quality of life they had currently and what they would prefer to have, demonstrated by the following quotes:

You fair living situation [in the scenario]. Yeah, I think I’ve got fair living situation. It’s not what I would choose but it’s a…  PWD017

Oh, okay. Everything great except your memory for ten years. Well, I’m pretty sure he’s not ready to die yet. And he’s got the poor memory.  CA014

This was evident in both the BWS and the DCE_TTO tasks.

In completing the DCE_TTO task, it was also evident carers used knowledge of the current state of the person with dementia to assist in making their choice. For example, when asked why they had chosen a particular scenario a carer replied:

Why is because I think he feels… because the bits that aren’t there are about poor physical health… and I think he’d tolerate…. He’s thinking in his mind is it would be um, its far worst to have lack of memory because his physical health is good.  CA007

However, it should be noted that participants (both people with dementia and carers) did describe it as being difficult to make choices, and sometimes needed to be reorientated to differentiating between their current and preferred states. Participants described “Yeah, I’m still having a bit of difficulty...
differentiating right” (PW014) when presented with the $\text{DCE}_{\text{TTO}}$ scenarios.

The interviewer needed to prompt the participant in some cases to be clear that they were not reporting the current state but were reporting their preferred state. For example:

CA016: The fair mood. It's got good mood. ‘Cause he would class himself with a poor memory, for a start …

Interviewer: Yup, yeah. But they're not asking him what he has now-

CA016: No, but I'm just comparing-

Or in some cases, the prompting indicated that the participant had needed to be reoriented to the task to ensure they chose the preferred state rather than the current state. This was usually during the first task, when the participant verbalised confusion at the scenarios not reflecting the current state of the participant. For example:

CA017: Excellent living situation, excellent memory, she said no to that. They both say she's got excellent memory….

Interviewer: So, would she choose to, does she think scenario A is better or scenario B is better ?

CA017: What would be better? Oh……Better, now I'm getting it. Okay. I'm a bit slow.

These participants generally went on to successfully complete the tasks with this better understanding of what was required of them. However, a small proportion of people with dementia (N = 3) provided some data but began to experience difficulties and became frustrated part way through the interview and were unable to fully complete the tasks. In these instances, the interviewer decided to cease the interviews prematurely.

Another strategy adopted by participants to ease decision-making was to “draw” a more detailed picture of the choices under consideration by defining what the quality of life states meant for them in the context of their own lives. For example, some participants described good or excellent living situations as living in a “nice house” (PWD006) or having things at home “looking nice” (PWD005) or just being able to stay in their own home (CA023). Another participant interpreted an excellent living situation as having a big house and plenty of space:

My living situation you'd have to call excellent. We got four bedroom now, so the garden, and it's only me and the wife. PWD018

In relation to having fun, one participant interpreted having fun as being able to travel and not just “sitting at home” (PWD007). Similarly, another participant contextualised having fun as getting out of the house and being sociable:

Well I like, we like it when we go Friday night for the … Um, because you're, your meeting … with, with the other people, PWD006

3.3 | Additional strategies to simplify decision-making

Two additional strategies were adopted when participants were engaged in the $\text{DCE}_{\text{TTO}}$ task. First, participants simplified the decision-making task by identifying attribute levels that were the same across two $\text{DCE}_{\text{TTO}}$ scenarios; for example, both scenarios may have fair mood and good physical health, and removing them from their considerations, focusing only on the attributes that differed in terms of the levels presented within each choice:

So the living [situation is the same in both], so it's only the other four variables. CA007

You have a good ability to do things for fun [in the scenario]. I think that… that's the same as both, yeah, yeah. PWD017

Secondly, participants focused on survival duration as the most important aspect of $\text{DCE}_{\text{TTO}}$ scenarios.

Well I've no intention to die any time… Well you want to live as long as you can, don't you?… Well you're not gonna volunteer to die early, are you? PWD018

I'd rather live more than one year… I feel that um, I've still got some years in me. PWD006

Though there was evidence of some participants selecting options based predominately on better survival duration, others were prepared to trade off lower survival durations for better quality of life:

Well, it's a better way of living for- for the one year I've got, PW005

(choosing 1 year over 7 years based on better memory and living situation)
Because, your quality of life is better. Who wants to live with a rotten quality of life for longer? CA009 (choosing 1 year over 7 years
based on memory and ability to do things for fun attributes)

In general, the interview transcripts revealed that those with significant cognitive impairment struggled to stay on task more than those with minor cognitive impairment. For example, one participant with significant cognitive impairment failed to fully complete the DCE\textsubscript{TTO} task, responding to some of the DCE\textsubscript{TTO} choice questions but not all of those in the full set. Another participant with significant cognitive impairment struggled with the concept of the BWS task, initially focusing on the quality of attribute labels only rather than the quality of life attribute and level presented, and finalised his choice of worst attribute level when the context of his reasoning suggested he meant this attribute level to be chosen as the best. This apparent anomaly in reasoning and choice was picked up by the interviewer and, on probing, the participant revised his response to concur with his reasoning.

4 | DISCUSSION

This study provides one of the first examples internationally to actively engage people with dementia and their carers using two relatively new approaches: DCE\textsubscript{TTO} and BWS in valuing quality of life states for the development of a preference-based scoring algorithm for a dementia-specific quality of life instrument. Although this is a relatively small-scale study, the findings were generally positive. Almost all participants in this study were able to complete both tasks and participants were generally positive about engaging in the tasks despite their inherent difficulties. The transcripts revealed that those with significant cognitive impairment generally struggled more to complete the tasks than those with minor cognitive impairment. Overall, our findings suggest that those scoring 2 or lower than 2 on the GPCOG may find both DCE\textsubscript{TTO} and BWS tasks significantly more challenging than those scoring 3 or higher, though some usable data were elicited.

The reliance on the carer to provide details of the person with dementia's diagnosis may be considered as a limitation of this study. However, the finding that 85% of the people with dementia interviewed received a GPCOG score that indicated cognitive impairment increases our confidence of the presence of at least the early stages of dementia, even if a formal diagnosis was not confirmed.

This study has demonstrated the value of an interviewer mode of administration in facilitating quality of life state valuation with people with dementia and carers, rather than the online modes of administration used in general population samples. Whilst the adoption of an interviewer mode of administration is more resource intensive, the advantages in this context and with this population are evident in aiding understanding of the hypothetical choice scenarios presented and prompting participants to indicate their preferences.

The individual-centred frame of reference adopted for this valuation study reflects current convention. However, a relationship-centred perspective is potentially important in influencing quality of life state valuations in this population. To that end, future research should investigate carer perspectives on their own quality of life states (and by extension, the person with dementia’s perspective on the carer quality of life state).

Whilst a range of decision-making strategies were adopted, we did not find any conclusive evidence from this qualitative think aloud study for the superiority of DCE\textsubscript{TTO} over BWS tasks or vice versa for the valuation of quality of life states in this increasingly prevalent population.

5 | CONCLUSIONS

This study provides useful insights into the participation of people with dementia and family carers in economic valuing of dementia-specific quality of life states. It demonstrates the potential for the more widespread adoption of these approaches to be successfully applied with people with dementia and family carers. Data of this nature are essential for economic evaluation to inform decision-making, as it can facilitate the assessment of the benefits of dementia care services and supports from the perspective of those who matter the most, people with dementia and their carers.

ACKNOWLEDGEMENTS

This study was supported by funding provided by the NHMRC Partnership Centre: Dealing with Cognitive and Related Functional Decline in Older People known as the Cognitive Decline Partnership Centre (CDPC) (grant number GNT9100000). The contents of the published materials are solely the responsibility of the Administering Institution, The University of Queensland, and the individual authors identified, and do not reflect the views of the NHMRC or any other funding bodies or the funding partners.

CONFLICT OF INTEREST

The authors declare no conflicts of interest.

ORCID

Julie Ratcliffe https://orcid.org/0000-0001-7365-1988
Claire Hutchinson https://orcid.org/0000-0003-4289-8886
Rachel Milte https://orcid.org/0000-0001-7533-6260
Kim-Huong Nguyen https://orcid.org/0000-0002-2592-9372
Alyssa Welch https://orcid.org/0000-0002-8873-9496
Tracy Comans https://orcid.org/0000-0003-2840-3496
REFERENCES

1. Australian Institute of Health and Welfare. Dementia in Australia. Cat. no. AGE 70. Canberra, ACT: AIHW; 2012.
2. World Health Organization. Dementia: A Public Health Priority. Geneva: World Health Organization; 2012.
3. Economics Access. Keeping Dementia Front of Mind: Incidence and Prevalence 2009-2050. Sydney: Access Economics; 2009.
4. Brown L, Hansnata E, La HA. Economic Cost of Dementia in Australia, Alzheimer’s Australia, Canberra; 2017.
5. Ratcliffe J, Pezzullo L, Doyle C. Health Economics, Healthcare Funding and Service Evaluation: International and Australian Perspectives. In: de Waal H, Lyketsos C, Ames D, O’Brien J, eds. Designing and Delivering Dementia Services; 2013.
6. Drummond MF, Sculpher MJ, Claxton K, Stoddart GL, Torrance GW. Methods for the Economic Evaluation of Health Care Programmes, 4th edn. Oxford, UK: Oxford University Press; 2015.
7. Brazier J. Measuring and Valuing Health Benefits for Economic Evaluation. Oxford, NY: Oxford University Press; 2007.
8. Comans TA, Nguyen K-H, Mulhern B, et al. Developing a dementia-specific preference-based quality of life measure (AD-5D) in Australia: a valuation study protocol. BMJ Open 2018;8(1):e018996.
9. Mulhern B, Rowen D, Brazier J, et al. Development of DEMQOL-U and DEMQOL-PROXY-U: generation of preference-based indices from DEMQOL and DEMQOL-PROXY for use in economic evaluation. Health Technol Assess (Winchester, England). 2013;17(5):v-xv, 1-140.
10. Nguyen K-H, Mulhern B, Kularatna S, Byrnes J, Moyle W, Comans T. Developing a dementia-specific health state classification system for a new preference-based instrument AD-5D.(Report). Health Qual Life Out 2017;15(1), 21.
11. Rowen D, Mulhern B, Banerjee S, Tait R, Watchurst C, Smith S, Brazier J. Comparison of General Population, Patient, and Carer Utility Values for Dementia Health States. 2014; 35(1), Medical decision making. ISSN 0272-989X.
12. Brodaty H, Pond D, Kemp N, et al. The GPCOG: a new screening test for dementia designed for general practice. JAGS. 2002;50:5.
13. Brodaty H, Kemp NM, Low LF. Characteristics of the GPCOG, a screening tool for cognitive impairment. Int J Geriatr Psychiatry. 2004;19(9):870-874.
14. King N. Doing template analysis. In: Symon G, Cassell C, eds. Qualitative Organizational Research: Core Methods and Current Challenges. Los Angeles; London: SAGE;2012:426.
15. Ryan M, Watson V, Entwistle V. Rationalising the ‘irrational’: a think aloud study of discrete choice experiment responses. Health Econ. 2009;18(3):321.
16. Whitty JA, Walker R, Golenko X, Ratcliffe J. A think aloud study comparing the validity and acceptability of discrete choice and best worst scaling methods. PLoS One. 2014;9(4):e90635.
17. Lancsar E, Fiebig D, Hole A. Discrete choice experiments: a guide to model specification, estimation and software. PharmacoEconomics. 2017;35(7):697-716.
18. Lancsar E, Louviere J, Donaldson C, Currie G, Burgess L. Best worst discrete choice experiments in health: methods and an application. Soc Sci Med. 2013;76(1):74-82.

How to cite this article: Ratcliffe J, Hutchinson C, Milte R, et al. How do people with dementia and family carers value dementia-specific quality of life states? An explorative “Think Aloud” study. Australas J Ageing. 2019;38(Suppl. 2):75–82. https://doi.org/10.1111/ajag.12646