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Hospice patients can participate in carefully designed choice experiments to value supportive care outcomes.

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Abstract

Background:

Values used in economic evaluation are typically obtained from the general public, which is contentious when the measure aims to target a life-course stage such as the end-of-life.

Objectives

To assess the feasibility of obtaining values for the ICECAP-Supportive Care Measure from patients receiving advanced supportive care through a hospice.

Methods

Participants completed eight best-worst scaling questions in a think aloud interview to explain choices in different hypothetical end-of-life scenarios. Analysis focused on errors in completion of the best-worst scaling task (assessed by three independent raters), and thematic analysis of the associated qualitative data to provide insight into task difficulty and choices.

Results

Twelve hospice patients were recruited. Most were able to complete the task and prioritise aspects of supportive care with either no difficulty (n=50%) or difficulty in one of the eight scenarios (n=25%). Two patients (n=17%) were unable to comprehend the hypothetical nature of the task. Qualitative data confirmed good engagement with the task and identified the importance the respondents attached to maintaining dignity.

Conclusion

The majority of those at the end-of-life are able to complete a short, interviewer-administered, best-worst scaling task. To maximise participant engagement, it is recommended that the task is short and initiated with an example. Scenarios are best presented on show-cards in large print. A full valuation of ICECAP-SCM with those at the end-of-life is feasible.

Background

Assessing the cost-effectiveness of clinical interventions requires a score from a measure that meaningfully represents the value of an improvement in quality of life. One such measure is the ICECAP Supportive Care Measure.[1] Designed for people at end-of-life, ICECAP-SCM contains seven questions on choice, love and affection, freedom from physical suffering, freedom from emotional suffering, dignity, support and preparation.[1][2]

ICECAP-SCM scores were generated from survey responses from 6,020 members of the general population.[3] Respondents were asked to complete a stated choice experiment, to give meaningful values with interval scale properties. Using general population values for the ICECAP-SCM is contentious. There are arguments for valuation by people with experience of end-of-life, who may have different priorities.[4] Where respondents are frail, however, such exercises may be impractical. We needed to explore if hospice patients were able to participate in task-based research prior to a larger scale study that would compare hospice patient and general population values. This paper reports the feasibility of obtaining best-worst-scaling (BWS)[5][6] values for ICECAP-SCM from hospice patients.

Methods

Participants were recruited through one UK adult hospice. Participants had to be receiving hospice care, well enough to provide consent and able to speak English. Patients were identified by the hospice consultant and deemed clinically well enough to participate (CR), and interviews were conducted by two experienced researchers (CB, PK).

Audio-recorded interviews took place in private hospice rooms or participants' homes. Participants were presented with eight scenarios, developed by the research team to represent a particular end-of-life state according to the different levels on the seven ICECAP-SCM items *e.g. I am able to have the help and support that I need **most of the time;** I **often** experience significant physical discomfort etc*. For each scenario participants were asked, *'what would be the best thing about being in that state, and what would be the worst thing?'* Task design is discussed elsewhere.[7] Participants were asked to 'thinkaloud'[8-10] as they responded, and subsequently to comment on the valuation task.

Ethics approval was provided by Wales Research Ethics Committee 5 [Ref: 14/WA/1144].

Analysis focused on:

1. Completion rates and time taken to complete the task.

2. Completion errors. Verbatim transcripts were analysed for evidence of errors by three raters (CB, JC, PK), classifying four types of error:[11][12]

a. Comprehension – Participants were unable to understand the BWS task or its hypothetical nature;
b. Judgement – Participants knew what was expected of them in terms of BWS and understood the attributes, but could not judge differences between levels;
c. Response – Participants did not respond, or response was felt to be socially desirable;
d. Struggle – Participants had difficulty answering the question, although they completed the task.

Identified errors were discussed and agreed by all raters.

3. Thematic analysis identified key themes related to completion of, and engagement with, the task (CB, AH).

Results

Twelve participants were recruited (between April-September 2015) to achieve saturation. Recruitment was dependent on staff availability and was therefore uneven, with eight participants interviewed in August 2015. Participants were aged between 44 and 78, with a range of diagnoses (see Table 1). The mean time for survey completion was 44 minutes (range 26-63).

Completion of the task

Table 1 shows errors made by participants. Six (PT02, PT05, PT07, PT08, PT09, PT12) were able to complete the task with no errors. Two experienced major difficulties with the task. One (PT06) did not grasp the hypothetical nature, making errors on each scenario, and not providing responses for most items. The task was not started with the other (PT11) as she clearly did not understand it. The remaining four participants experienced varying degrees of difficulty. PT04 had major difficulties understanding the first half of the task, with comprehension errors for scenarios 1-4 and a response error for scenario 5; further explanation regarding the differences between the levels enabled completion of the final three scenarios. PT01 and PT03 made single errors early in the task, and PT10 made an error at the end of task, possibly indicating fatigue.

Table 1: Nature of error by participant

Participant	Scenario 1	Scenario 2	Scenario 3	Scenario 4	Scenario 5	Scenario 6	Scenario 7	Scenario 8
PT001 Age 68 Lung cancer; Breast cancer		Struggle						
PT002 Age 61 Friedreich's-ataxia								
PT003 Age 62 Cerebellar Atrophy	Struggle					Judgement		
PT004 Age 44 Chronic Heart Failure	Comprehen*	Comprehen	Comprehen	Comprehen	Response			
PT005 Age 78 Cancer								
PT006 Age 64 Lung cancer; brain metastases	Comprehen	Comprehen	Comprehen	Comprehen	Comprehen	Comprehen	Comprehen	Comprehen
PT007 Age 65 Ovarian cancer								
PT008 Age 63 COPD; Throat cancer; Breast cancer								
PT009 Age 71 Motor Neurone Disease								
PT010 Age 63 Multiple system atrophy					Struggle			Judgement
PT011 Age 71 Heart failure	Comprehen	Comprehen	Comprehen	Comprehen	Comprehen	Comprehen	Comprehen	Comprehen
PT012 Age 75 Bowel cancer; Liver metastases								

*Comprehension

Issues with the task

The example and first two scenarios appeared to cause participants the most problems. As they progressed, responses became clearer and quicker:

"Right at the beginning, I'm thinking, 'What do you want out of me on this?' you know? But… I got it then… As you go through it got easier." (PT01).

Participants had difficulty making 'trade offs' in scenarios with nuanced, yet meaningful, differences in symptoms, care or experiences:

"You had to concentrate… they are very subtle, but sometimes or often, or rarely – it can make a big difference." (PT02).

"They're all very similar, aren't they?... there's like a hair's breadth between them" (PT05)

Those who needed more guidance seemed to struggle to grasp the hypothetical nature of the best and worst states, and the differences between scenarios:

"It's merging into one…I can't make a worst one because they're just repeating themselves (PT04)".

"I can't answer this, I'm finding that a struggle, all of them, to be honest… They're all contradicting, I just can't understand them at all" (PT06).

Towards the end of the task, some participants lost concentration.

"They're all the same, aren't they?" (PT10)

Engagement with the task

Once over the initial issues, participants were able to engage with the task. Many informants were able to make trade offs in relation to maintaining dignity and self-respect, particularly where the scenario highlighted poor experience.

"It's very important to keep my appearance… makes you feel like a woman, I can't do other things, so it makes you feel better" (PT003).

"I think you need to maintain your dignity in all aspects of life. When the carers come in to give me a wash and get me dressed for the day, they always put a towel over my body to protect my dignity and they did that when I stayed in the Hospice as well. They maintained my dignity to the highest level" (PT004).

"My worst thing, as I said, is not being able to keep myself clean and tidy…. That's always my worst fear" (PT008).

The focus and nature of these comments suggests that informants were engaged with the task.

Discussion

BWS has been used in healthcare research to value health outcomes and investigate preferences.[13] This research shows BWS is possible with people near the end-of-life even if they are quite unwell. However, time and patience are needed to convey the hypothetical and complex nature of the task. Although two of the 12 participants were unable to provide usable data, most were able to engage with the task, albeit with some requiring more explanation. The learning and fatigue effects identified here are important for random-utility modelling to ensure realistic and unbiased capability scores.

Although the study was relatively small, it demonstrates that people approaching the end-of-life can engage in the BWS task, and highlights the potential difficulties. In comparison with DCE, BWS may be less 'cognitively burdensome'.[14], easier for participants near the end-of-life to understand and respond to extreme options more consistently.[15] This study was not of sufficient size to assess comparability with the large scale general population survey data. Recruitment facilitated solely by the hospice ensured that participants were aware of their prognosis; nevertheless, it does mean that the feasibility assessment was undertaken with a particular group of end-of-life patients.

The work has generated suggestions for future work application of BWS with an end-of-life population. The use of an example at the start of the task was found to be particularly helpful; showcards (in large font) for participants to use also helped, particularly for those with hearing and sight impairments or memory loss. Although the formal wording of 'best' and 'worst' attributes in the scenario was maintained, terminology such as 'least worst' or 'least bad' for scenarios where most attributes were negative, was also helpful. Future research should involve short tasks conducted by supportive and encouraging researchers with sufficient experience to judge whether to pursue the task. Further methodological research could explore the benefits of verbal examples, as well as the feasibility of accessing those at the end-of-life through routes other than the hospice.

Overall, this study suggests that a full valuation of ICECAP-SCM would be feasible, although relatively resource intensive. Some interviews are likely to be unproductive, and researchers need to be prepared to spend time recruiting informants and interviewing them in a relaxed and flexible manner. Valuation work requires careful design to ensure a representative sample in terms of age, ethnicity, diagnosis and care setting.

References

1. Sutton E, Coast J. Development of a supportive care measure for economic evaluation of end-of-life care, using qualitative methods. *Palliative Medicine* 2014;28:151-57.
2. Bailey C, Kinghorn P, Orlando R, et al. 'The ICECAP-SCM tells you more about what I'm going through': a think-aloud study measuring quality of life among patients receiving supportive and palliative care. *Palliative Medicine* 2016 doi: 10.1177/0269216315624890
3. Huynh E, Coast J, Rose J, et al. Values for the ICECAP-Supportive Care Measure (ICECAP-SCM) for use in economic evaluation at end of life. *Social Science & Medicine* 2017;189:114-28.
4. Coast J. Strategies for the economic evaluation of end-of-life care: making a case for the capability approach. *Expert Review of Pharmacoeconomics & Outcomes Research* 2014;14(4):473-82.
5. Flynn TN, Louviere JJ, Peters TJ, et al. Best-worst scaling. What it can do for health care research and how to do it. *Journal of Health Economics* 2007;26:171-89.
6. Louviere JJ, Flynn TN, Marley AAJ. Best-worst scaling: theory, methods and applications. Cambridge: Cambridge University Press 2015:1-352.
7. Coast J, Huynh E, Kinghorn P, et al. Complex valuation: applying ideas from the complex intervention framework to valuation of a new measure for end-of-life care. *Pharmacoeconomics* 2016;34:499-508. doi: 10.1007/s40273-015-0365-9 [published Online First: 29 December 2015]
8. Willis GB. Cognitive interviewing: a tool for improving questionnaire design. Thousand Oaks, CA: Sage Publications 2005.
9. Ericsson K, Simon H. Verbal reports as data. *Psychological Review* 1980;87:215-51.
10. Ericsson K, Simon H. Protocol analysis: verbal reports as data. Cambridge, Massachusetts: MIT Press 1993.
11. Tourangeau R, Rips L, Rasinski K. The psychology of survey response. New York: Cambridge University Press 2000.
12. Al-Janabi H, Keeley T, Mitchell P, et al. Can capabilities be self-reported? A think aloud study. *Social Science and Medicine* 2013;87:116-22.
13. Cheung KL, Wijnen BFM, Hollin IL, et al. Using best–worst scaling to investigate preferences in health care. *PharmacoEconomics* 2016;34(12):1195-209.
14. Marley AAJ, Louviere JJ (2005). Some probabilistic models of best, worst, and best-worst choices. Journal of Mathematical Psychology, 49, 464-480.
15. Potoglou D, Burge P, Flynn T, Netten A, Malley, J, Forder J, Brazier JE. (2011) Best–worst scaling vs. discrete choice experiments: An empirical comparison using social care data". *Social Science & Medicine.* **72** (10): 1717–1727.