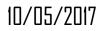




How do people make decisions about 'best' and 'worst' quality of life states? A qualitative exploration of best-worst scaling responses to the ASCOT measure of care-related quality of life

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Background

- There is an increasing number of ranking methods used to elicit stated preferences:
 - Discrete choice experiments (DCE)
 - Time trade-off (TTO)
 - Standard gamble (SG)
 - Best-Worst Scaling (BWS)
- Although TTO and SG are the most preferred and established choice-based format methods used within health and policy research, recent literature argues that the BWS task is easier and elicits a more informative and efficient preference ranking method within each situation (Whitty et al., 2014)



Background

- BWS is used increasingly in the context of health, such as valuing health and quality of life states (e.g. Lancsar & Louviere, 2006; Netten et al., 2012; Ryan et al., 2009; Whitty et al., 2014)
- BWS assumes rational responses, i.e. complete, transitive, (monotonic, & continuous) (Ryan et al., 2009)
- However, little is known about how people make decisions within BWS in the context of valuing health and quality of life states



Aim of the current study

- Aims
 - To provide a deeper understanding of the acceptability, feasibility and validity of the BWS task for valuing quality of life states
 - I. Validity → Do people have complete and continuous preferences for quality of life states?
 - II. Is the BWS technique acceptable and feasible for valuing health / quality of life states?
- We hoped to provide evidence to help guide data collection and analysis for preference studies generally and for the EXCELC project



Methods

- BWS (Flynn, 2010; Flynn et al., 2007):
 - Two experiments:
 - **ASCOT-S:** 8 questions covering 8 different attributes
 - **ASCOT-C:** 7 questions covering 7 different attributes
 - Each experiment followed a fractional-factorial orthogonal main effects plan with 32 choice situations, split into 4 blocks of 8 tasks
 - Due to a small number of participants, each of the four blocks of 8 tasks for each study were only shown to a small subset of participants. One additional task was also included for each block to assess completeness (9 tasks shown to each participant).
 - ASCOT-S: 8 interviews
 - ASCOT-C: 12 interviews



Methods

• BWS:

Best		Worst
©	My home is not quite clean or comfortable enough	0
Ø	I don't feel at all safe	۲
©	I get adequate food and drink at OK times	0
©	I don't feel at all clean or presentable	O
Ø	I have some control over my daily life, but not enough	0
۲	I have adequate social contact with people	O
Ø	The way I'm helped and treated makes me think and feel better about myself	Ø
O	I'm able to spend my time as I want, doing things I value or enjoy	O

Task 1a. Imagining that you are not able to care for yourself, which of these eight situations do you think would be the best and the worst for you?

An example of a BWS task using the wording from the ASCOT service user instrument



Methods

- Verbal protocol analysis (Boyatzis, 1998; Braun & Clarke, 2006; Willis, 2015)
 - Interviews were conducted in a private room at the university campus
 - Participants instructed to complete the BWS experiment on the computer
 - Think aloud methods: describe thoughts while completing the task
 - Some concurrent probing if participant fell silent, and retrospective probing after completion
 - Audio-recorded, transcribed & coded using thematic analysis
- Participants:
 - Males and females from the University of Kent campus
 - Students and University of Kent Staff members
 - 18 years old or above
 - English as a native language



 An underlying theme that emerged amongst participants was whether they were able to accept the principle of putting themselves into the hypothetical situations while completing the BWS task

"Yeah, so I'm just imagining if I am at this stage where I can't do everything for myself, I sort of can imagine myself in the kitchen, I don't know why I'm just sort of imagining myself there. [Pause] It'd take a lot longer to do a lot tasks, just like getting up and going to bed and things." **(P8)**

"It gets quite overwhelming 'cause there's the eight. It's like watching the same movie eight times in a row but it's only slightly different each time and it's like I'm trying to find, okay, where's the difference? But I'm not trying to do that but, erm, it becomes a difficult task to remember I'm trying to think I'm a carer. Yeah. It's like groundhog day." (P1)

 In order to accept the principle of putting themselves into these situations, some drew from personal experiences, either drawing from their own situations or from those of their loved ones' situations

"I'm just going through imagine you're in a situation where you're helping and caring for someone who is no longer able to care for themselves. Well I don't have to think too hard about that, I have an independent but 89 year old mother who lives a distance away, lives by herself, will not have--, come and live with my wife and I, but I also helped care for my father before he died and he had Parkinson's disease. [Pause] Life may be different. It certainly is different. It throws a completely different spanner into the works I can tell you." (P15)



 The priming of the hypothetical quality of life states was also of interestsome participants imagined being / caring for someone who is older, others imagined someone who is younger and with illness or accident:

"I just imagine if I was 80 or something it's probably the last thing that's going to really matter to me is how present--, but if you're someone who's younger then that's probably still important. So it depends. I mean for me because I was thinking of someone who's elderly that's why I thought." **(P1)**

"So I should imagine I'm in a situation where illness, accident or old age I'm no longer able to do everything I might expect myself without some assistance,' okay. Okay, illness, accident or old age? Okay, I can imagine that because I recently messed up my back so it's easy to imagine [laughs] that kind of lifestyle." (P4)

"Are we talking about caring for someone who has capacity or someone who doesn't have capacity because that would be different? I would give different answers for each one." (P10)



• Some participants reflected on the level of difficulty of the task

"I'm looking forward to the next question 'cause this one's going to be even harder trying to tease out which is my second best and worst. [Pause]. And I'm not looking forward to the question after this 'cause it's going to be even harder isn't it?" **(P17)**

"Did you find it easy or difficult to complete the best/worst exercises?' It was fairly easy for me because I know from what I value and there were some where you had to think about it quite a bit." **(P20)**

 Some participants reflected on their level of certainty of the task and whether they were doing the task correctly:

"And, yeah, I think it's going to be pretty straightforward at this point, feeling fairly confident." (P3)

"I'm not sure again if I'm filling it out right, I'm really not confident that I'm filling this out in the right way but I'm going to go with it." (P9)



 Some participants seemed to find the task tedious. This was shown through reflections on the length of the task and the repetitiveness of the task:

Length

"There's so many questions." (P1)

"I'm looking like I'm nearly halfway through. So I'm feeling like this is quite a long survey [laughs] at this point. I might have been a bit--, if at home I might have thought how long--, how much longer is this going [laughs] to go on to be fair. It feels quite long only because they're very similar statements and the format is the same and I would say at this stage looking at being not even halfway through I'm thinking have I got another 20 minutes of this similar type of questioning? I might be a bit bored and I might not want to continue, but I will continue." (P9)

Repetitiveness

"They're all quite similar questions aren't they, 'cause so it's the same question at the top, each task is the same, 'I do some of the things I value or enjoy,' so they're just kind of like moved from--, is that right, they're just kind of like rephrased, all the tasks are just rephrasing the question maybe." (P16)



Results: Learning

• A proportion of participants showed aspects of learning of the BWS task

"So I'm thinking that one of the best aspects of that list would be, erm, hmm--, so I've see you've added in--, there's some of the ones from before but there's some different ones there as well." (P9)

"Okay, so we've got second best again, I finally understand these questions [laughs]." (P4)

• A subset of participants also talked about learning of their own preferences

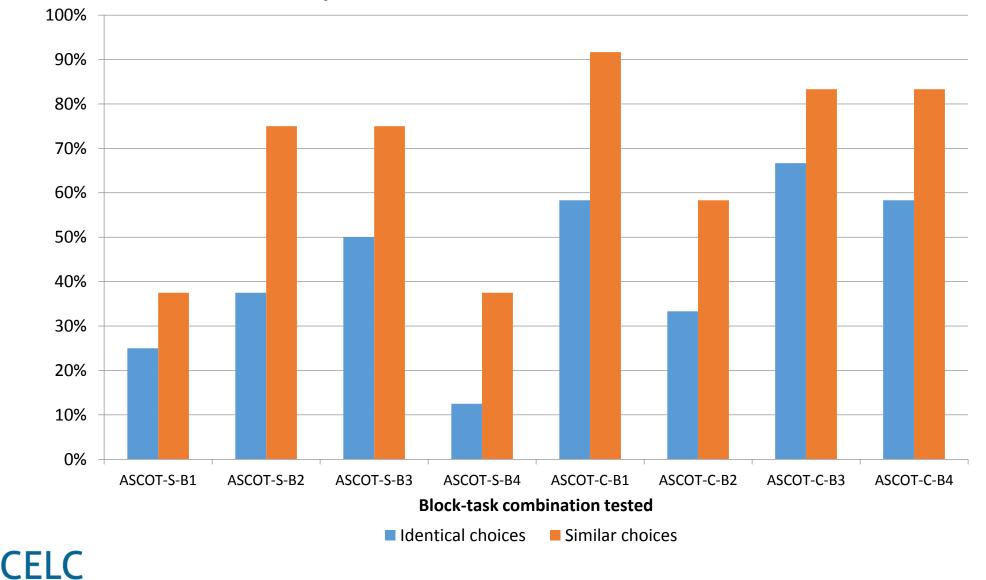
"So then you change kind of what order you're putting them in. So the task is basically the same the whole time. [Pause] So constantly you're kind of like re-ranking certain things that I think are important. So, like, safety and control are really, really important so they're constantly changing between whether they're best or worst if that makes sense. So whereas other ones I don't really care that much about so, erm, like I don't feel like I'm looking after myself as well as--, sometimes I can't look after myself well enough that one doesn't really factor to me in comparison to feeling as safe as I want." (P12)

"It's making me question what I've already done because it's sort of putting it in a different way, making you maybe rethink some bits, but ... I think it also depends what sort of person you are like when you're older as well 'cause you might have been a very social person or you might not have been so you don't as much sort of, as much of that around you." (P7)



Results: Completeness

Consistency of choices for individual block-task combinations



Results: Continuity

- Heuristics:
 - Participants spoke of a number of **heuristics ("short-cuts")** they reportedly used to complete the BWS task

1. Importance

"So the social element once again is best because that's important." (P13)

2. Strength in wording of QoL aspects

"So what's positive? That one, that one, that one, okay, so there's a few positive ones still whittled down. I have as much control over my daily life as I want, that's pretty good. I have as much social contact as I want, that's pretty good. The way I'm helped undermines, no. I'm able to do enough of the things I value and enjoy with my time. I think as much control is going to be best. Worst is either the not getting food and drink when you want it or not feeling presentable, or actually, the way--, so this one's worded a bit more strongly this time, completely undermines the way I think, that sounds quite bad." **(P8)**

3. Grouping of QoL aspects

"The worst for this I don't have any space or time to be myself 'cause I think that--, there's I feel I'm neglecting myself but I think that comes under that as well, so I think they're quite joint." (P20)



Results: Continuity

- Heuristics:
 - Participants spoke of a number of heuristics ("short-cuts") they reportedly used to complete the BWS task

4. Familiarity of QoL aspects

"Now looking down the list and working out if I've seen any of these options before." **(P6)**

5. Previously chosen QoL aspects

"...the second worst would be, erm--, and you've got a negative one there I feel less than adequately safe. Erm, so I'm not going to pick that one 'cause I picked that one in the first instance. I feel I have no encouragement and support. So I'm going to pick that as the worst. And click on." **(P9)**



Results: Continuity

- Trading:
 - A large proportion of participants considered more than one aspect or attribute ("traded-off") in the BWS profile, despite the use of heuristics

"...I think the best is, 'I have adequate space and time to be myself,' it would either be that one or, 'I have adequate social contact with people,' but I think, 'Adequate space and time to be myself,' maybe implies that I do have social contact as well as part of that." (P18)

• Non-trading behaviour

"I think adequate control over my daily life that's more overarching than the other statements so that one would be the best of what's left." **(P11)**



Discussion

- Overall, the tasks were found to be acceptable and feasible. However:
 - Some participants needed to be able to accept the principle of putting themselves into the hypothetical quality of life state
 - Priming tends to be very important the more specific, the better
 - Changes to the instructions helped with understanding of the task, particularly of instructions to put themselves into the imaginary state
 - Some participants found the task difficult and were uncertain on whether they were doing the task correctly
 - Some participants found the task tedious: too long & repetitive



Discussion

- Completeness:
 - High rates of inconsistency. These findings are similar to the works of Whitty et al. (2014), although previous work (Netten et al. 2012) suggests DCE is infeasible in this context because of inconsistency in situations. BWS also provides more information for a given set of choices compared to DCE.
 - Higher consistency when 1st and 2nd choices were combined. May suggest that BWS
 preferences have high random error components.
 - The 2nd task was repeated, would results be different if 4th/5th/6th task was repeated? (see similarity to Ryan et al. (2009) for DCE task)
 - Some participants also showed evidence of learning during the task
- Continuity:
 - Participants tended to use a number of heuristics as strategies to reduce the cognitive burden of the task
 - Regardless of the number of reported heuristics, some participants did show evidence of trading off between the aspects



Conclusions & Future Research

- Our findings suggest that the BWS is an acceptable and feasible task, but do need to make it as accessible as possible
- Formatting / adapting instructions to ensure understanding of the task and imaginary situations is critical > what makes the most difference?
- Fairly high inconsistency indicates high levels of random error > large samples are needed
- Length and repetitiveness of the task is a key issue, and can potentially be more problematic where instruments have many domains / levels > what is the optimum length?



Thank you very much!



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