How do individuals value health states? A qualitative investigation

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ABSTRACT

Despite the importance of health state values in informing resource allocation in health care, there is arguably little known about how individuals value health. Previous studies have shown that a variety of non-health factors and beliefs are important in valuing health, but there is less evidence in the literature about how individuals' beliefs affect their preferences or what role non-health factors play in the process of forming preferences. This study investigated the thought processes of 21 U.K. based participants in March 2013 who valued health states using semi-structured interviews and a think-aloud protocol, with the aim to better understand the relationship between health states, the individual's underlying beliefs, and the individual's preferences.

Participants followed several stages in valuing health. First, participants interpreted the health states more concretely, relying on their imagination and their experience of ill health. Participants judged how the concrete health problems combined with their personal interests, circumstances, and environment would affect them personally. Ultimately, participants valued health by estimating and weighing the non-health consequences of the health states. Six consequences were most frequently mentioned: activities, enjoyment, independence, relationships, dignity, and avoiding being a burden. At each stage participants encountered difficulties and expressed concerns.

The findings have implications for methods of describing health, for example, whether the focus should be on health or a broader notion of well-being and capability. This is because the consequences are similar to the domains of broader measures such as the ICECAP measures for adults and older people, and the Warwick-Edinburgh Mental Wellbeing Scale. The findings suggest the need for testing whether individuals are informed about the health states they are valuing. Participants valued health by estimating the non-health consequences of health states and these estimates relied on individuals' beliefs about the interaction of the health state and their personal and social circumstances.

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1. Introduction

To measure the benefits of health interventions, health economists ask members of the general public to value health states. These values are important in determining resource allocation in health care because economists use these values to calculate Quality Adjusted Life years (QALYs) (Drummond et al., 2005). QALYs are the preferred measure of benefit of health interventions in cost-effectiveness analyses conducted for the National Institute for Health and Care Excellence (NICE) (NICE, 2013), and for similar agencies such as the Scottish Medicines Consortium (Cairns, 2006)

and the Dutch National Health Care Institute (NZi, 2015). QALYs, and hence health state values, have an important role in informing resource allocation decisions in health care.

Various techniques are used to value health states (Brazier et al., 2007). These techniques include the Time Trade Off (TTO) and Discrete Choice Experiments (DCEs) (Brazier et al., 2007). These techniques require participants to imagine alternatives where they live in certain health states for a certain number of years and to make choices between those alternatives (Brazier et al., 2007). While health state valuation techniques are well established in the health economics literature, there have been questions about whether participants are able to validly complete these tasks (Baker and Robinson, 2004; Brazier et al., 2007; Lloyd, 2003). Such tasks are cognitively complex and participants are likely to have little experience with the health states they are valuing (Brazier et al., 2007; Hausman, 2006). In addition, preferences are believed to

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be constructed and not pre-existing (Slovic, 1995) further casting doubt about the ability of individuals to undertake such tasks (Lloyd, 2003). The concern about the ability of participants to value health states has prompted research into better understanding how individuals value health.

Little is known about how people evaluate health states (Hausman, 2006). Early qualitative work by Robinson et al. (1997) investigated the thought processes of participants completing the TTO and the Visual Analogue Scale. Several studies have shown that a range of non-health factors, from the family situation to the desire to avoid being a burden, are important in valuing health (Baker and Robinson, 2004; Osch and Stiggelbout, 2007; Robinson et al., 1997; van der Pol and Shiell, 2007). Although these studies provide information on the range of factors considered in health state valuation, none of them provide an explanation of how individuals value health states and the role of non-health factors in developing preferences over health states. Understanding how individuals value health can provide information on whether individuals complete health state valuation tasks as expected by researchers and provide information about how health state valuation tasks could be improved.

The aim of this study was to investigate how people value health states, specifically this study sought to answer the following questions: (a) what makes a health state better than another? (b) what is the role of the non-health factors in developing preferences over health states? and (c) what is the connection between individuals' beliefs about non-health factors, the health state, and preferences over health states?

2. Methods

Think-aloud interviews followed by a qualitative semi-structured interview were conducted with participants in the UK. During the interview participants completed both TTO and DCE health state valuation tasks. A think-aloud protocol means that participants were asked to verbalise their thoughts while completing each valuation task, which was used to understand participants' thought processes (Ericsson and Simon, 1993). Think-aloud interviews have been used in the health economics field to investigate tasks such as questionnaire completion (Al-Janabi et al., 2013) and health state valuation (Baker and Robinson, 2004). A concurrent think-aloud protocol was used, which means that data were obtained while participants were completing the task. This avoids participants having to recall their thoughts after a task had been completed, which may result in participants adding information generated after the task had already been completed (Ericsson and Simon, 1993). After the valuation task, a semi-structured interview was conducted to further explore participants' thoughts and beliefs. Individual semi-structured interviews allow for in-depth investigation and detailed understanding of personal motivations and decisions (Coast, 1999; Ritchie, 2003, 37). At the end of the interview, participants completed a standard background questionnaire.

Each participant completed eight DCE and three TTO tasks (see Table 1). The number of states allowed the interview to be completed in one hour and to spend equal amounts of time on both tasks. These tasks were chosen because they were being considered for the EQ-5D-5L valuation (Devlin and Krabbe, 2013). Both the order of the DCE and TTO techniques as well as the health states within each technique were randomised because of the possibility of participants' thought processes being influenced by their earlier choices. In the DCE task participants were asked to choose between two health states. The DCE was implemented as a self-complete method using pen and paper. The composite-TTO using TTO boards was used (Devlin and Krabbe, 2013) (tasks

Table 1
Health states used in study.

DCE state A[a]		DCE state B[a]	
Years	State	Years	State
10	33243	10	33234
10	21221	10	12131
10	13323	10	31332
8	43312	10	33411
5	34454	5	43544
10	23211	10	12311
5	33341	5	53321
8	22432	10	22233
TTO states[a]			
13321			
13443			
54435			
31212			

[a] Each digit represents the level of each dimension, (i.e. 1 is no problems and 5 is unable/extreme problems). The order of the digits is the order of the dimension in the questionnaire.

available from authors). The health states were described using the EQ-5D-5L, a frequently used measure of health status that contains five dimensions: mobility, usual activities, self-care, pain or discomfort, and anxiety or depression (Herdman et al., 2011). Each dimension has five levels ranging from no problems to extreme problems/unable to. The health states were selected so that participants valued problems in each domain and with different severities.

2.1. Sampling

We aimed to recruit 20 participants based on reviewing similar research. The sample size of qualitative work is generally small due to diminishing returns, lack of need for statements about prevalence, and rich data (Coast, 1999; Spencer et al., 2003, 83). Participants were purposely sampled by age and gender because there is some evidence that age and gender are related to health state values (Dolan and Roberts, 2002) and this could be the result of different thought processes. Participants were recruited by emailing three sources: an online directory of voluntary, community, faith sector, and health or social care organisations in Sheffield (Sheffield Community Information Service, 2015), a list of students and staff from the University of Sheffield, and the snowball method (where participants in the study identify further participants (Ritchie et al., 2003a)). Six randomly selected organisations from the Sheffield community organisation groups were contacted, these organisations were focused on a range of activities from Scrabble to Handbell ringers. Participants were reimbursed a £10 gift voucher. The ethics committee of the School of Health and Related Research at the University of Sheffield gave ethical approval for this study.

2.2. Interview protocol

All interviews were conducted by one of the authors (MK) on the University of Sheffield campus in Sheffield, England. The interviewer was a PhD student, who had undergone training in qualitative methods. The think-aloud protocol guidelines, describing the instructions for the participants, were taken from Ericsson and Simon (1993). The think-aloud section of the interview started with a practice task of choosing between two cars to familiarise participants with thinking aloud. A standard text was read to participants explaining the think-aloud process. If participants became quiet during the interview, they were reminded to

'please keep talking'. This prompt is recommended because it is less directive than other possible prompts (Ericsson and Simon, 1993, 256). If participants had not verbalised their choice or had done so only minimally, they were asked to 'repeat everything you can remember about your thoughts'.

Following the completion of all the valuation tasks, the semi-structured interview questions focused on understanding participants' motivations for their responses and their interpretation of health states; participants were also given a chance to comment on the valuation tasks (interview guide available from authors). Occasionally questions were asked during the think-aloud section of the interview, but only after a participant was finished with valuing a health state. These questions were based on participants' comments and were meant to clarify their comments. Questions during the think-aloud protocol were only asked where the interviewer thought that waiting until the end of the interview was not appropriate (e.g. the participant would likely forget the point). This was generally avoided to avoid influencing the participants' thought processes during the valuation tasks. Consent was required from each participant before the interview started. Interviews were audio recorded and transcribed verbatim.

2.3. Data analysis

Both the data from the think aloud and the semi-structured interview were analysed. Framework analysis was used to analyse the transcripts (Spencer et al., 2003). Framework involves five stages: familiarisation, identifying a thematic framework, indexing, charting and mapping, and interpretation (Ritchie and Spencer, 1994). First, the transcripts were imported in Nvivo (QSR, 2012) to enable data management and facilitate the analysis. Then, the transcripts were reviewed and a list of key ideas and recurrent themes were developed. All the transcripts were then indexed, meaning that sections of the transcripts that refer to a theme were identified and marked. A matrix with all themes and participants was created and the relevant comments in each cell were entered. Using these charts, a descriptive and explanatory analysis were conducted (Spencer et al., 2003). This process was iterative and each transcript was reviewed at least three times. The authors reviewed the emerging themes and discussed the interpretation of the findings collectively at each stage of the analysis.

During the interpretation stage a descriptive and an explanatory account were developed. The descriptive account focused on "identifying key dimensions" and "mapping the range and diversity of each phenomenon" (Spencer et al., 2003, 214). The aim of the explanatory account was to link the themes together to explain how people formed preferences over health states. Linkages can be mentioned explicitly by the participants or the researcher can look for the linkages by examining whether certain themes are closely associated in the data (Ritchie et al., 2003b, 253).

3. Results

In total, 21 interviews were conducted. Two (10%) participants were recruited from Sheffield community organisations, fourteen (67%) participants were recruited from the students and staff list of the University of Sheffield, and five (24%) participants were recruited using the snowball method. The participants' background characteristics are shown in Table 2. Interviews were conducted in March 2013 and lasted about 60 min.

Three main themes were developed during the framework analysis describing how participants value health states. These themes are: (i) interpretation and concretisation of a health state, (ii) conversion factors, and (iii) non-health consequences of health states and the weighing of the consequences. The themes and their

Table 2
Participants' background characteristics.

	Sample	UK population[a]
Number of participants	21	–
Female (%)	11 (52%)	50.8%
Average Age	42	39
Age range	19 to 65	–
Age bracket 18 to 29	6 (29%)	20%
Age bracket 30 to 49	6 (29%)	36%
Age bracket 50 to 59	5 (24%)	15%
Age bracket 60 above	4 (14%)	29%
First degree or higher (%)	13 (62%)	27%[b]
Student (%)	6 (29%)	8.8%
Employed (%)	14 (67%)	59%
Retired (%)	1 (5%)	13%
Previous illness (Personal, Family, or Friends) (%)	16 (76%)	–
Average EQ-5D score (%)[c]	0.88	
Range EQ-5D score (%)	0.479 to 1	–
Single (%)	12 (57%)	–
Married (%)	8 (38%)	–
Divorced (%)	1 (5%)	–
Children (%)	6 (29%)	–
Religious (%)	9 (43%)	–

[a] Office for National Statistics, 2011.
[b] Includes everyone 16 and above.
[c] Based on cross-walk value set (van Hout et al., 2012).

sub-themes are described in the next three sections. Next, the themes are linked together to form an explanatory account of health state valuation.

3.1. Theme 1: the interpretation of a health state

Participants made a wide range of comments about interpreting the EQ-5D-5L domains and attribute levels. The EQ-5D-5L provides an abstract description, such as "moderate problems in walking about", but the participants generally converted the abstract description into a more concrete feeling or image:

> If it's severe [mobility problems] I, I would kind of think of that as perhaps you can only walk very short distances, or you maybe need to use a wheel chair (Participant 4)

> I mean, not sure, slight problems I can quantify that as say well, like trouble getting the toothpaste cap off (Participant 3)

While interpreting the dimensions and levels, participants used their imagination and experience of health problems. Participants referred to several sources of experience, such as personal experience; experience of family, friends, or acquaintances; work experience; and knowledge of celebrities, the news, or documentaries. The following quotes illustrate the use of experience and imagination:

> I used to be a special needs training teacher and working with children in wheel chairs ... (Participant 7)

> ... I haven't suffered most of these problems myself nor fortunately have I had relatives or friends who had them really. Uhm, so really it's just, I'm just I'm using my imagination. (Participant 10)

Some participants read more into the health state than was written by guessing the disease that caused the health state or by guessing what is 'implied' by the health state:

> ... that would imply to me that this this health state involves some kind of loss of upper body mobility uhm, what that might be I don't know. (Participant 9)

Participants occasionally expressed doubt about their ability to accurately imagine what a health state is like because of their lack of experience with the health problems:

Perhaps you would get a better handle on this if you spoke to people who did have some of these problems, cause I mean I'm imagining what it's like, and I've got some slight insight what it's like to have pain or slight insight into what it's like to not to, but I have not really because I'm happy today, I've been happy all my life, I mean I've been fit all my life pretty much so. (Participants 10)

Participants also expressed doubt about the potential lack of experience of others:

I think mental health is like one of those things that unless you know someone, or you've experienced it, that you'd probably have no concept of. So may be physical problems might come to the fore, for some people. (Participant 4)

Participants occasionally commented on a changed understanding of the descriptive system during the task:

Before … I couldn't separate walking from the usual things, whilst yes I can see that I can do my usual things without necessarily walking. (Participant 21)

Occasionally certain states were not believable to some participants:

You have slight problems doing your usual activities, but you're extremely anxious or depressed. I've already said that causes more problems for doing activities than physical problems … I'm just querying the actual states you've created. (Participants 6)

As a result of not believing health states, participants sometimes 're-wrote' the health state and changed the dimension level to one that they felt was more likely:

I would contend that possibly not being able to do my day to day activities would make me depressed, in fact I know it does, so I would probably go for life B (Participants 16)

Participants also re-wrote states by adding treatment. Thirteen people mentioned treating 'pain or discomfort' or 'anxiety or depression', but only two participants mentioned treating mobility problems. An example of adding treatment is below:

Severe pain and discomfort, there are medicines available to deal with that, and there are things like pain clinics, and referrals from your GP to go and deal with that. Moderately anxious or depressed I would say definitely look at some perhaps stronger or different medication. (Participant 19)

Several participants mentioned having difficulties with the attribute labels and the labels were seen as being subjective and difficult to interpret:

When it comes to physical pain I don't really make distinctions beyond a certain point after moderate, I can't distinguish between severe and extreme (Participants 13)

Five participants queried the ranking of extreme compared to severe, although they did consider extreme as worse than severe:

Is extreme meant to be worse than severe? (Participants 17)

This theme illustrated how participants interpreted the EQ-5D-5L health states. Using their imagination and experience, the participants concretised the health states. However, the process of interpreting the health state was not straightforward because participants expressed doubt about their knowledge, changed their understanding of the descriptive system, added information to the health state, did not believe some health states, re-wrote some health states, and struggled with the labels of the EQ-5D-5L.

3.2. Theme 2: conversion factors

Conversion factors are personal and social factors that affect how participants valued health states. Conversion factors were grouped under four categories: (1) personal interests and circumstances, (2) other people's reaction to ill health, (3) the ability to adapt or change expectations of life, and (4) available support.

The personal interests, values, and circumstances of a participant determined the effects of a health state. The same problems with self-care or mobility can cause different consequences depending on a participant's personal circumstances:

Again uhm, I think I'm not someone who has a shower every day, I think there's a bit of a fetish about cleanliness. (Participants 6)

… it's very subjective upon how that would impact my personal life on a day to day basis. Uhhm and that would constantly change when I go back home to see my family because mobility becomes less of an issue, because you're stuck in the country side and nobody sees nobody for a couple weeks. (Participants 15)

Participants considered the social environment and how people in wider society view different health problems:

I suppose some people are embarrassed about having to use wheel chair … I don't think these … if you've got physical disablements … people don't single you out as much. (Participant 8)

Some participants stated that they expected to adapt to a health state or change their expectations of life, for example by changing their usual activities:

But if I did have uh problems doing my usual activities … so I may then choose perhaps something else to do … I can move on to something that was less intense than doing tiny cross-stitching. (Participant 14)

Participants considered many sources of support, such as family and friends, charities, government support, caretakers, the physical and social environment, available technologies, and treatment possibilities:

The society where I live … there's a lot of accommodation for people with disability … So I'm probably quite lucky to be in that environment, and if I had moderate problems walking about, there would be things in my workplace put in place to accommodate those things. (Participant 11)

Knowledge of conversion factors was relevant:

You look at what's in the news … and then it's quite publicised that things like depression, or any kind of mental illness, there's not a lot of help out there for. (Participant 11)

When valuing health states participants considered a set of conversion factors, which determined the way in which ill-health

affected them personally. Participants had to consider which conversion factors were relevant for them and how health problems would interact with conversion factors.

3.3. Theme 3: consequences of health states

Participants considered the consequences of a health state for their life. The consequences of a health state are the non-health effects that are caused by health problems. Health problems could have a range of consequences, for example on an individual's independence, dignity, and level of burden imposed on others. The consequences are reported in Table 3. The most frequently mentioned consequences were: activities, enjoyment, independence, relationships, dignity, and avoiding being a burden.

Choices between health states were based on a deeper consideration of non-health consequences. For example, in the next quote the choice between life A and life B was initially explained as a choice between mobility and self-care, but the choice between mobility and self-care was in turn based on a consideration of independence:

I would probably choose life B··· I think from a personal hygiene point of view if you're able to keep yourself clean and dress yourself, I think that outweighs having severe problems with walking about uhhm … there are aids that can be used, wheel chairs, frames, sticks etc., and you would need assistance if you had severe problems washing and dressing. So, it's more of a more of looking at it from an independence point of view, from having your own independence, that's how I look at it. (Participant 19)

Some participants mentioned difficulties with estimating the consequences of the health problems:

Yeah, it's just it's knowing how that would affect you really, whether actually your enjoyment of life would be sort of diminished. (Participant 5)

Some participants indicated that they had changed their thoughts about the consequences over the course of the interview:

I've become more aware of it in my own mind … slight problems walking about might not be the end of the world. In that, when I first came into the room, having problems walking about, and I'm sure when you listen back on that you'll see what I'm saying, was

the be all and end all. I need to be mobile, but now I've thought about things, things are changing. (Participant 12)

Some participants made comments about the importance of the consequences, which were occasionally related to age and personal values. An example is provided below:

Personally, at all costs I want to maintain a reasonable level of independence for as long as I could. For me personally that would be extremely important, uhm. Particularly because I don't want to be a burden on my wife, and because I'm fairly independent person really and I like doing things for me self. (Participant 10)

The theme of consequences demonstrates the extent to which participants focused on the non-health effects of the health state. Assessing the consequences was not always straightforward and was difficult for some participants. The non-health effects, which describe what an individual's life would be like given a health state, are an important aspect of valuing health.

The next section aims to explain the process of valuing health from participants reading the health state to expressing their preferences over health states by describing links between the three themes.

3.4. An implicit explanatory account

The explanatory account developed in this section is implicit. There was little indication of explicit linkages mentioned by the participants. For example, a participant may explicitly mention that personal relationships are important to their decision, but not explicitly how relationships influenced their preferences. However, by reviewing the transcripts patterns emerge about how the themes are linked. These patterns occur because participants frequently mention certain themes together. This implicit explanatory account is based on these patterns.

There are three stages that explain how participants valued health states (see Fig. 1). These stages do not imply that participants follow the process in an orderly fashion, and Fig. 1 is an orderly account imposed on a non-orderly process.

3.4.1. Link 1: The link between experience with ill health, imagination, and the EQ-5D health state

Upon reading an EQ-5D-5L health state participants often

Table 3
List of all consequences mentioned by participants, along with example quote.

| Consequence	Illustrative quote
Ability to support others	"(…) how it affects those other family members (…) still being able to support them"
Achievement	"(…) life is more than just existing but achieving something"
Activities	"I've been ill and it stops you from doing activities you see"
Being a burden	"(…) other people would need to sacrifice their time to help me"
Career and work	"You cannot fulfill or pursue your career"
Change in living conditions	"(…) what changes to housing are gonna be needed, would it mean moving?"
Cognitive functioning	"(…) actually can't think properly when you're in a lot of pain … it's very difficult to focus"
Confidence	"(…) these are the things that give me a lot of confidence"
Dignity	"(…) washing or dressing is more sort of personal, (…) it might be harder to have help with that because they feel more embarrassed"
Enjoyment	"(…) whether actually your enjoyment of life would be (…) diminished"
Independence and control	"(…) it seems to me that it's very important to be independent"
Income	"(…) the impact that health problems could have on your ability to earn."
Lack of transport	"(…) you can still get to things like a hospital and the doctors without having to wait for an ambulance"
Motivation in life	"(…) the less you have the volition to do the things you were going to do"
Purpose and contribution	"(…) feeling of a sense of worth and also contributing"
Relationships	"(…) would I be losing friends or losing contact with people?"
Specific time-related goals	"(…) seeing my children grow up"
Time per day spent on ill health	"(…) that's like an hour of your day, doesn't really matter"
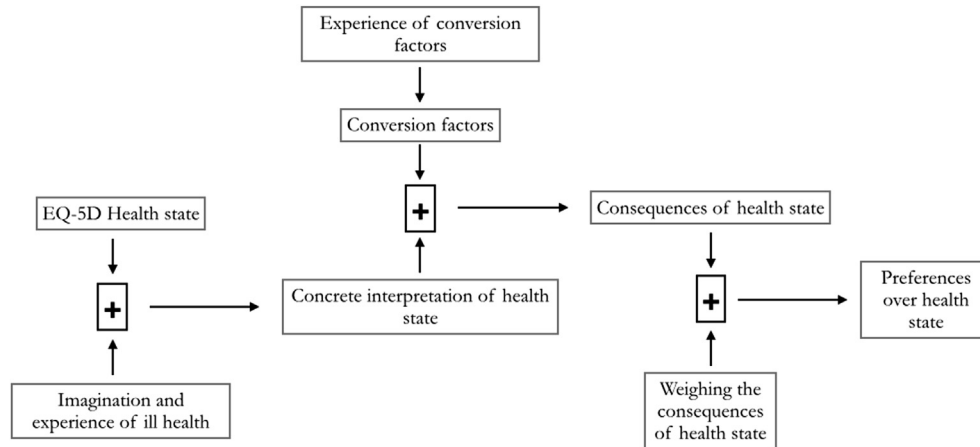
Figure 1. Themes, and links between themes, that explain the process of health state valuation.

considered what that health state would be like in concrete terms. In developing a concrete image of the health state, participants considered previous experience with ill health and used their imagination. In the quote below, a specific experience with ill health ('put your back out') is used to convert abstract health problems ('slight pain') to a more concrete image ('problems putting your socks on'):

> *The pain and discomfort in life A is only slight ... I mean I'm thinking to myself ... what's slight really? ... I think we all you know, you sort of put your back out, you have slight problems putting your socks on in the morning ... it's a nuisance (Participant 10)*

The comments from the participants suggest that there is a link between the EQ-5D health state, imagination, and the experience with ill health. These three together are used to develop a concrete interpretation of the health state. This concrete interpretation is the first stage in valuing health.

3.4.2. Link 2: The link between concrete interpretation of the health state, conversion factors, and consequences

A link was found between the concrete interpretation of a health state and conversion factors. The data suggest that participants consider conversion factors and the concrete interpretation together to determine the consequences of health states. In the next quote, not being able to walk about is concretely interpreted ('confined to a house'). Those problems, combined with the participant's social environment lead the participant to believe that the consequence would be becoming a burden and unhappy:

> *If I can't walk about ... then, that will once again confine me to a house or to a residence and that will make me more depressed ... it's going to be a personal impact, and it depends on the social scenario a lot. If at this stage I'm partnered with someone, and I'm constantly having problems with walking about, obviously my partner would be very understanding, I would imagine so, but I would feel that I'm imposing a lot on them. So that would make me very upset. (Participant 13)*

3.4.3. Link 3: The link between the consequences, weighing the consequences, and preferences

A link was found between the consequences of ill health and preferences over health states. This link was mediated by

determining the importance of the consequences. In the quote below, the participant explains the importance of ability to support others and career prospects and how it influenced his/her health state valuations:

> *I think work isn't the most important thing in my life ... I think family are, you know work is something that you definitely have to think of, but I don't have a career and I'm not about career progression ..., so it wouldn't be the first thing that would come to my priority, it would be more about family ... the choices that you make depend on how it affects those other family members, let's say for example I, if you've got a family member that relies on you quite a lot, then that's something that's gonna be on the forefront of your mind ... you you still being able to support them. (Participant 4)*

Considering and weighing the consequences is the final stage in the process of valuing health. The process thus ranges from reading to the EQ-5D-5L descriptive system, to developing a concrete image, to considering conversion factors, and finally the consequences of ill health.

4. Discussion

The think-aloud evidence presented in this paper suggests that participants go through several stages while valuing health states. The EQ-5D state description is combined with a participant's experiences and imagination to form a concretised health state. The concretised state is combined with conversion factors to determine the consequences of the health state. Participants in this study mentioned six consequences most frequently: activities, enjoyment, independence, relationships, dignity, and avoiding being a burden. These consequences are then weighed to evaluate the health states. The utility of a health state is best described as "the desirability of life given a particular state of health" (Tsevat, 2000, 162) and not a measure of health. Preferences over health states are complex cognitive evaluations that include individuals' beliefs about the interaction of the health state and their personal and social circumstances.

Other qualitative studies on the process of health state valuation have found that participants consider non-health factors such as religious beliefs and available support (Baker and Robinson, 2004; Osch and Stiggelbout, 2007; Robinson et al., 1997; van der Pol and Shiell, 2007). This study expands on those findings by describing how non-heath factors influence health state valuation.

A distinction was made between two types of non-health factor. One set, which were named 'conversion factors', are personal and social factors that interact with the health state. For example, when participants discuss available support such as sheltered housing (Baker and Robinson, 2004), they are considering conversion factors. The second set, the consequences, are the final effect of the health state on an individual's life.

The six most frequently mentioned consequences (activities, enjoyment, independence, relationships, dignity, and avoiding being a burden) are supported by previous research. Some of the dimensions of the ICEpop CAPability measure for Adults (ICECAP-A) (attachment, achievement, enjoyment, and autonomy) (Al-Janabi et al., 2012), of the ICECAP-O (attachment, role, enjoyment, and control) (Coast et al., 2008), of the Warwick-Edinburgh Mental Well-being scale (WEMWBS) (Tennant et al., 2007) (e.g. feeling loved and feeling cheerful), and important quality of life dimensions affected by mental health (relationships and a sense of belonging, activity, well-being, and autonomy, control and choice) (Connell et al., 2014) are similar to the consequences found in this study. There is thus an overlap between the consequences found in this study and domains identified in quality of life and well-being research. The consequences appear closer to the concept of quality of life than the concept of health status (Karimi and Brazier, 2016). This overlap indicates that the consequences may be generalizable to a larger sample than in this study.

The importance of the consequences in valuing health may have implications for how the benefits of health care should be measured and described. The final six consequences appear closer to the ICECAP-A or WEMWBS domains than the EQ-5D domains. This may be an argument for directly using one of these broader 'well-being' measures in economic evaluation, which avoids the participants having to estimate the consequences from the health states. However, a disadvantage would be the possible lack of sensitivity of such a measure to physical health conditions (Mukuria et al., 2015). The accuracy of directly measuring the non-health consequences of health may have to be traded off with reduced sensitivity. Another approach may be to collect data using health status questionnaires and to map these to a well-being measure (Mukuria and Brazier, 2013; Peasgood et al., 2014).

Participants encountered some problems while valuing health states. For example, they struggled with the placement of the extreme and severe labels used in the EQ-5D-5L and the distinction between the levels could be improved. Some participants attempted to re-write the health state, in particular when the state was deemed unrealistic. The psychology literature has identified a tendency of individuals for "restructuring the decision problem to create dominance and thus reduce conflict and indecision" (Slovic, 1995, 369). Care should be taken to avoid health state descriptions that participants may find unrealistic. Participants also considered treatments while valuing the health state, even though they were instructed not to do so.

Health state valuation methods could be improved by allowing participants to reflect and deliberate on the consequences of health states. This study has shown that many beliefs and judgements are involved in constructing preferences over health states. As the psychological literature suggests, individuals do not always have a set of pre-existing preferences but rather have to construct their preferences (Fischhoff, 1991). Individuals have to make judgements about the consequences of a health state, and the TTO and DCE tasks require participants to make these judgements during the valuation task. Some participants expressed doubt and reservations about predicting these consequences. In addition, as they valued more states participants' understanding of the valuation task and participants' beliefs sometimes changed. Indeed existing research has suggested that participants may change their values after group

deliberation (Robinson and Bryan, 2013; Shiell et al., 2003; Stein et al., 2006), although there is not always an effect at aggregate level (Shiell et al., 2003; Stein et al., 2006). All of this suggests that participants may benefit from a more structured approach, where participants are given time to reflect and deliberate on the consequences before they make judgements on the (un)desirability of different health states.

The findings of this study about the process of health state valuations open up areas for future research. First, research could focus on more fully understanding the health state valuation process described in Fig. 1. For example, there was limited data in this study about how participants weighed the consequences and it was not clear whether they used compensatory decision-making or a simplifying heuristic (Lloyd, 2003). Existing models generally assume compensatory decision-making, where different attributes are traded against each other, rather than heuristics that simplify the process by, for example, making choices only based on one attribute (Lloyd, 2003). Second, whether members of the public are informed about health states can be assessed by investigating whether participants are able to judge the consequences correctly. This is important because some participants expressed doubt about whether they were able to do so. Third, the framework that was provided could be tested quantitatively. For example, some of the non-health consequences or conversion factors could be specified along with the health state to see whether the health state values will change. This could be similar to work which investigated the effect of specifying different levels of life satisfaction along with health state values (Dolan et al., 2013).

One limitation of this study is the use of the think-aloud protocol for investigating participants' thought processes. Participants may have not fully verbalised their thoughts and what participants say may be unrepresentative of their thoughts (Wildman, 1995). In addition, there may be subconscious processes that affect responses to health state valuation tasks. These limitations cannot be avoided in the think-aloud protocol and would mean that the provided framework is incomplete, but not necessarily wrong. There may also be a concern that thinking aloud will change a participant's thought processes and that participants find thinking aloud difficult and distracting. There is no evidence available on whether individuals value health states differently when thinking aloud. However, when comparing the performance of a control group and a think-aloud group on a range of tasks such as information retrieval, the think-aloud group was slower but their performance was not changed (Ericsson and Simon, 1993, 84–89; Hertzum et al., 2009). There is concern that individuals use simplifying heuristics to make decisions in such complex tasks as health state valuation, for example they may only focus on one health dimension (Lloyd, 2003). Besides participants occasionally 're-writing health states', the use of heuristics was not evident in our data. This could potentially be due to the think aloud process and because this study was not mainly aimed at uncovering heuristics.

The sample in this study was not representative of the general population. The majority of individuals in the sample were identified via the university mailing list and only those with access to email would be able to receive the advertisement. The sample was more educated, contained more students, less retirees, and was younger than the UK population (Office for National Statistics, 2011). It is therefore difficult to assess whether the themes that emerged in this study are generalizable. One aim of qualitative research is to evaluate the range of views rather than to provide statistical measures about incidence or prevalence of those views (Coast et al., 2004; Spencer et al., 2003, 83). This aim is, arguably, still achieved using this sample, but the methods in this study could be extended to a more representative sample.

Another limitation of this study is that, compared to the descriptive stage, the explanatory analysis requires more interpretation by the researchers. To verify whether an interpretation is justified, Miles and Huberman (1994) suggest to look for outliers, to look for negative evidence, and to find and test rival explanations. In the data, no outliers were found. All participants used a similar process to value health states. Some potential negative evidence was that several participants noted that they had difficulty explaining their choices. This was only encountered three times, two of which referred to justifying the precise indifference point of the TTO, rather than the entire TTO process. Two rival explanations are known to the authors. First, Murray et al. (2002, 736) "define health state valuations to be simply indices of overall levels of health." The data in this study do not support that theory. Participants frequently mentioned non-health factors and no participant valued the states in a way that is compatible with valuation as an index of health. For example, no one claimed that one choice represents 'more health' or was 'healthier' than another choice. A second theory is that responses to a health state valuation tasks could be an "initial shock reaction to, or fear associated with, that state" (Dolan and Kahneman, 2008, 223). The findings of this study would suggest that individual's health state valuations are not entirely based on their affective reaction because individuals provide reasons for their valuations. Furthermore, the importance of conversion factors such as adaptation suggests that participants think beyond the short-term effect of a change in health state and reflect on long term implications of ill health. The affective-based theory thus cannot explain the findings in this study, which suggest that it is incomplete. In summary, both rival theories are not well supported by the findings of this study.

5. Conclusion

This study sought to describe how individuals value health states because no overall explanation was available in the literature. A wide range of factors influenced the valuation of health states and valuing health was found to be a cognitively complex and subjective task. Participants must consider the practical implications of an abstract state, how it relates to their personal and social circumstances, make accurate estimates of the consequences of ill health on their life, and weigh up those consequences. Various problems were encountered at each stage, for example, participants expressed a changing understanding of the task and reservations about the adequacy of their experience. Understanding how participants value health, and the problems they encounter, suggests the need for undertaking research on using descriptive systems that measure non-health consequences, exploring whether individuals are informed, and allowing participants more time for reflection and deliberation during the valuation task.

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