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Responses to standard gambles: A true measure of health-related
quality of life?

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Paper prepared for HESG, UEA,

Jan 2002

INTRODUCTION

It is often considered that responses to individual choice-based value elicitation procedures, such as standard gamble (SG) and time trade (TTO), are the appropriate basis on which to assess health-related quality of life. In particular, the standard gamble (SG) method is often considered to be the 'gold standard' for the elicitation of utility values due to its foundations in expected utility theory. Whilst these scores are commonly used as quality adjustment factors in QALY calculations, little qualitative work has been carried out in order to gain an understanding of how respondents answer such questions. In order to interpret SG or TTO responses as a measure of health-related quality of life, a number of assumptions have to be made. First, we assume that respondents set out to maximise their utility according to their personal preferences over the health states in question. However, variability in responses to SG and TTO questions has been found to be better explained by non-health factors, such as having children, than to variation between health states (Tsevat, 2000). A previous qualitative study showed that concern for becoming a burden on their relatives influenced the TTO responses of elderly respondents (Robinson et al, 1997). This suggests that responses to such questions may be reflecting something other than the self-interested preferences of a (health related) utility maximiser.

Second, we assume that the respondent answers the question that is posed by the researcher making use only of the information presented in the study. In contrast, respondents in contingent valuation studies have been found to re-interpret the question and bring additional 'information' to the hypothetical scenario (Fischhoff et al, 1993). Such findings suggest that respondents are 'constructing' their responses to such questions. The notion that preferences for all but the most familiar of goods are constructed, rather than revealed, is discussed in Fischhoff's philosophy of basic values (Gregory et al, 1993). The process of construction required in providing valuations for complex and unfamiliar goods leaves such values susceptible to biases and framing effects. Given the unfamiliarity and complexity of health state elicitation methods in general, and the SG procedure in particular, it would not be surprising if similar processes were at work here too. We aimed to explore the factors and thought processes that respondents invoked when responding to SG questions.

The study was designed in order to obtain a set of valuations to for use in a decision analysis of anti-hypertensive medication for the prevention of stroke and cardiovascular disease. A qualitative study was carried out alongside the SG exercise in order to document the thought

processes respondents bring to bear in formulating their response. This was considered a necessary step in determining how SG values ought to be interpreted and subsequently used.

METHODS

Patients typical of those diagnosed with hypertension, but who did not themselves suffer from the disease, were randomly selected from the computer records in one general practice in Newcastle Upon Tyne. The stratified sampling was based on Morbidity Statistics in General Practice (MSGP) data on the incidence of hypertension. Descriptions of health states associated with stroke, heart disease and anti-hypertension medication were devised from the literature. The descriptions, reproduced in Figure 1, included two different severities of stroke, four severities of heart disease- defined by the New York Heart Association (NYHA) classification system- as well as an 'on treatment' state.

Quantitative methods

Respondents were first asked to rank the states, together with normal health and death, from best to worst. They were then asked 8 SG questions, the purpose of which was to find the point of indifference between Option A - an intermediate health outcome for sure and Option B - some chance of a better health outcome and some chance of a worse outcome. The chances of the better and worse outcome with option B were initially set at 50 in 100 and respondents asked whether they prefer Option A, prefer Option B or think there is nothing much to choose between them. The chances of the better and worse outcomes with option B were then changed until the point of indifference was found. All states were assessed against normal health and death whilst the 'on treatment' state was also assessed against normal health and the mild stroke state. The utility values were calculated on a scale from 0 (dead) to 1 (normal health) directly for all health states. In addition, an indirect value was also computed for the 'on treatment state, using a 'chaining' procedure. Further details of the SG procedure used are available from the authors.

Qualitative methods

Data collection

Two main qualitative data collection methods were used: speaking aloud during the SG, and a semi-structured interview which immediately followed the SG. This combination of methods was chosen to enable a richer and more holistic approach to data generation than a single interview or simply taping the SG. The standard gamble exercise was taped recorded and respondents were encouraged to make comments as they were making their choices, to share

their considerations and explanations. In this way, respondents had the opportunity to share thoughts about their choices as they made them, as well as reflecting on their choices in the context of the whole procedure. At times there was some discussion of their comments during the SG. More often they were noted by the researcher and returned to in the interview which followed.

A semi-structure interview followed the SG and was driven by a topic guide together with the researcher's observations of the SG and respondent's comments made during the SG. The topic guide was revised during the course of data collection and varied as new themes were integrated. Interviews began with a broad approach and typically started with an open question such as "What was going through your mind when you gave your answers to the SG?" More specific questions came later in the interview, including those relating to individuals' own responses. The topic guide was flexible, intended only as an 'aide memoire', and interviews varied between respondents depending on their responses.

Box 1: Topic Guide

What were you thinking about during the exercise?

What sort of things were important to you/ 'driving' your answers?

Probe for

Knowledge of conditions/ experience

Non health-related issues e.g. family

Impact on others

How did you feel about the exercise?

Probe for

Difficult/ easy/ became easier

Rules of thumb

Concerns about consistency

How did you deal with the probabilities?

Probabilities and risk attitudes

Threshold effects

Notion of 'good odds'

If responses were similar to several – probe for reasons

If preference for immediate death – probe for reasons

Data analysis

SG commentary and interviews were transcribed verbatim. Although symbols and codes were not used, interruptions, hesitations and any audible emotion, such as laughter were transcribed. Transcription was done mostly by AR and RB with some secretarial help. Field notes were made to record researchers' immediate impressions and to help shape the topic guide and data analysis. Transcripts were imported into Nvivo qualitative software and a series of attributes were associated with each transcript (age, sex, occupation, education, utility values...). Coding

of text was conducted by AR or RB and a small subsample of transcripts were coded by both. Ongoing discussion of emergent themes during data generation and concurrent analysis meant that a coding frame was built up iteratively, grounded in the data, and themes were developed jointly.

The data analytic process involved the following steps which are common to most qualitative research: familiarisation; sorting, ordering and indexing data; building themes; mapping and linking themes; and interpretation/ building explanations. Constant comparison was used and analysis included seeking contradictory evidence as themes were generated.

RESULTS

Quantitative results

Of the 31 respondents interviewed, one withdrew consent and a further two did not appear to understand what they were required to do. The 28 patients for whom data were complete had a mean age of 65, with a range from 41 to 87. Thirteen (46%) were men, 3 (11%) were university graduates, whilst 25 (78%) had no further education of any kind. The aggregate utility values are shown in table 1. For those subsets of states with a 'logical' preference ordering, the aggregate valuations are in the expected order. For example, mild stroke is valued more highly and than severe stroke and NYHA Grade I heart disease more highly than Grades II to IV. The last two rows show that the valuation attached to the 'on treatment' state is higher when calculated indirectly than when compared directly to death.

Table 1: Aggregate utility values

Health states (described in figure 1)		Mean (std dev)	Median (interquartile range)
Stroke:	State L (mild)	0.55 (0.24)	0.58 (0.44-0.70)
	State S (severe)	0.14 (0.20)	0.00 (0.00-0.23)
Heart disease: (NYHA grade)	State O (I)	0.70 (0.17)	0.68 (0.60-0.84)
	State M (II)	0.61 (0.16)	0.65 (0.50-0.68)
	State R (III)	0.58 (0.21)	0.58 (0.48-0.73)
	State P (IV)	0.44 (0.22)	0.48 (0.38-0.60)
Anti-hypertensive medication	State H (direct)	0.78 (0.20)	0.85 (0.65-0.93)
	State H (indirect)	0.87	0.90

At the individual level, none of the 28 respondents assigned severe stroke a higher score than mild stroke and only one respondent gave the states the same value. In contrast, 18 respondents attached a higher value to at least one grade of heart disease than to another that was logically better. Nine of the remaining 10 respondents assigned the same value to two or more of these health states, leaving only one strictly consistent set of responses over the heart disease states. It is likely that the difference is due to the similarity of the description of the heart disease states under the NYHA classification system and confusion that ‘slight’ related to the most severe form of the disease and ‘strenuous’ to the least (this was also reflected in problems respondents had in ranking the states).

Qualitative results

The analysis reported here is based on data from the SG and in the qualitative interview that followed. Quotes, which are used to illustrate our findings, are identified by respondent age, gender and the data source (SG or INT). The qualitative data are extensive, and cannot be reported in their entirety, rather an attempt is made to give a broad picture before focussing on the themes of particular interest. The analysis focuses on the central observation that when faced with SG questions, respondents incorporate a broad range of influences into their choices. They ‘construct’ the decision scenario based not only on the information presented to them by the researcher, but on an array of personal, contextual and external factors.

Based on commonalities and shared ‘threads’, themes were built up and refined. A diagrammatic representation of the analytic framework is shown in Figure 2. The data are gathered together under three super ordinate themes: “Individual and experiential influences”, “The construction of the standard gamble”, and “Respondents’ concerns with the SG”. The results are presented in three parts, reflecting the structure shown in Figure 2.

I. Individual and Experiential Influences

Shown in the first third of Figure 2, this theme represents the factors respondents ‘brought to’ their choices. Experience of the illness under consideration was commonly cited by respondents, but individuals’ age, living situations, religious beliefs, families and professions were also recognised influences. Their comments were also linked to their perceptions (discussed later) that other people in different contexts would respond differently.

Personal context

There was recognition among respondents that their answers were contingent upon particular features of their life, most usually age and current health status. Respondents seemed to view the impact of age on responses in two different ways. Some related age to their willingness to accept a higher risk of death:

When you are at rest and you are in pain and this sort of thing, I think your quality of life gets really low and if there's a 50/50 chance of having something done then all the better. I would agree to go for it- especially at my time, 70 year old you know. My life expectancy isn't about more than 10 or 15 years, so therefore I would go for option B to get a better quality of life for the last few years. 8SG (70, M)

Or alternatively, that you are more accepting of minor complaints as you get older;

Well I find that when you are older I find that you do get a little bit breathless and that, but that's just you come to the understanding that if you age then that's what nature gives you, but that's about the best I can do with that. We are past our three score and 10 you know. 14SG (72, M)

Similarly, family circumstances, religious beliefs and attitude to gambling were given as reasons behind the SG responses. The recognition that values were based on current personal circumstances, led respondents to hypothesise that their responses are likely to a) change with their circumstances and b) be different from those of other people (a theme which was also returned to in their concerns about aspects of the SG).

I thought that as you get older, issues of mortality and everything else that become less important. I think it's a case that the fear of dying diminishes and I think issues of faith, like if you are a Christian and believe in that sort of thing, so if you are a Christian these options tend to, the lines tend to be a bit more blurred I think, so that's something that could possibly have an impact. 28 SG (46, M)

Many respondents were clearly bringing to the exercise strongly held prior beliefs about their reluctance to be left in a severely disabled state, such as health state S. This often took the form of respondents expressing support for euthanasia or describing how they themselves would ‘take steps’ to end their own life were they to become incapacitated.

I'll tell you what I would do pet if I was in that state, I would take a pill, I would polish myself off, there's nobody to look after me. 23SG (80, F)

I mean your speech is something you have to use to let people know what you want and you cannot perform any of your usual activities, that would be really, really hard for me. I mean you are just a vegetable aren't you? Well, for me I would be a vegetable and I wouldn't want that, you could give me a pill and put me to sleep. 35 INT (61, F)

Experience

‘Experience’ was used as a label to represent the prior knowledge about the health states respondents brought to the SG exercise. This often took the form of detailed discussions of the experience of family or friends who had suffered (and, in some cases, died) from stroke or heart disease. Such first hand experience of the health states fed into the valuation processes in one of two ways. First, there were respondents who would do anything to avoid suffering the same fate themselves and would cite this as a reason for their willingness to accept high risks of death. Alternatively, other respondents would recall how their relative coped with, and adapted to, even quite severe disability and this held less fear for them than unfamiliar health conditions. Other sources of information respondents were drawing on included professional experience and media coverage.

Well this one obviously reminds me of a stroke and my father had a lot of strokes and em... don't like that one at all. That would be preferable to that for me. Like I say, that's more based on bad memories than medical fact because I lived with my father with him like that and it wasn't very nice. 13SG (42, M)

This is just reflecting on my husband, because that's exactly what he's like. At first I think would find it very hard, but hopefully I would fight through it and learn to do other things with my body like he did. I don't know which way to put it, finding new interests and keeping yourself busy and just learn from day one. That's exactly how we took it with my husband, I mean he was like that for 20 year exactly like that, but we got on with life and he lived a happy life. And I would hope I could do the same. 17 SG (70, F)

II. 'Construction' of the SG

This central theme describes how respondents constructed the SG task for themselves by introducing their own details and interpretations to the scenarios. It was common for respondents to observe that the choice was too 'abstract' and that there was not enough information on which to base their decisions. Respondents appeared to compensate for this lack of context by elaborating on the scenarios for themselves.

Well, I would think you would probably be in a wheel chair, if you had all of them, yes you would be in a wheel chair, so therefore the feeling of helplessness. But then it depends who's helping you because some people can uplift you the way they go on er (pauses) but then of course you go into Newcastle and Eldon Square and you see them whizzing along in their wheelchairs but er, you see your speech is slurred, it's very hard to understand you, that would be terrible that, you'd have to use sign language really. 18 INT (75, M)

Many respondents were keen to make the choice more real by making an assumption about what 'Option B' would actually entail. Most commonly, it was described as 'an operation', but 'tablets' and 'serum' were also used to conceptualise the hypothetical choice. Whilst this allowed respondents to engage in the task, there was evidence that this may have affected their ability to take the risk information at face value. For example,

Well, it would be a waste of time going to hospital and wasting all that money and putting the surgeons to all that work, because you are going to die anyway"... "Nobody is going to give a 100% chance of dying, they just wouldn't do it. Personally, I would, but the wife wouldn't let me. I wouldn't want to be in that state- if it was 100% I would just say to get out of it - euthanasia- legalise it. I think the wife would be a bit choked at that like. 6 SG (65, M)

So to choose normal or death there must be some kind of tablet to take to have them two options. I know its imaginary but you can't give someone to say right, that's how your going to be but we can give you can option, you can rather take this tablet or this serum if you can end up having a normal life or it can kill you. 27 SG (50, F)

Individuals' views and experiences of the medical profession also fed into their construction of the scenario:

No, you know I don't trust any doctors these days you hear such bad reports about them, don't you and the hospitals are enough to put the fear of God into you it is. The lives they are losing now its awful isn't it? I'll leave it like that. I hope you don't come back to me for causing bother 23 SG (80, F)

Well it would have to be Option A because I'm not a one for taking chances, because if you go into hospital now you get bugs and all sorts and you are not sure to come out, they used to save you at one time, but they don't now, in my humble opinion like. 14SG (72, M)

Another elaboration respondents brought to the SG scenario has been labelled 'anticipated adaptation'. This sub-code describes respondents speculating about how they may adapt to the health state through time and their ability to develop coping strategies.

That's right, slight physical activity, as I say you know thinking of it now and not being in that position I would think well ok I have to reorganise my lifestyle to a certain extent and I'll have the frustration of not being able to do quite as much as I do now, but on the other hand I thought I could probably adjust to it but until you are actually in the situation of having to continually adjust and not be able to go out on a fairly vigorous walk or do what you normally do I don't know how frustrated I would feel, because it is difficult to envisage something that hasn't yet happened. 21 INT (68, F)

This one here is a case of you're running for a bus and you're out of breath, well Ok, walk for the bus and if this bus has gone another one will come along, just slow down, that's all you have got to do, you don't need to go into any of this, just slow down. 6 SG (65, M)

An important theme which was linked to individuals' hypothesising of the scenarios was that of the importance of others in the decisions made. The effect of any choices on family was a particular concern. The apparent significance of this to many of our respondents led us to draw this out as a separate theme 'Considering Others'.

Considering others

Illness as burden on others

This theme describes how respondents were considering the welfare of others when answering SG questions concerning their own health. This was often expressed as a desire not to become a physical burden on their loved ones.

Once I got past that point, where I couldn't function and I would require a lot of input to help me along. I would have a problem with that and I probably would want to take action to prevent me being a burden on other people and if that's death compared to paralysis and incapacity, then I believe it all quality of life for the individual and for those around and it would be unfair

and from the same respondent,

I still would not like to be a slobbering, heavy, burden on her when she is still young and em being able to get on with her life and having a better quality of life and that tempers my responses to these situations and that's when age becomes a factor- it would. No, I wouldn't want to be a burden. 28 INT (46, M)

The concern over the impact on relatives extended beyond those relating to becoming an actual physical burden on them, but also to the mental anguish their illness would subject them to.

But it is up to a point whether if you are going to be a drudge to the wife and all this sort of thing, I said oh no I wouldn't like to. I would hate to, I have only got one daughter and she lives abroad like, she lives in Holland but she comes over 3 or 4 times a year to see us, but I would hate to be inconveniencing in any way. 14 INT (72, M)

I have got two unmarried daughters that live in Newcastle and I would hate to think of them being faced with the option of having to put me into permanent care, which they would have to do, but they would hate it and so all of these things naturally colour your judgement. 21 INT (68, F)

Death as loss to others

The other way in which the impact on family and friends was considered, but which is likely to have exactly the opposite effect on responses to the SG questions, is in how respondents considered the impact of their death on others.

I would go for A, definitely. Yes, you are risking your life unnecessarily there, you see you have to take things into consideration, not just yourself. You have got to think of your wife, your own children and your grand children, they will miss you if you are gone- it doesn't matter what you think, what they think is the view, you know. 6 SG (65, M)

and from the same respondent,

But erm when your own children are grown up now, they come to see, they still love you, your grandchildren run up and 'granddad', 'grandma', this sort of thing, you'd be pretty bloody selfish you know to think of yourself and then all of a sudden there's an empty chair you know, and when they come in you're not here. You know that's selfish a way of looking at it, that's why you've got to weigh the odds, you know

I would say, if it was me on my own with nobody else to worry about, then I would be prepared to go for option B even if the chances of not surviving were starting to be quite high. Even 70/30 or something, I don't know. But, I've got a wife and son which might move it up again towards the top. 20 SG (45, M)

Duty and responsibility

As suggested in the last quote, issues of duty and responsibility were also playing a role in SG responses. In particular, actively choosing to risk death in the SG was considered to be 'irresponsible' and 'selfish'.

If it was a known risk, I think I would stick with A because that's something that, you know, frustrating, but you can cope with it and I think it would be a little bit irresponsible for my family you know to risk any chances of immediate death knowingly. 21 SG (68, F)

and from a woman who had an adult son with Down's syndrome,

I think I would probably choose that because as I say I have my son and things like that. But if it was just me by myself I would take a chance, you know to think that you could get to your normal health. I think I would just take option A, I wouldn't like it much, but... Its very difficult, as I say, because of my son yes I would because at least I would be here. 32 SG (56, F)

These respondents appear to be saying that their responsibility to 'be there' for their dependents is overriding their own views of the health state in question and that they would make different choices if they only had themselves to consider.

III. Respondents' concerns with the SG

Many of our respondents spontaneously commented on the answers they had given and the values which would be derived from them. There were various concerns about the appropriateness, accuracy and meaning attributed to the values. Three categories were derived from their responses: "concerns about the applicability of values", "concerns about the SG procedure" and "concerns about the realism of the choice". Each of these is expounded below and evidence is presented supporting the themes.

Concerns over the applicability of their values.

Respondents considered others throughout their discussion, their comments reflected a recognition that others would respond differently to the questions posed. Some queried whose values *should* be elicited.

...you have got to experience things before you would know what you would do yourself as far as I am concerned, you really do have to experience these things, people with high blood pressure or heart trouble I think they are the people who should be doing the survey like this because you would probably get a better idea from them. 15 INT (68, F)

There was an impression that the views given would differ from others or be atypical.

Yes I should think so, I think my mind is pretty much set . Because I think a lot of people think of how they would like to live and a lot of people don't want to be vegetables. I mean OK, there some might be they are not happy with it but they want to live as long as possible even in a vegetable state, but I wouldn't. 8 INT (70,M)

You see, there's a lot of people who would be quite happy to be in a chair for the rest of their life and just be a vegetable and not know what time of day it was, not me, I wouldn't like that at all. 15 SG (68,F)

No, I would have to pop off (laughs). I bet nobody else answer like me. 23 SG (80,F)

As reported above under the 'anticipated adaptation' theme, respondents were also speculating that their views may be quite different in a 'real-life' situation, than their ex ante hypothetical responses suggest.

I suppose to alternate is to see how people actually react when they are actually in the situation which might be different to what they say I mean quite easily I would say I am cautious about this because most people react quite differently when it actually came to that decision. 11 INT (63,M)

Its hard to tell if you are actually in that state then you would probably think more clearly what it means, I've never been in that state so I can't tell what its like. Human beings are very adaptable though some more adaptable than others. 2 SG (65,M)

Concerns about the SG procedure

Although this was not included in the topic guide, or among the research objectives at the outset, respondents' views of the SG formed an important theme which emerged during analysis. There

were a range of concerns surrounding the SG procedure which were voiced during and after the exercise.

*Q. Just in general so how do you feel about being asked to do that type of exercise?
Well really you were asking me to split hairs I said to you would you go 84½, these are decisions I think to be made over a period of time taking into account all the circumstances and the probabilities of survival, so that was the only thing that, I wasn't uncomfortable about any of the questions but that's how I felt about the exercise as a whole. 20 INT (45, M)*

This respondent queried the responses throughout the SG. There was a sense that although he was prepared to give a value when pressed, that he felt there was some question over the meaning which should be attached to his responses. Others queried the reliability of their responses.

Its difficult to estimate this really, I'm not sure how reliable these statements are to be honest. And of course I guess the thing is that this is all the information you have got which is not a lot to go on really. Well I might go for B on that, I'm not really sure about that. 11 SG (63, M)

and during the subsequent interview, he went on to query the appropriateness of the SG:

*Q. Can you just say little bit about what was going through your mind when you were thinking about that?
Well before the difficulty of thinking about a sort of hard probability of some minor problems compared with a low probability of some more disastrous occurrence and it seems to me I cannot see any logical way of making a sensible comparison between them to be honest. There seems to be a serious difficulty there. 11 INT (63, M)*

A number of respondents expressed explicit concerns over the consistency or 'rationality' of their responses, whilst others appeared to have more general concerns about getting it 'right'.

*Q. What did you mean when you said it seems a bit hypocritical?
When I mentioned hypocritical I thought I'd gone against what I had said earlier. Even when I changed one of my percentages I had a re think, you know that time I went back which is, you have to give it a lot of thought. I don't know whether I went for the better odds, but I know I changed my mind on one of them. 31 INT (63, M)*

Well, if you are completely rational, you could work out the ranking order of those original things as some were better than others. I mean it was pretty obvious most of the time which was worse, but when you had one there and then another there, it was hard to be completely rational. 2 INT (65, M)

No I think I could live with that to be perfectly honest. I'm pleased this isn't a game show. 23 SG (80,F)

Concerns about the realism of the choice

This theme reflects more general concerns about the process of value elicitation whereby respondents are expected to make rapid responses to hypothetical questions. In particular, there were some comments which reflected an awareness that decisions might be considered

differently with more time to reflect. For some it was an issue of decision making style, for others an issue of the reliability of a response given so quickly.

Well, that was a problem, because I do like to mull things over, that's the way I am, I'm not impulsive at all, my wife's the same if we're thinking of buying something we'll talk about it for weeks before we actually go out and buy it, you know. 2 SG (65, M)

that's the problem I have and given 10 or 15 seconds to think about are going to go for life or death isn't a realistic proposition, gives you gut reaction, sometimes they are as reliable as anything but that's what I was thinking about. 20 INT (45, M)

As I say its also clouded as well because its not a realistic option, you know having been a nurse, I know its not a realistic option, so that makes it even more confusing, but working on a purely hypothetical level, I think if it was as high as 50/50 I would be morally bound to take option B. 21 SG (68, F).

The view was also expressed that, were they to be faced with the real situation, they would consult with others before responding and take the views of their families and doctors into consideration. Respondents also returned to the lack of detail in scenarios, a theme discussed under the 'construction of the SG' section above.

DISCUSSION

Qualitative techniques

Generating qualitative data alongside quantitative measurement entails particular challenges. Whilst there are obvious advantages of using concurrent think aloud techniques, this can be difficult for many people. This was witnessed in the reticence of several respondents to talk during the SG and a desire to concentrate on a task they wanted to perform 'correctly'. Following piloting, we chose to allow respondents the opportunity to raise issues that occurred to them during the SG process as well as conducting a retrospective interview immediately following the exercise. Wherever possible, both researchers were present during data collection and the interview was carried out by the researcher not administering the SG. This had several advantages: detailed notes could be made during the exercise so that respondents' own words could be used to explore issues in more depth during the interview; observation of the SG allowed for facial expressions and gestures to be noted as well as verbal data; and the 'mood' of the interview was often markedly different between the SG and the interview. Although resource-intensive, we felt that there was much gained by a flexible and responsive approach to data collection, and by including several data sources.

Nevertheless, reference to the topic guide demonstrates that there were topics on which we did not gain sufficiently coherent data for inclusion in our results. In particular, responses to

questions about their handling of probabilities and use of ‘rules of thumb’ or heuristics were difficult to interpret. Likewise, we are unable to say anything decisive at this stage about specific departures from the axioms of expected utility theory. Whilst more detailed consideration of the data may yet provide some fruitful insights, it may be that such issues are better addressed by an alternative research design.

Implications for preference elicitation techniques

Many of the findings we report under our 3 super ordinate themes (“individual and experiential influences”, “construction of the standard gamble” and “concerns with the SG”) have implications for how the responses are to be interpreted and subsequently used. As space does not permit a detailed discussion of all points of interest, we focus here on those findings that have direct implications for the direction of future research. Of particular interest is the extent to which respondents appear to be ‘constructing’ the SG exercise for themselves by elaborating on, and making assumptions about, the basic scenario they are presented with. This highlights the fact that respondents may be answering a rather different question than that posed by the researcher.

It is likely that such a divergence may help explain the inconsistencies that are commonly found in preference elicitation studies. For example, respondents who imagined risky ‘Option B’ as a surgical procedure would clearly find it implausible that they would be offered surgery that carried with it a 100% probability of death. Thus, it would not be surprising to find within-subject preference reversals between responses to SG and alternative elicitation methods. Similarly, previous research has showed that older respondents found the worse than dead TTO scenario implausible, a finding which helped explain differences in the valuations of population sub groups (Robinson et al,1997). Clearly more qualitative research into how respondents re-interpret the value elicitation question may offer further insights that help explain the quantitative data.

Another important finding was the extent to which respondents were considering others when responding to individual questions about their own health. Elicitation techniques such as SG and TTO ask individuals to trade off probability of survival or life years in order to avoid a given deficit in their health status. As health is only one component of the life we are asking people to sacrifice, it is not surprising that the responses to such questions are only health-related *in part* and that other considerations do come into play. It has been argued recently that the values used in QALY calculations ought to reflect the value of the individual’s *life*, rather than the value of

their health (Tsevat, 2000). In other words, it is not *health-related* quality of life that we set out to measure at all, but some more encompassing measure of utility. The question then becomes; just *how* encompassing ought this measure to be? The qualitative results presented here showed that respondents considered the impact their survival with an impairment and their death would have on family and friends. If the utility of others is entering into the respondent's own utility function, then the maximisation process will simply be taking account of the externality. Whilst this may give rise to problems of double counting if mutually dependent utility functions are to be aggregated, such externalities do seem a reasonable thing to consider when assessing the true impact of a health state.

In the data reported here, however, respondents seemed not only to be considering others along with self, but were apparently giving *more* weight to the utility of others than to their own. Consider the quote from the woman who made it clear she was selecting the option that was better for her son, rather than herself. Are we justified in interpreting choices made out of duty and obligation to others as a measure of preference over health states? The problem of interpreting such choices as a measure of utility is discussed by Sen (1981);

Choice may be guided by considerations other than pleasure, desire, or anything else related to a person's own fulfilment. You drown with your ship doing your duty but desiring escape, and the choice based definition of utility declares that you have once again- as always!- succeeded in maximising your utility. The husband and wife in O'Henry's 'the gift of the Magi' can be given the good news that they did after all maximise their respective utilities¹.

Sen, 1981, p 206

Sen goes on to argue that choices may be used as evidence towards utility, but that defining utility in this manner is 'bizarre'. Rather, the link between choices and desires is an empirical one as, whilst it may be correct over certain types of choices, there are powerful motives for choice other than personal desires. Broome also argues against choice-based utility measures, but offers a more practical solution for health status measurement; the 'choice-less' VAS procedure (Broome, 1993). Whilst space does not permit a discussion of the relative merits of value elicitation techniques (and there are certainly many problems with the scores generated by VAS techniques), further research is clearly needed in order to clarify what considerations are, and are not, legitimate for inclusion in QALY calculations.

¹ O'Henry's 'the gift of the Magi' tells of a married couple who are too poor to buy one another a Christmas present. What the wife really desires is a set of combs for her beautiful long hair, whilst the husband wants a chain for his treasured pocket watch. The husband sells his watch to buy the combs for his wife only to return home on Christmas Eve to find that she has sold her hair to buy him a chain for his watch.

Another finding of interest is that respondents spontaneously voiced concerns about their SG responses and questioned how applicable their values would be in other settings. This suggests that respondents may have reservations about the use of their responses in resource allocation decisions. One way of tackling this is in reflecting back to respondents the policy implications of their own individually-derived valuations and eliciting their reaction. Just such an approach was undertaken in a study involving road traffic injuries whereby respondents were presented with the policy implications of their WTP, and SG responses (Jones lee et al, 1995). The results showed that the 'social' trade-offs lay somewhere between the relative weights derived from their WTP and SG responses, but were much closer to SG than WTP. Similarly, in their work on DALYs, Nord and others take an iterative approach to arrive at an 'reflective equilibrium' between individual and social values (Nord et al,1999). Whilst a limited amount of qualitative work has be done in order to explore how responses to individual and social value elicitation techniques differ (see Dolan & Green, 1998), this remains an important area for further research.

CONCLUSION

This research was prompted by an interest in the variety of sources and influences which individuals draw on in their responses to SG questions. It is to be expected that these may vary with age and circumstance, and the comments of these respondents supported previous data which have drawn out distinctions based on age and experience of illness. There are , however, two main findings from the qualitative data which are perhaps of greater interest. These are a) the potential implications of the construction of a scenario from the information provided and a vast reservoir of experience, context and influences in which the SG is set, with particular emphasis on the consideration of others; and b) the concerns that respondents have about the accuracy and appropriateness of the values derived from the SG.

ACKNOWLEDGEMENTS

The authors are indebted to the 28 respondents who gave their time voluntarily and provided us with such a rich data set. We thank Dr Dave Whitford and staff of the West Farm Avenue General Practice, Longbenton, Newcastle Upon Tyne, for their help and co-operation. We are grateful to Eileen Coope for providing secretarial support to the project. The research was funded by an MRC training fellowship awarded to Angela Robinson. Rachel Baker is funded by an MRC HSRC Phd studentship.

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Figure 1: The health state descriptions

<p style="text-align: center;">State L</p> <ul style="list-style-type: none"> • Your arm and leg are a little weak on one side • Your speech is a little slurred but people understand you • You may be unable to perform some of your usual activities • You can look after yourself as usual <p>FOR THE REST OF YOUR LIFE</p>	<p style="text-align: center;">State S</p> <ul style="list-style-type: none"> • One side of your body is totally limp (paralysed) • Your speech is slurred-it is very hard to understand you • You are unable to do perform most of your usual activities • You cannot look after yourself without help <p>FOR THE REST OF YOUR LIFE</p>
<p style="text-align: center;">State O</p> <ul style="list-style-type: none"> • <u>Strenuous physical activity</u> brings on some or all of the following: <ul style="list-style-type: none"> - Fatigue – feeling tired - palpitations – an undue awareness of an increased heart rate/pulse rate - breathlessness - chest or anginal pain • You feel comfortable at rest <p>FOR THE REST OF YOUR LIFE</p>	<p style="text-align: center;">State M</p> <ul style="list-style-type: none"> • <u>Normal physical activity</u> brings on some or all of the following: <ul style="list-style-type: none"> - fatigue - feeling tired - palpitations - an undue awareness of an increased heart rate/pulse rate - breathlessness - chest or anginal pain • You feel comfortable at rest <p>FOR THE REST OF YOUR LIFE</p>
<p style="text-align: center;">State R</p> <ul style="list-style-type: none"> • <u>Slight physical activity</u> brings on some or all of the following: <ul style="list-style-type: none"> - fatigue - feeling tired - palpitations - an undue awareness of an increased heart rate/pulse rate - breathlessness - chest or anginal pain • You feel comfortable at rest <p>FOR THE REST OF YOUR LIFE</p>	<p style="text-align: center;">State P</p> <ul style="list-style-type: none"> • <u>At rest</u> you may experience some or all of the following: <ul style="list-style-type: none"> - fatigue - feeling tired - palpitations - an undue awareness of an increased heart rate/pulse rate - breathlessness - chest or anginal pain • Any physical activity causes increased discomfort <p>FOR THE REST OF YOUR LIFE</p>
<p style="text-align: center;">State H</p> <ul style="list-style-type: none"> • You have to take tablets twice a day to control your blood pressure • You may not experience any side effects of these tablets <p><u>But</u></p> <ul style="list-style-type: none"> • Up to 25% (1 in 4) people taking these tablets suffer one or more of the following symptoms: <ul style="list-style-type: none"> – Fatigue (tiredness), dizziness, headache, upset stomach, dry cough, flushing, sweating, dry mouth, cold hands and feet. – The tablets cause sexual problems (impotence) in approximately 10% of males who take them. <p>FOR THE REST OF YOUR LIFE</p>	

Figure 2: Diagrammatic representation of qualitative findings

I. Influences and experience

Personal Context

- Age
- Health state
- Risk attitudes
- Personality/ beliefs
- Views of death and euthanasia

Experience

- Own experience of illness
- Family and friends
- Professional knowledge
- Media

II. Individuals' construction of the SG

Consideration of others

- Illness as a burden on others
- Death as a loss to others
- Duty and responsibility

Construction of the SG decision

'Construction' of..

- The health state/ scenario
- The 'treatment' (option 'B')
- Personal response, adaptation, coping
- *Effect on others*

III. Concerns about values

Applicability

- Values are different to those others would give
- Values may change with experience

SG procedure

- Validity, reliability & precision.
- Concerns with consistency

Realism

- Decision style and time to think
- Sharing decision with others
- Lack of information

Utility Value

