

Identification and measurement of carer utility *-A qualitative study of process utility in care-giving-*

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ABSTRACT

Many health and social care interventions impact on unpaid carers. Economic evaluation of such interventions requires the identification and measurement of the welfare (utility) change experienced by carers. This paper draws on ongoing qualitative research conducted with carers, to illustrate and discuss challenges associated with identifying and measuring this utility change.

Phase 1 of the qualitative research was a meta-ethnography (synthesis of existing qualitative research), which was used to determine conceptual attributes of care-giving. Phase 2 is using semi-structured interviews with carers to discuss their likes and dislikes, the conceptual attributes drawn from the meta-ethnography and potential levels for these attributes.

Initial findings suggest carers' utility is influenced by a number of factors in addition to health. These factors were summarised into 6 conceptual attributes: relationship, social support, organisational support, control, activity and fulfilment. Collectively these were termed process utility. The interviews with carers illuminated three challenges in measuring carer utility: (i) divergence between decision utility and experienced utility, (ii) heterogeneity and (iii) interdependence with recipient. Addressing these challenges—for interventions that impact on carers—has the potential to advance both the usefulness and accuracy of the resulting economic evaluation.

1. INTRODUCTION

1.1 Informal care—a policy challenge

Current health policy relies on unpaid help from family and friends as an input into the care of many patients. The amount of this informal care required, particularly for older patients can be substantial. Carers for people with dementia, for example, will often be on call 24 hours a day arranging care, doing housework, as well as feeding, washing, toileting, and reassuring the person they care for. Estimates of the equivalent annual cost of providing these services through the formal sector in Britain in the 1990s were around £30bn [1].

Current UK government policy emphasises supporting older people to live at home [2]. Given an ageing population, demand for informal care will increase over the coming decades. Moreover, changing attitudes towards caring for older parents [3] as well as changing family structures and working patterns may constrain the supply of informal care. Therefore, there is a need to identify how best to support carers and to implement policies to maintain this valuable resource.

1.2 Informal care—an economic evaluation challenge

It has long been recognised that specific attention needs to be paid to considering informal care inputs in economic evaluation [4]. Because informal care is a non-market input, the direct financial cost cannot be measured for use in an economic evaluation. As an alternative, carers time input can be costed indirectly. This can be done by looking at the cost of a similar market good, or by looking at value of time (work or leisure) foregone through care-giving [5-7]. While the latter (opportunity cost) method in particular has theoretical appeal, problems have been identified with using these revealed preference methods to measure an value informal care: they have been applied inconsistently [7], and the valuations lack sensitivity to the carers' preferences [8] and any positive aspects of care-giving.

Stated preference techniques have been used recently to assess the value of carer time. Two studies elicited willingness-to-pay (WTP) and willingness-to-accept (WTA) values for marginal changes in carer time [9, 10], whilst a third obtained money valuations of carer time through a discrete choice experiment (DCE) [11]. These methods are arguably more sensitive for carers than revealed preference methods and theoretically able to capture positive aspects of caring. However, the idea of 'compensating' additional care input frames

care-giving in a negative way. Furthermore, the methods—particularly WTP—may be inappropriate to elicit preferences when money is low on the carer's list of priorities [8].

The alternative to valuing informal care as an input is to consider the impact on carers through the consequences or effects aspect of an economic evaluation. Brouwer et al. have suggested this is appropriate in addition to considering informal care as an input of cost [6]. Several economic evaluations have included the health effects of interventions on carers [12-14]. The appropriateness, however, of using health effects as an outcome measure for carers has been questioned [15]. Doubts were raised about the sensitivity of QALYs to either the burden or satisfaction experienced by carers [15].

Recent work has extended the positive dimension of caring into economic evaluation [16, 17]. The CarerQol instrument consolidates existing instruments for measuring carer burden and satisfaction into a single measure [17]; another study by the same author explores utility related to the process of care-giving [16]. The latter study demonstrates that the identity of the care provider has a substantial and highly variable impact on the happiness of both carer and recipient. This work has not, however, investigated the factors that gave rise to the process utility. Knowing more about these factors would aid discussion both about how to measure the broader consequences of interventions on carers and of policy-making for the support of carers.

1.3 The contribution of qualitative methods

Empirical research in health economics is overwhelmingly quantitative, focusing on validating or falsifying hypotheses, and generating generalisable findings [18]. Qualitative methods, however, also have much to offer health economics in terms of understanding behaviour, designing preference elicitation studies and exploring unexpected results [18]. Upcoming publications that illustrate the strengths and applications of qualitative methods include an exploration of NICE's use of cost-effectiveness evidence [19], the development of attributes for a dermatology DCE [20] and an investigation of WTP responses [21].

Qualitative methods have been extensively used in health and social care research and have been utilised extensively to explore the experience of care-giving [22-27]. Interviews allow the researcher to investigate and probe unexpected responses and findings, both within the interview and in subsequent interviews.

1.4 The objective and structure of the paper

This paper reports work to determine and explore the factors that are important to people when they are providing unpaid care. In economics parlance, the paper reports the findings of work to determine the attributes of care-giving (for the carer). The paper proceeds by reporting the methods and preliminary findings of interviews with carers, and discusses the findings in the context of economic evaluation.

2. METHODS

Interviews are being conducted as the second stage in the qualitative development of a discrete choice experiment (DCE) to quantify preferences for care-giving. Because individuals' responses to DCEs are affected by the information presented to them, careful qualitative work is required to develop the DCE and understand the study population [28-30]. Not only does the qualitative work ensure that the attributes and levels of the DCE are grounded in the experience of the study population, it can also offer additional insights into the study topic area.

Two stages of qualitative work are being conducted to develop a DCE to study preferences for *providing*¹ informal care. First, a meta-ethnography was used to synthesise existing qualitative research on care-giving to develop conceptual attributes of care-giving [31]. Second, semi-structured interviews are being conducted with carers to discuss their experiences, what they like and dislike about care-giving, and the wording and potential levels for attributes.

2.1 The meta-ethnography

The meta-ethnography is reported in detail elsewhere [31]. Meta-ethnography is a technique to synthesise the findings of qualitative studies in a particular topic area. It can be used to exploit existing qualitative research to aid the design of preference elicitation experiments. In this study, a detailed search of qualitative literature produced 44 potential papers for inclusion. These were sifted to 6 (the minimum number to retain the diversity of the larger set). These studies reported the experience of carers who differed in: gender, relationship to recipient, ethnicity and type of care provided. The studies were synthesised and conceptual attributes of care-giving, which were not refuted by any of the individual

¹ Italics used because DCEs are usually used to study preferences for *consuming* a good or service

studies were drawn out. Both process and outcome attributes were important to carers. However, process attributes appeared to be important to carers *both* in their own right *and* as influences over the outcomes. To avoid double-counting by measuring both outcomes and factors that influence outcomes, the decision was made to focus on process attributes of care-giving.

2.2 The interviews

Interviews are being conducted to validate and supplement the findings of the meta-ethnography. As well as covering the experience of caring, the interviews were conducted to check the coverage, wording and levels of the attributes. The approach taken is similar to the exploratory work in studies of preferences for dermatology appointments and quality of life states [20, 29].

2.2.1 Sampling

Ethical approval for the interviews was obtained from an NHS multi-centre research ethics committee. Carers are being recruited for interview using two methods: (i) via 4 Bristol based support charities and support groups, and (ii) through another study on public preferences for financing care in old age [32]. In (i), invites to interview and information sheets were distributed to carers by the 4 carer support groups. Carers who were interested in taking part responded to the research team and an interview was set up with them. In (ii), letters were written to carers inviting them to take part. If they responded and agreed, then an interview was arranged with them. Carers are being sampled purposively as far as possible. The aim is to interview a sufficient number and diversity of carers to reach saturation and ensure the DCE is grounded in the experience of a broad range of carers.

2.2.2 Conduct

Carers were asked where they wanted to be interviewed and informed consent (including consent to digitally record the discussion) was requested and obtained prior to the interview. Interviews were conducted iteratively and the findings were used to inform the questions in subsequent interviews. Typical interview questions are shown in figure 1. All interviews began by asking the carer to talk about the person they cared for, the care they provided and how they felt about it. This helped to get the carer talking and provided context and prompts for later questions. Following the open ended questioning, carers were presented with the conceptual attributes from the meta-ethnography written on cards. They were asked what came to mind when they saw the statement and were offered alternative ways

of wording the attribute and asked which they preferred. At the end of the interview carers were shown the 6 attribute cards together and asked whether they thought these attributes covered all the issues that were important to them, whether anything else came to mind and whether there was anything they wanted to add about the task.

Figure 1—Example questions from interviews

Opening questions:

Could you tell me a bit about *<the person you care for's>* condition?

What sort of care do you provide for them?

How does that affect you?

Attribute question:

Reading that, *<attribute card>*, what does that make you think of?

Probing questions:

Is *<attribute, or factors respondent associates with attribute>* important to you? Why?

What is important to you about *<attributes/ associated factors>*?

Closing questions:

What do you think of the list *<of attributes>*?

Thinking about the care you provide, is there anything that I've missed *<from list of attributes>*?

In later interviews the emphasis shifted from discussing all the attributes to discussing the more contentious aspects of the attributes and presenting and discussing potential levels to the carers. A best-worst scaling (BWS) task [33] will be used in the forthcoming DCE and full BWS scenarios will be piloted in the final interviews with carers.

Emphasis was placed during the interviews on letting the carers talk through their story, rather than constraining too tightly to a schedule around the DCE design. This had the advantage of: enabling the development of a rapport with the carers, not limiting them to talking only about the original attributes and generating new insights about the care-giving experience (expanded on in the discussion).

2.2.3 Analysis

Interviews were transcribed verbatim. Research notes were written between interviews to record findings and to inform the conduct of later interviews. After 6 interviews framework methodology [34, chapter 9] was used to organise the data from the interviews into a grid, with the interviews as rows, and themes as columns. This enabled the research team to process the findings by theme (looking down the table) and interview (looking across the table). The conceptual attributes that emerged from the meta-ethnography were used as coding headings for the transcripts and themes for the framework grids. Three grids were produced to record: (i) reactions to attributes, (ii) discussion of attribute wording, and (iii) general discussion. An example of the template used is shown in figure 2. Illustrative quotes with supporting text were entered into the grid cells. The findings were compared across interviews to assess the consistency of response on the attributes and to determine which attributes and issues needed to be probed in more depth. The analytical technique for this process is similar to constant comparison [35], which aims to combine the rigour of coding with the richness of theory development.

Figure 2—Template for framework analysis of interview findings

	Relations hip	Institutional support	Informal support	Outside activities	Control	Duty fulfilment
AL01						
AL02						
.....						
ALN						

3. RESULTS

3.1 Meta-ethnography

Six process attributes were drawn from the meta-ethnography: relationship, institutional support, informal support, activities, control and duty fulfilment. These attributes reflected the fact that the process of care-giving had positive as well as negative dimensions.

3.2 Interviews

9 interviews have been conducted to date. The interviews have lasted between 40 minutes and 1 hour 45 minutes, consent was given by all respondents to digitally record the

interview. With the exception of one carer, all carers were 65 or over and they were all caring for someone over 65. Figure 3 shows the characteristics of carers interviewed to date.

Figure 3—Characteristics of carers interviewed to date

	Gender, ethnicity	Relation	Years	Disability of recipient	Tasks*
AL01	F Black Jamaican	Wife	2	Mobility and sight	1,2,3
AL02	M, White British	Husband	11	Alzheimer's	1,2,3
AL03	M, White British	Husband	6	Alzheimer's	1,2,3
AL04	M, White British	Husband	3	Alzheimer's	(1),2,3
AL05	F, Black Jamaican	Wife	2mths	Physical after AMI	(1),(2),3
AL06	F, White British	Wife	3	Dementia	1,3
AL07	F, White British	Wife	2	Dementia, Parkinson's	1,2,3
AL08	M, White British	Husband	5	Dementia	1,2,3
AL09	F, White British	Daughter	29	Paranoid Schizophrenia	3

* 1=housework (hovering, washing, cooking), 2=personal care (dressing, bathing, toileting recipient), 3=organisational care (arranging formal care, transport, assistance with medication). Parentheses indicate carer receives help in these tasks.

Carers talked at length about their experience, often requiring little prompting during the interview. A strong sense of moral duty came across from the carers, that it should be them that was providing the care for the recipient. Some carers equated the more personalised care they offered with a higher quality of care for the recipient:

As long as I'm physically able, all I want to do is look after [wife's name] at home, not because I think I'm better—well I suppose in a way I do think I'm better than anybody else, but when you're caring for your own wife, you're satisfied in your mind [AL03—husband caring for wife with Alzheimer's, p. 4]

I wouldn't like to pass it on to someone else and I don't think she would like it either, which is the most important thing really. If I passed it onto to someone else I don't think she'd survive. [AL04—husband caring for wife with Alzheimer's, p. 16]

These quotes suggested a somewhat complex relationship between preferences for the process of care-giving and preferences for the outcome of care-giving. These two carers appear to have a preference for providing the care themselves because of a *belief* that it leads to better quality of care. In the case of AL04, this preference for providing the care himself is influenced by his belief that it will result in better health prospects for the recipient.

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When the attributes were presented to the carers they were generally understood and seen as being relevant. Figure 4 summarises how the attribute definitions and wording developed through the interviews.

Figure 4—Development of process attributes through interview phase:

Attributes of process utility in care-giving following meta-ethnography stage

<p>Relationship <u>Definition:</u> Feelings that bind the carer and recipient together <u>Label:</u> “<i>Relationship between you and the person you care for</i>”</p>
<p>Institutional support <u>Definition:</u> Assistance from the public, private and voluntary sector organisations in terms of benefits, respite care, practical information and time off work <u>Label:</u> “<i>Financial and caring assistance from organisations</i>”</p>
<p>Informal support <u>Definition:</u> Personal help in caring and emotional support that the carer receives from family, friends, neighbours and work colleagues, as well any spiritual support the carer may derive from their religion. <u>Label:</u> “<i>Support in caring from friends and family</i>”</p>
<p>Activities <u>Definition:</u> Opportunities that the carer has to engage in physical activities and socialising outside their caring environment. <u>Label:</u> “<i>Social and physical activity outside caring</i>”</p>
<p>Control: <u>Definition:</u> Carers’ ability to effectively manage their caring duties. <u>Label:</u> “<i>Control over the caring</i>”</p>
<p>Duty fulfilment: <u>Definition:</u> Whether the carer feels that they are fulfilling a duty by providing informal care. <u>Label:</u> “<i>Fulfilling a duty by caring</i>”</p>

Attributes of process utility in care-giving following 9 interviews

<p>Getting-on <u>Definition:</u> Communication and ability to relate to the recipient <u>Label:</u> “<i>Getting-on with the person you care for</i>”</p>
<p>Organisational assistance <u>Definition:</u> Assistance from the public, private and voluntary sector organisations in terms of benefits, respite care, practical information and time off work. <u>Label:</u> “<i>Assistance from organisations and the government</i>”</p>
<p>Social support <u>Definition:</u> Personal help in caring and emotional support that the carer receives from family, friends, neighbours and work colleagues. <u>Label:</u> “<i>Support in caring from friends and family</i>”</p>
<p>Activities <u>Definition:</u> Opportunities that the carer has to engage in physical activities and socialising (in particular maintaining social networks) outside their caring environment. <u>Label:</u> “<i>Activity outside the caring</i>”</p>
<p>Control: <u>Definition:</u> Degree to which carers’ are in charge of the care for the recipient. <u>Label:</u> “<i>Control over the caring</i>”</p>
<p>Fulfilment <u>Definition:</u> Positive feelings derived from providing care to the recipient stemming from: maintaining their dignity, being appreciated, engaging in fair behaviour, gaining new skills, contributing to the care of a loved one. <u>Label:</u> “<i>Fulfilment from caring</i>”</p>

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The two attributes that were most contentious were 'relationship' and 'duty fulfilment'. Discussion of relationship often evoked comments about the carers' marriage and past relationship. These appeared to be descriptors of their circumstances rather than influences over the utility they gained from care-giving. Exploration of the transcripts revealed that 'relationship' factors did appear to influence their utility, but it was more about the moods of the recipient and their (lack of) communication. This is illustrated by two quotes:

There are times when I lose it, especially when she gets really stroppy and obstinate. I mean she has hit me, and things like that and I've had to restrain her sometimes. She can get angry and come at me with her fists...she'd never do anything like that before [AL04—husband caring for his wife with Alzheimer's, p. 12]

I'd be the first to admit, after you been asked something 7 or 8 times, you know it's only human nature to snap back and then you think I needn't have done that, but its out. [AL06—wife caring for her husband with dementia, p. 4]

A new formulation of the attribute, 'getting-on with the person you care for', was presented to the carers, and although this was preferred, the reason was not clearly articulated:

I: "If we...instead of saying the relationship with the person you care for...we had getting on well with the person you care, would that be better?"

P: "Yeah I think so, because we're talking about...you see if you were talking about looking after someone you don't know, that relative, that's part of it. But if you're looking after somebody you've lived with for 50 years, it's not is it?" [AL04—husband caring for his wife with Alzheimer's, p. 15]

I: "if we call this heading just 'getting on with the person you care for'. Would that be better than using the word relationship?"

P: "Yeah"

I: "It's better then? Because...is that what's it's about, about getting on with them?"

P: "Yeah because if you get on with the person, that relationship, will be a relationship" [AL05—wife caring for her husband with physical disabilities, p. 9]

Future interviews will explore what carers understand by the phrase 'getting-on on with the person you care for' and whether it is an appropriate attribute.

The attribute 'duty fulfilment' posed a problem because carers often felt duty was an inappropriate way of describing their reason to engage in care-giving:

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"It's not a duty. It's not a duty. To me, its not a duty..." [AL02—husband caring for his wife with Alzheimer's, p. 24]

"I think its...I feel that it's ... duty is probably a bit strong a word, but umm...." [AL06—wife caring for her husband with dementia, p. 13]

The interviews suggested two things. First, although a number of carers indicated they performed their caring role out of a sense of obligation or responsibility (which appears on the face of it to be the same reason as duty), duty was an inappropriate word to use with some carers. Second, that fulfilment—a positive source of process utility from care-giving—was derived from many other sources in addition to meeting their responsibilities. These included, maintaining the dignity of the recipient:

P: I like her to keep her up...to keep herself together you know, as much as possible...

I: Dignity?

P: Yeah exactly. [AL04—husband caring for his wife with Alzheimer's, p. 2/3]

Being appreciated:

...sometimes she'll look up to me and give me such a priceless lovely smile, which says it all and then the other morning she laid down for a bit and looked up to me and said, "you're lovely, I love you." It came out as clear as a bell. Well you can't put a price on that can you? [AL03—husband caring for his wife with Alzheimer's, p. 10]

Engaging in reciprocal/fair behaviour:

P: She looked after me, so I owe it to her to look after her.

I: Reciprocating the care?

P: Yeah, it's reciprocal isn't it? It's an obligation in many ways, in the old sense of being obliged. You know. [AL02—husband caring for his wife with Alzheimer's, p. 26]

Gaining new skills:

[laughs] You know I've never been a very practical person about having to change door handles, electric light bulbs and loo cisterns [laughs] but I'm learning fast! [AL06—wife caring for her husband with dementia, p. 15]

Contributing to the care of a loved one:

But then it's a joy to know that I can do my little bit for him. [AL05—wife caring for her husband with physical disabilities, p. 11]

Carers appeared to have fewer problems relating to the remaining four conceptual attributes and so these attributes required less refinement through the interviews. There were however differences in interpretation of attributes between carers, as exemplified by these responses to being presented with the 'control' attribute:

It [control] invokes making sure she gets the right treatment as far as I can. [AL02—husband caring for his wife with Alzheimer's, p.18]

I like to think that I have control over the caring, not in a dogmatic way at all, but my sole aim in my life now is to keep Bridget at home. [AL03—husband caring for his wife with Alzheimer's, p. 4]

Well someone trying to tell me that I'm not doing my job properly, which I've never been accused of yet anyway...and I would imagine...if I was caring for a complete stranger, that would be a different kettle of fish... then I would expect someone to control me, make sure that I was doing the job properly [AL04—husband caring for his wife with Alzheimer's, p. 11]

Finally many of the carers interviewed to date were looking after patients with dementia or Alzheimer's and they were frustrated by NICE's recent decision to restrict coverage of Alzheimer's drugs. Technology coverage decisions are, however, unlikely to be an issue of concern to all carers. There is a need to consider how best to modify the attributes or supporting information to capture and reduce all issues of concern to carers down to a set of generic attributes. In this 'NICE' example, it may mean modifying the 'organisational assistance' attribute to include something about how well carers feel they are heard or taken account of by the 'system', which could apply to all carers.

4. DISCUSSION

4.1 Methodological: using qualitative interviews to help determine attributes and levels for a discrete choice experiment

The qualitative interviews were used to take the findings of the meta-ethnography to the carers to validate and enrich them. As far as the authors know, this is a novel approach. The broad similarity between the interview findings and the meta-ethnography findings suggests that meta-ethnography is a promising approach for reducing a wealth of

qualitative data into key attributes to describe a good or service for a DCE. The preliminary findings here—that the attributes are modified in light of the interviews—suggests it would be advisable for researchers to ‘pilot’ the attributes that come out of a meta-ethnography, before using them in a full DCE. This is likely to be particularly important when researchers are unfamiliar with the topic area, the topic is complex or the researchers do not feel they are up-to-date with the language used by the subject group.

One possible limitation of work could be that the introduction of the attributes ‘led’ the carers into concluding these were the main issues in caring. The research team acknowledged this possibility and attempted to minimise the risk of it in two ways. First, the interview opened with an unstructured discussion, where the carer could raise any points they wanted. Second, the interview ended with the carer being asked for a frank assessment of whether the attributes captured all the areas that were important to them.

A key strength of conducting the interviews has been the wealth of additional information on the experience of care-giving that has been generated. This has been useful in gaining insights to respondents’ initial thoughts when they see an attribute. Findings from this provide a warning to selecting attributes without rigorous development work, in that what the researcher anticipates the attribute is capturing and what the respondent is thinking about are not necessarily the same things. This issue was exemplified by AL01, who interpreted ‘duty fulfilment’ as doing daily tasks, literally fulfilling her duties for the day.

The interviews have, so far, mainly focussed on determining the attribute coverage and wording. In recent interviews carers have also been asked to identify the level on the attribute most applicable to them and comment on whether the number of levels were sufficient to cover all the situations they could find themselves. The limited feedback on this received so far, indicates that carers will be broadly spread across the—initially 4—levels presented to them. There may however be a case for reducing the number of the levels to 3. AL09 suggested that few respondents would identify with the top level, because people would rarely think they’ve got *all* the support, assistance, control they want. This finding will be explored in future interviews.

4.2 Identification of carer utility: the importance of process

In conducting an economic evaluation in healthcare, Drummond et al. suggest that the consequences of an intervention should be: (i) identified, (ii) measured, and (iii) valued [36,

p.19]. Whether these consequences are limited to health effects, depends on whether the researcher's approach is welfarist, extra-welfarist or decision-maker [36, p. 18]. In the context of carers, it is unclear what the likely consequences of an intervention will be. The work reported here was about developing the attributes of care-giving. These attributes will be of interest to policy-makers, or those conducting economic evaluation, only if interventions impact on the level of these attributes. To illustrate this possibility, it may be useful to distinguish between 3 types of intervention that could impact on carers: (i) interventions (such as drugs) for the care recipient, (ii) interventions that involve a substitution between hospital and home care, and (iii) interventions (such as respite care) that directly aim to help the carer. Using examples of these three types of interventions we can develop plausible scenarios—shown in figure 5—to demonstrate how the interventions may alter the attribute level and thus carer utility.

Figure 5—Potential impact on process utility for carers of 3 interventions

(i) <u>Drugs that stabilise patient mood swings</u> : increases carer's ability to manage their life and the recipient's life and helps them get on better with the recipient. Carer process utility increases via increase in level of control and ability to "get-on" with the patient/ care recipient.

(ii) <u>Early discharge to hospital at home of carer's elderly spouse</u> : carer's opportunities for outside activities are limited, but they are pleased to have their spouse at home where they can be the one to look after them. Impact on carer process utility ambiguous without quantification of activity/ fulfilment trade-off.

(iii) <u>Expansion of carer support groups</u> : carer gets better access to information and respite care and has a new social outlet. Carer process utility increases via increase in level of organisational support and activities attributes.

The attributes, whilst relatively novel in the context of carer utility, parallel discussions in the broader economic literature of issues that are important to individuals, but traditionally neglected by economics. The concepts underpinning the fulfilment attribute are consistent with work showing the ability to *contribute* to political processes is valued regardless of the outcome [37] and '*fair*' processes are often preferred even when they may not maximise an individual's 'pay-off' [38]. Deriving benefit from greater control and ability to engage in outside activities appears consistent with the importance Sen places in his work on personal freedoms and capabilities [39]. For some of the carers it appeared to be important to be able to control the care-giving, regardless of the actual outcomes. Likewise, some

carers valued the *opportunity* to engage in outside activity and this appeared to be more important than the actual amount of activity that they engaged in.

One danger of including process utility in economic evaluation is the potential for the double-counting of welfare gains. This appears a possible problem in assessing process utility from care-giving. In this study, the quote on page 9 from AL04 appeared to show the carer having a strong preference for a process he *believed* would lead to a better health outcome for the recipient. It could be argued that taking into account his preference and his (or the patient's) preferences over health outcomes would represent a form of double counting. One way round the problem of potential double-counting would be to focus on optimising the process rather than the outcomes of care. While the importance of 'process' may be limited in some health settings, for example in analysing the benefits of acute life saving interventions, for interventions that impact on carers there appears to be a far stronger case for consideration of process effects. The carer-recipient relationship is very different from the relationship between a healthcare professional and the patient. The objective (or intended outcome) of the carer is less clear and the delivery of care is likely to extend over a much longer period.

Finally, it has been suggested that processes should not be evaluated as processes per se, but in terms of their impact on outcomes and costs [40]. The problem with this stance in relation to informal care is that outcomes from care-giving are unclear, but carers (and patients) have clear preferences over the process by which it should take place. It seems wasteful and unjustified to ignore those preferences, especially when they encompass such a significant part of their life. Where carers are concerned, it seems clear from the evidence so far that the means are important, as well as the ends.

POSSIBLE HESG DISCUSSION POINTS

4.3 Measurement of carer utility

Decision vs. Experienced utility

(Health) economists tend to use preference-based methods to make judgements about the welfare consequences of interventions. It has been suggested that these provide only a partial insight into individuals' welfare (or utility), which is a dynamic concept [41, 42].

Tapping into *experienced* utility as opposed to *decision* utility has been proposed as a more appropriate basis for public policy [43]. Relating this issue to carers, many respondents

indicated it was their responsibility to care for the recipient and therefore a sense of responsibility would be associated with higher (decision) utility, however it is debateable whether feelings of responsibility would be exhibited through higher levels of happiness/satisfaction day-to-day (experienced utility). In other words measuring a carer's decision utility and experienced utility may provide different policy prescriptions.

Heterogeneity

Carers are an extremely heterogeneous group [8]. Not only do they vary in their objective characteristics (hours, tasks, relationship), but also, significantly, in their attitudes towards being a carer [16] and their preferences for support [44]. This begs the questions: should we—and if so, how should we—reflect this heterogeneity in economic evaluations?

Interdependence

Through their interview responses, carers indicated that they were affected by the well-being of the person they looked after. While health-related utility may not be closely correlated for carer and recipient [45], the value of process appears to be [16]. If utility valuations between carer and recipient are interdependent, to what extent does considering both in an economic evaluation represent double-counting?

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