

What do people value when they provide unpaid care for an older person?

A meta-ethnography with interview follow-up

ABSTRACT

Government policies and demographic changes mean that unpaid (informal) carers will increasingly be relied on to deliver care, particularly to older people. As a result, careful consideration needs to be given to informal care in economic evaluations. Current methods for economic evaluations may neglect important aspects (attributes) of informal care. This paper reports the development of a simple measure of the caring experience for use in economic evaluations. A meta-ethnography was used to reduce qualitative research to 6 conceptual attributes of caring. 16 semi-structured interviews were then conducted with carers of older people, to check the attributes and develop them into the measure. Data were analysed using Framework. Six attributes of the caring experience comprise the final measure: Getting-on, Organisational Assistance, Social Support, Activities, Control and Fulfilment. The final measure (the Carer Experience Scale) focuses on the process of providing care, rather than health outcomes from caring. Arguably this provides a more direct assessment of carers' welfare. Following work to test and scale the measure, it may offer a promising way of incorporating the impact on carers in economic evaluations.

INTRODUCTION

Friends and family members who act as unpaid (or informal) carers are integral to the well-being of many patients. The informal care required, particularly for older patients, can be substantial. A family member of someone 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. While caring can often put people under strain, it can also be an important source of happiness in people's lives (Brouwer, Van Exel, Van Den Berg, Van Den Bos & Koopmanschap, 2005). Government policies to shift care into the community, coupled with ageing populations suggest that informal carers will be increasingly relied upon to provide care. In order to evaluate the wider effects of health and social care interventions on carers, careful consideration needs to be given to informal care in economic evaluations.

Carers are rarely considered in economic evaluations (Brouwer, 2006) and the methods for including informal care are subject to some limitations. Quality Adjusted Life Years (QALYs) are the favoured method of measuring the impact (or effects) of an intervention (National Institute for Clinical Excellence, 2004; Russell, Gold, Siegel, Daniels & Weinstein, 1996). However, QALYs only cover health and may miss broader quality of life impacts on carers. Empirically, for example, QALYs were unable to detect any gains to carers from stroke training (Patel, Knapp, Evans, Perez & Kalra, 2006), while theoretically QALYs may lack sensitivity to the psychological impacts of caring (McDaid, 2001). Another option is to consider informal care as a cost input. Approaches have been developed to assign informal care a monetary value (Posnett & Jan, 1996; Van Den Berg, Brouwer & Koopmanschap, 2004). These methods estimate the opportunity costs of providing care, but do not incorporate the

positive aspects of caring. In summary, both QALYs and the monetary methods may miss important aspects (attributes) of the carer's welfare.

Various other quality of life measures have sought to capture the caring experience but are of limited use in economic evaluations. Deeken, Taylor, Mangan, Yabroff & Ingham, (2003) identified 28 generic measures, covering different aspects of care. The measures tend to focus on specific areas such as strain and needs and may therefore, like the economic methods, miss important attributes of carers' welfare. A second limitation of existing measures is their reliance on simple sum scores. These scores can give a misleading indication of overall attainment, as carers may value certain dimensions in the measure more than others (Van Exel, Brouwer, Van Den Berg, Koopmanschap & Van Den Bos, 2004). This limits the usefulness of such measures in economic evaluations. Preference-based measures are an alternative to sum score measures. In a preference-based measure each potential response profile is assigned a 'utility' score. These scores can be derived through economic techniques such as discrete choice experiments, time trade-offs and standard gambles.

This paper reports the development of a concise measure of the caring experience for use in economic evaluation. To ground the measure in the issues that are important to carers, two phases of qualitative research were used. First, a meta-ethnography of qualitative research was used to identify the key attributes of the experience of caring. Second, interviews were used to consolidate the attributes and develop the final measure. The literature search and interviews focussed on the experience of caring for an older person. This was in recognition of the importance of informal care in the total care provided to older people. This has implications for the generalisability of the measure, which are discussed in the final section of the paper.

METHODS

The meta-ethnography

Meta-ethnography is a technique to synthesise qualitative research, or develop *“translations of qualitative studies into one another”* (Noblit & Hare, 1988, p. 25) and has been applied in a variety of settings (Beck, 2002; Britten, Campbell, Pope, Donovan, Morgan & Pill, 2002; Campbell, Pound, Pope, Britten, Pill, Morgan et al. 2003). This study employs the meta-ethnography framework to synthesise existing qualitative literature into conceptual attributes of the caring experience. This appears to be the first time that meta-ethnography has been used in the development of a quality of life measure (for carers or patients).

Identifying studies for inclusion

A broad search was conducted for studies that explored either the experience of caring for someone, or preferences for aspects of providing care. The search consisted of: (i) two online ‘key word’ literature searches; (ii) a ‘hand-search’ through all recent articles in five key journals; (iii) advice from researchers in the field, and (iv) citation tracking. Details of the two online searches are provided in appendix A. The first online search focused on identifying papers that mentioned preferences, older people and informal care in the title or abstract. The second search focused on papers that mentioned a qualitative approach (such as phenomenology) as well as older people and informal care. In the hand-search, five journals (Social Science and Medicine, Qualitative Health Research, Age and Ageing, Aging and Society and Sociology of Health and Illness) were screened for relevant papers from January 2001 to September 2005. The studies identified through the four search techniques were collated and then purposively sampled. Given the complexity of qualitative data synthesis, it is common to select 4-10 studies for synthesis (Beck, 2002; Britten et al., 2002; Campbell et al., 2003; Doyle, 2003). Further, it has been proposed that a

purposive sampling strategy should be employed to narrow the boundaries of the synthesis if more than 10 studies are initially identified (Sandelowski, Docherty & Enden, 2005). In this study, the initial set of qualitative papers was purposively sampled to obtain the minimum number of studies that retained diversity across 4 sampling characteristics. Sampling characteristics were selected to reflect the characteristics that may alter the caring experience: sex, ethnicity, relationship and illness (Pearlin, Mullan, Semple & Skaff, 1990). All three authors participated in this sampling exercise.

Recording and comparing the study findings

Characteristics, concepts and quotes from the final set of studies were listed in a grid. This grid was used to compare studies and to start to identify the concepts that were relevant in caring across studies. Studies were then paired and directly compared as a second method of generating overarching concepts. A coding exercise was then conducted. The study texts were re-read a number of times and the findings were coded, either using a concept generated earlier, or a newly created concept.

Combining the study findings

Illustrative quotes were listed under the relevant concept in a descriptive account. Text was added around the quotes, providing a narrative about how the quotes related to one another. For each concept, a line of argument was created. Essentially a line of argument is an attempt at a common interpretation of the meaning of that concept across all studies (Campbell et al., 2003). The final stage of the synthesis involved moving from the set of concepts to a list of the attributes of the caring experience. Concepts were discarded if they simply described aspects of the caring experience (e.g. caring is 'challenging'). The remaining concepts were split between those that related to outcomes from caring (e.g. the health impact of caring) and

those that were aspects of the caring experience (e.g. benefit payments). All three authors worked together to understand the relationships and possible overlaps between these concepts and then distil the concepts into a concise set of attributes.

Interviews

Semi-structured interviews were conducted to move from the conceptual set of attributes to the final measure. The interviews were used to check the coverage of the attributes, refine the attributes into suitable statements for use in a measure and assign 'levels' to the attributes. An iterative approach was taken where data collection and analysis were conducted concurrently. The interview structure was adapted throughout to take account of feedback from earlier interviews, using an approach similar to previous work to determine attributes for dermatology appointments (Coast & Horrocks, 2007).

Conduct

Ethical approval to interview carers of older people (informants) was obtained from West Midlands Multi-centre Research Ethics Committee. Informants were recruited for interview via local charities and another study in which the two co-authors were involved. Informants differed in terms of the disability of the person they were caring for and whether or not they belonged to a carer organisation.

Informed consent was obtained prior to the interview and informants chose the location of the interview. All interviews began with open-ended questions about the care recipient, the care provided and the informant's feelings about providing care. Responses to these questions provided the context and prompts for later questions. Following the open-ended questions, carers were asked more specific questions, which depended on the stage (iteration) of the interviews.

In the first iteration, loosely interviews 1 to 6, informants were presented with the attributes from the meta-ethnography. They were asked what they associated with the attribute and were offered alternative ways of wording the attribute and asked which they preferred. At the end of the interview, informants were shown the six attributes together and asked whether they thought they covered all the issues that were important to them and whether there was anything they would like to add. In the second iteration, loosely interviews 7 to 11, the emphasis shifted to discussions about the more contentious aspects of the attributes and potential levels for the attributes. The third iteration, loosely interviews 12 to 16, was effectively a 'mop-up' session for unresolved issues, as well as an opportunity to assess whether informants could complete the measure.

Analysis

Interviews were transcribed verbatim. Research notes were written between interviews to record findings and to inform the conduct of later interviews. After each iteration, Framework (Ritchie & Lewis, 2003) was used to organise the data from the interviews into grids, 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 provided initial coding headings for applying the transcripts to the Framework grids. Three grids were initially produced, to record: (i) reactions to attributes, (ii) discussion of attribute wording and (iii) general discussion. Illustrative quotes with supporting text were entered into the grid cells. The findings were compared across interviews to assess the consistency of response to the attributes and to determine which attributes needed to be probed in more depth. Themes were updated on the grids through the second and third iteration to reflect new issues that emerged through the interviews and changes in the focus of the iteration. Descriptive

accounts were written up after each iteration of interviews, to record the study findings and inform the next stage of development.

Verbatim quotes from informants are used to illustrate the findings. Ellipses (...) are used to denote missing speech; 'umm', 'err' and repeats of words, which do not add to meaning, are removed without the use of ellipsis.

FINDINGS

Meta ethnography

50 publications were identified as possibilities for inclusion in the meta-ethnography to generate conceptual attributes for the measure. 6 publications were rejected because they employed quantitative methods or were secondary qualitative research. Table 1 shows the study characteristics of the remaining 44 papers. Purposive sampling of this set resulted in a set of 6 studies for the meta-ethnography. These studies listed in Table 2.

<Table 1>

<Table 2>

The characteristics of each of the six studies, as well as the concepts and quotes that emerged from the studies were listed in a grid. Greater understanding of the meaning of the concepts to carers in general was developed, first through comparing the studies in pairs and then creating a descriptive account. Concepts and quotes were compared between the two studies, as in the following example, where Cheung et al. [D] and Harris et al. [F] were paired. In Cheung et al. [p. 162, D] carers suggested that events were overwhelming them: "I'm very worried about the future. The way it is

now, the future is really out of my hands" (Cheung & Hocking, 2004). In Harris et al. [p. 553, F] carers reported the positive side of developing a routine: "No one takes better care of her than I do. I have set up a system that works." (Harris, 1993). Both of these quotes appeared to emphasise the importance of control. The descriptive account drew together a range of quotes from different studies under common concepts. An explanatory narrative around these quotes helped initiate a common explanation of the concepts to carers. Formal interpretations (translations) of the concepts in each of the other studies were then generated. Table 3 shows how this concept of control was translated back into each of the studies.

<Table 3>

Meta-ethnography requires the development of common concepts across the studies. To identify the concepts that could be used to develop attributes, the list of concepts was then split into three categories: descriptors of caring, outcomes of caring and aspects of the process of caring (Table 4). Concepts that simply described caring, rather than affected carers, for example 'commitment', were labelled as descriptors and not used to develop the attributes. Carers appeared to be affected both by the concepts relating to the process of providing care and the (health) outcomes of that caring. Furthermore, the process concepts appeared to impact on the outcomes. The following quote shows how one carer's inability to engage in activities outside caring appeared to be detrimental to their health:

I should walk and I should swim, but I have had to give up those two things because it takes up too much time away from him ...I do miss my long walks which I should do because I am a diabetic [Lewis (1995), p.60]

Including both health outcomes and process may therefore lead to double counting. Given that the health of carers is likely to be related to a number of factors outside caring, focussing on the process of caring offered a more direct way of measuring the caring experience.

<Table 4>

Relationships between the concepts in the final column were mapped out. For example, 'benefit payments and respite care' were both forms of support provided by outside institutions to help carers. Through mapping relationships between the concepts in the third column, six conceptual attributes of the caring experience were derived and are listed in table 5.

<Table 5>

Interviews

Interviews, to consolidate the attributes and develop levels and wording for the measure, were conducted between July 2006 and February 2007, with 16 informants who were caring, or had recently cared for someone over 65. Interviews lasted between 40 minutes and 1 hour 45 minutes and informed consent was given by all informants to digitally record the interview. In two cases the care recipient was present during the interview (contributing in one case). Table 6 contains basic information about the characteristics of the informants.

<Table 6>

The findings from the interviews are presented in the remainder of this section, first illustrating how the interviews shaped the final set of attributes, and second outlining how levels were assigned to the attributes to create the measure. Selected quotes are used to show: (i) new issues that emerged through the interviews; (ii) the importance of the attributes to the informants; (iii) the varying interpretations of the attributes; (iv) how the language was evolved to describe the attribute; and (v) the development of levels for the attributes. As a result of the interviews, the descriptive titles of some of the attributes were modified. The following section lists the quotes under the final attribute descriptor, with the original descriptor from the meta-ethnography in brackets.

Attribute 1: Getting on with the person you care for (Carer-recipient relationship)

The development of recipient health (particularly mental health) problems fundamentally affected the day-to-day relationship between the carer and recipient. It could limit, or even end their ability to communicate and cause frequent (sometimes violent) arguments. Understandably when these happened they caused significant distress to the informants:

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. [Informant 4, male, cares for wife with mental health problems]

While relationships often deteriorated after the onset of illness and caring, they could also improve too:

...you do get quite a lot closer to someone you know, which is nice...I think we're closer, cos we're more friendly so we'll do things like we'll go out for lunch together you know and spend real time [together] [Informant 11, female, cares for mother with physical health problems]

What seemed to be valued by informants, was an ability to 'get-on' with the person they cared for, which in turn was influenced both by their ability to communicate with the person they cared for and avoid arguments with them. The 'relationships' attribute, which emerged from the meta-ethnography led some informants to digress about their marriage vows. 'Getting on' was therefore introduced as a term to better reflect the issues that emerged from the interviews. The new terminology was presented to informants and was generally preferred to the initial formulation.

Attribute 2: Assistance from organisations and the Government (Institutional support)

Informants interacted with a range of health, social care and voluntary organisations in carrying out their caring role. They frequently mentioned how benefit payments were low and how support groups were helpful. They commented on the (lack of) flexibility in respite care and problems in obtaining information about what support was available:

[Talking about the importance of a carer support group] Sometimes you do things you think are beneficial for the person you are caring for and then you hear other views and you think, "perhaps I'm not quite right and I would be better doing it a different way". [Informant 3, male, cares for wife with mental health problems]

[Talking about paid support from social services] ...it takes a really long time to get anything going so they were sending somebody in to do stuff for her

and then there's so many restraints about what they will and won't do.

[Informant 14, female, cared for Aunt with an undiagnosed illness]

The variety of contacts informants had with various agencies indicated the breadth of issues that needed to be covered by the attribute. This led to work to refine the language used in describing the attribute. There was a trade-off involved in keeping the attribute concise yet informative. An initial formulation: "financial and caring assistance from organisations" was rejected because carers did not think of the health or social services as 'organisations'. The addition of "and Government" helped to some degree. To prevent the statement becoming overly long the "Financial and caring" part was removed and included as supplementary information along with some examples of assistance the carer may receive (appendix C).

Item 3: Support from family and friends (Informal support)

Informants talked about both the practical and the emotional support they received from their family and friends. Practical help could be assistance with housework or looking after the care recipient for a while, while emotional support was usually received through simply having someone to talk to:

In fact, if the children do help out occasionally, it does give one a break. Just get right away. I knew once I landed [on holiday, away from recipient] there was nothing I could do. [Informant 6, female, cares for husband with mental health problems]

...you know, hoovering, dusting and other things... yes I get a lot of that from friends you know, when it was really bad, I get caring from friends [Informant 1, female, cares for husband with physical health problems]

The interviews mainly acted to confirm the importance of social support to carers. They also indicated that carers were likely to have different levels of support. While some carers were well supported, others either did not have family or close friends or were unable to turn to them for help.

Attribute 4: Activities outside caring

When probed about their ability to do things outside caring, some informants suggested that this was something that had disappeared from their life:

Nothing. There used to be... my social life was quite brilliant, you know the dance band thing [Informant 4, male, cares for wife with mental health problems]

A limitation on outside activities was acknowledged by a number of informants, although the importance they placed on this differed:

You need something else apart from caring for somebody... its very difficult just ... being there for somebody all the time because to sit with them all the time just repeating the same things over and over again ...[it] really gets you down [Informant 12, female, cares for mother with mental health problems]

I don't tend to go out much in the evenings at all and I haven't been away on any holiday for maybe 10 years. Maybe it's something I would like to do... [Informant 15, male, cares for mother with physical health problems]

Again the interviews acted to confirm the importance of including an attribute to cover 'a lack of outside activities' in the measure. The interviews also highlighted the importance of wording the attribute broadly, to encompass the numerous activities

(e.g. socialising, spending time with other family members, study, holidays, hobbies and physical activities) that people missed out through providing care.

Attribute 5: Control over the caring

Some informants felt that being independent was very important. They wanted to be the one making the decisions about the care of the person they looked after, and saw this as an integral part of ensuring they received a high standard of care. Being in control seemed to be particularly important for some male informants:

When I'm with my wife, I'm the one in control. I'm the one who's got to face it anyway. I want to be in control, completely and utterly in control. [Informant 4, male, cares for wife with mental health problems]

On the other hand, one informant recognised that control over some aspects of caring might have to be relinquished:

I've always been quite an independent person but I think I'm going to have to succumb and say, "please give me a hand" [Informant 6, female, cares for husband with mental health problems]

The phrase 'control over the caring' caused some confusion, with informants reacting to it in a variety of ways. An alternative formulation of the attribute was developed for the measure, which asked about 'control over aspects of the care'. This appeared to have a more consistent meaning to informants and was generally preferred.

Attribute 6: Fulfilment from caring (Duty)

Duty emerged through the meta-ethnography as an important issue in making caring rewarding. During the interviews, informants identified a number of other sources of

positive feelings from caring, including: making someone happy, maintaining their dignity, being appreciated, gaining new skills and contributing to the care of a loved one:

...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? [Informant 3, male, cares for wife with mental health problems]

I was quite happy to do it because obviously I had a close relationship with her and I was happy to be able to return care that she'd given me when I was younger for example. I mean it is quite rewarding in the sense that she really looked forward to us coming down and she really enjoyed us visiting her. [Informant 14, female, cared for Aunt with undiagnosed illness]

I was glad and very proud for doing it because in our community she was oldest ... and everybody praised me you know for that. [Informant 16, female, cared for mother with physical health problems]

Problems were also encountered with the use of the word 'duty'. A couple of informants stated that caring was not a duty, or that duty was too strong a word. To encompass the range of positive feelings from caring in more appropriate language, the term 'fulfilment' was used for the attribute.

Setting levels for the measure

A small number of informants were asked for their views on the number (three or four) and wording of the attribute levels. Informants expressed varying views on the

number of levels: while some informants indicated that four levels would cover the different caring situations more thoroughly than three, one informant suggested that the top level (“all”) could be deleted, because it was the least likely to be chosen and another informant expressed a preference for three levels over four, saying four “looks too much”. A couple of informants queried the use of ‘amounts’ (a lot, some, a little) to describe attributes, which could fluctuate on a day-to-day basis:

...it's a day-to-day thing because there's no two days alike you know... You get these situations ... where you think: “Oh God how much longer have I got to put up with this sort of thing?” Another day, no problem, that's where you obviously get on well [Informant 8, male, cares for wife with mental health problems]

‘Frequency’ levels (rarely, sometimes, mostly) were applied to the ‘getting-on’ and ‘fulfilment’ attributes. These appeared to better capture the dynamic nature of these issues in the caring experience. Informant feedback on levels, language and attributes was taken together to develop the final measure—the Carer Experience Scale (laid out in appendix C).

DISCUSSION

A measure for of the caring experience for use in economic evaluation was developed through a meta-ethnography and a set of semi-structured interviews with carers. The six attributes of the measure were not altered substantially during the interviews, suggesting that meta-ethnography is a useful framework for identifying the attributes of a quality of life measure. Aside from acting as a ‘check’ on the meta-ethnography findings, the interviews were useful in consolidating the meaning and content of the six attributes, most notably in the attribute that ended up being

'fulfilment'. Through the interviews it was clear that there were multiple ways in which caring could be rewarding aside from enabling carers to perform their 'duty'.

Rewarding aspects were combined to create the fulfilment attribute. The interviews were also useful in refining the way the attributes were presented. Several words ("control", "relationship" and "duty") caused problems when used with this sample and these were adjusted in the final measure. The interviews suggest that caution should be exercised when using value-laden words, which can be open to misinterpretation in the context of caring.

Each attribute needed a set of levels, and developing these required a balance to be struck between sensitivity and conciseness. Having more levels allows a larger number of caring situations to be covered, potentially improving the sensitivity of the measure. However, having fewer levels keeps the measure more concise and better enables responses to be scaled using a preference-based valuation exercise. In this study, balancing these concerns meant three levels were selected. Informant feedback was also incorporated to ensure the levels were sensitive to the situations that carers may find themselves in. This resulted in the top and bottom levels using terms like 'most' and 'a little', rather than 'all' or 'none'.

There were overlaps in the attributes of the measure developed here, with those in existing measures, but also some important differences. Table 7 compares the attributes found in this study with the attributes found in two reviews of measures used with carers. The two reviews and the findings of this study show the caring experience extends beyond health outcomes with a strong emphasis on psychological and social attributes. Broadly five attributes (activities, support, assistance, fulfilment and getting on) of the caring experience in this study map onto dimensions found by Deeken et al. (2003) and Brouwer, Van Exel, van Gorp & Redekop (2006). It should be noted however that most measures do not include all

these attributes and often place a different emphasis on the attributes. For example, few instruments include anything on “assistance from organisations” and if they do it normally relates specifically to information provision.

<Table 7>

Control was the one attribute identified in this study that does not appear to be included in existing carer measures. The literature reviewed in the meta-ethnography and the interviews showed that many carers had a preference for taking a key role in decision-making about the recipient’s care. This sort of control appeared to be a particularly important issue for spousal carers who were often living alone with the care recipient. It is unclear why other carer measures do not include items on control, but it may be related to their greater focus on specific outcomes of poor control (for example depression) in carers. An alternative or additional explanation is that public involvement in health care decision-making is currently a high priority in the UK (Department of Health, 2004). While this would not account for the salience of control in the meta-ethnography, it might help to explain why control featured prominently in the narratives of the informants in this study.

Both the Deeken et al. (2003) and Brouwer et al. (2006) reviews found that emotional and physical health are included in the majority of carer measures, however these were not directly included in the measure developed here. Although health emerged as an issue through the meta-ethnography and interviews, it was often linked to another attribute. Carers, for example, valued the physical activities outside caring, in part to prevent their own health from deteriorating. The literature also shows links between ‘experience attributes’ and health, for example ‘fulfilment’ (Cohen, Colantonio & Vernich, 2002) and ‘control’ (Miller, Campbell, Farran, Kaufman & Davis, 1995). It was decided that including both experience attributes and health

attributes in the Carer Experience Scale may therefore lead to double counting of the welfare effects on carers.

Most measures also include a dimension to pick up financial problems encountered by the carer. Financial problems did not, however, emerge as an independent theme, through the meta-ethnography or interviews, in this study. To some extent, state financial support is included in the measure through the “assistance from organisations” attribute, although out-of-pocket expenses incurred through caring would not be covered. One caveat to including a financial attribute is that it creates the potential for double counting if the measure is used in an economic evaluation. If carers incur out-of-pocket expenses then these may end up being considered on both the cost and outcome side. Indeed, in a previous trial with an economic evaluation alongside, the financial strain attribute of the carer measure was omitted to avoid this happening (Gunnell, Coast, Richards, Peters, Poundsford & Darlow, 2000).

The application of meta-ethnography in this context was exploratory and therefore there are limitations associated with this work. It should be noted that there is substantial debate about the use of meta-ethnography generally. Critics highlight the danger of decontextualising and deconstructing original findings (Finfgeld, 2003). In this research, meta-ethnography was used in a reductive manner, to condense qualitative research into a set of six attributes. The developers of the method intended it to produce “substantive interpretations” of the subject material (Noblit & Hare, 1988, p. 9) and may take issue with the perceived reductiveness. The meta-ethnography could potentially have been carried out with a larger set of studies, or a series of initial syntheses for specific sub-groups of carers. The advantage of using meta-ethnography is that the attributes are richer than if they had been based on a single study and while there may be further insights from including a wider set of

studies in the meta-ethnography, this should be weighed against the greater complexity and time required to conduct the synthesis.

Two potential limitations were noted with the interview process. To build on the meta-ethnography, the findings were presented to informants during the interviews. A danger is this could have been done in a way that constrained informants, so that they did not bring up other important topics. Attempts were made to reduce the chances of this happening, first by starting interviews with an open discussion where informants could freely mention the issues that were important to them (for example they were asked “what do you like and dislike about providing care?”) and second by offering them an opportunity to introduce additional issues at the end. A second potential limitation is that the sequencing and characteristics of the informants limits the generalisability of the findings. Most of the interviews conducted in the first iteration were with spouses of people with dementia. There is the possibility that the attributes might particularly reflect the issues that were important to dementia carers, however later interviews did not suggest this. Furthermore, interviewing solely adult carers of older people may mean the measure is not appropriate for certain groups of carers, for example parents caring for disabled children, or children caring for a parent. To assess this, further work is needed to assess the validity and feasibility of the measure amongst different groups of carers.

The approach taken to developing the measure in this research differed from that adopted by many other authors. Typically attributes in carer measures are sourced from other (often just one) studies (Deeken et al., 2003). Further, if qualitative work is conducted to determine attributes, little information is provided to show how and why the final set of attributes was derived. This causes problems when trying to review the study methods. In this study, a concise set of attributes covering the caring experience was developed from first principles. Effort was made to offer as much

clarity about how and why the final set of attributes and levels were selected for the measure. Detailed psychometric testing, which has gone into refining and validating some of the other measures developed so far, has not been conducted here. Again, further work is needed to test various aspects of the validity of the measure.

The final set of attributes reflects the need to go beyond health outcomes when measuring the impact of an intervention on carers. The impact of outside intervention on the caring experience is likely to be complex. Intervention, for example, may improve a carer's feelings of being assisted and free them up to do more outside activities, but it may limit their feelings of control. These tradeoffs in the caring experience are unlikely to be picked up in existing measures. Following work to validate and score the measure, the Carer Experience Scale may offer a promising method for incorporating the broader caring experience within economic evaluations.

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Appendix A: Online Literature Search Strategy

Search 1: 'Preferences', August 2005

Cinahl, EMBASE, PsychINFO, Medline (1966 -): (*caregiver* or *caregiver burden* or *home nursing* or *home care* or *caregiv** or *home nurs** or *carer** or *informal car** or *home care**) AND (*preference**) AND (*aged*)

Sociological abstracts, ASSIA: (*caregiv** or *informal car** or *carer**) AND (*preference**)

Search 2: 'Qualitative methods', October 2005

Cinahl, EMBASE, Medline (1966 -): (*caregiver* or *caregiver burden* or *home nursing* or *home care* or *caregiv** or *home nurs** or *carer** or *informal car** or *home care**) AND (*phenomenology**, *ethnograph**, *grounded theory*, *grounded approach* AND (*aged*))

PsychINFO: (*caregiv** or *informal car** or *carer** or *home car** or *home nurs**) AND (*phenomenology** or *ethnograph** or *grounded theory* or *grounded approach*) AND (*old* or *aged* or *elderly*)

Sociological abstracts, ASSIA: (*caregiv** or *informal car** or *carer**) AND (*phenomenology** or *ethnograph** or *grounded*) AND (*old* or *aged* or *elderly*)

Terms in italics are MeSH terms

Appendix B: Studies included in the meta-ethnography

- A. Adamson, J. & Donovan, J. 2005, "'Normal disruption': South Asian and African/Caribbean relatives caring for an older family member in the UK", *Social Science and Medicine*, vol. 60, pp. 37-48.
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Appendix C: Descriptive system for a carer experience scale

PLEASE TICK ONE BOX FOR EACH GROUP to indicate which statement best describes your current caring situation.	
<p>1. Activities outside caring (<i>Socialising, physical activity and spending time on hobbies, leisure or study</i>)</p> <p>You can do most of the other things you want to do outside caring <input type="checkbox"/>₁</p> <p>You can do some of the other things you want to do outside caring <input type="checkbox"/>₂</p> <p>You can do few of the other things you want to do outside caring <input type="checkbox"/>₃</p>	
<p>2. Support from family and friends (<i>Personal help in caring and/or emotional support from family, friends, neighbours or work colleagues</i>)</p> <p>You get a lot of support from family and friends <input type="checkbox"/>₁</p> <p>You get some support from family and friends <input type="checkbox"/>₂</p> <p>You get little support from family and friends <input type="checkbox"/>₃</p>	
<p>3. Assistance from organisations and the Government (<i>Help from public, private or voluntary groups in terms of benefits, respite and practical information</i>)</p> <p>You get a lot of assistance from organisations and the Government <input type="checkbox"/>₁</p> <p>You get some assistance from organisations and the Government <input type="checkbox"/>₂</p> <p>You get little assistance from organisations and the Government <input type="checkbox"/>₃</p>	
<p>4. Fulfilment from caring (<i>Positive feelings from providing care, which may come from: making the person you care for happy, maintaining their dignity, being appreciated, fulfilling your responsibility, gaining new skills or contributing to the care of the person you look after</i>)</p> <p>You mostly find caring fulfilling <input type="checkbox"/>₁</p> <p>You sometimes find caring fulfilling <input type="checkbox"/>₂</p> <p>You rarely find caring fulfilling <input type="checkbox"/>₃</p>	
<p>5. Control over the caring (<i>Your ability to influence the overall care of the person you look after</i>)</p> <p>You are in control of most aspects of the caring <input type="checkbox"/>₁</p> <p>You are in control of some aspects of the caring <input type="checkbox"/>₂</p> <p>You are in control of few aspects of the caring <input type="checkbox"/>₃</p>	
<p>6. Getting on with the person you care for (<i>Being able to talk with the person you look after, and discuss things without arguing</i>)</p> <p>You mostly get on with the person you care for <input type="checkbox"/>₁</p> <p>You sometimes get on with the person you care for <input type="checkbox"/>₂</p> <p>You rarely get on with the person you care for <input type="checkbox"/>₃</p>	

Table 1—Characteristics of 44 qualitative studies identified through the literature search

Carer sex	Carer relation to recipient	Carer ethnic group	Reason for recipient requiring care
Female/male 33	Relative 21	Not specified 39	Dementia 13
Female 7	Spouse 8	Black/Asian 1	Not specified 12
Male 4	Child 7	Minorities 1	Old 3
Not specified 1	Anyone 5	Turkish/Moroccan 1	Terminal illness 3
	Child/parent 1	Thai 1	Cognitive impairment 3
	Child/spouse 1	Filipino 1	Multiple sclerosis 2
	Not specified 1		HIV 2
			Lung disease 2
			Other 4

Table 2—Studies included in the meta-ethnography and their characteristics in relation to the sampling criteria

Study¹	Carer sex	Carer relation to recipient	Carer ethnic group	Reason for recipient requiring care
Adamson, UK	Both	Relative	Black/ South Asian	Dementia
Baker, US	Both	Anyone	Minorities	HIV
Cheung, Australia	Both	Spouse	Not specified	Multiple Sclerosis
Harris, US	Male	Spouse	Not specified	Alzheimer's disease
Lewis, US	Female	Daughter	Not specified	Not specified
McGarry, UK	Both	Relative (>75)	Not specified	Not specified

¹Full references in appendix B

Table 3—Translating the studies into one another

Study	Meaning of 'Control'
Adamson	Carers value being able to organise their work commitments around their caring activities.
Baker	Carers control the situation by managing the stigma and understanding of the disease of the recipient.
Cheung	Carers do not feel they have long-term control over their lives. Some feel they can adapt to day to day living, while others are very worried about the lack of control.
Harris	Carers are protective of their caring role and are reluctant to relinquish control to people whose care may be inferior.
Lewis	Control could be linked to respite care. Carers valued being able to find the right type of respite care to relieve the burden of providing care.
McGarry	Maintaining control of caring was essential when dealing with tasks such as assisting with providing medication.

Table 4—Concepts relating to caring identified through the meta-ethnography

Descriptions	Carer outcomes	Aspects of the process of providing care
Challenge	Physical health	Benefit payments
Commitment	Emotional health	Control
Continuity		Duty
Predetermination of role		Family role (support)
Social norms		Freedom
Uncertainty		Impacts on others
		Information
		Love
		Reciprocity
		Religion
		Respite care
		Social and physical activity
		Workplace flexibility

Table 5—Attributes of the caring experience from the meta-ethnography

Attribute	Description
<i>Carer-recipient relationship</i>	Feelings (such as love, friendship, reciprocity, closeness) that bind the carer and recipient together
<i>Institutional support</i>	Assistance (such as benefits, respite care, practical information and time off work) that the carer receives
<i>Informal support</i>	Personal help in caring and emotional support that the carer receives from family, friends, neighbours and work colleagues, as well as any spiritual support the carer may derive from their religion
<i>Activities outside caring</i>	Opportunities that the carer has to engage in physical activities and socialising outside their caring environment
<i>Control</i>	Carers' ability to effectively manage their caring duties
<i>Duty</i>	Carers' perception of whether they feel they are fulfilling a duty by providing informal care

Table 6—Characteristics of study informants

Informants (n=16)	
Sex	
Male	5
Female	11
Age of carer	
<65	7
65 +	9
Relationship between carer and recipient	
Spouse	8
Non-spouse	8
Years providing unpaid care	
<5 years	11
5 years +	5
Tasks (personal care, housework, organisation)	
All 3	5
1 or 2 tasks, or help received	11
Main disability of care recipient	
Mental	9
Physical	7

Table 7—Attribute comparison across studies

This study	Deeken et al. (2003) (22 measures reviewed)	Brouwer et al. (2006) (9 measures reviewed)
1. Activities outside caring	a. Social Life (13) b. Time (11) c. Respite/ leisure/ privacy (15) d. Activities (ADL, IADL) (11)	(i) Problems with daily activities (8)
2. Support from family and friends	e. Support (14) f. Family life (18)	(ii) Support (5)
3. Assistance from organisations and the government	g. Information needs (6)	
4. Fulfilment	h. Spiritual (4)	(iii) Fulfilment (6)
5. Control		
6. Getting on with the care recipient	j. Relationship with patient (5)	(iii) Relational problems (8)
Not explicitly covered by Carer Experience Scale	k. Physical health (20) l. Emotion health (21) m. Finances (19)	(v) Physical problems (8) (vi) Mental problems (6) (vii) Financial problems (8)

Note: figures in parentheses indicate the number of times a measure including that item or dimension was identified