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ADAPTATION, ACCEPTANCE AND ADAPTIVE PREFERENCES IN HEALTH AND CAPABILITY WELLBEING MEASUREMENT AMONGST THOSE APPROACHING END OF LIFE

Running Head: Adaptive preferences at end of life

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ABSTRACT

Objectives: Adaptive preferences occur when people subconsciously alter their views to account for the possibilities available to them. Adaptive preferences may be problematic where these views are used in resource allocation decisions because they may lead to underestimation of the true benefits of providing services. This research explored the nature and extent of both adaptation (changing to better suit the context) and adaptive preferences (altering preferences in response to restricted options) in individuals approaching the end of life.

Methods: Qualitative data from 'thinkaloud' interviews with 33 hospice patients, 22 close persons and 17 health professionals were used alongside their responses to three health/wellbeing measures for use in resource allocation decisions: EQ-5D-5L (health status); ICECAP-A (adult capability); and ICECAP-SCM (end of life capability). Constant comparative analysis combined a focus on both verbalised perceptions across the three groups and responses to the measures.

Results: Data collection took place between October 2012 and February 2014. Informants spoke clearly about how patients had adapted their lives in response to symptoms associated with their terminal condition. It was often seen as a positive choice to accept their state and adapt in this way but at the same time, most patients were fully aware of the health and capability losses that they had faced. Self-assessments of health and capability generally appeared to reflect the pre-adaptation state although there were exceptions.
Conclusion: Despite adapting to their conditions, the reference group for individuals approaching end of life largely remained a healthy, capable population, and most did not show evidence of adaptive preferences.

Key words: UK; adaptation; adaptive preferences; end of life; EQ-5D-5L; ICECAP-A; ICECAP-SCM.

KEY POINTS FOR DECISION MAKERS

- Adaptive preferences may be problematic for decision makers, if they rely on self-assessed measures.
- This study explores adaptive preferences in those approaching end of life, using three measures: ICECAP-SCM, EQ-5D-5L, ICECAP-A.
- Although patients clearly adapted to their failing health state, for the most part their self-assessments reflected their pre-adaptation state, suggesting that these measures are appropriate for use in economic evaluations of interventions at end of life.

1. Introduction

The potential for adaptive preferences is an important issue in the self-assessment of health and wellbeing states that are used in evaluating health and care interventions. Adaptive preferences occur when one response to poor quality of life or poor care [1] is to adjust aspirations downwards [2]. This 'adaptation problem' is explored by Qizilbash [3] in the context of gender inequality, giving the following example:

> *Clearly a woman who responds to her living conditions by adopting commonly held beliefs and desires consistent with her having a subordinate role in the household would exemplify the 'adaptation problem' (Qizilbash, 2006, [3] p.93)*

Adaptive preferences may be particularly problematic in people approaching end of life (EoL), where individuals are likely to experience significant health deterioration. If those in objectively poor states (poor health or receiving poor care) adapt their preferences such that they 'over-rate' their state, and thus 'under-rate' improvements in that state (thus resulting in one form of 'response shift' [4]), they may be disadvantaged in funding decisions taken based on improvements in self-rated measures, an approach common in economic evaluation.

Any self-assessments of quality of life used in economic evaluations may be vulnerable, although adaptation to a particular state resulting in adaptive preferences is a concern that the capability approach tries to address. Sen has argued that capability provides a more appropriate evaluative space than utility, as it enables evaluation of the scope of opportunities available to individuals, rather than satisfaction with the situation they find themselves in [5, 6]. Adaptive preferences may still be problematic, however, if the relevant group define the important capabilities – as recommended by Sen, who advocates a participatory approach [7, 8] – and/or if the capabilities are complex, person-centred and cannot be objectively observed.

Recently developed capability indices used with patients to evaluate health and social care interventions include the ICECAP suite of instruments [9-11] and other measures targetting specific sub-groups [12, 13]. These were developed using participatory approaches and contain complex capabilities, not amenable to objective assessment. The OxCAP instruments [14, 15] are based on Nussbaum's ten central human capabilities [16] rather than

a participatory approach, but still contain complex concepts and rely on self-report. All may, therefore, be subject to adaptive preferences.

Measuring capability at EoL may be valuable as it enables evaluation of what matters to individuals: the opportunity to manage their own EoL at this sensitive and personal time [1]. If self-assessments of capability are to be used in evaluating health and care interventions, it is important to understand the extent to which adaptive preferences may affect these measures. Health status measures used in economic evaluation may be equally vulnerable to this issue in people approaching EoL. This research therefore aims to explore whether such individuals appear to adapt to failing health, and to determine the influence of adaptation, through development of adaptive preferences, on self-completion of three measures of health and capability wellbeing in assessing EoL care.

2. METHODS

This research was conducted alongside a study of the feasibility of measure completion at EoL [17] and focuses on issues around adaptation and adaptive preferences. The overall research design was a 'thinkaloud' study [18-20] with subsequent semi-structured interviews [21]. Ethics approval was obtained from North Wales NHS Research Ethics Committee – West (ref: 12/WA/0076).

Three measures were included. ICECAP-SCM [11, 22] is a capability wellbeing measure for those at EoL comprising seven items expressed as capabilities (e.g. I am able to have): choice, love and affection, freedom from physical suffering, freedom from emotional suffering, dignity, support and preparation. EQ-5D-5L is a health measure commonly used in economic evaluation containing five questions focusing on mobility, self-care, usual activities, pain/discomfort and anxiety/depression [23]. ICECAP-A is a capability measure for the general adult population [9, 24] comprising five items expressed as capabilities: stability, attachment, autonomy, achievement, enjoyment. The equivalent measure for older persons (ICECAP-O) was not used as participants were not expected to be exclusively of older age.

Data were collected from those receiving care for a life-threatening illness and approaching EoL, those close to that person ('close persons') and health professionals involved in their care. Sampling was conducted through one UK adult hospice, with patients recruited through the community service, day hospice and in-patient unit. Inclusion criteria were minimal: receipt of hospice care; consent to participate; and ability to communicate in English. All recruitment started from the patient; close persons and health professionals were identified by the patient and only contacted with the patient's consent.

Previous thinkaloud studies of capability measures have ranged in size from 20 [25] to 50 [26] participants. Sampling aimed to obtain sufficient numbers for the thinkaloud [17] and to reach saturation [21] for findings arising from the semi-structured interview; it was expected this would be achieved with around 35 patient, 20 health professional and 20 close person interviews.

Interviews took place at the hospice or a place of the informant's choosing (usually the home) and were conducted by CB, RO and PK. All participants were asked to complete the

three questionnaires about the patient's health and wellbeing, whilst speaking their thoughts aloud; wording on the non-patient questionnaires referred to 'the person you are close to' (close persons) or 'the person you are caring for' (health professionals) and in some interviews phrasing such as 'you should think how your father would answer the questionnaire' was used to assist the respondent. Questionnaires were randomly ordered except for a few very unwell in-patients; here, the ICECAP-SCM was completed first in case the patient became too fatigued to complete the interview. After questionnaire completion, all informants who reached this part of the interview were probed further for views about the questionnaires.

All interviews (including thinkaloud and semi-structured elements) were digitally audio-recorded and transcribed verbatim. To explore adaptation and adaptive preferences the data were analysed using constant comparative methods [27, 21]. The primary analysis focused on patients' own assessments, supplemented by data from close persons and health professionals. Transcripts were read and re-read, and categories and sub-categories developed to describe emerging themes [21, 28]. Independent analysis of the adaptation theme was conducted by JC (using analytic accounts generated in Microsoft Word [28]) and CB (using NVivo10 to develop associations, relationships and models from the original nodes and generate a theoretical model of adaptation). The final interpretation considered emerging themes in the context of the scores given in completing the measures, and was agreed by both analysts. Quotes are presented verbatim with the use of ellipses to represent missing text; phrases such as 'you know' or repeats of words that do not add to meaning are excluded without use of ellipses.

3. RESULTS

Interviews were conducted between October 2012 and February 2014. Eighty two eligible patients were approached; 33 agreed. Non-participants felt unwell/fatigued (n=17), felt it 'was not for them' (n=14), had recently participated in other studies (n=4) or provided other/no reasons (n=14). From these 33 patients, 22 close persons and 17 health professional interviews were generated, resulting in data from 72 participants. At this point, analysis suggested that saturation within themes associated with questionnaire completion [17] was achieved and recruitment was stopped.

Eight patients were recruited from the community, 14 through day hospice and 11 from the in-patient unit. All were aged over 50 (13 aged 50-69, 10 aged 70-79, 10 aged 80+); 12 were female. Thirty one patients hasd cancer-related diagnoses, and two were suffering from motor neurone disease. Fifteen close persons were spouses/partners, three were friends and four sons/daughters. Eight health professionals were doctors, seven were nurses and two allied health professionals.

Five patients were unable to complete the interview. All 33 patients answered the ICECAP-SCM. Two (PT19, PT29) were unable to complete any further questionnaires. One patient (PT24) was able to complete ICECAP-SCM and EQ-5D but then the interview was ended. Two further patients stopped partway through their final questionnaire: EQ-5D (PT20); ICECAP-A (PT30). Close persons and health professionals completed all three measures.

3.1 Awareness and adaptation

3.1.1 Patient awareness of loss of capability

Most patients were only too aware of their loss of capability as a result of their illness and the approach of the end of life. They tended to contrast their current capability with their previous activities, and discuss changes in response to their illness and the increasing disability that it imposed. Some informants felt that their capability had decreased considerably:

I can't walk at all now whereas before I could take a few paces (PT02)

I've got a lot of pains in the shoulders and I can't move me arm there. Oh, it's terrible. I want to do things but I can't. (PT14)

Many changes were related to ability to carry out tasks and activities associated with maintaining an independent lifestyle. These included housework, gardening, working, shopping, decorating and caring for others. Other changes were related to the ability to do enjoyable activities including hobbies, sporting activities and entertainment:

I am not able to mow the lawn and things like that, whereas before my illness I could do most things! (PT01)

I can't walk any distance… I have to wait for somebody else to come and take me shopping, I can only take myself to one block of shops which is five minutes walk away (PT03)

I like to go to concerts. So I'm not able to go to concerts at the moment… (PT10)

… I used to work in the gardens, but I can't even do that, the privet hedges, I used to do the neighbour's, but I can't even do that. (PT26)

3.1.2 Patient adaptation to loss of capability

Many patients spoke clearly about how they had adapted their lives in response to symptoms associated with their terminal illness, to be able to live a valuable life.

I lead a full life as much as I'm able to, because of health problems I am a little bit restricted… (PT12)

The clearest adaptations were in activities that had become restricted, but some informants also spoke about adaptation to pain, relationships, dignity, mobility and decision making.

It's all been hard to adapt, hasn't it, but it's that… It's so personal, having somebody to help with that … it's hard for everything, isn't it, but that's the worst, definitely. (PT21)

I use the stick because I don't feel safe, steady. I use the stick for that reason. (PT14)

I have pains in my side yesterday when I woke up, and the only thing is is to get on with life and put your pains at the back of your mind, get on and do the garden, and do other things… you don't realise your pain's there then. You just carry on. See it's normal. (PT17)

I know that I mustn't make big decisions the fourth week of every four week span, that's because I [have] blood transfusions (PT03)

Informants spoke about adaptations in the *type* of the activities undertaken, the *quantity* of activities undertaken and the *way* in which they did those activities. Some informants spoke about how they had shifted activities towards those more suited to their failing health.

I can't work on my clocks anymore, I realise that, but I can work on many things. Cupboards, chairs and simple things I can do. (PT07)

I do crossword puzzles or jigsaw puzzles or things like that. I make a lot of my own cards. Just to keep my mind active, and my fingers out of mischief, like… I used to do loads of knitting and sewing … I can't do that any more … but, I do the best I can. (PT28)

Informants also talked about adaptations in the extent of their activity as well as adaptations in how they conducted an activity:

I used to cut the grass, the lawns, I used to do them both at the same time… do one and then do the other. Now I just do one now and do the next one the next day. (PT18)

I find it difficult to get my shoes and my socks on… I manage to get my socks on, and I do it by getting my leg up and I'll go down and down and down and I get the sock on like that. So… it's a bit of an involved process, but I can do it. I've still got my socks on [laughs] (PT07)

Perhaps unsurprisingly, patients seemed to show increasing adaptation as their illness trajectory changed and they coped with new challenges and found new ways to meet their own objectives.

3.1.3 Patient acceptance and adaptation

For many informants coming to terms with their illness and prognosis (referred to here as 'acceptance') was a large part of their ability to adapt to their changed circumstances. This acceptance seemed to be in part a choice, albeit somewhat forced, and in part an inevitability as EoL approached. A clear part of acceptance was being aware that their condition was terminnal. This enabled people to accept their circumstances, make decisions and move on with their lives.

life has improved, and I am… aware of my situation, that I'm going to die of cancer. (PT18)

There also appeared to be an element of choice in accepting the situation. Respondents talked about choosing to 'carry on with life' and not 'worrying' about things.

> *I lead a full life as much as I'm able to … I just don't let things bother me. I've accepted the illness… (PT12)*

Although for some there was an inevitability about this 'choice', for many an active decision to accept the situation appeared to be a positive choice that would improve the informant's life.

> *if I go round in my head thinking 'It's awful and I don't want this' I'm gonna end up feeling depressed permanently… (PT21)*

There were, however, also informants who did not appear to be in a state of acceptance and consequently, did not seem to have adapted their activities as other patient informants had:

> *I like going out to eat. I like holidays. I like to go out more often than what I do, but when I go out I'm always in discomfort… So you never feel free… You're always tied in with the circumstances... (PT23)*

A number of factors appeared to aid acceptance and thus ability to adapt to the disease and prognosis. These included time and certainty about prognosis.

> *…I've accepted the illness; I've had it since 1976 when I had a pneumonectomy for lung cancer. (PT12)*

> *…I've been up and down, up and down, a real rollercoaster, it's almost a relief... to think... there aren't many options left. (PT35)*

Adaptation and acceptance also appeared to be aided by the ability to change focus. Informants talked about focusing on the things that were particularly important to them (such as living life to the full, doing what is needed, focusing on the important things in life such as basic needs and family, and leaving behind a legacy of some sort) on the one hand, and on the simple things in life on the other.

> *I'm trying to resolve the things that are important to me. I am trying to get my oldest lad interested in carrying on with my clocks. (PT07)*

> *I found enjoyment in small things… sitting here, if I'm watching the odd little bird… especially if it's a little robin or something, you think 'Ah, that's nice'. So your little things still please you. (PT22)*

Appropriate help and support also appeared to aid adaptation, including support from services, family and friends, and physical aids.

> *I do go to the shops, but I can't carry the shopping now like I used to, so… my daughter carries the shopping … I might carry just something light, because I have to use a stick. (PT14)*

Finally, patients' willingness to accept their situation and to adapt to it also appeared to be enhanced by a sense that their life had been fulfilling prior to the diagnosis/prognosis. This perception that they had already had a good life seemed to aid informants in accepting their condition and adapting to what they could do with their remaining time.

> *Up until I was diagnosed I'd had a good life. Active. I'd worked most of that time, had a family, got grandchildren… none of us go on forever… and I think you just have to think back on what has been and not dwell on too much of what you can't do now. Think more of what you can do. Otherwise, well, you'd just be miserable all the time. (PT22)*

3.1.4 Close person and health professional perceptions

Health professionals and close persons suggested that the person at EoL was aware of the changes to their capabilities.

> *But all the things that she used to do like walking the dog and looking after the house and cleaning and going out to work, she can't do and she obviously misses that (HP02).*

A small number of health professionals and close persons talked about how the person at EoL had adapted their activities or was unable to pursue them at all.

> *He's unable to do any of his usual activities, say even just reading… his life was his job really… he had to give that up a long time ago (HP05).*

On a small number of occasions, close persons and health professionals also commented on their own feelings about how the person at EoL was having to adapt to their new situation.

> *I feel rotten because I know how much it must be hurting him because he has always been a private [person] and he hates people being disrespectful to him and he respects everybody and he expects the same back… (CP18)*

A small number of health professionals and close persons touched on the notion that patients had accepted their current poor health state. As in the patient accounts, there

seemed to be a divide between those who had actively accepted their state and those whose acceptance was rather more forced.

> *He seems quite a pragmatic sort of gentleman… I think he would say, 'I'm satisfied with life as it is at the moment, knowing that I have this illness.' (HP09)*
>
> *She gets on with it. But maybe that's just her wanting to be in control rather than…not admitting they're as bad. (HP04)*

3.2 Adaptation and self-assessment of capability

Despite evidence that patients were adapting their behaviour and routines to changes in their health, in itself this does not tell us whether patients' had also adjusted their aspirations in response to these changes. If patients discussed severe limitations that they faced in their capability or health, but then rated their current state as relatively high, this would suggest the existence of adaptive preferences. Most informants, however, appeared to self-assess their health or wellbeing states in line with their pre-adapted state, that is, how they were before this phase of their illness. Supplementary Table 1 presents quotes from the early part of the analysis, when patients' awareness of their adaptation and the nature of their adaptation was discussed. Supplementary Table 1 also presents the relevant self-assessments recorded by the informants on the different measures in related attributes. For the majority of quotes, the self-assessments appear to reflect the pre-adaptation state, for example, indicating extreme problems with mobility at the same time as stating 'I can't walk any distance' (PT02) or indicating capability for 'quite a lot of' (but not full) enjoyment when stating a reduced set of enjoyable activities (PT28). There are, however, some exceptions. PT17 appears not to have adapted his self-assessment for pain, which is rated as severe, but refuses to compromise in other areas and indicates full capability on all aspects of ICECAP-A. PT26 appears to have adapted his notion of usual activities on EQ-5D-5L to exclude his pre-illness activities, thus giving him a perfect score for this item, despite noting his limitations and rating his capability for independence as being in only a few things.

Among close persons and health professionals, where available for comparison, many ratings were identical to patients for these quotes relating to adaptation (see Supplementary Table 2). Where they did differ, this was generally by one level; whilst differences occurred

in both directions, there was a slight tendency for them to be lower than the patient's rating. There was one example of extreme difference, also with PT26, where the close person did not adapt the meaning of 'usual activities' in the EQ-5D-5L in the same way as the pateint, instead focusing on the period before their illness.

4. Discussion

Whilst there is evidence that those approaching EoL adapted their lives, particularly their activities, to their illness, this did not appear to strongly influence self assessments of capabilities or health. Rather, these self-ssessments generally suggested significant loss in capability and health and did not appear to be affected by the 'adaptation problem' (i.e. adaptive preferences). Although adaptation was related to acceptance (here, meaning coming to terms with the illness and prognosis), for some people acceptance appeared more challenging; an individual's ability to accept may depend on complex interplay of psychological, experiential and care-related factors. It may be that, whilst informants self-assess capability and health in line with their pre-adaptation state (before they were unwell), they somehow adjust the relationship between capability/health and utility to allow them to achieve greater utility from a poorer capability/health state. The 'acceptance' observed here may be the means by which such a shift takes place. Further, because these patients would otherwise be miserable in a state they cannot change, resigning themselves to the state of terminal illnesss and their subsequent adaptation seems largely positive from the patients' perspectives; the ability to accept and adapt may be valuable to patients as their condition deteriorates and death becomes inevitable.

There seem to be at least two possible explanations for why there was adaptation, but adaptive preferences were not observed here, the first of which is time. For most patients, their time post-diagnosis was relatively short compared to their whole life; their expectations and aspirations are likely to have been established during the longer, less constrained, period of their life. Second, is context, with informants nearing EoL continuing to participate in a world where most people's lives are not constrained; they thus see others enjoying a life with the capabilities they once enjoyed themselves.

These data contribute to the general literature on adaptation and adaptive preferences, but in the context of health and end of life rather than income or poverty. There has been some exploration of adaptation to health states, including by Sen [29], but generally in terms of ongoing poverty in developing countries [2]. The EoL context differs from examining health across whole populations, with more extreme losses in capability over relatively short periods. Qizilbish argues that the 'adaptation problem' may be more related to specific capabilities than general values [3] and there is some evidence here that patients who value

enjoyment, for example, make efforts to find new means of enjoyment enabling them to meet this core need; nevertheless, they remain aware of the constraints on their activity. The research may also contribute to further understanding of response shift in relation to adaptation.

This work has both strengths and limitations. Despite challenges in recruiting participants in EoL care settings [30], people at EoL contributed empirical data that enhance the meaning behind the values obtained. The thinkaloud technique ensured that people focused on specific issues in their discussions and provided qualitative and response data on the same issue, enabling reasons behind responses to be understood. For a few patients, it was not feasible to obtain information from all three questionnaires, because of fatigue. Further, these data were only collected on one occasion from each respondent, and therefore it was not possible to explore the impact of adaptation on longitudinal changes in scores. Finally, all patients received EoL care through specialist hospice services, the availability of which is constrained [31]; many people approach death without such specialist services, and differences in experiences may affect levels of acceptance and adaptation.

Overall, whilst there was evidence that many patients receiving palliative care had adapted to their frail health and approaching death, there was less indication of problematic adaptive preferences in terms of their self-assessed scores on the capability or health measures. Self-assessment of health and capability at EoL can thus generally be expected to give an assessment that reflects patients' health and capability as others might see it, and researchers can continue to use this approach. Further research should investigate whether these findings are reflected in other EoL settings.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author (JC). The data are not publicly available due to them containing information that could compromise research participant privacy/consent.

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Supplementary Table 1: Quote used in the paper and the associated patient self-assessments on pertinent items of ICECAP-SCM, ICECAP-A and EQ-5D-5L; note that higher coding scores for ICECAP-A and ICECAP-SCM indicate a better situation (4 to 1) whereas higher coding scores for EQ-5D-5L indicate a worse situation (1 to 5).

Patient ID	Quote	ICECAP-SCM	ICECAP-A	EQ-5D-5L
PT01	I am not able to mow the lawn and things like that, whereas before my illness I could do most things!		no capability for independence (1); no capability for achievement and progress (1)	extreme problems with usual activities (5)
PT 02	I can't walk at all now whereas before I could take a few paces			extreme problems with mobility (5)
PT03	I can't walk any distance… I have to wait for somebody else to come and take me shopping, I can only take myself to one block of shops which is five minutes walk away	able to have help and support most of the time (4)	capability for independence in a few things (2)	slight problems with mobility (2); slight problems with usual activities (2); moderate pain (3)
PT03	I know that I mustn't make big decisions the fourth week of every four week span, that's because I [have] blood transfusions	able to make decisions some of the time (3)	capability for independence in a few things (2)	
PT07	I can't work on my clocks anymore, I realise that, but I can work on many things. Cupboards, chairs and simple things I can do.		capability for a lot of enjoyment (4)	moderate problems with usual activities (3)

PT07	I find it difficult to get my shoes and my socks on… I manage to get my socks on, and I do it by getting my leg up and I'll go down and down and down and I get the sock on like that. So… it's a bit of an involved process, but I can do it. I've still got my socks on	able to maintain dignity and self-respect most of the time (4)	capability for independence in many things (3)	slight problems with self care (2)
PT10	I like to go to concerts. So I'm not able to go to concerts at the moment…		capability for quite a lot of enjoyment (3)	slight problems with usual activities (2)
PT14	I've got a lot of pains in the shoulders and I can't move me arm there. Oh, it's terrible. I want to do things but I can't.	always experiencing physical discomfort (1)	capability for independence in a few things (2); capability for a little enjoyment (2)	severe pain (4)
PT14	I use the stick because I don't feel safe, steady. I use the stick for that reason.		unable to feel settled and secure in any areas of life (1)	slight problems with mobility (2)
PT17	I have pains in my side yesterday when I woke up, and the only thing is is to get on with life and put your pains at the back of your mind, get on and do the garden, and do other things… you don't realise your pain's there then. You just carry on. See it's normal.	often experiencing physical discomfort (2)	full capability in all aspects of ICECAP-A (4,4,4,4,4)	slight problems with usual activities (2); severe pain (4)
PT18	I used to cut the grass, the lawns, I used to do them both at the same time… do one and then do the other. Now I just do one now and do the next one the next day.		capability for achievement in many aspects of life (3); capability for independence in many things (3)	moderate problems with usual activities (3)

PT21	It's all been hard to adapt, hasn't it, but it's that… It's so personal, having somebody to help with that… it's hard for everything, isn't it, but that's the worst, definitely.	able to maintain dignity and self-respect most of the time (4)		moderate problems with self care (3)
PT26	I used to work in the gardens, but I can't even do that, the privet hedges, I used to do the neighbour's, but I can't even do that.		capability for independence in a few things (2)	no problems with usual activities (1)
PT28	I do crossword puzzles or jigsaw puzzles or things like that. I make a lot of my own cards. Just to keep my mind active, and my fingers out of mischief, like… I used to do loads of knitting and sewing … I can't do that any more … but, I do the best I can.		capability for achievement and progress in a few things (2); capability for quite a lot of enjoyment (3)	moderate problems with usual activities (3); no anxiety or depression (1)
PT28	My health and my situation is restricting me from doing what I want to do … You just, er, phone 'em, or write to 'em, or whatever, and do the best you can	able to be with people who care about her most of the time (4)	capability for quite a lot of love friendship and support (3)	

Supplementary Table 2: Quote used in the paper and the associated CP and HP self-assessments on pertinent items of ICECAP-SCM, ICECAP-A and EQ-5D-5L (where available)

Patient ID	Quote	ICECAP-SCM	ICECAP-A	EQ-5D-5L
PT 02	I can't walk at all now whereas before I could take a few paces *HP02: … they are unable to walk about and, sadly for [patient] at that time,that's actually quite new and so mentally that's quite harsh for her because about six weeks ago she was struggling short distance with a Zimmer frame*			HP: identical rating to patient of extreme problems with mobility (5)
PT07	I can't work on my clocks anymore, I realise that, but I can work on many things. Cupboards, chairs and simple things I can do. *CP07: usual activities.. I'd say once again he has moderate problems because a lot of it is problems climbing the stairs, problems when he gets up from chairs* *CP07: I think he gets a lot of enjoyment and pleasure… he likes his garden and that growing and so on.* *HP07: Usual activities, again, only seeing him in a clinic environment, he doesn't make himself any drinks while he's here, we do that for him, so perhaps moderate problems again with his usual activities.* *HP07: Enjoyment and pleasure – he always tells me how enjoyable his life has been. Great memories he talks about a lot, and he talks about the pleasure of his wife and his family… I would be reluctant to put he has a lot of enjoyment and pleasure, because I'm sure there are some things that he wishes he could do more of. I think quite a lot of enjoyment and pleasure.*		CP: identical rating to patient of capability for a lot of enjoyment (4) HP: lower rating than patient of capability for quite a lot of enjoyment (3)	CP: identical rating to patient of moderate problems with usual activities (3) HP: identical rating to patient of moderate problems with usual activities (3)

PT07	I find it difficult to get my shoes and my socks on… I manage to get my socks on, and I do it by getting my leg up and I'll go down and down and down and I get the sock on like that. So, it's a long – it's a process, it's a bit of an involved process, but I can do it. I've still got my socks on *CP:, I'd say that… it's more of a case of encouragement … he does actually err shower on his own and he does actually dress himself… So I'd say slight.* *CP: he's independent from the point of view that he can still do some things, such as he's gone to Marie Curie today and he's driven himself. But he isn't completely independent…I'd say there are a few times that dad is able to be independent.* *CP: … dignity and self-respect … I would say most of the time… I think it's only on the odd occasion that he doesn't get on with somebody who comes in...* *HP: Self-care – not having seen him at home erm, that's quite difficult to answer, but erm he doesn't have any formal carers, so I would say [patient] would think he has some moderate problems washing or dressing himself.* *HP: Independence – again, I've only ever seen him in this environment, where he's been relatively independent, but there are restrictions, such as his mobility … So I'd say he's independent in a few things.* *HP: … I think coming here, he was being treated with the respect and erm some dignity. I don't know about home life, but erm from here I would say that he erm – he'd be happy with most of the time.*	CP: identical rating to patient of able to maintain dignity and self-respect most of the time (4) HP: identical rating to patient of able to maintain dignity and self-respect most of the time (4)	CP: lower rating than patient of capability for independence in a few things (2) HP: lower rating than patient of capability for independence in a few things (2)	CP: identical rating to patient of slight problems with self care (2) HP: lower rating than patient of moderate problems with self care (3)
PT10	I like to go to concerts. So I'm not able to go to concerts at the moment…		CP: lower rating than patient of capability for	CP: lower rating than patient of severe

	CP: he's certainly got problems with the usual activities… he's a great one for going to symphony concerts … he's very inhibited in doing that now. I think he probably has severe problems in carrying out usual activities. *CP: Enjoyment and pleasure – well Peter's enjoyment and pleasure was him going to concerts and he's unable to go to concerts now so he's lost a lot there, he likes reading, he's quite an avid reader of books from the mobile library … he's able to continue doing that. but I think the fact that he can't take himself out very easily he's lost a lot of what he, what he enjoyed doing. … a lot of that enjoyment and pleasure has been reduced and I think probably he can have a little of that now.* *HP: I would have said he, he would, erm, have some problems doing usual activities [hmm], but I, I would say it was minimal. So I would say that he has slight problems* *HP: because I don't know him 100%, it's hard for me to say… I would say, probably, [patient] can have a little enjoyment and pleasure, would be my view, what I know of him, all right.*		a little enjoyment (2) HP: lower rating than patient of capability for a little enjoyment (2)	problems with usual activities (4) HP: identical rating to patient of slight problems with usual activities (2)
PT18	I used to cut the grass, the lawns, I used to do them both at the same time, do you know what I mean? Do one and then do the other. Now I just do one now and do the next one the next day. *CP: usual activities he has slight problems, he doesn't do it as often as he used to but he used to always wash up when I'd cooked and he stopped that… he has mowed the lawn which is his usual activity, he does one, one day and one another day* *CP: …at the moment I don't think he thinks he can achieve and progress in any aspects of life because as far as he's concerned life's finished, as he keeps telling me. I wish to God he could achieve in something and progress because that would mean he's looking on the positive side but he's not, he's looking on the*		CP: lower rating than patient of capability for achievement in no aspects of life (1) CP: higher rating than patient of capability for complete independence (4)	CP: higher rating than patient of slight problems with usual activities (2)

	negative side so no, he cannot achieve and progress while he's got this negativity about him. *CP: He would not be anything else but independent because he hates you doing things for him, he will not allow you to do things for him that he can do his self*			
PT21	It's all been hard to adapt, hasn't it, but it's that… It's so personal, having somebody to help with that. You can… you know, it's hard for everything, isn't it, but that's the worst, definitely. *CP: dignity… Oh yes, I would say that was most of the time. She wouldn't let anybody get away with er, not, yeah. Yeah, definitely.* *CP: Right, self care… moderate today. This is about an average day really. Erm…doesn't very often get better, erm but it does get worse, so yeah, yeah, moderate today.*	CP: identical rating to patient of able to maintain dignity and self-respect most of the time (4)		CP: identical rating to patient of moderate problems with self care (3)
PT26	I used to work in the gardens, but I can't even do that, the privet hedges, I used to do the neighbour's, but I can't even do that. So the grass is all grown. The privet's slightly growing. It's only because of the cold that's keeping it from growing… *CP: he hasn't worked since '95… when he retired then he did do all the housework, cooking, ironing, you name it… this has sort of deteriorated since coming out of hospital… he doesn't do any of that* *(No text in relation to capability for independence)*		CP: higher rating than patient of capability for independence in many things (3)	CP: lower rating than patient of severe problems with usual activities (4)
PT28	So I've done quite a few paintings now that I didn't realise I could do. And I do crossword puzzles or jigsaw puzzles or things like that. I make a lot of my own cards. Just to keep my mind active, and my fingers out of mischief,		CP: higher rating than patient of capability for achievement and progress in many	CP: lower rating than patient of severe problems with usual activities (4)

	like… I used to do loads of knitting and sewing … I can't do that any more … but, I do the best I can. *CP: Right, achievement and progress…I'd say in a few aspects of life. Many. No, oh I don't know. It's a toss between these two here now… I'll say that one, okay.* *CP: Enjoyment and pleasure She has … that one. We have quite a lot, we try to do little things … one thing we always find is we've got to keep your sense of humour, no matter what.* *CP: they have severe problems doing their activities, I'd say that because she still tries and she has to as we say go and sit because she wobbles everywhere…* *CP: [sighs] I'd say they can be slightly anxiety and depressed.*		things (although unsure between this and identical rating to patient) (3) CP: identical rating to patient of capability for quite a lot of enjoyment (3)	CP: lower rating than patient of slight anxiety or depression (2)
PT28	My health and my situation is restricting me from doing what I want to do … You just, er, phone 'em, or write to 'em, or whatever, and do the best you can *CP: They have quite a lot of love, friendship and support. Because she has got a lot of family and even if they're not around she'll phone, or they'll phone her, so they… So she knows there's always somebody around and I'm always on the other end of the phone anyway.* *CP: I'd say that one. They are able to be with people who care most of the time. Yeah. She's always got some of us around her, even if it's the little one driving her mad.*	CP: identical rating to the patient of able to be with people who care about her most of the time (4)	CP: identical rating to the patient of capability for quite a lot of love friendship and support (3)	