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“The ICECAP-SCM tells you more about what I’m going through” – A think aloud study measuring quality of life amongst patients receiving supportive and palliative care.”

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“The ICECAP-SCM tells you more about what I’m going through” – A think aloud study measuring quality of life amongst patients receiving supportive and palliative care.

Background: The ICECAP Supportive Care Measure (ICECAP-SCM) is a self-complete questionnaire developed to aid economic evaluation of supportive care interventions.

Aim: To determine the feasibility of completing ICECAP-SCM alongside EQ-5D-5L and ICECAP-A (generic measures used in economic evaluation) amongst patients receiving hospice care, close persons and healthcare professionals.

Design: Participants were asked to ‘think-aloud’ whilst completing ICECAP-SCM and two other generic measures used in economic evaluation, EQ-5D-5L and ICECAP-A, and then participate in a semi-structured interview. From verbatim transcripts, five raters identified the frequency of errors in comprehension, retrieval, judgement and response. Qualitative data were analysed using constant comparison.

Setting/participants: Eligible patients were identified from one UK hospice by a research nurse. Close persons and healthcare professionals were identified by the patient. 72 semi-structured interviews were conducted with patients (n=33), close persons (n=22) and healthcare professionals (n=17).

Results: Patients and close persons reported that the ICECAP-SCM was most appropriate for measuring their quality of life. It appeared more meaningful, easier to complete and had fewest errors (3.9% amongst patients, 4.5% amongst close persons) compared to EQ-5D-5L (9.7% amongst patients, 5.5% amongst close persons). Healthcare professionals acknowledged the value of the ICECAP-SCM but had fewer errors in completing **the EQ-**

5D-5L(3.5% versus 6.7%). **They** found it easier to complete because it focuses on observable health states.

Conclusions: The ICECAP-SCM is feasible to use and perceived as appropriate for evaluating palliative care interventions. Healthcare professionals with limited knowledge of the patient who act as proxy completers may find the measure difficult to complete.

Key Statements

What is already known about the topic?

- Measuring the quality of life at the end of life is complex
- Generic healthcare instruments currently used to measure the quality of life amongst patients receiving supportive and palliative care have been heavily criticised for lacking sensitivity to deteriorating healthcare states
- The ICECAP-SCM is an instrument that measures capability and sense of wellbeing developed for use in evaluation of palliative and supportive care interventions.

This is the first study that investigates the feasibility of using ICECAP-SCM in comparison to the measures traditionally used in economic evaluation (EQ-5D-5L and ICECAP-A) amongst patients receiving palliative care, their close persons and healthcare professionals working in the hospice.

What this paper adds?

- The study demonstrates that the ICECAP-SCM is a feasible tool to measure the quality of life amongst patients receiving supportive and palliative care, it assesses

attributes that are important to people at the end of life, is easy to complete and carries less risk of error in completion than EQ-5D-5L and ICECAP-A.

- The ICECAP-SCM is also a feasible measure for close persons to complete in terms of appropriateness and knowledge required for accurate completion.
- The ICECAP-SCM can be difficult for some healthcare professionals who may have limited knowledge about the patient.

Implications for practice, theory or policy.

- This paper provides insight into the measurement of quality of life for those approaching death, those close to them and those involved in their care.
- The ICECAP-SCM captures the subtleties required to measure the quality of end of life care more appropriately for patients and people close to them and may be useful in evaluating future palliative care interventions.
- The ICECAP-SCM is offered to researchers internationally for future research studies to measure end of life care appropriately, more easily and with less risk of error.

INTRODUCTION

The review of end of life care strategies across the UK¹, Australia² and Canada³, along with the identification of palliative care needs across Europe⁴ and the recent global mapping worldwide⁵ have led to increased interest in end of life care research. Some of this research is concerned with the effectiveness and cost-effectiveness of interventions and raises the question of measurement. Since the implementation of the National End of Life Care Strategy in the UK¹, there has been increased focus on providing better care at the end of life with independent hospices being major providers of that care. In the UK, hospices provide approximately 80% of all adult inpatient care beds, in addition to day care services and home care³⁸.

Meaningful information on outcomes in supportive and palliative care is required and it has been recognised that self-reported outcomes are particularly valuable⁶. A range of generic preference-based measures have been developed to assess cost-effectiveness of interventions within healthcare⁷ of which the most commonly used is EQ-5D-5L⁸⁻⁹. However, generic measures have been criticised for their sparse descriptive capacity¹⁰⁻¹². Their tendency to focus exclusively on health is also perceived by many as inadequate for informing decision making in advanced progressive illness and at the end of life¹³⁻¹⁵.

There are alternative measures for economic evaluation being developed based on Amartya Sen's capability approach¹⁶⁻¹⁷ which encourage a broad evaluative space through a focus on what a person feels able to do and who they are able to be. These include measures which assess the ability of a person to achieve a good life¹⁸⁻¹⁹ and achieve a good death²⁰. We do not know, however, whether it is feasible or acceptable for people at the end of life to complete these instruments. Whilst information from individuals themselves is important for

credible and trustworthy evaluation in research, it may be difficult to ask patients to complete such measures directly either because of fears of causing distress²¹ or because of fluctuating capacity and the frequently changing condition of people who are extremely ill. It is therefore important to ascertain whether such measures can also be completed by potential proxies including both those close to the patient and health professionals.

The aim of this study was to understand how people at end of life complete measures that might be useful in economic evaluation of health interventions, explore any difficulties in completion, and ascertain views about the different measures. This paper reports the findings from the study focusing on the completion of three measures by patients receiving hospice care, by family and friends close to the person at end of life ('close persons') and by health professionals. The three measures considered are EQ-5D-5L which assesses health status²², ICECAP-A which is a generic measure of capability well-being for adults¹⁸, and ICECAP-SCM which is a generic measure of capability in relation to end of life²⁰.

METHODS

This was a ‘think aloud’ study²³⁻²⁵ in combination with semi-structured interviews²⁶. A think aloud study is a cognitive interview; the patient is asked to verbalise his or her thoughts whilst completing a task (here, completing the three outcome measures). The think aloud approach enables the evaluation of the meaning of individuals’ answers and the degree to which individuals encounter problems in completing the measure as well as the nature of these completion problems. The research was conducted under the guidance of the Ethics Group for the EconEndLife research programme as part of an European Economic Research Council Fellowship (ref) and gained ethics approval from North Wales NHS Research Ethics Committee - West (ref: 12/WA/0076).

Sampling & recruitment

Numbers used in think aloud studies are variable. Two previous think aloud studies of capability measures have been conducted, one with 20 individuals²⁷ and the other with 50²⁸. In this study, we sampled to obtain sufficient numbers both to make sense of the scoring for the think aloud and to reach saturation²⁶ in the semi-structured element of the interview. It was anticipated that up to 35 patient, 20 health professional and 20 close person interviews would be required to achieve saturation.

Participants were recruited through a hospice from the community service, day hospice and in-patient settings. The hospice provided care in day hospice, in-patient and community services for people who were receiving specialist palliative care for any advanced progressive illness. It is based in a semi-urban location and the care it provides is typical of palliative care services nationally in the UK. Annually it has 400 hospice inpatients, 475 patients under the

community palliative care team and 120 patients within the hospice day centre. Patients were recruited purposively from each of these areas to enable the recruitment of people at different stages in their illnesses and at different levels of dependency²⁹⁻³¹. Patients were identified by the research nurse at the hospice (RP) who assessed eligibility and made initial contact and introduced the study; if a person was interested in participating, full study information was then provided by the researcher (CB, RO or PK). To enable all types of patients to participate, the inclusion criteria were broad; patients had to be receiving care through the hospice for an advanced progressive illness, consent to participate and be able to communicate in the English language (as the questionnaire is at this stage only available in English). Patients consented to their own participation and were asked to nominate, and consent to the participation of, close persons and health professionals who they felt would know them well enough to be able to complete the measure on their behalf. These potential proxies were then approached and consented separately. In cases where potential participants lacked capacity, a personal consultee could be appointed to enable approaches to be made to close persons and/or health professionals. In practice, this was not required.

Instruments investigated

EQ-5D-5L

The EQ-5D-5L is a measure of health status commonly used in economic evaluation⁸. The National Institute for Health and Clinical Excellence (NICE) recommend the use of EQ-5D-5L to assess the benefits of health and social care interventions³² because it has been weighted according to the social preferences of the UK population. It has five attributes each with five levels ranging from no problem to extreme problems. The five attributes of mobility, self-care, usual activities, pain/discomfort and anxiety/depression are used to ask about the participant's health state 'today'.

ICECAP-A

The ICECAP-A is a relatively new measure of capability wellbeing,^{18, 34} which is starting to be used for economic evaluation and has recently been recommended by NICE as an option for evaluating the impact of social care interventions³⁷. Participants are asked to rate aspects of quality of life ‘at the moment’ across five areas: stability (able to feel settled and secure); attachment (able to have love, friendship and support); autonomy (able to be independent); achievement (able to achieve and progress); and enjoyment (able to have enjoyment and pleasure). There are 4 response levels to each attribute ranging from 1 (no capability), through 2 (a little) and 3 (much), to 4 (full capability). Validity and reliability of the ICECAP-A in the general population have been established^{33, 39} but it has not previously been used with those at end of life. The ICECAP-A is available to view at

<http://www.birmingham.ac.uk/research/activity/mds/projects/HaPS/HE/ICECAP/ICECAP-A/index.aspx>

ICECAP-SCM

The ICECAP-Supportive Care Measure (ICECAP-SCM)²⁰, is a capability wellbeing instrument developed for use in evaluation of palliative and supportive care interventions. The focus of the measure is to assess whether individuals have the opportunity for a good death²⁰. The instrument has seven attributes derived from qualitative data collected from those at various stages along the trajectory towards death. Participants are asked to indicate their wellbeing “at the moment” in terms of: choice (being able to have a say); love (being able to be with people who care about you), freedom from physical suffering, freedom from emotional suffering, dignity (being able to maintain dignity and self-respect), support (able to have help and support) and preparation (having the opportunity to make preparations)²⁰. There are 4 response levels to each attribute ranging from no capability (1) through a little

capability (2), some capability (3) to full capability, generally expressed as experiencing a lot of an attribute (4). The ICECAP-SCM is available to view at

<http://www.birmingham.ac.uk/research/activity/mds/projects/HaPS/HE/ICECAP/Evaluation-of-End-of-Life-Care/ICECAP-SCM.aspx>

Data collection

Interviews took place at the hospice or another place of the informant's choosing. Clearly the subject of the interviews was a sensitive one, and efforts were made to ensure that patients were comfortable with the interviewer and that support was available during and after the interview from trained professionals. There were three interviewers (CB, PK and RO). Interviewers were either experienced in dealing with patients (pharmacist, nurse) and/or had previous experience of conducting research interviews on sensitive topics. None had any prior contact with any participants. Interviews began with collection of basic socio-demographic information and a warm up exercise to practice the think aloud technique³⁵. All three groups were then asked to complete the three questionnaires about the patient's health and wellbeing as perceived from the patient's perspective. Close persons and healthcare professionals were asked to concurrently verbalise their thoughts during the completion of the measures, using the 'think aloud' technique. If informants were silent for longer than 10 seconds they were prompted to "keep thinking aloud". The order of questionnaires was randomly allocated except where it was anticipated the patient may not be able to complete all three. In this case, the ICECAP-SCM was presented first, given that exploration of this particular instrument was the primary aim of the research. Following completion of all the questionnaires, a semi-structured portion of the interview explored informants' views about the questionnaires and the process of completion, focusing on issues such as the clarity of

instructions, the ease of answering, the sensitivity of the questions, interactions between the measures, and the ability of the questionnaires to capture the person's health and quality of life. Informants were given the opportunity to stop the interview at any point and particular attention was paid by interviewers to whether the informant was distressed or fatigued.

Data analysis

All interviews were digitally audio-recorded, fully transcribed, and analysed in two ways. First, the segments of the transcript relating to the completion of items on each of the questionnaires were separated by questionnaire and item. This was then presented to five independent raters (CB, JC, PK, KA, LJ) in conjunction with information about the scores given by the informants. Raters were asked to identify, in relation to each segment, whether: (a) it was free of error, OR (b) any one of four types of response problem was present - comprehension (understanding the question in the way that the researcher intended); retrieval (successfully retrieving the appropriate information to answer the question from long-term memory); judgement (correctly judging how the recalled information should be used to answer the question) and response (providing a valid response to the questionnaire)³⁶ OR (c) there was no error, but the informant had experienced 'struggle' in arriving at their response²⁸. Examples of the different errors can be found in Appendix 1. Where three or more raters identified the same error, this was automatically coded as an error of that type. Where three or more raters identified an error but classified the error types differently, the error was discussed and consensus about the nature of the error was agreed amongst the research team. Where two raters identified an error, this was also discussed amongst the research team to ensure that errors were not being missed. Where errors were indicated by only one rater or where no raters indicated an error, this was classified as not an error without

further discussion. Error rates are presented as percentages for comparability, given that ICECAP-SCM contains more items than the other two measures.

Constant comparative methods were used to analyse the interview data. Transcripts were read and re-read, and categories and sub-categories developed to describe emerging themes²⁶. NVivo10 was used to organise and manage the data (CB). Associations, relationships and models were developed from the original nodes (CB and JC) and used to provide insight into the measure completion and cause of errors. Transcriptions were not returned to participants due to the unnecessary distress this may have caused, particularly if a patient's state had worsened considerably.

FINDINGS

Interviews were conducted between October 2012 and February 2014. Eighty two eligible patients were approached to take part; of these 33 agreed. Among the 49 who chose not to participate, 17 felt too unwell or fatigued, 14 felt it 'was not for them', four had recently participated in other studies and one did not want to be audio-recorded. Thirteen gave no reason. From the 33 consenting patients, 22 close person and 17 health professional interviews were generated. Consent rates for close persons and healthcare professionals are not meaningful to present as patients had frequently already obtained consent informally before identifying the relevant persons to the research team: any reported figures would therefore be artificially high and, indeed, almost no close persons or healthcare professionals subsequently refused a request for interview. Overall there were 72 interviews available for analysis. At this point, analysis of the qualitative data suggested that saturation within themes was achieved and recruitment was stopped. Characteristics of individual patients, close persons and health professionals are given in table 1. The length of interviews varied between 20 and 45 minutes.

Patient measure completion

All patients completed the ICECAP- SCM and in most cases also completed the ICECAP-A and EQ-5D. Error (including struggle) rates are given in table 2. There were some errors on all measures although the type of errors differed across the three measures as shown in table 3. The smallest percentage of errors was in completion of the ICECAP-SCM for which the absolute number of errors was also smaller, despite the larger number of attributes and the higher completion rate (9 compared with 16 for EQ-5D-5L and 12 for ICECAP-A). One attribute within ICECAP-SCM was entirely error free (Support); the

attribute generating most errors was 'Preparation'. As well as having four errors, the item 'Preparation' also had two instances of non-completion. It seemed that the major problem with completing this item arose from the difficulty in discussing advance care and funeral planning with people who are close:

That's a difficult one, 'being prepared.' The financial affairs are in order. We haven't got the funeral planned, because my wife won't talk about it. She won't talk about how she'll manage with the money if she was left on her own. She don't want to know (PT27).

This was also the attribute where there was the greatest distinction made by informants between their capability (what they are able to do) and their functioning (what they do or have done):

That's a difficult one. It's not really that I haven't had the opportunity; the opportunity's been there, it's just that I haven't done anything yet (PT22).

I've thought about it, but I've never gone to do anything about it... I don't know what to put there...I'll have to go for that one ... (PT17).

The attributes of the ICECAP-SCM appeared to be understood by all participants and completion was found to be feasible within all groups, including those inpatients very near the end of life. The measure was perceived by patients as being able to accurately and appropriately record their quality of life and on the whole patients preferred it compared to the other measures.

It [ICECAP-SCM] seems like a better choice than the other two, because, it's more about me, what I'm really like (PT26).

That [ICECAP-SCM] tells you more about what I'm going through (PT27)

Those at the very end of life (those in the inpatient unit, n=14) felt the ICECAP-SCM was most relevant to their situation, whilst those at earlier preferred the ICECAP-A; few appeared to express a preference for EQ-5D-5L as the most appropriate measure.

This questionnaire [ICECAP-SCM] is designed, I guess, for someone in a specific situation where they're, maybe, in the last run-in, they're in a hospice situation...an in-patient and I'm not, so it may not be applicable to all. Well, it won't be (PT06).

That [EQ-5D-5L] is for somebody who's not really, you know, in a bad way at all, isn't it? (PT09)

One aspect of both ICECAP-SCM and ICECAP-A that was seen as advantageous relative to EQ-5D-5L is that they ask about how a person is 'at the moment' rather than 'today'. Because of the highly fluctuating nature of patients' conditions, they found answering questions about 'today' quite difficult at times:

I'd best put 'moderate pain' because it comes in bouts, it isn't constant, my pain (PT12: EQ-5D-5L).

Patients also expressed concern over the 'usual activities' on the EQ-5D-5L, asking for clarification about whether usual activities related to what had been usual pre-diagnosis or what was usual now.

What do you mean by usual activities? Usual before I was diagnosed or usual compared with the last year? A very tricky question (PT06: EQ-5D-5L)

Close Person Completion

Completion of the measures amongst close persons was similar to that for patients. Fewest errors were found on the ICECAP-SCM and most errors were made in completion of

the EQ-5D-5L (See table 2). Close persons were more likely to view the ICECAP-SCM as the most appropriate of the measures in relation to their loved ones' quality of life.

Generally perceptions of the ICECAP-SCM were positive, with it being described as 'open', 'more appropriate' 'timely' and 'most important'.

I think those [questions on the ICECAP-SCM] those are important questions (CP15)

It seems to have everything on it with care, being with people who care, physical suffering, emotional suffering, it's all those really. (CP27).

Some close persons found completion of ICECAP-SCM more upsetting than that of EQ-5D-5L as they reflected on how their loved one had changed over the period of their illness.

One or two were, but not difficult, it's an emotional time ... it reminds me when you are asked, 'Are they unable to do anything for themselves?' for argument's sake. ... it spells it out more clearly to you that that it's happened, it's happening, and it's never going to change now (CP05).

Others felt that some ICECAP-A questions appeared 'inappropriate' and 'insensitive' for people within the hospice setting.

I think the, that last one there [ICECAP-A], would be the least appropriate for me... where he's in a hospice. He's completely reliant on other people. He can't do any of the things that would have given him pleasure and such like... those things don't relate to him in the same way as they might relate to us. (CP34).

As with patients, the timeframe for EQ-5D-5L was perceived as problematic because of the rapid fluctuation of symptoms such as pain and nausea.

Well at the moment he's between two things really, one minute he'll be quite positive, and then another time he can be really depressed (CP26).

It was clear that the accuracy and ease with which the scale could be completed, depended on the relationship of the 'close person' to the patient.

He keeps it very close to his chest about his emotions, and I don't get it very often. So when I get it he is really very down, and that only happens when he's in pain (CP06).

Unsurprisingly, given the patient findings, the ICECAP-SCM preparation question, which focuses on being prepared, financial affairs and funeral plans, was perceived as problematic for some close persons. Nevertheless, only one error resulted here, from lack of information.

She doesn't talk about funerals. She doesn't talk about anything in that department, and I would not, as a friend, go into that. I know [patient name] is okay. I should imagine if I'm sitting here, [patient name] would say to me, 'I've got it sorted', but she wouldn't go into details with me (CP08 - friend)

I had to struggle with some of them because I'm not, I'm not close enough to him (CP10 – neighbour).

Other close persons, especially spouses, were more confident in answering.

The opportunity is there and it always will be within the family and friends for anything that he wishes... he likes the way down south in America they have the funeral with the jazz band... On the recording you can't see that I'm smiling, but we were only discussing it yesterday afternoon in the garden. (CP09 - wife).

Health Professional Completion

Whilst all health professionals were nominated by the patient on the basis that they knew them, it was apparent that some had more in-depth knowledge of their patient than others. This made answering some questions difficult for some health professionals, especially questions on the ICECAP-SCM that were perceived as more “subjective”.

“They [on the ICECAP-SCM] were a bit more subjective, I think that’s the right word, you know, feelings and pleasure” (HP34 -Medical Doctor, Core Trainee).

“I think in this clinic area, we’re a little bit more focused on the task and the treatment that we’re providing. Even though we do look outside of that, we have to stay in a certain structure, I suppose. So that’s[ICECAP-SCM] quite hard to – to answer some of those” (HP07-Hospice Consultant) .

This was in contrast to EQ-5D-5L, where health professionals who only saw patients less frequently at clinic or day hospice were more confident in their response.

“the EQ-5D is more straightforward to answer because it's more like mobility, self-care, usual activity and pain discomfort, where it was more straightforward” (HP04- Day Hospice Staff Nurse).

Generally, the nurses (n=7) and one experienced healthcare assistant that participated tended to have a more holistic view of the patient and were able to answer quite confidently and without errors or struggle. Doctors (n=8) completing the measure, tended to focus more on managing symptoms.

“It’s knowing her better, maybe having seen her in a different environment, I think it makes a difference. I’ve seen her in her environment, it’s a lot more personal” (HP08 - Community Clinical Nurse Specialist).

The one social worker who completed the measure focused largely on the patient’s social care.

Health professionals were aware that their knowledge of the patients was limited by their tending to see them at particular times and in different settings, such as when they attended day hospice or as an inpatient during a crisis.

“It’s not like I’m a wife or a husband or mother of somebody who you’re with a lot of the time and you see their ups and downs. The fact that they’re here (day hospice) often means they’re feeling a bit better anyway. So I tend to see her when she’s in a better mood” (HP04 – Day Hospice Staff Nurse)

“some of these things are perhaps things that we’ve never specifically discussed in our clinic” (H09 – Hospice speciality doctor).

Health professionals were also aware that it was difficult to get to know some patients well, either because of their personality, or because of the illness trajectory.

“Whilst I know on the day-to-day basis what his issues are I haven’t been able to find out exactly how he feels about life and his situation at the moment... some people give more information than others” (HP10 - Community Macmillan Nurse).

Inevitably these influences on knowledge affected how well health professionals could answer questions, and some errors were made due to lack of knowledge.

I have to say that I don't know, having only just started to talk about those things with [patient name] (HP08 – Community Clinical Nurse Specialist).

Despite difficulties in answering some ICECAP-SCM questions, health professionals felt that it contained appropriate attributes for assessing end of life.

“I think it [ICECAP-SCM] would be good, because these are some things that we don't actually very often ask our patients... I quite like those questions” (HP34 - Hospice Speciality Doctor).

On the other hand, the EQ-5D-5L was felt to be restrictive and would result in a more negative view of quality of life than experienced by the patient.

“It looks [at] what people can actually do, that is only a very small factor of quality of life. I see it as involving lots of other things” (HP34 -Medical Doctor, Core Trainee)

As with close persons, health professionals were concerned about some attributes of ICECAP-A in the context of end of life care, particularly in relation to the Achievement attribute.

“I think an awful lot of people see a series of losses that they don't really have time to adjust to as they go along, so it's a difficult one” (HP23 - Hospice Speciality Doctor.

“I don't like that question because the general trend is they are deteriorating anyway. They can't achieve and progress and that feels harsh to say” (HP13 – Consultant).

Having had the experience of looking after many patients at different stages in their illness, health professionals also tended to place their patients on a trajectory, comparing them to others who experience better or worse quality of life.

“I suppose I am seeing other patients that have or are able to do much less and enjoy much less (HP34 -Medical doctor, Core Trainee)”

DISCUSSION

This paper has examined the ability of patients at different stages on the trajectory towards death, those close to them and those caring for them, to complete three measures that could potentially be used in economic evaluation of care at the end of life. There were some errors in completion of all three instruments. Amongst patients, the ICECAP-SCM had the lowest proportion of errors, around half of that for ICECAP-A and around a third of that for EQ-5D-5L. There was little variation in error rates between the three measures for close persons, although that for ICECAP-SCM was marginally lower. In contrast, among health professionals, error rates were highest for ICECAP-SCM, with around twice as many errors as for EQ-5D-5L. This increase in errors amongst this group seemed to relate largely to the level of knowledge about a patient. This suggests that careful targeting of those health professionals who have the best knowledge of the patient is important if the measure is to be completed by this group.

This is the first study to consider error rates in completion of these three instruments in the end of life setting, the first to consider error rates in completion of ICECAP-SCM, and the first to explore error rates in completion by proxies in this setting. There is therefore a limited literature with which to compare the findings obtained here. The only study that has compared self-completion of ICECAP-A and EQ-5D-5L using a similar method is that conducted amongst the general population by Al-Janabi et al²³. Error rates found across the two studies were not dissimilar, with the patient error rate for ICECAP-A here of 7.3% being slightly lower than that in the general population (9.4%) and the error rate for EQ-5D-5L here of 9.7% being marginally higher than that for the general population (8.8%). This suggests that completion of these instruments in a population of patients at the end of life is no more prone to error than their completion amongst members of the general public.

The study has a number of strengths, but also some limitations. It comprehensively covers all those who might be asked to complete instruments about patient health and wellbeing at the end of life. The study was conducted using a rigorous process for error identification and the number of raters was higher than in other similar studies^{27, 28}. The inclusion of further discussion in the interview after the conduct of the thinkaloud exercise allowed issues of completion to be explored, and this has helped to provide interpretation around the feasibility of completion of these measures. There are, however, also limitations in the study. For the most severely ill patients it was not always possible to collect information on all measures; for this group, the order of measures was also not randomised and this may have resulted in lower error rates for ICECAP-SCM than the other measures in this group if error making is associated with fatigue. Given that this non-random allocation only occurred in three cases, it is unlikely to have had a major influence on the findings. A second limitation arises because patients were sampled at one site and only through the hospice setting, a place for end of life care that is more associated with some trajectories towards death than others. The majority of patients in this study had a cancer diagnosis. Patients experiencing sudden death, for example, are very unlikely to be cared for in a hospice setting, and, currently, this is also the case for those experiencing trajectories associated with organ failure or a lengthy decline into frailty. Further work is in progress to explore the feasibility of completion amongst these groups. A third limitation is that all participants recruited to the study identified their ethnicity as white-British. Research into the feasibility of ICECAP-SCM amongst other ethnic groups would be valuable.

Despite the limitations, this work suggests that each of these measures can be completed with a relatively low number of errors by both patients and their potential proxies. Given this, the question as to which of these measures to use in empirical studies, may relate more to which measures are found by patients to relate appropriately to their situation, which are

found to be sensitive to change and, importantly, the normative framework within which the economic evaluation is being conducted. This paper offers some suggestion that the ICECAP-SCM was seen positively by patients and those caring for them; as yet, however, there is no information as to construct validity, reliability and sensitivity to change, and further research is needed in this area. Nevertheless, for those conducting economic evaluation within a capability framework in which the purpose of end of life care is seen as being to provide the opportunity for a good death, this measure offers a potential way forward, particularly for those near the very end of life. Similarly, for those working within a health maximisation framework, the EQ-5D-5L has relatively few errors, particularly when completed by a proxy; the instrument was, however, less favoured by patients.

Overall, this paper provides helpful evidence that it is feasible to use these measures with a patient population at the end of life, and that patients find the ICECAP-SCM, particularly, to be appropriate to their setting and context.

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