

An assessment of the construct validity of the icecap-o index of capability in Australian national transition care and clinical rehabilitation programmes

Ratcliffe J¹, Laver K², Couzner L², Quinn S¹, Crotty M²

¹ Flinders Clinical Effectiveness, Flinders University, Adelaide, South Australia

² Department of Rehabilitation and Aged Care, Flinders University, Adelaide, South Australia

Paper presented to the MRC HTMR Workshop on The use of ICECAP measures in clinical trials and economic evaluation

University of Birmingham, February 15th-16th 2011.

Corresponding author:

Julie Ratcliffe

Flinders Clinical Effectiveness

Flinders University

Bedford Park

South Australia

Tel +61 8 8275 1297

E-mail: julie.ratcliffe@flinders.edu.au

Abstract

Aims: The ICECAP-O index of capability is a new instrument designed to measure and value the quality of life of older people. Advantages of the ICECAP-O include its focus upon a broader concept of quality of life than health alone and its potential for application in economic evaluation across health, transition care and aged care sectors. This study aimed to determine the construct validity of the ICECAP-O in care transition and clinical rehabilitation programmes for older people.

Methods: A questionnaire containing the ICECAP-O was administered using a face to face interview mode of administration with patients participating in in-patient medical rehabilitation (n=100), out-patient day rehabilitation (n=55) and the Australian National Transition Care Programme (n=26). The relationships between the ICECAP and other instruments including the EQ-5D, Herth Hope Index, Modified Rankin Scale (a measure of disability completed by the health care professional), CTM-3 (quality of care transitions) and socio-demographic characteristics were examined.

Results: The mean ICECAP-O scores for all three groups were broadly similar (in-patient; mean 0.759, range 0.390-1.000; out-patient mean 0.815, range 0.410-1.000; transition care mean 0.788, range 0.436-1.000). The ICECAP-O was found to be inversely correlated with the Modified Rankin Scale (Spearman's $r = -0.286$; $P < 0.01$) indicating that as the level of disability increased, capability decreased. The ICECAP was also found to be positively correlated with the EQ5D (Spearman's $r = 0.418$; $P < 0.01$) and the Herth Hope index (Spearman's $r = 0.402$; $P < 0.01$) and positively correlated with the quality of care transitions as measured by the CTM-3 instrument (Spearman's $r = 0.259$; $P = 0.0291$). The distribution of responses to the ICECAP-O indicated that whilst the majority of participants reported high levels of love and friendship, many participants expressed some concern about their future and reported limitations in their independence and ability to do things that made them feel valued. In general, participants reported more problems in relation to the physical dimensions of the EQ-5D (mobility, self care and usual activities) and EQ-5D values were on average well below general population norm levels for this age group (mean 0.53, SD 0.32).

Conclusion: The findings from this study demonstrate the strong empirical relationships between the concepts of health, disability, hope and capability and provide support for the construct validity of the ICECAP-O in clinical rehabilitation and transition care settings. Relationships between the ICECAP-O and other measures were mostly as anticipated indicating that whilst health related



quality of life and hope were positively associated with capability, the level of disability and older person's perceptions of poor quality care transitions impacted negatively upon capability. The ICECAP-O shows promise in providing a new and rigorous approach to the measurement and valuation of quality of life for future application in economic evaluation across health, transition care and aged care sectors.

Introduction

Population ageing is a phenomenon taking place in almost every country and region throughout the world and the population of Australia is no exception. Currently approximately 2 million Australians (almost 10% of the total population) are aged 70 years and over and this figure is set to double during the next two decades. It is estimated that by 2045, one in four Australians will be aged 65 years or more and nearly one in ten will be 80 years or over [Productivity Commission, 2005]. This demographic transformation poses major challenges for public policy as many indicators suggest that ageing will exert substantial upward pressure on health and aged care expenditures in the coming decades [Australian Government Treasury, 2007]. A recent influential policy report by the National Health and Hospital Reform Commission, established by the Australian Federal Government to develop a long-term health reform plan for a modern Australia, highlighted the current fragmentation between aged and health care services for older people and recommended improved integration between community and hospital sectors [National Health and Hospitals Reform Commission, 2009]. This policy report highlighted the need for common assessment and evaluation tools across health and aged care services, calling for a single common integrated assessment approach to the provision and evaluation of services. Health care policy makers within the United Kingdom, Canada and the United States have also called for greater integration between health, social and aged care sectors for older people, suggesting that this will lead to improvements in their health, independence and well-being [Glendinning, 2003, Department of Health, 2001, MacAdam, 2009, Kodner, 2006].

In the quest for greater integration between sectors, economic evaluation tools that can be used to facilitate resource allocation decision-making across sectors will be required. Traditionally health related utility measures, principally the quality adjusted life year (QALY), have been utilised to value the benefits of health care services and programs within the framework of economic evaluation [Weinstein et al, 2009]. However, QALYs have been criticised for their focus upon health alone as many health and aged care services impact upon quality of life more broadly [Higginson and Carr,



2001]. For example, rehabilitation interventions may include education, problem solving and the provision of aids, e.g. electric wheelchairs and walking aids, in order to promote independent living. Whilst the provision of these interventions may have little or no impact upon health, they may lead to significant improvements in an individual's quality of life [Hopman and Verner, 2003]. These improvements may not be reflected by the traditional approach to cost utility analyses which incorporates QALY's as the main measure of outcome.

The Index of Capability for older people (ICECAP-O) is a recently developed instrument for measuring and valuing the benefits of health and social care interventions within an economic evaluation context. The ICECAP-O focuses upon quality of life more broadly rather than health alone and therefore has the potential to be utilised in the economic evaluation of health and aged care services in Australia and internationally [Coast et al, 2008a]. The developers of the ICECAP-O aimed to identify the attributes that were most important to older people in determining their quality of life through a review of the literature and interviews with older people [Grewal et al, 2006]. A set of functioning's that were most important to people were developed, namely; attachment (feelings of love, friendship and companionship), role (having a purpose that is valued), enjoyment (having a sense of pleasure and joy from personal and communal activities), security (feeling safe and secure and not having to worry) and control (being independent and able to make one's own decisions). Coast et al. discovered it was the person's capability to achieve these functioning's, rather than their level of functioning *per se*, which determined their quality of life. Thus, while an individual's state of health impacts on capability, it is not the sole determining factor. The ICECAP-O has the potential for application across the health and aged care sectors in comparing the value of different interventions to older people; including services that may improve quality of life without necessarily improving health (e.g. electric wheelchairs, meals on wheels and carer respite services), and interventions that improve both quality of life and health (e.g. joint arthroplasty and antidepressant medication). The developers of the ICECAP-O have provided early evidence for the construct validity of the ICECAP-O measure [Coast et al., 2008b]. The instrument has a preference based scoring algorithm which was developed by applying best-worst scaling discrete choice experiment [DCE] methods to value quality of life states defined by the ICECAP-O with a representative sample of older people aged 65 years and over [Coast et al, 2008a].



Presently, the most popular mechanism for estimating QALYs within the context of economic evaluation is to employ generic preference based measures of health. The EQ-5D is one of the most widely applied generic preference based measures of health which has been applied both within Australia and internationally [EuroQol group, 2004; Brazier et al, 2007]. Its purported advantages include its simplicity, brevity and its ability to be applied across all patient groups in a variety of settings. The EQ-5D has been applied previously in a number of studies focused specifically on older people [Brazier et al 1996; Coast et al, 1998; Holland et al, 2005]. A previous community based study by Coast and colleagues found a strong relationship between aspects of health, as measured by the EQ-5D and aspects of capability [Coast et al, 2008b].

The Herth Hope Index (Appendix 1) is designed to measure the concept of hope [Herth, 1992]. Hope can be defined as 'a positive motivational state that is based on an interactively derived sense of successful goal directed energy and planning to meet goals' [Snyder et al., 1991]. Several studies have found a positive correlation between hope and quality of life in a variety of patient populations [Davis, 2005, Sigstad et al, 2005, Yadav, 2010, Evangelista et al, 2003]. It has been found that individuals recovering from major health events including heart failure and stroke report higher levels of hope than healthy individuals from the general population [Rustoen et al., 2005, Laver, 2009]. The concept of hope is thought to play a central role in rehabilitation as individuals with higher levels of hope have been found to perform better in terms of setting and achieving their rehabilitation goals [Snyder et al., 2006]. The Herth Hope Index consists of 12 statements each with a 4 point Likert scale. The tool is scored using a simple summative scoring system ranging from 12 [lowest hope] to 48 [highest hope]. The tool has demonstrated good construct validity [Herth, 1992] and internal consistency [Lin et al., 2003] and has been applied previously in a variety of clinical settings including palliative care [Benzein and Berg, 2005] and organ transplantation [Evangelista et al, 2003]. The relationship between hope and capability has not previously been well documented. However, it is plausible to expect that hope may also impact positively upon capability.

The Modified Rankin Scale (Appendix 2) is an instrument which describes global disability, including basic activities of daily living (for example walking, dressing) and instrumental activities of daily living (for example shopping, meal preparation) [Van Swieten et al, 1988]. The Modified Rankin Scale is commonly applied in post-acute and rehabilitation sectors and is scored by a health care



professional who determines a global score based on interview style questions with the participant regarding their level of independence in various activities. The participant is assigned a score ranging from 0 (no symptoms at all) to 5 (severe disability). The Modified Rankin Scale has demonstrated construct and convergent validity, and good test-retest reliability in clinical rehabilitation settings [Banks and Marotta, 2007].

The Care Transitions Measure (CTM-3) is a validated instrument that has been developed to capture the essential domains of successful care transitions from the perspective of the patient [Parry et al, 2008] (Appendix 2). The measure originated from qualitative analysis of focus group discussions reflecting the actual experiences of older persons with chronic illness and their caregivers who had recently made transitions between different care settings. Respondents use a Likert scale (strongly disagree, disagree, agree, strongly agree, and don't know/don't remember/not applicable) to respond to the measure which contains the following three statements: 1. The hospital staff took my preferences and those of my family or caregiver into account in deciding what my healthcare needs would be when I left the hospital 2. When I left the hospital, I had a good understanding of the things I was responsible for in managing my health. 3. When I left the hospital, I clearly understood the purpose for taking each of my medications. The responses to each statement are coded and transformed to give a total CTM-3 score ranging from 0 to 100 with higher scores reflecting a better quality of care transition. The relationship between the quality of care transitions and capability has not previously been examined. However, as with the concept of hope, it is plausible to expect that the quality of care transitions may also impact positively upon capability.

During an episode of illness, patients may require care from different practitioners in multiple settings. This is particularly the case for older people as they often suffer from chronic illnesses. For example, in a given month, an older person may receive care from his or her general practitioner, a specialist clinician and nursing team during an inpatient admission, a different clinician and nursing team during a brief stay in a rehabilitation facility and finally, from a visiting nurse practitioner in the community. These situations may often lead to fragmented care where different components of the health and aged care sectors (e.g. different professionals and different institutions) work independently of one another, or worse, at cross purposes. It has been noted that when multiple providers operate independently with no single plan of care, older patients in particular may be adversely affected, experiencing so called "transfer trauma". This fragmented care can result in conflicting recommendations regarding self-management of chronic disease, confusing medication



regimes with a high potential for error and duplication, inadequate follow-up care and support and inadequate patient and caregiver preparation to receive care at the next healthcare setting. The Australian National Transition Care Programme was established in 2005 with the aim of improving care transitions for older people at the end of an inpatient hospital episode. Transition care is characterized as goal-oriented, time limited, therapy focused, and necessary to complete the care recipient's restorative process, optimize their functional capacity, and assist them and their families to make long term arrangements for their care in the community or in a residential care facility. Transition care can be provided for a period of up to 12 weeks, with a possibility to extend to 18 weeks if an older person is assessed as needing an extra period of therapeutic care. An older person must be assessed by an Aged Care Assessment Team as someone who would be suitable for transition care. This includes consideration their ability to benefit from the services transition care offers (eg low intensity therapy including physiotherapy and occupational therapy) within the allowable time limits.

Given that the ICECAP-O is a relatively new instrument it is important that further work is undertaken to trial the application of the instrument in different settings with populations of older people and to explore the relationship between the ICECAP-O and other instruments. This study aimed to determine the construct validity of the ICECAP-O in care transition and clinical rehabilitation programmes for older people in South Australia. The relationships between the ICECAP and other instruments including the EQ-5D, the Herth Hope Index, the Modified Rankin Scale, the CTM-3 care transitions measure and socio-demographic characteristics were examined.

Methods

Participants

Eligible patients participating in in-patient medical rehabilitation, out-patient day rehabilitation and the Australian National Transition Care programme were invited to participate in the study. To be eligible for inclusion, patients needed to have sufficient cognitive ability, determined by a Mini Mental State Examination score of 24 out of 30 [Folstein et al, 1975], and be able to communicate effectively enough to complete the questionnaire (as determined in consultation with their medical team including the speech pathologist). The study sample was obtained sequentially

over a four month period for in-patient rehabilitation and a six month period for out-patient day rehabilitation and the Australian National Transition Care programme.

Instruments

Two versions of a questionnaire were designed for administration as a face to face interview containing three main sections. Section A included a series of attitudinal statements reflecting the individual's attitudes towards and experiences of rehabilitation and care transitions, Section B comprised a discrete choice experiment, Section C comprised the ICECAP-O and EQ-5D plus either the Herth Hope Index (version 1: in-patient rehabilitation group) or the CTM-3 care transitions measure (version 2: out-patient day rehabilitation and transition care groups) and a series of socio-demographic questions. In addition to the self report tools, version 1 of the questionnaire included the Modified Rankin Scale [Van Swieten et al, 1988]. This instrument was designed to be completed by a health care professional directly involved in the provision of the participant's care. Basic socio-demographic information including age, gender, country of birth, living situation, diagnosis, income and level of education was also elicited.

Procedure

Ethics approval was sought and granted from the Flinders Clinical Research Ethics Committee, the Medical Advisory Committee from Griffiths Rehabilitation Hospital and Queen Elizabeth Hospital Ethics committees in South Australia. Patients who met the eligibility criteria were referred by key contact people at each hospital (triage staff or occupational therapists). All eligible patients were approached and provided with verbal and written information about the study. Informed consent to participate was gained prior to questionnaire completion.

Data Analysis

Data was analysed using SPSS version 17. The ICECAP-O and EQ5D were scored using the published UK general population algorithms pertaining to each instrument [Coast et al, 2008a, Dolan, 1997] and basic descriptive tests were used to provide a summary of respondent's characteristics. Chi-squared tests were used to examine the association between categorical

variables and Spearman's rho to examine the association between ordinal variables. A priori hypotheses were formed about the expected relationships between the ICECAP-O and the other measurement tools and socio-demographic data based upon previous assessments of validity for other measures and evidence of relationships from previously published studies (where available), and the views of the research team members where other evidence was not available.

Health

It was anticipated that there would be a strong relationship between health status and capability, supporting previously published studies presented by the developers of the ICECAP-O [Coast et al, 2008b, Grewal et al, 2006]. Specifically, that there would be a strong relationship between capability as measured by the ICECAP-O and health related quality of life as measured by the EQ-5D. It was hypothesised that the attributes of physical health [mobility, self care, usual activities] would be particularly strongly associated with capability. Similarly it was predicted that capability would be inversely related to disability as measured by the Modified Rankin Scale implying that as the level of disability increased, overall capability would decrease. It was hypothesised that the ICECAP-O attributes of control, role and enjoyment were more likely to be associated with health related quality of life than the attributes of security and attachment since the former attributes are more closely associated with physical health and disability.

Hope

Given the previous evidence linking higher levels of hope to improvements in quality of life and the finding that rehabilitation patients with higher levels of hope have been found to perform better in terms of setting and achieving their rehabilitation goals, it was hypothesised that people with higher levels of hope as measured by the Herth Hope Index, would also tend to report higher levels of capability. However, it is also possible that at least a proportion of individuals with higher reported levels of hope may also classify themselves in poorer health-related quality of life states and with lower levels of capability, given that hope is likely related to coping in times of ill health.

Quality of care transitions

Previous studies have indicated that there may be a positive relationship between the quality of care transitions and health related quality of life [Coleman et al 2004; Crotty et al 2008]. Given the strong

relationship between health status and capability previously identified, it was therefore anticipated that there may also be a positive relationship between the quality of care transitions and capability with those individuals who scored more highly on the CTM-3 exhibiting higher levels of capability according to the ICECAP-O.

Socio-demographic characteristics

Coast et al [2008b] in their previous community based study found strong relationships between socio-demographic characteristics and capability, particularly in relation to age and general well-being. However, it was predicted that age would not be found to be as strongly associated with capability in this clinical population since all of the study participants were fairly clinically homogeneous in terms of their significant levels of health impairment due to a recent experience of an acute episode of illness or disability. Given that older people may experience higher levels of social isolation, and it has been found previously that individuals who live alone are more likely to experience loneliness [Cattan et al, 2005; Iliffe et al 2007], it was predicted that there would be a significant association between the attachment, role and enjoyment attributes of the ICECAP-O and residential status with study participants living with others reporting higher levels for these attributes than those study participants who were living alone.

Results

A total of 196 individuals were approached for inclusion in the study of whom 181 (92%) agreed to participation. The characteristics of the study participants are presented in Table 1. A significant proportion, 41% (n=74), of the study participants had a diagnosis of stroke as their main reason for admission. The second most common reason for admission was bone fracture/joint replacement (16%, n=29). All of the remaining participants had a variety of diagnoses that could broadly be described as 'de-conditioning' or the effects of decreased physical activity following medical illness or non-surgical fracture. The majority of participants were females (60%, n=108) and the mean age of participants was 76 years (range 27-92) with the vast majority [88%, n=159] being 65 years or older. The mean EQ-5D score for the total sample was 0.526. Although the mean EQ-5D score for the group receiving transition care was lower than for the other two groups these differences were not found to be statistically significant (p=0.780). The mean EQ-5D scores for all three groups were substantially below the mean EQ-5D scores reported by Coast et al in their community based study

of older people ranging in age from 65 to 95 years (mean 0.76, SD 0.270) reflecting the significant levels of health impairment in this clinical population relative to community based samples. The distributions of responses to the ICECAP-O are presented in Table 2. It can be seen that while the vast majority of participants (88%, n=88) reported high levels of love and friendship (attachment), almost half of the participants (48%, n=48) expressed either 'some' or 'a lot of' concern about their future (security), 45% reported limitations in their independence (control) and 52% reported limitations in their ability to do things that made them feel valued (role).

Health

The distributions of responses to the EQ-5D are presented in Table 3. The majority of participants reported at least some problems in one or more dimensions. In general, participants reported more problems with the physical dimensions of the EQ-5D (mobility, self care and usual activities) which is consistent with what was expected for this clinical population. Table 4 illustrates that increases in mean EQ-5D scores were evident with increases in capability levels particularly pertaining to participants' ability to do valued activities (role), and improved levels of enjoyment and control. Similarly there were trends towards increasing mean EQ-5D scores as the levels of security and attachment increase. There is also a clear pattern of association between disability as classified by the Modified Rankin Scale and levels of enjoyment and control with increases in disability being associated with lower levels of enjoyment and control on average. Contrary to prior expectations, no clear relationship was found between the role attribute and the level of disability. However this finding may be a reflection of the relatively small number of individuals (n=6) reporting themselves at the lowest level of the role attribute. Table 5 illustrates that the ICECAP-O was found to be inversely correlated with the Modified Rankin Scale (Spearman's $r = -0.286$; $P < 0.01$) indicating that as the level of disability increased, capability decreased. The ICECAP was also found to be positively correlated with the EQ5D (Spearman's $r = 0.418$; $P < 0.01$) indicating that as the level of self-reported health status increased, capability increased.

The relationships between health, disability and each of the five capability attributes comprising the ICECAP-O (Table 6) indicates that as anticipated the individual capability attributes were found to be strongly related to total scores on the EQ5D, (with the notable exception of the role attribute of the ICECAP-O which was found to be unrelated ($p=0.898$)), further demonstrating that overall health status does impact upon capability. Overall, the individual responses to the EQ-5D dimension relating to usual activities exhibited the strongest association with responses to the individual

capability attributes, demonstrating statistically significant relationships with all five capability attributes. Disability as measured by the Modified Rankin Scale exhibited a strong association with the control attribute of the ICECAP-O and a weak association with the security attribute. However no significant associations were found between the Modified Rankin Scale scores and levels of attachment, role and enjoyment. The mean score for the EQ-5D was found to be 0.526 for the total sample and 0.538 for the sample aged 65 years or over (n=156). These mean scores are well below previously reported norm values from the general population in the UK of 0.78 for adults in the 65-74 years age group and 0.73 in the 75 + years age group [Kind et al, 1999]. The mean ICECAP-O score for this population was 0.779 for the total sample and 0.787 for those aged 65 years or over (n=151). This is lower than reported by Coast et al [2008a] who found a mean ICECAP score of 0.814 in a community based general population sample of older people. However the difference in mean values between this clinical population and the community based population is not as pronounced for the ICECAP as for the EQ-5D.

Hope

Table 4 illustrates that there was a clear pattern of increased mean Herth Hope Index scores with higher levels of the ICECAP-O indicating that, in general, individuals with higher levels of hope as measured by the Herth Hope Index, also reported higher levels of capability. However, it is important to note that the range of responses to the Herth Hope Index was relatively small (IQR 34.5-37) indicating relatively small levels of differentiation in levels of hope across this population. The ICECAP-O scores were found to be positively correlated with the Herth Hope Index (Table 5: Spearman's $r = 0.402$; $P < 0.01$) although only weak associations were found between two of the five attributes of the ICECAP-O and the Herth Hope Index (Table 6).

Quality of care transitions

In general, those participants categorising themselves in levels 3 and 4 for each capability attribute also tended to report lower quality of care transitions with lower mean CTM-3 scores (Table 4). As expected there was a positive correlation between the quality of care transitions as measured by the CTM-3 instrument and ICECAP-O scores (Table 5: Spearman's $r = 0.259$; $P = 0.049$). Weak associations were found between the role attribute of the ICECAP-O and the CTM-3 dimensions relating to the management of health and the purpose of medications (Table 6)

Socio-demographic characteristics

As expected Table 6 illustrates that there were no significant relationships between age and each of the five capability attributes in this clinical population. There was also a weak association between the role attribute of the ICECAP-O and residential status but contrary to prior expectations, neither attachment or enjoyment were found to have a statistically significant association with residential status. None of the remaining socio-demographic characteristics exhibited statistically significant associations with the individual attributes of the ICECAP-O instrument.

Discussion

The findings from this study demonstrate the strong empirical relationship between the concepts of health, hope and capability as measured by the EQ-5D, MRS, HHI and ICECAP-O and provide support for the construct validity of the ICECAP-O in a clinical rehabilitation setting. Although, as expected, participants reported lower levels of health related quality of life and capability than previously reported studies undertaken in the general population, the relationships between the ICECAP-O and other instruments were mostly as anticipated. The results indicate that health related quality of life, disability and hope were all strongly and positively associated with capability. The quality of care transition was also positively associated with capability with those individuals reporting higher quality of care transitions reporting higher levels of capability on average. Previous studies have highlighted that older adults moving between different healthcare settings are particularly vulnerable to receiving fragmented care and have indicated that there is a potentially strong relationship between quality of life and a reduction in fragmented care [Coleman, 2003; Sherman 2006]. The findings from this study provide support for this proposition.

This is the first study, to our knowledge, which has examined the construct validity of the ICECAP-O in a clinical setting. There are some similarities between our findings and the findings of Coast et al. [2008b] who examined the construct validity of the ICECAP-O in a general population community based sample in the UK. Coast et al. also found strong correlations between capability, disability and health status. There are however some important differences in findings. The UK general population study found a strong relationship between age and capability which was not found in this study. This is most likely due to the differences in the study samples. The participants in this study were generally in a poor health state, all recovering from an episode of acute illness. Their clinically homogenous nature may therefore have weakened the potential influence of socio-demographic



characteristics on capability in contrast to what may be expected in a relatively healthy community based general population sample.

There are several limitations to this study. Firstly, the sample size was relatively small. However, our total consent rate for participation of 92% was very high and therefore suggests good representation of older people from the South Australian clinical rehabilitation population. The second limitation is the inclusion of a minority of study participants [n=22] under 65 years of age given that the ICECAP-O was initially developed for use with older adults. At the time of the administration of this study, only the ICECAP-O instrument was publicly available. However, the instrument developers have since produced a capability index for all adults aged 18+ [the ICECAP-A] which may be more appropriate to use in further studies where younger people are also included. In addition, Australian general population specific scoring algorithms are currently being developed for both the EQ-5D [Cronin et al, 2009] and ICECAP-O [Flynn et al, 2010] instruments and future studies applying these instruments in an Australian context should attempt to apply these new country specific scoring algorithms once these become publicly available.

It is also important to highlight that whilst self report measures of health related quality of life are commonly used in clinical and economic evaluation, there may potentially be compromised validity of these measures in a proportion of this population of older people. Several studies have found that older patients with cognitive impairment may have difficulty understanding the concept of quality of life, and may lack insight into their functional ability [Novella et al., 2006, Hulme et al, 2004, Bryan et al, 2005]. In this study, a total of 19 participants were defined by the occupational therapist [applying the Modified Rankin Scale] as grade 4 – having a moderately severe disability [defined as being unable to walk and attend to own bodily needs without assistance] on the scale of 1 to 5 where 1=no symptoms at all and 5=severe disability. Despite this, one participant [n=1] within this group reported that they had no problems with self care, and, three participants [n=3] reported that they were able to be independent in many things. Further research is required to investigate the relationship between patient's own self report of health status and capability and the assessment of proxy assessors including family carers and/or health care professionals involved in the delivery of care.

Finally, this study was essentially opportunistic, the instruments being presented as part of a wider study to assess patient preferences for alternative rehabilitation programs. Therefore this study was

designed to elicit responses at one time point only. Further studies should be conducted in a clinical setting to apply the ICECAP-O with older people at more than one point in time in order to determine its sensitivity to change over time and to assess the test re-test reliability of the instrument.

Conclusion

In summary, the ICECAP-O shows promise in providing a new and rigorous approach to capturing the value of different interventions across health, social and aged care sectors. By focusing upon quality of life more broadly, the ICECAP-O offers new insights into the benefits of interventions which may be more appropriate than traditional measures of health for the economic evaluation of new innovations in aged care service delivery. The ICECAP-O instrument may be more widely applicable than traditional health focussed instruments in facilitating decision making regarding the allocation of scarce resources across health, social and aged care sectors. Whilst the findings from this study provide some support for the construct validity of the ICECAP-O in this particular patient population, further research is required to explore the construct validity of the ICECAP-O in other settings and with older people exhibiting different clinical characteristics.

Acknowledgements

The authors thank Professor Joanna Coast for her thoughtful comments on a previous version of this paper. The financial support from an Australian NHMRC Health Services Research Strategic Award Grant 402791 entitled 'Transition Care: Innovation and Evidence' is gratefully acknowledged.

References

- Australian Government Treasury 2007, *Intergenerational Report 2007*, Canberra.
- Banks J, & Marotta C. 2007. Outcomes validity and reliability of the modified rankin scale: implications for stroke clinical trials. *Stroke* **38**: 1091-1096.
- Benzein E, & Berg, A. 2005. The level of and relation between hope, hopelessness and fatigue in patients and family members in palliative care. *Palliative Medicine* **19**: 234-240.
- Brazier J, Walter S, Nicholl J, Kohler B. Using the SF-36 and Euroqol on an elderly population. *Quality of Life Research* 1996; 5: 195-204.



- Brazier J, Ratcliffe J, Salomon J, & Tsuchiya A. 2007. *Measuring and Valuing Health Benefits for Economic Evaluation*. Oxford: Oxford University Press.
- Bryan S, Hardyman W, Bentham P, Buckley A, & Laight A. 2005. Proxy completion of EQ-5D in patients with dementia. *Quality of Life Research* **14**: 107-118.
- Cattan M, White M, Bond J, & Learmouth A. 2005. Preventing social isolation and loneliness among older people: A systematic review of health promotion interventions. *Ageing and Society* **25**: 41-67.
- Coast J, Peters T, Richards S, Gunnell D. Use of the EuroQol among elderly acute patients. *Quality of Life Research* 1998; **7**: 1-10.
- Coast J, Flynn T, Natarajan L, Sproston K, Lewis J, Louviere J, & Peters T. 2008a. Valuing the ICECAP capability index for older people. *Social Science and Medicine*, **67**: 874-882.
- Coast J, Peters T, Natarajan L, Sproston K, & Flynn T. 2008b. An assessment of the construct validity of the descriptive system for the ICECAP capability measure for older people. *Quality of Life Research* **17**: 967-976.
- Coleman C, Smith J, Frank J et al. 2004. Preparing patients and caregivers to participate in care delivered across settings: the care transitions intervention. *Journal of the American Geriatrics Society* **52**: 1817-1825.
- Coleman E. 2003. Falling through the cracks: challenges and opportunities for improving transitional care for persons with continuous complex needs. *Journal of the American Geriatrics Society* **51**: 549-555.
- Cronin P, Norman R, Viney R, King M, Street D, Burgess L, Brazier J, & Ratcliffe J. 2009. Can time trade off be implemented online? A case study from Australia using the EQ-5D [poster]. *iHEA 7th World Congress*. Beijing: China.
- Crotty M, Gyles L, Cameron I et al. 2008. National Evaluation of the Transition Care Programme. Commonwealth Government Department of Health and Ageing, Canberra.
- Davis B. 2005. Mediators of the relationship between hope and well-being in older adults. *Clinical Nursing Research* **14**: 253-272.
- Department of Health. 2001 National service framework for older people. London.
- Dolan P. 1997. Modelling valuations for EuroQol health states. *Medical Care*, **35**: 1095-1108.
- Euroqol. 2004. *Measuring self reported health: an international perspective based on EQ-5D*, Hungary: Springmed publishing.
- Evangelista L, Doering L, Dracup K, Vassilakis M, & Kobashigawa J. 2003. Hope, mood states and quality of life in female heart transplant recipients. *The Journal of Heart and Lung Transplantation* **22**: 681-686.
- Flynn T, Huynh E, Terlich F, & Louviere J. 2010. What are Australian preferences for quality of life? Results from Best-Worst Scaling studies to value the ICECAP instruments. *AHES*: University of Sydney.
- Folstein M, Folstein S, & McHugh P. 1975. Mini mental state, A practical guide for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research* **12**: 189-198.
- Glendinning C. 2003. Breaking down barriers: integrating health and social care services for older people in England. *Health Policy* **65**: 139-151.



- Grewal I, Lewis J, Flynn T, Brown J, Bond J, & Coast J. 2006. Developing attributes for a generic quality of life measure for older people: Preferences or capabilities. *Social Science and Medicine* **62**: 1891-1901.
- Herth, K. 1992. Abbreviated instrument to measure hope: development and psychometric evaluation. *Journal of Advanced Nursing* **17**: 1251-1259.
- Higginson I. & Carr A. 2001. Using quality of life measures in the clinical setting. *BMJ* **322**: 1297.
- Holland R, Lenaghan E, Harvey I, Smith R, Shepstone L, Lipp A, Christou M, Evans D, & Hand C. 2005. Does home based medication review keep older people out of hospital? The HOMER randomised controlled trial. *BMJ* **330**: 293.
- Hopman W, & Verner J. 2003. Quality of life during and after inpatient stroke rehabilitation. *Stroke* **34**: 801-805.
- Iliffe S, Kharicha K, Harari D, Swift C, Gillman G. & Stuck A. 2007. Health risk appraisal in older people 2: The implications for clinicians and commissioners of social isolation risk in older people. *British Journal of General Practice* **57**: 277-282.
- Kind P, Hardman G, & Macran S. 1999. UK Population Norms for EQ-5D. *Centre for Health Economics* York: University of York.
- Kodner D. 2006. Whole-system approaches to health and social care partnerships for the frail elderly: an exploration of North American models and lessons. *Health and Social Care in the Community* **14**: 384-390.
- Laver K. 2009. Goals, hope and response shift: the first six months after stroke. *Rehabilitation and Aged Care [Masters thesis]*. Adelaide, Flinders University.
- Lin C, Lai Y, & Ward S. 2003. Effect of cancer pain on performance status, mood states, and level of hope among Taiwanese cancer patients. *Journal of Pain and Symptom Management* **25**: 29-37.
- Macadam M. 2009. Moving toward health service integration: Provincial progress in system change for seniors. In *Canadian Policy Research Networks [Ed.]*. Ontario.
- National Health and Hospitals Reform Commission. 2009. A Healthier Future for all Australians.
- Novella J, Boyer F, Jochum C, Jovenin N, Morrone I, Jolly D, Bakchine S, & Blanchard F. 2006. Health status in patients with Alzheimer's disease: An investigation of inter-rater agreement. *Quality of Life Research* **15**: 811-819.
- Parry C, Mahoney E, Chalmers S, Coleman E. 2008. Assessing the quality of transitional care: further applications of the care transitions measure. *Medical Care* **46**:317-22.
- Rustoen R, Howie J, Eidsmo I, & Moum T. 2005. Hope in patients hospitalized with heart failure. *American Journal of Critical Care* **14**: 417-425.
- Sigstad H, Stray-Pedersen A, & Froland S. 2005. Coping, quality of life, and hope in adults with primary antibody deficiencies. *Health and Quality of Life Outcomes* **3**:31.
- Snyder C, Irving L, & Anderson J. 1991. Hope and health. In Forsyth D, & Snyder C. [Eds.] *Handbook of social and clinical psychology: the health perspective*. New York: Pergamon Press.
- Snyder C, Lehman K, Kluck B, & Monsson Y. 2006. Hope for rehabilitation and vice versa. *Rehabilitation Psychology* **51**: 89-112.
- Productivity Commission. 2005. Economic implications of an ageing australia. *Research report*. Canberra.

Van Swieten J, Koudstaal P, Visser M, Schouten H, & Van Gijn J. 1988. Interobserver agreement for the assessment of handicap in stroke patients. *Stroke* **19**: 604-607.

Weinstein M, Torrance G. & McGuire A. 2009. QALYs: The Basics. *Value in Health* **12**: S5-S9.

Yadav S. 2010. Perceived social support, hope, and quality of life of persons living with HIV/AIDS: a case study from Nepal. *Quality of Life Research* **19**: 157-166.

Table 1: Characteristics of participants

| Characteristic | Inpatient Rehab (n=100) | Outpatient Rehab (n=55) | Transition Care (n=26) | Total (n=181) |
|------------------------------|--------------------------------|--------------------------------|-------------------------------|----------------------|
| Number of females (%) | 68 (68.0) | 25 (45.5) | 15 (57.6) | 108 (59.7) |
| Mean age (IQ range) | 74.9 (67-85) | 75.0 (69-80) | 81.3 (78-86) | 75.8 (69-84) |
| Residential status: | | | | |
| Living alone (%) | 59 (59.0) | 15 (27.3) | 15 (27.3) | 93 (51.4) |
| Living with spouse (%) | 29 (29.0) | 36 (65.5) | 5 (19.2) | 70 (38.7) |
| Living with others (%) | 12 (12.0) | 3 (5.5) | 1 (3.8) | 16 (8.9) |
| Living in a nursing home (%) | 0 | 1 (1.8) | 1 (3.8) | 2 (1.1) |
| Country of birth: | | | | |
| Australia (%) | 79 (79.0) | 41 (74.5) | 22 (84.6) | 142 (78.5) |
| Other (%) | 21 (21.0) | 14 (25.5) | 4 (15.4) | 39 (21.5) |
| Mean EQ-5D score (SD) | 0.529 (0.323) | 0.538 (0.254) | 0.490 (0.282) | 0.526 (0.297) |
| Mean ICECAP-O score (SD) | 0.759 (0.150) | 0.815 (0.151) | 0.783 (0.170) | 0.779 (0.154) |
| Reason for admission: | | | | |
| Stroke | 50 (50.0) | 23 (41.8) | 1 (3.8) | 74 (40.9) |
| Functional decline | 6 (6.0) | 6 (10.9) | 2 (7.7) | 14 (7.7) |
| Fracture/joint replacement | 4 (4.0) | 9 (16.4) | 16 (61.5) | 29 (16.0) |
| Poor mobility | 14 (14.0) | 2 (3.6) | 4 (15.4) | 20 (11.0) |
| Other | 26 (26.0) | 15 (27.3) | 3 (11.5) | 44 (24.3) |

Table 2: Distribution of responses to the ICECAP-O (n=181)

| | <i>Inpatient Rehab (n=100)</i> | <i>Outpatient Rehab (n=55)</i> | <i>Transition Care (n=26)</i> | <i>Total (n=181)</i> |
|---|--|--|---------------------------------------|--------------------------|
| Attachment | | | | |
| I can have all of the love and friendship that I want | 58 (58%) | 35 (64%) | 10 (39%) | 103 (57%) |
| I can have some of the love and friendship that I want | 30 (30%) | 13 (24%) | 12 (46%) | 55 (30%) |
| I can have a little of the love and friendship that I want | 9 (9%) | 5 (9%) | 4 (15%) | 18 (10%) |
| I cannot have any of the love and friendship that I want | 0 | 1 (2%) | 0 | 1 (1%) |
| Missing | 3 (3%) | 1 (2%) | 0 | 4 (2%) |
| Security | | | | |
| I can think about the future without any concern | 20 (20%) | 17 (31%) | 13 (50%) | 50 (28%) |
| I can think about the future with only a little concern | 31 (31%) | 22 (40%) | 7 (27%) | 60 (33%) |
| I can only think about the future with some concern | 28 (28%) | 9 (16%) | 6 (23%) | 43 (24%) |
| I can only think about the future with a lot of concern | 20 (20%) | 6 (11%) | 0 | 26 (14%) |
| Missing | 1 (1%) | 1 (2%) | 0 | 2 (1%) |
| Role | | | | |
| I am able to do all of the things that make me feel valued | 14 (14%) | 13 (24%) | 6 (23%) | 33 (18%) |
| I am able to do many of the things that make me feel valued | 32 (32%) | 22 (40%) | 7 (27%) | 61 (34%) |
| I am able to do a few of the things that make me feel valued | 46 (46%) | 15 (27%) | 8 (31%) | 69 (38%) |
| I am unable to do any of the things that make me feel valued | 6 (6%) | 5 (9%) | 4 (15%) | 15 (8%) |
| Missing | 2 (2%) | | 1 (4%) | 3 (2%) |
| Enjoyment | | | | |
| I can have all of the enjoyment and pleasure that I want | 24 (24%) | 18 (33%) | 6 (23%) | 48 (27%) |
| I can have a lot of the enjoyment and pleasure that I want | 36 (36%) | 22 (40%) | 9 (35%) | 67 (37%) |
| I can have a little of the enjoyment and pleasure that I want | 33 (33%) | 12 (22%) | 8 (31%) | 53 (29%) |
| I cannot have any of the enjoyment and pleasure that I want | 6 (6%) | 1 (2%) | 3 (12%) | 10 (6%) |
| Missing | 1 (1%) | 2 (4%) | 0 | 3 (2%) |



Control

| | | | | |
|---|----------|----------|----------|----------|
| I am able to be completely independent | 9 (9%) | 13 (24%) | 2 (8%) | 24 (13%) |
| I am able to be independent in many things | 45 (45%) | 26 (47%) | 13 (50%) | 84 (46%) |
| I am able to be independent in a few things | 36 (36%) | 14 (26%) | 8 (31%) | 58 (32%) |
| I am unable to be at all independent | 9 (9%) | 2 (4%) | 3 (12%) | 14 (8%) |
| Missing | 1 (1%) | 0 | 0 | 1 (0.6%) |

Table 3: Distribution of responses to the EQ-5D (n=181)

| | <i>Inpatient Rehab (n=100)</i> | <i>Outpatient Rehab (n=55)</i> | <i>Transition Care (n=26)</i> | <i>Total (n=181)</i> |
|--|--|--|---------------------------------------|--------------------------|
| Mobility | | | | |
| I have no problems in walking about | 14 (14%) | 14 (26%) | 4 (15%) | 32 (18%) |
| I have some problems in walking about | 83 (83%) | 41 (75%) | 21 (81%) | 145 (80%) |
| I am confined to bed | 3 (3%) | 0 | 1 (4%) | 4 (2%) |
| Self Care | | | | |
| I have no problems with self care | 39 (39%) | 36 (66%) | 7 (27%) | 82 (45%) |
| I have some problems with self care | 59 (59%) | 16 (29%) | 19 (73%) | 94 (52%) |
| I have many problems with self care | 2 (2%) | 3 (6%) | 0 | 5 (3%) |
| Usual activities | | | | |
| I have no problems with performing my usual activities | 12 (12%) | 9 (16%) | 5 (19%) | 26 (14%) |
| I have some problems with performing my usual activities | 70 (70%) | 35 (64%) | 10 (39%) | 115 (64%) |
| I am unable to perform my usual activities | 18 (18%) | 11 (20%) | 11 (42%) | 40 (22%) |
| Pain/Discomfort | | | | |
| I have no pain or discomfort | 46 (46%) | 16 (29%) | 13 (50%) | 75 (41%) |
| I have moderate pain or discomfort | 43 (43%) | 34 (62%) | 10 (39%) | 87 (48%) |
| I have extreme pain or discomfort | 11 (11%) | 5 (9%) | 3 (12%) | 19 (10%) |
| Anxiety/Depression | | | | |
| I am not anxious or depressed | 49 (49%) | 30 (55%) | 19 (73%) | 98 (54%) |
| I am moderately anxious or depressed | 43 (43%) | 19 (35%) | 7 (27%) | 69 (38%) |
| I am extremely anxious or depressed | 8 (8%) | 4 (7%) | 0 | 12 (7%) |

Table 4: Distribution of mean EQ-5D, Herth Hope Index, Modified Rankin Scale and CTM-3 values across levels of capabilities

| Attribute | Mean EQ-5D (n=181) | Mean HHI (n=100) | Mean MRS (n=100) | Mean CTM-3 (n=81) |
|---|--------------------|------------------|------------------|-------------------|
| Attachment | | | | |
| I can have all of the love and friendship that I want | 0.53 | 36.25 | 3.09 | 72.10 |
| I can have a lot of the love and friendship that I want | 0.54 | 36.00 | 2.90 | 75.11 |
| I can have a little of the love and friendship that I want | 0.43 | 35.13 | 3.22 | 59.88 |
| I cannot have any of the love and friendship that I want | 0.09 | N/A | N/A | 66.67 |
| Security | | | | |
| I can think about the future without any concern | 0.56 | 37.95 | 2.95 | 67.41 |
| I can think about the future with only a little concern | 0.58 | 36.97 | 3.00 | 76.67 |
| I can only think about the future with some concern | 0.51 | 34.96 | 3.00 | 74.07 |
| I can only think about the future with a lot of concern | 0.37 | 34.28 | 3.25 | 66.67 |
| Role | | | | |
| I am able to do all of the things that make me feel valued | 0.63 | 37.64 | 2.79 | 75.73 |
| I am able to do many of the things that make me feel valued | 0.58 | 36.67 | 3.00 | 76.44 |
| I am able to do a few of the things that make me feel valued | 0.47 | 35.48 | 3.20 | 65.70 |
| I am unable to do any of the things that make me feel valued | 0.35 | 34.00 | 2.83 | 63.58 |
| Enjoyment | | | | |
| I can have all of the enjoyment and pleasure that I want | 0.64 | 36.68 | 2.88 | 75.00 |
| I can have a lot of the enjoyment and pleasure that I want | 0.55 | 37.00 | 2.97 | 72.40 |
| I can have a little of the enjoyment and pleasure that I want | 0.44 | 35.52 | 3.15 | 68.06 |
| I cannot have any of the enjoyment and pleasure that I want | 0.34 | 32.33 | 3.50 | 63.89 |
| Control | | | | |
| I am able to be completely independent | 0.66 | 37.22 | 2.44 | 75.56 |
| I am able to be independent in many things | 0.60 | 36.64 | 2.91 | 73.50 |
| I am able to be independent in a few things | 0.46 | 35.45 | 3.22 | 67.42 |
| I am unable to be at all independent | 0.16 | 33.86 | 3.56 | 62.22 |



Table 5: Relationship between the ICECAP-O and other measurement tools calculated using Spearman's rho

| | <i>ICECAP-O</i> |
|-----------------------|-----------------|
| EQ-5D | 0.418** |
| Herth Hope Index | 0.402** |
| Modified Rankin Scale | -0.286** |
| CTM-3 | 0.259* |

** correlation is significant at the 0.01 level

* correlation is significant at the 0.05 level

Table 6: Tests of association (P values) between capabilities as measured by the ICECAP-O and other characteristics using chi-squared tests (n=181)

| | <i>Attachmen t</i> | <i>Security</i> | <i>Role</i> | <i>Enjoyment</i> | <i>Control</i> |
|-------------------------------------|------------------------|-----------------|-------------|------------------|----------------|
| Age (n=177) | 0.98 | 0.90 | 0.38 | 0.83 | 0.56 |
| Gender (n=178) | 0.40 | 0.65 | 0.59 | 0.22 | 0.36 |
| Residential status (n=178) | 0.33 | 0.48 | 0.022* | 0.20 | 0.75 |
| Country of birth (n=178) | 0.12 | 0.18 | 0.15 | 0.67 | 0.96 |
| Reason for admission (n=178) | 0.32 | 0.94 | 0.49 | 0.53 | 0.17 |
| EQ-5D: mobility (n=178) | 0.61 | 0.13 | 0.89 | 0.002** | <0.001** |
| EQ-5D: self care (n=180) | 0.29 | 0.73 | 0.010* | 0.032* | <0.001** |
| EQ-5D: usual activities (n=180) | 0.075* | 0.073* | <0.001** | 0.005** | <0.001* |
| EQ-5D: pain/discomfort (n=180) | 0.051* | 0.006** | 0.757 | 0.220 | 0.064* |
| EQ-5D: anxiety/depression (n=180) | 0.229 | 0.010* | 0.048* | 0.034* | 0.083* |
| EQ-5D: overall value (n=176) | <0.001** | 0.009** | 0.898 | <0.001** | 0.006** |
| CTM3: hospital staff (n=81) | 0.918 | 0.572 | 0.635 | 0.961 | 0.645 |
| CTM3: managing health (n=81) | 0.160 | 0.859 | 0.069* | 0.302 | 0.590 |
| CTM3: purpose of medications (n=81) | 0.772 | 0.455 | 0.074* | 0.348 | 0.265 |
| CTM3: overall score (n=81) | 0.967 | 0.956 | 0.351 | 0.874 | 0.281 |
| Herth Hope Index (n=92) | 0.541 | 0.031* | 0.151 | 0.096* | 0.381 |
| Modified Rankin Scale (n=99) | 0.263 | 0.096* | 0.192 | 0.278 | <0.001** |

** Strong association, significant at the 1% level or higher.

* Weak association, significant at between the 1% and 10% level.



Appendix 1: Herth Hope Index

Listed below are a number of statements. Read each statement and place an [X] in the box that describes how much you agree with that statement *right now*.

| | Strongly Disagree | Disagree | Agree | Strongly Agree |
|--|------------------------------|-----------------|--------------|---------------------------|
| 1. I have a positive outlook toward life. | | | | |
| 2. I have short and/or long range goals. | | | | |
| 3. I feel all alone. | | | | |
| 4. I can see possibilities in the midst of difficulties. | | | | |
| 5. I have a faith that gives me comfort. | | | | |
| 6. I feel scared about my future. | | | | |
| 7. I can recall happy/joyful times. | | | | |
| 8. I have deep inner strength. | | | | |
| 9. I am able to give and receive caring/love. | | | | |
| 10. I have a sense of direction. | | | | |
| 11. I believe that each day has potential. | | | | |
| 12. I feel my life has value and worth. | | | | |



Appendix 2:

Modified Rankin Scale

| | |
|---|---|
| 0 | No symptoms at all |
| 1 | No significant disability despite symptoms; able to carry out all usual duties and activities |
| 2 | Slight disability; unable to carry out all previous activities, but able to look after own affairs without assistance |
| 3 | Moderate disability; requiring some help, but able to walk without assistance |
| 4 | Moderately severe disability; unable to walk without assistance and unable to attend to own bodily needs without assistance |
| 5 | Severe disability; bedridden, incontinent and requiring constant nursing care and attention |

Care Transitions Measure CTM-3

| | Strongly Disagree | Disagree | Agree | Strongly Agree | Don't know/NA |
|---|--------------------------|-----------------|--------------|-----------------------|----------------------|
| 1. The hospital staff took my preferences and those of my family or caregiver into account in deciding what my healthcare needs would be when I left the hospital | | | | | |
| 2. When I left the hospital, I had a good understanding of the things I was responsible for in managing my health | | | | | |
| 3. When I left the hospital, I clearly understood the purpose for taking each of my medications | | | | | |