Chapter 3

The ICECAP-O Measure

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3.1 Analytical Synopsis

The ICECAP-O is a measure of capability in older people. It focuses on wellbeing defined in a broad sense, rather than health states, and is founded on Amartya Sen's conceptualisation of capability. The ICECAP-O contains five attributes: *Attachment*, *Security*, *Role*, *Enjoyment* and *Control*. A measure focusing on the capabilities of older people may be especially valuable for the evaluation of programmes targeting public health, interventions crossing health and social care boundaries, multidisciplinary actions and economic evaluations.

There is a lack of measures such as the ICECAP-O in the context of either research or health and social care interventions in Sweden. Therefore, a Swedish version of the ICECAP-O was established, by following guidelines for translation and cross-cultural adaptation, including forward–backward translation, committee

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H. Falk Erhag et al. (eds.), *A Multidisciplinary Approach to Capability in Age and Ageing*, International Perspectives on Aging 31,
https://doi.org/10.1007/978-3-030-78063-0_3

review and pre-test. Studies evaluating the reliability and validity of the Swedish version of the ICECAP-O showed that it seems to measure what it is supposed to measure, and that acceptability is satisfactory. Even so, the attribute *Control* might be considered in need of a minor overhaul for use in the Swedish context, and a layout adapted for visually impaired people is considered desirable. In addition, a short statement in parentheses after each attribute, with an example clarifying its meaning, is proposed to support a more thorough guidance.

The Swedish version of ICECAP-O also showed high test–retest reliability for the index score, but agreement for individual items was problematic. Further studies on more diverse groups of older people, in different contexts and with different time frames, are needed. As a final point, we recommend the use of the ICECAP-O in health and social care, and in the evaluation of interventions and longitudinal research studies where older people’s wellbeing is in focus.

3.2 Introduction

The Investigating Choice Experiments for the Preferences of Older People—CAPability Index (ICECAP-O) (Grewal et al., 2006) is a self-rated measure that focuses on wellbeing defined in a broad sense, rather than just health. In general, wellbeing measures aim to capture when people feel satisfied or content with life. They often contain indicators of the quality of people’s relationships, their positive emotions, resilience and the realisation of their potential (Diener & Seligman, 2004). Wellbeing is associated with numerous benefits related to health, work, family and economics (Lyubomirsky et al., 2005).

The ICECAP-O is one of the few measures of wellbeing that taps into the concept of capability, i.e. the opportunities to ‘do’ and ‘be’ the things that a person deems important in life. It was originally developed for use in economic evaluations by researchers at the University of Birmingham in the UK. The ICECAP-O is tailored for older people (aged 65 years and older), and is founded on Amartya Sen’s conceptualisation of capability (Sen, 1993, 2009). Capability is considered a more appropriate evaluative space than function (health status) because two people may both have a specific function, but only one may have the actual possibility to fulfil this function in action or in being (i.e., capability). This approach advocates assessing capability (what a person *can* do) rather than functioning (what a person *actually* does), in order to avoid imposing a specific idea of what a good life constitutes, and to reflect the importance of freedom to choose (Sen, 1993).

Older people might not have equal opportunities to enjoy good health due to factors at the individual (micro), group (meso) and/or societal (macro) levels. The combination of personal factors, including physical health and cognition, group factors such as family, friends and community, and societal factors, exemplified and executed by laws and healthcare services, may at any given time form the basis for a person’s capability set; i.e., what the person actually can or cannot do (Sen, 2009). For instance, two older people may both value being as independent in everyday life

as possible. One of these person's legs works well resulting in needing few resources to be mobile, while the other person may have an impairment/disability resulting in an increased need for resources, e.g., technical aids and/or assistance from another person, to achieve the same level of mobility. Hence, capability could be considered as the effective possibilities that a person has to convert their resources into achieving a desired goal (Sen, 1993), such as being independent in everyday life, as illustrated in the example.

A measure that captures the capabilities of older people may be especially valuable for the evaluation of programmes targeting public health, interventions crossing health and social care boundaries, multidisciplinary actions and economic evaluation (Coast et al., 2008a). It may also be useful in longitudinal research studies exploring aspects of older people's health and wellbeing, such as the H70-studies (Rinder et al., 1975; Rydberg Sterner et al., 2019) conducted by the Centre for Ageing and Health (AGECAP) at the University of Gothenburg, Sweden.

3.3 Development of the Original ICECAP-O

The ICECAP-O measure was first developed based on findings from rigorous qualitative and quantitative research with older people in the UK (Coast et al., 2008a, b; Flynn et al., 2011; Grewal et al., 2006). In addition to the ICECAP-O, which is tailored for older people, there is also a version targeting all adults, the ICECAP-A (Al-Janabi et al., 2012), and a version for use in end-of-life care, the ICECAP-SCM (Coast et al., 2016). The final English-language version of the ICECAP-O contains five attributes that were found to be important for capability: *Attachment* – love and friendship; *Security* – thinking about the future without concern; *Role* – doing things that make you feel valued; *Enjoyment* – enjoyment and pleasure; and *Control* – independence (Coast et al., 2008a). The ICECAP-O has a four-level response option scale that is described as statements representing: 'none', 'a little', 'a lot', and 'full capability'. For example, the response options for the last attribute, *Control* – independence, are: 'I am able to be completely independent' (level 4), 'I am able to be independent in many things' (level 3), 'I am able to be independent in a few things' (level 2), and 'I am unable to be at all independent' (level 1). The response option values (4 to 1), are anchored to a best–worst scaling, ranging from 1.00 (full capability) to 0.00 (no capability). A total index score, based on a tariff computed from population-based values in the UK, is thus obtained (Coast et al., 2008a; Flynn et al., 2007). In a survey study, including 809 individuals aged 65 years and older in the UK, the mean ICECAP-O index score was 0.832. Seven percent of the participants in this study gave answers indicating that they considered themselves to be in the top ICECAP-O state (1.00 = full capability). The same study also found that poor physical and psychological health, living alone and infrequent socialising were associated with lower measured capability according to the ICECAP-O.

That impaired physical health is associated with a lower mean index score was also confirmed for osteoarthritis patients requiring joint replacement (Mitchell

et al., 2013). In an Australian study (Couzner et al., 2013), in which 786 people aged 65 years and older participated, men had a slightly lower mean index score (0.821) than women (0.836). In this study, an association with lower levels of the index score were found for people born outside Australia, those having an injury or disability and those with a lower income.

Reliability, validity and feasibility testing for the English-language version of the ICECAP-O, as well as versions translated into other languages, are ongoing. There is evidence, for example, of construct validity (Coast et al., 2008b), face validity (Horwood et al., 2014) and validity for a post-hospitalised older population in the Netherlands (Makai et al., 2013). The ICECAP-O questionnaire is freely available on the University of Birmingham's webpage (University of Birmingham, 2021).

3.4 The Swedish Version of the ICECAP-O

There is a lack of measures such as the ICECAP-O in the context of research or health and social care interventions in Sweden. Implementing a questionnaire developed and tested in a specific context (e.g. the UK) in a dissimilar context (e.g. Sweden) requires cross-cultural adaptation. Therefore, a Swedish version of the ICECAP-O was established by following guidelines for translation and cross-cultural adaptation, including forward-backward translation, committee review and pre-test (Guillemin et al., 1993). Thereafter, two studies nested within an ongoing comprehensive population-based study of health among older people, the Gothenburg Birth Cohort Studies (H70), Sweden (Rinder et al., 1975; Rydberg Sterner et al., 2019), were performed.

3.5 Reliability Testing

The first study (Hörder et al., 2016), examined test-retest reliability and item relevance. It included 39 70-year-olds from the H70 study (Rinder et al., 1975; Rydberg Sterner et al., 2019), who answered the ICECAP-O on two occasions at approximately two-week intervals. The mean ICECAP-O index score was 0.86 on test occasion one and 0.84 on test occasion two. This result indicated that the index has good test-retest reliability, similar to that observed in a Dutch study (Van Leeuwen et al., 2015) that focused on frail older adults. On the other hand, the absolute agreement for each item was only low to moderate in the study. Good reliability for the index, despite the low absolute agreement for individual items, could be explained by the fact that most item changes involved shifts from 'full capability' (level 4) to 'a lot' (level 3), and these levels have very similar weighting in the tariff, in contrast to the much larger difference in weighting between the two lowest levels, 'a little' (level 2) and 'no capability' (level 1) (Coast et al., 2008, b). Furthermore, about

40% included both lower and higher ratings on individual items on the second test occasion, resulting in a relatively consistent index score.

Our study was the first to examine test–retest agreement for individual ICECAP-O items. A partial explanation for the observed item inconsistency might be related to the age of the participants. In a general population-based British study that utilised the ICECAP-A (adult) (Al-Janabi et al., 2015), greater age was associated with more inconsistent item ratings. Another possible explanation for test–retest item inconsistency might be related to differences in available time for completion of the questionnaire. On the first occasion, the ICECAP-O was included in an extensive questionnaire packet that was administered in connection with a comprehensive health examination. In contrast, the retest was completed at home at the participant's leisure. This meant that participants were free to take their time and reflect upon ICECAP-O item response options, which could have had an impact on both interpretation and choice of response. In a think-aloud study, people were shown to vary in interpretations when rating capabilities (Al-Janabi et al., 2013).

Previous studies have shown slightly lower reliability for the ICECAP-A index compared to EuroQoL (Al-Janabi et al., 2013), a well-known Quality of Life measure. As highlighted by others (Al-Janabi et al., 2013), more thorough guidance might be one way to achieve more consistent interpretations of capabilities. In addition, participants' ratings of item relevance showed that attachment was valued most highly, followed by control, role, security and finally enjoyment. This order is similar to that observed in the original British study on older people (Coast et al., 2008a).

Some important limitations of the test–retest study need to be mentioned. The sample was relatively homogeneous and small in size. Therefore, reliability testing is necessary for other age groups. A wider variation in medical conditions and functional abilities is to be anticipated in older age groups, and this would be expected to result in a larger variation in item responses.

3.6 Validity Testing

The second study (Gustafsson et al., 2017) evaluated the face and content validity and acceptability of the ICECAP-O. The applied method was cognitive interviews, which is a research method used to detect any problems respondents are having in understanding survey instructions and items, and in formulating answers (García, 2011). Eighteen 70-year-old community-dwelling individuals from the previously mentioned H70 study participated.

Overall, the results showed that the attributes listed in the ICECAP-O measure were interpreted as anticipated and the extent to which participants 'struggled' to complete the measure was moderate. Three participants (18%) had problems completing the measure, compared with 25% reported for the original British version (Horwood et al., 2014). The participants discussed all the attributes in the ICECAP-O measure during the interviews in terms of both significance/meaning and

disincentives for capability, indicating that they were all relevant and essential for the purposes of the measure. The results also showed that most participants perceived the attributes to be understandable, even though the meaning of *Control* carried some uncertainty. One possible explanation is that participants in the study were community-dwelling 70-year-olds who had remained in relatively good health with no or little experience of being dependent in the activities of daily life, attributes that characterise ‘the third age’ (Baltes & Smith, 2003). Finally, participants made suggestions for an improved questionnaire format with larger text size to meet the needs of visually impaired respondents, as well as the addition of a short statement in parentheses after each attribute giving a description or an example to clarify its meaning. The latter suggestion was intended to support a more thorough guidance when considering the answer options.

This study also had some issues regarding its methodology that need to be highlighted. Firstly, only 18 older people were recruited, which some may consider too few, but the number of participants is in accordance with Lee’s (2014) recommended sample size of approximately 15 participants in cognitive interviews within cross-cultural research. However, in addition to being 70 years old and community dwelling, all the participants were in relatively good health, lived in the same city, had a generally high education level and only two lived alone. These factors imply that this study entailed a relatively homogeneous group of participants, which may have affected the results. Further evaluation of face and content validity, and also acceptability, by including more diverse groups of older people in terms of age, health status, and ability to speak Swedish, as well as including those living in senior housing and rural areas, is thus recommended.

3.7 Summary

The Swedish version of the ICECAP-O seems to measure what it is supposed to measure, and acceptability is satisfactory. Even so, the attribute *Control* (i.e., independence) might be considered in need of a minor overhaul for use in the Swedish context, and a layout adapted for visually impaired respondents is desirable. In addition, a short statement in parentheses after each attribute with an example clarifying its meaning is proposed in order to support a more thorough guidance. The Swedish version also showed high test–retest reliability for the index score, but agreement for individual items was problematic. Further studies that include more diverse groups of older people in different contexts and with different time frames, are needed.

3.8 Conclusion

To conclude, the Swedish version of the ICECAP-O provides a promising approach to self-reported capability in the older population. ICECAP-O seems to capture the capability of older people and may therefore be especially valuable for the evaluation of programmes targeting public health, interventions crossing health and social care boundaries, multidisciplinary actions, economic evaluations and longitudinal studies. These assumptions are in line with a review from 2019 (Proud et al., 2019), reporting that publications relating to the ICECAP-O have now shifted from assessments of its psychometric properties to the utilisation of the measure in different contexts. Consequently, we recommend the use of the Swedish version of the ICECAP-O in evaluations of health and social care, and in interventions and longitudinal research studies where older people's capabilities are in focus.

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