THE ICECAP-SCM TELLS YOU MORE ABOUT WHAT I'M GOING THROUGH”—MEASURING THE QUALITY OF LIFE AMONGST PATIENTS RECEIVING SUPPORTIVE AND PALLIATIVE CARE

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Introduction The ICECAP Supportive Care Measure (ICECAP-SCM) is a self-complete questionnaire developed to rate quality towards the end of life, particularly for economic evaluation. It measures a person’s capability to experience a good life and death.

Aim(s) and method(s) The study aimed to determine the feasibility of completing ICECAP-SCM alongside EQ-5D-5L and ICECAP-A (measures commonly used for economic evaluation). Each measure was completed by hospice patients (n=33), close persons (n=22) and healthcare professionals (HCPs n=17) in a ‘think aloud’ semi-qualitative interview. Five raters identified the frequency of error (e.g. misunderstanding, poor memory) from interview transcripts. Qualitative data were analysed using constant comparison, focusing on issues affecting response.

Results Amongst patients, fewest errors were identified for ICECAP-SCM (3.9%) and the most for EQ5D-5L (9.7%). Amongst close persons there were also fewest errors in the ICECAP-SCM (4.5%) compared to ICECAP-A (5.5%) and EQ-5D-5L (5.5%). HCPs had most errors for ICECAP-SCM (6.7%) and fewest for EQ-5D-5L (3.5%). Qualitative data suggested that HCPs found EQ-5D-5L easiest to answer because it focuses on health states which could be directly observed. The ICECAP-SCM appeared more meaningful to patients near the end of life and close persons; it was also easier to complete.

Conclusion(s) This paper provides insight into the meaning of quality of life for those approaching death, those close to them and those involved in their care. Complexities in disease trajectories and adaptation to poor health make quality of end of life difficult to measure. The ICECAP-SCM captures the subtleties required and may be useful in evaluating future palliative care interventions.