



Review

Quality of life instruments for economic evaluations in health and social care for older people: A systematic review



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ABSTRACT

Gaining health may not be the main goal of healthcare services aimed at older people, which may (also) seek to improve wellbeing. This emphasizes the need of finding appropriate outcome measures for economic evaluation of such services, particularly in long-term care, capturing more than only health-related quality of life (HrQoL). This review assesses the usefulness of HrQoL and wellbeing instruments for economic evaluations specifically aimed at older people, focusing on generic and preference-based questionnaires measuring wellbeing in particular.

We systematically searched six databases and extracted instruments used to assess HrQoL and wellbeing outcomes. Instruments were compared based on their usefulness for economic evaluation of services aimed at older people (dimensions measured, availability of utility scores, extent of validation).

We identified 487 articles using 34 generic instruments: 22 wellbeing (two of which were preference-based) and 11 HrQoL instruments. While standard HrQoL instruments measure physical, social and psychological dimensions, wellbeing instruments contain additional dimensions such as purpose in life and achievement, security, and freedom.

We found four promising wellbeing instruments for inclusion in economic evaluation: Ferrans and Powers QLI and the WHO-QoL OLD, ICECAP-O and the ASCOT. Ferrans and Powers QLI and the WHO-QoL OLD are widely validated but lack preference-weights while for ICECAP-O and the ASCOT preference-weights are available, but are less widely validated. Until preference-weights are available for the first two instruments, the ICECAP-O and the ASCOT currently appear to be the most useful instruments for economic evaluations in services aimed at older people. Their limitations are that (1) health dimensions may be captured only partially and (2) the instruments require further validation. Therefore, we currently recommend using the ICECAP-O or the ASCOT alongside the EQ-5D or SF-6D when evaluating interventions aimed at older people.

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Introduction

The growing number of older people worldwide and the associated higher demand for healthcare increasingly put pressure on public funds. Hence, there is growing need to make funding decisions about various health and social services aimed at older people. Cost-utility analysis (CUA) can support policy makers to optimally allocate health and social care resources within limited budgets by comparing two or more healthcare interventions to investigate their relative value for money (Drummond, Sculpher, Torrance, O'Brien, & Stoddart, 2005). CUA is increasingly used in

the curative sector for such comparisons. In CUA, the benefits of these interventions are commonly expressed in Quality-Adjusted Life-Years (QALYs), a utility-based health measure comprising both length and health-related quality of life (HrQoL). To assess HrQoL improvements, typically patients' health states are measured (using standardized instruments) using health dimensions such as mobility, pain and anxiety. Subsequently, these health states are valued (on a scale from 0 – dead – to 1 – perfect health). Such outcome measures are appropriate for curative services, where the goal is to improve health. However, in other fields of healthcare, such as mental health, social care, public health, and care for older people, a focus on health dimensions of quality of life (QoL) may be less appropriate if health improvement is not the only or even the main goal of the services provided (Al-Janabi, Flynn, & Coast, 2012). A relevant question is how to broaden the scope of

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outcome measurement within a CUA to include QoL domains that are intentionally affected by interventions in other fields of healthcare, in particular care for older people.

Current QALY measures using a quality adjustment factor that is based on domains of HrQoL only, may not be appropriate to evaluate interventions for older people such as long-term care. This holds since the latter interventions may be aimed at improving non-health aspects of QoL, such as maintaining independence, dignity, comfort or social interaction. Evaluating such interventions using HrQoL-instruments would likely undervalue the benefits. One of the most important challenges for performing CUA in the context of interventions aimed at older people thus concerns the availability of outcome measures attuned to the goals of services consumed by older people (Coast, Flynn, et al., 2008). The aim of this paper was to review the literature to investigate the existence of such appropriate outcome measures, which would facilitate CUA in the context of health and social care for older people.

Older people consume a variety of health and social services. These may be curative services such as hospital care, as well as long-term care services provided by nursing homes, residential homes, and home care. Often, elderly consume a combination of such services within an illness episode. The benefits of such a varied list of services should be evaluated using outcome measures that adequately capture the value of all services provided (Coast, Flynn, et al., 2008). This may be particularly difficult in long-term care. To illustrate this, consider an intervention aimed at reducing the frequency of restraining older people in a nursing home setting to prevent them from falling (Huizing, Hamers, Gulpers, & Berger, 2009). While reducing the use of physical restraints may not directly improve a patient's health (Huizing et al., 2009), such an intervention aims to restore dignity, freedom of movement, and control, outcomes that transcend health. If such an intervention were to be evaluated in a CUA, it is pivotal that outcome measures allow for capturing benefits 'beyond health' in order to provide adequate information on the costs and benefits of the intervention. Below we discuss some of the desirable characteristics of such instruments.

A first desirable characteristic of instruments attuned for evaluation of care for older people, is that such instruments should capture QoL dimensions transcending health. HrQoL instruments commonly used in CUAs measure health as a multi-dimensional construct minimally measuring psychological, physical and social dimensions (WHO, 1948), while for economic evaluation of services aimed at older people, particularly in long-term care other dimensions may also be relevant, such as affection or control. Instruments covering such dimensions 'beyond health' can be labeled as wellbeing instruments. There are two main conceptualizations relevant for the scope of wellbeing instruments. The first one focuses on wellbeing as an inherently subjective concept and thus holds that wellbeing does not contain health dimensions (Morgan, Grootendorst, Lexchin, Cunningham, & Greyson, 2011). By distinguishing between functional HrQoL dimensions and subjective wellbeing dimensions, both HrQoL and wellbeing are components of the overarching concept of QoL. The second conceptualization treats wellbeing as representing individuals' welfare (Nussbaum, 1993), which is dependent on individuals' functioning, thus encompassing HrQoL dimensions (see Fig. 1). In this view, wellbeing can be seen as synonymous with overall QoL. In this paper, wellbeing will be referred to in the latter meaning.

This second conceptualization may offer the opportunity to jointly explore treatment effects on health with other impacts on wellbeing. By broadening the evaluative space of a CUA (Coast, Flynn, et al., 2008), wellbeing instruments are, in principle, better equipped than HrQoL measures to capture the full benefit of interventions aimed at older people, also when these aim at

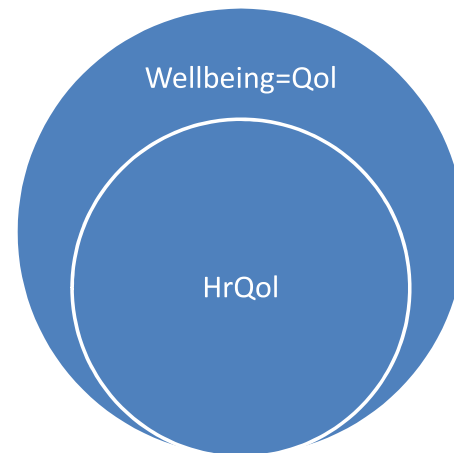


Fig. 1. Conceptualization of wellbeing and Quality of life.

outcomes beyond health. However, wellbeing instruments based on the subjective notion of wellbeing may not explicitly or completely capture health. This deserves attention, since the aim must be to adequately capture all relevant outcomes of interventions in order to come to a complete comparison of costs and benefits in an economic evaluation. While some wellbeing instruments may include health as an underlying concept (Hyde, Wiggins, Higgs, & Blane, 2003), it remains unclear whether existing outcome measure capture all wellbeing domains adequately and in such a way that allows inclusion in CUAs. To overcome this problem, it has been suggested that combinations of HrQoL and wellbeing instruments could be used in economic evaluations in older people (Davis, Liu-Ambrose, Richardson, & Bryan, 2013). Moreover, the lines between HrQoL and wellbeing measures may not always be easy to draw nor have been consistently drawn (when definitions of HrQoL or wellbeing differ between measures). Therefore, in reviewing measures that may be useful in economic evaluation of services aimed at older people, particularly in long-term care, we will include both measures labeled as HrQoL as well as measures of wellbeing. This allows an open and consistent categorization of instruments.

A second desirable characteristic of outcome measures for application in CUA in older people is that the classification system of health or well-being states is combined with a preference-based scoring system, as is the case for popular HrQoL instruments like the EQ-5D and SF-36. Preference-based instruments normally consist of (1) a descriptive system defined by the dimensions and answer categories of the instruments (states), and (2) a (pre-scored) weighting system reflecting the valuation of the states described with element (1) by a relevant population (e.g. general public) (Brazier, Ratcliffe, Salomon, & Tsuchiya, 2007). The weighting system thus allows particular states as described with the descriptive system to be transformed into a 'utility score', commonly reflecting the average strength of preference for the various states described. In case of HrQoL, these scores are typically anchored to a standardized scale, with 1 representing the utility of the best imaginable health state, and 0 representing the value for the state 'dead'. Negative values relate to health states valued as 'worse than dead'. For wellbeing instruments, anchoring on a 0–1 scale is also possible, 1 representing the best imaginable wellbeing instead of best imaginable health, while 0 can represent 'dead' or, more logically perhaps, the value for the worst level of all included domains in the descriptive system. Additionally, negative values for wellbeing instruments may also be allowed depending on the theory behind the instrument. Here, we will not limit our search to

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