Is a QALY still a QALY at the end of life?

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A B S T R A C T
Recent research into end of life and palliative care has focused on the development of a replacement for the quality adjusted life year (QALY) as an outcome measure. Reasons given range from the lack of anticipated survival benefit from treatment to the inappropriateness of death as an anchor for valuing health states, or the increased value of time to the individual at the end of life. The Palliative Care Yardstick, has been proposed as an alternative. In this paper, I argue that the QALY should not be abandoned as an outcome measure in end of life and palliative care populations and suggest possible methods for generating empirical data to support or refute this. I show why the arguments made for replacement of the QALY are not supported by current evidence and how in some cases the abandonment of the QALY framework would lead to an unjustifiable inequitable distribution of resources.

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1. Introduction

The quality adjusted life year (QALY) has become the gold standard measure of outcome in economic analysis. The Washington Panel of Cost-Effectiveness (Gold, 1996) recommended its use in economic evaluations in 1996 and it is currently recommended in the methodological guidance for technology appraisal issued by the UK National Institute for Health and Clinical Excellence (NICE) (National Institute for Health and Clinical Excellence, 2008a). Although there are arguments against its use in evaluating healthcare technologies and interventions (Carr-Hill, 1991) it is widely used in practice and there is consensus that its use in resource allocation decision making is appropriate. Although the QALY is arguably most widely applied to the measurement of health benefits in health technology evaluations, conceptually its use is not limited to healthcare – subject to the development of appropriate instruments it could be used to measure benefits in a number of fields where improvements in quality of life are assessed (Moore and Viscusi, 1990; Kharroubi et al., 2005).

Some researchers have begun to question whether or not the QALY, when applied in the standard evaluation framework of health economics, is an appropriate measure of health outcome for patients nearing the end of life when curative treatment is no longer considered appropriate or possible. End of life and palliative care is aimed at meeting the often complex physical, emotional, medical, spiritual and social care needs of those with advanced and progressive life limiting illness, as death approaches. As treatment it is often primarily about caring for the patient (and their carers) rather than attempting cure.

There are two underlying assertions behind the belief that QALY is not suitable in this patient group. The first is that patients nearing the end of life are sufficiently distinct from other population groups that the standard evaluation methodologies should not apply (Coast and Lavender, 2009). The second is based on the supposed ‘QALY problem’ – that there exists some subset of interventions which are considered desirable by both the public and decision makers but would not generate sufficient QALYs to be considered cost-effective (Hughes, 2005; Normand, 2009). In this paper, I discuss the arguments made in favour of supplanting the QALY with an alternative outcomes framework. Taking each key argument in turn, I argue that the critiques of the QALY in end of life care are not supported by the evidence. I also argue that the case for valuing time spent in the terminal phase of life more highly...
than time during other stages of life is currently without empirical support and is potentially inequitable.

2. Quality of life and economic evaluations

Economic evaluation of healthcare technologies and interventions occurs within a social decision making framework where decision makers typically try to maximise health outcomes (Claxton, Paulden, Gravelle, Brouwer, and Culyer, 2011). This framework is established within a wider welfarist or extra-welfarist framework, where the objective is typically to maximise social welfare (Briggs et al., 2006). Under strict assumptions about the separability of health and consumption, and constancy in the social consumption value of health, maximising both health outcomes and social welfare may be equivalent. However under real world conditions, where there is assumed to be a latent yet unknowable social welfare function, the objective of decision makers to maximise health outcomes gains legitimacy through the role of socially legitimate authorities, such as NICE (Paulden and Claxton, 2011).

The functioning of the analytical framework, irrespective of whether the objective is the maximisation of health or of social welfare, is contingent upon it being possible to assign some measure of value to the benefits of resources spent on providing healthcare. In order to make comparisons between alternative courses of action, some form of common metric is required for valuing these benefits. Cost-benefit analysis seeks to place a financial value on health benefits, such that costs of an intervention and its consequences can be measured in units of currency. Cost-effectiveness analysis, and in particular cost-utility analysis, seeks to extend the analysis of outcomes beyond monetary terms. Increasingly, evaluations are using outcomes measured as quality adjusted life years, or QALYs.

Although it is recognised that the QALY has limitations (Briggs et al., 2006), its strengths have led to its widespread adoption. The QALY allows for a comparison of both quality and length of life in a single metric that can, in theory, be applied to any healthcare activity (Drummond et al., 2005). The QALY is central in the distribution of scarce healthcare resources, and it is incumbent on decision makers to ensure that the tools they use to make judgements about the care people receive are fit for purpose.

Recently, the appropriateness of this analytical framework has been challenged. Coast and Lavender (2009), presented a review of many of the arguments against the QALY. In particular, it has been argued the QALY, as currently conceptualised, is unable to satisfy a number of conditions for use and is therefore rendered unsuitable (Carr-Hill, 1991) for allocating resources, particularly in end of life care (Coast and Lavender, 2009; Normand, 2009; Hughes, 2005). Within end of life care, there are several arguments that have developed to challenge welfarist and extra-welfarist notions of how outcomes should be measured and valued. These arguments are used to support the assertion that there is something about end of life care populations that make them distinct (Coast and Lavender, 2009). Justifications for these viewpoints are numerous and encompass both normative and empirical arguments. These arguments are that:

- Preference based measures of health are valued using death as an anchor point, which is not valid in a patient group where death is expected imminently;
- Time is valued differently at the end of life than it is other life stages; and
- There is a ‘QALY problem’ – that is, there exists some group of interventions that are desirable according to both the patients and the public but that would not normally be considered cost-effective.

For the remainder of this paper, 1 address each of these arguments in turn before making the case for the retention of the QALY for use in end of life care, subject to improvements in measurement and valuation methodologies.

3. The case against the QALY

The theoretical underpinnings for use of the QALY are based on an idea that patients can trade less time in full health against longer periods of time in ill health (Coast et al., 2008a), despite limited opportunity for life extension in the population who face the end of life. This idea is just one possible implication of adopting a measure of health that combines both quality and quantity of life. To illustrate, consider Fig. 1. A patient receiving usual care dies at time (t1,qUC). Under intervention A, the patient dies at (t1,qA) with an improvement in quality of life, but not quantity. With intervention B, the patient now dies at (t2,qB) – a reduction in length of life but an even greater improvement in quality. It is clear that it is possible for increases in QALYs to occur even if life cannot be lengthened. Equally, it is evident that extending life does not necessarily result in gains in QALYs.

It is not necessary for there to be an extension of life in order for there to be a gain in QALYs. Any such restriction on the QALY framework would mean that all cost-effectiveness analyses for treatments that are life enhancing rather than life extending would be invalidated. Although treatments at the end of life may be more concerned with care than cure, and potential gains to length of life are likely to be small, there is still the potential for improvements in quality of life – arguably the main objective of palliative care. In fact, it is possible that an intervention may reduce length of life but improve quality to a sufficient degree that it would be preferred to one that lengthens life but does not improve the quality of that life.
Patients often choose not to receive treatment where they perceive the loss in quality of life as outweighing potential gains in length of life (Sharf et al., 2005).

It may also be true that the attributes of care that are considered important to the dying may not be the same as those that are considered important to the living (Coast and Lavender, 2009). Coast and Lavender argue, based on evidence from Groenvold (1999) which is also supported by evidence from Higginson (see for example Higginson and Sen-Gupta, 2000) that health status is less important to patients than other dimensions of quality of life at the end of their life. One possible response to this is that if the decision maker’s objective is set by a socially legitimate authority, then concern with health only, and not other dimensions of quality of life, is entirely appropriate (Claxton et al.). This argument presupposes the answer to the normative question of what is the appropriate aim of the socially legitimate authority. Where that authority has democratic legitimacy, the question of which domains are included in the decision making framework has reduced relevance.

Assuming that the question is of relevance, it raises the related issue of whether non-health domains can be considered within the QALY within a welfarist or extra-welfarist economics framework (Brouwer et al. 2008; Coast et al., 2008b). The welfarist approach is argued to be concerned with the utilities achieved by individuals, as assessed by individuals themselves (Hurley, 1998; Brouwer et al., 2008). This confines the evaluative space to the individual utility, and societal welfare functions using classical utilitarianism logically follow from this (Brouwer et al., 2008). The extra-welfarist approach extends this evaluative space in a manner that takes it beyond the Paretoian framework (Brouwer et al., 2008). Culver’s definition of extra-welfarism encompasses the non-goods characteristics of individuals, such as the pain they experience, their ability to take part in their normal activities or their general well-being (or happiness) (Culver and Wagstaff, 1991). This, as Brouwer et al. 2008 note, is a rejection of the focus on the individual utility of welfarism and ‘broadens the evaluative space’ to include other domains of life beyond health. There is no conceptual reason why such broader, non-health domains, could not be encompassed within the evaluative space of a measurement instrument within the extra-welfarist framework.

The difficulty then is not that non-health domains cannot be considered when estimating QALYs, but rather that to date they are not. If an instrument lacks validity in a population group, it is inappropriate, no matter the characteristics of the population (Streiner and Norman, 2003). The appropriate response is not to dismiss the analysis framework, but to develop measurement instruments that are valid (Stevens, 2009). The validity of standard measurement tools such as the EQ-5D has been questioned in other patient groups, notably children (Stevens, 2009). If the importance people at the end of life place on domains such as spirituality or preparedness for death are greater than concerns for mobility or the experience of pain, it is not inconceivable that an instrument could be developed that accounted for this. Work with children has shown that the domains measured by the adult EQ-5D were not considered valid in a child population, and a new general health instrument has been developed in response (Stevens, 2010, 2011). The same approach could be used with patients at the end of life; to a certain degree the solution to this problem is straightforward (in principle, if not practice) – find out what is important to people, then measure it.

A further argument against the current evaluation framework is that the preferences people express for health states, from which QALYs are derived, may not be stable towards the end of life (Coast and Lavender, 2009). That is to say, that as an individual approaches the end of life, they may consider the time/health trade-off for the same health state differently than they would have at previous life stages. A review by Coast and Lavender (2009) found that whilst some individuals would not trade any length of life in order to live at perfect health (see Arnesen and Norheim, 2003) others would prefer to only live a very short time in a particular health state (see Dolan and Stalmeier, 2003). A similar instability of preferences can be observed when taking values from both patient and general populations in other areas of healthcare (JD Stein, 2003; Suarez-Almazor and Conner-Spady, 2001). The empirical evidence thus reflects a broad range of views about how individuals who are approaching the end of life value both time and health.

The problem of the stability of preference over time is lessen in importance when it is considered how preferences for health states should be derived. A consensus has developed that the value placed on health states should be determined by the general population rather than by specific patient populations (Dolan, 1999; Gold, 1996). If so then this instability of preferences assumes lesser importance. The argument that general population preferences should be used is based on the notion that the general population bears the costs of providing care (through taxation in the case of the NHS) and should therefore have some determination over how that care is directed (Dolan, 1999). Because we cannot know which patient group will bear the opportunity cost of an allocation decision, it may be unethical to allow vested interests to determine which treatments are funded (Wailoo et al., 2009). Because the instability of preferences arises as a difficulty when patients are asked to determine preferences, by following consensus and deriving health state values from the general population the practical importance of the problem is removed, even though the conceptual and methodological problems may remain.

It has also been argued that death is not an appropriate anchor point for valuing health states experienced by people at the end of life (Coast and Lavender, 2009). This is of particular importance when patients themselves are asked to express their preferences for health states (though it is less important when the general population are asked to value health states). Although no empirical evidence is available to suggest that patients find the commonly used time-trade off and standard gamble methodologies unaccept-able, it is intuitively an appealing argument. Being asked to trade time for full health when one is aware that the time they are trading does not exist (using currently practised time-trade off methodologies) may not be acceptable to respondents (Arnesen and Norheim, 2003; Coast and Lavender, 2009), though Devlin and colleagues have shown that short time-trade offs are acceptable (Devlin et al., 2011). Being asked to gamble health that patients are aware they can never gain may also be conceptually difficult for respondents. There is potential merit in this argument therefore with respect to the conceptual acceptability of commonly used valuation methodologies for health states that are experienced at the end of life.

The most substantive and long-standing argument (Weinstein, 1988) that the QALY is not appropriate for use in end of life care is that the value of time is inconsistent across an individual’s life, and that as death approaches, the value of time to an individual increases. This is the underlying value judgement behind the end of life policy recently implemented in the UK. The UK Department of Health, via NICE, has instructed technology appraisal committees to consider life extending treatments at the end of life as of potentially greater value than other treatments (National Institute for Health and Clinical Excellence, 2009). The NICE end of life care policy applies only to a certain subset of treatments. These are: where a treatment is available to patients with a life expectancy of less than two years; where the gain in life expectancy is believed to greater than three months; and where the patient population is small. If a treatment satisfies these criteria, and exceeds the generally accepted upper cost-effectiveness threshold limit of £30,000 per QALY, then special consideration can be given to approval.
Treatments that do not meet the end of life criteria would not typically be approved if they exceed the £30,000 per QALY threshold. The implication of this instruction from NICE to the appraisal committees is that the time an individual spends in the terminal phase of life is of greater value to them, and thus to society, than an equivalent period of time at any other stage of their life. It is also implicit that the opportunity cost of valuing time greater at the end of life is acceptable, despite it being unknown who will bear that cost.

Normand (2009) describes this problem in terms of the additivity of time. Within a welfarist framework, it is a necessary condition that the marginal benefit is the same for each individual and intervention (Weinstein, 1988). These benefits can then be summed to generate a social welfare function (assuming constancy in the social consumption value of health between individuals or interventions). If time is not valued the same at the end of life as it is at other times, it is argued (Normand, 2009) that it would then not be possible to simply sum the QALYs gained from an intervention to estimate the total welfare. This objection ignores the option of weighting health gains differently for different populations according to a set of social preferences for certain health gains relative to others. If it were theoretically possible to incorporate weighted values for health states into the QALY estimation process, then the additivity of time ceases to be a problem.

If it were deemed desirable to value time more heavily at the end of life, the most obvious approach would be to incorporate these values into the current estimation of QALYs through the application of an equity weight. However, no formal framework yet exists that would allow for this. Though it is conceptually possible to include equity weights in healthcare decision making, practical difficulties still exist in doing so and until these are addressed, weighting should be avoided (Wailoo et al., 2009).

Weighting different health gains has been argued to be acceptable under two conditions – that a weighting would reduce an existing inequality or that some forms of ill health are due to individual choice (such as smoking related illnesses) rather than bad luck (Dolan et al., 2011). It is clear that whilst some causes of ill health leading to death are due to individual choice, these criteria would not cover all individuals at the end of life and so such an exception could not apply to weighting health at this time differently. It is then necessary to demonstrate that the application of a weighting system to health at the end of life would reduce an existing inequality experienced by individuals at the end of life.

From an empirical perspective, the extent of the problem of valuing time differently (and thus what weights to apply) has yet to be demonstrated. It is not clear whether both individuals and society value time at the end of life greater than time at other life stages. Some research on the social value of lifetime health suggests the opposite – that health losses in childhood are more highly valued than health losses at other times (Edlin et al., 2009). Further empirical evidence could potentially resolve the issue. Choice experiments might be used to determine patient and public priorities for care throughout life, whilst large scale data sets could be explored, with appropriate controls for confounding factors, to understand how peoples’ preferences for health care spending change as they age or approach death.

Even in the case that convincing empirical evidence were available to demonstrate that time at the end of life is perceived to be of greater value from a societal perspective, it would need to be demonstrated that favouring this health above other health does not lead to an inequitable distribution of resources, where such an objective is a legitimate social aim (in the UK, through the NICE Social Value Judgements document (National Institute for Health and Clinical Excellence, 2008b)).

Key criticisms of the use of the QALY in evaluating end of life care (Coast and Lavender, 2009; Normand, 2009; Hughes, 2005; Arnesen and Norheim, 2003; Dolan and Stalmeier, 2003; Coast et al., 2008b) have not raised issues of equity. One potential such criticism might be that the use of cost-effectiveness analysis incorporating QALYs is ageist; most people die in old age, and so the bulk of end of life care is provided to this group. Supporters of this argument suggest primarily that the older a patient is the less likely they are to gain sufficient QALYs from interventions to make them cost-effective (Harris, 1994, 1996). It has been found that the charge of ageism in cost-effectiveness is in general without merit (Edlin et al., 2008; Pauluden and Culyer, 2010) and that in the case of treatments at the end of life, NICE decision making practices may in fact favour treatment (Pauluden and Culyer, 2010). The NICE Citizens Council has also found that health should not be valued differently depending on the patients’ age (National Institute for Health and Clinical Excellence, 2008b). Other forms of inequity that may arise in health care are no more unique to patients at the end of their life than they are at any other stage given the heterogeneity of the end of life population and should be addressed in that context.

A further objection to the standard analytical framework is the so-called ‘QALY problem’. Briefly stated, it has been proposed that there may be some interventions that are deemed desirable by the public and decision makers but that would not be accepted as cost-effective using the standard analytical approaches used in other areas of healthcare (Normand, 2009; Hughes, 2005). Despite the protestations of the progenitors of the claim (Normand, 2009), this is largely a case of special pleading and is not a phenomenon unique to end of life care. The QALY problem rests on a set of assumptions about the decision making process that does not always hold. It depends, for instance, on the threshold cost per QALY that a society is willing to pay for interventions being firmly established. This is not the case in the NHS, where the threshold lies between £20,000 and £30,000 per QALY. Although some treatments used in palliative care might lie above this threshold (Bravo et al., 2007), as argued by some (Normand, 2009), other treatments remain comfortably within it (Bravo et al., 2007), making the accusation of systemic discrimination difficult to justify. Such a situation is not unique to treatments used in palliative care (Dreztke et al., 2011). It is also not the case that the threshold is some fixed number, set in stone (Culyer et al., 2007). The actual threshold value is politically determined and in principle is subject to democratic conventions.

Another assumption that must hold for the QALY problem to be accepted requires acceptance of the notion that the preferences of one group of patients should be valued more highly than the preferences of other patients. Even were this true, such an assumption would, as described earlier, lead to a situation where an inequitable distribution of resources would be encouraged, as it is not possible to tell which patient group bears the opportunity costs of providing additional end of life care.

An alternative measurement framework, the Palliative Care Yardstick (or PaLy) has been proposed to replace the QALY (Normand, 2009). The aim of the PaLy is to allow for the allegedly higher value placed on end of life care by society to be incorporated into the decision making process. No firm proposal or methodology of how the PaLy would operate has yet been made available. The argument implicit in the PaLy is that time spent at the end of life is of greater value than other time; time is therefore not additive and so the PaLy, not the QALY, should be applied. Chochinov (2011) in a recent paper proposed a similar concept to the PaLy based on a similar argument.

4. The case for the QALY

It is clear following cross examination that the case against the application of the QALY in end of life care is unsubstantiated by the
either empirical or rhetorical evidence. However it remains important to elucidate the arguments in favour of retaining the QALY. There are two key arguments. The first is that, applied as it is within an extra-welfarist framework, it remains the best method available to resource allocation decision makers for ensuring that health care resources are distributed in accordance with preferences. The second is that those attributes that have led to the widespread adoption of the QALY – chiefly its ability to rate changes in morbidity and mortality in a single measure and to enable comparison between competing demands for resources – are as applicable in this population as in any other. To a large degree, the case in favour of the QALY involves the re-statement of arguments made above, however it is worth briefly re-emphasising these points in isolation from the arguments against the QALY.

That the QALY can sit within an extra-welfarist framework such as that described by Brouwer et al. (2008) and Culyer (1989) is a key strength. This framework allows for the valuation of quality of life in a way that is consistent with societal preferences as it permits flexibility in which domains of life should be included in the social welfare function. This flexibility means that it is possible to include domains of life that fall outside any standard definition of health within the QALY calculation (Brouwer et al., 2008). It has been argued that this flexibility is seldom applied (Coast et al., 2008b). But the fact that researchers have not taken advantage of this flexibility is not a criticism of the framework itself.

The application of QALYs within an extra-welfarist framework can also help to address issues of equity. Should it be deemed desirable to allocate resources in such a way as to create a more equitable distribution of health, the application of equity weights have been shown to be theoretically plausible (Wailoo et al., 2009). If it were shown that the distribution of resources to individuals at the end of life were currently inequitable, it would be possible to apply an equity weight to the QALY to address this. An equity weight would account for social preferences across different equity related criteria, such as those found in the NICE Social Value Judgements (National Institute for Health and Clinical Excellence, 2008b) document. The equity weight would then be used to adjust the QALY so that these social preferences are explicitly accounted for in economic evaluation. Although it is not clear on what grounds end of life care patients are treated inequitably, should a suitably compelling argument emerge, an equity weight could be derived and applied as required. The inclusion of specific equity weights within the QALY calculation could also improve decision making transparency (Wailoo et al., 2009). Currently, where equity criteria are considered in the decision making process it is not necessarily clear how or why such criteria are applied.

The other great strength of the QALY is that it enables comparisons to be made between competing demands for resources at both a technical and allocative level combining both quality and quantity of life in a single metric. Even where one of these domains does not change significantly, it is possible that improvements can be made in the other. Some interventions, such as thrombolysis are provided with the intention of extending life and not with an explicit aim of improving its quality. Other interventions, such as home nursing support are aimed primarily at improving the quality of a life, not extending it. That a metric exists which allows for comparison between interventions with such widely differing objectives is important. It enables the consideration of the relative merits of each treatment – should resources be directed towards saving the life of a single individual, or improving the quality of life of many?

In principle it is possible within the extra-welfarist framework to accommodate the different needs of different patient groups within the calculation of benefits from treatment, whether these are directly health related or fall under some other domain important to patients’ quality of life. What comprises good quality of life is a question that has been debated for thousands of years. Whilst modern thinking differs from that of Aristotle (who felt that a good life could only be lived by a small subset of the population – a subset which did not include, women or children), it is still a nebulous concept, open to differing interpretations. Researchers operating in an extra-welfarist framework have managed to include non-health domains within preference based quality of life instruments (Stevens, 2009), suggesting that incorporating into the QALY non-health domains that may be effected by the provision of some form of healthcare is certainly possible. There is to date no convincing argument that such an approach could not be applied in end of life care. As the QALY framework explicitly allows for the introduction of quality of life into the measurement of benefit, a preference based instrument could be developed which takes account of the domains of relevance to the population. It is appropriate then that the QALY remains the key measure of outcome in economic evaluations of end of life care, until and unless some other metric is devised that is considered more appropriate.

5. Directions for empirical research

Many of the arguments against the QALY in end of life care lack convincing empirical support and this may be related to perceived difficulties in conducting research with people who are facing death. Current evidence on how people value time at different stages of their lives remains equivocal. Due to the subjective nature of the question, it is unlikely that a definitive answer could be reached empirically and normative judgements must be made. If the judgement is that time at the end of life is to be valued more highly, empirical evidence would be needed to inform the application of an appropriate weight. In addition, there remains the problem of using death as an anchor point, and seeing it by definition as a negative health state outcome, as well as the question, relevant for many disciplines in planning end of life care, of the stability of preferences over time.

The most commonly used methods for valuing health state utilities are the time-trade off (TTO) and the standard gamble (SG) each of which use death as anchor point. However, alternative methods for valuing health states are increasingly being explored – discrete choice experiments (DCEs) and best–worst scaling (BWS). These methods retain some of the key strengths of the TTO and SG, particularly in requiring individuals to choose between different scenarios representing different levels of health. Importantly however, as a specific anchor point for valuing health states they do not necessarily require the length of life trade or gamble used in the TTO or SG. In other words death as an inevitable outcome becomes ‘acceptable’.

Although the application of DCEs and BWS exercises for valuing health states is not yet widespread, recent non-valuations studies have shown that respondents in a range of health care populations are capable of understanding and completing DCE and BWS exercises (Ratcliffe et al., 2011; Douglas et al., 2005; Ryan et al., 2006). The development of DCE or BWS studies to value health states experienced by end of life populations would not be conceptually difficult – scenarios for ranking are derived from the measurement instrument to be valued and can be selected in a similar fashion to scenarios selected for TTO or SG studies. The methods are also known to be acceptable to end of life populations (Douglas et al., 2005) and to provide robust health state valuations (Potoglou et al., 2011). Whilst many technical challenges remain it is possible to envisage DCE or BWS exercises for the purposes of valuing end of life health states that do not require trading against death as an alternative. Such experiments, conducted using a general
population sample across all age groups, would help address empirical questions such as how best to value health states in end of life populations as well as provide a general population value set for the health states. They might also lead to more robust and acceptable values for calculating QALYs, and overcome the objection that death is not an appropriate anchor point for valuing health states in this population.

The stability of preferences over time may be resolved through recourse to empirical evidence. The hypothesis that preferences do not remain stable over time could be tested using a large, random sample of the adult general population, capturing a broad range of ages. If each respondent values the same health states using the same methods, it would be possible to explore the stability of health state values across age groups. Whether preferences are unstable according to known proximity to death and not just age could be tested using a sub-sample of patients identified as end of life. As most, but not all individuals die when they are older, it is necessary to test for both age related effects and effects that may be caused by proximity to death. If evidence is conclusive that preferences vary according to age or proximity to death this could have important implications for how QALYs are calculated – for example, the application of a weighting system.

6. Conclusion

Although the arguments against the QALY for use in end of life care are numerous, there still exists no viable proposed alternative way of measuring health benefits for the purposes of resource allocation decision making. Even if it were accepted that the QALY was not suitable, the needs of decision makers would still exist. Any proposed replacement measure would have to share many of the attributes of the QALY. Crucially, it would need to be suitable for the comparison of the opportunity cost of competing demands for resources and would thus need to be compatible with the QALY or provide a wholesale alternative for use across all healthcare evaluation. This would permit interventions in the end of life population to be considered on the same grounds as interventions for all other conditions. Any alternative system must therefore demonstrate that it is robust both conceptually and operationally for the measurement of health and other domains as applicable for the valuation of health – or perhaps life – states and for comparison of opportunity cost.

At present, the arguments levied against the use of the QALY in end of life care are not sufficiently convincing to warrant the development of an alternative system of expressing outcomes in health care. What many of the arguments have highlighted is the need to improve the methods by which we measure and value health and quality of life in people nearing the end of their lives. Convincing arguments exist to extend the measurement of benefits beyond those directly related to the health of an individual; this could be achieved through the dominant extra-welfarist framework under which resources are frequently allocated. It is also important to consider the way that standard valuation methods are applied to quality of life as experience by the end of life patient population, irrespective of whether values are to be elicited from this patient group themselves or the general population. Exploration of alternative methods for valuing health states – or more broadly, ‘life states’ – such as discrete choice experiments or best worst scaling could be pursued.

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