

**RESEARCH METHODOLOGY:
DISCUSSION PAPER—METHODOLOGY**

Are guidelines for measurement of quality of life contrary to patient-centred care?

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Funding information

Disher is supported by a Canadian Institutes for Health Research, Killam Trust (or Foundation), Nova Scotia Health Research Foundation, Dalhousie Faculty of Graduate Studies, and the Dalhousie University. Campbell-Yeo is supported by a Canadian Institutes of Health Research New Investigator Award

Abstract

Aims: A discussion of how quality-adjusted life years are used to inform resource allocation decisions and highlight how assumptions underpinning the measurement of quality of life are contrary to the principles of patient-centred care.

Background: Cost-effectiveness analyses (CEAs) can provide influential guidance for health resource allocation, particularly in the context of a budget-constrained public health insurance plan. Most national economic guideline bodies recommend that quality-adjusted life year weights for CEA be elicited indirectly (public preferences). This has potentially important implications for healthcare provision and research, as it discounts the ability of a person experiencing an illness to describe how it affects their quality of life.

Design: Discussion paper.

Data sources: Guidelines for the conduct of health economic evaluations, influential methodological and theoretical texts, and a review of PubMed conducted in April 2017.

Implications for Nursing: Nurses are increasingly interested in leveraging methods from health economics to aid in decision-making and advocacy. In this analysis, we highlight how taken-for-granted approaches to the measurement of quality of life may discount the experience of patients and lead to decisions that are contrary to the principles of patient-centred care. Nurses conducting or reading research using these methods should consider whether the approach used to measure the quality of life are appropriate for the population under consideration.

Conclusion: Since patient and public health preferences can differ in both magnitude and direction, guideline bodies should re-evaluate their partiality for public preferences in the reference case.

KEYWORDS

cost-effectiveness, health economics, nurse, nursing, QALY, quality of life

1 | INTRODUCTION

Cost-effectiveness analysis (CEAs) of healthcare interventions is important for modelling assumptions when making policy decisions and to inform the efficient use of resources (Briggs, Claxton, &

Sculpher, 2006). Cost-effectiveness analyses measure the cost associated with a one unit increase in an outcome of interest. When this is a quality-adjusted life year (QALY), the analysis is sometimes referred to as a cost-utility analysis (CUA), though CEA and CUA are often used interchangeably. The appeal of the QALY is that it allows

an analysis to capture the value of reduced mortality and improved quality of life simultaneously (Drummond, Sculpher, Claxton, Stoddart, & Torrance, 2015). Quality-adjusted life years are calculated by multiplying the years spent in a given health state by the estimated utility associated with it. Perfect health would have a utility value of one, indicating that each year of life is equal to one QALY, while a severe disease state may be associated with a utility value of 0.5, suggesting it takes 2 years of life to earn one QALY. Utilities can be derived by having patients themselves work through an elicitation exercise (patient preferences) or by having them complete a standardized questionnaire that describes their health state which then maps to utility values that were assessed by the general public (public preferences). The patient perspective is therefore represented in both methods through their evaluation of their health (e.g., ability to walk without assistance), but the methods differ in whose health preferences are used to assign the utility to that health state. Most importantly for nurses who are interested in CUA to contribute to policy, research, and practice decisions is evidence that patient and public preferences can differ in both magnitude and direction (Doctor & Bleichrodt, 2010; Ogorevc, Murovec, Fernandez, & Rupel, 2017; Tengs & Lin, 2003; Tengs, 2002). In the context nurses' historical commitment to and advocacy for patient-centred approaches to research and clinical care, the decision to use public preferences may inappropriately discount patient preferences and prevent the adoption of healthcare interventions that maximize population health. This surfaces a critical policy question: Do public preferences provide the most effective understanding of the value of healthcare interventions?

2 | BACKGROUND

When used to inform policy and resource allocation decisions, CUAs are typically one component of a broader health technology assessment process. The formal process of health technology assessment and the role of CUA within it vary by institution and jurisdiction but typically include consideration of costs and cost-effectiveness alongside safety; efficacy; patient preferences; and social, legal, and ethical impacts (O'Donnell, Pham, Pashos, Miller, & Smith, 2009). In the United Kingdom, health technology assessments including CUA are performed on a national level for the National Institute for Health and Care Excellence (NICE) with decisions enforced across the entire National Health Service. A similar process is used in Canada to provide reimbursement recommendations to Provinces and Territories. In the United States, CUA/CEA is excluded from Medicaid decisions through an act of Congress but is represented in the health technology assessment process of the Academy of Managed Care Pharmacy who provide recommendations to member drug plans (The Academy of Managed Care Pharmacy, 2016) and the Institute for Clinical and Economic Review (ICER) (Neumann, Sanders, Russell, Siegel, & Ganiats, 2016). Cost-utility analyses are also conducted by independent researchers to provide additional evidence for clinicians choosing between technologies, procedures, or treatments.

Why is this research needed?

- Health economics offer methods that are valuable to nurses and nurse researchers.
- Cost-effectiveness analyses can provide convincing evidence to assist resource allocation decisions and their focus on maximizing quality of life would appear a good fit with nursing's traditions of knowing.

What are the key findings?

- Economic guidelines recommend methods that assign value to health states based on how members of the general public imagine how that health state affects the quality of life.
- When asked directly, patient's impressions are different than those from the general public both in terms of magnitude and what aspects of the illness are most important.
- These differences could feasibly direct resources away from interventions, drugs, or technologies that target patient important aspects of illness.

How should the findings be used to influence policy/practice/research/education?

- Nurses reading or conducting economic evaluations should consider which method of measuring quality of life is applicable to their population.
- Taken-for-granted assumptions regarding whose perspectives are prioritized should be questioned.

Generally speaking, the incremental cost-effectiveness/cost-utility ratio (ICER/ICUR) is the primary outcome of the economic evaluation of healthcare interventions (Drummond et al., 2015). The ICUR allows for comparison of the cost per additional QALY of one intervention compared against another (Briggs et al., 2006). Whether an intervention is cost-effective is based on an ICER threshold which reflects the stated or implied value (e.g., through historical patterns of funding) of a QALY. When applied to questions of resource allocation, health economists argue that this value should represent the opportunity cost of resource allocation under a constrained budget. This provides an interpretation of the ICER threshold as the value above which more health would be displaced by adopting a new intervention, through the displacement of more cost-effective alternatives, than it creates. The NICE has a publicly stated ICER of £20,000–30,000/QALY. Recent work by Claxton and colleagues suggests that, based on estimated QALY returns associated with historical National Health Service spending, this threshold should be reduced to £12,936/QALY. If the ICER is less than the decision maker's willingness to pay threshold, then the new intervention is considered cost-effective (Canadian Agency for Drugs and Technology in Health (CADTH), 2017). This approach has implications for

policy as the way utility values are derived has a profound influence on outcomes of relative cost-effectiveness, for example, an intervention that is intended to improve some aspect of disability. If one method of elicitation gave very low utility values for disability states, then interventions to reduce disability would perform more favourably compared with life-saving interventions compared with an approach that gave those same disability states a higher utility value.

Utility values are derived through one of three methods: the standard gamble, time trade-off, or a discrete choice experiment (Drummond et al., 2015). For the standard gamble, participants are asked whether they would risk a procedure that would restore perfect health with a probability of instant death with the point of indifference being the utility value. The time trade-off participants are asked to choose between, for example, living for 70 years with blindness and 60 years in perfect health. In discrete choice experiments, aspects of a health state are modified over a repeated series of choice-based questions and preferences derived. The three methods typically yield different results for the same health state (Drummond et al., 2015).

An additional characteristic that influences the utility estimated for a health state is whether they are elicited directly from patients who are experiencing them or from a representative sample of the general public (Canadian Agency for Drugs and Technology in Health (CADTH), 2017). Patient preferences can be thought of as answering the question: "How do patients experiencing this health state rate their quality of life?" whereas public preferences answer the question: "What does a member of the general public imagine their quality of life would be if they were to experience the given health state?" An example of a commonly used tool based on public preferences is the EuroQoL-5D (EQ-5D-5L), a 5-item questionnaire administered to patients whose responses then map to one of over 3,000 health states with utility values estimated from the general public (Herdman et al., 2011).

While differences in elicitation methodology (e.g., standard gamble vs. time trade-off) and perspective of health preferences (patients or the general public) can both lead to differences in the utility estimated for a given health state (Drummond et al., 2015), this manuscript will focus on the implications of the latter. It is estimated that 76% of studies that use QALYs as an outcome measure use utility values elicited from the general public (Glick, Doshi, Sonnad, & Polsky, 2015). This discussion paper will introduce the theoretical and methodological arguments underpinning why public preferences dominate the literature, highlight how these principles minimize the patient voice, and offer an alternative approach to guide nurses conducting or interpreting CUAs.

3 | DATA SOURCES

Discussion is guided by primarily of key texts identified through the ISPOR key resources website (International Society for Pharmacoeconomics and Outcomes Research (ISPOR), 2017), with additional reference to theories of epistemic injustice (Fricker, 2007) and the

work of Avedis Donabedian (Donabedian, 1966). These data are supplemented by our familiarity with relevant citations and a supplementary search of PubMed in June 2018 which helped to identify recent relevant methodological or theoretical publications. The search took the form of (QALY or "quality-adjusted life year" OR "quality adjusted life year" OR utilities) AND (direct OR indirect OR public OR patient) AND (elicitation OR preferences). Manuscripts published since 2010 were included. The search returned 463 records of which eight are considered in this discussion (Gandjour, 2010; Karimi, Brazier, & Paisley, 2017; Ogorevc et al., 2017; Prosser, Grosse, & Wittenberg, 2012; Stamuli, 2011; Versteegh, Knies, & Brouwer, 2016; Weyler & Gandjour, 2011).

4 | DISCUSSION

The most well-known difference between public and patient preferences is that the public tend to estimate lower utilities for the same health states (Karimi et al., 2017; Neumann et al., 2016; Stamuli, 2011). This causes CUAs to favour interventions that improve the quality of life over life-saving interventions, although the full implications are complex and reviewed in detail by Brazier et al. (2005). New evidence suggests that public and patient preferences may differ in other important ways as well. In a study of over 600 participants with either metastatic breast cancer or rheumatoid arthritis, Ogorevc et al. (2017) compared health weights derived using patient versus public preferences and found a statistically significant difference between them. Patients identified pain as more important for determining quality of life, while public preferences were more concerned issues of self-care. Thus, a significant problem arises in that utility values directly influence the health outcomes in CUAs and the way we measure them influences what aspects of illness are perceived as important to target for intervention.

4.1 | Structure, process, and outcome

Nursing has a long history of focus on the centrality of the patient experience in guiding care. In her notes on nursing, Florence Nightingale promotes a holistic approach to care grounded within the interaction between the patient and their environment (Nightingale, 1974). Modern nursing care retains this focus on the experience of the patient and advocates for the importance of a holistic view of health centred on the aspects of life that are important to patients (Wright & Leahey, 2013). This patient-centred approach leads to plans of care that address the aspects of health that are relevant to patients and their families. The QALY itself would seem to be a good fit within this tradition, since it draws focus to the subjective experience of health. If, for example, a CEA were conducted using cost per fracture avoided as an outcome, the nurse evaluating the intervention would have to imagine the impact a fracture may have on a patients' quality of life. This extra step is not theoretically required within a CUA. The congruence of CUA with patient-centred care is,

however, diminished the more public and patient preferences diverge.

The implications of the reliance on public preferences to guide decisions related to health improvement can be assessed within a Donabedian (1966, 1988) framework. Donabedian argues for the ability to quantify and examine healthcare quality across three domains: structure, process, and outcome (see Figure 1). *Structure* is the initial component of the framework and encompasses the infrastructure in a healthcare system; *Processes* are interactions and networks of relations that exist in the health system including the effective delivery of care and the quality of the “rapport” between patients and the health system; and, “outcome”, which is a multifaceted concept, encompassing the alleviation of some measure of risk and symptom relief; the return of functionality and the sense of “feeling cured,” which must go along with the technical aspect of being cured.

Campbell, Roland, and Buetow (2000) argue an extension to the Donabedian framework, stating the quality of health outcomes may alter, strengthen, or maintain the nature of the health system (i.e., structures and processes) operating as a “feedback loop,” suggesting the system is a “learning” system, where a particular outcome will reinforce the antecedents that led to that outcome. Current guidelines for the conduct of economic evaluations have the most direct implications for the structure and outcome components of the Donabedian framework. Cost-utility analyses contribute to decisions regarding what technologies are reimbursed (and thus available a part of the health system structure) and QALYs themselves are an outcome of that system. Routine use of public preferences thus creates an environment that structures itself around optimizing imagined health states instead of experienced ones and marginalizes the voices of patients and limits their access to interventions (structure) that address the aspects of illness most relevant to them and then evaluates the system using a metric that disguises these shortfalls.

4.2 | The insurance and social contract principles

Perhaps the strongest arguments for using public preferences are the insurance and social contract principles. The insurance principle is based on the belief that health systems are essentially insurance companies (Canadian Agency for Drugs and Technology in Health (CADTH), 2017; Gandjour, 2010). Since insurance is purchased before an event is experienced, health system decisions should reflect the preferences of a generally healthy population (Versteegh & Brouwer, 2016). This argument provides a logical answer to why public preferences should be used when deciding between competing treatments since improvements in health should be viewed from the perspective of a healthy individual's perception of the disease. Similarly, the social contract principle states that “society should create mechanisms to allocate resources to prevent and reduce illness and improve health and longevity” (Neumann et al., 2016). Since the benefits of these health systems are enjoyed by society as a whole, it is society as a whole (i.e., the general public) whose preferences are relevant. While these arguments are compelling, we find it

insufficient given the centrality of patient report in modern health care (Busse et al., 2015; Price, 2004) in addition to the ease with which they can form the foundation for the opposite argument (Brazier et al., 2005).

A patient in pain rightfully expects their self-report of that experience to be central to guiding treatment and would be loath to rely on the ability of a disinterested member of the general public to imagine the impact their pain may have on their quality of life. The readily available self-report of the effect of health states on quality of life ought to be given a similar prominence. Consider a scenario where two countries are setting priorities for funding of treatments for cancer. One country follows the insurance principle and elicits public health preferences while the second uses patient preferences. Consistent with results from Ogorevc et al. (2017), the public imagines that the most detrimental impact of living with cancer is the loss of independence with self-care. Cancer patients themselves, however, state that pain is the most detrimental aspect of the illness. The differences in health preferences lead the first country to prioritize treatments that improve independence with self-care, while the second country prioritizes pain-relieving treatments. If it was possible to measure the quality of life of individuals in both countries, we would find that the country that used public preferences has lower overall population health. This would directly contravene the stated purpose of economic evaluations, which is to provide a road map to maximizing population health (Drummond et al., 2015).

Brouwer, Culyer, van Exel, and Rutten (2008) state that the extra welfarist allow for representatives of the healthcare system to make allocation decisions based on their interpretation of what they ought to do given their mandate (typically assumed to be to maximize population health). This provides the basis for decision makers to include considerations other than maximization of welfare (e.g., ethical considerations, health for its own sake) when allocating resources. The same principle also provides sufficient basis for decision makers to justify the use of patient preferences by saying that the public ought to have health care administered in a way that will maximize their experienced utility. Since patients have the most insight into how their illness affects experienced utility (Brazier et al., 2005) and some evidence suggests that their health valuations are more consistent with underlying assumptions of the QALY (Weyler & Gandjour, 2011), then these preferences are the natural choice.

4.3 | The “veil of ignorance” and adaptation

A primary concern for those arguing for use of public preferences is that it is vital that decisions about utility values are made behind a “veil of ignorance,” by a general public that does not have a specific stake in decisions being made (Versteegh & Brouwer, 2016). This argument assumes that patient preferences are susceptible to influence by those with special interests, either through organized or unorganized means. An individual with arthritis may therefore be tempted to overstate the degree to which pain influences their quality of life, potentially highlighting their condition as a priority for healthcare spending. By having the public value of health states



FIGURE 1 The structure–process–outcome framework of health system evaluation (Donabedian, 1966, 1988) [Colour figure can be viewed at wileyonlinelibrary.com]

without having experienced them, proponents argue that this potential bias is avoided. However, since questionnaires based on public preferences like the EQ-5D-5L still require patients to describe their health state, the use of public preferences does not necessarily prevent patients from selecting more extreme health states or overstating the benefit of treatment (Brazier et al., 2005). Second, the assumption that the general public is free from the influence of special interests is difficult to justify. The discussion of patient and public health preferences has been largely influenced by the 1996 panel on cost-effectiveness in health (Gold, Siegel, Russell, & Weinstein, 1996). Since this time, special interest groups have shown that they can influence the preferences of large proportions of the population. For example, through successfully encouraging policies that run counter to the best interests of the population based on artificially inflated fears of risk and resulting disability or death in both prostate and breast cancer (Cassels, 2012a,b; Cassels & Moynihan, 2012).

A related argument to the need for a veil of ignorance is the problem of adaptation. Briefly stated, it is assumed that if given the option, individuals would choose a healthy life free of disability (Drummond et al., 2015). Those who are chronically ill or disabled do not have this option, and thus, their preferences represent some combination of denial and re-evaluation of the benefits enjoyed in perfect health (Stamuli, 2011; Versteegh & Brouwer, 2016). Disability theorists and particularly those in the disability pride movement would argue that this view represents another in a series of paternalistic discounting their subjective experience (Barnes, 2016, p. 123). Miranda Fricker (Fricker, 2007) uses the terms testimonial and hermeneutical injustice to describe the ways those living with serious illness or disability are placed in a disadvantaged position in respect to their position as knowers. Of these, it is testimonial injustice that most directly captures the issues faced by preferring public preferences. Testimonial injustice describes how the stated preferences of those in less privileged epistemic positions are discounted or ignored (Fricker, 2007). This is precisely what happens when we prefer the stated utility values of the public over those experiencing illness. The result is that

economic evaluations are biased towards those aspects of illness and disability that the public imagines are the most important, as opposed to the stated preferences of those who are currently experiencing the condition. Furthermore, Brazier et al. (2005) argue that it is likely that adaptation is already considered in public preferences since a 70 year old who is administered the EQ-5D-5L likely has a different interpretation of the limitations of their mobility compared to a 17 year old with a similar level of disability.

Together, the popularity of the insurance principle along with the perceived importance of the veil of ignorance and concern that adaptation biases health state valuation has resulted in 64% (25/39) of guidelines listed on the ISPOR guidelines directory prefer public preference elicitation. In some cases, these guidelines allow for the use of patient-derived preferences in a secondary analysis (Canadian Agency for Drugs and Technology in Health (CADTH), 2017; Neumann et al., 2016). In the next section of this discussion, we offer an approach informed by a Donabedian framework that suggests an a priori partiality for patient versus public preferences is inappropriate.

4.4 | A possible solution

Before turning to consideration of a possible alternative, it is relevant to be reminded of the overall purpose of CEA as described in guidelines, which is to “maximize some specific policy objective (e.g. improving the overall health of the population)” (CADTH, 2017, p. 13). There are clearly cases where we should prefer patient preference elicitation over generic public preferences from a health maximization standpoint and that preference should grow as differences between decisions informed by either increase. There may also, however, be cases in which a public health preference elicitation might be preferred. We argue that a preference for one approach over the other is only appropriate on a case-by-case basis and not in a general sense. We argue there should be guidance that equally values public and patient preference elicitation without an a priori preference. For decisions regarding treatments intended to improve or

cure a given condition, we should prefer patient preferences. This ensures that decisions of treatment are focused on treating the aspects of illness that are important to patients, thus improving population health. When the consequences of a decision are faced primarily by the healthy population (e.g., a large-scale vaccination programme) using their utility values, we can accurately capture the desire to avoid disabling complications.

Our approach allows for the resolution of testimonial injustice faced by those experiencing a given illness, whose stated QALY weights are currently ignored in favour of the beliefs of the general public (Fricker, 2007). In the context of Donabedian's (1966) analysis, this nimbleness in preference elicitation is an element of structure which establishes the pathways of possible processes that can occur to provide health care, both to individuals and society. The measurement of outcome captures the therapeutic impact on the patient and the functional impact on the system. Following Campbell et al. (2000) assertion of "learning" in the system, such a flexible structure in elicitation would allow for systemic adaptation that focuses on building a health system that optimizes outcomes for the population most affected by decisions.

4.5 | Objections

One potential argument against the adoption of flexible requirements for preference elicitation is that it would introduce methodological heterogeneity (Canadian Agency for Drugs and Technology in Health (CADTH), 2017). Elicitation of patient preferences relies on individual investigators to appropriately develop and administer questionnaires that can be complex and time consuming (Prosser et al., 2012; Ungar, 2011). Public preferences have been validated with large samples of patients from diverse backgrounds using a set of expertly developed tools. By allowing the decision under consideration to dictate the method used, an additional layer of variability in the results is introduced. However, although direct elicitation methods are more complex, additional training can produce valid and reliable measures. Referring to Donabedian's (1966) model, this demonstrates how the interaction of structure and process in the development of refining a flexible approach can assist in maximizing population health.

An additional concern is the diversion of resources from a particular health sector if direct elicitation revealed higher than previously measured quality of life (Menzel, 2014). However, the counterpoint is likely true under the current scheme of evaluation, as the approach we have used to date has unjustly ignored the stated utility values of those bearing the weight of a decision. More importantly, if the public and those afflicted with an illness differ in an aspect of an illness as being the most important from a quality of life standpoint, this creates the possibility for *new* decisions, for *new* processes to emerge. For instance, new opportunities for therapeutics open and these pathways will align with what the individuals themselves identify as important.

A key theoretical benefit of the QALY is that it can be used to compare interventions across diseases. Our approach would create

several conceptual and methodological issues in the short term. The first is that it is possible to elicit public preferences regarding health states themselves and then apply them to any number of diseases while elicitation of patient preferences requires the comparably massive task of eliciting preferences from a representative sample of patients in every disease of interest. In the case of health technology assessment, this representative sample is typically preferred to come from the country where the decision is being made (NICE, 2013). There are valid concerns regarding the feasibility of such an endeavour, and thus, this approach would decrease the flexibility of the QALY across diseases. This creates a related issue when decisions to reimburse a technology are made without knowing which technologies are displaced as a result. In these cases, it would not be possible to measure the displaced QALYs directly and there is a need to rely on an empirically derived ICER that captures the opportunity cost of investment in new technologies (Claxton et al., 2015). If this ICER is derived using public preferences, as it feasibly would be in the current environment, then decisions based on patient-elicited preferences would be incompatible and would potentially displace more health than they create. We question whether a valid empirically derived ICER is feasible itself given the substantial assumptions and compromises required by currently published efforts (Claxton et al., 2015). Furthermore, the derived ICER would only be valid when QALYs are derived using the same tool, since estimates of population QALYs will differ if derived from different scales or methods (time trade-off vs. standard gamble). Finally, the issue remains as to whether this threshold measures the right opportunity cost at all. If the goal of a health system (or hospital manager, or clinician) is to maximize the health of those under their care, then it remains unclear how any threshold based on publicly derived preferences is sufficient. Assuming the existence of sufficient data to estimate an empirical threshold, then decisions based on this threshold can only be expected to maximize imagined utility, since actual experienced utilities can differ significantly. Our approach would likely require abandonment efforts to judge ICURs against national thresholds and reduce to some degree the authority granted to the CUA by virtue of its connection to opportunity cost. We believe that perhaps the more modest goal for CUA to operationalize assumptions and clarifying trade-off is appropriate, particularly in light of how CUA is already used within HTA in addition to the artificial nature of most ICUR thresholds. This is a difficult objection and one that highlights the compromises required to use CEA to make regional, provincial, or national decisions where the technology displaced is commonly unknown. The lack of comparability across diseases is perhaps less problematic for individual centres or clinicians who could feasibly be aware of the trade-offs induced when new technologies are introduced.

5 | IMPLICATIONS FOR NURSING

Researchers conducting health economic evaluations should carefully consider the implications of using patient versus public preferences. For interventions targeted at prevention, valuing the quality of life of

the consequent health states is best done using public preferences. For interventions intended to improve existing health, patient preferences should draw attention to the aspects of illness most important for those experiencing it and thus should be preferred. Recognizing that elicitation of patient preferences is not feasible in all cases, utilities based on public preferences can be used but should be accompanied with additional outcomes (e.g., unadjusted life years or cases averted) and authors should caution against over-reliance of cost-per-QALY results for resource allocation or clinical decisions. In keeping with the second US panel on cost-effectiveness recommendations for additional research regarding how patient and public preferences differ (Neumann et al., 2016), when patient preferences are used and where considerations for participant burden allow, a sensitivity analysis using public preferences should also be conducted to allow for consideration of the effects of elicitation method.

When reading an economic evaluation, clinicians should note whether the method of utility value elicitation is consistent with the population who will receive the intervention. Use of public preferences should by no means be considered a fatal flaw, but a consideration of the implications will help inform to what degree the study should influence practice.

6 | CONCLUSION

Quality-adjusted life years are the most commonly used outcome in CEA and are thus influential either when used as part of a broader health technology assessment process, or as an aid for clinical decision-making. Despite many approaches to health technology assessment providing opportunities for patient input outside of the CUA, the decision to use patient versus public preferences in CUA remains nontrivial. While this is a normative question without a “right” or “wrong” answer, we find the typical justifications for public preferences inconsistent with the stated goals of maximizing population health. Since methods result in utility values that can differ in both magnitude and direction, a preference for public health preference elicitation for all problems represents a form of testimonial injustice which guarantees poorer experienced population health. We highlight how indirect preferences may be preferred for questions of prevention, but direct preferences should be preferred when evaluating interventions to improve of cure a given disease. This argument aligns with the patient-centred focus of nursing, the goal of maximizing population health, and the system design perspective offered by Donabedian (1966).

AUTHOR CONTRIBUTIONS

All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE [<http://www.icmje.org/recommendations/>]):

1. substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;

2. drafting the article or revising it critically for important intellectual content.

CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

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How to cite this article: Disher T, Beaubien L, Campbell-Yeo M. Are guidelines for measurement of quality of life contrary to patient-centred care? *J Adv Nurs*. 2018;74:2677–2684. <https://doi.org/10.1111/jan.13820>

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