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Proxy Evaluation of Health-Related Quality of Life:

A Conceptual Framework for Understanding Multiple Proxy Perspectives

A. Simon Pickard, PhD* and Sara J. Knight, PhD†

* *From the College of Pharmacy, University of Illinois at Chicago, Chicago, Illinois; and the*

† *Mental Health and Urology Services and the Interdisciplinary Research Program to Improve Care for Older Veterans, a Research Enhancement Award Program of the Health Services Research & Development Service, Department of Veteran Affairs, San Francisco Veterans Affairs Medical Center, and the Departments of Psychiatry and Urology, University of California–San Francisco, San Francisco, California.*

Abstract

Proxy assessment of health-related quality of life (HRQL) may be sought to substitute for, or to complement, patient self-assessment. The viewpoint from which the proxy is asked to assess the patient is a subtle yet important aspect of proxy assessment. Proxy assessments can be elicited by asking a proxy to assess the patient as they think the patient would respond (ie, proxy-patient perspective) or for the proxy to provide their own perspective on the patient's HRQL (ie, proxy-proxy perspective). In this article, we introduce a framework for differentiating between and understanding HRQL assessments according to rater viewpoint. The difference between patient self-assessment and the proxy-patient perspective is defined as the *inter-rater* gap, whereas the difference between the proxy-patient and proxy-proxy perspective is described as the *intra-proxy* gap. The *inter-rater* gap represents the difference between patient self-assessed HRQL and the proxy ability to comprehend the patient view. The extent to which the proxy-proxy perspective is informative will depend upon the proxy's ability to provide reinforcing or complementary information, ie, represented by the *intra-proxy* gap, on the HRQL of the patient. We refer to the framework to emphasize the importance of delineating between proxy perspectives in study design and HRQL measurement and to guide inquiries into the validity and interpretation of the meaningfulness of the proxy HRQL assessments from each viewpoint. Future research and use of proxy raters of HRQL in clinical trials, population health monitoring, resource allocation, and clinical management can be informed by explicit consideration of the suggested framework.

Keywords

proxy; health status; caregiving; quality of life; provider/patient communication

Health-related quality of life (HRQL) is an important outcome that helps clinicians and researchers understand how individuals feel about their health. Although there is no consensus on the definition of HRQL, HRQL assessment can be conceptualized as involving 2 components: (1) an assessment of health status, which encompasses physical, psychologic and social functioning; and (2), an emotional evaluation or affective response to the health status assessment.¹ The subjective nature of HRQL assessment would dictate that the patient is the

Reprints: A. Simon Pickard, PhD, Center for Pharmacoeconomic Research & Department of Pharmacy Practice, College of Pharmacy, University of Illinois at Chicago, Room 164, MC 886, 833 South Wood Street, Chicago, IL 60612. E-mail: pickard1@uic.edu..

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primary informant in the assessment. However, self-assessment of HRQL can be challenging or impossible for some patients, such as the very young, the frail elderly, and the cognitively impaired.^{2,3} In such instances, a proxy such as a health care professional or family caregiver may be asked to assess the patient's HRQL.

Proxy assessments address some troublesome issues about internal validity (ie, ability to detect HRQL differences) and external validity (ie, generalizability) in outcomes research. Proxy assessment may substitute for patient self-assessment in clinical trials that include HRQL outcomes to avoid excluding patients who cannot respond for themselves. Missing data can result in biased estimates of treatment effect as the result of nonrandomly missing data, diminish the power of a study to detect changes over time or differences between groups, and compromise generalizability.⁴

In addition to substitution for patient assessment, proxy assessments can inform clinical decisions about patient care by reinforcing information provided by self-assessment or by providing additional, complementary information about the patient. In clinical settings, lack of complete information on patient HRQL may result in inadequate relief of suffering and suboptimal clinical decision-making. A patient's ability to self-assess HRQL may be limited in advanced disease or in end-of-life care, particularly if they have adapted to pain or other symptoms, have concerns that potentially life-saving treatments may be taken away, have stoicism or anxiety about pain management, or otherwise have the tendency to minimize the impact of these problems on their ability to function and their well-being.⁵⁻⁸ Under such circumstances, family member observations of the impact of pain or other symptoms on the patient's experience (eg, sleep, social activity) may be able to provide complementary or more comprehensive information than the patient may provide.^{9,10} The importance of an alternative viewpoint on HRQL to inform medical decision-making also is evident in childhood conditions, such as epilepsy and cancer. For example, shared decision-making is informed by parent-reported HRQL of children, as parents have an important role in defining what they believe to be best for their child and evaluating the potential success of treatment options.¹¹

Thus, proxy assessments may substitute for patient self-assessment of HRQL, or complement/reinforce self-assessment by eliciting the proxy's view of patient HRQL. We delineate between proxy perspectives follows: a proxy may assess a patient as the proxy thinks the patient would rate his or herself [proxy-patient], or the proxy may assess the patient from the proxy's perspective [proxy-proxy] (eg, parent reported HRQL of a child). The proxy-patient viewpoint is intended to elicit substituted judgment, where the proxy projects themselves into the *body and mind* of the patient for the purpose of responding to the HRQL assessment. In contrast, the proxy-proxy perspective purposefully elicits an assessment of HRQL that may diverge from the patient's own perceptions without compromising the validity of either construct.

Each proxy perspective has the potential to provide valuable information that may converge or diverge to varying degrees with patient self-assessment of HRQL. Accordingly, the main purpose of this article is to present a framework for understanding the information provided by proxy raters of HRQL according to proxy perspective elicited and to discuss the advancement of HRQL measurement on the basis of proxy perspective. This article is presented in 3 sections. First, the proxy literature is appraised in terms of methodological consideration given to the proxy perspective. In the second section, we propose a conceptual framework for understanding how different proxy perspectives may inform HRQL assessment. Third, we discuss implications of the proposed framework for health services research and medical decision-making.

STUDIES OF PROXY ASSESSMENTS OF HRQL

The use of proxies to assess HRQL has been examined in wide range of disease states and patient subgroups, including people with stroke,^{4,12–14} people with dementia,^{15–18} people with amyotrophic lateral sclerosis,¹⁹ people with prostate cancer,^{20,21} people with various cancer diagnoses,²² people diagnosed with brain cancer,^{23,24} the elderly,^{25–28} veterans,²⁹ people with hip fracture,³⁰ people with disability,³¹ people with head injury,³² people with multiple sclerosis,³³ patients with childhood asthma,³⁴ patients with childhood cancer,³⁵ and people with epilepsy.^{11,36} In studies of some of these conditions, it is not uncommon for 20–50% of the subjects to have his or her HRQL assessed by proxy.³⁷ A common analytic approach to investigations of the validity and reliability of using proxies to respond on behalf of patients is to examining mean differences and concordance between patient-proxy dyads among patients who are capable of HRQL self-assessment.³⁸

Sprangers and Aaronson³⁸ noted that in general, significant others and health care providers underestimate patient self-reported HRQL; health care providers and significant others provide similar assessments to each other; and health care providers underestimate the pain of their patients. A recent review stated that proxy raters tended to report more HRQL problems than patients themselves but were reasonably accurate.³⁷ In general, better levels of agreement were reported between patient and proxy on symptoms and domains of health that are more concrete or observable, whereas proxies tended to perceive worse HRQL on the subjective domains, although the degree of response bias appears to depend on the specific domain.³⁹ For example, in end-stage amyotrophic lateral sclerosis, family caregivers rated patients as having less energy, greater suffering, and greater weariness than patients indicated themselves.¹⁹ Among different types of proxy raters, agreement and reliability of proxy respondents for people with disabilities tended to be best for relatives, with friends lower, and health care proxies lowest.³¹ The same study found that proxies tended to overestimate impairment and underestimate HRQL, although the pattern was reversed for pain measures, which proxies consistently underestimated. Level of agreement between patient and proxy tends to decrease with illness severity.³²

HRQL studies of the proxy-patient perspective (eg, where proxies were clearly instructed to respond as “they though the subject/patient would” or “to try to view the situation as the patient would”) included patients with brain cancer,³ Alzheimer disease,¹⁸ prostate cancer,²¹ a range of cancer diagnoses,²² in the elderly;²⁵ and in the elderly disabled.²⁶ The alternative viewpoint, the proxy-proxy perspective, was clearly described in studies of children in the Dutch population,¹ stroke,³ and childhood cancer.³⁵ Many of the studies in the literature, however, are ambiguous or vague about the proxy viewpoint elicited. Text such as “the questions should be answered in a way that the proxy believed best described the patient’s circumstances”;³⁶ “caregivers assessed patients’ HRQL as proxy respondents”;¹⁶ “. . . items were included in family member ‘questionnaire’ but were slightly reworded to allow for an observer rating”;²³ and “the proxy was asked to respond on behalf of the patient”^{12,14,15} may imply completion of the questionnaire as *if they were the patient*, but also may imply that the proxy complete the questionnaire *for the patient*. Finally, many studies did not provide any text on instructions to the proxy or describe how the measure may have been modified.^{17,19,20,24,28–32} The variation in proxy perspectives among studies may be a possible source of inconsistent responses by proxies, resulting in divergent findings on similar domains when comparing across studies.³⁴

Factors explaining systematic variance between patient and proxy assessments have been investigated. For example, Magaziner et al³⁰ identified several factors associated with systematic differences in health status assessments by elderly hip fracture patients and their proxies: female proxies, proxies who lived with the patient, proxies who assisted patients with

activities of daily living, and proxies who were not first-order relatives of the patient significantly underrated patient ability to independently perform both instrumental and physical activities of daily living, in comparison to male proxies, proxies who did not reside with the patient, proxies who provided minimal patient assistance, and first-order relatives, respectively. Patient depression has also been identified as a factor contributing to less patient and proxy agreement on the index-based summary score of the EQ-5D in elderly patients visiting the emergency room.²⁸ Burden and psychologic distress in caregivers was a significant predictor of patient and proxy differences in psychosocial scores in veterans.²⁹ Although these and other factors have been identified as exerting an influence on agreement, the findings have been inconsistent across studies.³⁸ Because many of these studies fail to specify the proxy perspective elicited, the extent to which lack of clarity about proxy viewpoint may have contributed to inconsistencies among study respondents, and between studies, is a legitimate issue. In the next section, we describe a framework that clearly delineates between proxy perspectives and discuss the potential role for each proxy perspective.

A CONCEPTUAL FRAMEWORK FOR UNDERSTANDING PROXY PERSPECTIVES

Figure 1 represents the proposed framework for understanding how potential differences may arise in HRQL assessment depending on the proxy perspective. Three perspectives of HRQL assessment are shown: patient self-assessment (ie, patient-patient perspective), proxy assessment from the patient's view (ie, proxy-patient perspective), and proxy assessment from the proxy's view (ie, proxy-proxy perspective). The first part of the term (ie, patient, proxy) refers to the source of the assessment, and the second part of the term (ie, patient, proxy) refers to the perspective of the assessment.

In this framework, we begin by considering factors that contribute to the assessment of HRQL. When assessing quality of life by proxy, the reference against which one judges HRQL is a key issue. HRQL assessment is inherently subjective because it requires the assessor to make judgments about health. Self-assessments of HRQL represent the patient's views and comprehension of his or her health and well-being. To understand how assessments of HRQL may differ according to perspective, constructs and factors that have been demonstrated and/or theorized to influence HRQL ratings are discussed in the context of the framework.

Inter-rater differences between patient self-assessment and proxy assessment from the patient perspective are represented by region "a" (Fig. 1). This region is defined as the *inter-rater gap*. The extent of the *inter-rater gap* may vary according to the domain of HRQL (eg, physical, social, emotional) being evaluated. Systematic variance between raters of HRQL has been attributed to rater characteristics such as psychologic state (ie, depression,^{23,24} chronic pain⁴⁰) and sociodemographics (ie, age and sex).^{25,41} Rater characteristics such as age and type of proxy (health care professional versus family caregiver) have been identified as contributing to different levels of agreement between patient and proxy.^{33,34} In addition, expectations may represent another factor that contributes to differences between raters, although this is better supported by theory rather than by empirical evidence. According to Calman's often-cited hypothesis about quality of life, an individual's quality of life rating is a function of the gap between their expectations and their present experience.⁴² This would imply that HRQL ratings would be less favorable for a given health state when the rater has higher health expectations. Quality of life can be improved by aligning expectations with reality, and reduction in expectations is a psychologic mechanism that contributes to adaptation to chronic illness.⁴³ Lack of reduction in expectation by proxy raters may explain, in part, the general observation that proxies tend to undervalue HRQL compared with patient self-assessment.³⁸

As shown in Figure 1, aspects of the HRQL assessment are common to both proxy perspectives. However, as already suggested, HRQL assessment from the proxy-proxy perspective can impart unique information, represented by region “b” of Figure 1, defined herein as the *intra-proxy gap*. The *intra-proxy gap* represents the extent to which HRQL assessments from the proxy-patient and proxy-proxy perspective are different. The proxy-proxy perspective can potentially provide an assessment of the patient that expands upon and/or clarifies the patient’s view of their HRQL, and may be desirable in addition to assessment from the patient perspective. The extent to which the proxy-proxy perspective is informative will depend upon the proxy’s ability to provide reinforcing or complementary information on the HRQL of the patient, a quality that is sometimes described as additive empathy in the literature on counseling and psychotherapy.^{44–46} This may be particularly relevant in situations where the proxy can knowledgeably expand upon the health state of the patient, such as when the patient is cognitively impaired.

A proxy-rater who is able to distinguish her or his view of the patient from the patient’s own view has the potential to provide insight into a patient condition by HRQL assessments from both the patient-proxy and proxy-proxy perspectives. Proxy-patient judgments are optimally consistent with the patient’s view of their HRQL, without embellishment. Proxy assessment from the proxy-proxy perspective is informative when the assessment reinforces or elaborates upon HRQL beyond what the patient would report if they were capable. The proxy-proxy perspective requires willingness to disclose HRQL information that may be discrepant with the patient perspective. Proxies may be reluctant if they are concerned that the patient may disagree with the proxy-proxy view or perceive that conflict may result from the disclosure. Consequently, trust and tolerance in the proxy/patient relationship may influence proxy assessments.

Validation of Proxy Ratings According to Perspective

Studies of proxy assessments of HRQL have generally used statistics of agreement between patient and proxy ratings to provide evidence of the validity of proxy ratings.^{37–39} However, the proposed framework suggests that the perspective of the judgment (ie, proxy-patient versus proxy-proxy) should guide the strategy to establish evidence for the validity and reliability of proxy assessments.

For studies that seek to evaluate the validity and reliability of HRQL assessment from the proxy-patient perspective, statistics of agreement between patient self-assessment and proxy-patient assessment are appropriate when patient self-assessment is possible. In the context of the framework, the magnitude of the inter-rater gap is being evaluated. The smaller the inter-rater gap between self-assessment and proxy-patient assessment, the stronger evidence for the validity of the proxy-patient perspective to substitute for self-ratings of HRQL. Research that illuminates the external validity of assessments from the proxy-patient perspective when patient self-assessment is unavailable, ie, the extent to which proxy ratings from the proxy-patient perspective can be generalized to patients who cannot respond on their own behalf, continues to be a priority for future studies of proxy assessments.³⁷

In contrast, the framework explicitly identifies HRQL assessment from the proxy-proxy perspective as being potentially valid while diverging from the patient perspective. The proxy-proxy perspective may provide clinically relevant information particularly when the patient is unable to self-assess their HRQL, but can be important even when the patient can self-report. For instance, an anosognosic stroke patient confined to bed may report that they have no problems with mobility. Conceivably, the stroke patient’s spouse may be able to replicate patient self-assessment, and hence no inter-rater gap, yet provide a different assessment from the proxy-proxy perspective that indicates the patient has extreme problems with mobility, thereby introducing clinical meaningful information that constitutes the intra-rater gap.

Examination of the validity of the proxy-proxy perspective based assessment may be accomplished by having the proxy concurrently perform proxy assessment from the patient perspective. As illustrated in this example, differences between the proxy-proxy and proxy-patient based assessments performed by the same proxy, ie, within subject variance at a given time, can provide support for the validity of ratings from the proxy-proxy perspective when it diverges from the proxy-patient perspective. When patient self-assessment can be obtained, support for the proxy-proxy perspective may be found by comparing statistics of agreement between patient self-assessment, proxy-patient, and proxy-proxy assessment. In addition, correlations with external anchors such as clinical measures may provide evidence of the validity of proxy assessments from each perspective. For example, proxy-proxy assessment of patient sleep disturbance might be corroborated by strong correlations with an electroencephalographic measure of sleep. Another approach to validation is to elicit patient feedback, when available, on proxy ratings from each perspective by asking patients if the proxy assessments reinforce or expand upon his or her experience in an accurate or useful way. This approach is supported by conceptual and empirical work on empathy that suggests patients may respond with recognition to observations that clarify their subjective experience, particularly if the information is provided with cooperative and supportive intent, even when observations elaborate beyond the patient's immediate awareness.⁴⁷

DISCUSSION

The conceptual framework outlined in this article followed from: (1) the need to recognize that different proxy perspectives can be elicited; (2) the need to develop a basis for selecting and understanding the potential information imparted from a proxy assessor according to the perspective elicited. In this section, we discuss how the framework can inform the standardization of HRQL measures and studies using proxies, as well as inform clinical management, research, and health policy.

Through the framework, we have sought to call attention to the need for proxy versions of HRQL measures to be standardized according to proxy perspective, clearly stating the specific perspective to be taken by proxy raters in the instructions and item wording, and subsequently described in the methods section of the work. If a specific proxy viewpoint is not clearly expressed in the instructions and not carefully incorporated into wording of the items, the perspective elicited in a study may be inadvertently placed at the proxy's discretion, creating unintended error variance in the proxy assessments. The viewpoint of the proxy should be disclosed in every study employing proxy assessments, and the chosen viewpoint(s) briefly defended to enhance the informational value of the literature as well as provide greater insight into the comparability of patient-proxy dyadic agreement across studies.

Research agendas that investigate the hypothesized intra-proxy gap will help to elucidate the extent and nature of the difference in different contexts, and factors that may explain systematic differences that contribute to the gap. Such investigations may serve to support the validity of each perspective, to evaluate the informational value contributed by the proxy perspective in different clinical settings, and to guide the selection of proxy perspective for a given application or purpose of the measurement.

Different proxy perspectives on HRQL may provide information that is potentially important to patient management and treatment, particularly in the evaluation and monitoring of vulnerable patient populations, such as cancer patients, the critically ill, the emotionally distressed, and the cognitively impaired. Each perspective may be valuable to clinicians when receiving caregiver input on treatment decisions. Studies of shared decision making across a variety of conditions have shown that patient's spouses and families may be involved in, and impact, the decision making process.^{48–55} For example, spouses of patients with prostate

cancer may have a major role in deciding between treatment alternatives, and the choice of treatment can have quality of life trade-offs and affect the spouse as well as the patient in intimate ways.⁵⁴ In cancer control, patients may minimize symptoms or problems as a part of the normal coping process, in an effort to please their physicians, or out of fear that active treatment may be discontinued if their condition appears to decline.⁵⁶ Such insights into a patient subgroup can help health care providers acknowledge the potential importance of eliciting a particular proxy perspective, such as the proxy-proxy perspective, when the goal is to provide a comprehensive view of the patient's experience including information that the patient may be unable, or reluctant, to express.

Studies of HRQL in pediatric oncology have indicated that information provided by patients, parents and healthcare professionals is often complementary and each has a valid and important perspective.^{57,58} For instance, the parent of a young child with leukemia may assess social or emotional functioning differently than would the child, in part because the child's life experiences and expectations are different from the parent, yet arguably, neither assessment is less important or valid than the other. Studies that compared both significant others and health care provider to patient self-report^{55,59,60} found that differences between the 2 types of proxy raters generally were minimal, although spouses tended to provide ratings for pain, social functioning, and overall HRQL that were more concordant with patient self-assessment.⁵⁵ Thus, significant others may be preferable to health care providers when eliciting the proxy-patient perspective, but further research is needed to evaluate whether proxy rater type influences assessments from the proxy-proxy perspective.

The selection of proxy viewpoint should be guided by the goals of the medical care or investigation. Research that identifies factors that contribute to systematic (intra-rater) differences in assessments based on proxy perspectives will further inform the selection of proxies and choice of perspective for a given application. Study designs that incorporate different proxy perspectives to examine HRQL may help to address phenomena such as response shift and patient adaptation to adverse health states by enhancing the stability of estimates of HRQL.

Proxy assessment of HRQL may help to resolve conflict in medical decision-making, but it is important to note that proxy raters also may contribute to conflict. For example, the patient may deny pain is an issue, yet their spouse might reveal through a proxy-proxy assessment that they perceive the patient to be in moderate pain because the patient is groaning in their sleep. Such conflict may require the health care provider reflect upon ratings of HRQL from different perspectives and discuss the motivation for each assessment in collaboration with the patient and their family to formulate a decision as an advocate of the patient's best interest.⁶¹

In studies that inform health policy, such as economic evaluations of health care interventions, the perspective from which HRQL is valued is an issue of debate. Dolan et al⁶² distinguished between the following perspectives for eliciting valuations of health: (1) the respondent herself, in which case she is being asked for her personal preferences; (2) people other than the respondent, thus eliciting her social preferences; or (3) both the respondent and other people, which involves the elicitation of her socially inclusive personal preferences.⁶² The proxy-patient and proxy-proxy perspectives conceivably elaborate upon those perspectives for valuing HRQL, and may have an important role. It has been shown that real patients often give valuations higher than societal preferences, attributable in large part to adaptation.⁶³ Consequently, *ex post* personal preferences produce smaller incremental gains compared with societal preferences for better health states associated with a new medical technology. Proxy-patient and proxy-proxy perspective based health state valuations provided by a proxy who has insight into the patient's condition may reduce discrimination against patients with permanent disabilities or chronic conditions by mitigating discrepancies that arise between

personal and societal valuations, such as response shift, different vantage points, and focusing illusion, whereby people forget to consider obvious aspects of unfamiliar health states.⁴³ Such an application of different proxy perspectives on HRQL broadens the scope of investigations into valuations of health that have been emphasized as areas requiring future research in medical decision-making.^{64–66}

In summary, we have proposed a framework that delineates between proxy assessment from the patient and proxy perspective to better inform study design, methodology, measures, and medical decision-making. The merits of the framework, and specific concepts hypothesized to motivate proxy assessment, will depend upon thoughtful empiric research that investigates the proxy-patient and proxy-proxy viewpoints in well-designed studies. Such research is needed to determine the importance of proxy viewpoint, to assess the need for standardized HRQL questionnaires specific to each proxy perspective, to inform the design of studies that may require proxy raters, and to understand how proxy assessments can better inform medical decision making at the bedside and at the policy level.

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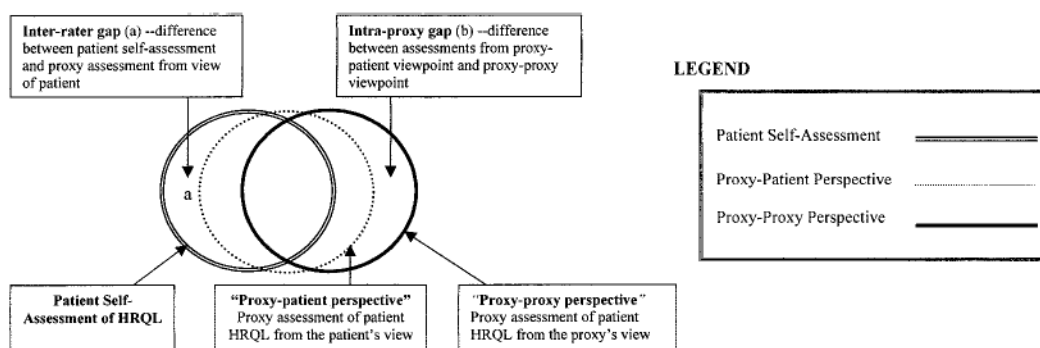


FIGURE 1.
Conceptualized interrelationship between patient and proxy assessments of HRQL.