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Health, health-related quality of life, and quality of life: what is the difference?

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Abstract

The terms health, health-related quality of life (HRQoL), and quality of life (QoL) are often used interchangeably. Given that these are three key terms in the literature, their appropriate and clear use is important. This paper reviews the history and definitions of the terms and considers how the terms have been used. It is argued that the definitions of HRQoL in the literature are problematic because some definitions fail to distinguish between HRQoL and health or between HRQoL and QoL. Many so-called HRQoL questionnaires actually measure self-perceived health status and the use of the phrase QoL is unjustified. It is concluded that the concept of HRQoL as used now is confusing. A potential solution is to define HRQoL as the way health is empirically estimated to affect QoL or use the term to only signify the utility associated with a health state.

Key points for decision makers

- The term HRQoL is not well defined and most definitions of HRQoL do not sufficiently differentiate the term from health or QoL
- Measures of HRQoL are usually more appropriately named measures of self-perceived health status
- A clearer use of HRQoL would be to only use it to signify empirical studies of how health affects QoL or to signify the utility associated with a health state

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1. Introduction

The SF-36 and the EQ-5D are described variously as measures of 'health status' [1,2], 'health-related quality of life' (HRQoL) [3,4], or 'quality of life' (QoL) [5–7]. This is just one example of the indiscriminate use of these terms. Confusion remains in the literature about the meaning of these terms and little agreement exists on their definitions. Given that these are three key terms in the literature, their appropriate and clear use is important. The purpose of this article is to review the history and definitions of the terms, to consider how the terms have been used, and to suggest a way forward.

Section two of this paper will discuss the history of these three terms. Next, we provide various definitions from the literature and then consider whether those definitions sufficiently differentiate between the three terms. A key concern is whether HRQoL can be differentiated from health status or QoL. Next, two HRQoL questionnaires are reviewed in an attempt to answer what HRQoL questionnaires actually measure. Finally, a potential way forward is suggested.

2. History of the terms

The use of the terms QoL and health status preceded the use of HRQoL. QoL was already discussed in the medical literature in the 1960's [8,9]. QoL became more important in health care as medical treatment became able to extend length of life sometimes at the expense of quality of life or improve quality of life without extending length of life [10]. Simple measures of death rates were no longer enough to measure changes in population health [11]. Measurement of quality of life was also important because of a desire to measure outcomes beyond morbidity and biological functioning [12][13].

The recent history of health status measurement can be traced back to the early 1970's. These health status measures were motivated by a desire to measure the output of health care systems [14]. One of the first attempts to measure and value health was the Health Status Index [14]. The HSI improved previous outcome measures in two ways: (i) it was a generic measure of health rather than a disease or population specific measure, and (ii) the states defined by the HSI were valued on a cardinal scale based on value judgements, ignoring a common conventional assumption that health was valued in terms of its economic benefit. The states in the HSI ranged from "Well-being" to "Disabled" to "Death" [14].

It was the literature on health status measures that introduced the term HRQoL. For example, Kaplan and Bush [10] use the term HRQoL in their discussion of the term Quality-Adjusted Life Years (QALYs) as the measure of the value of a year in full health. According to Kaplan and Bush [10] the term 'Well-Year' is more appropriate than the term QALY because it implies "a more direct linkage to health conditions; i.e., to denote the health-related quality of life" [10]. The term HRQoL was adopted in other influential papers (see for example [15]) and spread from there.

3. Definitions of terms

Although these terms are widely used in the literature, there remains debate about the definition of all three. In the next few paragraphs, we present a variety of definitions to demonstrate the scope for confusion in the literature.

3.1. Health status

A highly influential definition of health was provided by the World Health Organisation (WHO). The WHO defines health as “a state of complete physical, mental and social well-being, and not merely the absence of disease and infirmity” [16]. This definition was influential in the development of the Medical Outcomes Study Short Form family of measures (such as the SF-36 [17]) and the EQ-5D [18](p. 1). Key aspects of the WHO definition are the inclusion of social well-being and the emphasis on more than the absence of disease. Not everyone agrees on the inclusion of social well-being in the definition of health [15]. Patrick, Bush, and Chen [19] define health as “an individual's level of function”, where “optimum function” is judged in comparison to “society's standards of physical and mental well-being”.

3.2. Quality of life

Defining QoL has proven challenging [20][21] and many approaches to defining quality of life exist [22]. There are approaches based on human needs, subjective well-being, expectations, and phenomenological viewpoints [23]. A related literature on well-being distinguishes between approaches based on objective lists, preference satisfaction, hedonism, flourishing, and life satisfaction [24]. Examples of definitions of QoL are: “a conscious cognitive judgment of satisfaction with one's life” [25] and “an individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” [26].

Although many definitions of QoL focus on subjective judgements, some authors have argued that objective factors should be included in QoL [27–29]. For example, QoL has been defined as “an overall general well-being that comprises objective descriptors and subjective evaluations of physical, material, social, and emotional well-being together with the extent of personal development and purposeful activity, all weighted by a personal set of values" [28].

3.3. Health-related quality of life

Defining HRQoL has also been problematic [30] and at least four definitions of HRQoL can be identified in the literature. First, HRQoL can be defined as “how well a person functions in their life and his or her perceived wellbeing in physical, mental, and social domains of health” [31]. Functioning refers to an individual’s ability to carry out some pre-defined activities [31,32], while well-being refers to an individual’s subjective feelings [31].

A second definition relates HRQoL directly to QoL: “quality of life is an all-inclusive concept incorporating all factors that impact upon an individual’s life. Health-related quality of life includes only those factors that are part of an individual’s health” [15]. Non-health aspects of QoL, for example economic and political circumstances, are not included in HRQoL [15].

A third definition of HRQoL focuses on the aspects of QoL that are affected by health. For example, HRQoL is defined as “those aspects of self-perceived well-being that are related to or affected by the presence of disease or treatment” [33]. This definition is sometimes stated in a narrower version, where HRQoL “is used to

identify the sub-set of the important or most common ways in which health or health care impact upon well-being" [24].

The fourth, and final, definition of HRQoL focuses on the value of health. For example, HRQoL can refer to the "values assigned to different health states" [34](p. 83). These values, or utilities, are used calculate QALYs and to measure the benefits of health technologies. The values used to calculate the QALY are on a scale where zero is equal to dead and one is equal to full health [34]. Values less than one are meant to reflect the loss of quality of life because of living in ill health [34].

4. Difference between the three terms

Even in the 1980's there was a concern that the three terms were used indistinguishably in the literature [9,35] and this concern remains [12,36,37]. This section attempts to highlight the differences between the three terms. It is easiest to distinguish Health and QoL. It is acknowledged that "quality of life is more than health status, clinical symptoms, or functional ability… health is only one dimension of quality of life" [22]. Indeed, all the definitions of QoL provided earlier would be influenced by factors commonly accepted to be not part of health [38], such as material and economic circumstances. Satisfaction with life is influenced by health but health status only explains a small part of life satisfaction outcomes [39]. Health and QoL are therefore distinct concepts.

Distinguishing between HRQoL and both health status and QoL is more problematic because some definitions of HRQoL resemble health status and others resemble QoL. In particular, the first two definitions of HRQoL provided above (HRQoL as functioning and well-being and HRQoL as the health aspects of QoL) do not seem to add much to the concept of health. If HRQoL is functioning and well-being in physical, psychological, and social domains then HRQoL is a particular type of description of health, as the WHO defines health. It describes health using functioning and well-being rather than, for example, clinical symptoms or biological variables [32]. It is thus a type of health measure, and not a type of QoL measure. Similarly, if HRQoL is the health aspect of QoL then HRQoL is the same as health. The first two definitions of HRQoL do not distinguish HRQoL from health.

The third definition of HRQoL (the aspects of QoL which can be affected by health) is difficult to distinguish from QoL. This definition raises the question of what aspects of QoL are not affected by health. It is hard to imagine important aspects of QoL that are not at least somewhat affected by health; especially if the indirect influence is considered (e.g. health affects income and hence housing, education and so forth) [37]. Perhaps more reasonable is the variant of this definition, where HRQoL is the aspects of QoL most affected by ill health. In practice, this definition may not narrow down the number of domains much because it is problematic to define 'most'. Health problems are diverse and therefore aspects most impacted by health may be different for different diseases or health problems. For example, the QoL aspects affected by mental and physical health may be different. In practice, a generic HRQoL measure would have to include most aspects of QoL. This definition does not differentiate HRQoL from QoL.

Finally, the fourth definition of HRQoL refers to the value of health states. One source of difficulty in discussing HRQoL is that preference-based measures or multi-

attribute classification systems such as the SF-6D or EQ-5D can generate both health profiles and index values. The profile is a health state described by the questionnaire. The index value is the result of preference elicitation tasks where respondents (typically members of the public) are asked how many years of their life they are willing to sacrifice or how much risk with their life they are willing to take to avoid ill health [15]. Individuals' responses in preference elicitation tasks reflect predictions of how health affects their life (though they may also consider the impact on others). Qualitative research has shown that participants consider a wide variety of non-health factors when valuing health states [40]. If respondents' preferences are based on how health affects QoL and if respondents estimate the effect of health on QoL correctly then the utility of a health state could be referred to as health-related quality of life (although health-adjusted quality of life may be more accurate). But whether respondents' preferences only reflect quality of life is not certain [41] and may depend on which definition of QoL one believes to be correct.

In summary, the definitions of HRQoL provided earlier seem to either collapse into definitions of health, QoL, or reflect the value of health. Yet, frequently the health state profile, and not just the utility associated with a profile, is referred to as HRQoL. It is thus instructive to review what typical HRQoL questionnaires actually measure.

5. What do HRQoL questionnaires measure?

Two popular measures of HRQoL contain the following domains: physical functioning, role limitations, social functioning, pain, mental health, and vitality in the SF-6D [3]; and mobility, usual-activities, self-care, pain or discomfort, and anxiety or depression in the EQ-5D [42]. From the HRQoL definitions above, only the first accurately describes the above domains (i.e. health described using functioning and well-being). Typical HRQoL questionnaires do not measure the 'health aspect of QoL' because that would imply that they are a subset of QoL measures. As such, they would have to describe QoL, for example, by measuring life satisfaction associated with different health status. Typical HRQoL questionnaires also do not measure the most important ways health affect QoL because the domains of HRQoL measures are not generally QoL domains. The HRQoL domains mentioned above can be contrasted to a QoL questionnaire, such as the Personal Wellbeing Index (PWI) [43]. The PWI asks about satisfaction with: standard of living, health, achievement, personal relationships, personal safety, community-connectedness, and future security [43]. These are not domains frequently found in HRQoL questionnaires, yet all these domains are likely to be affected by ill health.

The domains of the SF-6D and the EQ-5D would fit the WHO health definition, although the questions range across the WHO classification scheme of impairment, activity limitation, and participation restriction [44](pp. 56-68). HRQoL questionnaires could therefore be said to measure self-perceived health status [36,37,41], unless the connection between measuring functioning and well-being and QoL is justified. Yet, there have not been many explicit justifications for differentiating HRQoL from health status. Guyatt et al. [45] argue, "health status was judged to be more narrow in scope and it omitted the necessary element of valuation by the patient". But neither the EQ-5D nor the SF-6D contain patient valuation. In a review of over 159 questionnaires in 75 articles, it was found that only 8.5% of HRQoL questionnaires included an aspect of evaluation or importance [46]. Measures of HRQoL describe health in broader terms (functioning and well-being) than clinical measures, but the

broad description is of health and not of QoL. It is therefore more justified to classify typical HRQoL measures as measures of self-perceived health status.

6. Conclusion

The concept of HRQoL overlaps with that of health and QoL and this may lead to confusion. There is a relatively clear distinction between QoL and health (although even this depends on the specific definitions used for each) but the distinction between HRQoL and both health and QoL is difficult to make. Many HRQoL measures are in fact measures of self-perceived health status [36,37]. This paper has clarified that HRQoL questionnaires describe health using functioning and well-being but this has little to do with QoL as it is known in the wider literature. The concept of HRQoL as currently used is potentially confusing and unhelpful. Perhaps the field should consider going back to the distinction between measures of health status and measures of quality of life. HRQoL can then be used in two ways. One, to signify the utility associated with health (as measured by valuing health status questionnaires, e.g. using the EQ-5D with an attached value set). Second, HRQoL can be used to mean just that – the way health (as measured by health status questionnaires) affects QoL (as measured by QoL questionnaires) as empirically estimated using statistical techniques.

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