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Mini Review

Quality of Life Measurements from the Patient Perspective: Capturing the Heterogeneity of the Patient Experience in a Standardised Way

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Abstract

For patients, quality of life is the confluence and interaction of multiple factors related to both the disease and to how life is lived with and beyond the disease. When tasked with completing a quality-of-life questionnaire, patients may well wonder for whose benefit this is, which really needs to be made clear. We discuss some of the issues around quality-of-life questionnaires and the challenge of the heterogeneity of the patient experience.

Patient summary: This mini-review discusses quality-of-life measurements from the patient perspective and the need to take account of the patient's life and not just the disease.

Across the plethora of instruments available for measuring quality of life (QoL), there seems to be little or no consensus among those creating these diverse instruments as to what QoL actually means [1,2]. For patients, QoL is the confluence and interaction of multiple factors, some related to the disease and others directly or indirectly related to an individual's life notwithstanding the disease [3,4]. A challenge for creators of QoL instruments is to generate questions that relate not only to the disease, signs and symptoms, treatments, and side effects, but also to how these are experienced and lived by the patient. Asking about the former is relatively easy as shown in the European Organisation for Research and Treatment of Cancer (EORTC) QLQ-PR25 questionnaire, in which, by selecting one of "Not at all", "A little", "Quite a bit", or "Very much", the patient is asked to respond to "Have you had to urinate frequently during the day?" and "Have you had to urinate frequently during the night?" [5]. There is no indication as to what *frequently* might mean and the choices available are similarly loose. As the questionnaire is aimed at a subjective evaluation by the patient, the looseness of language is perhaps understandable; however, this excuse cannot be made for failure to ascertain the extent to which urinary frequency bothers the patient. Methodologically, this absence seems a significant lacuna. Frequency and an individual's response to it are personal constructs. However, what matters to patients is the extent and impact of disruption to their activities of daily living [6].

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The question then concerns the purpose of QoL measures. In the literature, the consensus appears to be that this type of data are collected to understand the longer-term effects of treatments and how patients cope with these, which seems to be more for the benefit of the treating clinician than for the patient, a point underlined by the lack of mention of the QoL instrument being used as a basis for a patient-clinician discussion. This should not be surprising, as also absent is discussion of whether the results from a QoL instrument completed during a trial should find their way into the patient's medical notes. In trials, some generic QoL questionnaires (such as the EQ-5D) are used in health economic analyses for policy-making, intended to have a benefit to all future patients, even if not an immediate benefit for the individual completing the questionnaire at the time.

A systematic review of the measures most frequently used in prostate cancer concluded that the measures discussed required further "methodological reviews", as none of them properly addressed all of the relevant psychometric measures. Interestingly, "responsiveness", a listed psychometric criterion defined as "the ability of a questionnaire to detect clinically significant changes over time" [2], was only found in a small proportion of the QoL questionnaires reviewed [1]. Responsiveness is only possible when there are repeated measures linked to individual patients. If there is a return of information to the patient's clinical team, linking the data to individual patients enables their treating clinicians to be aware of clinically significant changes and, depending on the questionnaire, how they are living with their disease and treatments.

Across the spectrum of academic literature on QoL questionnaires, meaningful discussion of their construction and of the involvement of patients is rare. Besides the detailed and replicable account by Lee et al [7] of how and why their questionnaire was developed, the development of instruments is discussed in general terms only, as seen in the account by van Andel et al [8] of the creation of EORTC-QLQ-PR25. The problem is that without knowing how and why an instrument was created, one is left to surmise its purpose.

To capture the heterogeneity of patient experience in a standardised way, account needs to be taken of this very heterogeneity, as well as the treatment followed, the institution, and the individual patient's circumstances. Clinically, two patients can have apparently similar experiences of their disease and treatments and yet be living them entirely differently [3]. Individuality requires a move away from the overdependence on Likert-type items; useful though they are at investigating what is going on, these items fail to express how or why something is happening. The patient is more than just a disease, but is a social entity into whose life the disease and treatments have intruded. It is therefore necessary to move beyond the clinical and venture into the social and psychological aspects of the disease on personal, interpersonal, and wider social levels [4,9]. The questionnaire needs to be meaningful to patients, present questions that patients would like to be asked, allow the responses that patients would like to give, and be delivered in a manner that suits patients, especially as it will ask about intimate parts of their life and experience. If patients feel that they are participants and not subjects, they are more likely to want to complete the instrument, especially if it is short, has open questions as well as Likert-type items, and feeds back to their medical notes, thereby giving a basis for discussion at future appointments, and so they are not left potentially feeling as if they are speaking into a void. Patients have suggested that, when discussing symptoms or side effects, it is better to ask questions that establish whether they have a particular symptom or side effect, potentially rating it on a scale but then also asking "How are you coping with [whatever]?" [3],

In the context of prostate cancer, reviews of QoL measures seem to be consistent in highlighting a requirement for more research [1,2,6,7]. This is certainly true for the patient's relationship to the measures; such is the heterogeneity of the patient population that it is conceivable that no single measure is universally appropriate. Instead, a set of branches to which the patient is directed according to their responses could be used. The "static" patient-reported outcome measure seeks to compare "individuals in terms of traits or dimensions common to everyone", which assumes that such common traits exist, but context in its diverse dimensions needs to be taken into account [10], which will possibly reduce response rates but will inevitably enhance the richness of the data acquired.

Conflicts of interest: The authors have nothing to disclose.

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