

# The Use of Patient-reported Outcomes at an Individual Level – Benefits and Challenges

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## Abstract

The aim of this article is to review the application of patient-reported outcomes (PROs) in clinical care and consider its benefits, challenges and potential improvements. Previous studies demonstrated that health-related quality of life (HRQoL) data provide information to clinicians on patient health status, QoL, symptoms and wellbeing, along with any changes in these, and helps clinicians judge the needs of patients and tailor treatments accordingly. In addition, the benefits of the application of HRQoL tools include the involvement of patients in informed decision-making in terms of their treatment or care, higher patient satisfaction with healthcare services, improved patient–clinician relationships and better communication. In many studies, health professionals have expressed their interest in using these measures but feel they need to better understand them. Despite the wide use of information-gathering questionnaires and their promising results, it is still a challenge to predict the full value of these measures in clinical care. This article addresses these major concerns.

## Keywords

Health-related quality of life (HRQoL), patient-reported outcomes (PROs), patient–physician relationship, patient–physician communication, computer-adapted testing (CAT), tailor-made healthcare

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While the need to assess the impact of a disease and its treatment on the functional, psychological and social health of patients was raised eons ago, clinicians have only recently embraced the importance of health-related quality of life (HRQoL).<sup>1</sup> Over the past decade greater interest has been centred on HRQoL at an individual patient level<sup>2</sup> by clinicians and other health and social care professionals, recapturing, without question, the ancient idea of including patient-reported outcomes (PROs) as part of patient medical records.<sup>3</sup> PROs gain more importance when seen to aid the management of individual patients.<sup>2</sup> PROs are increasingly used in oncology because both cancer and its treatment are severely debilitating and clinicians consider the outputs of these questionnaires when making patient management or treatment decisions.<sup>4</sup> Furthermore, patients want to be well-informed about treatment options and to be involved in any decisions in terms of their treatment and care.<sup>5</sup> Previous studies by the European Organisation for Research and Treatment of Cancer (EORTC) have proved that HRQoL measurement findings may help when choosing the best treatment options for oncology patients.<sup>4,5</sup> HRQoL has also proved to be a prognostic variable that can be important in guiding treatment decisions when alternatives demonstrate similar survival outcomes.<sup>6,7</sup>

## Measuring Health-related Quality of Life

HRQoL is a subjective, multidimensional construct that encompasses domains such as general health, physical symptoms, physical

functioning, emotional wellbeing, cognition, role functioning, social wellbeing, sexual functioning and spirituality.<sup>8,9</sup>

While PROs measure patient self-view of health status and wellbeing, health outcome measurements (HOMs) measure changes in the health status<sup>3</sup> and wellbeing of patients as a result of medical intervention, or the lack of it. This implies that HOMs are responsive to change following an intervention and they can be repeated over time.

## The Patient Perspective

It is generally accepted that patients are the best judge of their own HRQoL and, correspondingly, patient perspective is the gold standard for measuring HRQoL and the primary source in terms of what issues are to be included in such an assessment tool.<sup>10</sup> This is important when developing HRQoL instruments, considering the fact that traditionally patient improvement was evaluated using purely clinical parameters.<sup>5</sup>

## The Clinician Perspective

Stephens et al. found that patients and clinicians assessed the same symptoms differently: clinicians often assessed severe symptoms as 'less severe', healthcare professionals (HCPs) valued matters related to symptoms and treatment side effects more highly than patients and the greatest difference in mean scores was for symptoms related to pain.<sup>11</sup>

## The Selection of Questionnaires

When measuring HRQOL/PROs the questionnaire(s) used must be appropriate. The modular aspect, which is the combination of generic and disease-specific measures, allows for a general judgement of perceived health status and provides adequate information for the assessment of disease symptoms related to a specific tumour site, along with the adverse effects associated with a given treatment.<sup>5</sup>

## Communication Concerns

### Patient–Clinician Communication

The patient–clinician relationship is a particular kind of interpersonal relationship where both parties have pre-determined roles and standards of behaviour.

Contemporary research into patient–clinician communication has focused mainly on a patient’s personal characteristics, such as preference for information provision, participation in decision-making, understanding of their illness, treatment choice and motivation to self-manage.<sup>12</sup>

Recently, the patient-centred model has dominated the educational and research literature on patient–clinician communication. However, favouring only one model may prevent clinicians from developing the relationships and communication skills to enable them to adjust to various situations. Based on the nature of the problem and the degree of severity, researchers suggest that there are four types of relationship in which patients and clinicians can engage where the role of the clinician varies: expert-in-charge, expert-guide, partner and facilitator.<sup>12</sup> The appropriate combination and application of these relationships can lead to better communication and, consequently, better patient–clinician relationships and improved disease management.<sup>12</sup>

### Communication of Quality of Life Concerns

In a study by Detmar et al., almost all patients expressed a willingness to discuss the physical or emotional aspects of their disease. However, one-quarter of the patients were only willing to discuss the physical aspects of their disease. The reluctance was greater concerning matters of social functioning and family life, with 28–36% of patients waiting for the doctors to raise a topic first and another 20% choosing not to discuss these concerns at all. This suggests that patients may be uncertain about which matters are appropriate for discussion with their physicians.<sup>13</sup>

### Patient Benefit

These considerations led to hypotheses and trials relating to the education of physicians. A trial by Stewart et al. found that state-of-the-art continuous medical education (CME) did not improve overall objective communication scores, but was related to patient satisfaction and ‘feeling better’.<sup>14</sup> A review of effective patient–physician communication and health outcomes written by Stewart et al. found that effective communication has a positive influence not only on the emotional health of the patient but also on symptom resolution, functional and physiological status and pain control.<sup>15</sup>

### Clinician Concerns

The majority of clinicians felt that discussion of the physical aspects of patient health was primarily their responsibility but that psychosocial health problems should be discussed with other

healthcare providers.<sup>11</sup> Clinicians may feel they are unable to change the cause of psychosocial disturbances and therefore concern themselves only with symptoms that they can help, such as pain.<sup>11</sup>

In the case of emotional and social functioning, all clinicians indicated that they generally defer initiating the discussion of these topics with patients.<sup>11</sup> This confusion surrounding the appropriate allocation of responsibility may hinder the discussion of psychosocial matters, which can impede appropriate symptom identification and thus increase the risk of inadequate treatment,<sup>16</sup> as clinicians tend to overlook difficulties and symptoms that are not obvious or not explicitly mentioned by the patients.<sup>17</sup> Fieldman-Stewart and Brundage found that monitoring HRQoL over time improves the memories of patients and the ability to describe their problem.<sup>18</sup>

## Practical Implications

### Increased Satisfaction

Detmar and Aaronson reported a small-scale study involving six clinicians and patients. Prior to the appointment with the clinician, the patients completed an HRQoL questionnaire with clinically reviewed results. The study reported that patients were more satisfied with the consultation even though the time taken was not significantly longer.<sup>19</sup>

### Emotional Support

When reviewing the literature, Stewart found that emotional support is an important dimension of communication and that studies are designed to help patients improve their information-seeking skills and provide information about treatment. One study that provided training to physicians in handling emotions and exchanging information led to changes in outcomes in terms of emotional status, pain, functional status, blood pressure and blood sugar levels.<sup>16</sup>

### Clinical Benefits

The combined clinical and HRQoL results from a study by Bottomley et al. suggest that intensive therapies may achieve similar survival outcomes without sacrificing patient HRQoL. This trial gave patients a choice: if, for example, the patient had a busy lifestyle demanding rapid treatment, regardless of toxicity, the more aggressive treatment option was chosen. If the patient was elderly and had no economic needs, the choice may be a less aggressive therapy. If survival opportunity is basically equal, HRQoL can help practising clinicians give patients choices.<sup>20</sup>

## Current Application of Patient-reported Outcomes in Clinical Practice

### Interest in and Feasibility of Health-related Quality of Life

Most of the questionnaires measuring the HRQoL of patients are developed for use in randomised clinical trials (RCTs) instead of clinical practice at an individual level. This may be one of the reasons why 82.5% of clinicians consider HRQoL data essential for effective cancer patient care, but only 26% of respondents to the same study used formal HRQoL questionnaires in their practice.<sup>21</sup> The other reason is that many of them feel that the current HRQoL measures are too complicated, time-consuming or costly for incorporation into clinical practice. This study also revealed that logistical considerations may deter the use of PROs by physicians.<sup>21</sup>

Despite these study findings and considerations, the benefits gained at an individual level led to the implementation of PROs in clinical

practice. Bezzak et al. suggested that in order to maximise physician use of HRQoL information, the data must be presented in ways that are more clinically relevant.<sup>21</sup>

### Computer-adapted Testing

To overcome some of the logistical drawbacks, results related to computer-adapted testing (CAT) proved encouraging in some studies, and showed that even elderly patients or those with terminal illness have little problem in using moderately complex technology when suitable interfaces are provided.<sup>4</sup> CAT opens the door to a new class of questionnaires that can focus on the specific domains important for patients under given circumstances or in specific situations. For example, a question could ask about how easy it is to walk a short distance. For a 'no problem' response, the next question could be about jogging rather than a question about confinement to bed, leading to positive interaction. CAT techniques allow for a reduction in the number of questions asked by using closely targeted items to obtain a more precise evaluation of patient condition.<sup>4</sup>

### Conclusion

The use of PROs at an individual level has proved to be useful in clinical practice. For the wider application of HRQoL measures and to gain greater benefit from these measures, it is necessary to provide opportunities for clinicians and healthcare workers to better familiarise themselves with the purpose and application of HRQoL, as well as the interpretation of their outcomes.

Training related to PROs must cover considerations such as the selection of key instruments and their development, administration and scoring. Logistics is another important factor. Advising HCPs on how to organise the implementation of these measures may decrease the burden on them and lead to a greater use of PROs in clinical practice. The adequate distribution, collection, analysis and interpretation of PROs is a prerequisite and integral to their success. The availability of baseline HRQoL questionnaires should be a standard criterion for comparison, especially when HRQoL assessment is carried out in patients with different kinds of chronic health condition before treatment, particularly those with cancer. CAT gives the opportunity to present tailor-made questions in any clinical setting to provide prompt information to HCPs.

More research is required in terms of how to manage the differences between the views of patients and clinicians in relation to HRQoL issues to be covered at clinician–patient encounters. National and local healthcare systems may need different solutions. It is necessary to involve other HCPs, not just clinicians, in communicating QoL concerns. The aims of PRO instruments are different. Some of them are intended to be used for monitoring a treatment, others for predicting treatment preferences or likely response to a given therapy. Educating HCPs on these differences must also be part of their CME. Further research and training is also required on how to interpret HRQoL outcomes in terms of prediction of survival.

Well-developed, integrated, international and national systems that take into consideration all the factors that can influence patient outcomes, including age, gender, cancer site, cultural differences, type and combination of questionnaires, administration setting

and clinical data, may facilitate the application and improve interpretation of PROs at an individual level and lead to better HRQoL.

Another question requiring more research is: 'What are the most effective ways to communicate PRO results directly to the patient?' The lessons learned from this article are that patient concerns in psychological and family matters are not raised as often as patient needs may require, given that there appears to be a serious reticence among both clinicians and patients to discuss such matters. Regardless of the outcome of consultations that included PROs, patients did appreciate the use of PROs in clinical settings and showed higher satisfaction with medical care and even better health outcomes in many symptoms and domains.

The measurement of how patients with different personalities are likely to interpret their own data should be considered a requirement, as this area could hold fruitful research findings.

Clinicians are now able to consider planning cancer treatments on the basis of PROs. This may help fulfil, at least in part, the continually increasing expectations of patients and address the needs of the increasing number of patients requiring chronic care in an ageing society.

In many types of cancer survival is increasing, which may lead to extended needs for medical and psychological management. Treatment options that lead to a higher QoL may be the outcome of HRQoL research. It also makes room for and facilitates the informed decision-making of patients. Given the proven prognostic value of PRO data, patients and clinicians may benefit from applications that could lead to a higher quality of care at all disease stages. Based on our reasoning and the evidence presented, we consider HRQoL an essential element for clinicians to assess and consult with their patients, not only in clinical trials but also in clinical practice, because it can lead to an improvement in the care of patients. ■



Agnes Czibalmos is a paediatrician. She started her career as a practising physician and an associate professor, and later held different positions in public health. She has been involved in quality of life (QoL) and health-related quality of life (HRQoL) research for more than a decade. Dr Czibalmos is a member of the Stakeholder Dialogue Group of the Directorate General of Health and Consumers (SANCO) of the European Commission, and advises on process matters to facilitate stakeholder involvement. She served as an evaluator of project proposals submitted to the Research Framework Programmes and the Public Health Programme of the European Commission and is the author/co-author of 13 scientific papers.



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