

# Chapter 12

## Health Literacy and Patient –Reported Outcomes

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### ABSTRACT

*Modern healthcare needs to identify parameters for high-quality care. Quality improvement is the key for advancing in healthcare, and the new assessment tool shifts from a disease-centered outcome to a patient-centered outcome. Clinical outcome such as morbidity and mortality are directly connected and interdependent from patient-reported outcomes: well-informed patients who decide with their healthcare provider what treatment is best for them have better outcomes and higher patient satisfaction rates. These subjective data collected by rigorous, meaningful, and scientific methods and presented in a utilizable format can be used to create care objectives towards which both the surgeon and their patient can travel. Time has come to carry patient-centered outcomes from research into decision making and daily care plans. This chapter outlines a focus beyond life-prolonging therapy, aiming to minimize the negative effects of treatment, optimize quality of life, and align medical decisions with patient expectations.*

### INTRODUCTION

*The physician should not treat the disease but the patient who is suffering from it – Maimonides 1134-1204*

The goal of medicine is to improve the quality and duration of life through the treatment or prevention of disease. How do we measure this impact? Quantity of life is easily calculated, but quality of life is subjective and difficult to measure. Objective health measures do not necessarily correlate with patient values (Contopoulos-Ioannidis, Karvouni, Kouri, & Ioannidis, 2009). By allowing patients to report their opinions on quality of life, through patient reported outcomes (PROs), quantitative data of meaning can

DOI: 10.4018/978-1-6684-2414-8.ch012

drive medical progress. PROs are now widely accepted as valid outcome measures, and this is reflected in the utilisation of PRO data in approval pathways for medical interventions.

PROs are self-reported assessments that quantify symptoms, physical function or emotional well-being; related either to a specific condition, or to general quality of life (Higgins, Green, & The Cochrane Collaboration, 2011). Typically, a PRO instrument consists of several items (questions or statements) to which a Likert scale or binary response is recorded. Individual statements can be scored and sometimes an overall score is calculated. Some scores also include a generic overall scale which can be compared to the contributing individual item scores. PROs can also contain temporal data; asking about experiences either at a singular moment in time, or over a period of time. This subjectivity is the value of the derived data, but utilisation of data comes with some caveats.

PROs are at risk of bias from the researchers that generate them, the populations in which they were generated, and the cultures in which they are accepted. For example, the Nottingham Health Profile (NHP), was derived from statements made by individuals seeking healthcare in Nottingham, UK, and reflects the overall culture of this area at the time it was generated. From 2,200 statements made by patients, 88 were picked by researchers to represent quality of life, reflecting the values of the researchers. The NHP became a widely-accepted measure of 'quality of life'; reflecting the culture of health research at the time. It has fallen from favour due to the lack of validation studies, which reflects the current more rigorous academic culture. Such flux is a reason for reticence in accepting PRO data, but with appropriate methodological development, objectivity and validity can be measured, and such hurdles overcome.

Although the quality of PRO data is improving, the variety of PRO instruments and poor data reporting causes a challenge in synthesising PRO data (King et al., 2017). The importance of PRO data for policy makers, researchers and clinicians has seen the development of initiatives to try and increase their use, and improve the quality of PRO data collection (Table 1). PROs are often confused with patient reported experience measures (PREMs) which measure patients attitudes towards healthcare. Such confusion can also drive inappropriate responses to PRO data and can confound PRO studies (Black, Varaganum, & Hutchings, 2014). The health community must become more literate in PRO methodology if they are to collaborate with patients to generate the weight of evidence required to change clinical practice in a way that is meaningful to patients. This chapter describes the fundamental aspects of PROs; how they are collected, utilised and analysed, before proceeding to speculate how they might, in future, be integrated into clinical practice.

## **INTRINSIC QUALITIES OF PRO DATA**

The clinician must be careful when they collect and use PRO data. Several strategies exist for making judgements on the utility, relevance and interpretation of collected PRO data (McLeod, Coon, Martin, Fehnel, & Hays, 2011; Mokkink et al., 2010). Accurate use of PRO data requires an understanding of the qualities of PROs; and this requires an understanding of some basic psychometric theory. PRO data analysis is based on two psychometric theories, Classical Test Theory (CTT) and Item Response Theory (IRT); which are discussed in the latter part of this chapter. The understanding of these theories requires comprehension of the terms that underpin them.

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