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REVIEW ARTICLE

Measuring Patients' Experience of Rehabilitation Services Across the Care Continuum. Part I: A Systematic Review of the Literature



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Abstract

Objective: To identify empirically tested survey instruments designed to measure patient experience across a rehabilitative care system.

Data Sources: A comprehensive search was conducted of the MEDLINE (PubMed), CINAHL (EBSCO), and PsycINFO (APA PsycNET) databases from 2004 to 2014. Further searches were conducted in relevant journals and the reference lists of the final accepted articles.

Study Selection: Of 2472 articles identified, 33 were selected for inclusion and analysis. Articles were excluded if they were unrelated to rehabilitative care, were anecdotal or descriptive reports, or had a veterinary, mental health, palliative care, dental, or pediatric focus. Four reviewers performed the screening process. Interrater reliability was confirmed through 2 rounds of title review (30 articles each) and 1 round of abstract review (10 articles), with an average κ score of .69.

Data Extraction: Data were extracted related to the instrument, study setting, and patient characteristics, including treated disease, type of rehabilitation (eg, occupational or physical therapy), methodology, sample size, and level of evidence.

Data Synthesis: There were 25 discrete measurement instruments identified in the 33 articles evaluated. Seven of the instruments originated outside of the rehabilitative care sector, and only 1 measured service experience across the care continuum.

Conclusions: As providers move to integrate rehabilitative care across the continuum from hospital to home, patients experience a system of care. Research is required to develop psychometrically tested instruments that measure patients' experience across a rehabilitative system. Archives of Physical Medicine and Rehabilitation 2016;97:104-20

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Patient-centered care is increasingly recognized as a health system priority. For patient-centered care to be achieved, and to know where and what to target for quality improvement, we need more insight into patients' experiences during encounters with the health care system. With an aging population, more people are living with chronic disabilities that require rehabilitative care, requiring new approaches to delivering and measuring services in multiple care settings. As health care systems move to integrate service delivery between settings and providers in geographic

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regions,³ oversight and funding bodies are beginning to explore how to measure patients' overall experience of the health care system and its individual service delivery organizations.⁴

Rehabilitative health services aim to restore or reclaim functions that individuals were previously capable of accomplishing.⁵ The measurement of patient experience is particularly relevant in rehabilitative health services because coordination and continuity of care are often challenged by medical complexity and comorbidities and the involvement of multiple health care professionals across care settings.^{6,7} Although there is a large and growing body of literature on tools to measure patient experience, ⁸⁻¹¹ there is limited literature on the measurement of patient experience in rehabilitative care.¹²

Confounding the development of reliable and valid patient experience measures is the definitional ambiguity between patient experience and patient satisfaction. Jenkinson et al¹³ describe

experience as a report of what occurred in a patient's health encounter and satisfaction as their evaluation of that encounter. Therefore, patient satisfaction is less objective in its representation of reality, ¹⁴ and patient experience is more helpful in pinpointing areas for improvement. ¹³ Difficulties with patient satisfaction measurement include the lack of a strong conceptual foundation and consistent way of measuring satisfaction ⁴ and difficulty interpreting and therefore acting on results because of the complex heterogeneity of expectations that moderate patients' satisfaction with their care experience. ^{15,16}

High levels of patient satisfaction in rehabilitative care reported in many studies^{15,17-19} support the notion of a satisfaction ceiling effect that overstates the positive and is conceptually separate from negative experiences sustained during the same care encounter.^{20,21} This conceptual uncoupling of experience and satisfaction is further supported by Nairn et al,²² who suggest there is no correlation between poor experience, determined in their study by the timeliness of pain relief and the degree of pain relief achieved and satisfaction.

Therefore, patient experience is conceptually different than patient satisfaction; it therefore warrants a different framework of understanding before it can be explored as a measure of health system performance. This article (the first part of a 2-part article) suggests a conceptual framework and systematically identifies articles from the peer-reviewed literature that empirically tests instruments designed to measure patient experience of rehabilitative care. We focus on patient experience survey questions that might be used to measure an integrated rehabilitative care system and identify specific issues for quality improvement. The second article (part II)²³ provides a thematic analysis of the articles selected for review, their survey instruments, and questions to identify key dimensions of the patient experience in a rehabilitative care system. These dimensions guide the development of a framework for rehabilitative care patient experience performance indicators.

Conceptual framework

The framework of reference guiding this literature review is illustrated in figure 1. Patient experience refers to an individual's perspective of the presence or absence of elements of a health care provider's service delivery model. The core elements of a patient-centered or family-centered care model^{24,25} include principles such as information sharing, respect and honoring differences, partnership and collaboration, negotiation, and care in context of family and community. Drawing from formative services marketing literature, a quality service experience was progressively conceptualized as having 5 dimensions (reliability, tangibles, responsiveness, assurance, empathy²⁶⁻²⁸) that have been empirically tested across a range of industries using the SERVQUAL instrument ²⁶

Patient satisfaction, on the other hand, suggests an individual's "pleasure or disappointment" that comes from comparatively assessing a service against their personal values and expectations of it. ^{29,30(p789)} The magnitude and direction of the gap is determined by the patient's experience compared with their expectations, preferences, and values. If a patient expresses satisfaction with a service, one assumes therefore that they are happy after its consumption and that their expectations have been met. Some have referred to this as a "zone of tolerance." ^{31(p1)} The zone acknowledges that there is a range where patients will report satisfaction because of the effects of the various moderators of

Patient Satisfaction/Dissatisfaction An evaluation continuum based on patient perceptions of service quality Patients' evaluation of their experience influenced by the magnitude and direction of the gap in patient service expectations/preferences and their experience Patient Experience Influences patients' "lived experience" of service dimensions such as reliability, responsiveness, assurance, empathy and tangibles

Fig 1 Systematic review conceptual framework to situate patient experience.

Care Delivery Model

i.e. patient centered care

expectations and preferences and the likelihood that each service encounter will generate a different history because of the heterogeneous nature of service delivery. In the zone, adequacy is measured by achieving the minimal threshold of service that will be adequate to satisfy an individual's minimal service expectations. Below this service level, patients will express frustration at perceived inadequacy of their service quality; at the upper level of the zone, they will be delighted with the service and highly satisfied. Measures of these dimensions more often than not refer to satisfaction in either the question (eg, I am satisfied with the services I received) or in the response options (eg, not at all satisfied, extremely satisfied). The contrast between patient experience and patient satisfaction in this conceptual model is therefore the difference between living a care event and feeling contentment about the way it fulfilled your service expectations.

Search strategy

We conducted a search of peer-reviewed literature on empirically tested measures of patient experience, particularly those developed for systems of rehabilitative care. We used a search and review method with prespecified inclusion and exclusion criteria and documentation of procedural decisions. The search methodology, including the search terms (appendix 1), was developed in collaboration with a health sciences librarian. Figure 2 details the selection process.

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