

KEYWORDS: patient-centered care, patient perspective, quality of care, patient satisfaction, patient experience, evaluation instruments, health delivery systems, healthcare evolution, patient feedback

# The Patient Perspective of Quality Care: A Literature Review

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## ABSTRACT

The traditional approaches to health delivery, which ignore patient preferences, are increasingly being replaced by a more patient-centric model. In order to understand the current trajectory of this approach, it's important to break down past and present global health care systems and understand how different stakeholders are using the patient perspective as a feedback tool. This literature review explores the different reasons why patients are becoming more active participants in their health care, how various delivery models are evaluating the patient perspective, and how these findings can be used for internal operations in the future. The review concludes that the methodology and instruments used to evaluate the patient perspective depend heavily upon specific intentions driving the evaluation. Furthermore, as global health systems become more patient-centric, organizations are implored to review their internal resources and values to determine *why* and *if* a patient-centric care system is appropriate for their operation.

## INTRODUCTION

In the summer of 2018, Médecins Sans Frontières (Doctors Without Borders) requested a literature review on the patient perspective of quality of care. Interest in this work is part of a larger and more specialized medical and operational reflection on the quality of care at MSF. Producing a literature review on the current conceptual and methodological approaches to evaluating the patient perspective would help update MSF's knowledge on the topic and contribute to future operational approaches. I had around nine weeks to complete and synthesize my research. Although I didn't restrict the databases, almost all of the documents I found were available on PubMed, Wiley, GoogleScholar, and ScienceDirect. Since this review was explorative, I used a "snowball" research strategy. The following paragraph describes the foundation of my research.

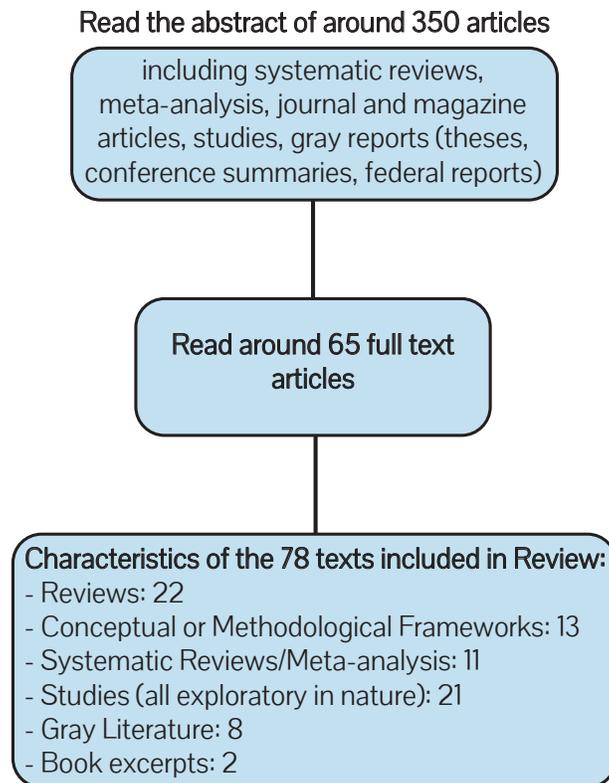
Following an initial search of "quality of care from the patients' perspective," I separated the search results via discipline. I read either the full article or the abstract of around 21 articles from different disciplines that posed a baseline question about the patient perspective (two from health care market analysts, two from consumer behavior analysts, three from federal agencies, five from medical institutions/journals, and nine public health research centers and journals). These provided me with a landscape of which disciplines are interested in the patient perspective, and the questions that drove their respective research. I noted five keywords that were referenced in almost all the

articles: "patient perspective," "patient-centered," "quality of care," "patient satisfaction," and "patient experience." I used these keywords both individually and together to refine my subsequent database search. Most of these keywords retrieved at least 100,000 results, and so they were only used at the starting point in the research. The more I read, the more my knowledge on the topic increased and drove my search strategy. Figure 1 indicates the scope of the articles that I read over these nine weeks and those that were used in this review.

Although economic and sociological theories are referenced in many articles, almost all of the primary sources that I read and/or included in the final review came from either medical or public health journals.

## BACKGROUND

Since the 1960s, health organizations have increasingly shown interest in how patients perceive the quality of their care. The traditional, biomedical approach to health delivery views patients as passive receivers of care, and only evaluates service quality with standardized benchmarks such as medical efficacy. A "democratization of health care services" (Calnan, 1988) has phased out this approach and progressively values patients for their role in evaluating health care quality. When patient preferences are included in the evaluation and design of health services, their overall utilization of services, quality of life, access to care, and medical efficacy improve (Greene, Tuzzio & Cherkin, 2012).



**FIGURE 1.** | Flowchart of article scope and search procedure

The body of research on the patient perspective is growing as patients continue evolving into active participants of their care (Norman, 2010), and can be used to understand the current trajectory of the evolution.

## LANDSCAPE

The patient perspective is a multifactorial subject, and almost all branches of social and human sciences have contributed to its clinical evolution. These disciplines have posed baseline patients' perspective of quality of care (PPQC) evaluations from a number of different angles, including but not limited to:

- How patients interpret their experiences of the health care system;
- How patients perceive specific or all dimensions of their healthcare interaction;
- How and why patients vary in their perception of services;
- How perception of care relates to health outcomes;
- How patients give greater value to specific dimensions of their healthcare interaction.

For concrete improvements in health care to occur, the term *quality of care* must be defined and measurable (Peabody, 2006). The International Organization for Standardization defines *quality of care* as "the degree to which a set of inherent characteristics fulfills requirements" (ISO, n.d.). These "requirements" differ

within and between policymakers, researchers, doctors, patients, settings, levels, and time periods. Likewise, different organizations and researchers vary in the way they measure quality. Health administrators worldwide are increasingly using the patient as an indicator (i.e., measurement) of the health care quality; however, the value given to patients' perspectives depends on how quality is interpreted by the organization (Nylenna et al., 2015). Organizations with a patient-centered definition of quality – centered on the needs and expectations of their patients – would thus value the patient perspective as a focal quality measure. Oppositely, organizations that use a biomedical definition of quality – which equates health care delivery to health outcomes – consider the patient perspective as just one of many quality measures. Thus, the way *quality of care* is interpreted is important for understanding the different objectives and methods behind PPQC assessments (Levesequé et al., 2012), since the manner in which organizations value the patient perspective will subsequently reflect the depth of their evaluations.

## DECONSTRUCTING THE HEALTH SYSTEM FOR THE PATIENT PERSPECTIVE

Avedis Donabedian's 1966 model prevails as the dominant framework for both the patients' perspective and general assessments of quality of care. He

categorized quality of care into three concepts: *structure*, *process*, and *outcome*. *Structure* is defined as the physical and organizational components of care settings, such as personnel, facilities, and other physical resources. *Process* is defined by services' specific clinical encounters, such as patients seeking care and providers' treatments and recommendations. These two aspects work together to influence the *outcome*, which describes the effect of care on the patients and the overall population, including changes to health status, behavior, and health literacy.

Within the structure/process/outcome model, outcomes are considered the greatest indicator of service quality to most healthcare organizations (Sitzia & Wood, 1997). Although outcome measurements are only reliable if they reflect the service's true relationship between its structures and processes (Gilbert & Knapp, 1987), health outcomes are also influenced by distinct individual and environmental factors that are hard to account for in clinical practice. For this reason, quality improvement initiatives are forgoing outcome evaluations, and instead are shifting focus to the structures and processes of care.

As previously discussed, measures of quality depend on how quality is defined (Donabedian, 2003). Accordingly, PPQC assessments vary in the process and structural dimensions included in their evaluations. Some researchers use popular frameworks, such as the market-based SERVQUAL model (tangibles, reliable, responsive, assurance, empathy) (Parasuraman, Ziethaml & Barry, 1988) or the Institute of Medicine's STEEEP acronym (safety, timely, effectiveness, efficient, equitable, patient-centered) (IOM, n.d.). Other researchers create their own dimensions by identifying definable quality criteria through patient focus groups and interviews (European Patients Forum, n.d.; Elwyn et al., 2007; Papp et al., 2014), and then use exploratory regression analysis and structural equation modeling to determine the main categories.

Since patients have countless clinical and nonclinical interactions during a single health care encounter, it is almost impossible to receive quality feedback from a general evaluation. Additionally, questions that focus on specific aspects of health services produce greater response variability, and thus studies often evaluate distinct service interactions, such as the interpersonal skills of doctors or the cleanliness of facilities. Oftentimes, follow-up studies are conducted to provide more interpretable feedback of a baseline evaluation. A preliminary study may reveal that communication is an important component of healthcare for patients in a clinical setting, but its operational value depends on identifying the specific features of communication (Salt, Rayens & Frazier, 2014). Thus, it is important to tailor questionnaires and surveys to be as specific or broad as necessary.

## DRIVERS OF PATIENT PERSPECTIVE EVALUATIONS

### Filling in Gaps in the Health System

PPQC evaluations are an efficient way to improve cost, efficiency, and organizational accountability by addressing overlooked gaps in the health system (Sofaer and Firminger, 2005). For example, patients often go through multiple providers and services for certain illnesses. If communication between providers is fragmented, treatment inconsistencies and medical errors may pose safety risks to the patient (Tarrant et al., 2015). Eliciting the patient's perspective of how their care was handled can act as a "safety net" to surveil operational missteps.

Other times, researchers evaluate PPQC to identify patient-driven behaviors (i.e., service utilization, treatment adherence, repeat visits) that often cause large discrepancies in health outcomes. Despite improvements in access and quality of health services, both non-governmental and governmental health care systems frequently have low utilization patterns. Research reveals that the perceived quality of care is one of the leading determinants of service utilization (Reerink and Sauerborn, 1996; Karim et al., 2016; Haddad et al., 1998), so health organizations use the patient perspective to understand why patients aren't using their services. Nevertheless, utilization patterns aren't always caused by perceived low quality of care (Atkinson and Haran, 2005). For example, many HIV positive men avoid seeking treatment due to the greater social stigma and legal consequences of having sex with other men (Beyrer et al., 2012). External influences which affect service utilization may require assessments of the patient perspective to include people who don't directly interact with the health care system (Baltussen and Ye, 2006). This approach requires a greater holistic understanding of the environment, instead of just the health care structure.

### Patients as Consumers

In a market-based approach to PPQC evaluations, patients are not only viewed as health care recipients, but as active consumers of a service (Wagner and Bear, 2009). Health systems often use patient evaluations to improve their services and stand out compared to competing providers (Crow et al., 2002), which is often reflected in the types of evaluation instruments used.

Patient feedback has become standardized in many governments as a way to promote market competition, accountability, and transparency between and within their services. Since 2002, trusts of England's National Health Service (NHS) are legally required to conduct annual surveys of their patients' recent health care experiences (Coulter, 2018). These surveys integrate feedback from in-patient, out-patient, and specialist services to measure

and supervise hospital performance between trusts and services over time, all of which are then published to help patients make an informed decision when choosing a health care provider. The NHS also uses The Friends and Family Test (FFT) as a feedback tool, which combines the likelihood of patients recommending services with follow-up questions to create an experience rating. Since its launch in April 2013, the FFT has become the biggest source of patient opinion in the world. Similarly, the United States uses Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) surveys to make comparisons between hospitals, create financial incentives for hospitals, and enforce service transparency. At time of publication, national or regional surveys of patients' experience of care had been introduced in most of Europe, Australia, Canada, Hong Kong, Japan, South Korea, Mexico, New Zealand, and the United States.

### Patient-Centered Care

In 2001, the Institute of Medicine (IOM) stressed moving toward a completely patient-centered delivery system “respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide *all clinical decisions*” (italics added for emphasis) (IOM, 2001). Since the IOM's publication, reaching a patient-centered care system has become a goal for many health organizations around the world, yet organizations have different interpretations of patient-centered care. While some organizations may think that basic assessments of the patient perspective qualify as a patient-centered health system, the patient perspective should be thought of as a scale of integration. At one end of the scale, the patient perspective is assessed after an interaction with a health service (reactive). At the other end, their perspective and needs are considered at each level of the health system (proactive). This end represents a truly patient-centered delivery system, but requires a complete cultural shift in the organization, planning and delivery of health services (Fix et al., 2018). For patients to turn into active “team members,” management-level participation, such as patient and family advisory councils, must be considered (Niehaus, 2017). A patient-centered care system tailors the delivery of care for each individual patient, and therefore requires a shift in the traditional doctor-patient power dynamic (Greene, Tuzzio & Cherkin, 2012). Most doctors, however, are trained to deliver care based on a biomedical understanding of health, and many hospitals that believe they have a patient-centered care system continue to deliver care through a biomedical attitude (Laine and Davidoff, 1996). In this regard, patient-centered care is still in its infancy and requires more than standard in-depth qualitative interviews to completely account for the patient perspective.

### CONCEPTS

As was briefly addressed in the landscape, the popularity of PPQC evaluations has created an extensive body of research. This number is so large because studies focus on a specific component of health delivery (interpersonal versus functional, socio-demographic variables, disease type, clinical setting, geography reason) and are based on different theoretical frameworks. Nonetheless, most of the studies reviewed used either *satisfaction* or *experience* (oftentimes both) to conceptualize patients' perceptions of their quality of care (Bowling et al., 2012; Sixma et al., 1998). Donabedian's quality measurement model saw satisfaction as a patient-reported outcome measure and patient-reported experiences as structure and process measures. It is extremely difficult to understand the specific ways that each contribute to a greater understanding of the patient, because their respective definitions and conceptual foundations vary across literature. Studies often claim to measure the same concept, yet vary in methodology, framework, and instrument. For example, studies may use experience to measure satisfaction to measure experience, satisfaction and experience as different but interchangeable, and experience and satisfaction as completely distinct and separate domains.

These varying interpretations create methodological inconsistencies across literature. For example, a study researching patients' overall satisfaction and perception of Zambian healthcare facilities measured satisfaction with a question from the US Consumer Assessment of Healthcare Providers and System Adult Visit Questionnaire (CAHPS) (Dansereau et al., 2015). The CAHPS was created to measure patient experience, and the US Department of Health & Human Services goes so far as to differentiate between experience and satisfaction measures on their website (AHRQ, 2017). Consequently, the unclear global distinction between the two domains has resulted in instruments being used interchangeably. Although this may not have large repercussions, researchers often end up using an instrument that doesn't effectively evaluate their objectives. Nonetheless, it is important to review each concept to understand its role in PPQC evaluations.

### Satisfaction

Satisfaction is the most common method used to evaluate patient perceptions of health care quality and is interpreted as a reflection of overall service quality (Williams, 1994). As previously discussed, organizations in competitive markets increasingly view the patient as a consumer of services and are adopting consumer evaluation measurements used by other service industries. Although satisfaction was originally used for quality assessments (Woodside, Frey & Daly, 1989), its ability to predict health-seeking behavior, such as

treatment adherence, has made it an invaluable measure of overall healthcare quality by health systems (Felipe et al., 2018). Satisfaction is often used to infer a patient's perception of their care, yet they are not one in the same. Even so, *patient satisfaction* and *patient perception of care* has been used interchangeably in literature, which has led to conceptual confusion between the two.

Despite its popularity, the term "satisfaction" has received heavy conceptual and methodological criticism. One of the biggest criticisms is that there is no universal definition. This has led satisfaction to be defined and operationalized by researchers in a number of different ways; oftentimes, studies claim to measure satisfaction but don't define it in their design methodologies. The most common definition of satisfaction draws from the expectancy-disconfirmation paradigm, in which satisfaction is a reflection of expectations and perceived performance (Forero and Gomez, 2017). This definition has contradictory theoretical implications: expectations are believed to be one of the primary determinants of satisfaction (Thompson and Sunoi, 1995), yet research reveals that there is little consistent empirical evidence that satisfaction actually results from the fulfilment of expectations. This inconsistency could potentially be due to the theoretical ambiguity of the term "expectations," which I expand upon later. These factors make it difficult to infer whether satisfaction reports vary due to differences in patient expectations or experiences.

Another criticism is that satisfaction is an inadequate reflection of quality. Satisfaction does not imply high quality service, only acceptable service, which constrains its ability to reveal how patients perceive their care. Because people interpret satisfaction differently (Collins and O'Cathain, 2003), if patients have a limited understanding of the health care system, they might record high satisfaction even if poor standards have been met. For quality assessment initiatives on a clinical level, this can be misleading – a study on overall satisfaction with lower limb arthroplasty resulted in both satisfied and unsatisfied patients equally recommending the procedure to a friend (Lane et al., 2016).

Additionally, many studies produce unrealistic reports of satisfaction due to unstable designs and unreliable instruments. Satisfaction surveys often receive unrealistically high reports of satisfaction. This can be simply due to the wording on survey questions. A test of visit-specific questions revealed that a six point direct rating of satisfaction ("very satisfied" to "very dissatisfied") yielded less response variability than a five point indirect rating of the same aspects but was scaled "excellent" to "poor." In one study, statements that were framed positively (i.e., "This health facility is clean. Do you agree or disagree?") had 88% responses of satisfaction, but the same questions received significant drops in satisfaction reports when asked in a negative manner.

## Experience

"Perceived quality" is a subjective, cognitive assessment of what and how something happened, which is why many view patient experience evaluations as the most effective way to understand the patient perspective (Kumah et al., 2017). Patient perspective has received recognition on a policy level: patient experience, alongside clinical effectiveness and safety, is considered one of the "three pillars of quality" at the epicenter of NHS health programs. Unlike the unreliable results of satisfaction measurements, patient experiences are consistently correlated to clinical effectiveness and safety, regardless of disease types, demographics, and study designs (Doyle, Lennox & Bell, 2003). Correspondingly, although there is no gold standard to capture experience, the instruments used to measure it have notably greater internal consistency and theoretical development. Instruments are often developed from literature reviews, in-depth interviews, and focus groups. Both the United States and the United Kingdom have used the Picker surveys for measuring patient experiences using their services. In these surveys, each item is coded as a dichotomous "problem" score (defined as an aspect of health care that the patient thinks could be improved). Overall, the body of research primarily focuses on in-patient hospital settings in Western countries.

## Expectations

Patients' expectations of health services influence how they perceive the quality of their care. In 2000, the World Health Report prioritized evaluating how often a population's non-health expectations are met as a measure of a health system's responsiveness and overall performance. As summarized by Conway et al. (1997), "patient expectations of the process of care, his/her role in this process and the expectation of the overall outcome of treatment will all influence the patient's evaluation of the service throughout the health care process and on its completion." Nevertheless, there is no consensus as to the best way to define or measure expectations within the health care setting (Iverson et al., 2012). Numerous theoretical constructs have been proposed by psychologists and other researchers (social learning theory, expectancy value theory, equity and discrepancy theory, self-efficacy theory), but they are often ignored in study designs. In a systematic review on the concepts and measurements of patient expectation assessments, 61% of the identified papers did not include any reference to a theoretical framework.

A large body of literature suggests that expectations can predict or influence health outcomes. For example, a "sham surgery" by McRae et al. (2004) showed that patients' beliefs about the treatment they received influenced its effectiveness. This relationship was validated in a study in

which women who expected nausea after chemotherapy were five times more likely to experience it than those who didn't expect nausea (Roscoe et al., 2018). In this study, expectation was interpreted as a sum of past nausea experiences and general knowledge about nausea after chemotherapy. These results suggest that different theories of expectation are more applicable in certain care settings. Exploring expectations may be beneficial in understanding overall quality of care assessments and may be able to explain variance in both treatment outcomes and perceptions of care. However, global findings are generally uncertain of the strength of the correlation between expectations and outcomes. A meta-analysis on pre-surgery expectations and post-surgery outcomes found a strong association between the two (Auer et al., 2016), yet a systematic review of primary care settings reported inconsistent findings (Rao, Weinberger & Kroenke, 2000). It is important to note, though, that the studies included in these reviews used different instrument designs and conceptual frameworks. Such differences weaken the internal validity of results and any comparisons that could be made. Although the relationship between expectations and health outcomes is unreliable, accurate assessments of patient expectations are undeniably critical for a delivery system responsive to patients' needs. At an individual level, doctors are often in the best position to understand these expectations, but Levenstein et al. (1986) reported that doctors fail to elicit 54% of patients' reasons for visiting them and 45% of their worries.

## METHODOLOGIES

As discussed earlier, some studies evaluate the patient perspective based on a predetermined definition of quality, while others define and measure what patients perceive as important about their care. The difference between the two is the way researchers account for the subjectivity of perceptions. For example, in order to have an in-depth understanding of individual experiences, it is important to make sure measures of experience do not turn into reports of experience. Nonetheless, reports can intend to reflect objective interaction for accountability reasons (Bleich, 2009). Questions such as "Were you asked to schedule a follow up appointment?" are objective reports that don't elicit a perception of quality but can be used as an assurance and surveillance mechanism. Similarly, if patient satisfaction is linked to greater service retention, and patient satisfaction is provably linked to waiting time, clinics may ask subjective questions ("How satisfied were you with your waiting time?") to ensure satisfaction and service retention (Labonte et al., 2016). The most consistent methodological similarities and differences in PPQC evaluations are presented in the following subsections.

## Qualitative

Qualitative research seeks a holistic, exploratory understanding of a larger concept through words, making it favorable for eliciting attitudes that cannot be revealed through quantitative methods (Pope, van Royen & Baker, 2002). Depending on the situation and research question, certain qualitative approaches may be more appropriate than others. Methods such as ethnographies and interviews are best for conceptualizing external factors that may influence treatment perception. For example, an ethnographic study of a Chinese cancer support group found discussions of food, eating, and diet were a recurrent theme throughout the research process. Culturally-specific concerns of the relationship between food and health informed these individuals' experiences of eating issues during and after cancer treatment (Bell, 2009). Thus, researchers must tailor their research methods to accurately capture their intended depth of evaluation. Qualitative approaches must be conducted by experienced and trained researchers in order to obtain an accurate representation of the population. Not all patients feel comfortable speaking up about their concerns, which means that focus group results may use the opinions of a few to represent the concerns of many.

## Quantitative

Quantitative approaches use different methods to achieve a representative sample of a population. For large-scale, broad assessments, quantitative approaches are often the preferred method. Health organizations use patient feedback as a means to increase their overall population health "given a set of fixed resources and operational constraints" (Derose and Petitti, 2003). Although quantitative methods often standardize the patient experience, these methods are often necessary when the objective is to maximize health across individuals. This approach reflects the current practices of Western public health systems, which use patient feedback to compare quality of service across providers. In order to ensure that differences in results aren't due to differences in measurement methodology, governments use standardized questionnaires for feedback collection (i.e., US's CAHPS, UK's Picker Surveys). Quantitative methods provide little opportunity for patients to identify new areas of concern, so it is recommended that questionnaires have an area where patients can leave comments. Since perceptions are multidimensional constructs, single-item (global) questions have limited practicality and can be unreliable indicators of care quality. In one study, patients who indicated that they would recommend their hospital to others also indicated problems in all dimensions of their experience (Jenkinson et al., 2002). Terms such as "recommendations" are subjective and don't accurately capture experiences in

detail.

Assessments that aim to completely understand PPQC should only test measures of quality as defined by the respondents. Such in-depth understanding requires some form of preliminary qualitative research. Thus, even if a study uses quantitative methods, its contents are usually based on qualitative research that captures how patients define and perceive their care. Additionally, if questions are scored but not weighted, the fact that some constructs are considered more important than others will be overlooked. This is especially true in experience questionnaires, such as the Picker survey, where questions are framed as “problem” scores but don’t explore how much of a “problem” the situation is for individuals. Calculating the relative importance of these dimensions not only elicits individual patient preferences, but can reveal the appropriate level of intervention.

## INSTRUMENT DESIGN

### Design

An adequate instrument consists of one that is both reliable and valid. Frameworks for creating and evaluating reliable and valid instruments for the health care setting have been detailed elsewhere (Weldring and Smith, 2013; Pseudovs et al., 2007; Kimberlin and Winterstein, 2008). When designing instruments to represent the views of the patient, it is important that the patient perspective is actively considered throughout all stages of research design (Siriwardena, 2014). Designing instruments based off of existing or professional assumptions can threaten the instruments’ content validity. Evidence also suggests that patient engagement can improve study design, execution, and translation (Garces et al., 2012). When instruments are designed to evaluate data-sensitive outcomes for organizations, it is important for the instrument to possess strong reliability and validity. However, instruments used for large scale quality improvement initiatives might compromise a high reliability and validity for other aspects, such as cost utility.

A scale developed by Haddad et al. (1998) to measure lay people’s perceptions of the quality of primary health care in Guinea is an example of how to create a valid questionnaire completely representative of the views of the population in question. Researchers initially conducted an exploratory study of 21 homogeneous focus groups, 17 key informants, and six exit interviews in 11 different villages. After being translated and transcribed, 44 quality attributes were identified. Existing taxonomies were used to group the attributes into five different categories. In the second phase, 72 respondents were recruited randomly from nine new villages to undertake a role-playing survey aimed at ranking the criteria in degree of importance. This survey confirmed the predominant roles of certain criteria that were seen as more important

quality measurements. The questionnaire was pre-tested on 12 people to allow for word adjustment and was subsequently administered to include the criteria, as well as: (i) intention to use the evaluated facility again; (ii) respondents’ general opinion of the quality of services, technical competency and interpersonal skills of staff, effectiveness of the care, and adequacy of the existing resources and accessibility of services; and (iii) socio-demographic characteristics. After being completed through household and exit interviews, the scale was narrowed down to 20 of the original items. Aggregation procedures were tested to construct global scores of the specific dimensions, and statistical analysis was performed to confirm the reliability and validity of the scores. Although this entire process may appear tedious and methodologically rigorous, it is necessary for assessing the determinants that patients find important.

### Adaptation

There are various proposed protocols to follow when adapting questionnaires. Choosing the appropriate tool can be difficult and requires attention to the disease type, patient demographic, validity and reliability. Studies that use old instruments should still initially test them on their new respondents using qualitative methods, even if the instrument was designed for the same health care setting. A study that assessed how patients with depression viewed a validated mental health questionnaire confirmed that it covered appropriate aspects of service provision. However, in-depth interviews with the patients revealed that it was still too generic to capture the diversity of their experiences. Quantitative methods need to be supplemented with in-depth qualitative approaches. Therefore, a validated instrument may be invalid for a different study.

A study by Flaherty et al. (1988) concluded that instruments used across cultures must first have their content tested for contextual, conceptual, semantic, and technical cross-cultural validity. This protocol was followed in a study to assess the cross-cultural validity of the HCAHPS survey in five different European languages (Squires et al., 2012). The results of this study indicate that patients considered the HCAHPS relevant to the experiences in their home country. The only methodological issues that arose were the demographic-related questions. Questions relating to education level were given “poor” relevance scores by the patients and deemed unnecessary in the survey design, which highlights the fact that translated instruments need to be rigorously tested on the target population for cross-cultural relevance, in addition to translation accuracy.

## CONCLUSION

The patient perspective is a complicated, multidimensional concept, and it seems that every PPQC

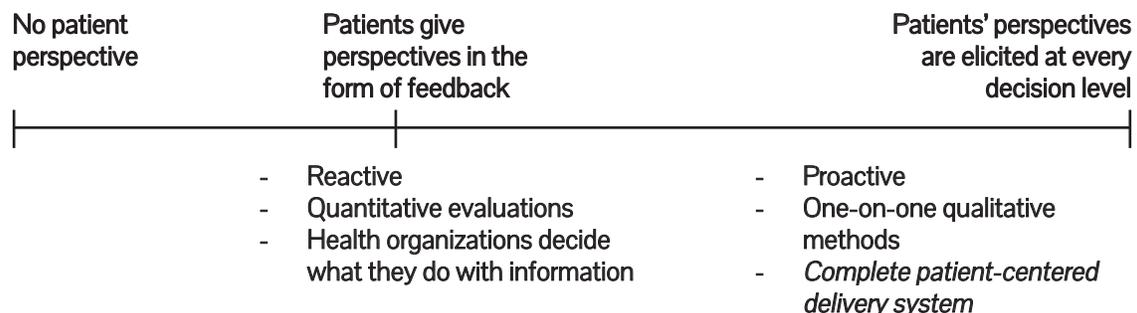
evaluation has some form of methodological criticism. Despite its global popularity, it seems that many health organizations are evaluating the patient perspective just for the sake of it, but are unsure what to do with their findings. Accounting for the patient perspective is meaningless if results aren't taken into consideration and put into practice, yet there is a very small body of literature detailing successful feedback operations. The systematic review *Understanding and Using Patient Experience Feedback to Improve Health Care Quality* identified only 12 studies that detailed how patient feedback was used for quality improvement. Evidently, dissemination of feedback at an organizational and individual level needs greater research. Additionally, most of the literature on the patient perspective is from Western, developed health care systems. More studies need to focus on underdeveloped and developing health care systems, especially as calls for greater global access to care have overshadowed the need for such care to be of high quality (National Academy Press, 2015). It can be difficult to improve the quality of care while meeting patients' expectations and needs on a limited budget, but many studies highlight doctors' interpersonal skills as a top determinant of quality for patients (Mohammed, 2016). Thus, it should not be assumed that major resources are needed to improve quality of care, which is why it is critical to capture the patient perspective.

Although health care seems to be working toward a patient-centered delivery system, organizations need to account for and overcome their current barriers first and foremost. Unfortunately, an overwhelming majority of the current patient-centered care literature is comprised of conceptual reviews from psychological and behavioral health reviews. There are limited case studies of patient-centered care systems that have been successful, which may be because a patient-centered care system isn't a "one-size-fits-all" model. Interpersonal factors, such as patient-centered communication skills, need to be accounted for, as well. However, the personal beliefs and values of medical personnel may hinder the process of establishing clear, respectful and mutual goals with

patients, which can result in difficulty changing their attitudes toward patients (Wensing, 2002; Visser, 2014). The purpose and measures of patient evaluations must be valued by the staff. When health teams themselves sought patients' evaluations of care, the perceived benefits of the evaluations were consistently reported by staff (Baldie et al., 2018), which demonstrates the importance of organizations being in complete consensus during any patient-centered care initiative.

Not every patient wants a decision-making role in their treatment. A truly patient-centered delivery system must work toward understanding the preferences of the individual, but this should not assume that every patient is willing to discuss their preferences. Patient-centered care is about patient autonomy, therefore the patient should choose to decide whether they want to be actively involved in their care process. A number of frameworks have been proposed to understand how to match patient preferences of information with treatment decisions. One quantitative survey measures which patients desire to ask questions and be informed about their medical decisions (Krantz, 1980). Nevertheless, a majority of preference frameworks are conceptually based and have little empirical evidence.

It is important for organizations to understand where they currently lie on the scale of integration. Reflection needs to happen for future operations. Where does the organization want to be on the scale, and why? Is it simply to follow the global paradigmatic shift in health delivery? Or is it because the patient perspective could help resolve some of the difficulties that are currently seen in care settings? Having a clear direction is important for knowing what the next step needs to be for different field sites, which is accomplished by identifying systematic, professional and individual tensions, barriers or conflicts that are present. Understanding patient integration as a scale serves as a reminder that health systems do not have to be either completely paternalistic or patient-centered. Tradeoffs will have to be made, and having a clear, definitive reason for integrating the patient perspective is necessary in order to take the next step.



**FIGURE 2.** | *Scale of integration*

It is apparent that the patient perspective is a complex topic, and that an integrated patient health system requires a deeper understanding of the individual patient. It is recommended that every field site is approached using in-depth qualitative research methods to understand both clinical and nonclinical factors that could pose a barrier to implementing the patients' perspective for operational purposes.

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## Mentor Details

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This article was prepared with mentorship from Marianne Viot.

Marianne Viot has over 14 years of international and local professional experience for University, UN Agency, NGO and Private Sector working on Health Issues, Educational Programs and Online Communications & Advertising. Currently, she is operations manager at Medecins Sans Frontier (France).

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