

Médecins Sans Frontières – CRASH – RIDER

LITERATURE SYNTHESIS

**The Patient Perspective of Quality of Care:
A Review of the Literature**

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RIDER is an interdisciplinary network bringing together MSF, Epicentre and the Crash. Its mission is to support MSF's executive and associative branches in the production of rigorous and useful knowledge for action, using social sciences and epidemiology.

The work of the RIDER members can take different and flexible forms including : *methodological support* for a piece of work fully managed by the sponsor, *co-steering* a study project involving external researchers and MSF project managers or the *realization of our own study projects*.

The current project was initiated in spring 2018 by the Crash. Considering ongoing in-house research projects and reflections, MSF-Crash decided to produce a literature review on the appraisal of quality of care from a patient perspective. Interest in such a work is part of a larger and more specialized medical and operational reflection on the quality of care. A literature review would help to enrich MSF's approaches with up-to-date researches on the topic.

A first presentation of the findings (by Hannah Barnett who produced the review) , followed by a group discussion were held in Paris on August 23rd 2018. Ten participants from the Operations and Medical Departments, as well as from the Crash attended this restitution coordinated by the Rider.

We hope that the present report will feed further discussions on the topic.

EXECUTIVE SUMMARY

Introduction. MSF-Crash requested a literature review on the patient perspective of quality of care. Interest in this work is part of a larger medical and operational reflection on the quality of care in MSF projects. It aims to support ongoing initiatives on the quality of care and, more specifically, on the common use within the organization, of the ill-defined concept of “patient-centered approach”.

Method. Considering the limited time frame of this work (9 weeks), the literature review below is the result of a thorough and targeted search (online databases and MSF grey literature) rather than an exercise aimed at being exhaustive.

Results. This work describes and defines a variety of concepts around quality of care. It explains the complexity of defining the problem and of addressing the questions, given the lack of empiric studies. Finally the author – based on MSF questioning – reorients the discussion around the “scale of integration” of the patient’s perspective of care. She emphasizes a need within MSF to clarify and find out which vocabulary to use for which operational purpose, in order to reflect “real life” considerations.

Discussion & Operational use. This work can be shared widely within MSF OCP, particularly within the Med-Ops departments. Depending how this work echoes the ongoing work by the medical department and the Crash as well as questions arising from the field (etc.), it will be interesting to see how it can help discuss and structure a common definition of quality of care and patient centeredness.

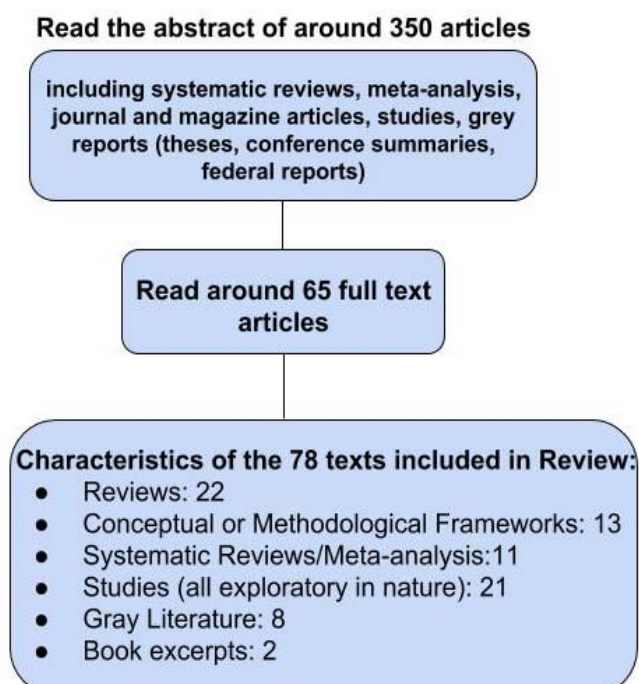
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INTRODUCTION

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 MSFs' knowledge on the topic and contribute to future operational approaches. I had around 9 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 (2 from healthcare market analysts, 2 from consumer behavior analysts, 3 from federal agencies, 5 from medical institutions/journals, and 9 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 5 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 almost always 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. The flowchart below indicates the scope of the articles that I read over these 9 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 patients’ 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). The body of research concerning the patient perspective is growing as patients continue evolving into active participants of their care (Norman, 2010).

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 patients’ perspective of quality of care (PPQC) questions from a number of different angles, including but not limited to:

- How patients interpret their experiences of the healthcare 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 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’s 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.

1. DECONSTRUCTING THE HEALTH SYSTEM FOR THE PATIENT PERSPECTIVE

Avedis Donabedian's 1966 model prevails as the dominant framework for both the patient's 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 provider's 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 their *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 Medicines'* STEEP acronym (safety, effectiveness, patient-centered, timely, efficient, equitable) (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 healthcare 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 the facilities. Often, 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).

2. 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 (Sofaer and Firminger, 2005) by addressing overlooked gaps in the health system. 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 patients' 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 healthcare systems frequently have low utilization patterns. Research revealed 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) and so health organizations use the patient perspective to understand why patients aren't using their services. Nonetheless, utilization patterns aren't always caused by low perceived 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 effect service utilization may require assessments of the 'patient perspective' to include people who don't directly interact with the health system (Baltussen and Ye, 2006).

Patients as Consumers

In a market-based approach to PPQC evaluations, patients are not only viewed as healthcare recipients, but as active consumers of a service (Wagner and Bear, 2009). Thus, health systems often use patient evaluations to improve their services and stand out to competing providers (Crow et al, 2002).

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 are legally required to conduct annual surveys of their patients' recent healthcare experience (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, which are then published to help patients make informed decisions when choosing a healthcare 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 the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) surveys to make comparisons between hospitals, create financial incentives for hospitals, and enforce service transparency¹.

Patient-Centered Care

In 2001, The Institute of Medicine (IOM) stressed moving towards 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. They may think that basic assessments of the patient perspective qualify a patient-centered health system; instead, the patient perspective can 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 perspectives 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 thus 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 believe to have a patient-centered care system yet 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.

3. CONCEPTS

As briefly addressed in the *landscape*, the popularity of PPQC evaluations have 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 I reviewed used either *satisfaction* or *experience* (oftentimes both) to conceptualize patients’ perceptions of the 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

¹ Regular national or regional surveys of patients’ experience of care have been introduced in most of Europe, Australia, Canada, Hong Kong, Japan, South Korea, Mexico, New Zealand, and the United States.

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 use experience to measure satisfaction; 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 commonly used method for evaluating patient perceptions of healthcare 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 behavior², 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. **Erreur ! Signet non défini.** The most common definition of satisfaction draws from the expectancy-disconfirmation paradigm, in which satisfaction is a reflection of

² In this definition, health seeking behaviors describe patients who actively undertake processes to alleviate or cure their perceived ill-health.

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 could potentially be due to *expectations* own theoretical ambiguity, which I expand upon later. This makes 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 provided. 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 6- point direct rating of satisfaction (“very satisfied” to “very dissatisfied”) yielded less response variability than a 5-point indirect rating of the same aspects but scaled “excellent to poor.” In one study, statements that were framed positively (“this health facility is clean. Do you agree or disagree?”) had 88% responses of satisfaction, but the same questions received extremely 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. This is why many view patient experience evaluations as the most effective way to understand the patient perspective (Kumah et al., 2017). It 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, its instruments 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 in 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). The most well-known experience instruments are documented elsewhere, but the body of research primarily focuses on inpatient 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." Nonetheless, there is no consensus of the best way to define or measure expectations within the healthcare 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 didn't 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. This suggests 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 can explain variance in both treatment outcomes and perceptions of care. However, global findings are generally uncertain of the strength 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). However, 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 patients' expectations is 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. However, Levenstein et al. (1986) reported that doctors failed to elicit 54% of patients' reasons for visiting them and 45% of their worries.

4. METHODOLOGIES

As discussed earlier, some studies evaluate the patient's 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, for an in-depth understanding of individual experiences, it's important to make sure *measures* of experience don't turn into *reports* of experience. Nonetheless, reports can reflect an objective interaction for accountability reasons (Bleich, 2009). For example, 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 this next section.

Qualitative

Qualitative research seek a holistic, exploratory understanding of a larger concept through words, making it favorable for eliciting attitudes that can't 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 their experiences of eating issues during and after cancer treatment (Bell, 2009).

Qualitative approaches must be conducted by experienced and trained researchers in order to get 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 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, when the objective is to maximize health across individuals, these methods are often necessary. This reflects the current practices of Western public health systems that use

patient feedback to compare the quality of services. 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 a multidimensional construct, 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 the hospital others also indicated problems in all dimensions of an experience questionnaire (Jenkinson et al., 2002).

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 from 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 and 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.

5. 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 healthcare 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 through 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 evaluate data-sensitive outcomes for organizations, then it's important the reliability and validity of the instrument is high. 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 quality of primary health in Guinea is an example of how to create a valid questionnaire completely representative of the views of the population studied. The researchers initially conducted an exploratory study of 21 homogeneous focus groups, 17 key informants and 6 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 5 different categories. In the second phase, 72 respondents were recruited randomly from 9 new villages to undertake a role playing survey to rank the criteria in degree of importance. This confirmed the predominant role of certain criteria that were important in quality measurements. The questionnaire was pre-tested on 12 people to allow for word adjustment and 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, 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 focused 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, they are necessary in 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 test them first 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, and that quantitative methods need to be supplemented with in depth qualitative approaches. Thus, 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 be tested for content, context, 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 indicated 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. This highlights the fact that translated instruments need to be rigorously tested on the target population for cross-cultural relevance as well as translation accuracy.

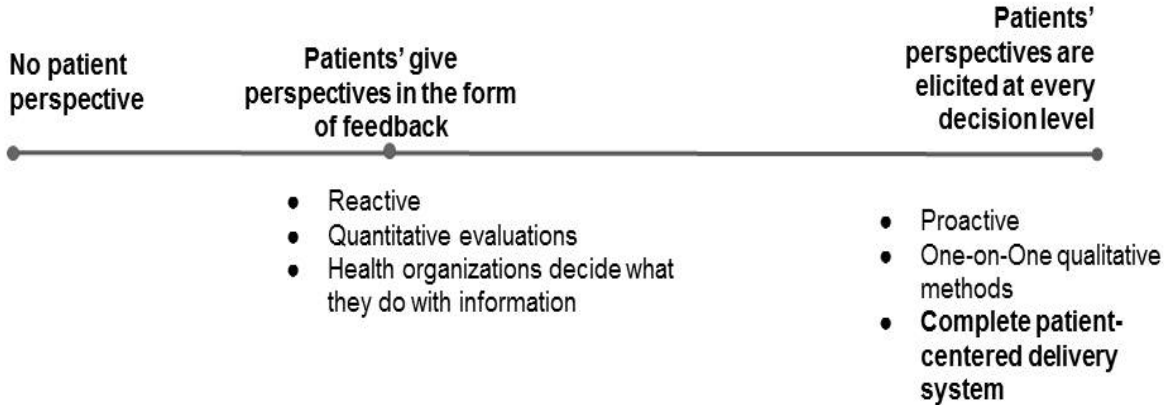
DISCUSSION

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, and are unsure what to do with the findings. Accounting for the patient perspective is meaningless if results aren't put into practice, yet there is a minimal 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 systems. Greater studies need to focus on under-developed and developing health 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).

Although healthcare seems to be currently working towards a patient-centered delivery system, organizations need to first account for and overcome the current barriers. Unfortunately, an overwhelming majority of the current patient-centered care literature are conceptual reviews from psychology and behavioral health reviews. There are limited case study examples of 'patient-centered' care systems that have worked. This 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. However, personal beliefs and values of medical personnel may hinder the process of establishing clear, respectful and mutual goals with patients, and can make their attitudes towards patients hard to change (Wensing, 2002; Visser, 2014). This means that 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).

Not every patient wants a decision-making role in their treatment. A truly centered patient delivery system must work towards understanding the preferences of the individual. However, this is not to assume that every patient is willing to discuss their preferences. Patient centered care is about patient autonomy, thus they have the choice 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 exists that measures which patients desire to ask questions and be informed about their medical decisions (Krantz, 1980). Nonetheless, a majority of preference frameworks are conceptually based and have little empirical evidence.

Referring back to the 'scale of integration' concept I introduced in the "patient-centered care" section:



It is important for MSF to understand where they currently lay on the scale. For future operations, reflection needs to happen. Where does MSF want to be on the scale, and *why*? Is it because MSF wants 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 the different field sites. This is done by identifying systematic, professional and individual tensions, barriers, or conflict that are present. Understanding that patient integration is a scale serves as a reminder that health systems don't have to be either completely paternalistic or completely patient-centered. Tradeoffs will have to be made, and having a clear, defined reason for integrating the patient perspective is necessary in order to take a next step.

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. I recommend that every one of MSF's field sites is approached using in-depth qualitative research methods to understand both clinical and nonclinical factors that could pose as a barrier to implementing the patients' perspective for operational purposes.

RESTITUTION OF THE LITERATURE REVIEW ON THE PATIENT PERSPECTIVE OF QUALITY OF CARE

A first presentation of the findings of the literature review was followed by a group discussion held in Paris on Aug. 23, 2018. Ten participants from the Operations and Medical Departments, as well as from the Crash attended this restitution coordinated by the Rider.

Key takeaways from the discussion

- 1) Some field teams have initiated collecting patient feedback in the form of surveys or questionnaires. However field teams and HQ support teams are experiencing a lack of guidance and tools which would allow them to go further in developing such approaches.
- 2) Before considering the implementation of this type of approach (from collecting patient feedback to developing a patient-centered approach), we need to consider how to engage with patients. A participant mentioned: *"We need to bridge the gap and train our staff about the concepts first"*.
- 3) More globally, our model of care delivery is outdated. It was framed on different epidemiological situations and policies. The emergence of chronic diseases in many MSF settings sheds light on the discrepancies in care delivery and the pathologies we are facing today. This ought to push us to look for new models of care delivery.

In a nutshell

A reflection needs to happen, aiming at clarifying the following questions: **"why do we want to do it?"** Is it because we think it is important? Or have we identified barriers, such as bad feedback from patients? Or is it simply a question we wanted to address? [...] How can we provide a different approach that actually optimizes our quality of care instead of just adopting a slogan?

How to move forward? Some suggested:

- Creating an *ad hoc* forum where reflections and initiatives would be mediated and shares?
- Identifying projects or fields currently implementing concept some sort of "quality of care" initiative and providing specific support (Hospital Management Cell / Rider / Ops-Med Dept / others)?

More ideas?

Share your thoughts at: rider@paris.msf.org

RECOMMENDED DOCUMENTS

Title	Author	Year	Discipline	Type of Document	Focus
Patient perceptions of the quality of health services	Sofaer and Firminger	2005	Public Health	Literature Review and Conceptual Model Proposal	Identifies conceptual and methodological issues that make measuring and defining patient perspectives difficult. Using qualitative studies, a conceptual model for understanding these issues is proposed. Sofaer and Firminger's review provides greater details on many of the topics touched upon in this paper.
What is Good Quality Healthcare?	Nylen et al.	2015	Health Services	Literature Review	This paper provides an overview of key components in the quality debate within health care, including different perspectives and dimensions of the quality of care. It expands upon using the patient perspective as a quality indicator, and how this reflects a shift in quality improvement from individual responsibility to systems thinking.
The measurement of patients' expectations for health care: a review and psychometric testing of a measure of patients' expectations	Bowling et al.	2012	Consumer Behavior	A literature review and semi-structured exploratory study	This detailed review provides an overview of all the conceptual and theoretical approaches to understanding and measuring patients' expectations.
Patient Satisfaction: A Valid Concept?	Williams and Brian	1994	Psychological Medicine	Conceptual review and critique	This text is one of the most heavily cited and leading satisfaction critiques in literature.
The measurement of satisfaction with healthcare: implications for practice from a systematic review of the literature	Crow et al.	2002	Inter-disciplinary (Economics, Psychology, Applied Statistics, Sociology, Medical Services)	Systematic Review	Crow et al.'s systematic review summarizes results of studies that investigate methodological issues, identify determinants of satisfaction in different healthcare settings, exploring gaps in existing knowledge, and synthesize their findings. Qualitative and quantitative studies are used to provide case-and-point analysis of the issues behind satisfaction measures.
How to Conduct Qualitative Research on the Patient's Experience	Chenail and Ronald J	2011	Qualitative Health Research	Review	This review addresses the critical components to patient-centered care, and how different qualitative designs can be used to create studies to meet patient-centered research needs.
Understanding and Using Patient Experience Feedback to Improve Health Care Quality: Systematic Review and Framework Development	Kumah et al.	2017	Public Health	Systematic Review and Framework Development	Kumah et al.'s review addresses the fact that many health organizations don't know what to do with the results of their PPQC evaluations. They provide an empirically based framework to help organizations and managers understand what to do with patient experience feedback.
Eliciting Patient Perspective in Patient-Centered Outcomes Research: A Meta Narrative Systematic Review.	Garces et al.	2012	Public Health	(Gray Literature) Meta Narrative Systematic Review	This review conducted a comprehensive search of all studies that discussed or used patient-driven research strategies. It identifies the barriers of engaging the patient at each step of the process.
What Does Quality Mean to Lay People? Community Perceptions of Primary Health Care Services in Guinea	Haddad et al.	1998	Interdisciplinary Health Research	Study	This study exemplifies how perceptions of care may be influenced at a community level. Their study design has been used by many other studies in developing countries, and provides a great framework for approaching perspectives in developing health systems (which is often lacking in literature).

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