

Understanding Patient Expectations of Health Care: A Qualitative Study

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Abstract

Understanding and measuring patient expectations of health care is central to improving patient satisfaction and delivering patient-centered care. However, most empiric research in this field has focused on measuring patient expectations for specific diseases only. Patient expectations common to a variety of settings and clinical contexts need to be better understood to design measures with wider utility. We aimed to understand how patients express and conceptualize their expectations of health care across a range of clinical contexts and conditions. Semi-structured interviews were conducted with patients presenting to a major metropolitan hospital, informed by interpretive phenomenological analysis. Sampling continued until thematic saturation. Interview topics explored the illness experience, interactions with clinicians, how patients communicated and conceptualized their expectations of health care, and the nature of these expectations. The 26 participants conceptualized and described their expectations in 3 distinct domains: (1) health outcomes, (2) individual clinicians, and (3) the health-care system. Importantly, these domains were consistent across a variety of clinical contexts, participant demographics, and medical conditions. Despite variation in expectations due to individual patient circumstances, we identified 3 conceptual domains within which expectations consistently lie. When designing measurement tools for patient expectations, we suggest incorporating questions specifically addressing the 3 domains we have identified. With such measures, clinicians and health-care providers can be empowered to provide and monitor patient-centered care with outcomes tailored to what patients desire.

Keywords

qualitative research, expectations, satisfaction, patient-centered care, quality improvement

Introduction

The importance of understanding patient expectations of health care is being increasingly recognized. Expectations can significantly influence health outcomes (1), including the effects of medical treatment such as cardiac surgery (2), joint replacement (3), and chemotherapy(4). Indeed, the well-studied placebo response is underpinned by patient expectations of the benefit of a treatment (5). Accordingly, it has been suggested that every clinical encounter should begin with a determination of the patient's expectations (6).

Furthermore, expectancy theory in psychology proposes that satisfaction is primarily determined by the difference between that which is expected and what is received (7,8). This concept was supported by a large survey study which found patient satisfaction was primarily determined by whether health-care expectations were met (9). Therefore, a crucial step to improving patient satisfaction and delivering patient-centered care is to first understand patient expectations of health care (10,11).

In 2017, the authors conducted several studies investigating the experience and expectations of patients admitted to hospital with acute low back pain (LBP) (12,13). We found patients had distinct expectations of health care regarding the need for investigations such as imaging studies, treatment modalities, and the provision of follow-up appointments. Findings were used to develop an LBP model of care for consumers and adapt local services to improve the care of patients with LBP.

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However, our findings primarily showed disease-specific patient expectations. For example, we found patients with acute LBP held strong expectations that their treating doctor would organize urgent scans of the lumbosacral spine to investigate their symptoms. This expectation of care is well documented in other LBP studies (14), but not necessarily relevant to patients presenting with other medical problems. Expectations such as this, referred to as “treatment-specific expectations,” are rarely comparable between different conditions (15). Patients also described expectations which could potentially apply to the treatment of other conditions. This finding suggested there may be common aspects of patient expectations across a range of clinical contexts, although our study was not able to confirm this.

Similarly, a large proportion of the studies investigating patient expectations have been undertaken in the context of specific illnesses or conditions (15–21). Further empirical evidence investigating how patients communicate their expectations across a range of clinical contexts is needed. This has been highlighted by several reviews that have emphasized the need for a more standardized assessment of patient expectations (7,22,23). We therefore aimed to design a study to investigate the expectations of health care of patients, presenting to a public hospital, across a range of medical conditions and clinical contexts.

The theoretical concept of expectations has been extensively studied in psychological research with significant heterogeneity in terminology, integration of theoretical models, and approaches to measurement (7,8,15,24–27). In this study, we adopt Laferton’s definition of expectations, which refers to beliefs about the incidence of specific future events or experiences (15). Laferton’s model expands on previous conceptual frameworks that considered self-efficacy (beliefs that one can carry out the actions necessary for successful management of a condition) as the only aspect of expectations regarding patient behavior (15,28–30). Instead, self-efficacy is considered alongside behavior outcome expectations (beliefs that certain actions will lead to beneficial health effects), which are collectively referred to as “personal control beliefs.” Laferton also distinguishes between generalized expectations such as “dispositional optimism” and specific expectations related to individual circumstances (31,32).

We designed this pragmatic study to gather the views of a broad sample of patients from a diverse population who were actively seeking care for a range of health conditions within a busy public hospital. Our research question was “Are there common aspects in how patients conceptualize and communicate their expectations of health care across a range of medical conditions and presentations?”

Methods

We report our investigation in accordance with the Standards for Reporting Qualitative Research (33).

Theoretical Framework

Interpretive phenomenological analysis (IPA) was adopted, which is well suited for exploring how participants make sense of their world and experiences (34). Interpretive phenomenological analysis is phenomenological in that it aims to examine and interpret personal experience through the perceptions of individuals, rather than attempting to produce an objective description of the event itself. Concurrently, IPA acknowledges and incorporates the researcher’s active role in the process of understanding the participant’s world view in trying to gain this understanding. Thus, there is a 2-stage interpretation process, with the researcher trying to make sense of the participant trying to make sense of their world (34).

Our research approach was informed by Stewart and colleagues’ patient-centered framework, underpinned by 4 principles: (1) exploring health, disease, and the illness experience; (2) understanding the whole person; (3) finding common ground; and (4) enhancing the patient–clinician relationship (35).

Stewart’s framework is therefore well suited with IPA, which views the person as a cognitive, linguistic, affective, and physical being (34). Similarly, in accordance with the World Health Organization, we defined “health” as a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity (36).

Context

This study was conducted in a 300-bed teaching hospital in an outer metropolitan, growing area of Sydney, Australia, from January through December 2018. The 300-bed major metropolitan hospital in South-West Sydney provides a full range of services—including subspecialty medical and surgical facilities—well suited to recruiting a diverse cohort into the study. South west Sydney is socially, economically, culturally, and linguistically diverse, with 43% of the population born outside of Australia. The majority of the population lives in local government areas with higher levels of socioeconomic disadvantage compared to the state of New South Wales (37). The South Western Sydney Local Health District Human Research Ethics Committee (LNR/18/LPOOL/67; Local Project Number HE18/041) approved this research.

Researcher Characteristics

C.E. is a consultant rheumatologist and teaching program director at Campbelltown Hospital. C.E. did not provide medical care for participants during the study. W.H. and I.H. are experienced qualitative researchers and educators with medical backgrounds. W.H. has expertise in participatory and health consumer engaged research.

Table 1. Semi-Structured Interview Prompts.*Participant demographics*

- What is your age?
- What is your occupation?
- What is your ethnicity/nationality?
- What is the highest level of education you have completed?

Basic Medical history

- Why did you attend this hospital/clinic?
- What are your previous medical problems?

Patient experience and expectations of care

- Can you tell me about your experience so far in the hospital/clinic? Did this meet your expectations? Can you tell me more about your expectations prior to coming to hospital, and from here onwards?
- What do you hope your treating team/doctor will do for you from here?
- Who are the doctors involved in treating your condition? What role did each of these doctors play in managing your condition?
- Which other health-care professionals have been involved in your care?
- Do you feel that the doctors and other team members worked together? How do you know this?
- Has the treatment you have received so far met your expectations? Why/why not?
- What qualities in a doctor [or health-care professional] do you think are important in treating your condition? For example, being a good listener.^a
- What advice would you give to a training doctor [or health-care professional] who is learning how to treat patients with your condition?^a
- Is there anything else you want to discuss?

Closing and thanks

^aThese questions were very helpful in understanding patient expectations of health-care professionals in our previous qualitative study in patients with low back pain.¹

Sampling Strategy and Data Collection

We invited adult patients (>16 years old) deemed fit to participate by their treating nurse or clinician to participate in the interview study. Participants were recruited from a diverse range of clinical environments to incorporate a broad range of presentations and conditions. These included inpatient general medical and surgical wards, orthopedic and cardiology wards, and outpatient clinics. We chose not to recruit patients in critical care environments (such as the emergency department or intensive care unit) because the interviews required privacy and time for patients to think through their responses. Written informed consent was obtained from all participants.

We continued to recruit patient participants until we reached thematic saturation of identified themes, with interview findings analyzed throughout the data collection process. Semi-structured interview prompts (Table 1) focused on the patient's current presentation and experience of health care in relation to their medical condition(s). These were developed based on the literature on patient expectations as well as a previous qualitative study we conducted

exploring the patient experience in hospital (7,8,12,15,24). Interview topics explored the illness experience, interactions with health-care clinicians, how patients communicated and conceptualized their expectations of health care, and the nature of these expectations. C.E. conducted the interviews which were audio-recorded and transcribed verbatim by an external medical transcription service.

Data Analysis

Transcripts were studied in detail by C.E. with an emphasis on understanding how patients conceptualize and express their expectations of health care in their individual contexts. Initial notes were collected and developed into codes and subsequently themes in an iterative process of interacting with the interview findings. In keeping with IPA, the research process involved asking critical questions of the texts such as, "How do participants communicate their expectations of care? Is this influenced by their self-reported medical condition?" Interview field notes were also utilized in this process. To enhance dependability, researchers met regularly throughout the study period to discuss these questions, review the findings in detail and confirm the final themes.

Qualitative data analysis software (NVivo QSR, version 10, Melbourne, Australia) assisted this process through the use of the "manual coding" and "memo" functions. The memo function was used to record insights and ideas regarding each interview transcript. Coding was performed manually by creating "coding nodes" which could then be organized and grouped during the analysis process.

Results

Participant characteristics are summarized in Table 2. Thematic saturation was reached after interviewing 27 patients, with 1 patient declining participation due to abdominal discomfort. The mean age was 65 (range 19-85), with a broad range of self-reported medical and surgical conditions such as cellulitis, knee replacement surgery, allergies, and pneumonia.

When discussing expectations of health care, we identified 3 distinct domains in which participants conceptualized this: (1) health outcomes, (2) individual clinicians, and (3) the health-care system. These conceptual domains were consistent across a variety of clinical contexts, participant demographics, and medical conditions.

Expectations of Health Outcomes

Participants viewed improvement of their health as the most important outcome of their hospital visit, which depended on a combination of factors, including the actions of clinicians, available treatment options, and their own decisions. The nature of these expectations of health outcomes varied considerably, with some participants describing specific requests:

Table 2. Participant Characteristics.

Participant no.	Age	Gender	Country of Birth	Occupation	Level of Education	Self-Reported Diagnosis	Ward or Clinic
1	47	Male	Australia	Administrative officer	Tertiary	Osteoarthritis	Inpatient
2	71	Male	Australia	Retired	Tertiary	Cellulitis	Inpatient
3	69	Female	Australia	Retired	Tertiary	Arrhythmia	Inpatient
4	55	Female	Italy	Unable to work	High school	Septic arthritis	Inpatient
5	70	Female	England	Retired	High school	Knee replacement	Inpatient
6	71	Male	Australia	Retired	High school	Infection	Inpatient
7	71	Male	Australia	Retired	High school	Urinary tract infection	Inpatient
8	54	Male	Australia	Unable to work	High school	Cellulitis	Inpatient
9	73	Male	Chile	Retired	University	Diabetes	Outpatient clinic
10	48	Female	Australia	Lecturer	Tertiary	Allergies	Outpatient clinic
11	36	Female	Bangladesh	University student	Tertiary	Asthma	Outpatient clinic
12	19	Male	Indonesia	Chef	High school	Eczema	Outpatient clinic
13	77	Male	Australia (Aboriginal)	Retired	High school	Vomiting	Inpatient
14	85	Female	Australia	Retired	High school	Cancer	Inpatient
15	58	Female	Australia	Teacher	University	Swollen knee	Outpatient clinic
16	76	Female	Australia	Retired	High school	Bullous pemphigoid	Outpatient clinic
17	83	Male	England	Retired	University	Leg ulcer	Inpatient
18	68	Female	Australia	Retired	High school	Breast cancer	Inpatient
19	75	Female	Australia	Retired	High school	Pulmonary embolism	Outpatient clinic
20	81	Male	Korea	Retired	University	Pneumonia	Outpatient clinic
21	67	Female	Australia	Retired	High school	Shortness of breath	Outpatient clinic
22	71	Female	England	Retired	High school	Back pain	Inpatient
23	42	Male	New Zealand	Sales	University	Rash	Inpatient
24	72	Male	Australia	Retired	High school	Lymphoedema	Inpatient
25	81	Male	Australia	Retired	High school	Cellulitis	Inpatient
26	75	Female	Greece	Retired	High school	Neck pain	Outpatient

We've got to find out what the particular bug [germ] is that's been getting into the bladder, so that I can manage it and make sure it doesn't happen again. (Participant 7)

I would like to get the filter in my veins taken out and try to work out how I can have a better quality of life. (Participant 8)

However, there was often an acknowledgement that despite the best efforts of clinicians, there may be limits regarding what is achievable. Notably, in these cases, participants conceptually separated their expectations of health outcomes from expectations of clinical staff.

I just want to be pain free but I know that's not possible at the moment. They're doing everything they can. (Participant 15)

Well, I knew there was nothing they could do to help me. I just wanted them to look after me. (Participant 14)

Sentiments such as this usually referred to a chronic condition, signifying a degree of acceptance regarding the limitations of health care. Participants also described their own actions and decisions as an essential component of improving their health:

Well, it's going to depend a lot on me because I'm here because of me and the things that I was doing wrong. (Participant 17)

Thus, despite the perceived underlying causes or prognosis of their condition, participants had well-formed expectations that their health problems would be addressed.

Expectations of Individual Clinicians

Additionally, patients clearly articulated their expectations of individual clinicians they interacted with. The nature of these expectations varied considerably between respondents.

Some focused on intrinsic qualities of health-care workers, for example professionalism:

Approachability, friendliness—what do you call it—I’ve had a stroke, I lose words—professionalism—being professional. (Participant 3)

On the other hand, several patients reported specific expectations of what a staff member should do for them:

I’d like them to explain what the medication reactions mean and advise what I can do to safeguard myself in future, so I know exactly what to say should I have to go hospital and have another operation. (Participant 10)

In reflecting on their previous experiences with health-care workers, participants often expressed intense emotions, signifying the impact of these experiences on their subsequent expectations of future health and life.

It was clear that interactions with clinical staff were often a deeply personal experience for participants, leading to well-formed and clearly articulated expectations of how clinicians should behave in certain circumstances:

I want them to understand what we’re going through. I mean people will say it’s only arthritis but it’s surprising what pain arthritis gives you, you know? And somebody who listens to you. I mean, I won’t mention any doctors’ names but the other day one of them just would not listen to me what I was saying . . . Just wasn’t listening to me. I’m the one who’s got this and I know what I’ve experienced. The other doctor I’ve had here, he was marvelous. He listened to me. (Participant 22)

Expectations of the Health-Care System

With minimal or no prompts, participants openly discussed their interactions with and perceived limitations of the “health-care system.” This “system” was conceptualized as an entity in itself, with health-care workers functioning inside its rules and constraints. Thus, despite appreciating the efforts of individual staff members, patients often vented their frustration with the system as a whole:

The doctors have been very good . . . I’m happy with what’s happened . . . but the health system sucks [ie, is awful/terrible]. (Participant 1)

Related to the earlier finding that patients, particularly those with chronic disease, assume some responsibility for managing their health, they also assumed responsibility for navigating and manipulating this system, independently of their treating clinicians:

I’m on dialysis for ten years and I’ve had a kidney transplant that lasted ten years. I’ve been in and out of various institutions, you get to understand what goes on and how it works and

what a patient actually has to do to get the right thing done. (Participant 7)

Even when discussing the actions of specific clinical staff, participants still referred to an all-encompassing system which influenced their health care—for example, through the quality of training:

I feel that the nurses need more training because some of them don’t listen to the patients—what the patients say and then what they need. (Participant 4)

Participants appeared comfortable with openly criticizing the health system as a whole, conceptually separating the “system” from the individual clinicians they encountered. They articulated distinct expectations of this system and how it can influence the quality of the care they receive.

Discussion

This study provides new, empirical evidence to further our understanding of how patients conceptualize and describe their expectations of health care. Using a theoretical lens to conduct an IPA, we found patients describe expectations in 3 distinct, but related domains: (1) Health outcomes, (2) Individual clinicians, and (3) The health-care system.

Our findings provide direct evidence on how patients actually express their expectations of health care. We found that regardless of participant demographics and the clinical context (eg, hospital setting and diagnosis) in our sample, expectations consistently fell into the 3 domains described above. These domains are interrelated; for example, the “health system” is made up of individual health-care workers, and “health outcomes” are largely determined by the quality of care delivered by this system. However, when patients described their expectations, clear distinctions were noted.

Two cases illustrate this point well. One participant was satisfied with how he was treated by individual doctors, but simultaneously disappointed with the “health system,” which did not meet his expectations. In this respect, our findings overlap with Ferlie and Shortell’s model of the health system, which includes 4 distinct components: the patient, care team, local organization, and larger system/environment (38). Additionally, it is known that system factors such as accessibility and cost of health care can influence patient perceptions (39). For example, in the 2003 World Health Survey, individuals who received care from a private health-care facility were less likely to report high levels of satisfaction than those receiving care from a public provider (40). Thus, although the interaction between patients and the health system is complex, our key finding was that patients conceptually distinguish individual health-care workers from the system itself.

In another case, we observed specific expectations describing how a participant wanted to be treated in a

compassionate manner by clinicians, although their condition was perceived as incurable. In this case, there was a noteworthy separation of expectations regarding “health outcomes” and “individual clinicians.” This distinction is important as the hopes and expectations of people with poor perceived health outcomes are easily overlooked (41).

Our findings are now considered with respect to Lafer-ton’s integrative model of expectations in patients undergoing medical treatment (15). This distinguishes between generalized, behavior, and treatment outcome expectations. The model also incorporates temporal aspects of the disease and treatment. The concept of “treatment outcome expectations” correlates well with our “health outcomes” domain, in that patients are anticipating the benefits and side effects of particular treatments. Similarly, the concept of “personal control beliefs” correlated well with our results, with patients often referring to perceived benefits of treatment or behaviors. However, as discussed earlier, we found patients held expectations of their treating clinicians which were distinct from their health outcome expectations.

This deviates from the theoretical model which does not explicitly deal with patient expectations of clinician behavior. In the context of social learning theory, these would be referred to as “specific expectations,” which have developed out of previous experiences with other clinicians (42).

In the literature around patient-centered care, understanding patient expectations of the clinician is vital, and known as “exploring patient cognitions,” or “understanding the whole person” (10,43). Furthermore, patients are seen as partners alongside their health-care providers (44). Inherent to this partnership is a common understanding that both patient and clinician are working together inside a larger health system. Thus, patients become part of the health-care system and actively begin interacting with the system as well as the individuals inside it. This understanding of the patient journey may help explain our observations of 3 distinct but interrelated conceptual domains. We suggest more work is needed to better integrate theoretical models of patient expectations into the practice of patient-centered care.

Our study findings have important implications for researching and recording patient expectations of health care. First, when designing methods to measure these, we suggest incorporating questions specifically addressing the 3 domains we have identified. This will help ensure the multiple dimensions of patient expectations are understood, including those regarding their treating clinicians.

Furthermore, in view of the complex interplay observed between individual patients and the health-care service, our findings suggest that a qualitative component should be included in any method attempting to measure expectations. Most surveys and scales of patient expectations are quantitative in nature (7) and may not capture how patients in institutional contexts identify and express their expectations of care in that context. We suggest capturing these is

fundamental to effective communication and connection with patients and their needs.

As previously outlined, most studies of patient expectations have been conducted in the context of a specific illness or treatment, such as joint replacement surgery (3). This has helped produce detailed accounts of what patients expect in specific contexts. Such approaches, however, may be of limited value to clinicians and researchers seeking to explore patient expectations in differing or novel clinical contexts. The present study suggests that although the nature of expectations will vary with individual patient circumstances, the conceptual domains within which they lie remain consistent. Our findings raise intriguing questions. How do patient expectations of the health-care system as a whole influence the individual patient-clinician relationship? Is there one domain with more influence on patient satisfaction and health-care outcomes?

There are a number of limitations to this study. First, this was conducted at a single institution, although one servicing a large population with few alternative centers, and only included adult patients in clinics and medical/surgical wards. Participants were identified by nursing staff and treating clinicians, both of which could have influenced our findings toward certain patients. Our interview questions did not explore how expectations were formed, such as through details of previous interactions with the health service, so we cannot state that a wide range of prior experiences, which do influence expectations and hopes, was sampled.

The use of IPA enabled the study investigators to understand the participants’ perspective while also acknowledging the researcher’s own conceptions. This included reflecting on the clinical backgrounds of study investigators and the influence of this on the research. For example, patients were aware of the interviewer’s medical background, which could have led to more positive descriptions of experiences with doctors. However, our data show that patients were willing to relate experiences which had affected them deeply, perhaps because they framed the interview as a doctor-patient encounter with the mutual respect and trust expected of such interactions. Adopting Stewart’s theoretical framework of patient-centered care facilitated this reflexive process.

To further understand patient expectations and test transferability of our findings, similar studies are needed in varied contexts. This may include a greater variety of patient experiences and demographics (eg, pediatric patients) and clinical contexts such as critical care wards. We hope that this could lead to the development of more rigorous and feasible methods to measure patient expectations. Improved understanding of patient expectations can also inform health care service planning (45,46), and the design and delivery of health-care training programs (47). With such measures, clinicians and health-care providers can be enabled to provide and monitor patient-centered care with outcomes tailored to what patients desire.

Authors' Note

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions. The South Western Sydney Local Health District Human Research Ethics Committee (Local Project Number HE18/041) approved this research.

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