What Do People Want from Their Health Care? A Qualitative Study

Abstract

Summary: Existing research on the patient experience has focused on patients in the hospital and other medical settings. We investigate the perceptions of people who may not self-identify as being patients. This innovative approach of the “street study” aims to understand what people want from health care. This cross-sectional descriptive study population was made up of adult volunteers who were randomly selected at four types of settings in Washington, DC: coffee shops, metro stops, senior centers, and community centers. Participants were asked to recall a positive and negative experience with health care and to explain the factors that made it such. They were also asked what can be done to most improve health care in the US. Data were analyzed using grounded theory methodology. Of the 51 subjects interviewed, 28 were female and 23 were male, with an age range of 20-89. Of the 12 themes identified, the three most cited as being critical to their health care experiences are having a doctor who listens to them, who is caring and compassionate, and who explains well. When people are asked about their health care experiences, they speak about the interaction between them and their doctors. The doctor-patient relationship remains at the heart of people’s perceptions of health care. Thus, the authors believe that innovations that aim for patient-centeredness should aim to strengthen the doctor-patient relationship.

Keywords: Doctor-patient relationship, patient-centered care, patient-centered innovation, research methodology, patient interviews.


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Introduction

In recent years, there has been an increased recognition that health care delivery needs to be focused on the needs of the patient. The Institute of Medicine has deemed patient-centered
care as a dimension in its own right, 1 and many innovations highlight patient-centeredness as a primary goal. 2

There is a growing body of literature addressing the question: “What do patients want from health care?”, 3 including some contributed from patients themselves. 6 This is a step in the right direction — but such research tends to involve studies of hospitalized patients or others who are drawn from an existing patient pool (ie, primary care offices). Such research is limited, and may not reflect the broader views of those who comprise the health care system and participate in health care.

We sought to investigate the experiences and perceptions of people who have not necessarily had exposure to health care settings, and who may not self-identify as being patients. We used an innovative methodology of the “street study” that literally took us to the streets to find out what people want from their health care.

**Methods**

This was a cross sectional descriptive study based on semi-structured interviews. The study population was comprised of individuals recruited from four different settings in Washington, D.C.: coffee shops, metro stops, senior centers, and community centers. Over a 3-week period in October-November 2013, a convenience sample of adults over age 18 were approached by the primary interviewer. Of the 60 approached, 51 agreed to participate in the voluntary interview. No monetary or other compensation was provided. This study was approved by the Institutional Review Board at George Washington University.

Participants were asked their age and gender. They were then asked two questions, the answers to which were directly transcribed. These questions were revised based on a telephone survey of Mayo Clinic patients that was pretested within a focus group of ten local community members. 3 First, respondents were asked to recall a positive and negative experience with health care, and to explain the factors that made it such. Second, they were asked what can be done to most improve health care in the US.

Interviews were conducted by the second author, a medical student with a degree in anthropology with experience in narrative interview technique. Responses were recorded verbatim during the interview and de-identified except for age and gender.

For questions with descriptive data, the transcripts were analyzed in accordance with grounded theory and the thematic method of qualitative analysis. 7 A primary data coder reviewed the transcripts, performed a preliminary manual coding of the themes for each question, and identified representative quotes for each theme. A secondary coder independently compared the primary coder’s themes and representative quotes against the transcripts. The two coders discussed the draft analysis and reconciled minor differences.
After major themes were identified, percentages were manually tabulated and checked twice for accuracy. Frequencies and descriptive statistics were calculated using Microsoft Excel 2012 (Microsoft Corp., Redmond, WA).

Results
Fifty-one subjects of the 57 approached (90%) agreed to be interviewed. Among the respondents, twenty-eight were female; 23 were male. Ages varied from 20-89. Sixteen were recruited from cafes, 11 from metro stops, 12 from senior centers, and 12 from community centers. Other demographic information, such as socioeconomic status, race, and primary language spoken, were not recorded.

To the first question, about positive and negative experiences with health care, all respondents (100%) cited examples of an interaction with their doctor. Some (47%) cited additional examples of interacting with other health care professionals. None gave examples of interactions with insurance companies, hospital administration, legislators, or other health care stakeholders. All (100%) also mentioned their interaction with their doctor in response to the second question, about how to most improve health care in the U.S. To this question, none cited the role of other health care stakeholders or proposed health systems changes except in relation to the interaction with their doctor.

Using grounded theory and thematic analysis, 12 themes were identified (Table 1). Table 1 also includes representative respondents’ comments. The three comments most cited by people as being critical to their health care experiences are having a doctor who listens to them, having a doctor who is caring and compassionate, and having a doctor who explains well.

Table 1. Results of thematic analysis for major contributors to positive and negative experiences in people’s health care.
Discussion

The most striking finding of our study of what people want from their health care is that every participant answered this question as to what they wanted from the doctor. This confirms anecdotal reports that people understand medical care as the interaction with their doctor, and with growing research on the importance of shared-decision making in medicine. \[8\] As policymakers and administrators propose innovations and measures of quality, they will need to consider the strong emphasis people place on the importance of the doctor-patient relationship. This may be reflected in policies that allow patients to select and keep their doctors, and incentives to encourage doctors to spend time with patients.

Consistent with past studies of patients, people prioritized so-called soft skills of doctors. Most people commented on the importance of a doctor who listens, cares, and explains issues to patients. Several studies have shown that, when choosing doctors, patients rarely mention technical expertise, but rather concentrate on empathy and ability to provide clear explanations. \[3\][4] \[5\]

While studies of hospitalized patients and those who just received medical care have found that wait times decrease patient satisfaction, \[9\] few people brought up the inconvenience of waiting at a doctor’s office. When the issue of waiting was brought up, it was primarily in reference to access to seeing the doctor when urgent issues arose.
Many brought up the need for pleasant interactions with other staff and the impact this has on their entire health care experience. This will be increasingly important as doctors work in inter-professional teams. Powers and colleagues wrote about teaching customer service to health professionals; \[10^{[15]}\] our study’s findings underscore the importance of such interdisciplinary training.

Some respondents specifically address the issue of cost and reducing unnecessary testing. There is growing recognition that doctors need to be conscious of the cost of their recommendations, \[11^{[16]}\] and awareness by patients that more tests and treatments may not result in a better outcome. \[12^{[17]}\] Our study provides further evidence that people—even those who do not have active medical concerns—want their doctors to evaluate and to explain the necessity of interventions. More efforts will be needed to educate providers about practicing this type of high-value care.
Some respondents are concerned about how their doctors get paid. Dozens of studies have established that pharmaceutical and medical device company payments to doctors influence treatment recommendations. 13 [18] Comments from study participants substantiate that some patients have concerns about doctors’ conflicts of interest, and that doctors can improve people’s trust in them by disclosing their financial affiliations.

There are some who specified other important elements of health care such as holistic care and sharing language and culture. This underscores that patient-centered care must be tailored to the individual—not a monolithic, “one size fits all” application. 10 [15]

There are some limitations to this study. Some may question whether the best research method is a qualitative study of people’s experiences. We specifically chose not to use a validated survey instrument and to use grounded theory methodology to allow for more
robust and nuanced answers. There may also be bias in sampling. We attempted to mitigate this by going to several diverse settings: for example, by interviewing patients at community centers that serve a low-income population. With a respondent rate of 90%, we do not expect that there is systemic bias in those who did not choose to participate.

Another limitation could be perceived lack of confidentiality. It was made clear to the participants that the answers were anonymous, and that the interviewer was not in any way involved in their medical care. That the answers were reflective of perceptions is suggested by the high number of critical comments. In addition, it remains unclear whether people’s perceptions of good care actually correlates with better outcomes. This is suggested by studies showing that perceptions of trust and empathy lead to better health outcomes, \[13\] \[18\] \[14\] \[19\] but how patient-centeredness improves objective measures of health care will need to be investigated in future studies. \[15\] \[20\]

This methodology to investigate what people want from their health care allows us to go beyond the experiences of those who are in the midst of or have just received medical
treatment, to engage people in the full spectrum of participatory care. Perceiving oneself as a patient is temporal; this study takes this perception into account. We aim to use this methodology in future studies to substantiate our findings, and to further investigate differences in attitudes and perceptions among people of various demographic groups.

**Conclusions**

Our use of an innovative methodology of the “street study” finds that people perceive health care as the interaction with their doctor. What people want from their health care goes to the core of the doctor-patient relationship. Doctors need to listen, to care and be compassionate, and to be transparent and open with patients. They need to be accessible, practice in interdisciplinary teams, and demonstrate that they have patients’ best interests at heart. Innovations that aim for patient-centeredness should encourage doctors to practice medicine in the way that patients need. We hope future studies will make use of our methodology to ensure that patients — people — are at the center of caring partnerships that prioritize dignity and respect.
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References

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