Need to Intervene: An Exploratory Study of Nurses’ Experiences With Patienthood

Marian A. O. Cohen, PhD1, Jim McQuaid, PhD1, and Ruth Remington, PhD, RN1

Abstract
Much has been written about the patient experience, but there is little information about experiences of providers as patients. Since lay patients and providers have differing perspectives and expectations, it is important to identify those elements shared by those in each group and those that diverge. This study identified experiences of nurses as being a patient or a family caregiver of a patient as well as identified assessments of the healthcare system by nurses. An exploratory study using a self-administered electronic questionnaire with a group of registered nurses was conducted. Assessments of the system by responders were positive when addressing quality of care, interactions among healthcare personnel, and interactions with patients. However, when discussing their experiences as patient, nurses reported they encountered problems with coordination of care, responses of medical personnel, attention to details of care, and responses to their attempts to become more involved. Results confirm issues raised by patients who are not medical experts in patient satisfaction studies. Adding a professional perspective highlights where problems with the healthcare system lie.

Keywords
patient perspective, clinician as patient experience, nurse perspective, nurse as patient, healthcare system, satisfaction with care

Introduction
A recent report notes that “patient harm during healthcare is a leading cause of morbidity and mortality internationally” (1, p1) and “is a serious problem across medical care settings” (1, p8). Frequently, patients are not aware of the harm created because they lack the medical and/or technical expertise with which to judge their care. Patients are not generally able to assess events including diagnostic errors, medication mistakes, or iatrogenic infections (2). Patients often lack medical knowledge needed to properly assess competence of providers and care received (3). Inadequate health literacy (note 1) leads to poorer healthcare choices and quality of care and makes evaluation of the choices and care more difficult (4). Lack of ability to adequately evaluate care could lead to nonadherence with medical advice, decreased satisfaction with care, and put patients at risk of adverse outcomes.

Without technical expertise, healthcare consumers—like all consumers—fall back on alternative criteria to assess care provided (5). Patient satisfaction was more strongly correlated with perceived rapport of patients with providers and less with perceived provider technical competence of patients. Patient perceptions of caring behaviors are different from clinician perceptions (6) and have been shown to affect patient assessments of patient–clinician relationships (7). Even when patients have some health literacy, they usually still lack access to the body of knowledge and expertise that providers of healthcare possess (8).

Much has been written about the patient experience, for example, satisfaction with care and perceptions of provider competence, interpersonal interactions, and professionalism of providers. Going back decades, the primary focus of such work has been on patient satisfaction (9,10). According to Kamra et al, the World Health Organization argues that patient satisfaction is most important in evaluating healthcare system performance (11). However, as noted above, patients are not medical experts, and thus may not be the best assessors of care (8,12). This study sought to gain a professional perspective on patient experiences and healthcare system performance.
healthcare service quality (11). By many accounts, however, patient satisfaction has never been fully defined (2,4), and the “construct has little standardization, low reliability, and uncertain validity” (12, p. 8).

Satisfaction is a subjective affective component of evaluation. Theories of patient satisfaction (13–15) focus on those subjective variables, but “... to date, no one has presented a unifying theoretical framework to guide either researchers or healthcare practitioners in their efforts to improve patient satisfaction” (14, p. 7). The literature has consistently demonstrated that evaluations of care of patients are paramount in assessing patient satisfaction (10). Interpersonal interactions are among the most important factors shaping in patient satisfaction (15). The interpersonal relationships between patient and provider affect subjective perceptions that frame objective realities.

The concern has been that professionals evaluate healthcare services just from the standpoint of providers of care. Given the recent report about the prevalence of poor outcomes, including a professional evaluation, is critical to providing better medical care (1). This study expands beyond satisfaction to the broader patient experience. Adding a provider perspective to patient assessment would identify comprehensive measures to improve patient satisfaction with care and minimize preventable harm.

As noted, often, descriptions of experiences by patients are expressed without an understanding about what is happening or why. Those in the best position to knowledgeably comment on care are providers of care. However, little is known about the experiences of providers as patients or as caregivers when a family member is ill. How does knowing the system, from an “inside” perspective, affect providers’ perceptions of the care provided or the role that the provider may play in the help-seeking and caregiving processes? Full understanding of the effectiveness of the healthcare system and the range of patient experiences requires information from many types of patients, including those who are experienced in care delivery.

While the experience of being a recipient of health care is important, there is little empirical research on experiences of healthcare providers. Most information comes from (a limited number of) books or articles written primarily by physicians or nurses about their own experiences (16–28). There are also reports written in the form of blogs and news articles (29–37). While such information is useful, it is largely anecdotal and does not necessarily describe experiences in general. At a time in our history when healthcare resources are being strained and constrained, and there is more and more concern with patient satisfaction and quality care, it is crucial to have a greater understanding of what makes for quality care, especially from a patient’s perspective. Specifically, our goals in this study were to identify experiences of one group of providers, registered nurses, who were a patient or a family caregiver of a patient and to identify nurses’ assessments of the healthcare system. Nurses represent the largest group of healthcare providers in the United States (38). This research would provide both the perspective of patients and an overall perspective of the healthcare system—enabling the respondents to evaluate the system from their two points of view, nurse and patient—and thereby providing a more complete picture of satisfaction.

The experiences of nurses will help to identify administrative, practice, and interpersonal factors that can enhance the provision of quality care. Knowledge gained from this exploration will provide a deeper understanding of the experiences of patients and family caregivers in the current healthcare system.

Method
We report the results of an exploratory study of the experiences of one group of providers, registered nurses. Researchers used an available subjects sample of licensed Registered Nurses (N = 55) in an RN to BSN Nursing Department degree program during spring 2018. This exploratory study utilized an investigator-developed self-administered questionnaire to measure attitudes of participants about the healthcare system.

Using both qualitative and quantitative response formats, questions were developed in Qualtrics following a comprehensive literature review (10,11,26,39) and in consultation with practicing physicians and the nurse member of our research team. Part I of the questionnaire measures assessment of the healthcare system by participants. Participants who had a recent personal experience with the healthcare system as either a patient or a caregiver for a family member with a serious medical condition (regardless of care setting) completed Part II of the questionnaire describing their experiences.

Before completing the questionnaire, respondents provided informed consent. In order to avoid respondents feeling coerced, the professor was not present during administration. Willing respondents used their personal laptops to complete the questionnaire, while nonparticipating students used their laptops at their discretion. All students attending class on the day of administration (N = 55) chose to participate in Part I, and 45 participants completed Part II.

Results
Description of Sample
The majority (83.6%) of respondents were female. They ranged in age from less than 30 years old to 69 years old. Over half (58.2%) had graduated from nursing school within the last 10 years, but 18% had graduated at least 26 years ago. The age range and range of years within which respondents had graduated were important, as they included those relatively new to the field and those who were long-time practitioners. Areas of specialization were also wide ranging, from rehabilitation to practice within specialty areas to school-based practices. Most worked in hospitals, schools, clinics, or long-term care facilities.
Assessment of the Healthcare System

The first set of questions asked respondents to rate how well the current healthcare system is working. Likert-type scales and “yes–no” questions were designed to elicit evaluations of the system purely from the practitioner’s point of view. Table 1 identifies those who said they believed the system is working “well” or “very well” with regard to specific aspects of care.

With the exception of affordability of care, the majority of respondents said the system performs “well” or “very well” with respect to aspects of provision of care measured. Respondents were then asked what needed to be changed to improve conditions within each of the abovementioned categories.

To provide more high-quality patient care (note 2), respondents noted that more and better communication and coordination among providers of services and between patients and clinicians are needed. They also pointed to the need for more staffing (note 3).

Respondents noted the need for more time spent with each patient, removal or reduction of communication barriers, and better staff–patient ratios in order to improve interactions with patients.

To improve coordinated care among healthcare personnel, respondents noted the need for better communication, more teamwork, and greater access to medical records (note 4) (15). The respondents acknowledged this might involve changing the culture of the healthcare system.

Respondents noted the need for more care options in more remote areas, greater transportation options to enable patients to reach care, and more primary care providers in order to improve accessibility of care. They advocated for more patient education, more support for hospitals and providers, and expanded roles for some medical personnel (e.g., nurse practitioners).

Fewer than 50% of respondents said the system is performing well with regard to affordability of care. To improve affordability, respondents noted the need for greater access to insurance and control over costs. To help control costs, they suggested a reduction in “unnecessary” care and greater focus on preventive measures that could be undertaken by patients (note 5) (40,41).

Additional comments provided by the nurses focused on further discussion of their concerns with provision of care generally. Several nurses noted focus should be on patient outcome and not on cost; there is inequitable provision of care, with patients with “connections” or more education, especially about medical issues, getting better care than others; there should be quality care provided for all; medical personnel are not always as caring and supportive as they might be; the facility in which care is provided makes a difference, addressing the inequality of care within the system as a whole; communication (types and content, and by whom) is a significant problem in the delivery of health care; and, generally speaking, given their experiences, there is a need for an advocate for everyone.

Experiences With the Healthcare System

A second set of questions (using qualitative and quantitative formats) asked the nurses about their own experiences as a patient or a caregiver for a relative with a serious medical condition. This set of questions was designed to assess experiences of those with medical knowledge when acting as a recipient—rather than provider—of medical care.

Over 82% of respondents said they had either been a patient or been a caregiver when a serious medical condition had occurred. Ninety-six percent said they felt the need to intervene, based on their medical knowledge, in the care being provided (note 6). Most of the situations (56.6%) occurred in general hospitals. Over 63% of the time, respondents felt their intervention was able to address a problem and reduce life-threatening conditions or potential significant complications, such as inadequate initial care, failure to consider underlying conditions important for developing an appropriate treatment regimen, problems with therapeutic management; carelessness of providers, and inadequate postoperative care. The problems that led respondents to intervene are consistent with the types of errors that often lead to preventable harm (1).

Table 2 summarizes the ways in which the nurses intervened as well as the frequency with which they did so. Types of interventions were not mutually exclusive; nurses cited multiple types of interventions in some instances.

These types of interventions suggest that these nurses judged, based on their clinical experiences, that there was information not being satisfactorily provided to the patient and/or that suitable/relevant information was not being sought about the patient by healthcare personnel. Based on their expertise as medical professionals, many of our respondents clearly perceived that care was not being provided adequately.

When asked how their interventions were received by other medical personnel, 48.5% of respondents reported...
some form of negative reaction (eg, personnel becoming annoyed/upset and interventions perceived as overstepping/interfering), whereas 40% reported positive reactions (eg, personnel being appreciative and/or welcoming of the input, receptive, or respectful of the respondents’ contributions) and 11.4% reported neutral responses (eg, no response in particular, not sure, and no issues).

Fifty-eight percent of respondents said their interventions changed the course of treatment, and 56.8% said their interventions changed the outcome of the event. From the standpoint of the respondents, their interventions made an important difference in the experience.

Nurses noted the need to “translate” for their family member because communication by the staff was inadequate; that problems resulted from poor initial care; the hope that their own background would make the staff more cooperative and supportive but that did not happen; and the perception that without their own knowledge and expertise the experience and outcome would have been worse.

Discussion

The findings reveal important information in 2 realms: assessments of the healthcare system generally and results of personal experiences with the system.

In terms of provision of care generally and in terms of their own experiences with the healthcare system, respondents provided evidence in line with findings of Panagioti et al (1).

Assessments of the Healthcare System

Assessments of the system by respondents generally were positive when addressing quality of care, including interactions among healthcare personnel and interactions with patients. Interestingly, however, when discussing their own experiences, many of these nurses expressed concerns about coordination of care and dismay or discomfort with how medical personnel interacted with them and/or their family members. Assessments were even less positive when discussing access and affordability. This was true when asked directly about their ratings of the system as well as in their open-ended comments about their own experiences and about the system in general.

Experiences With the Healthcare System

Nurses reported that they encountered obstacles: coordination of care; responses of medical personnel to their expressed concerns or their questions; attention to details of care (in terms of gathering relevant information and providing information); and responses of medical personnel to their attempts to become more involved in the care. That the overwhelming majority of respondents felt the need to intervene, and to become involved in different ways (Table 2), is telling. Satisfaction has been found to be a “function of expectations and perceived product performance” (11, p313), and many of these respondents felt their expectations were not being met. While there were few comments about accessibility or affordability in their own experiences, there were comments made about quality of care and receptivity of medical personnel to engage them in care delivery. In over half the cases, nurses felt their interventions changed the course of treatment and the outcome of the event for the better.

When patients are less health literate and lack medical expertise, they may not realize how disadvantaged they are when interacting with the healthcare system. Such patients might be less able to advocate for themselves, effectively communicate with medical staff, and assess the quality and adequacy of care they receive.

The results of this exploratory study confirm many of the issues raised in patient satisfaction studies with patients are not medical experts, but adding a professional perspective can highlight where problems with healthcare delivery and use of our healthcare system lie. Such information is critical in addressing where improvements can and should be made both in the system in general and with regard to how individual practitioners provide care. More research that can identify effective and generalizable interventions to improve patient satisfaction is needed (42). Including the perspective of the patient–provider, as this study does, is an important step in that direction.

Limitations

As an exploratory study, the sample size was small and limited to practicing registered nurses enrolled in an RN to BS program at a university. Given the location of the university in a state considered to have one of the best health delivery systems in the country (43), experiences and responses may differ from those of providers across the country.

To address these limitations, we have used these findings as a foundation for a larger study, currently in progress. This new, nation-wide, study expands the scope of the research by including physicians in addition to nurses and increases sample size, thereby improving generalizability of findings. The expanded study will allow us to compare nurse and physician responses from around the United States and facilitate a better understanding of the patient experience. Expanding the scope of the study will better enable us to identify both what works well in the healthcare system and areas in need of improvement.

Authors’ Note

The study received approval from the Framingham State University Institutional Review Board.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.
Funding
The author(s) received no financial support for the research, authorship, and/or publication of this article.

ORCID iD
Marian A. O. Cohen, PhD https://orcid.org/0000-0001-9438-8517

Notes
1. The US Department of Health and Human Services defines health literacy as “the degree to which individuals have the capacity to obtain, process, and understand basic health information needed to make appropriate health decisions.” https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-health/interventions-resources/health-literacy (2019, accessed January 10, 2020)
2. Phrases in italics refer to questionnaire items.
3. The need to match resources to demand was also a factor in patient satisfaction (41).
4. Teamwork has a positive indirect association with patient satisfaction through employee well-being, their job satisfaction, and engagement with work (15).
5. Preventive measures would be in line with support of nurses for greater patient education regarding health and illness. Health literacy has been identified as an important factor in patient satisfaction and, as demonstrated by these respondents, a critical factor in receiving quality care
6. This finding suggests that expertise of nurses enabled them to gauge the quality of care being received from more than just a subjective perspective.

References
1. Panagioti M, Khan K, Keers R, Abouzour A, Pipps D, Kontopantelis E. Prevalence, severity, and nature of preventable patient harm across medical care settings: systematic review and meta-analysis. BMJ. 2019;366:34185.
2. Junewicz A, Youngner S. Patient satisfaction surveys on a scale from 0 to 10: improving health care or leading it astray? Hastings Cent Rep. 2016;46:43-51.
3. Ng J, Luk B. Patient satisfaction: concept analysis in the healthcare context. Patient Educ Couns. 2019;102:790-96.
4. MacLeod S, Musich S, Gulyas S, Cheng Y, Tkatch R, Cempellin D. The impact of adequate health literacy on patient satisfaction, healthcare utilization, and healthcare expenditures among older adults. Geriatric Nurs. 2017;38:334-41.
5. Beckert J. What is sociological about economic sociology? Uncertainty and the embeddedness of economic action. Theory Soc. 1996;25:803-40.
6. Thomas D, Newcomb P, Fusco P. Perceptions of caring among patients and nurses. J Patient Exp. 2019;6:194-200.
7. Hojat M, DeSantis J, Gonnella J. Patient perceptions of clinicians’ empathy: measurement and psychometrics. J Patient Exp. 2017;4:78-83.
8. Bennett M, Feldstein M. Correlates of patient satisfaction with mental health services in a health maintenance organization. Am J Prev Med. 1986;2:155-62.
9. Johansson P, Oleni M, Fridlund B. Patient satisfaction with nursing care in the context of healthcare: a literature study. Scand J Caring Sci. 2002;16:337-44.
10. Senic V, Marinkovic V. Patient care, satisfaction and service quality in health care. Int J Consum. 2013;37:312-19.
11. Kamra V, Singh H, De K. Factors affecting patient satisfaction: an exploratory study for quality management in the health-care sector. Total Qual. 2016;27:1013-27.
12. Gill L, White L. A critical review of patient satisfaction. Leardsh Health Serv. 2009;22:8-19.
13. Ross C, Frommelt G, Hazelwood L, Chang RW. The role of expectations in patient satisfaction with medical care. JHCM. 1987;7:16-26.
14. Ferrand YB, Siemens J, Weathers D, Fredendall LD, Choi Y, Pirrallo RG, et al. Patient satisfaction with healthcare services: a critical review. Qual Manag J. 2016;23:6-22.
15. Moore A, Hamilton J, Kruzel J, Moore LG, Pierre-Louis BJ. Patients provide recommendations for improving patient satisfaction. Mil Med. 2016;181:356-63.
16. Bynder H. Doctors as patients: a study of the medical care of physicians and their families. Med Care. 1968;6:157-67.
17. Spiro H. When doctors get sick. Perspec Biol Med. 1987;31:117-33.
18. Klitzman R. When Doctors Become Patients. New York: Oxford University Press, 2007.
19. Zeitz K. Nurses as patients: the voyage of discovery. Int J Nurs Pract. 1999;5:64-71.
20. Kay M, Mitchell G, Clavarno A, Doust J. Doctors as patients: a systematic review of doctors’ health access and the barriers they experience. BJGP. 2008;58:501-08.
21. Clerico E, Lott TF, Harley C, Walker RK, Kosak E, Michel Y, et al. Caring for the nurse in the hospital environment. JJHC. 2011;15:14-21.
22. Tomlinson J. Lessons from the “other side”: teaching and learning from doctor’s illness narratives. BMJ.com. 2014. Accessed January 10, 2020. http://careers.bmj.com/careers/advice/view-article.html?id=20017843
23. Palatnik A. The nurse as the patient. Nun Crit Care. 2014;9:4.
24. Cardow A. Returning to work a better nurse. Can Nurse. 2017;113:44.
25. Awdish R.In Shock: My Journey From Death to Recovery and the Redemptive Power of Hope. New York: St. Martin’s Press, 2017.
26. Elyan R, Ahmad M. Assessment of the quality of nursing care from perspectives of nurses who experienced hospitalization as patients. J Nurs Care Qual. 2017;32:369-74.
27. Pryor J. Editorial: reflections from the other side. JARNA. 2017;20:2-3.
28. Schuler M. Changing roles, changing perspectives—vulnerability as a patient. J Patient Exp. 2019;6:5-6.
29. Parker-Pope T. When doctors become patients. New York Times. February 8, 2008. Accessed January 4, 2021. https://well.blogs.nytimes.com/2008/02/08/when-doctors-become-patients/
30. Manheimer E. When doctors become patients. New York Times. Opinion, September 2, 2011: A21.
31. Campbell K. The doctor becomes the patient: lessons learned from wearing a gown. 2012. Accessed January 4, 2021. https://drkevincampbellmd.wordpress.com/2012/10/17/the-doctor-becomes-the-patient-lessons-learned-from-wearing-a-gown/

32. Salwitz J. Doctor as patient. 2012. Accessed January 10, 2020. http://thehealthcareblog.com/blog/2012/11/04/the-doctor-as-patient/

33. Spogen D. What happens when the doctor becomes the patient? Am Fam Physician. 2012. Accessed January 10, 2020. https://www.aafp.org/news/blogs/leadervoices/entry/what_happens_when_a_doctor.html

34. Robinson W. We have your biopsy results: what one doctor learned from suddenly becoming a cancer patient. January 2016. Accessed January 10, 2020. TheSunOrg.com.

35. Shahine L. When the doctor becomes the patient: what I learned from having a surgical complication, 2017. Accessed January 4, 2021. https://www.huffingtonpost.com/entry/when-the-doctor-becomes-a-patient-what-i-learned-from_us_583b5deebe4b050d6e187d61

36. Valtorella L. 32 Healthcare leaders describe their last trip to the hospital. 2018. Accessed January 10, 2020. https://www.beckershospitalreview.com/hospital-management-administration/32-healthcare-leaders-describe-their-last-trip-to-the-hospital.html

37. Graham J. Even doctors can’t navigate our ‘broken health care system’. Medscape. 2019. Accessed January 10, 2020. www.medscape.com.

38. American Association of Colleges of Nursing. Nursing Fact Sheet. Published April 1, 2019. Accessed January 4, 2021. https://www.aacnnursing.org/news-Information/fact-sheets/nursing-fact-sheet

39. Thomas Craig KJ, McKillop MM, Huang HT, George J, Punwani ES, Rhee KB. U.S. hospital performance methodologies: a scoping review to identify opportunities for crossing the quality chasm. BMC Health Serv Res. 2020;20:1-13.

40. Voda A, Bostan I, Tiganas C. Impact of macroeconomic and healthcare provision factors on patient satisfaction. Curr Sci. 2018;115:43-48.

41. Ogbonnaya C, Tillman C, Gonzalez K. Perceived organizational support in health care: the importance of teamwork and training for employee well-being and patient satisfaction. GOM. 2018;43:475-503.

42. Davidson K, Shaffer J, Ye S, Falzon L, Emeruwa IO, Sundquist K, et al. Interventions to improve hospital patient satisfaction with healthcare providers and systems: a systematic review. BMJ Qual Saf. 2017;26:506-606.

43. 2018 National Healthcare Quality and Disparities Report. Agency for Healthcare Research and Quality; September 2019. AHRQ Pub. No. 19-0070-EF.

**Author Biographies**

**Marian A. O. Cohen**, PhD, is a retired professor of sociology at Framingham State University and Director of the Center for Social Research. She has conducted research on a variety of social issues, including those related to education, community well-being, the elderly, and health and illness. Her research and scholarly interests focus on psychiatric disorders and issues of health care and the medical system.

**Jim McQuaid**, PhD, is assistant professor of sociology at Framingham State University. He specializes in consumer action in the markets for death care and health care.

**Ruth Remington**, PhD, RN, is nurse practitioner and retired professor of nursing at Framingham State University. Her research interests have primarily been in geriatric issues, including models of care, and nonpharmacologic interventions for symptoms of dementia.