

Defining Patient Advocacy in the Post-Quality Chasm Era

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Patient advocacy is a concept that generally refers to efforts to support patients and their interests within the context of the health care system. As discussed in the issue brief that introduces this issue of the *North Carolina Medical Journal*, a more specific or applied definition of patient advocacy is difficult to articulate, in part because the term has been used in many different ways. For example, the role of advocate is often ascribed to certain professions, especially the “helping professions” of nursing and social work.¹ Others associate patient advocacy with particular kinds of care, such as mental health or palliative care, in which vulnerable patients’ autonomy may be in jeopardy.² A third use of patient advocacy is to denote the work of policymakers, legal professionals, and activists who work to improve health care for people marginalized by socially stigmatizing diseases such as HIV.³ Given the variety of contexts in which the concept is used, research can help us better explicate *patient advocacy*, a task necessary for advancing both scholarly and applied efforts to improve health care quality.⁴

Our research goal was to explore the concept of patient advocacy as defined by those known as leaders in advocacy practice. Specifically, we wished to gain a better understanding of the personal and professional roles associated with patient advocacy as well as its primary goals, methods, rewards, and challenges. Toward this end, we surveyed a national sample of leaders in patient advocacy practice in 2005, using a confidential, online questionnaire known as the University of North Carolina Patient Advocacy Survey.^a

Participants

We constructed a sampling frame of 203 patient advocacy leaders with the goal of recruiting a purposive, non-probability sample of respondents from a wide variety of advocacy interests and backgrounds. First, we included 161 invitees of the University of North Carolina Patient Advocacy Summit. This national conference, held in Chapel Hill in 2003 and 2005,

brought together advocacy leaders from many sectors of the US health care system.⁵ Second, we asked that each invitee recommend others for the survey whose perspective on patient advocacy was believed to be important. In this way, we obtained an additional 42 names with viable email addresses.

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Questionnaire Development and Administration

We developed a self-administered, online questionnaire to investigate the concept of patient advocacy. The 35-item survey contained both closed- and open-ended questions based on five dimensions of interest: (1) personal and professional roles associated with patient advocacy; (2) its primary goals and methods; (3) important next steps; (4) its definition; and (5) rewards and challenges associated with its practice. Additional items assessed the demographic characteristics of respondents. The survey took approximately 20 minutes to complete and was pretested by seven people with varying levels of health-related knowledge and experience.

a The North Carolina Patient Advocacy Survey can be found in its entirety online at <http://www.ncmedicaljournal.com>.

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We invited each participant via email to complete the web-based questionnaire. Those who did not respond were emailed reminders 7 and 20 days after the original invitation. A drawing for a \$100 gift certificate to an internet retailer was offered as incentive for participation. The University of North Carolina School of Public Health Institutional Review Board approved this unfunded study.

Analysis

To analyze quantitative data, we used the Statistical Package for Social Sciences (SPSS) software. First, we derived overall frequencies for each item. Second, for summary purposes, all items with Likert-style response options were collapsed into "high" and "low" categories. Qualitative data were coded according to our five dimensions of interest and analyzed thematically for areas of consensus and divergence.

Respondents

Of 203 possible respondents, 112 accessed the survey site and gave consent, for an overall response rate of 55%. Respondents came from many backgrounds with the greatest number designating the fields of public health (20.2%) and medicine (19.3%) (see Table 1). The majority of respondents were female (74%), white (92%), and held graduate-level degrees (86%).

In terms of advocacy experience, most respondents (73%) reported having worked on health-related advocacy issues for

nine or more years. Respondents reported practicing health-related advocacy in various contexts (see Table 2) with their primary advocacy interest spanning 13 different areas (see Table 3). Primary reasons for becoming involved in health-related advocacy were similarly diverse, with about one-quarter (26%) indicating that a family member or friend's experience as a patient motivated them.

Table 2.
Percentage of Patient Advocacy Survey
Respondents Who Practice Advocacy in
Various Contexts^b

	Percent (n)
Member or leader of a nonprofit organization	28.4 (31)
Researcher or evaluator of health care services	18.3 (20)
Member or leader of an academic institution	13.8 (15)
Provider of health care services	12.8 (14)
Member or leader of a governmental agency	2.8 (3)
Other	17.4 (19)
Not applicable	6.4 (7)
Total	100 (109)

Table 1.
Percentage of Patient Advocacy Survey
Respondents by Professional Background^b

	Percent (n)
Public health	20.2 (22)
Medicine	19.3 (21)
Law	9.2 (10)
Humanities	5.5 (6)
Education	4.6 (5)
Journalism	3.7 (4)
Nursing	3.7 (4)
Business	2.8 (3)
Social work	2.8 (3)
Government	2.8 (3)
Other	25.7 (28)
Total	100 (109)

Advocacy Roles

Survey respondents perceived a number of different groups to be directly and indirectly important to patient advocacy efforts:

- When asked which of seven groups "often" or "sometimes" take on the role of patient advocate, three-quarters or more of respondents indicated patients themselves (75%), family members or friends (86%), nurses (81%), social workers (86%), and hospital patient representatives (77%). Almost half (51%) indicated that physicians do so.
- The majority of respondents wished all these groups were more active in advocacy efforts with over three-quarters saying they would like to see patients themselves (82%) and physicians (84%) take more of a role in patient advocacy.
- The majority of respondents also felt that a "big role" or "somewhat of a role" in health care advocacy is played by leaders of nonprofit organizations (83%), educators of patient advocates (93%), and activists and grassroots organizers (96%).

^b Data on three respondents were not provided.

- Over two-thirds of the respondents wished to see hospital administrators (75%) and legislators (68%) take more of a role in patient advocacy initiatives.

Advocacy Goals, Methods, and Next Steps

When we asked respondents to rate the relevance of various advocacy goals, the vast majority named as “very relevant” the goals of improved patient-provider communication (94%), patient-centered care (92%), quality improvement and patient safety (90%), and increased access to care (85%).

In terms of advocacy methods, almost two-thirds of respondents (63%) reported that patient/consumer education is a method “often” used by patient advocates. In terms of methods that should be used more often than they currently are, almost three-quarters indicated organizational change in hospitals (73%) and provider education or curriculum reform (72%).

In terms of important “next steps” for patient advocacy, over half of the respondents assigned a “high priority” rating to coordinating advocacy efforts more effectively (67%), raising public awareness about advocacy issues (66%), and training more advocates/training advocates more effectively (58%).

Table 3.
Percentage of Patient Advocacy Survey
Respondents by Their Primary Advocacy Interest^c

	Percent (n)
Education of advocates	13.0 (14)
Consumer health advocacy	12.0 (13)
Advocacy by patients’ family or friends	9.3 (10)
Advocacy by clinicians	9.3 (10)
Research in advocacy related topics	9.3 (10)
Hospital or organizational change	6.5 (7)
Advocacy by patients themselves	5.6 (6)
Legislation or policymaking	5.6 (6)
E-health or internet advocacy	2.8 (3)
Inclusion of advocates in the planning of research	1.9 (2)
Grassroots organizing	0.9 (1)
Legal advocacy	0.9 (1)
Media advocacy	0.9 (1)
Other interest	6.5 (7)
No single major interest	15.7 (17)
Total	100 (108)

c Data on four respondents were not provided.

Definitions of Patient Advocacy

Qualitative data indicated that respondents defined patient advocacy along the four themes of: (1) taking a multipronged approach; (2) empowering patients; (3) creating a culture of patient-centeredness; and (4) improving health care quality. Each of these themes is illustrated with a representative quotation below.

- (1) Taking a multi-level approach that includes both individual- and systems-level advocacy.

“Patient advocacy is supporting and empowering patients to make informed decisions, navigate the system to get the health care they need, build strong partnerships with providers while working towards system improvement to support patient-centered care. Patient advocates are dedicated first and foremost to the well-being of the patients they serve.”

— Educator of advocates

- (2) Empowering or activating patients by facilitating patients’ education, their greater involvement in decision-making, and their ability to more easily navigate the health care system.

“Efforts to ensure that patients have the information and the self-determination they need so that patient needs are forefront in decisions about patient care.”

— Health services researcher

- (3) Changing hospital and provider culture to be more patient-centered.

“Patient advocacy is the bilateral appreciation that the focus of medical intervention should be ‘patient-centered.’ [Patient-centeredness] includes the sharing of decision-making, risks, cost effectiveness, treatment regimens, goals, and expectations. [Patient advocacy] must be implemented with an appreciation of the individual patient and physician in the global context of health care.”

— Nonprofit leader

- (4) Improving health care quality, particularly in regard to patient safety and access to care.

“Assisting people (either as case advocacy on behalf of individuals or class advocacy on behalf of a group) with the process of receiving health care, maximizing their health, and assuring that all people have access to safe and comprehensive health care.”

— Health care service provider

Rewards and Challenges

The rewards associated with practicing patient advocacy were most often described in terms of satisfaction derived from helping others, improving provider practice as well as health systems more broadly, and improving patients' health outcomes. For example, in response to the question about rewards, one respondent wrote:

"Witnessing and hearing one-on-one success stories from patients' perspectives. Observing measurable changes in policies and laws that create a more empowering environment for those in need of health care services."

— Public health researcher

In terms of challenges, respondents noted the slow pace of change, the emotional and frustrating nature of the work, an antagonistic attitude among some providers, and the lack of funding for advocacy practice and research.

"The deep-seated ambivalence, if not outright hostility, of providers to the notion that patients are more important than they are and should ultimately be more powerful than providers in determining health care decisions."

— Researcher of consumer health advocacy

"The gap between information and real change in provider practices that are obviously deficient and producing systemic inequalities in care, compounded by the rigidity of current funding streams and federal regulations for blending or modifying funding to increase provider coordination of care."

— Provider of health care services

Our data suggest that survey respondents define the concept of patient advocacy using the language of health care quality improvement. Likely reflecting the influence of the Institute of Medicine of the National Academies' (IOM) *Crossing the Quality Chasm* report,⁶ many respondents identified patient-centered care, with its dual aims of improved patient-provider communication and increased patient safety, as the ultimate goals of patient advocacy. Like the IOM, survey respondents emphasized the importance of a multipronged approach aimed at helping individual patients navigate the system while at the same time working to address the system-level problems that create the need for advocacy in the first place.

In terms of advocacy roles, survey respondents associated patient advocacy practice with many different groups, including patients' family members and friends, the helping professions of social work and nursing, nonprofit organizations, and those involved in activism and grassroots organizing. Respondents wished to see two central figures of the medical encounter, patients and physicians, take more of a role in advocacy, but they also focused on calling for system-level change.

Quantitative data indicated that they would like to see hospital administrators and legislators take more of a role in patient advocacy, while qualitative data emphasized the importance of organizational restructuring and policymaking to bring about change.

Despite differing professional backgrounds and advocacy foci, respondents tended to define the rewards and challenges of advocacy practice in similar terms. While advocates enjoyed the opportunity to help patients and improve health care systems, they expressed frustration about encountering opposition to their perspective, as well as about the slow pace of change and lack of funding for their work.

Our data suggest a fair degree of consensus among a diverse sample of respondents in this field as to the primary goals of patient advocacy. Both quantitative and qualitative data indicate that patient-centeredness, patient safety, improved patient-provider communication, and, to a lesser extent, access to care are of concern to patient advocates. Given these shared goals, the time would seem ripe for fostering a greater degree of collaboration among advocates who have traditionally been divided along lines of population, disease, and professional interests. The fact that respondents most often prioritized the coordination of advocacy efforts as an important next step lends further evidence to this claim. By collaborating more closely, patient advocates could potentially strengthen their chances for success while at the same time mitigating some of the sense of frustration that seems to attend such work.

This exploratory study provides insight into how patient advocacy leaders conceptualize their work. With the majority of our participants claiming more than nine years in patient advocacy, our data suggest that we drew from a group of experienced leaders. Nevertheless, it is important to note that our sample size was small and, furthermore, the experiences and perceptions of advocacy "leaders" who were targeted for this survey likely differ from those of day-to-day practitioners. Additionally, about half our survey respondents were culled from two conferences we hosted, and their answers may reflect discussions they had with us and with each other. Finally, although our data suggest that we were successful in recruiting respondents from a broad range of professional backgrounds and advocacy foci, it may be that our snowball sample failed to tap areas of advocacy unknown to us or to conference participants.

Despite these limitations, we believe our preliminary findings suggest areas of consensus as to the goals of patient advocacy that we, in North Carolina, are well-positioned to pursue. In terms of leadership, we may look to a pragmatist but forward-thinking legislature and executive branch as well as to our many committed and experienced advocacy groups. By promoting networking and collaboration among these and other health care and political leaders, innovative practitioners, and committed patients, we have the potential to advance the mutually reinforcing goals of increasing patient-centered care, enhancing patient safety, improving patient-provider communication, and expanding access to care. **NCMJ**

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say anything

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