

**Agency for Healthcare Research and Quality
Final Progress Report**

Title: Patient Advocacy Summit: Patients at the Center of Care

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Structured Abstract:

Purpose: This grant was used to bring together individuals committed to patient advocacy from a wide spectrum of personal and professional backgrounds and to provide them with high-quality, research-based, up-to-date information about patient advocacy.

Scope: Patient advocacy is a newly emerging field within the healthcare professions. Two recent reports published by the Institute of Medicine in 1999 and 2001 helped establish the need for this approach by identifying the twin problems of medical error and poor-quality healthcare and highlighting the enormous costs borne by patients, caregivers, providers, and society as whole as a result of these system failures. Patient advocacy contributes a unique perspective concerning the central role of the patient in the medical encounter and employs a range of methods and strategies to achieve the goal of truly patient-centered care.

Methods: Patient advocates come from a wide range of academic disciplines, professional roles, and personal life experiences. The intent of this grant was to bring together leaders in patient advocacy to begin to more clearly define the field, to discuss the requisite skills and competencies needed by those who seek to practice within it, and to determine next steps for research, teaching, and action.

Results: Our final products include a patient advocacy conference, a textbook, a national survey, and a graduate-level course offered through the School of Public Health at the University of North Carolina at Chapel Hill.

Key words: Patient Advocacy, Patient-centered Care, Quality of Care.

Purpose:

The primary aim of the conference was to provide participants with high-quality, up-to-date, research-based information about patient advocacy from a public health perspective. The secondary aim was to allow individuals from a broad range of personal and professional backgrounds who share a commitment to patient advocacy to interact with each other, share ideas and information, and begin to develop partnerships. The long-range goals following the conference included the formation of a functional patient advocacy network with a venue for sharing information related to this topic, the development of academic tools (i.e., a textbook and a course) to facilitate broad dissemination of research and intervention ideas and the prioritization of new research efforts in this field.

Scope:

Patient advocacy is a newly emerging field within the healthcare professions. Two recent reports published by the Institute of Medicine (*To Err is Human* in 1999 and *Crossing the Quality Chasm* in 2001) helped establish the need for this new approach. Together, they served to identify the twin problems of medical error and poor-quality healthcare and to highlight the enormous costs borne by patients, caregivers, providers, and society as whole as a result of these system failures. In particular, *Crossing the Quality Chasm* emphasizes the importance of respecting patient experience and authority. Identified as “patient-centered care,” this concept is defined in the report as “care that is respectful of and responsive to individual patient preferences, needs, and values and ensur[es] that patient values guide all clinical decisions” (2001, p. 6). Patient advocacy contributes a unique perspective concerning the central role of the patient in the medical encounter and employs a range of methods and strategies to achieve the goal of truly patient-centered care.

The defining feature of a patient advocate is someone whose primary goal is to act in the best interests of patients, often individuals who are not able to advocate for themselves. Beyond this basic definition of role, patient advocacy has many faces. Patients, friends, and family members work alongside healthcare providers as advocates. Advocates may serve one specific individual or an entire category of people. They may seek change at the individual, community, institutional, or policy levels. Grassroots organizations, non-profits, internet support groups and chat rooms, medical schools, local family practices, parents, and children all play a vital role on the patient advocacy scene. As often as not, individuals may fall into multiple categories, both personal and professional. What sets advocates apart from others is their cognizance of their role (i.e., that they self-identify as advocates and consciously seek ways to fulfill this identity).

It is helpful to conceptualize patient advocacy within the context of the social ecological framework. The four levels of the framework provide us with a holistic perspective that helps organize our thinking and action related to advocacy. On the individual level, we want to make sure that patients are educated and informed in ways that meet their needs. On the interpersonal level, we want to support and empower all participants in a medical encounter by improving communication and collaboration between doctors and patients. On the organizational and community levels, we are hoping to create and use a

variety of different approaches (pilot programs, patient narratives, intervention strategies, and advocacy organizations) to transform our medical culture into a more patient-centered environment. Finally, on the policy level, we seek to translate consumer voices into policy and law.

Of course, the diversity of these goals necessitates a corresponding variety in terms of methodological approaches to change. Fortunately, the range of activities that advocates currently engage in is quite broad. Advocates provide education to, and raise the consciousness of, individual patients and families, the medical community, and society as a whole. Advocates offer counsel, guidance, and support for those trying to negotiate the healthcare system. Advocates share their own experiences with individuals and groups, use media outlets to sway public opinion, and ideally gain the attention of decision-making bodies. They form coalitions and rely on strategic alliances. Advocates collect evidence, conduct research, prepare reports, serve on committees, testify to Congress, and occasionally take to the streets in protest. All these endeavors, undertaken to advance the well-being of patients or groups, to improve the health of communities, or to enhance the quality and equity of healthcare, are methods of advocacy.

The consensus arising from a multitude of different healthcare perspectives is clear: everyone needs access to patient-centered care; therefore, everyone needs to take responsibility for ensuring that our system is able to provide it. Patients and providers can learn to communicate more effectively with one another, to work together as partners in trying to reach health goals and effectively treat chronic disease. This partnership is a vital component of the well-being and satisfaction of both parties. Caregivers also need to be educated, empowered, and included, as appropriate, in creating a care plan for each patient. From both a practical and ecological perspective, individual and interpersonal change is important but not sufficient. In order to address patient safety, medical error, and healthcare quality, we must also examine larger system factors. The problems in our healthcare system are both pervasive and entrenched; thus, innovative approaches must be applied to achieve broad social change. For example, we must consider changing the way we teach medical education, the way we write prescriptions, the way we meet the needs of the uninsured. The overarching goal of patient advocacy is to achieve patient-centered care by creating safer systems and involving patients in their own care.

Methods:

As we seek to study patient advocacy from an academic perspective, we recognize both the value inherent in the diversity of this field and the need for individuals and groups to begin to collaborate around their shared goals and challenges. Over time, we can see that roles for advocacy are becoming more numerous and interest in more formalized advocacy education is increasing. This conference arose from our desire to unify and coordinate patient advocacy efforts for the purpose of improving healthcare quality.

We wanted to provide an opportunity to bring together participants from the initial 2003 conference and additional emerging leaders within the field. The conference was intended to be a forum in which patient advocacy stakeholders could review and share ideas based upon our existing knowledge base as well as work toward determining the

next steps for research, teaching, and action. In particular, we planned to solicit guidance from our participants on the development of a textbook, a course, and, eventually, a center for consumer health advocacy to be housed within the UNC School of Public Health.

Thus, the format for the conference was intended to be participatory. We invited 36 respected advocates, specializing in six different topic areas, to present their work via a professional paper and a seminar session. Conference participants were given several opportunities throughout the conference to reflect upon the information being presented, to engage in small- and large-group discussion, and to network with one another. Throughout this event, we sought to emphasize and model the collaborative spirit that successful patient advocacy efforts require.

Results:

Our final products include a patient advocacy conference, a national survey, a textbook, and a graduate-level course offered through the School of Public Health at the University of North Carolina at Chapel Hill.

Conference

The second conference, entitled *Patient Advocacy Summit II: Patient Advocacy, Patient-Centered Care*, was hosted by the Department of Health Behavior and Health Education at the University of North Carolina at Chapel Hill School of Public Health on March 16-18, 2005. This conference was the sequel to the initial Patient Advocacy Summit held in November 2003 and was attended by 75 patient advocates. The first conference was focused on establishing the scope of the problem with the healthcare system in the United States and beginning to identify potential solutions, but this second conference was designed to allow participants to engage in focused seminar sessions lead by experts from across the country. Each session was hosted by a moderator and included two to three panelists. The topics discussed in these seminars included the following:

Hospital Advocacy: Changing the Norms, Culture, and Rules

Consumer Health Advocacy: How Social Movement Change Healthcare

Clinical Advocacy: Motivating Patients as Partners

Grassroots Advocacy: Coalitions for Change

Access to Information and Support: Literacy, the Internet, and Communication

Educating for Change: Creating Future Advocates

In preparation for these seminars, panelists were asked to prepare a research-based paper focused on their subject area of interest. A total of 36 authors collaborated to produce seventeen manuscripts. We compiled these submissions into a conference notebook and distributed it to all participants prior to the conference. The papers were intended not only to spark conversation during the actual conference but also to form the basis for an academic textbook and university-based patient advocacy course. We asked that the authors speak about patient advocacy from a public health perspective,

specifically acknowledging the needs of underserved and marginalized populations including the uninsured, low-literacy groups, and ethnic minorities.

After the conference, an online survey was conducted for the purpose of evaluating the conference. Of the 75 participants, 35 responded to the survey (47% response rate). Although the topic of patient advocacy in general was relevant for all respondents, 91% identified the development of a patient advocacy textbook as relevant to their work and 79% believed the same about the development of a patient advocacy curriculum. The majority of respondents found the conference materials that we provided (general instructions, invitation letter, participant biosketches, chapter drafts, and the 2003 conference report) very useful to them. Participants provided feedback on each of the two keynote speakers (Maggie Hoffman and Susan Frampton) as well as each of the sessions that they attended and the final meeting, which focused on establishing viable work groups and planning for the future. Seventy-five percent of respondents were very likely to participate in a third patient advocacy conference, and 90.6% were very or somewhat likely to recommend it to others.

Overall, short answer feedback to open-ended questions within the survey was very positive. In particular, participants indicated that the conference succeeded in its goal to bring patient advocates together from a variety of different backgrounds and provide them with an opportunity to learn from one another. More than half the respondents mentioned networking opportunities as one of the most productive aspects of the summit for them. Their comments included the following:

The most productive [aspect] for me was hearing other peoples' visions and perspectives of patient advocacy. I was exposed to some new ideas that I thought were extremely helpful.

While many of us 'do patient advocacy', many of us do not have the time to reflect on what we do and how it fits into the bigger field. I appreciate learning more about what others are doing and about the different levels of 'interventions'.

I found the sessions I was part of to be very provocative, stimulating, and informative to the topic. I especially enjoyed being part of such a distinguished group of scholars, practitioners, and advocates each committed to advancing the field of advocacy – I left energized and inspired.

Networking with other advocates because it's early enough in the development of this discipline that we still need to learn who's doing what where.

Thank you for inviting me to participate in your fascinating conference, and for giving me the opportunity to share about my work. The folks you convened were so interesting, with such varied perspectives; it was both stimulating and pleasurable to spend time with them.

In response to a question about what would be important to consider in terms of shaping the textbook, conference participants overwhelmingly emphasized the need to identify a specific target audience and to make a decision about whether the book would primarily be marketed to consumers/lay people or academics. Respondents also offered individual suggestions for the textbook, such as emphasizing the diversity within the field and incorporating textboxes to help flesh out key concepts. When asked their opinions about the structure for the next conference, respondents reflected on the tension between maintaining a broad versus defining a more narrow scope of inquiry and suggested providing opportunities for participants to tailor the event according to their own interests.

In terms of limitations, there was some uncertainty regarding the overall mission of the conference. They expressed disappointment with the quality of initial chapter drafts and confusion regarding how much of the conference was supposed to be devoted to the textbook vs. a discussion of issues in the field at large. Some participants felt that the structure of the seminar sessions was not particularly well suited to providing chapter authors with detailed feedback. Suggestions were made about how this could have been improved. In addition, comments indicated that some conference participants were viewed as being closed-minded and opposed to genuine collaboration. All in all, the conference tried to accomplish many things at once and might have benefited from a more narrow and defined focus and a less hectic agenda.

Textbook

Out of seventeen papers submitted for the conference, 13 eventually developed into book chapters. Editors commissioned eight additional chapters (two by the editors themselves). The 600-page textbook, *Patient Advocacy for Healthcare Quality: Strategies for Achieving Patient-Centered Care*, has been accepted for publication by Jones and Barlett. It is currently in press and scheduled for release in June of 2007. In total, 48 authors contributed to this work, edited by Jo Anne Earp, Elizabeth French, and Melissa Gilkey. The textbook chapters are organized according to the five overarching strategies of the social ecological framework:

Strategy 1. Individual Level: Understanding What Patients Are Doing Now and What Providers Can Do to Support Them

Strategy 2. Interpersonal Level: Improving Providers' Ability to Communicate and Create Relationships

Strategy 3: Organizational Level: Transforming Hospital and Medical School Culture to Support Patient and Family-Centered Care

Strategy 4: Institutional Level: Making Consumers' Voices Heard in Policy and Law

Strategy 5: Advancing Education and Professional Roles in Advocacy

The defining feature of a patient advocate is someone whose primary goal is to act in the best interests of the patient, often someone who is not able to advocate for him or herself. Thus, the book concludes with a discussion of professional and lay roles within the

advocacy spectrum. This final strategy section examines the “how’s” and “why’s” that lead many individuals to transfer their involvement from self-advocacy or advocacy on behalf of loved ones to advocacy on a larger scale.

Similar to the field of advocacy itself, the book approaches the topic of advocacy from a number of different perspectives. Some authors focus on specific populations in need of advocacy, including children and their parents, ethnic minorities, patients with low literacy, but others focus on specific types of services, such as long-term and end-of-life care. Some chapters examine advocacy from a particular perspective, such as that of clinicians, educators, and patients/consumers, but others explore a particular strategy, such as policy change, research advocacy, and grassroots organizing. Finally, some chapters address different topics within advocacy, such as communication, patient safety, and e-health, but others look at advocacy in specific settings, such as a hospital or long term care facility.

Throughout the book, an emphasis is placed upon the centrality of patient-centered care, the importance of ethics in advocacy, and the need for evidence-based research. The book affirms the belief that skilled communication is essential for effective medical care and that this kind of patient-centered care should be accessible to everyone. In order to achieve broad-based innovation and social change, every participant in the healthcare system, from the clinician to the food services technician, needs to be educated about how to deliver high-quality care. These goals are ambitious but also vitally important. After finishing this book, our readers will recognize that advocates think big.

The intent of this textbook is to give a face to the children, the parents, the elders, the patients who represent those in need of advocacy. In addition to presenting research, evidence, science, and statistics, we also provide stories---stories of people whose lives have been transformed by illness and by advocacy, of kitchen tables that have given birth to revolutionary legislation. But patient advocacy also extends to the needs of those who cannot truly be described as patients because they have no doctor. Making healthcare more accessible is especially important for those who face significant barriers in our current system---low-income and underserved populations, individuals who struggle to obtain high-quality healthcare, those who lack access to healthcare altogether.

Attached to this report is a copy of our book proposal and table of contents. The published edition of the text will be available in July 2007.

Survey

A national survey, entitled *What is Patient Advocacy?*, was conducted by the UNC School of Public Health to explore concepts related to patient advocacy. In 2005, a purposive sample of advocacy leaders from all levels of healthcare were invited to complete an online questionnaire. Respondents were asked to define patient advocacy and to identify important roles, aims, and methods related to the concept. A total of 112 respondents completed the survey, representing a response rate of 55%.

Respondents defined patient advocacy via four themes: (1) taking a multi-level approach that includes both individual- and systems-level advocacy; (2) increasing patient power by facilitating patients’ education, involvement in decision making, and ability to

navigate the healthcare system; (3) changing hospital and provider culture to be more patient centered; and (4) improving healthcare quality, particularly in regard to patient safety and access to care. A few illustrative responses include the following:

Patient advocacy is supporting and empowering patients to make informed decisions, navigate the system to get the healthcare 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.

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

Standing with patients to assist them in meeting their needs by intervening at various levels of the health and social 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.

Patient advocacy is the bilateral appreciation that the focus of medical intervention should be 'patient-centered.' This includes the sharing of decision making, risks, cost effectiveness, treatment regimens, goals and expectations. This must be implemented with an appreciation of the individual patient and physician in the global context of healthcare.

Although we acknowledge the methodological limitations of this relatively small cross-sectional study, we see it as a vital way to begin defining the field and to suggest directions for future research and programmatic efforts. Moreover, we plan to continue to use these survey questions as a tool to track change over time in attitudes and perceptions related to advocacy. Already, we have asked the students in our patient advocacy course to complete the survey and plan to compare these results with the responses of other students in the future.

Course

This interdisciplinary course was based upon the recognition that health advocacy involves a blend of medical, social, legal and economic issues. Incorporating these multiple perspectives allowed us to approach problems from different angles of vision and with tools from a variety of disciplines. By emphasizing the possibility for creative solutions and system change, we hoped to help students better understand the perspectives of different stakeholders, including patients, caregivers, physicians, public health professionals, nurses, social workers, lawyers, heads of nonprofits organizations, and others. At the same time, the course emphasized the utility of applying a public health perspective to the assessment of our healthcare system, recognizing that many different factors at multiple levels contribute to current problems with patient safety, access to medical care, and care fragmentation in our healthcare system.

Patient Advocacy: Healing the Healthcare System, the first patient advocacy course to be offered at the University of North Carolina at Chapel Hill School of Public Health, was piloted during the fall semester of 2006. Sixteen students enrolled in this interdisciplinary, graduate-level class, representing a broad range of health disciplines, including health policy and administration, pharmacy, nursing, occupational therapy, and maternal and child health. Each class period was designed to include lecture, activity, and discussion. In addition to the primary instructors, Jo Anne Earp and Elizabeth French, 13 guest speakers from across the University and the country were invited to deliver guest lectures on topics including patient safety, research advocacy, communication tools, and strategies, and the problem of the uninsured in the United States.

We incorporated several unique components into the course. Students were required to analyze a contemporary narrative (*The Spirit Catches You and You Fall Down* by Anne Fadiman) from the perspective of a patient advocate and to engage in a group discussion about issues that they identified in their papers. Three class periods were devoted to examining healthcare from the perspective of patients, healthcare providers, and caregivers. In each case, we invited a panel of three community members to represent each constituency under discussion (i.e., three individuals who had been, or were continuing to be, patients served as the panel in one case; a panel of three healthcare providers served as the panel for a second course period; and three caregivers led the third seminar. Students also conducted individual interviews with a patient, caregiver, or provider of their choice and reflected on the experience in the context of a written assignment and a class discussion. The class was intended to expose students to many different facets of patient advocacy and to provide them with an opportunity to develop and practice effective communication skills.

Final course evaluations have not yet been processed. However, we administered a mid-course evaluation halfway through the semester and received excellent feedback. Students were asked to evaluate the course based upon general categories, such as readings, assignments, and class discussion and to provide detailed feedback about their response to each guest speaker. Students expressed satisfaction with creative assignments that added value to their learning and were not mere “busy work.” They especially enjoyed, and learned from conducting, their individual interviews with patients, providers, and caregivers. They also appreciated the small class size and the opportunity for everyone to actively participate in the conversation. Class discussions were characterized as thought provoking, pertinent, well coordinated, and welcoming to a wide range of viewpoints. Their comments included the following:

I really feel like all healthcare professionals should be required to take the course.

I enjoyed learning and hearing about others' opinions and ideas on healthcare issues. Many of the topics discussed in class opened my eyes to the problems with our healthcare system.

Everyone's voice is valued.

I feel as though the class provides a good start towards improving the healthcare system.

I enjoy the discussion, the readings, and the back and forth commentary. It's really nice to have a good variety of perspectives in the room and not everyone from the same program, etc.

Students also provided us with several ideas about how we can improve the course in the future. They requested more time for class discussion versus lecture and expressed a desire to break up into smaller groups so that everyone would have more opportunities to speak. They also emphasized the importance of incorporating more diversity in the selection of guest speakers in terms of education, socioeconomic status, and race/ethnicity. Some felt that our guests did not really represent those most in need of advocacy and did not, therefore, communicate appropriate urgency. Students felt that receiving background information on each speaker in advance as well as knowing the questions ahead of time for the panel discussions would have helped them prepare more effectively and use class time more efficiently. Occasionally, students felt overwhelmed, either by the amount of information or the magnitude of the problems with our healthcare system. They expressed a need for more processing time, more reflection on what they might be able to do as individuals to make a difference.

Because we asked student to complete this mid-course evaluation, we were able to respond to their feedback and to implement some of their suggestions during the second half of the semester. We will keep the larger structural changes in mind as we prepare for the second course in Fall semester, 2007. We hope to continue to offer the patient advocacy course on an annual basis as well as potentially making course materials available in an online format.

List of Publications and Products:

Earp, JA, French, EA, Gilkey, M. (Forthcoming). *Patient Advocacy for Healthcare Quality: Strategies for Achieving Patient-Centered Care*. Jones & Bartlett Publishers.

Documents Submitted under Separate Copy:

Conference:

Conference Participant Biosketches
Conference Agenda

Book (JAE):

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Proposal

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Melissa's article

Course (KME):

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