Integrating caring into patient-centered care through interprofessional education and ethics: The Caring Project

Jane S. Mahoney, PhD, RN, PMHCNS-BC
Cynthia Mulder, LCSW
Susan Hardesty, MD
Alok Madan, PhD

In an era of health care that is driven by biological and technical advances, there is a need to safeguard the caring component of care, the humanistic part of care. With this in mind, the authors constructed a Patient-Centered Caring model consisting of three overlapping constructs: delivering customer service, understanding the illness experience, and providing trauma-informed care. These practices operate within an interprofessional competency context. The authors describe an interprofessional educational project focused on understanding the illness experience and providing trauma-informed care to faculty, staff, and administrators in an inpatient psychiatric setting. The authors discuss the project through a number of ethical lenses that may help explicate the ethics of patient-centered care and caring and can be useful in the development of interprofessional competence. (Bulletin of the Menninger Clinic 81[3], 233–246)

Jane S. Mahoney is Director of Nursing Practice and Research, The Menninger Clinic, and an associate professor, Menninger Department of Psychiatry & Behavioral Sciences, Baylor College of Medicine, Houston, Texas. Cynthia Mulder is a senior social worker and Director of Education and Training, The Menninger Clinic, Houston, Texas. Susan Hardesty is a clinical associate professor, Menninger Department of Psychiatry & Behavioral Sciences, Baylor College of Medicine. Alok Madan is McNair Scholar and a senior psychologist, The Menninger Clinic, and an associate Professor, Menninger Department of Psychiatry & Behavioral Sciences, Baylor College of Medicine.
Correspondence may be sent to Jane S. Mahoney, Menninger Department of Psychiatry & Behavioral Sciences, Baylor College of Medicine, 12301 S. Main St., Houston, TX 77035; e-mail: jmahoney@menninger.edu

In an era of health care that is driven by biological and technical advances, there is a need to safeguard the caring component of care. *Patient-centered care* is a popular term in contemporary health care, referring to respectful care that includes attention to the patient's unique values, beliefs, needs, circumstances, and preferences in guiding shared clinical decision making (Institute of Medicine, 2001). Presumably, at the core of patient-centered care is a healing relationship between the patient and professionals providing care. A healing relationship is based on caring and extends to a positive relationship with patients' family members, who are key stakeholders in the patient's health and illness (Epstein, Fiscella, Lesser, & Stange, 2010; Hernandez, Conrad, Marcus-Smith, Reed, & Watts, 2013).

To highlight the caring component of patient-centered care, we constructed the Patient-Centered Caring Model. The model is composed of three overlapping constructs: delivering customer service, understanding the illness experience, and providing trauma-informed care. These practices operate within an interprofessional competency context.

The purpose of this article is to describe an interprofessional educational project designed to create a shared mental model of patient-centered caring among all professional groups in the organization vis-à-vis the Patient-Centered Caring Model. The project took place at The Menninger Clinic, a private not-for-profit psychiatric hospital affiliated with Baylor College of Medicine and located in Houston, Texas. The goal of the project was to prepare participants for improving working relationships with each other in order to construct a more compassionate, caring, patient-centered, and safer environment in which to deliver health care.

The educational initiative was one arm of a larger project aimed at identifying the interprofessional core competencies for patient-centered caring. The scope of this article is to focus on training related to understanding the illness experience and providing trauma-informed care and to discuss the educational program from an ethical point of view. Future work will include findings from a qualitative study identifying the interprofessional competencies needed to demonstrate delivery of patient-centered caring.

Background

The illness experience is told and enacted through the illness narrative. Patients and family members communicate experience-centered illness events to create a new experience for the listener that will foster empathy and understanding (Mattingly, 1998). Ideally, the patient and family members are capable of informing the rest of the treatment team, not only about the biopsychosocial aspects of the patient's health concern, but also about the personal humanistic and existential aspects of their lived illness experience. Caring is possible when the professional members of the health care team offer an empathic stance toward, and take action in, supporting the patient and family based on an understanding of the illness narrative (Frank, 1995; Kleinman, 1988; SunWolf, Frey, & Keänen, 2005).

This is particularly important when the clinical team practices shared decision making, because the illness narrative informs the patient and family preferences with regard to treatment decisions. Caring is enhanced when the professional members of the team take steps to maintain an awareness of the patient's previous lifetime trauma experiences and to mitigate health-care-related trauma for the patient. In doing so, the professional team integrates what matters most to the patient and family with the biopsychosocial information needed to design an effective treatment plan of care.

The effectiveness of the plan also depends on a holistic frame of care that includes integrated professional teamwork. The holistic frame considers the patient as an interactive whole, the family and the patient as an interactive system, the treatment team as an interactive group in concert with the patient and family, and the treatment plan as dynamic to adjust to the patient and his or her needs (Klein, 1990). Such a complex constellation requires, in part, interprofessional education to create a shared mind among the professional groups about how to incorporate patient and family illness narratives into the plan of care and how to situate the patient and family members as core members of the treatment team.

The Patient-Centered Caring Model is based on several assumptions. Patient-centered caring begins when patients and their families are welcomed with warmth and hospitality and understand what will happen while receiving care. Personalized caring reflects that the professional empathically understands what it means for the patient and family members to live with a condition. Such caring includes respectfully including patients and families in shared decision making. When people know that the health care professionals collaborate with each other to do everything possible to keep them emotionally, physically, socially, and morally safe, they experience patient-centered caring.

Collaboration among professionals is essential for patients to experience caring. Interprofessional collaboration enhances health care systems and positively affects patient outcomes; thus, interprofessional education is critical to strengthening collaborative practice. When presented in an interprofessional context, health care education offers learners the opportunity to learn how to think, work together, and develop knowledge, skills, and attitudes to support collaborative practice. Therefore, health care systems are challenged to implement postlicensure educational strategies based on improving the practice culture through teamwork and creating a shared mental model among professional groups about key practice principles (World Health Organization, 2010).

Interprofessional education is necessary to improve teamwork and team communication (Priest et al., 2008) as effective teams rely on the application of knowledge, skills, and attitudes used to optimize collaborative performance (Weaver et al., 2010). This is the case throughout health care, including mental health care. Although most inpatient mental health services are based on an interprofessional practice model, prelicensure training is lacking in this area; therefore, the task of educating the teams often falls to health care organizations.

This article will outline the content of the educational offerings, known as the Caring Project, related to understanding the illness experience and providing trauma-informed care. We will describe the educational strategies used to train a large interprofessional group about Patient-Centered Caring Model constructs. In addition, we will discuss the educational arm of the project in relation to the values and ethics of the interprofessional competency domain identified by the Interprofessional Education Collaborative Panel (2011).

The Caring Project

The Patient-Centered Caring Model was disseminated at The Menninger Clinic through a series of interprofessional educational offerings known as the Caring Project. A series of events were held to inform administrators, faculty, and staff about the initiative. The events were presented in a tea format, which allowed for a relaxed, hospitable atmosphere for us to generate interest in the project and enthusiasm for the upcoming training.

Understanding the illness experience

The illness experience training involved the National Alliance for the Mentally Ill of Greater Houston (NAMI) Provider training (Burland, 2013) and presentations and consultations with Eric Arauz (2012), national speaker, mental health consumer, and author. The NAMI Provider training was conducted in seven series, each composed of five 3-hour sessions aimed at presenting the patient and family member illness experience to providers in a unique way. The training format offered clinical staff the opportunity to bear witness to patient and family illness narratives. A crisis model of illness developed by patients and families was presented that helped inform the trauma base of the illness experience. While clinical staff members are familiar with illness stories, the training situated the clinical staff in the unusual position of listening, reflecting, and learning rather than diagnosing and intervening.

An interactive method, designed to increase clinical staff's awareness of, and empathy toward, the patient and family experience was used to engage participants through the use of health care consumers' and family members' testimonials about their experiences. This created a shift in focus from professional-as-expert to consumer-as-expert, enhancing the role of patients as active partners in their recovery process. This knowledge has the potential to increase the ability of the clinical staff to be more patient-centric and to approach care delivery with a caring attitude. Unlike much training in health care organizations that applies biomedical knowledge to health care delivery, this course teaches about the emotional aspects and practical consequences of mental illnesses.

A five-member panel of NAMI volunteers, consisting of consumers of mental health services, family members of consumers, and NAMI staff, presented the training. Each series was limited to 25 participants to allow for interactive learning. A total of 166 hospital clinical faculty and staff participated in NAMI Provider training.

The classes followed a manualized curriculum with didactic learning, personal stories, and experiential and group exercises in each session. Didactic material resources were provided to each participant. The curriculum was created by Burland (2013) and informed by the lived experiences of consumers of mental health services and their family members. In addition to limited didactic presentations, the panel employed a number of interactive strategies recommended for interprofessional education by Barr, Koppel, Reeves, Hammick, and Freeth (2005) such as problem-based and simulation-based learning.

Additional illness experience training was provided by Eric Arauz (2012), a mental health consumer, national speaker, and author. Arauz provided two 1-hour sessions during which time he gave an account of his life experiences with mental illness, the mental health care system, and his recovery journey. A total of 82 Menninger administrators, faculty, and staff attended one of the sessions. Arauz also met separately with various teams in an open forum to discuss challenges related to implementation of a truly patient-centered approach that were unique to each team.

Trauma-informed care

There was an overlap between the illness experience trainings and trauma-informed care trainings, as trauma narratives were embedded in the illness narratives. Trauma-informed care training strategies included simulations, webinars, workshops, reflective inquiry, deep dive discussions, and real-time, unit-based consultations. The trainings were provided by faculty from the Sanctuary Institute (http://thesanctuaryinstitute.org), a provider of trauma-informed training for organizations who care for vulnerable populations. The Sanctuary Institute is committed to restoring hope for those who have experienced trauma. The educational content covered trauma theory, making a commitment to trauma-informed care, examining parallel trauma processes shared by staff and patients, and developing skills with select sanctuary tools. The goal of the training was to educate the participants in ways to prevent hospital-related trauma and create a space in which patients feel physically, emotionally, socially, and morally safe (Bloom & Farragher, 2013).

Sandra Bloom, coauthor (Bloom & Farragher, 2013) and one of the founders of the Sanctuary Institute, provided an overview of the Sanctuary Model of trauma-informed care followed by a round-table discussion about the application of its practice. Two 2-day trauma-informed care workshops, Enhancing Trauma Awareness, were provided by faculty from the Sanctuary Institute. The workshops were planned for small groups of administrators and clinical managers, charge nurses, and clinical staff who have a specified interest in trauma-informed care. Thirty-three clinical professionals attended the workshops. In addition, the Sanctuary Institute provided two webinars so that all of our clinical staff could have the opportunity to benefit from the overview of the Sanctuary Model as a vehicle for trauma-informed care. A substantial number of the clinical staff who had not attended the Sanctuary Institute workshops participated in the webinars.

Following the formal trainings, the Sanctuary Institute provided on-site consultation over a 5-day period. During this time, the consultant attended meetings and other activities on the various units as well as hospital-wide committee meetings. In addition, the consultant met individually with key personnel and with groups of faculty and staff. Through real-time observations and discussions, she provided feedback regarding how we might reflect on our current practices and how we might integrate the Sanctuary Model more fully into how we care for patients and for each other. Through the various encounters with the Sanctuary Institute, we developed a shared mental model and shared language for trauma-informed care.

Discussion

There is some evidence that patient and family involvement in clinical education enhances professionals' skills related to issues most important to health care consumers. Involving clients in the interprofessional educational process makes explicit the position of the patient as the center of the team, thus enhancing patient-centered care (Cooper & Spencer-Dawe, 2006). However, little is known about how consumers are involved in health care education, particularly with regard to the development of interdisciplinary competencies with a focus on patient-centered care (Repper & Breeze, 2007). The Caring Project provides some guidance related to this issue because consumers of health services were partially responsible for the educational content.

The NAMI Provider trainings and the presentations and consultations provided by Eric Arauz provided critical information about what matters most to patients and their families. These contributions were useful for enhancing ethical interprofessional practice, one of the competency domains identified by the Interprofessional Education Collaborative Expert Panel. (2011). The expert panel suggested that the values and ethical competency are based on the development of a professional and an interprofessional identity that is patient-centered, built on a shared purpose and commitment to the common good in health care. The panel further asserted that the approach to a values and ethical competency should focus on positive relationships not only with patients but also among professionals. This involves effective teamwork that relies on a shared mental model of quality, safety, and ethical principles.

We propose that the educational activities described in this article can be examined through a number of ethical lenses that may help explicate the ethics of patient-centered care and caring and can be useful in the development of interprofessional competence. The NAMI Provider Training and the presentations and consultations provided by Eric Arauz were based on the lived experiences of people with mental illness, consumers as well as families. Much of these trainings involved listening to illness narratives.

The relevance of narrative to bioethics lies in the nature of illness narratives. Embedded in these stories are lessons about what good care entails and which actions are helpful and which are hurtful (Frank, 2016). Narrative ethics can be thought of as an expansion of principlism, the basis for much of bioethics. Principlism consists of four central principles: beneficence, autonomy, nonmaleficence, and justice (Beauchamp & Childress, 2012). One could posit that lessons learned from attending to illness narratives potentially support doing good for the patient (beneficence), self-determination (autonomy), causing no harm (nonmaleficence), and the right to be heard (justice).

However, Baldwin (2015) suggested that narrative ethics is unique and that normative ethical principles in health care do not align well with narrative care. Traditional standards limit the focus of ethical scrutiny to a narrow focus of a particular ethical principle. This is in contrast to recognizing the interpersonal nature of the story told by one person to another that includes context, trajectory, and meaning of the illness experience.

Others have suggested that narrative ethics relies upon reasoning and attention to emotion. This stance is based on the reality that many illness narratives have an emotional component that calls for mindfulness on the part of the listener (Guillemin & Gillam, 2015). The testimonials offered during the educational presentations were filled with emotional moments. We believe that the value of being the learner—that is, being in the receiving mode rather than the doing mode—created a worthwhile space for the listener to hear the illness stories not only as a narrative of disorder but also as a narrative of experience. In a busy clinical world, the opportunity to integrate both is a challenge. This challenge deserves attention in interprofessional education.

According to Paulsen (2011), caring requires attending to narratives. Frank (1995) suggested that the ethic of our time is the ethic of voice, thus the physical act of illness storytelling becomes an ethical act. Thinking about the stories is the foundation of narrative ethics. The ethic of listening is required for the voice to matter. The goal of eliciting and listening to the illness narrative is to attend deeply enough to be provoked to understanding and action in a new way.

Such was the potential impact of the NAMI Provider Training and Eric Arauz's educational activities in which the learner was immersed in encounters with patients and family members on a new level. Sufficient exposure to patients' and family members' illness narratives can foster an integrated view both of the person with a disease and of the person with a lived experience. Although these may seem to be opposing views, the lived experience with the rational treatment experience requires an integrative mind (Martin, 2007). In the case of interprofessional practice, this requires a collective appreciation of the value of integrative thinking. Moreover, such understanding can lead to a more holistic interprofessional patient-centric treatment plan that includes recognition of the human experiences of navigating everyday life with illness.

Listening with the intention of understanding allows for recognition of the burden of the catastrophic events in the illness story. Valuing such understanding can move the listener to take action to mitigate additional trauma related to hospitalization. Both sets of trainings illustrated the intense burden associated with hospitalization for those living with mental illness. Words alone were inadequate to describe what one speaker called the "crushing burden" of how admission to a hospital, in and of itself, is a traumatic event. Frank (1995) describes such narratives as chaos narratives. In the absence of a narrative order in which words fully explain an illness experience, chaos stories are hard to hear, yet these incoherent narratives told by the wounded storyteller call for the most profound humanistic caring.

Understanding the illness experience involves listening, attentively listening, to the voice of the suffering, one of the most difficult tasks for humans. The voices of the suffering are hard to hear, but such listening is a moral act that relies on what Frank (1995) called an ethic of listening. It includes a mentalizing stance, an open-minded, nonjudgmental, inquisitive position that is primarily an ethical stance. Mentalizing involves holding the mind of the other in mind in order to understand. This involves deep listening. The ethical principles of benevolence and respect are intrinsic to a mentalizing stance (Allen, Fonagy, & Bateman, 2008).

In order to create a safe space in which professionals can explore their own vulnerabilities, organizations need to maintain a culture that supports physical, emotional, social, and moral safety for patients, families, professionals, and all members of the organization. The trauma-informed care trainings and consultations provided by the Sanctuary Institute offered a model for creating and sustaining such a culture.

Shared decision making is based, in part, on shared ethical principles, the foundation of an ethical culture. In an ethical culture, everyone is involved in deciding about the most principled solutions to challenges within an organization, thus developing a shared mental model about ethical principles among interprofessional teams is essential. In an ethical culture, expectations are clear, and accountability is fostered. The climate supports responsibility, equity, and trusting relationships that support social responsibility and the common good (Bloom & Farragher, 2013).

Social responsibility, one of the commitments of the Sanctuary Model, calls for a commitment to a just culture, fundamentally an ethical principle. Framed in this way, social responsibility includes a widespread culture based on moral safety, the safety to speak up and be heard. It is based on a shared perspective of right and wrong. Trauma experience is about ruptured lives that desperately need the presence of ethical and moral consistency in the recovery process. Helping patients and families who live with illness to restore a sense of social justice is an essential component of healing (Bloom & Farragher, 2013).

Understanding the illness experience includes being open, hearing, and validating the illness narrative and incorporating the patient experience into collaborating with the patient to build a plan of care (Haidet & Paterniti, 2003). In doing so, a process of relational autonomy emerges, that is, autonomy that is socially constructed and based on sharing of information and perceptions among the patient, family members, and professionals. This is particularly important when an individual is living with a serious complex mental illness. In such cases, people look to others, generally interprofessional teams, to help guide decision making (Epstein & Street, 2011).

In contemporary health care, the dominate focus is on biologically and technically driven therapies, all of which are critical to good health outcomes. Such advances in health care have increased life expectancies, improved functioning, and supported recovery. However, health care is about so much more. It includes the essence of the human being and all that that person must deal with on a daily basis to navigate life. To this end, it is critical that the caring component of health care is integrated fully into the delivery of treatments.

"Life is more than permutations in the DNA molecule as the Fifth Symphony is more than vibrating air. And mental illness is more than an aggregate of errors in body physics and chemistry. It is a universal human experience which has a salvage function in maintaining the vital balance" (Menninger, 1963, p. 417). We suggest that attending to narrative ethics and the ethic of listening for the purpose of understanding the person more fully supports the vital balance Karl Menninger described.

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