


Patient Safety: A Consumer's Perspective

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Abstract

In this article we provide a reconceptualization of patient-centered health care practice through a collaborative person-centered model for enhanced patient safety. Twenty-one participants were selected and interviewed from the internationally diverse population of individuals attending the Chicago Patient Safety Workshop (CPSW) sponsored by Consumers Advancing Patient Safety (CAPS). Analysis of the participant transcripts revealed three findings related to patient experience: the impact and meaning of communication and relationship within the health care setting, trust and expectation for the patient and family with the health care provider, and the meaning and application of patient-centeredness. Researchers concluded that successful planning toward enhanced patient-centered care requires multiple perspectives, including the voices of the patient and family members who have experienced the trauma of preventable medical error. Collaborative initiatives such as the CPSW and CAPS offer a positive way forward for enhanced patient safety and quality of care.

Keywords

health care; health care, user's experiences; hermeneutics; relationships, health care; relationships, patient-provider; research, collaborative; safety, patient

Yes, I'll tell you about it [a consumer's experience], but I have to tell you that whenever I discuss this, the way my son explained it to me is that it is very much like putting your hand into a pocket full of razor blades. It is very painful and people don't necessarily see the little small cuts. But I feel it's very important that I speak out about my experience. My mother died as a result of medical error, and actually a series of medical errors.

Exposing the small cuts of living with the personal traumas of preventable medical errors requires more than attention to the quality of health care provided. Medical errors, or "any preventable event (such as a mistake related to medication, a mistake in diagnosing or treating a condition, or a problem with medical equipment) that may cause or lead to unintended outcome or patient harm" (Consumers Advancing Patient Safety, 2008, p. 2) needs to include a return to patient-centeredness. Even though patient-centered care is widely understood to be a key component for enhanced health care, the term is interpreted a number of different ways in medical literature. Definitions of patient-centeredness range from patient satisfaction about interactions with health care providers, to the role of

patient/physician attitudes, to how health care systems might affect patient-centered care.

Patient-centeredness is often explained in terms of patient satisfaction or the perceived social distance between the patient and the health care practitioner. For example, Cooper et al. (2003) found that race-concordant visits with their physician were longer in duration and perceived by the patient to be more positive and patient-centered. Street, O'Malley, Cooper, and Haidet (2008) viewed concordance in patient-physician relationships as perceived similarities of the patient with their physician on two dimensions: (a) personal beliefs and values; and (b) ethnicity (in race and community). Perceived similarities enhanced levels of trust, satisfaction, and intention to adhere to treatment protocol, whereas other factors such

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as patient-centered communication and efficacy of the patient influenced a sense of concordance (Street et al.). These findings suggest that factors such as patient and physician attitudes, as well as race concordance, play a role in patient-centered care. Another interpretation of patient-centered care suggests it is derived through the enablement of patients to share in their treatment decision-making process. In this case, patient-centered care is a function of the quality of the decision made, through a shared decision-making process with the patient, which leads to efficient health care and a more patient-centered care model (Holburn & Vietze, 2002; Longtin et al., 2010; Sepucha, Fowler, & Mulley, 2004).

The systems approach to patient-centered care pertains to improving patients' access to a continuity of care within and among various clinicians and settings. It also includes supporting patient self-management through systems that facilitate goal setting, and increased patient and family confidence in self-care (Bergeson & Dean, 2006). Similarly, Davis, Schoenbaum, and Audet (2005) described patient-centered care as a key component of a health system that ensures all patients have access to appropriate care, inclusive of the following dimensions: respect for the patient's values, preferences and expressed needs, information and education, emotional support to relieve fear, enhanced access to care, and involvement of family and friends.

Leape (2009) highlighted that to date, the major focus of patient safety has been directed at the implementation of safe practices. This focus corresponds with the current understanding of patient safety as "freedom from accidental injury" (Institute of Medicine & Committee on Quality of Health Care in America, 2000, p. 211). Thus, "ensuring patient safety involves the establishment of operational systems and processes that minimize the likelihood of errors and maximizes the likelihood of intercepting them when they occur" (Institute of Medicine & Committee on Quality of Health Care in America, p. 211). To achieve higher levels of patient safety, health care organizations require diversification of attention to other factors, including enhanced engagement of patients in their care (Leape).

Vincent and Coulter (2002) corroborated this belief in their assertion that patients and family members have a key role in the prevention of preventable medical harm and enhanced patient safety. They contended that the psychological consequences of medical injury must be recognized and dealt with effectively; improved communication with patients and facilitation of active partnerships should become central to patient safety strategies. Others have questioned whether patients should have a role in patient safety and, if so, what that role should entail (Lyons, 2007). Schwappach (2010), in a recent review of

literature, concluded that little is known regarding the feasibility and effectiveness of patient engagement as partners in safety issues. This is additionally complicated by differing attitudes, intentions, and behaviors of patients and health care professionals toward engagement in safety issues. Longtin et al. (2010) asserted that patient participation has become increasingly recognized and advocated as the key component in the redesigning of health care processes to enhance patient safety. Entwistle (2007) offered the view that certain interventions to support patient involvement in patient safety are not only justified, but are ethically required. The meaningful engagement of the patient in patient safety supports the development of respectful relationships, open communication, and empowered patients and family members (Hovey & Paul, 2007).

In reviewing the literature, a primary component in the identified debate of patient safety issues is the lack of the patient's voice and perspective about what their role in patient safety should be (Entwistle, 2007; Speraw, 2009). Hovey et al. (2010) provided a patient counter narrative to this debate, and advocated for a collaboration of patients/consumers/family members, health care practitioners, patient advocates, and academics to create a space for the voice of the patient to be heard. Our intent within this article is to make explicit how health care professionals (HCPs) offering a communicative and relational presence with the patient/family member can enhance patient safety. The perspective taken to forward this discussion is one grounded in person-/patient-centeredness in which the consumer (patient) takes on a shared role as educator, mentor, and expert alongside the health care professional (Abma, Nierse, & Widdershoven, 2009; Holburn & Vietze, 2002; Speraw).

Method

All patients must invariably be treated with care, both because of their neediness and because of their extreme vulnerability. In order to preserve this important recognition of distance, doctor and patient must gain some common ground where they can come to mutual understanding. Such common ground can only be provided by the dialogue they sustain between themselves. (Gadamer, 1996, p. 127)

Context

In the summer of 2008, Consumers Advancing Patient Safety (CAPS), a grassroots person-centered organization, hosted the Chicago Patient Safety Workshop (CPSW) on consumer engagement in selected patient safety topics. The invitation-only workshop hosted approximately 40 patients and family members—many of whom had

experienced preventable harm because of health care systems failures—and an equal number of other stakeholders comprised of health care professionals, organizational administrators, academic researchers, graduate students, philanthropists, government representatives, and facilitators. This community of change agents came together with the common goal of accelerating improvement in patient safety by developing measurable interventions that can be implemented in the Chicago region and beyond (CAPS, 2008).

Methodology

This inquiry was guided by the philosophical hermeneutics of Hans George Gadamer (1900-2002). Hermeneutics is a philosophically based research approach within the human sciences that focuses on gaining a deeper understanding of the nature or meaning of human experience. Hermeneutics is founded in the ontological understanding that the world is interpretable, and that we as humans are always in the process of interpreting that which is around us (Gadamer, 1989). Within this context, philosophical hermeneutics was chosen because of its utility to move narrative discourse from a factual and chronological recounting of events toward new and different understandings and meanings that preventable medical harm holds. The research team was comprised of individuals with differing perspectives on patient safety; these included patients/family members who had first-hand experience with preventable medical harm, academic researchers, members of CAPS senior leadership, and a health care administrator.

Interpretive inquiry involves the selection of participants who can best inform a perspective on a particular topic and invite new understanding of it. During the CPSW the workshop leaders extended an open invitation to participate in the research process. Twenty-one workshop participants (15 patient/family members and 6 health care professionals) consented to participate and be interviewed regarding their personal experiences with adverse medical events, what these events meant to them, how the events had influenced and continued to affect their lives, and ultimately how these experiences provided lessons to improve patient safety. Consent and release of data was obtained from the participants for their interviews to be used in multiple contexts including research, education, and media. The interviews were unstructured and conducted in a manner congruent with Gadamer's idea of a genuine conversation (Binding & Tapp, 2008; Gadamer, 1989) to allow the meaning of living with preventable medical harm, from the participant's perspective, to remain the central topic of exploration. Two of the authors (Hovey and Worsham) individually conducted the interviews,

each of which lasted approximately 1 hour. All interviews were audio and video recorded, and transcribed verbatim for analysis.

Analysis

In philosophical hermeneutics, interpretation is an ongoing process that begins with initial understandings of the research protocol; continues through the interview process, transcription, and textual analysis; and is finally explicated in interpretive writing. This approach relies on a deep engagement with the topic and textual data and attempts to generate new or different understanding rather than extracting or codifying themes.

The interpretation process consisted of two stages. In the first stage we read and reread the transcripts and then independently wrote interpretive memos. These memos represented each research team member's understandings of what the text and topic meant to him or her. During the second stage, the principal investigator (first author Richard Hovey) reviewed the interpretive memos and, through ongoing discussions with the research team, placed the most meaningful interpretations into a meta-interpretive document. In this way, the new understandings were discussed, altered, and refined, and constituted an authentic representation of the three most meaningful interpretations from the research team.

Research Findings

Belonging together always also means being able to listen to one another. When two people understand each other, this does not mean that one person "understands" the other. Openness to the other, then involves recognizing that I myself must accept some things that are against me, even though no one else forces me to do so. This is parallel to the hermeneutical experience. (Gadamer, 1989, p. 361)

The efforts of our collaborative process produced the following findings as important interpretations and understandings from the participants' interview texts: (a) the impact and meaning of listening; and (b) trust and expectation. A third finding became apparent that encompassed not only the two main findings of listening and trust, but other related interpretations of patient safety such as empowerment, respect, and social equality. The meta-interpretation and overarching interpretive discourse was related to patient-centeredness. The following is an exploration of the meaning of the two main findings from the patients' perspectives and a reconceptualization of patient-centered care as supported by the textual data,

which was interpreted into a metainterpretation representing patient-centered care.

Loss of Listening

An object is best viewed when held in our direct vision, by contrast to hearing which brings the sound into the body, thus reducing distance. Seeing occurs at a distance, detached, and is spatially separate from what it is to be seen. It is easier for us to shut our eyes and look away than close our ears and remain untouched and unmoved by what we hear because what is seen can be kept at a distance, but what we hear is understood by our entire body. (Levin, 1989, p. 32)

The following comments from a workshop patient participant are about the death of his son from preventable medical harm because of a failure to listen:

We were told throughout the day that his sleeping was normal. And afterwards when I speak about patient safety [to students] and tell my son's story, everybody shakes their heads and says no, he should have been easily woken up. And that is not what was told to us at the time [postsurgery]. It was obviously very frustrating because you know the first question my wife asks is, "So what you're telling me is if we told somebody else besides our nurse that he was not waking up they may have reacted differently and our son may still be here?" And the answer is yes.

Listening and hearing represented a powerful finding that offered significant potential for patient-centered engagement and interaction. As the resounding first finding to emerge from the research, the implication of not listening was representative as a consistent contributing factor in every preventable medical harm narrative. Listening, communicating, and forming relationships are often referred to as soft skills in biomedical research evidence and practice. The irony is that these often taken-for-granted human interactions can significantly enhance or diminish patient safety, and are frequently at the core of preventable medical harm (Baker et al., 2004). The assumption that well-educated health care professionals are inherently good communicators can be misleading. Becoming an effective/affective communicator is not about how well one understands a topic; rather, it is dependent on how well they can make information accessible for specific and diverse audiences (McWilliam, 2007).

One participant framed what being present for the patient/family member means from the patient's perspective:

I want a doctor who is understanding. I want a doctor who is patient. I want a doctor who is going to sit there and listen to every word that I have to say. And there are a lot of times we will say things that are completely irrelevant but, trust me, the communication that you are giving me as a doctor might be just as irrelevant because I don't understand it.

Skilled effective and affective communication is audience-specific. Consequently, a compelling and clear communication with one's peers might become almost incomprehensible to another group of people. Nevertheless, even if you are part of the health care community, speaking and understanding the language and culture is not ensured. The following quote illustrates the frustration and disbelief experienced by a mother who lost her daughter:

I guess my first reaction was this sort of, this disbelief, and I could not believe it was happening. First and foremost because I am a nurse by profession, and how could my daughter be dying and I could not [pause], I could not get the doctors and nurses to listen to me. I'm a mother but I'm also a nurse, and so I'm thinking, I know what I'm talking about and they're not listening to me.

The participant quoted was a nurse and mother; her role as a professional health care provider and as a mother/caregiver converged. In this situation there was no language barrier, no miscommunication, nor misunderstanding; there was only someone unheard. The participant, as mother and nurse, pleaded with health care providers to attend to her daughter, but no one listened. In her own words, she became perceived as a "hysterical mom," and her daughter died. The humanistic and tacit aspects of being an HCP were absent from this event. It leaves one to wonder why; how could person-centered care have been offered to this mother and her child?

The overwhelming nature of the quoted participant's experience demands reflection on why one chooses not to listen. This powerful experience demonstrates the need for practitioners to critically reflect on their own capacity to listen, and why their beliefs, values, and practices might influence their understanding of patient-centered care. Perhaps evidence-based practice is overly reliant on tools and best practices to guide complex humanistic and tacit patient interactions. Inconceivably, in this case the words spoken by the patient or family member were not heard, and were left unanswered.

Communication is enabled or obstructed through the way in which we invite people into conversations about their health, treatments, and concerns (Gadamer, 1996; Monrouxe, Rees, & Bradley, 2009). Feelings of being

devalued because of not being heard complicate the humanistic and tacit aspects of being a partner in one's health care. One participant explained how complex emotional reactions began with not being invited into a conversation:

Devalued . . . when you are a patient you are vulnerable anyway. You are probably at your most vulnerable. You doubt yourself, you think maybe there's something wrong with you. When you keep telling people something's wrong and nobody's listening, and by the time somebody listens and they identify that there is a problem. You know for me, personally, I get to the point where I'm thinking, "Oh, thank God. I'm not crazy," because I have kind of dismissed my own . . . my own concerns because of the way I've been dismissed. So I can't even say I'm angry. It makes me more vigilant to help change the system and help see . . . help health care communities see that we have value—you need to start listening.

Illness and the need for medical care can place an individual in a vulnerable position; actions or inactions that cause an individual to feel devalued or dismissed likely make the situation more difficult. We try to avoid these stressful encounters because of the toll they take on our sense of self, personhood, and personal efficacy. Listening to the other means not merely acknowledging that the other person has said something, but working toward understanding what has been said (Gadamer, 1989). This is akin to a hermeneutical understanding of another's perspective. In listening to the other, health care professionals are engaging in the art of interpretation:

Understanding and interpretation are related to verbal tradition in a specific way. But at the same time they transcend this relationship not only because all the creations of human culture, including non-verbal ones, can be understood in this way, but more fundamentally because everything that is intelligible must be accessible to understanding and to interpretation. What is true of understanding is just as true of language. Neither is to be grasped simply as a fact that can be empirically investigated. Neither is ever simply an object but instead comprehends everything that can ever be an object. (Gadamer, 1989, p. 402)

Mindfulness can be initiated through a transformative process, where an experience of a personally significant disorienting event creates a momentous disruption that cannot be resolved with old modes of behaviors. Transactional experiences of more of the same serve only to

confirm and/or extend what is presently known and accepted (Merriam, Caffarella, & Baumgartner, 2002). A change in perspective and interpretive insight occurs when we are contradicted by something that causes us to think differently (Moules, 2009):

I've got to find a way to get into their [HCP's] conversations so that I can be a part of the conversations, so that they'll talk to me and at least include me. So I had to start teaching myself how to temper myself and how to do that. But I just wanted to know. I just needed to know, so that I could know how I could help.

Patients, their family members, and health care professionals are people who come together at unfortunate times in the patients' lives. Language is the common ground on which substantive understanding and agreement becomes possible between people: "You understand a language by living in it" (Gadamer, 1989, p. 385). For the participant quoted above, it meant finding a way to connect, to find a common ground to converse about her child. She was already living the experience as parent of a patient, but needed to live as well with the language of inclusion, relationship, and patient- (person-) centeredness. The effect of the participant's connection to the doctors caring for her daughter was transformative, moving toward other possibilities, categories, and perspectives, such as patient-centeredness.

Loss of Trust

My three-year-old looked at me one day, about four months after my daughter died. He said, "Mommy, did the doctors hurt Annie?" You think about what was going on in his mind. And I said, "Well, it's more like she was falling and nobody tried to catch her."

The second finding focused on trust/mistrust and the expectations of HCPs. The consequence of losing trust in one's health care provider and the health care system created serious tension and apprehension for future encounters. This fear instilled a reluctance to reengage with the health care system, even though not doing so might create other serious health outcomes:

I felt that everything I ever thought about the world being good and kind was just gone. Then I found that we all—we still needed health care. I could not just run from the problem, and so we had a huge problem in our family in that the people who had done a great deal of harm to us, we still needed to

rely upon to take care of us. We were all very afraid, and we had to find some way to build trust and survive the experience.

This participant was faced with the dilemma of overcoming the apprehension of reentering the health care system after the experience of preventable medical harm. This invited consideration about the roles of trust, expectations, and relationships between the patient and physician, and between the patient and the health care system. The participant's suspicions about the health care system were countered by the real need for help from the very system she no longer trusted. How does one learn to trust again, to have confidence in a system that let one down so profoundly?

The word *trust* can be used as either a noun or a verb. As a noun, the word refers to something that exists between people, such as a confidence or reliance. It corresponds to good qualities such as fairness, truth, honor, or ability; a sense of responsibility to someone or something; the ability to behave responsibly or professionally (Soanes, 2000). Trust is an intersubjective phenomenon that is closely linked to some form of relationship, such as the doctor–patient relationship (Hovey, 2006). From this definition, it becomes evident that trust is not only something that can be developed, but is an expectation of someone in a position of social significance:

We have some—we have some great doctors. Following what happened to my son, we still visit his original cardiologist with my other children because they told us it's possible they may have the same condition. Sometimes I believe I have the same level of trust, but I have not been put into a position where I have had to question it. And I wonder, if I'm put in that or a similar type of situation again, you know, how trustworthy am I going to be and how demanding am I going to be to bring other people in to help, whereas I didn't before.

The verb *to trust* refers to something that is done or can be done (Soanes, 2000). Trust can also be an action, meaning to place confidence in someone's qualities and professional ability. In essence, trusting is having confidence in a person to do the right thing, take the right action, and be what they are socially constructed to be (Hovey, 2006):

I think if there was one word that's important to me that I've learned through patient safety and my situation and others is *trust*. We have to build a system that allows for patients to trust their physicians in every way, not only that the physicians are doing their best and learning from errors, but also ethically

that they're always acting honorably. And trust is the essence, I think, of good health care, and it begins during care, and then when something goes wrong we need to rebuild that trust relationship, so that's a big thing for me. (HCP)

Trust in this context could exist between a patient and her or his physician within the health care system. The focus is on a person living with the physical and emotional experience of preventable medical harm who has no other choice than to trust a physician and the health care system. The patient is unable to formally diagnosis his or her own illness or to prescribe treatments; the patient must enter into the health care system for these needs. The patient has reasonable expectations that they will be taken care of with appropriate timing, action, effective communication, and without excessive worry about preventable harm:

There is frustration, there is guilt; guilt as a mother because that is your child and you're supposed to protect them at all costs, and you failed ultimately. We were talking about a sort of the betrayal that you feel from within your medical community. It's just another thing when people who are medically trained have to work through, because you feel this great sense of betrayal from your community, from your peers and your colleagues.

Through this exploration into trust and expectations from the perspective of the person living with preventable medical error, it appears these human conditions played a significant role within the patient–HCP experience. Trust in the health care system was assumed by the patient through written or spoken guarantees of socially constructed expectations of care. Regardless of what and how trust is offered, it remains something that is experienced and conditional on its perceived presence or absence. Appropriately, trust is not something that can be applied as a procedure or through a set of instructions, in the same way that one cannot apply love or fear. However desirable it may be, these modes of being are more often reactions about or to something rather than attitudes adopted to achieve a purposeful, calculated outcome (Hovey, 2006). Trusting in another who meets expectations means reducing the potential for being disappointed, and for mistrust, which are conditions that can affect the patient and family member negatively.

Loss of Voice: The Need to Recover Patient-Centeredness

Giving patients permission to challenge and perhaps a phrase, a key trigger phrase that we can agree

on as health care providers and patients is a signal that we need to pay attention to what we're doing because we may be able to prevent a bad thing from happening if we pay attention in this scenario.

The third finding invited conversation about patient-centered care, what it meant for the patient, and what it might have looked like from the patient perspective. Ishikawa et al. (2005) suggested that patients are more likely to perceive their interactions with their physician as patient-centered when they have an opportunity to engage directly in the medical dialogue. This finding is supported by the following quote from one of the HCP participants:

I think one big piece is just allowing the patients and their family members to feel empowered with their ability to change things. Empower patients to know that what they're feeling, what they're seeing, and the knowledge that they have is important for us to be able to provide better care. And they're the only ones that can really give us that information.

A minimal amount of "talk time" (Ishikawa et al., 2005, p. 906) for patients should be safeguarded, even in a short visit. One health care provider participant spoke to bringing back the knowledge and experience to her health care practice:

I bring knowledge back to my floor, knowledge to help my staff members be able to function better when issues arise. I think about how to go and talk to patients and family members who are having issues of one nature or another, whether it be safety or something else. Just to be able to communicate with them and allow them to show their emotion and get out that piece. Because often times they're not given that opportunity.

Despite the benefits of a truly patient-centered model whereby the patient's and family's voice is honored, the following comment by one of the participants illustrated the barriers to patient involvement in their own care:

They [physicians] can be very territorial, no offense to them, when it comes to their knowledge in dealing with the patients. But I had to let them know that it was okay to let their guard down, that it was okay to include me, that I was not going to usurp their authority.

The shared voice of health care necessitates that at all times, all perspectives are being heard, acknowledged, and valued. It is not enough to know intellectually that hearing the patient's voice is important. One's perspective

needs to be transformed to understand what it means to listen, to believe, and to be willing and open to learn from the patient or family member. This kind of transformation is not one that can be achieved or completely realized through reading about it, or participating in simulated activities, or with actors as patients. It requires a significant disruption to one's perception about the other, and might only be enabled through meaningful interaction with the other (Levinas, 1996) when the other is a person or family member who has experienced preventable medical harm.

Patient-centeredness means to listen, to be present, and to promote mutual understanding within health care. The kind of understanding being forwarded here is an authentic one that is receptive to but not overcome by emotion. This approach cannot be fully constituted through the application of a method of effective communication, but is considered, always, with and from the humanistic and tacit relationship of the health care provider with the patient and family member.

Discussion

I'm putting a face on medical error. I'm able to touch the hearts of all those doctors and all those nurses and all those PharmDs [doctors of pharmacy] who want to do the right thing but occasionally need to be reminded that there is a face associated with every one of those adverse events.

The findings and metafinding we present in this article demonstrate the complexity of human interactions involved in the experience of preventable medical harm. Communication within health care—among health care providers, patients, and family members—can be explained theoretically through multiple perspectives such as convergence, concordance, and encultured interprofessional practice (Bleakley & Bligh, 2008; Cooper et al., 2003). In spite of this, listening, affective communication, and trust are constituents of a patient-centered approach that are frequently written about but not well understood from either an interpretation or application of a relational perspective:

Interpretation is not something pedagogical for us either; it is the act of understanding itself, which is realized—not just for the one whom is interpreting but also for the interpreter himself—in the explicitness of verbal interpretation. Thanks to the verbal nature of all interpretation, every interpretation includes the possibility of a relationship with others. (Gadamer, 1989, p. 397)

In practice, the patients and family members require someone who will listen and interact with a humanistic

and medically trained ear; one made possible within a (person-) patient-centered care model (O'Brien & O'Brien, 2002). An expression of person-centeredness exists when the HCP is responsive to the relational and communicative needs of the patient and family member, even if only engaged for a few minutes of time. The message from these research participants is not only about why someone listened or did not listen, but rather how patient-centered care was enhanced through attentive listening. What is called for is transformative listening (McWilliam, 2007), which means to bring the transactional method to life through interpretation, understanding, and emotion (Gadamer, 1996; Speraw, 2009). When working with vulnerable others we always need to have a sense of what they are experiencing, to remember what it feels like to be vulnerable, desperate, and overwhelmed. Here is where the art of medicine and hermeneutics need to reconnect to form a bond through the act of interpretation toward understanding.

“Certain flaws in modern medicine arise from its refusal of a hermeneutical self-understanding. In seeking to escape all interpretive subjectivity, medicine has threatened to expunge its primary subject—the living, breathing, experiencing patient” (Leder, 1990, p. 9). Patient-centered approaches will be disappointing if health care providers rigorously apply a procedure without sufficient respect for the context of the relationships and concordance necessary to flourish. When such an abstraction leads people to view patient-centeredness as a tool, poor results will generate efforts away from the relational aspects of patient safety toward amendment and validation of the tool. Instead of understanding and strengthening personal relationships when difficulty comes, people “doctor” with this technique. Consequently, misunderstandings about context translate patient-centered approaches from a useful method back to a set of soft skills (O'Brien & O'Brien, 2002).

We contend that patient-centered care is more than merely following a series of steps or a checklist of actions. Authentic patient-centeredness embraces the concept of “nothing about me, without me.” This slogan originated from the disability movement in South Africa (Leff, Campbell, Gagne, & Woocher, 1997, p. 489), and captures the essence of person- or patient-centeredness as a mode of involvement that is holistic and symmetrical. It has been used as well by Berwick as a way forward toward promoting patient-centered care (Davis et al., 2005). In fact, in terms of patient-centered care, the disability movement can contribute significantly to the understanding of how to implement patient-centered planning through the person-centered planning model (Holburn & Vietze, 2002; O'Brien & O'Brien, 2002). From a patient-centered perspective, the need for patients to become partners in their own health care requires self-determination and

empowerment. These are not concepts that can be merely adopted with an encultured professional group such as health care providers. Rather, they must be achieved through negotiation.

Implications for Future Research and Education

Reading these transcripts was difficult and draining. It felt like the end of a long journey in some way. I was moved and angered. I found myself thinking that all caregivers should experience the patient side of the experience in a hospital because it would make us all more humble, more generous, and more patient. Perhaps even more careful. (Researcher/participant)

Patient-centeredness is typically framed as a set of values and virtues learned from physicians as role models, and reinforced through structured educational input from medical educators. As medical students progress through their education, they have been shown to lose faith generally in the value of a socially aware approach to medicine that includes sensitivity to patients' life contexts, with male students showing much greater attitudinal erosion in this area than female students (Woloschuk, Harasym, & Temple, 2004). In the current educational and health care context, patient-centeredness is then, paradoxically, not learned from patients.

As Bleakley and Bligh (2008) discussed, medical education can be reconfigured toward a patient-centered care approach by engaging students in opportunities to learn from the patient as educator. Simulation and actors are often used in educational contexts to help HCPs become proficient in their communication with patients through demonstration, practice, and feedback. These experiences offer an opportunity for HCPs to transition their skills from feeling uncomfortable toward a sense of being present during the delivery of bad news, during the negotiation of treatment protocols, or providing disclosure of preventable medical harm to a patient/family member. However, at the end of the day, everyone knows these are simulated encounters and that the patients are actors. In a patient-centered model of planning, communication and learning with and from the patient requires engagement, an invitation for participation, and the opportunity for transformative learning (Mezirow, 1991).

The patient's voice needs to be lifted from its position of being perceived within health care as weak or silent. This article is an example of how the voice of the patient and family can be brought to the forefront to provide a way forward to secure and honor the role of the patient within patient-centered care for enhanced patient safety.

Patient-centeredness does not have to be difficult, and can be extremely powerful to aid in the recovery process: “[What] the apology meant . . . in one sense was very short. It meant so much. I was amazed at how my feelings could change.” Future research needs to be conducted that is patient-centered in context while bringing together health care practitioners to work collaboratively in creating a negotiated model and philosophy for enhanced patient-centered care. This is becoming a reality in the work of organizations like CAPS, to advocate with patients and family members for individual and collective patient-centered empowerment and negotiation with health care providers. Our hope is that this focus will be taken up by other organizations, and that further research will continue and extend the work done within this project.

Conclusion

Loss is a cavernous, empty place, filled with pain and longing for something that can’t be restored. It defines you in particular ways that nothing else does. You begin to know the journey, dreaded and unannounced, sometimes too well, the sickening sense of being abandoned, the dread when you remember after you have briefly forgotten, the sense of something missing that never really leaves, and the sadness, and the waste of someone’s life un-lived. (Researcher/participant)

The participant quoted above provided a poignant reminder that the result of preventable medical harm has long-lasting consequences and multiple losses. An emerging evidence base can be found in current literature regarding the patient–health care provider relationship, and the role communication plays in achieving enhanced patient safety (Baker et al., 2004; Bleakley & Bligh 2008; Ishikawa et al., 2005). In spite of this, the availability of theoretical knowledge does not necessarily translate into knowledge that is accessible or translatable into practice. We believe the overarching theoretical consideration that enables effective communication might be found in person-centered planning. O’Brien and O’Brien (2002) contended, “Person-centered planning begins when people decide to listen carefully and in ways that can strengthen the voice of people who have been or are at risk of being silenced” (p. 8). Consider that

Person-centered planning is both a philosophy and a set of related activities that leads to simultaneous multilevel change. From its beginnings, person-centered work has been a complex, interactive, dynamic, long-term process of personal, organizational, and social change—a process that can never

be reduced to or measured by its smallest parts. (Mount, 2002, as cited by Holburn & Vietze, 2002, p. xxi)

Although both simplistic and complex in description, person-centeredness requires the health care provider to be open to the integration and interpretation of multiple forms of available evidence received from empirical research and also from the patient and family member. In other words, successful translation and transfer of medical knowledge is also dependent on humanistic and tacit factors that make the knowledge meaningful and personally relevant. We contend that discussions about patient-centeredness need to be inclusive of the patient. We argue that it is important and valuable to consider not only the transactional aspects of patient safety (systems, protocols, strategies, and so forth), but also the relational aspects of patient-centered care that give it purchase and meaning within health care.

Hermeneutics, through the process of interpretation toward understanding, is accomplished through conversations about a common topic, a person, or a thing. During such a conversation, the intention is to reduce the distanced objective discourse and encourage conversation even if it becomes difficult and uneasy. In doing so we honor the conversation and what the other has to say to us, and offer a person-centered interaction that might become transformative with the possibility of learning with and from the other. Hermeneutic inquiry has the potential to uncover meanings and intentions that are, in a sense, hidden in the text; where researchers expand their understandings of text to not only include written accounts of experiences, but also human actions, interactions, behaviors, and decisions that are made:

The method of understanding will be concerned equally with what is common, by comparison, and what is unique by intuition; it will be both comparative and divinatory. But in both respects it remains “art,” because it cannot be turned into a mechanical application of rules. The divinatory remains indispensable. (Gadamer, 1989, p. 190)

Through the explication of multiple perspectives, hermeneutical inquiry creates a different or new way of understanding a topic rather than the accepted empirical normative definition of understanding. It is from this perspective that patient-centered care can be understood holistically and used to enhance patient safety. This will be challenging and complex work. If situated appropriately, person-centered planning could provide an inclusive, philosophically based approach to engage the patient/consumer and family member for enhanced patient safety.

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References

- Abma, T. A., Nierse, C. J., & Widdershoven, G. A. M. (2009). Patients as partners in responsive research: Methodological notions for collaborations in mixed research teams. *Qualitative Health Research, 19*, 401-415. doi:10.1177/1049732309331869
- Baker, G. R., Norton, P. G., Flintoft, V., Blais, R., Brown, A., & Cox, J. (2004). The Canadian adverse events study: The incidence of adverse events among hospital patients in Canada. *Canadian Medical Association Journal, 170*(11), 1678-1686. doi:10.1503/cmaj.1040498
- Bergeson, S. C., & Dean, J. D. (2006). A systems approach to patient-centered care. *Journal of the American Medical Association, 296*(23), 2848-2851. doi:10.1001/jama.296.23.2848
- Binding, L. L., & Tapp, D. M. (2008). Human understanding in dialogue: Gadamer's recovery of the genuine. *Nursing Philosophy, 9*(2), 121-130. doi:10.1111/j.1466-769X.2007.00338.x
- Bleakley, A., & Bligh, J. (2008). Students learning from patients: Let's get real in medical education. *Advances in Health Science Education, 13*(1): 89-107. doi:10.1007/s10459-006-9028-0
- Consumers Advancing Patient Safety. (2008). *The Chicago patient safety workshop proceedings final report*. Retrieved from <http://www.patientsafety.org/>
- Cooper, L. A., Roter, D. L., Johnson, R. L., Ford, D. E., Steinwachs, D. M., & Powe, N. R. (2003). Patient-centered communication, ratings of care, and concordance of patient and physician race. *Annals of Internal Medicine 139*(11), 907-915. Retrieved from <http://www.annals.org/>
- Davis, K., Schoenbaum, S. C., & Audet, A. M. (2005). A 2020 vision of patient-centered primary care. *Journal of General Internal Medicine, 20*(10), 953-957. doi:10.1111/j.1525-1497.2005.0178_2.x
- Entwistle, V. A. (2007). Differing perspectives on patient involvement in patient safety. *Quality and Safety in Health Care, 16*(2), 82-83. doi:10.1136/qshc.2006.020362
- Gadamer, H. G. (1989). *Truth and method* (2nd ed.). (J. Weinsheimer & D. G. Marshal, Trans.). New York: Continuum. (Original work published 1975)
- Gadamer, H. G. (1996). *The enigma of health: The art of healing in a scientific age*. (J. Gaiger & N. Walker, Trans.). Stanford, CT: Stanford University Press.
- Holburn, S., & Vietze, P. M. (Eds.) (2002). *Person-centered planning: Research, practice, and future directions*. Baltimore, MD: Paul H. Brookes.
- Hovey, R. B. (2006). *What does it mean to live with osteoporosis?* (Doctoral dissertation). Retrieved from Proquest Dissertations & Theses (AAT NR25705).
- Hovey, R. B., Morck, A., Nettleton, S., Robin, S., Bullis, D., Findlay, A., & Massfeller, H. (2010). Partners in our care: Patient safety from a patient perspective. *Journal of Quality and Safety in Health Care, 19*, e59. doi:10.1136/qshc.2008.030908
- Hovey, R. B., & Paul, J. (2007). Healing, the patient narrative-story and the medical practitioner: A relationship to enhance care for the chronically ill patient. *International Journal of Qualitative Methods, 6*(4), 53-65.
- Institute of Medicine, & Committee on Quality of Health Care in America. (2000). In L. T. Kohn, J. M., Corrigan, & M. S. Donaldson (Eds.), *To err is human: Building a safer health system*. Washington, DC: Institute of Medicine National Academy Press.
- Ishikawa, H., Hashimoto, H., Roter, D. L., Yamazaki, Y., Takayama, T., & Yano, E. (2005). Patient contribution to the medical dialogue and perceived patient-centeredness: An observational study in Japanese geriatric consultations. *Journal of General Internal Medicine, 20*(10): 906-910. doi:10.1111/j.1525-1497.2005.0200.x
- Leape, L. L. (2009). Errors in medicine. *Clinica Chimica Acta, 404*(1), 2-5. doi:10.1016/j.cca.2009.03.020
- Leder, D. (1990). Clinical interpretation: The hermeneutics of medicine. *Theoretical Medicine and Bioethics, 11*(1), 9-24. doi:10.1007/BF00489234
- Leff, H. S., Campbell, J., Gagne, C., & Woocher, L. S. (1997). Evaluating peer providers. In C. T. Mowbray, D. R. Moxley, C. A. Jasper, & L. L. Howell (Eds.), *Consumers as providers in psychiatric rehabilitation* (pp. 488-501). Columbia, MD: IAPSR Press.
- Levin, D. M. (1989). *The listening self: Personal growth, social change, and the closure of metaphysics*. London: Routledge.
- Levinas, E., (1996). *Basic philosophical writings* (A. T. Peperzak, S. Critchley, & R. Bernasconi, Trans. & Eds.). Bloomington, IN: Indiana University Press.
- Longtin, Y., Sax, H., Leape, L. L., Sheridan, S. E., Donaldson, L., & Pittet, D. (2010). Patient participation: Current knowledge and applicability to patient safety. *Mayo Clinic Proceedings, 85*(1), 53-62. doi:10.4065/mcp.2009.0248
- Lyons, M. (2007). Should patients have a role in patient safety? A safety engineering view. *Quality and Safety in Health Care, 16*(2), 140-142. doi:10.1136/qshc.2006.018861
- McWilliam, C. (2007). Foundations of continuing education at the cutting edge: Promoting transformative knowledge translation. *Journal of Continuing Education in the Health Professions, 27*(2), 72-79. doi:10.1002/chp.102

- Merriam, S. B., Caffarella, R. S., Baumgartner, L. M. (2002). *Learning in adulthood: A comprehensive guide* (3rd ed.). San Francisco: John Wiley and Sons.
- Mezirow, J. (1991). *Transformative dimensions of adult learning*. San Francisco: Jossey-Bass.
- Monrouxe, L. V., Rees, C. E., & Bradley, P. (2009). The construction of patients' involvement in hospital bedside teaching encounters. *Qualitative Health Research, 19*, 918-930. doi:10.1177/1049732309338583
- Moules, N. J. (2009). Therapeutic letters in nursing: Examining the character and influence of the written word in clinical work with families experiencing illness. *Journal of Family Nursing, 15*(1), 31-49. doi:10.1177/1074840709331639
- O'Brien, J., & O'Brien, L. (2002). *A little book about person-centered planning*. Toronto, Canada: Inclusion Press.
- Schwappach, D. L. B. (2010). Engaging patients as vigilant partners in safety. *Medical Care Research and Review, 67*(2), 119-148. doi:10.1177/1077558709342254
- Sepucha, K. R., Fowler, F. J., & Mulley, A. G. (2004). Policy support for patient-centered care: The need for measurable improvements in decision quality. *Health Affairs, 23*(Suppl. Web Exclusives), 54-62. doi:10.1377/hlthaff.var.54
- Soanes, C. (Ed.). (2000). *Oxford dictionary of current English* (3rd ed.). Oxford, UK: Oxford University Press.
- Speraw, S. (2009). "Talk to me—I'm human": The story of a girl, her personhood, and the failures of health care. *Qualitative Health Research, 19*, 732-743. doi:10.1177/104973209334517
- Street, R. L., O'Malley, K. J. O., Cooper, L. A., & Haidet, P. (2008). Understanding concordance in patient-physician relationships: Personal and ethnic dimensions of shared identity. *Annals of Family Medicine, 6*(3), 198-205. doi:10.1370/afm.821
- Vincent, C. A., & Coulter, A. (2002). Patient safety: What about the patient? *Quality and Safety in Health Care, 11*(1), 76-80. doi:10.1136/qhc.11.1.76
- Woloschuk, W., Harasym, P. H., & Temple, W. (2004). Attitude change during medical school: A cohort study. *Medical Education, 38*(5), 522-534. doi:10.1046/j.1365-2929.2004.01820.x

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