Living with chronic illness: A phenomenological study of the health effects of the patient-provider relationship

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Abstract

Purpose: To understand the patient–healthcare provider (HCP) relationship from the lived experience of women with chronic disease and determine how this relationship affects women’s health.

Data sources: Narrative accounts of 25 women’s relationships with HCPs in repeated group and individual interviews were audio-taped and transcribed verbatim. Interpretive phenomenology was used to explore the data using three interconnected modes of paradigm cases, exemplars, and themes.

Conclusions: Women with chronic disease believed their health was significantly affected by their relationships with HCPs. They experienced a greater sense of well-being and security in connected relationships and had more confidence and motivation to manage their illness.

Implications for practice: This research suggests that for women with chronic disease, relationships with HCPs that are connected, and characterized by partnership, and personableness result in the women feeling better in many dimensions. The context of today’s healthcare system often pushes the nurse practitioner (NP) to provide care more attuned to medical issues, leaving little time for the development of connected relationships. In spite of this pressure, NPs need to strive to develop relationships with patients that are intersubjective/connected.

Background

The patient–healthcare provider (HCP) relationship has long been considered an important element in the delivery of health care. Cultural and social changes, such as patient rights, informed consent, and women’s and gay rights, exert pressure on the system to be more responsive to patient concerns. Increased changes in healthcare delivery, especially with managed care, have resulted in doubt among patients of the once-sacrosanct authority of the HCP (McCloskey & Grace, 1997). Valuing women and women’s experience, feminist scholars have given recognition to the nurturing and caring involved in the traditional practices of women and to their importance in relationships beyond the mother/child dyad, including healthcare relationships (McCloskey & Grace; Noddings, 1984; Tronto, 1994). However, there are multiple competing concerns in the healthcare arena. Positivist traditions and the search for positive outcomes have led to a press for evidence-based practice. Economic pressure and the commodification of health care have made it difficult for HCPs to develop personal caring relationships with patients (Benner, 2001; Lagana, 2000).

The literature reveals a persistent concern with qualities or characteristics of the patient–HCP relationship that influences the patient, the clinician, the relationship itself, and the outcomes of care (Crites-Christoph, 1998; Langford, Bowsher, Maloney, & Lillis, 1997; Norbeck & Anderson, 1988; Pieranunzi, 1997; Spiegel, Stroud, & Fye, 1998; Strupp, 1993; Yarcheski, Scoloveno, & Mahon, 1994). More specifically, several studies have examined relationships between patients and nurse practitioners (NPs) demonstrating the qualities of the relationship that are important in the delivery of care (Covington, 2005; Donohue, 2003; Lawson, 2002; Williams & Jones, 2006). Technical skill and biomedical competence are frequently believed to be the primary determinants of quality care.
healthcare relationships and health outcomes. However, Balint (1957) pointed out almost a half century ago the importance of the provider’s capacity to attend not only to the patient’s symptoms but also to the patient’s concerns and expectations.

Hall, Roter, and Katz (1988) conducted a meta-analysis to determine the relationship between physician communication and patient outcomes. They concluded that information giving, positive talk, partnership building, as well as the length of the visit are predictors of patient compliance and satisfaction with care. In another meta-analysis of literature that evaluated the effectiveness of three classes of interventions on patient compliance with healthcare regimens, 133 studies conducted between 1977 and 1994 were examined (Roter et al., 1998). Five classes of compliance were identified that were measured by direct and indirect measures. Interventions included educational, behavioral, and affective programs. All intervention types produced significant effects for all the compliance indicators. No single intervention strategy was more effective than another; programs with more than one intervention were most effective. Most importantly, patients with chronic diseases, such as diabetes or cancer, benefited highly from the interventions. The researchers concluded that building rapport with the patient can have a significant influence on patient compliance with treatment protocols.

In a review of 21 randomized clinical trials that studied physician communication and patient outcomes, several significant findings were reported (Stewart, 1996). Physician information giving, partnership building, and emotional support led to improvements in several categories of patient outcomes, including emotional health, symptom resolution, physical functioning, quality of life assessments, and physiological measures of disease management. These three overviews demonstrate that characteristics of the relationship between HCPs and patients and features that improve their communication do matter in health care.

The literature is unambiguous in noting the importance of NPs in the delivery of primary care with positive health outcomes (Covington, 2005; Kinnersley et al., 2000; Kleinman, 2004; Venning, Durie, Roland, Roberts, & Leese, 2000). Patients expect NPs to be caring and to engage them with mutuality (Alexander, 2004; Donohue, 2003; Heller & Solomon, 2005). Even though NPs perceive that they provide service that is caring (Green, 2004; Kleinman, 2004), current demands of healthcare systems that reduce appointment time and place an emphasis on medical care (Alexander; Williams & Jones, 2006) make it increasingly difficult to deliver care that lives up to this ideal. As Lawson (2002) points out, particularly when patients who have chronic disease engage in behaviors detrimental to their health, NPs are less likely to involve them in negotiating plans for care.

In summary, there is a substantial body of empirical work that addresses how the encounter between the patient and the HCP affects patient health. In most of this research, an elemental or atomistic approach to the encounter has been taken. That is, the relationship and interaction have been broken down into its constituent parts, and researchers have attempted to identify elements that predict certain behaviors and responses and inhibit others. What has been learned is important. However, the elemental approach, by its very nature, blinds us to aspects of the relationship that may, in fact, be essential to understanding what makes it work, for example, the timing and pacing of the interaction, the feeling tone of the interaction, and the way in which the provider makes herself vulnerable to the risks that appear in the room when the patient is receiving a serious diagnosis or prognosis. The patients’ perspectives and voice are also largely missing from this literature.

This research addressed the patient–HCP relationship and how it works from the patient’s perspective. To date, no study has been found that attempted to understand the relationship from the patient’s perspective. Additionally, little effort has been given to the process of patient–HCP relating. The dialogical process of qualitative research makes it possible for the lived experience to be transformed into a textual expression that is reflexive reliving of the experience. These animated descriptions based on human actions and lived experience demonstrate patients’ meanings, concerns, and practices (Van Manen, 1990).

**Purpose**

The primary purpose of this research was to understand the patient–HCP relationship from the perspective of women with chronic disease. Our intent was to understand the meaning of the relationship for women and how they believed it affected their health. Specifically, we wanted to explore and articulate the full range of experiences women had with HCPs including relationships they experienced as comforting and helpful as well as those they found oppressive and troublesome. Women’s perceptions of how they believed their health was affected by the relationship were further explored.

**Conceptual framework**

Relational cultural theory is a theoretical approach that opens up ways of recognizing and talking about the experiences of patients in their relationships with HCPs. According to this model, the self is continuously...
developing in connection with others. "The movement of relating, of mutual initiative and responsiveness, is viewed as the ongoing central organizing dynamic of people's lives" (Jordan, 1997a, p. 343). According to this perspective, it is impossible to view oneself apart from or outside of relationships. The goal of development is not a separate, individuated self but rather the ability to participate in mutually empathic relationships, which foster the growth of all participants (Miller & Stiver, 1997). Relational confidence is the capacity to participate in a growing, moving, changing relationship. We seek to participate in connections that are meaningful and respectful. If successful, we have an increased sense of well-being, confidence, and vitality (Jordan, 1997b).

Relational cultural theory provided the framework and sensitizing concepts for our study of the health effects of the patient–provider relationship. Understanding the major concepts of the theory, empathy, mutuality, and empowerment provided the background against which the primary objective and the specific aims of the study were formulated.

Sample

Study participants were women between the ages of 35–55 who had a diagnosis of a chronic disease, spoke and wrote English, had no major mental illness, and could consent for themselves. No time limit was established for the length of diagnosis and participation, but all women in the study had been chronically ill for a period of years. Twenty-five women participated in the study, all but three were Caucasian. Two of the women were in their 30s, 5 in their 40s, and 18 in their 50s. Three of the women had asthma, 1 breast cancer, 1 stroke, 1 hepatitis C, 1 IgA nephropathy, and the remaining 18 had diabetes. Two of the women with diabetes had a second chronic disease, one cancer and the other multiple sclerosis. All but two of the women had some college education, and nine of them had graduate or professional education.

Method

The method for the study was interpretive phenomenology in the Heideggerian tradition, which holds that a person is self-interpreting and understands a situation directly according to the meaning it has for her (Levin, 1999). Accordingly, the researcher attempts to interpret what is always already understood, the taken for granted of everydayness. In this approach, it is believed that the nature of our everyday lived experience, the smooth functioning of everydayness, goes unnoticed or unarticulated and it is the work of interpretation to make explicit these aspects of human existence (Dreyfus, 1991).

In the process of interpreting, researchers must be attuned to everyday situations that they wish to articulate; this is influenced by the way the research is approached because it is believed that no objective stance is possible. Both researchers were mental health–psychiatric clinical specialists and had taught in university nursing programs extensively.

The University Committee on Human Research approved the study and written consents were obtained. All participants received $20.00 for each interview. Women were recruited through newspaper advertisement, flyers in private practitioner offices, a local healthcare center, support groups, and word of mouth. The interviews were conducted in private rooms at a local health center and hospital, in a private office, or in women's homes.

Data collection

Narrative accounts of positive, neutral, and problematic experiences and relationships with HCPs were elicited in repeated group and individual interviews. Open-ended information probes were used to initiate the interviews, to follow up on something said, or to fill in gaps in the narratives. All the interviews were audio-taped and transcribed verbatim, and transcriptions were checked for accuracy against the tapes. All the participants were first interviewed in one of the five interview groups that met two times for 1.5 h. These were followed by 11 individual interviews each lasting 1.5 h. Women were selected to participate in individual interviews if their narratives were particularly vibrant or if they seemed to have insufficient opportunity in the group to complete their narratives. Women described experiences with a variety of HCPs, including NPs, physicians, physical therapists, occupational therapists, music therapists, and psychotherapists. Field notes of impressions were recorded after each interview.

Data analysis

Analysis of the data involved multiple readings of the printed transcripts that began with the first group interview. The narratives of one respondent were contrasted to other respondent narratives. We examined both the whole and parts of the whole, returning repeatedly to the original text to uncover/discover meaning. We were looking for stories of both smooth functioning and also stories of breakdown, experiences that had not gone smoothly. Interpretive phenomenology includes the use of three interconnected modes of engaging the text: paradigm cases, exemplars, and themes. All three of these methods were used in this research. Paradigm cases and exemplars were identified. Paradigm cases are strong examples
of particular ways of being, of concerns, or of practices (Benner, 1994). They illustrate dramatically the meaning of a person’s lived experience. Exemplars are smaller units of analysis and reflect recurring themes. Finally, cross-narrative comparisons were made to determine whether or not common meanings could be identified that showed up in more than one case. Thematic analysis works out the themes of the text. This occurred simultaneously with the reading, rereading, and discovery of paradigm cases and exemplars. As paradigm cases and exemplars were compared to one another, broader understanding or themes were derived. Going through the text slowly, again and again, enabled identification of common strands of meaning throughout, from one case to another. When it was clear that the same theme showed up again and again, it became a part of the interpretive findings.

Findings

Relational continuum—Connection

Narratives suggested that a link with the provider that opened up communication and closeness was essential to every encounter. Yet, women in the study experienced extreme variations in the qualities of connectedness so that two poles, connection and disconnection, became apparent. The quality of connection was especially clear in the paradigm cases of partnership and personableness.

Partnership

In partnered relationships, the women in the study trusted and believed in the HCP so that in times of difficulty, they were able to rely on the HCP’s judgment. In this research, the terms “husband” and “coach” were used to describe the quality of relatedness some of the women experienced. They characterized a connected relationship as a “good” marriage and explained that they were better physically, emotionally, and spiritually as a result.

The case of Tillie was a paradigm for a connected relationship in which there was a partnership between her and the HCP. Tillie’s story presented the give-and-take in the working relationship they established where they enjoyed genuine, honest communication.

Tillie (age 41) was first diagnosed with diabetes at age 13 when she was taken to an emergency room in a disoriented state and met her current HCP. She said, “He saved my life” because emergency room staff had assumed that she was under the influence of illicit drugs until he arrived and ordered blood sugar levels to be drawn. Their 28-year relationship developed connection over time. She said,

It’s a combination of husband, coach and the other thing, partnership because Dr. L is always involved with me. He would say, “this isn’t quite working. I think you should do this, this and this.” I would say, “I really don’t think that will work” and I would explain why. And he would say, “Okay.”

In this example, Tillie described mutual respect. Both the HCP and the patient took responsibility, there was a give-and-take, and both were willing to listen to the other. They were able to be open and honest, say what they thought, and find a way to agree on the approach they would take. In another example, Tillie illustrated how this worked between her and her HCP.

My doctor said, “Well, you have this kind of, the dawn phenomenon. Get up at three and test your blood and let me know what it is.” And I said, “You want me to call YOU at three?” He gives me the stern look, “don’t you even think about it.” But when he tells me to do something I don’t want to do, I give him that uhhhhhhhh look and he goes, “I know.” So he knows he’s asking me to do somethingucky. “It won’t be for long. I need this information.” And so, he understands like, it’s a pain. But I understand its going to help me. So, there’s a give and take.

In this interchange, the daily impact of managing was transparent. Neither wanted to have to be up at 3:00 a.m. and they teased about this. The HCP acknowledged that sometimes what he asked of her he understood to be burdensome. His empathic attunement was important to her. She knew that he was making decisions based on what was best for her, and this contributed to her ability to do as he asked.

The story of Tillie going on the insulin pump illustrated the closeness and intimacy of their connection. What happened to her mattered to him and she knew this. She believed that he shared in her experience and that what she did had an impact on him. This is the quality of a “marriage” that Tillie and other women in the study talked about. She said,

He would say, “I really would like you to be on the insulin pump.” And say the reasons why. “What about this?” And I said, “No I don’t want to.” And he finally said, “I’m really confused about you. Why are you resisting this?” And I said, “You know that I faint when you give me a blood test. Don’t like needles.” He said, okay, “I understand that.”

There was between them a commitment to understand the concerns of the other and to negotiate the progress of treatment in a manner that was mindful of these concerns. Out of respect for Tillie’s reluctance, the physician paced recommendations to her readiness. His willingness to wait and to puzzle with her about her reluctance to try the pump enabled her self-exploration. One can imagine that a more aggressive treatment approach may instead have invited from Tillie resistance, retrenchment, and postponement.
Instead, Tillie felt respected, particularly when her provider stopped bringing up the pump as an alternative. And then my cousin, who went on the pump a few months before I did, said, "They have one of the Mini-Med pumps." And I called Mini-Med immediately and said, "Send the information on this thing." And when I told my doctor, I said, "Oh by the way, I called Mini-Med and let's talk about the pump." And he almost fell over. And I said, "Oh I'm sorry. I should have warned you."

From the narrative, it seems that the physician accepted Tillie's position on her diabetic management, and even though she did not want to do as he recommended, he continued to actively work with her to improve her health. His flexibility was key to how they worked together and, we might surmise, was key to her eventual willingness to take the leap.

And when I told him, the smile that came across his face was like, I mean like a shock and a smile. He was ecstatic! He, I mean, I think if I had said that he had won the lottery he would have been less excited than when I said I want to do this. When I got the (blood glucose) results that he had been dreaming that I would have I said, "Wow that's pretty good." And he said, "No. That's great!" And it was sort of like, yeeaahhh. And it was exciting for both of us. It wasn't like it was just like my victory. It was, we both shared in that dream. Sort of like getting the Gold Medal or something. It just was, it was a wonderful feeling.

From Tillie's perspective, the patience, encouragement, and support of the HCP were pivotal. His hope for better clinical management of her diabetes mattered to her as it paralleled her own hopes of better health. She believed that they were aligned in their desire for her to do better. When she succeeded, she believed that they shared in the success.

Having an HCP share the ups and downs of the chronic disease enabled Tillie not to feel alone. As she points out, she had several sources of help and support, but it was the support and caring of the HCP that mattered the most to her. He alone appreciated and understood the daily grind and threat of having a chronic disease. He had shared in moments of crisis and had helped her to survive them. His presence and help as she changed to the pump were essential to her. The results she was able to achieve, she believed, were the result of the efforts and hard work of both of them. These qualities of the relationship women in the study compared to a partnership or marriage were important in motivating Tillie and other women in the study.

The term marriage was an attempt by women in the study to capture the key qualities of their lived experience in which they shared with another person life and death struggles; emotional upheavals of fear, sadness, and joy; and finally the achievement of what had seemed impossible. The level of intimacy, while not what is usually considered when we think of a marriage, was significant enough for them to use the descriptive term as they described the relationship.

**Personableness**

Personableness was an important element that contributed to the strength and bonds of all relationships in this study. Women in the study expressed an ongoing need to be seen and recognized for whom they really were, and it was another qualitatively distinct aspect of connected relationships. Maintaining personableness was a dynamic process that enabled the women in the study to continuously represent their true experience within relationships as they arose. They did not feel a need to hold back, and they were able to discuss issues that were embarrassing or shameful. They felt comfortable asking questions, questioning advice, and disagreeing.

Meryl's narrative illustrates the quality of personableness. Meryl (age 55) was recovering from a cerebral vascular accident 6 years earlier. She had several HCPs who were part of her rehabilitation team whom she described as being "very real." In one narrative, she discussed her piano therapist whom she described as relating to her in a manner that illustrates this notion of personableness.

Well, she lives in a real cute bungalow. She has a great big music room that she added on. Two lovely grand pianos. And she has a nice sense of decorating. So she's always sitting in her chair. And I walk down through her garden which is lovely. ... the piano lesson is a half an hour. But I can't play for a half an hour. So we kind of, I'll play my piece and then we'll talk about her ill mother or my ill mother. Or her kids. Or my kids. And then she'll say, "Okay, let's try it again." And it's always better the second time. And she'll occasionally put her hand on my shoulder because in my attempt to make my fingers work, my shoulder goes up. And she'll just gently put her hand on my shoulder. And she's a very touchy, feely kind of woman. And she has this loud laugh. It's, a joyful laugh. And, she's just a wonderful person. So we talk about religion a lot. And we talk about rolling. Because she likes rolling and just whatever we're into. And when we're done, I feel like an equal and enjoy it and it's the one thing that I'm willing to do. Faithfully.

In this narrative, we saw that the HCP opened up to Meryl in a very inclusive way, she invited her into her own environment, her personal world. She did this not only by giving the lessons in her own home but also by giving personal information regarding her family, her beliefs, her values, and her unfolding experiences. She revealed herself personally. The positive influence on Meryl and her health was significant. In summing up her experiences, Meryl added.
I think what I like in all of my health care providers is that they are willing to share, be open, to be authentic with me. I think about my psychotherapist she occasionally brings up the issue of sexuality after the stroke. And without talking about her sex life, she shares what it’s like to be a woman in her 50s and dealing with some of the same things. And with my piano teacher, she’s also professional, but she will say something real. She told me that she had had an affair when she was in her 30s and she had left her husband and left her children, I mean she seemed so straight laced now. Can’t imagine that she ever would have had that type of a life, but just the fact that she was willing to share that with me, to laugh about it you know, now, she’s gone through it. She’s still married. And then my occupational therapist, just to share her resentment towards her husband is an example, of her being authentic with me. Think I crave that. I think we all crave that connection. I think this woman is sharing, all of these people are sharing a huge piece of their life. And how honored I feel that they’re willing to do that even though I’m paying them. They wouldn’t have to you know. They wouldn’t have to give of themselves, but they do.

Meryl expressed what others in the study have said: that connected relationships involved a degree of open, real communication from both the HCP and the patient wherein they were able to experience each other as persons who had everyday struggles and concerns. In these relationships, the HCP was not the expert who was above question. On the contrary, when providers revealed their own struggles and real-life experiences, the patients felt more connected and often were moved by the stories. Self-disclosure, authentic relating, balanced the relationship in such a way that the women felt respected as persons rather than being treated as “patients” or passive recipients of care. The provider’s willingness to disclose signaled that the women were valued as persons of substance and capability. Such signals strengthened their capacity to live with their illness and disclose weakness and difficulty.

Relational continuum—Disconnection

Disconnection was apparent in several of the relationships women in the study experienced with their HCPs. In these relationships, HCPs were described by the women as being cold and distant, typically those in which the HCP maintained a professional/clinical manner. Disconnected relationships were characterized by what the women perceived to be disrespect, condescension, poor communication, and little information or teaching. In disconnected relationships, the women in the study experienced the HCP as being unapproachable and often defensive. At times, they believed they were put into a category of patient type, and the health care they received was based on that group rather than being individualized. They described their experience in these situations as being the result of a detached stance by the HCP whereby it was impossible for them to be known. Paradigm cases of power/control and clinical mismanagement helped to illustrate this pole of the relational continuum.

Power/control

The use of power and control was seen in HCP behavior in which collaboration and support were either not present or inadequate. As a result, the women who experienced this type of relationship experienced alienation, helplessness, hopelessness, oppression, paternalism, loss of a sense of control over their lives, and dependency (Gibson, 1991).

Jean’s narrative was a paradigm of the negative consequences of encountering an HCP who related in terms of power and control. Jean (age 53) had type 2 diabetes. The relationship was problematic from the beginning, a “struggle” to use her description. The patient characterized the HCP as being very brusque, aggressive, and withholding of information and explanations. Jean described the HCP as being “grumpy, anesthetized, turned off, uncaring, an android.” Jean asked to be assigned to another HCP but the constraints of the agency made that impossible. She told the story of an interaction she had with the HCP in which she asked why she had not been told that she needed to limit her protein intake to 40 g per day in order to prevent kidney disease. She said,

And then that’s when she said, that “Most people are Type II diabetics, that most of them don’t care about what they’re eating or what they’re doing or testing their blood. And most people are too stupid to know the information.”

This was not the first time the HCP had made disrespectful remarks to Jean. It was a regular occurrence but its impact was immediate and significant. She was overwhelmed by the lack of caring demonstrated by the provider and found it inexcusable. Jean worried about the effect that not having her questions answered and not receiving adequate teaching might have on her health. In another example, she provided insight into the impact of not having the HCP respond to her needs and concerns regarding the management of her disease. The incident concerned her request of the HCP for an insulin pump.

Well, I was kind of caught between a rock and hard place. I wanted the pump, and so I was told I had to do these certain things. I had to get my blood sugars between this level and I had to do this for a couple of months. So I did that for a couple of months. And then I was told that, I didn’t need the pump. I only wanted it for convenience because my blood sugars were in
such great shape, what would I need the pump for? So it was kind of a power game. You know, because I kept pushing for it. You know, I kept asking when, when can I be eligible? When can I be eligible? When asked how this made her feel she responded, I did break down crying in front of her. You know, when I was told I was too good to have the pump. And she just said, well, I’ll see you next visit. And then left the room. That made me feel even worse. I cried all the way home.

In this narrative, the HCP acted with little regard for the patient and her concerns. She demonstrated a cold, detached manner as she used her power to control the situation. Her behavior and demeanor were disrespectful and cruel and diminished Jean and her concerns. Lacking empathy, her behavior was characteristic of the paternalism discussed by Henson (1997) in which care is similar to the style of strict fathers who intrusively impose values and choices. Jean felt helpless and hopeless and believed that the relationship with the HCP negatively affected her health.

At the time of the interview, Jean was considering whether or not to give up her health insurance altogether and manage her diabetes by herself. The quality of disconnection experienced by Jean was expressed by many women in the study. This relationship quality eliminated any possibility of collaboration between the women and their HCPs. The inappropriate use of power resulted in the women’s sense of alienation, oppression, and a loss of control over their lives. They were less likely to ask questions, reveal important information, or to follow through with recommended treatment.

**Clinical mismanagement**

The women in the study believed it was impossible to have a connected relationship with an HCP who did not manage their care competently. This was similar to research findings, which determined a link between clinical competence and interpersonal skills (Colliver, Swartz, Robbs, & Cohen, 1999). Women in the study entered HCP relationships assuming that the provider would be an excellent, knowledgeable clinician who stayed abreast of current practice standards.

Wanda described experiences with HCPs and the impact their mismanagement had on her health. Wanda (age 42) had numerous health problems, including obesity and hypertension. The interchange she described was with a new HCP to whom she had been assigned, the third in a short time, as a result of staffing changes. At the end of the first visit, the provider questioned why Wanda had an Accu-Check with her and then told her she was not a diabetic. Although she had not learned to use the Accu-Check and there had been no follow-up, Wanda had planned to ask for instructions during this visit with the new HCP. She explained that she did not know what to think. She wondered if the HCP had read her chart and worried about the consequences to her health and life if she was indeed diabetic. Wanda had a similar experience with a prior provider. She said.

The other HCP wanted to meet with me and she said, “Okay, your blood pressure is still a little high.” Then she said, “How’s your sugar?” And I go, “My sugar?” And she’s like, “Yes.” She said, “You’re diabetic.” I go, “Nooo.” She’s like, “Yeeees.” She said, “When you were diagnosed with the high blood pressure, didn’t Carol tell you?” I said, “No, she’s only been treating me for the blood pressure.” So she said, “No, you’re diabetic. And you have to do this.” And she ordered the monitor. And they delivered it. So now, the new HCP, because of course, both of the others are gone. She’s saying, “No, you’re not.”

Wanda was not sure that she could believe anything that she was told or if any information that she was given was accurate. She had worried that the diagnosis of hypertension might not be accurate because of the way it was measured and now she was more certain that she probably did not have hypertension.

See if it was the blood pressure, that’s the one that I thought they really are off on because the cuff, because my arms are hellacious. They use the regular cuff; it doesn’t give an accurate reading. I usually have to hold the cuff on because it wants to pop open and my arm feels like its bruising. It’s like bright red when they take it off. And she’s wanting to up my medication, so I’m like, “No.”

Wanda believed that she was in a system where no one cared about her. She did not believe that she could trust anything she was told by any HCP. This narrative illustrates what can happen when a patient who needs clear direction, follow-up, and support finds herself in an environment in which error results in the misdiagnosis or miscommunication about diabetes and perhaps hypertension. The patient did not monitor her blood sugar levels and received no follow-up for the diagnosed diabetes. She did not know whether or not she was a diabetic. She had been on medication for hypertension but doubted that she was hypertensive. She had severe anemia as a result of continuous vaginal bleeding but had not agreed to recommended surgery. She was frightened for her health and her life. As a result of incompetent and/or incomplete teaching and advice, Wanda did not have information she needed to make important health decisions. At times in the interview, she sounded angry and helpless and seemed immobilized.

Mismanagement of chronic healthcare problems is a serious issue. Women in the study who had been misdiagnosed or had gone undiagnosed for significant periods of time found it difficult to trust, not just the initial provider.
but subsequent HCPs from whom they received care. In addition, there seemed to be a contagion factor. Feeling more vulnerable, they were wary of any information they were given. In relationships with HCPs who demonstrated that they were not trustworthy, women in the study found themselves in double jeopardy. Not only did they receive poor and at times dangerous healthcare management, information, and advice, but also they experienced the fear of being alone with their health concerns.

**Discussion**

Articulated in the women’s narratives are the contrasting poles of the relational continuum of connection and disconnection. Connected relationships, characterized as being genuine and honest, increase reciprocal respect and trust. This finding is supported by Finfgeld-Connett (2006), Don'tje, Corser, Kreulen, and Teitelman (2004), Jordan (1997b), and Miller and Stiver (1997). Connected relationships set up the possibility for the HCP to believe in the patient and know that requests for care, attention, or time are based on the patient’s legitimate needs and concerns (Benner, 2001). Significance increases as HCPs try to understand women’s resistance to specific treatments and raises questions regarding current conceptions of patient compliance or adherence to planned care (Wuest, 1993).

Moreover, partnered relationships involve a level of intimacy in which women have a sense of equality, cooperation, negotiation, and shared decision making. In relational cultural theory, this is what Jordan (1997b) and Miller et al. (1999) refer to as mutuality, in that the patient and HCP are emotionally available to one another in a constantly changing process of receptivity and response.

Being connected in this way facilitates empathic attunement and compassion that is considerably different from technical, skilled empathy. In this study, women with chronic disease describe empathy that involves intersubjectivity described by Stolorow and Atwood (1992). It is also very similar to Halpern’s (2001) description of emotional reasoning. These authors describe a process that is both affective and cognitive, in that identification allows for a perceptual grasp of the other's experience, which is assimilated and responded to in such deep attunement that traditional boundaries and a separate sense of self are altered. It is this intersubjective experience that makes possible the personal and professional growth of both the HCP and the patient (Kleinman, 2004).

In addition, the personableness of the connection involves a degree of openness and exposure that enables both the HCP and the women to both reveal themselves and be seen and known for who they are. This is supported by Taylor’s (1991) discussion of the ethos of authenticity in which we are all called upon to live our lives being true to ourselves and not in imitation or performance of prescribed roles. Personableness is similar to what Covington (2005) describes as transcendent connectedness. This finding is significant as it is contrary to prescribed professional roles (Farber et al., 2000; Halpern, 2001). In adopting a “clinical gaze,” the HCP encounters the patient as essentially a collection of signs and symptoms (Benner, 2001; Toombs, 1993) rather than as a person.

**Implications**

This research suggests that for women with chronic disease, relationships that are connected, and that are characterized by partnership, and personableness result in the women being better off, as one of them said, “spiritually, mentally, and physically.” These results support what Alexander (2004), Green (2004), and Kleinman (2004) express as being important for NPs in the delivery of primary care. The context of today’s healthcare system often pushes the NP to provide care more attuned to medical issues, leaving little time for the development of connected relationships. In spite of this pressure, NPs need to strive to develop relationships with patients that are intersubjective/connected. As Kleinman points out, “Although NPs provide primary medical care, they define themselves as nurses who are, in the first instance, care—or—relationship-oriented, rather than disease—or—cure-oriented” (p. 268). This is particularly significant as we know that our patients expect care in which the NP is connected and present (Alexander; Donohue, 2003; Heller & Solomon, 2005).

NPs need to focus care that (a) is centered in the patient’s life and illness experiences including specific cultural needs (Benner, 2001; Frank, 1995; Toombs, 1993), (b) is attuned to the patient’s narrative of the illness/disease experience (Frank; Kleinman, 1988), (c) couples biomedical/clinical care with empathic attunement in which the NP is present authentically (Benner, 2001), and (d) uses emotional engagement and communication (Halpern, 2001). It is the relationship that helps to determine what experiences women will disclose to the NP. If the NP engages them with presence in connection, patients are more likely to disclose what matters to them.

**Conclusion**

Women with chronic disease believed their health was significantly affected by their relationships with HCPs. In connected relationships, the women experienced a sense of well-being in which they felt cared for and in which they were assured that they were not alone with their illness. Connectedness increased their sense of security and trust and reduced their levels of anxiety. Feeling more secure and trusting in the HCP enabled them to be themselves more completely in the relationship. They felt empowered,
more confident in their ability to manage their illness, and were more motivated to do the hard work their illness demanded both on a daily basis and during times of crisis. They were committed to the relationship with the HCP and engaged in self-exploration as a result.

Connected relationships also impacted the disease in more direct ways. The women reported that through connected relationships, they received more accurate diagnosis and treatments for their illness in a timely manner. They believed that the security and stability of the relationship enabled them to maintain continuity of care and increased their choices for care options and self-care activities. In general, the women described what they called better health care.

References


