Caring on the Ragged Edge: Nursing Persons Who Are Disenfranchised

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All of us at some level have a fear of the disenfranchised, whether it’s because we could be in that place or because there may be potential harm to us. But I seek to break that fear and see someone as a human. The more I work with her, the more I see her as human.

THE ABOVE words are from a nurse informant who has contributed to my search to understand the nature and meaning of caring on the ragged edge of society. What is it like to care for people when mainstream society often does not care? This study applies a hermeneutic phenomenological approach to bring to reflective awareness the unique nature of caring for disenfranchised and often outcast patients. To be disenfranchised is to be deprived of the rights and privileges of society. It is to be outcast, thrust beyond the walls of community. As nurse informants reveal, this practice involves fearless caring with clients who are separated and fearful. Often they are

The narratives of seven nurses who work with clients estranged from mainstream society are interpreted using a phenomenological strategy to reveal the metaphors of going around the wall of fear separating clients and community. Nurses explain four dimensions of meaning experienced through their fearless caring. Ten themes characterize Caring on the Edge; they are organized as three meta-themes: the Human Connection, the Community Connection, and Making Self-Care Possible. Key words: caring theory, disenfranchised, empowerment, marginalized, poverty, vulnerability

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blamed for their own problems. Such caring involves belief in the possibilities of marginalized people and taking a stance with them in difficult circumstances. Courage makes such hopefulness possible and hope makes courage possible.1

FOUNDATIONS FROM THE LITERATURE

Selected concepts form a foundation for exploring the results of this inquiry. Caring theory affirms the intrinsic value of all persons and identifies caring as a reciprocal process of learning from one another.2,3 By entering into the life world of the other, new possibilities for growth are recognized. Parse4 asserts the ever-present possibility of choice despite the estrangement, deprivation, and struggle of disenfranchised clients. People are inherently free to choose how they will live; possibility is ever-present in even the most desperate circumstances. Rafael5,6 has developed the concept of empowered caring, in which both nurse and client are active participants. Nurses practicing empowered caring have a heightened sense of interrelatedness and a strong sense of responsibility for engagement, in contrast to the long-standing nursing practice of avoidance and distancing.7 Empowered caring creates possibilities for choice and control. Smith8 synthesizes caring theory and Rogers’ Science of Unitary Human Beings to describe five constitutive meanings:

1. manifesting intentions that affirm human possibilities
2. appreciating the pattern of wholeness in another person
3. attuning to the rhythms of another
4. experiencing the infinite in the connection and sacredness of another
5. inviting creative emergence of the possibilities for another’s well-being

In a qualitative study of public health nurse family caregiving competencies, Zerwekh9 identified the central focus to be developing family capability to take charge of their own lives and make their own choices. Expert nurses working with vulnerable mothers believe in client capacity for choice. The groundwork for doing this is building trusting relationships and developing the capacity for self-help. In summary, caring nurtures possibility.

Swanson10 proclaims that nursing is informed caring for the well-being of others. This article concludes with an expansion of her five caring processes to incorporate dimensions vital to nurture human possibilities when caring on the ragged edge. Swanson emphasizes client capacity for choice while acknowledging that the range of possibilities is not equal for all persons.

METHOD

This inquiry was inspired by Ray’s phenomenological approach to study the lived experience of caring.11 The purpose is to learn anew the world of caring, not that previously encoded. First, the author’s presuppositions from practice, reflection, and study, as well as prior qualitative studies of expert nursing, were bracketed, setting them aside for the moment. Nursing leaders identified seven nurses who maintain compassionate and effective relationships with disenfranchised patient populations. These exemplary seven persisted in celebrating the wholeness and humanity of those on the ragged edge. They sustained interconnection with people from whom our society and most caregivers withdraw. Informed
consent for interviews was obtained through a process approved by the university’s Institutional Review Board. Interviews were recorded by extensive handwritten notes and concurrently recorded by audiotape. Three questions guided the interview:

1. What is it like to care for persons for whom mainstream often does not care?
2. Would you tell me about one or two experiences of caring for marginalized people that have special meaning for you?
3. What is the meaning of caring for the patient population you serve?

Following Ray’s strategy, interview dialogues proceeded using a clue- and cue-taking process after the initial question. Detailed descriptions were sought from the informants.

Answers were transcribed into text, and both the typed and handwritten notes were reviewed over and over to bring to awareness the nature of caring for disenfranchised people. Conscious dialogue with the text revealed themes, meta-themes, and metaphors that capture the essence of caring on the ragged edge. In this article, selected qualities of the nurses and their clients are captured and summarized. Then the nature of the client experience is explored. Finally, the meaning and essences of caring on the edge are presented.

THE SEVEN NURSES

Nurses’ ages ranged from 39 to 63 years old. They averaged 21 years of active practice as registered nurses; this ranged from 11 years of practice to 35 years. Three held associate degrees in nursing, two had bachelor’s degrees in nursing, and two had master’s degrees.

The nurse narrators describe their practice in community health, school nursing, critical care, mental health, health promotion, and oncology. Some of their clients live and die with devastating illnesses, including cancer and AIDS. Many are legal and illegal immigrants. Several are mentally ill and/or abusing drugs. Most are poor. All seven nurses speak vividly with profound conviction about their work. One views her clients as part of her extended family; her advocacy for them often gets her into “hot water.” Another describes her work building community among fearful psychiatric patients. A nurse who has practiced with the mentally ill and those living with AIDS proclaims the necessity of making authentic connections with clients. He faces his antithesis, “You who scare me.” The oncology nurse describes herself as a specialist with those who are angry and afraid. Another nurse informant describes her practice with people who have “been shut out of the human family” and considers all of us at risk of becoming marginalized because of illness. And finally, a nurse describing her work with impoverished Caribbean and Latin American immigrants explains her practice as Going around the Wall, which is a vivid metaphor for the work of caring on the ragged edge. The words of these nurses colorfully illustrate the following descriptions of their clients, the meaning of their practice, and the essential dimensions of their practice.

SEPARATION: CLIENTS BEHIND THE WALL

In the 25 nursing situations described in interviews, clients are characterized as separated from human community and as people
who are afraid and bring about personal fear in others. What we fear, we back away from. Separation and fear are pervasive themes describing the disenfranchised. A nurse explains, “They have been pushed out of the human family.” The client and the community, separated by a wall of fear, are illustrated in Fig 1. In another metaphor, Hilfiker imagines his homeless clients on an island separated from the mainland by deep waters; he practices what he terms “poverty medicine.” His narrative poignantly describes his clients’ despair. Not only are they abandoned by society, but also they have internalized their abandonment and now see themselves as unlovable and unable to influence the course of their lives. The wall separating them from the mainstream has devastating human consequences. An interviewed nurse uses yet another metaphor, that of a locked door, “The door is shut and you can’t get back in.” That all of us have the potential for being disfranchised is vividly illustrated by the tragedy of two nurse clients described by two different nurse informants.

She was a nurse who worked with us, born and raised in the local community, a single mother. She was diagnosed with lupus and unable to work. She could no longer be kept on the payroll, and had no income to afford insurance. No one came to visit her from her family. Eventually we had her in a geriatric chair, restrained, and incoherent. It was the nursing staff who brought her laundry home, fed her, and plaited her hair. Hospital administration seemed unable to acknowledge that this was happening to one of our nurses. We put her in the nurse’s station and she would let us know the phone was ringing because she would yell out. But one of the doctors happened to arrive on the floor and went crazy. Even though he had worked with this woman side by side, he wanted nothing to do with her. He didn’t want to see her. That experience with her as a coworker, as a woman, and as a...
potential patient myself made me realize what really happens. Her illness moved her further and further away from everyone. We all have the potential to be disenfranchised literally over night. The door is shut and you can’t get back in. Who will open the door?

He was a lieutenant commander, in the service for about 18 years. That’s all he knew. He was well respected as a nurse educator. It was 1986 and every 6 months we had what was called a command sweep. Everybody got tested for HIV. When you popped up positive, you were immediately withdrawn. You were shunned from community. When he came up positive, Naval Investigative Services set up a witch hunt. This was my colleague. He had given up certain aspects of his life in order to strive for his career. The embarrassment and humiliation in that man’s face is one thing that I will never forget. At a certain point he would break down with the fear of dying, dying alone; and the fear of having nothing: no insurance, no pension, no friends. His whole world was turned upside down. And I thought, “You are just one. How many?”

Many are the causes for such separation from human community. Certainly there is stigmatizing disease as has been described: physical and emotional illness. Perhaps they have had repeated alcoholic or drug-related relapses. Perhaps they are immigrants or without homes. Perhaps they are persistently poor with no sense of personal choice. Some proclaim defiantly to those who would help them, “You don’t know where I have walked.” Perhaps they are dirty and disheveled and talking to themselves. Perhaps they hear “voices tell them all day long that they are no good, ugly.” Whatever their clients’ circumstances, these nurses see themselves as fellow humans, vulnerable also.

**PERVASIVE FEAR**

Disenfranchised people are defined by their own fear and by the avoidance of others because they are afraid of their behavior or afraid of encountering their intense level of hardship and suffering. They make us weary; we develop “compassion fatigue.” The Wall develops as the community pulls away and builds barriers. One nurse explains that “what is unfamiliar makes us uncomfortable.” Another proclaims that unruly people are most afraid, “As soon as a person doesn’t follow the rules nobody wants to take care of him and those are the people who need the most care because they are really the most afraid.” She gives an example of a 5-year-old rural Mexican child refusing to follow the protocols needed for a bone marrow transplant. He could not get out of bed or leave the room. He threw things and would not do any of the traumatic treatments. Her response to his fear and agitation was to take him into her arms in a rocking chair and watch “The Little Mermaid” and rock and rock while administering his treatments.

Psychiatric patients may try to be frightening because they are afraid of other people as they perceive them.

They may act violent or be disturbing because they fear you. If they act up and talk loud, most people will back up. If you don’t feed into their behavior and act afraid, they see that doesn’t work. Then you reach them personally and
draw them out, “What’s really bothering you?”
A patient told me she was sometimes irritable
because when she looks at my face it would
change. It becomes colors and then the shape of
it changes. That must be horrific to try to trust
people, take medicine from people, and their
face is going from one kind of a face to another
kind of face.

Adolescents practicing dangerous drug
use and sexual behavior frighten us; they
take undue risks for immediate gratification
because they have no hope for their future.
The poverty brings the hopelessness and the
hopelessness causes these individuals to take
undue risk for immediate gratification. They’re so
poor and the men will come along and say, “I
am going to show you a better life, for the next
6 months move in with me and be my girlfriend
and I am going to support you with all these
material goods.” I say, “Five years from now
you finish high school, you go to the vocational
school, and you’ll be able to buy as many pairs
of shoes as you want once you’re working.” But
there is no way they can envision 5 years from
now. It’s poverty and hopelessness causing all
these risks: pregnancy and AIDS.

Sometimes the consequences of risk be-
havior and the dehumanized medical re-
sponse can be terrifying.
If they think the holocaust is over, it’s here. In
critical care, I had people that dreamed of coming
to this country and there they were dying in the
United States of America. Incontinent of urine
and feces, orange sputum dripping out of their
endotracheal tubes, and there wasn’t a person in
the place who could at least ask them in Creole,
“How are you?” They were Haitian refugees
dying of AIDS. If there was any group we would
want to say was disenfranchised, I’ve often
thought of them. Living their American dream,
dying in America.

Another nurse described his work with
the first US AIDS patients and with one
man in particular whose behavior was espe-
cially challenging and frightening.
They were the ones coming down with it first;
they were the ones who did all the wrong things
and made no apologies for it. Angelo had lived
his life very joyously. People loved him. That
was part of his ingratiating character. If you
stripped him down and took away the defenses,
there was nothing more than a shallow human
being who hadn’t received a lot of nurturing or
brain exercise. He was my antithesis. I thought,
“You are just too cool.” We had a wellness
program with exercise that made him more
healthy and then he went back to the same
situations that made him unhealthy: drugs,
indiscriminate sex, and unprotected partners. No
duty. Nonexistent sense of ethics. Angelo would
respond, “Yeah, there’s rules but they don’t affect
me.” So releasing my judgment was the hardest
thing I had to do with this population.

THE MEANING OF NURSING
THOSE WHO FRIGHTEN US
OR WHO ARE AFRAID

Interpretation of the nurses’ stories reveals
four dimensions of meaning. Nurses caring
on the ragged edge perceived the work as
rewarding because of the challenges over-
come, as a calling, as a family legacy, and as
an experience of common humanity.

Meaning as challenges overcome
This practice is described as gratifying,
rewarding, rejuvenating, invigorating, and
challenging. The nurses describe many
ways that they are nourished by the kind of
challenges involved. One nurse likens her
efforts to an athletic competition, “Fighting
for a way to help keeps me going. I won’t
stop until I can get whatever they need.”
The very reality that other people do not
care is the challenge that keeps the nurses
doing the work. Somebody has to “look out for the people.” A nurse concludes, “I am putting an end to letting them fall through the cracks.” Fearless caring is evident, “facing that fear with you, you who scared me because you are different.” After working with HIV patients practicing sex destructive of themselves and others, a nurse explains his reflections about working with the patients’ fears, “I am able to be a better human being as a result of facing my own prejudices and preconceived notions.” Challenges lead to personal growth.

**Meaning as calling**

Nurses used religious and nonreligious language to describe their internal conviction that “these are the people I am meant to help.” The most religious stance was from a nurse who proclaimed, “I have to answer to God. You never know who God is in disguise.” Another nurse described the work as “my sense of mission” and asks people of faith to view those infected with HIV as Jesus would view them. He would hope that at the end of his life he would be seen as “somebody who heard the call.” Says another highly experienced nurse, “I persist because, number one, I have a deep religious faith, and when I need strength I can go back and draw from my religion.” Another asserts that her work with the poor is “a call for my life—the driving force.” One nurse feels that she is a perfect match with her work, “I am a round peg in a round hole.” These nurses feel unique in the trusting relationships they develop and the strong effort they make on behalf of clients.

**Meaning as family legacy**

Four of the nurses spoke about their work with the disenfranchised as connected to their family histories. One had a brother who was terminally ill during her childhood and associates that legacy with her current calling. Another nurse explained her relationship with the poor who are mentally ill as “I come from my family.” She has a brother who is alcoholic and had an aunt who lived for many years in their extended family. The aunt used to scream out the windows and run up and down the stairs calling for the police. But she belonged to the neighborhood and therefore was accepted. Another nurse has a son who is schizophrenic, which has given her powerful insight into the suffering of her patients’ families. She recognizes the look on parents’ faces and talks to them about what to expect, “There will be good times and bad times. We have to reset what is realistic.”

Struggling to help the underdog is another family legacy.

I grew up in a poor family and my father always found a way to provide for us. My whole practice is a model from the way I was brought up. My parents were unbelievable people who were always for the underdog. They would give you the shirt off their back. They would do without everything so that we as children could have it. But also in the community my parents were right there when people needed help.

**Meaning as an experience of common humanity**

All nurses interviewed held strong convictions about common humanity with those that they were helping, and that every person has a right to sustenance and respect. Disenfranchised people are seen as fellow human beings, and the nurses assert that it is important that nurse and client see each other’s authentic humanity. In one nurse’s words, “This could be me. I value life. Every person deserves every opportunity.” “We are
all the same. Pain and anger fuel me. We need to be there.” Nursing presence represents humanity, perhaps as “the only caring person in hell.” Another nurse proclaims, “I’ve been on the other side of this bedpan.” Another colorful explanation is that authentic caring relationships only happen when “I open my raincoat to reveal my true self.” The underlying purpose of the work is proclaimed, “This work means life. To preserve a life and dignity. Dignity living.” Two nurses describe patients as family and, indeed, have members of their own family living with mental illness. Several nurses commented on the reciprocal experience of giving and receiving help and learning from clients, “They are giving back more than you’re giving.”

CARING FOR THOSE WHO FRIGHTEN US OR WHO ARE AFRAID

Reflection on the nurses’ narratives reveals that fearless caring with separated and often frightened clients has 10 themes that can be organized into 3 meta-themes: the Human Connection, the Community Connection, and Making Self-Care Possible (Fig 2). The nurse goes around the separating wall of fear. The power of fearless caring is illustrated in the nurses’ own words.

The Human Connection

This caring meta-theme is grounded in the nurses’ strongly held conviction that they share a common humanity with disenfranchised people. The Human Connection is characterized by actions that involve honoring their humanity, knowing the people, and sharing one’s own humanity.

Honoring their humanity

The nurses believe that they are consulted and trusted by clients because they treat them with respect. “I see their worth as people rather than treating them like a disease or symptom.” All the stories emphasize high regard for shared humanity. One nurse recalls honoring the humanity of a just-deceased penniless Mexican migrant worker who had no family. She agreed to not immediately call to arrange a county burial. After a few hours, his friends arrived with their finest cowboy boots and hats and pulled out rolls of bills to pay for a small service at a local funeral home. She was able to intercede with county officials. Although she could not do much for him when he was in critical condition, she could after his death. She proclaims, “It was a perfect ending for me. I think they saw that I was another human being that really cared about a respectful honorable way to acknowledge their friend’s death. This was the final act of caring.”

Knowing their humanity

Expert nurses practicing with marginalized people are able to discover what is going on in their clients’ lives. They know their past, they are familiar with their patterns, and they know how to ask questions to draw out their stories. A psychiatric nurse explains her insight into one woman’s refusal to take a shower, “I have found you have to sit down and ask them why, which was because she saw snakes in that shower.”

Another psychiatric nurse knows her patients’ patterns of drug abuse. She interceded when a patient, denying the seriousness of her problems, was not going to be admitted. “I know that when she overdoses on prescription pain pills, her mind starts to play
tricks on her, and she hallucinates and is delusional. She would go home, take more pills, and maybe really kill herself because her mother said that she was putting a knife to her chest.”

Sharing one’s own humanity

Nurses caring expertly for disenfranchised people do not hesitate to share their own worlds with clients and imagine themselves in the client’s position. “With this kind of population, like a new mother who has a drug-addicted child or a psychiatric patient or a homeless patient or an HIV patient, they have to perceive me as real. Is the interaction real?” The following words affirm that conviction.

Do what is natural to you without worrying about what anybody else is going to think. Cry with the patients. Allow yourself to express yourself. You can’t stay disconnected. The patients stay disconnected because they are embarrassed. They feel like totally nothing because they have to allow someone to help them with toileting. Let them know that, yeah, I’ve had experiences like this, too. It makes them feel more human.

The Community Connection

This meta-theme involves the overlapping dimensions of connecting the disconnected,
haunting the case, and mediating. The nurse links clients on one side of the wall with each other and with community services on the other side of the wall.

Connecting the disconnected

Going around the wall of fear, the nurses strengthen community among the disconnected as well as pulling in community resources on behalf of their clients. Caring requires going around the walls between estranged individuals and between estranged individuals and community. The following is a powerful anecdote about building community among hospitalized indigent psychiatric patients.

I tell them, “I expect you to help one another. I expect you to take care of one another.” They begin to realize that they are special, that they all need help. They kind of align and start doing positive things that they should be doing instead of a lot of negative bickering and fighting. I tell them that I expect more of them because they know what it’s like to hear things, to be afraid, to be alone, to be alienated, and for your family not to trust you. And I say, “Well, you know when you came in you were very manic too.” So you find one patient tagging behind another and telling us, “They are manic and give them something to do. They need something to do.” They need to reach out to one another.

All the nurses relate their aggressive efforts to get community services going on behalf of their clients. Examples range from mobilizing the fire department when housing is unsafe, to working with a grandmother to secure child custody when her daughter is abusing drugs, to accessing dentistry and affordable medications. One nurse describes a nursing role of “single handedly opening the door” to community services. Another colorfully describes her aggressive efforts to find help from the mainstream community for her disenfranchised clients.

We’ve been able to pull in all our resources. For one family we now have Family Builders, we have Medicaid for the children, and we got them food stamps. I visualize a giant wall and if I can tunnel through at any point, I just have to find a weak spot in that wall. I’m a little rat. Then behind the wall there is a maze with roadblocks.

At the same time, this nurse is intensely conscious of the importance of not making people dependent on all the resources she wants to mobilize for them. She describes a fiercely independent Appalachian woman who was “really adamant about wanting to be able to provide for her children in her own way. She wanted to be independent and was fighting to be responsible and not have all these people coming in and doing for her family that she’s worked so hard to hold together.” Pulling in resources must be expertly balanced with fostering personal power and self-sufficiency as the ultimate goal.

Haunting the case

Even when clients are connected to resource people and agencies, they may remain unheard and not get needed attention. One nurse describes herself as “haunting the case” in her unrelenting effort to get the mental health team to respond to client needs. Indeed, all the practice experts saw themselves as unique in persisting to advocate for disenfranchised individuals and

Pulling in resources must be expertly balanced with fostering personal power and self-sufficiency as the ultimate goal.
families. They are proud of their assertion when others give up.

*Meditating with the bureaucracy and making exceptions*

The nurses speak to team members and administrators on behalf of clients. One nurse describes herself as getting into “hot water” as she advocates for clients with viewpoints that counter those of administration or physicians or social services. Another advocate for the disenfranchised describes his primary role as mediator.

My place is to mediate. To do that, you’ve got to have people identify something about you. You’re the messenger. So if they see me as anywhere left or right of center, immediately their value judgment comes. So I try to stay very much in the center, very conservative. Stay within the system, yet clearly articulate the injustice.

Other nurses deal with the bureaucracy by quietly making exceptions to usual practice. When clients need “somebody to really close the door and sit down and look at them and talk to them,” one nurse informant promises to come at the end of the shift. She stays as late as patients need to talk. Another nurse visiting in the home describes making exceptions like giving people $5 for food or extra clothing if they are cold in winter.

*Making Self-Care Possible*

This meta-theme describes strengthening self-care by getting clients through emotionally, teaching them to understand themselves, helping them take control, and confronting fear at the community level.

*Getting them through emotionally*

These nurses specialize in working with people who are living in intense emotional turmoil, often alternating between anger and fear. A nurse explains her listening and consulting with a grandmother caring for four grandchildren with one daughter deceased and another diagnosed with chemical dependency.

The new mother was a cocaine addict and the newborn was with Grandma. Grandma had two sons, both incarcerated, and three daughters. One daughter had just died of AIDS and left her three little children. When the daughter was dying at Grandma’s house, HIV counselors had come in and talked down to the daughter and belittled the family. So the morning I first went she was at first very guarded about outsiders. But then she sat me down and she ranted and raved for maybe a full hour and a half, and then she broke down and wept. I validated her feelings as she went along, and this was my entry to her family.

Another describes her work with angry cancer patients in treatment as “getting them through the rough spots.” She describes one patient in particular.

She came to us with metastatic breast cancer, already throughout her back and hips. From what I can ascertain, she was a very angry person to start with. She didn’t trust anybody and didn’t want to do anything. If you sent her to another doctor, she would throw things and curse and have fits. Everybody would react by telling her, “If you don’t want to do the treatment, don’t do it.” I sat many, many hours with her to discover what it is she needed to know. And I finally realized that she needed everything explained, verbally and written down, and then re-explained. She had a very hard time understanding. If she didn’t understand, it angered her. Repeated explanations were hard on everyone working with her. She learned to bargain with me. I agreed to answer her questions as many times as she needed as long as she gave me a little leeway and time. Angry people have to have one center person to trust.
Teaching them to understand themselves

The nurses teach people to understand their own bodies and feelings in order to maximize their own health. They teach them to understand their disease and its management. One nurse says to clients, “You should know more about the illness than I do because you have to walk it, wash it, live it, breathe it.” If clients are not motivated by respect for others and their own body, an expert declares that he uses “selfishness and conceit” to motivate behavior change on their own behalf. The nurses teach clients to pay attention to their own condition.

Helping them take control

These nurses practice empowered caring by strengthening clients so that they can take charge, “always, always let them know they are in control.” Discovering what kind of control people need is essential. “Find out what they need to control and work out a plan.” The psychiatric nurses encourage clients to reject stereotypes, get back self-esteem, and look for a “niche in life.” One explains how to guide them to separate from the fearful hallucinatory voices and recognize their own capability.

Talk to them about the voices and let them know that the voices are part of the illness. Try to help them separate from the voices, which are not real, and get back to reality. And though all during the day the voices say you are bad, that’s just not real. But I see a good person. You help another person. I know what you can do.

The nurses help clients develop resilience to the stereotyping and rejection that can prevent a person from taking charge of his or her life. This involved “developing calluses” in the ostracized Navy nursing educator. The nurse sought to raise the educator’s sense of self-esteem and help him develop defenses when people were talking all around him about his being gay and having AIDS. The goal was to bring out his strengths and sense of control.

Confronting fear at the community level

Three of the nurses reflected on the need to break down the wall altogether so that caring becomes possible. One nurse was interviewed during a period when the United States was bombing Yugoslavia, intending to stop Serbian aggression against Kosovar Albanians. She fantasized about how she could demonstrate the profound suffering of her immigrant families on the national news, just as the suffering people of Yugoslavia had been portrayed on TV. She proclaims that “It’s like a war for them, comparable. If I could videotape it, ask somebody to walk with me for a day, and show that on the eight o’clock news.”

Another nurse had different fantasies, of an intensely supportive “cradle through high school” program. At-risk children would have “positive role models who could say there is a life beyond what they see at home. Let them be exposed 10, 12 hours a day to hope.” One nurse had actually taken action at the “big picture” or community level by developing an HIV educational program for the Roman Catholic diocese.

I speak to all the archdiocese schools. I speak to their PTAs. I speak to their principals and I speak with the message of compassion and understanding, using biblical references and papal encyclicals. I tell them, “I want you all to view HIV as Jesus viewed the Lepers, as he viewed Mary Magdalene, as he viewed anybody else who was cast out. He could do it and stand up for them in a time that was so frightening. I am asking you to let somebody else find fault, not you. Don’t judge.”
AN ELABORATION OF CARING FOR THE WELL-BEING OF OTHERS

Caring on the Edge is caring that courageously nurtures possibility in the face of separation and fear; nurses go around the wall of fear. Rather than developing yet one more theory, it is useful to consider how Swanson’s Caring for the Well-Being of Others can be expanded beyond perinatal context to capture the unique dimensions of caring for disenfranchised people. Her caring definition is reaffirmed, “a nurturing way of relating to a valued other toward whom one feels a personal sense of commitment and responsibility.”

Maintaining belief

Swanson asserts that caring is founded on a commitment to people and their capacity for change and growth. Many who live securely within the walls of social convention do not have any faith in those who are outside the walls, but it is affirmed by nurses who practice fearless caring. The meaning of Caring on the Edge includes the experience of being challenged through nurses’ engagement in caring when others see the same clients as overwhelming and frightening. The strong sense of purpose is sometimes connected to family history. Nurses caring on the edge are willing to acknowledge common vulnerability, “This could be me.” They grow and are empowered by their belief in clients’ possibilities.

Knowing and being with

Swanson describes “knowing” as striving to understand the reality of another person and “being with” as authentic presence that conveys “availability and the ability to endure with the other.” The Human Connection through Caring on the Edge is consistent with this caring process through honoring humanity, knowing humanity, and sharing humanity. These provide illustration and vivid detail regarding practice with clients whom this unique group of nurses chooses to be with and know.

Doing for

Swanson describes psychomotor nursing activities as well as interpersonal skills that include setting up programs or systems, “doing for the other what they would do for themselves if it were at all possible.” The Community Connection through Caring on the Edge significantly expands understanding of this caring process with extensive description of connecting, haunting, and mediating. Because the most fundamental underlying problem is estrangement for those on the edge, it is not surprising that a vital nursing activity is going around the wall of fear.

Enabling

This caring process fosters clients’ practice of self-care; the purpose is “to facilitate the other’s passage through difficult events and life transitions.” According to Swanson, enabling is practiced through coaching, informing, supporting, assisting the other to focus, helping the client to identify alternative choices, guiding him or her to think through issues, providing feedback, and affirming reality. Making self-care possible through Caring on the Edge expands
understanding of how this is done with marginalized clients by getting them through, teaching them to understand themselves, helping them take control, and confronting fear at the community level.

CONCLUSION

Questioning readers may assert that these nursing actions appear too individualized. They may say that nursing the disenfranchised is not "good enough" unless it focuses upstream and builds community capacity to challenge existing power structures. They might believe that those who "truly" care for the oppressed must guide them as a group to struggle against the sources of their oppression. Certainly this is the stance of critical theorists, whose position I have been advocating philosophically and politically for nearly 30 years.

However, we must honestly face the true circumstances of our own lives, those of our mainstream clients, and those of our marginalized clients. "More than a century after Marx, 80 years after women gained the vote in the United States, 55 years after the landmark Civil Rights Acts, and 30 years after the Stonewall rebellion for gay rights, no greater enigma exists in the social sciences than the participation of people in the very sociopolitical and cultural systems that oppress them." Fear and silencing keep us from "rising up" at all levels of organization and community; truth is rarely spoken to power for fear of repercussions. Although vulnerable people seldom rise up against those who oppress them, that certainly should not stop wise nurses from understanding the nature of power structures that deprive human beings from sustenance, rights, and dignity. As nurses, I believe we must challenge those oppressive structures through civic involvement at every personal and professional level. Likewise, by strengthening individual clients, we enhance the possibility of their acting as empowered communities.

We have much to learn from nurse colleagues courageously practicing on the ragged edge. We can validate, explain, teach, and replicate fearless caring with clients subject to innumerable societal injustices and fears. As the gap between rich and poor widens, a unique group of outstanding nurse colleagues persistently struggle to affirm humanity and build individual capacity of the most disadvantaged. They go around walls where others fear to tread in order to stand beside the fearful and the feared. They draw them into community where there is strength in numbers. They see human possibilities where others see no hope. Thus power is born when caring others value another and believe in human potential. Experiencing "concern and unconditional regard, the patient’s self-love and self-regard gradually increase. Self-regard begets a belief that one has the right to wish and act."}

REFERENCES