

Qualitative Cancer Genetic Counseling Research, Part II: Findings from a Exploratory Ethnographic Study in a Cancer Clinic

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This is a report of the preliminary findings of a brief exploratory ethnographic study in a cancer diagnosis and treatment clinic. The main research purpose was to explore the meaning of cancer and cancer treatment to patients themselves and to their relatives and close friends. The methods are described in detail in a paper focusing on the experiences of being a novice ethnographer (Peters et al. (2001) J Genet Counsel 10(2):133–150.). The preliminary results of this exploratory field-work indicate that the experience of attending a cancer treatment clinic for evaluation and/or treatment is a complex social, emotional as well as medical process for patients and families. Themes with relevance to genetic counselors that emerged from this early observation period included ideas about causes of cancer, the complex nature of families and kinship, coping and support, use of food, and healing. These initial findings have implications for genetic counseling practice and

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hopefully will stimulate more qualitative social and behavioral research in cancer genetic counseling.

KEY WORDS: hereditary cancer; genetic counseling; qualitative; behavioral; psychosocial; research; ethnography; anthropology; participant-observation; family.

INTRODUCTION

In order for cancer genetic counselors to fully grasp the meaning of cancer risk counseling and of the implications of being at increased genetic risk for developing cancer, it helps to appreciate what it means to have cancer from the "insider" perspective of those affected and their social support persons. Our genetic counseling clients may be exposed to images of cancer from a variety of sources including visual and print media, movies, television, literature, art, personal experience, family stories, and contact with affected relatives and friends. We suspect that the vivid public images of a prototypical patient in cancer treatment may become internalized. These internalized images may then drive the affective component of cancer genetic counseling for those at risk. Motivated by the wish to avoid replicating any memories of unpleasant cancer experiences of loved ones, people may either fervently seek or passionately avoid cancer genetic counseling, depending on whether they tend toward an information-seeking or information-avoiding coping style. To better understand some of the potential factors that may influence the cancer genetic counseling process, we decided to carry out ethnographic fieldwork in a cancer clinic at a large, urban medical center with the goal of gaining additional perspectives on the experience of cancer treatment for both patients and companions who accompany them to clinic.

This paper is a companion to a paper which discussed ethnography and study methods in more detail (Peters *et al.*, 2001). Therefore, this paper will only minimally cover methodology. The main focus will be on the results, grouped in terms of several themes as outlined in the Results section. After we have addressed our key findings and interpretations, we will then attempt in the Discussion to relate them to genetic counseling practice.

METHODS

This paper is based on data collected in an ethnographic study undertaken as a student assignment, with a primary reliance on participant-observation, carried out from February to June, 1999, in the cancer treatment clinic of the local Comprehensive Cancer Center. The methods are described in detail in a paper focusing more on the process and personal experience of conducting ethnographic research (Peters *et al.*, 2001). The study goals were to collect exploratory data about the experiences of patients and companions in a cancer clinic in order to better grasp

the implications of having cancer; to understand cancer treatment; and to generate questions, hypotheses, and ideas to guide clinical practice and future research.

The research was undertaken while serving as a hospital volunteer in a cancer clinic that provides initial evaluations, second-opinion consultation, treatment administration, and follow-up care as a "one-stop" cancer service.

Data derived from multiple sources, including learning the clinic layout and routines, observing where people went and what they did, overhearing conversations, informally chatting with clinic patients and companions, talking with another volunteer and the volunteer coordinator, talking with one or two of the oncology nurses, and consulting the literature. Assurances regarding ethical conduct of the research were addressed in a variety of ways as described in the companion paper.

Following ethnographic convention, our analysis occurred through an iterative process of collecting data alternating with analytic attempts to make sense of what had been seen and heard. The overarching goal of these activities is to capture the sense of what the people in the clinic are thinking, feeling, and experiencing. In ethnographic terms, this is called "grasping the emic perspective."

Analytic ideas emerged while making or reading notes, through regular systematic review of notes including review of instructor comments, in weekly class discussions with fellow graduate students, and through several lengthy conversations with co-authors. Validity in ethnographic work is generally established and supported by one's "paper trail," that is, the field and analytic notes (Hammersley and Atkinson, 1995) and through the process of self-reflection. This is a process by which the researcher considered the ways that the research findings were potentially influenced by the researcher's personal characteristics, in this case, those of a white, fifty-something, middle-income, highly educated, professionally employed, unmarried woman in relatively good health, as well as by her particular experiences as a cancer genetic counselor. More detailed personal statements from all three authors appear elsewhere (Peters *et al.*, 2001).

PRELIMINARY RESULTS AND ANALYSES

Cancer treatment takes place in a physical and social context of biomedicine which includes the complex social arrangements and cultural perspectives of physicians who diagnose and treat disease, of diverse personnel and institutions of care, and of industries such as pharmaceuticals, health insurance, and research (Hahn, 1995). Investigation of this broad range of social factors was beyond the scope of our small study; therefore, we narrowed the lens of our investigation to what could be directly observed in a particular cancer clinic. After several observation and analysis cycles, the emergent issues fell loosely into several overlapping, nonexclusive categories:

- Physical context
- Participants

- Genetic counseling and cancer risk
- Kinship and families
- Coping and support
- Food as a medium of social exchange and support
- Healing emotionally as well as physically

These themes are discussed here with the exception of physical context which is discussed in the companion paper (Peters *et al.*, 2001).

Participants in Cancer Treatment

The composition of the study group was adult male and female patients and their companions. Cancer Center literature indicated that each month, over 1,000 new and returning patients were seen in the clinic. Over the course of the ethnographic research, every effort was made to interact with as many clinic attendees as possible, usually several dozen per volunteer shift.

There was no demographic information available on participants in this study; therefore, all of the following are estimates based on unsystematic data collection from casual observation. The population was generally elderly (e.g., >60 years), as one would expect in a cancer clinic since cancer affects mainly older people. However, there were a significant number of middle-aged (e.g., 40s–50s) and young adult patients (<40 years) as well. The genders were fairly balanced between men and women. Racial distribution was largely Caucasian, with fewer African Americans than in the local urban population. Attire varied widely, with many of the patients wearing clothing that would be comfortable for their long treatment visits.

As a naïve volunteer and observer, the researcher assumed that every patient attending a “cancer clinic” would have cancer. This proved not to be the case. Some people were being seen because of suspicious signs or symptoms for a diagnostic consultation, second opinion, or diagnostic procedures such as bone marrow aspiration or biopsy. The types of diagnoses of the patients seen in the clinic during volunteer hours were melanoma, hematologic malignancies such as leukemia and lymphoma, and head and neck cancers. There were also patients who had received bone marrow transplantation and those receiving biological therapeutics that modulate the immune system. There were a number of patients with nonmalignant diagnoses being treated with chemotherapy, for example, multiple sclerosis, psoriasis, Sjogren’s disease, and scleroderma.

Early in the research, the investigator became aware of her preconceived notions of what someone in cancer treatment would look like, for example, pale, weak, and bald. This stereotype was apparently psychologically robust since it had persisted despite having a decade of experience in the cancer genetics field, as well as exposure to a number of friends and clients with various types of cancers and associated treatments. This stereotype was shattered one day during participant-observations with the realization that many clinic patients in the waiting

rooms were indistinguishable in appearance from their companions. This was both disconcerting and reassuring. It was disconcerting because it contributed to the researcher feeling socially awkward in not being able to determine by appearance alone whom to address as the identified patient. However, the normal physical appearance of many people with cancer was also reassuring as a catalyst to further absorbing the notion that one could move from perceiving "cancer patients" to perceiving "people with cancer." This process is similar to learning to put "person first" when dealing with people with congenital problems or disabilities.

Cancer Risk

During the period of participant-observation, people spontaneously talked about their ideas regarding the causes of their cancer and of ills in general. Patients' and companions' beliefs about what causes cancer could not be neatly categorized into environmental, genetic, or multifactorial risk factors. In fact, the concept of risk factors appeared much broader to patients and families than in the medical literature. This is not surprising given that both risk assessment and communication are part of a social process within a cultural context (Kenen, 1996). Thus, individual beliefs would be heterogeneous based on idiosyncratic experiences, knowledge, interests, and inclinations. For example, views about what causes cancer were mixed in with more general views about many of life's hazards and protections, for example, natural disasters, diet, exercise, religion, environment, pollution, and progress. Some specific paraphrases illustrate the diversity and complexity expressed: "Almonds are supposed to be protective." "God is supposed to protect and heal us." "Rockets poke holes in the ozone layer and allow bad rays to strike us on earth." "Bad things happen more often elsewhere, e.g., earthquakes in California." "There is more illness now than there used to be. I never before heard of so many people getting sick." This matches the author's experiences of speaking to lay audiences about cancer risks and finding interesting admixtures of genetic, cosmological, astrological, environmental, stress-related, psychological, and other explanations. External causes were generally seen as more potent than one's own actions in cancer causation.

Kinship and Family

Generally, genetics professionals have a relatively narrow definition of family in comparison to the sociological parameters. By family, we often mean those people who share genetic material: the more DNA sequence that people share, the closer the family ties. Thus genetic counselors often refer to first, second, and third degree relatives based on shared genetic material. The problem is that our underlying assumption, that is, that a biological relationship implies a social relationship, is not always met.

At times during the participant-observations, it was not clear who was a biological family member and who was not. This may be a more disturbing issue for an observer with a genetic counseling background since making an error in ascribing biological connection could have dire consequences for genetic diagnosis. However, even as a volunteer-observer, this uncertainty produced anxiety, similar to the situation described earlier of being unable to immediately know who is the patient. Once the source of the anxiety about not knowing social roles was identified, internally acknowledged, and worked through, it allowed the counselor/observer to more fully appreciate different aspects of family. While there were many siblings, parents, children, and spouses in clinic as companions to patients, there were many other people who functioned in the same support role but were either distantly or not biologically or legally related, but rather, what is known in the sociological literature as "fictive kin."

Some believe that it is not so much the family structure based on biological ties, but how the family as a social group functions that is of issue. Especially in times of crisis, people call on their families. Families may change their structures and functions in response to serious illness (Rolland, 1989, 1994). Rolland notes that the functioning of any family facing a health crisis should address how effectively it can reorganize its structure and make available resources to master the challenges.

For example, one day the researcher/volunteer met two African American women, chatting amiably with each other in the treatment area. They were taking a meal together which they had obviously coordinated, planned, prepared, and packed beforehand. When the research/volunteer asked if they were sisters, they said no and explained that they were cousins who lived nearby, were close during their own growing up years, now both had adolescent children about the same ages, and rarely had time to visit together anymore. Both were elementary school teachers with a great deal in common and took the clinic waiting time as an opportunity to catch up with each other's lives. They obviously cared greatly for each other. In other words, socially they felt and behaved like affectionate siblings.

On another occasion, the researcher observed two middle-aged white women sitting together in the treatment area, one receiving treatment and the other in the companion chair. When asked if they were relatives, the companion identified herself as "her sister with a different name." She went on to explain that they were close and supportive friends who had unofficially "adopted" each other. The companion had never had a biological sister and the patient's biological sister had already passed on. This important relationship might never have been apparent in a genetic counseling session with an emphasis on (and invitation to participate only to) biological relatives.

These relationships are important to recognize in the genetic counseling setting for several reasons. Fictive kin may contribute their own perspectives, beliefs, and attitudes to the genetic decision-making process. The presence or absence of

such a person may also influence the type and level of social support available to facilitate coping and follow-through with medical recommendations.

Coping and Support

The ways that people go about coping with cancer are quite diverse. These responses include trying to forget about the diagnosis, giving up, becoming more repressed overall, engaging in positive self-talk, soliciting positive responses from others, seeking social support, acceptance of the diagnosis and/or one's death, taking an active role in treatment, helping others to cope, or facing problems head on (Palmer *et al.*, 1993) Here we deal only with social support.

Based on observations of those attending clinic, people seemed to differ in the types and amounts of social support available to them. Many patients seemed to be married, others appeared to be single, divorced, or widowed. Some people appeared to have a close-knit circle of support, others seemed to function more on their own. There were many different sources of social support that people at the clinic most often seemed to mobilize, most commonly from spouse, family, and friends, in that order. Patients in treatment also have support from their physicians, nurses, and office staff of a clinic. Patients also provide support to each other in the clinic, as well as to the staff.

Touch is a means of support that is rarely used in genetic counseling or psychotherapy and was, therefore, new to the observer-participant in a volunteer context. When being oriented to the volunteer position, a veteran volunteer shared the following observation, "You can just tell when some people need a hug. Don't be afraid to touch them." Nonetheless, it was some time before the researcher brought herself to do this. One breakthrough moment occurred when a woman with a bald head due to ongoing chemotherapy treatment repeatedly invited the researcher to feel her scalp, while remarking, "I am lucky that I have a perfect head!" Indeed, the remaining short hairs were very soft, as was her scalp over a skull that was perfectly smooth. This brief touch in response to a patient's request proved to be a tender exchange for both.

Examples of support by family members were plentiful. One of the most poignant involved a woman who called herself a "veteran," that is, that she had survived a year beyond completing intensive therapy for leukemia and was currently cancer free. She was a fifty-ish woman with short salt-and-pepper hair and a shy smile. She confided that initially she had become rapidly and extremely ill and was near death despite all treatment efforts. Finally, she underwent a stem cell transplantation using her sister's cells. This was possible because she and her sister had "a perfect match" on tissue-typing, which she described as rare. She now feels wonderful to know that she literally has "a piece of my sister inside me" in the form of her sister's cells in the core of her being. She joked that she now also has

allergies, which she never had before, and that she was told that she “inherited the allergies from her sister” with the stem cell transplant. While it is probably true that there is a genetic basis for the allergies in receipt of T-cells with a “memory” of exposure to certain allergens, the underlying meaning of the story was to impress upon the researcher the importance of a blending of the biological and emotional closeness of the sisters through this transitional time of cancer treatment.

There are other ways that extended family also pitched in supportively. Relatives who were health care providers offered a special type of informational support to some people with cancer. Often they became mobilized in providing medical information or helping the patient to locate an appropriate specialist. They also apparently participated in medical decision-making at a distance. This may feel familiar to some genetic counselors.

Mutuality was commonplace in clinic observations. Gratefully receiving support, help, and gifts from others was held in high regard among many clinic attendees. Giving was as important as receiving, even when people believed that they have had little to offer at the moment due to severe illness. Such mutuality may be particularly significant. Several examples serve to illustrate some of the variety of support given and received in this clinic.

There were multiple observations of patients being very supportive of each other, visiting with each other, taking time to ask how it was going for the other person, making eye contact, and not shying away from hearing the details of the other person's experiences. In other words, they seemed to become fictive kin within each other's families. Examples of patients visiting other patients even when they didn't have chemotherapy scheduled on the same day made it clear that patients and relatives grew to know and care about each other over multiple treatment sessions and physician visits. This may have been an example of what Albert Schweitzer calls “the fellowship of those who bear the mark of pain.” (Schweitzer, 1947)

The professional staff's demonstrations of support at this clinic were remarkable. One could see how busy and sometimes frustrated they were; however, there were no observed occasions of the staff taking out their problems on a patient. Rather, I witnessed nurses coming into a staff area in tears over having missed a vein on the first few attempts at venipuncture. I saw them repeatedly warm heating pads in the microwave, partly to help with finding a vein, but also for comfort. As one nurse said, “Chemo is scary and sometimes unpleasant. The warm feeling sometimes helps people feel more comfortable.” Patients described some staff as “like family,” with one woman remarking, “they treat me like their mother.”

Conversely, the ways in which patients attempted to support staff were numerous. They made every effort to do what they could accomplish for themselves so as to avoid bothering staff. They effusively expressed their gratitude to staff both verbally and through actions such as baking or bringing sweets, flowers, or other gifts to clinic staff. The motivation behind such giving may be complex. For

example, perhaps there is some element of good heartedness and gratitude. There also might be the desire to lessen indebtedness of the patients to their health care providers, an attempt to equalize social relations in much the same way that one might feel an obligation to reciprocate an invitation to dinner. In some cultures, the person who has performed a favor for the other is considered in a place of higher power, and the power is not equalized until the opportunity to return the favor has been fulfilled. In these cases, it would be important for the provider to accept the gift as a way of normalizing relations with the patient.

Food as a Medium of Support and Exchange

As mentioned previously, food was ubiquitous in the clinic, especially on the treatment side of the facility. Undoubtedly this arose as a study theme in part because of the researcher's identified role as a volunteer, whose responsibility it was to offer food or beverages such as jello or ginger ale to clinic attendees. However, the avid interest in food and beverage was also an unanticipated finding, again because of preconceived stereotypes based on outdated images and information. In particular, the researcher assumed that those undergoing chemotherapy would be nauseated or apathetic at the sight, smell, or even the thought of food or drink. The opposite was the case, due in large part to advances in management of treatment side effects and control of nausea. Most people accepted a beverage, some accepted light food, and a few requested a sandwich or burger while they were spending a good portion of the day in treatment.

Food and drink also seemed to serve as important "currency" for exchange of reciprocal support. As a volunteer and representative of the clinic, the researcher was offering light beverages as a way of symbolically and practically nurturing the patients who attended. For their part, grateful patients and families often brought baked goods which covered every surface of the nursing stations and staff break rooms. At one point a patient handed the researcher a chocolate canoli saying, "You are always giving us something, here, you take this for a change."

In their roles in everyday life, people take on various tasks of preparing, serving, and eating food. This may be disrupted by the time and energy changes that often occur during cancer diagnosis and treatment. For example, a young Asian man and his mother were in the kitchen at one point having lunch that they had heated in the microwave. It smelled good. When asked who was the cook, the young man said that he was. The researcher asked how he learned to cook. At first he said that if he liked to eat good food, he should cook good food. Then he said that he did what had to be done while his mother was sick. She looked both proud and sheepish.

Actively attending to food seemed an issue particularly for wives and mothers, who often went to the kitchen or nearby coffee shop for a snack for their loved ones and even for other patients in treatment. The wives frequently and spontaneously

commented on appetite and food and took an active role in providing it. One middle aged Greek woman walked with me to the kitchen at various times to bring a beverage for one of the other patients while her husband was getting a chemotherapy infusion. She behaved like a mother to everyone, seemingly having sensitive antennae by which she could judge others' needs and often jumping up for anyone who needed something to eat or drink. I got the impression that she was more comfortable in this maternal helper role than sitting in more passive companionship with her listless spouse.

Given the meaning of food as a currency of social exchange in diverse social and cultural settings (McAllister, 1990), the loss of appetite was particularly distressing to some people attending treatment and clinic. One older couple was illustrative. The patient was initially a tall-statured, large-girthed, robust man who was always accompanied by his wife who didn't leave his side. Initially, they appeared terrified and unable to talk about any aspect of his diagnosis or treatment; however, they began opening up as the visits became weekly during the early treatment phase. Gradually, the man began losing weight, becoming weaker, and more apathetic as he progressed through therapy. Before I had even noticed a change, his wife started commenting more and more frequently on his loss of appetite and all of the efforts that she was undertaking to make his meals appealing. Aside from the practical implications of his failing health and interest in life, there was also an element of mutual loss of one of the only means by which she could offer support, hope, and encouragement.

Healing: Meanings, Rituals, Journeys

Several patients indicated that they felt their bodies heal before their emotions did. At first, they were busy coping with the cancer treatment with its attendant exhaustion, apathy, loss of appetite, and changes in bodily appearance. Later, when things slowed down, they gradually became aware of deeper feelings of fear, resentment, grief, elation, and glimmers of hope. Eventually, some seemed to integrate these feelings into a new understanding of what they have been through and who they are now as a result of these experiences.

In this clinic, patients attended fastidiously and compliantly to the many rituals of the biomedical profession as a means of healing. They came for appointments, sometimes from great distances, waited long hours, endured uncomfortable procedures, and returned repeatedly for more of the same. They expressed faith in their providers to help them get well. For example, some people mentioned the skill of their surgeon, or the humor of their doctor. One woman said, "I wouldn't dare defy what they tell me to do!"

Religious rituals were sometimes admixed with the medical. One elderly man with deep religious faith read books about miracles while his wife was saying the rosary during her chemotherapy. Several spoke of feeling reassured that they

would get well from receiving messages from friends and acquaintances such as “We have you in our prayers.”

Others adopted lifestyle rituals, that is, took a proactive stance to making lifestyle changes, such as trying to keep up their appetite, eating even when the taste was gone, returning to exercise and normal routine as soon as possible. One man was devastated emotionally when he was too weak to jog during the months of chemotherapy treatment. Later he became elated when able to resume running. A few mentioned using complementary healing methods such as eating three almonds per day. These healing strategies seemed loosely tied to their belief systems about the causes and prevention of cancer.

But beyond the question of causes and cures, having cancer means different things to different people. As Jean Shinoda Bolen in her book *Close to the Bone* (Bolen, 1996) puts it, “When an illness is truly a turning point, it is not merely a return to what was before, but a life altering passage” (p. 182). She also says “from the standpoint of the soul, a life-threatening illness is a spiritual journey—an adventure or an ordeal or an initiation—that is undertaken by the patient and can be shared by others” (Bolen, 1996, p. 115). For one woman at the clinic it meant gaining perspective on her priorities and putting her affairs in order. Others chose to take a class or finish a project left languishing. People who attend a cancer clinic are looking not only for cancer cures but also for deeper healing from the experiences of being diagnosed and treated for a life-threatening illness, perhaps in the original meaning of the root word for cure, *cura*, meaning care. Healing includes qualities of making whole and of reconciliation (Webster, 1994).

One woman told a story of a special quilt that had great meaning for her. She began by describing some beautiful cloth squares, which she had embroidered and played with as a child. Later she had stowed these away in a trunk, promising herself that she would someday make a quilt as an heirloom. Although forgotten for years, the embroidered cloth squares came to mind again while she was lying in the hospital bed for several months during her illness, treatment, and recovery. The woman decided then and there that she would proceed with the quilting plan, although she didn’t quite know how she would manage learning to quilt and completing all the work, given her compromised energy. She eventually decided to ask help from her church quilting group, saying “If I put together the squares to produce a front, would you make a back and quilt it for me?” to which they enthusiastically replied, “Honey, give us the whole thing and we’ll do it for you.” When seen at a subsequent clinic visit several months later, this woman said that the quilt had been completed and that she had given it to her eldest granddaughter as a keepsake. The woman was pleased to see her granddaughter repeatedly wrapping herself in the quilt, rather than keeping it pristine and untouched. We wondered together whether this signifies her completing the tasks/challenges of life in the literal threading together the individual patches of her life, a way of making her life narrative, and by extension, her life, whole.

It is not only the patient who has a search for meaning. An illness that happens to someone close to us can take us into the underground as a companion on the journey. Serious illness in a loved one can bring us "close to the bone, to the essence of who we are and what we are for at a soul level" (Bolen, 1996, p. 113). This returns us to acknowledgment of the importance of understanding the experiences of the "at risk" individuals and whether and how they may have been touched by cancer in a loved one.

DISCUSSION AND FUTURE DIRECTIONS

There are a number of ways that this small study relates to genetic counseling. The key findings may help us to

- Better understand the experiences of those of our consultands who have had cancer;
- Appreciate the attitudes, concerns, and preexisting notions of our consultands at increased cancer risk who may share some of the attributes of this study population;
- Elucidate some of our own counselor prejudices, misconceptions, attitudes, and beliefs about cancer;
- Shape the cancer genetic counseling practice in ways that take advantage of some of the field observations;
- Shape new genetic counseling research questions and approaches;
- Recognize and overcome limitations to our current knowledge and practice.

Understand Experience of Cancer Treatment

Understanding the cancer diagnosis, treatment, and survival experiences are pieces of the puzzle of understanding some of the images and expectations that our cancer genetic counseling consultands might bring to the counseling appointment. There are a number of ways that we can understand the experiences: directly or vicariously through personal communications, literature, or media accounts.

First-hand knowledge of some of the experiences of cancer treatment may enrich cancer genetic counseling practice, for both individual practitioners and for the profession. While the majority of genetic counselors do not have personal experiences with most rare genetic conditions, that is not the case with common diseases such as cancer. A number of genetic counselors have shared their own cancer diagnoses with selected individuals, a few with our entire professional society, and others have gone through cancer diagnosis and treatment with little public comment. We are all touched by these personal experiences among our membership in ways that we may not even be entirely aware.

Another way of forming a wider range of impressions of cancer treatment is through developing a genetic counseling literature on the experiences of our patients with cancer, either past, current, or potential future.

Understand At-Risk Status

Some of what people bring to the counseling session is a complex admixture of risk perception and personal identity coming together in a concept known as the "at-risk" status (Kenen, 1996). The person "at risk" of developing cancer is the main target of cancer genetic counseling and genetic susceptibility testing. This is a relatively new concept in medical care, somewhere between sick and well. It is only after at-risk status has been determined, assigned, and accepted that it can be considered a social role with expected role performances and norms. Subsequently, the at-risk person is expected to adhere to socially approved at-risk health behavior patterns, feelings, attitudes, and actions. For example, women at risk of developing breast cancer may be expected to take certain measures to reduce risk and to deal with their emotions since research has shown that they have psychosocial profiles similar to those already affected with cancer (Lerman *et al.*, 1996). There have also been characterizations of at-risk participants in large research projects. However, the underlying thoughts and feelings of this population have rarely been described other than in terms of absence or presence of psychopathology and factors that predict genetic testing and uptake of medical and surgical interventions.

During this pilot study, it became clear that people do not necessarily employ the same classification categories as genetic counselors do in discussing genetic, environment, and multifactorial risk. This has been confirmed in other studies, in which different lay-people may have very different mental models of breast cancer risk. Furthermore, few of these lay mental models corresponded closely with "expert opinion" about breast cancer risk. The implication is that the providers may not be talking about the same things as our consultands when we talk about risk. In fact, no two clients are probably talking about the same thing either. Although genetic counselors take pride in being able to accurately assess quantitative cancer risks and mutation probabilities, these estimates presumably will not alter our clients' risk perceptions unless we can elicit, appreciate, and integrate our explanations with their understanding of their phenomenological world and their feelings that derive from this world view.

Elucidate Counselor Notions

Because various types of cancer are so common, we will all undoubtedly know individuals who are affected, or will develop the disease ourselves at some point in our lives. Identification with the at-risk or the "affected" health status may

be easier for some counselors than others because of personal experience or psychosocial makeup. These potential identifications can both enrich and endanger the quality of our counseling. These past experiences may help us be empathetic when our experiences are congruent with a new client's. However, when our personal experiences differ from clients', we have the potential for breaks in empathy or rapport due to misunderstandings, or erroneous assumptions about their different experiences. Perhaps genetic counseling and medical training programs could incorporate more counseling training and/or ongoing supervision to identify and explore our own preexisting beliefs, attitudes, memories, and potential counter-transference experiences.

Dealing with our own personal issues is one of the ethical responsibilities of all genetic counselors as noted in our code of ethics (NSGC, 1992). As genetic counselors work with any area of practice that touches on personal issues, we have a responsibility to attend to our own physical and mental health. Being successful as cancer genetic counselors requires us to come to terms with what it means to be at risk of cancer and to deal with this awareness in ways that contribute to personal and professional growth. Studies such as this may serve as preliminary steps to this ongoing individual and collective consciousness-raising.

Shape Genetic Counseling Practice

The basic model of genetic counseling (Baker *et al.*, 2000) includes helping families to (1) comprehend the diagnosis and medical consequences; (2) appreciate the inherited aspect of the condition; (3) understand the options for dealing with genetic-based risks; (4) choose an appropriate course of action; and (5) make the best possible adjustment to the disorder (Ad Hoc Committee of the American Society of Human Genetics, 1975). Although assistance with decision-making, and psychosocial adjustment have long been part of the genetic counseling mission, the effectiveness of genetic counseling has been evaluated primarily by means of outcomes of knowledge, reproductive intentions and behavior, risk assessment, and uptake of genetic testing (Kessler, 1990). There has been little research tying together patient risk perceptions, beliefs and attitudes, the emotions related to one's risk, or to the literal content and process of genetic counseling (Michie and Marteau, 1996).

With our focus on relatives sharing biological inheritance, it is not surprising how necessarily narrow the genetic definition of family has become, as recorded in the genetic pedigree (Bennett, 1999; Resta, 2000). In contrast, in our study population, the nature of family and kinship seems much more fluid in people's minds, where people can "become" family through strong emotional attachment and through mutual giving and receiving of various forms of support. Traditional inheritance patterns of a person inheriting traits from one's parents through sexual reproduction do not fit situations where a woman can "inherit allergies" from her

sister via a bone marrow transplant. While this form of acquiring allergies almost certainly has a physical basis in the biology of the immune system, the main point was not a biological, but an emotional one of close attachment.

Some of the richness regarding popular views of the admixture of inheritance and support could perhaps be captured by introducing the family systems genogram into genetic counseling practice along with the pedigree (McGoldrick *et al.*, 1999). Eunpu has made suggestions regarding how this might be done (Eunpu, 1997) and Daly has already introduced this practice on a research basis into cancer family risk assessment (Daly *et al.*, 1999). This would give us an opportunity to spend more time eliciting family stories of health, illness, loss, and triumph. We could also invite consultands to bring to consultation whomever they feel close to, whether related biologically or not. For research purposes, a more detailed adaptation of the genogram combined with social network models might be useful (Kenen and Peters, 2000).

Research

Genetic counselors and social scientists have the potential to form creative research collaborations in which all parties play active roles. For example, during this pilot ethnography project, the value of multidisciplinary collaboration was again reaffirmed. The analysis process was tremendously enriched by the dialogue among the genetic counselor, anthropologist, and medical geneticist. This is detailed elsewhere (Peters *et al.*, 2001).

One potential contribution that genetic counselors may make is to help refine theoretical models by adding our realistic observations of the clinical populations. The health belief model underlying much behavioral research in cancer genetics posits that perceived threat or risk is determined by perceived susceptibility and perceived severity of the condition (Glanz *et al.*, 1997). From this paradigm, it is usually assumed that risk information provided by the genetic counselor influences counselees' perceptions of risk. However, there are data to suggest that people's prior risk perceptions and their own theories about illness before counseling, rather than the risk information that they are given by counselors, correlates better with intentions related to use of genetic information for life decisions (Shiloh and Saxe, 2000). Thus, theoretical underpinnings of biobehavioral research, the processes of risk conceptualization, and the genetic counseling goals could be investigated conjointly.

One of the unexpected findings of this research experience was the multiple layers of support and healing that occur in clinic, among patients, staff, family, friends. The social support literature alludes to different types of support such as tangible, emotional, social, and informational, as well as different levels and sources of support (Palmer *et al.*, 1993). Ways to improve socially supportive exchanges could be explored.

A significant aspect of these supportive interactions seems to be the mutuality that exists in giving and receiving support. People seem to feel good in giving to others. It isn't a matter of power over or pity for someone worse off than oneself. Rather, people seem genuinely gratified to give. Mutuality is another concept that bears examination in terms of support. The Wellesley College Stone Center has developed a model of relational health that describes how healthy human interactions and connections lead to the growth of people involved in mutually empowering and empathic relationships whereas relational disconnections lead to psychological problems and disordered relationships (Jordan *et al.*, 1991; Miller and Stiver, 1997). If we are dealing with adjustment to hereditary cancers in the larger context of genetic counseling, then we might be wise to broaden our attention to include the relational health of our consultands.

In fact, reciprocity may be healing. The relational theory has been applied to studying breast cancer patients. Using a perspective based on relational theory, the influences of several relationship factors on women's adjustment to cancer have been studied (Kayser *et al.*, 1999). Women who perceived their partner relationships to be highly mutual were more likely to rate higher on quality of life and self-care agency, and lower on depression. Results indicated that women who reported higher mutuality, fewer self-silencing beliefs, and fewer coping strategies of protective buffering experienced a more positive psychosocial adaptation to cancer. While these may not be everyone's experience, sorting out the various components of support in the context of cancer are useful. This may serve as a reminder to genetic counselors and other health professionals that we should consider how we might discover and expand the mutuality in our interactions with our clients in both structured and unstructured ways in order to better foster healing. For example, we could invite our consultands to teach us as we teach them, in a more even exchange of views than currently exists. Genetic counseling could have an explicit goal of healing. There is mounting scientific evidence that our physical and emotional health, feelings, beliefs, and attitudes are linked. We have the potential to make some of those links tangible to those who seek our help.

Limitations

This preliminary participant-observation experience has obvious limitations. These include the inexperience of the primary investigator, limited duration and depth of observations, and lack of systematically collected data. A major constraint was imposed by the practical need to limit the diversity of the population to those with particular diagnoses seen on a certain clinic day, thus limiting generalizability to people with other forms of cancer or illness. There were also limited opportunities for triangulating these observational results with other qualitative and quantitative methods that could improve the validity of the findings,

for example, interviews, surveys, video or audiotaping behaviors, and speech. The depth of understanding could have been increased with semistructured interviews with patients, family, nonfamily supporters, and selected staff.

This study provided interesting findings despite its limitations. A number of stereotypes and preconceived notions both about the clinic population and the treatment were dispelled. Theoretical categories, such as "family," "risk perceptions," and "family communications" which were previously thought of as "true" or "real" appeared much less clear-cut. Rather, our perspectives evolved to consider the lay use of these concepts as more fluid, dynamic, changeable, and unpredictable than those which have been cognitively defined for clinical practice or specific research purposes.

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