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Original Research

Evolution of the Colored Eco-Genetic Relationship Map (CEGRM) for Assessing Social Functioning in Women in Hereditary Breast-Ovarian (HBOC) Families

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The CEGRM was initially conceived as a simple, concise, visual representation of the social interaction domains of information, tangible services and emotional exchanges (Kenen, R., & Peters, J. (2001). *J Genet Counsel*, *10*, 289–309). A blend of the genetic pedigree, genogram, and ecomap, the CEGRM was developed to facilitate contemporary genetic counseling goals. An exploratory pilot study of 20 subjects showed that it was feasible, comfortable and efficiently accomplished, and that the process was useful both for assessment and as an intervention with study participants (Peters, J. A., Kenen, R., Giusti, R., Loud, J., Weissman, N., & Greene, M. H. (2004). *Am J Med Genet Part A*, *130A*, 258–264). Subsequently, we have extended the CEGRM to 150 women from hereditary breast/ovarian cancer (HBOC) families; three different investigators have successfully administered this tool. The preliminary findings from the exploratory study were confirmed in the larger sample. Engaging in the interactive, insight-promoting CEGRM process provides a novel tool for assessing the social context of genetic testing, and helping high-risk women better understand and integrate genetic information into their personal and family identities, health beliefs, and decisions.

KEY WORDS: genetic counseling; breast cancer genetics; genetic testing; family; friends; relationships; kin; social network; communications; pedigree; genogram; ecomap; psychosocial; psychological; social; familial cancer; hereditary cancer.

INTRODUCTION

The hereditary breast/ovarian cancer susceptibility (HBOC) syndrome is most commonly the result of a mutation in either the *BRCA1* or *BRCA2* cancer susceptibility genes. Women with deleterious *BRCA1/2* mutations have a greatly increased cancer risk of breast and ovarian cancer, with penetrance ranging from 50–85% to age 70 years depending on the study population (Easton *et al.*, 1995; Ford *et al.*, 1998; Struewing *et al.*, 1997; Thompson and Easton, 2002; Schneider, 2001). Breast cancer penetrance appears to be reduced by risk-reducing surgery, both breast and ovarian (Kramer *et al.*, 2005; Rebbeck *et al.*, 1999; Rebbeck *et al.*, 2002; Rebbeck *et al.*, 2004;

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Hartmann *et al.*, 2004). Both men and women may transmit these mutations, and the accompanying cancer risk, to approximately half of their offspring. Targeted, cancer site-specific surveillance and prevention are the cornerstone of managing this increased cancer risk.

There is now a large and substantial literature focusing on psychosocial aspects of HBOC (Braithwaite *et al.*, 2004; Broadstock *et al.*, 2000). Many of these studies focused on outcomes concerning individual levels of functioning and mental health problems such as depression and anxiety (Watson *et al.*, 2004). The weight of the accumulated evidence indicates that genetic education, counseling and testing significantly improve genetic knowledge. With few exceptions, adverse outcomes related to emotional functioning, such as significant anxiety and clinical depression, as a result of this process, appear to be uncommon. Some prospective studies have demonstrated increasing accuracy of perceived risk and reduction in cancer specific worry, especially for mutation non-carriers (Lerman *et al.*, 1996).

We chose a relational approach to our assessment by focusing on positive social outcomes beyond the realm of standardized psychometric tests. We have been particularly interested in understanding high-risk women and their health issues in the context of family and other social settings. Social context involves both a person's cultural milieu, e.g., ideas and values, as well as the structures of one's social contacts with individuals and groups, e.g., blended family, friendship networks, workplace and religious community (Stark, 2004).

The social context, viewed *in toto*, becomes a lens through which to view the family history, mutation status, medical management issues and personal adjustment to family cancer experiences and resultant risk. To fulfill our aim of understanding the bigger picture, we created the concept of the CEGRM in 2001 as a simple, concise, visual representation of the social interaction domains of information, tangible services and emotional exchanges (Kenen and Peters, 2001). There have been calls for new methods of social assessment in medical settings that are sensitive to the complexities of human interactions (Pistrang *et al.*, 1997). The CEGRM emphasizes the extended social system, including extended maternal and paternal families, in-laws and other non-bloodline members of the social network such as friends, neighbors, co-workers, and church members. As a blend of the genetic pedigree (Bennett *et al.*, 1995; Bennett, 1999), genogram (Rolland, 1989; McDaniel *et al.*, 1992; Eunpu, 1997; Daly *et al.*, 1999; McGoldrick *et al.*, 1999), family map (De Maria *et al.*, 1999) and ecomap (Hartman, 1978; Dunn and Dawes, 1999; Hodge, 2000), the CEGRM originated as a way to facilitate contemporary genetic counseling goals, one of which is to understand our clients in the context of their social milieu. The pedigree was selected as the basis for the CEGRM because it is familiar to most medical professionals and was already available for each of the participants in the study.

A brief exploratory study showed that the collaborative completion of the CEGRM was feasible, comfortable and efficiently accomplished, and that the process was useful both as an assessment of social exchanges and as a counseling intervention with study participants (Peters *et al.*, 2004). We have now extended the CEGRM to 150 women in families with HBOC, and present updated findings in this paper.

METHODS

Design

We are reporting on a cross-sectional sample of the social exchanges of women at high genetic risk of breast cancer presenting for their initial visit in a breast imaging clinical research study.

Participants

The study participants comprised 150 consecutive women seen in the National Cancer Institute's Breast Imaging research protocol (NCI Protocol 02-C-009) for unaffected women at very high risk of developing breast cancer. These include the original twenty participants. Each woman was between 25–56 years of age, belonged to a family with a known deleterious germline *BRCA1* or *BRCA2* mutation, and most had a first-degree or second-degree relative with a *BRCA*-associated malignancy.

TRANSFORMING A PEDIGREE TO A CEGRM

Procedure: Constructing the CEGRM

The procedure for constructing a CEGRM is presented in detail elsewhere (Kenen and Peters, 2001; Peters *et al.*, 2004). A brief summary, and modifications since the 2004 publication, will be reported here.

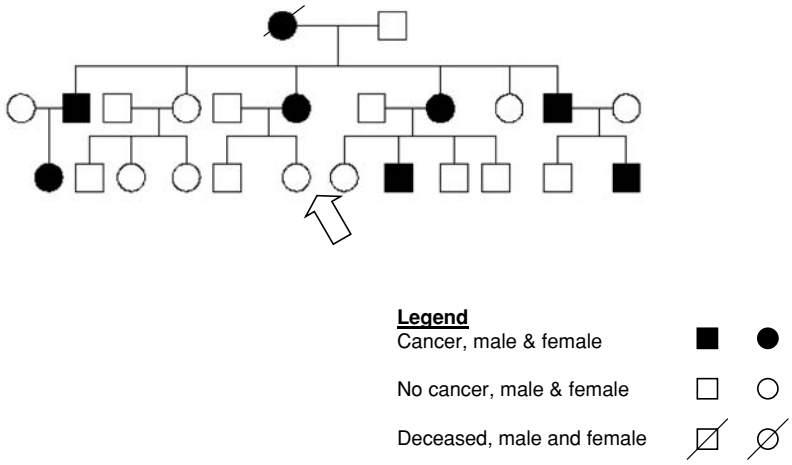

Fig. 1. Sample human genetic pedigree.

After completing written and verbal informed consent, the participant and the researcher together constructed the CEGRM, using the participant's computerized genetic pedigree as a template (see Fig. 1). Guided by the investigator using a semi-structured interview script, participants placed symbols intended to represent meaningful social exchanges with relatives and non-kin (see Fig. 2).

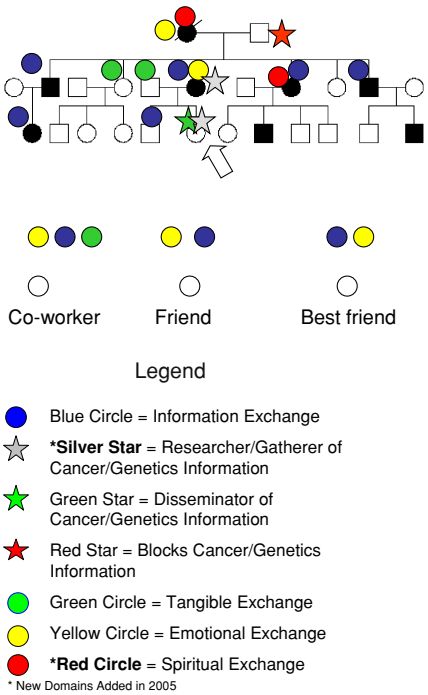

Fig. 2. Conversion of pedigree to CEGRM: Add non-kin & track social exchanges.

The three original research domains of information, services, and emotional interactions were expanded in the current CEGRMs to capture two additional domains: "information interactions" and "spiritual exchanges."

Information Interactions

The main information interaction domain was represented by a blue circle placed near the designated individual on the pedigree, in response to the query, "With whom in your family and among your friends do you share information about cancer and the genetic counseling/testing and cancer risk assessment that you have undergone?"

Because communication is so integral to the genetic counseling process, we probed more deeply regarding three subsets of information (1) gathering, (2) dissemination and (3) blocking. Questions were framed in terms of which individual(s) in a participant's social network fulfilled these roles regarding information.

Information Gathering

Silver stars were used to identify those people who most actively gathered information, through library research and internet searches, reading, talking to doctors and survivors, and other methods.

Information Dissemination

Green stars were used to represent people identified by the participants as key disseminators of

cancer genetics and related health information within the family and friendship networks.

Information Blocking

Red stars represented those whom the participants identified as preferring to avoid discussions of health information or whose need for privacy might impede information being freely discussed and transmitted within the family.

Tangible Services Exchanges

Social interactions in the area of tangible "services" and favors were represented with green circles; in particular, we targeted issues related to health or family. Examples included help with transportation, childcare, help related to prophylactic surgeries, financial help, and preparing meals.

Emotional Interactions

Yellow circles represented emotional interactions in response to questions such as "With whom do you share your feelings about being at increased cancer risk?" "Whom do you call when you get good or bad news?" Responses resemble the constructs of cohesiveness and affective involvement included in some standardized scales of family functioning (Olson *et al.*, 1985).

Religious/Spiritual Interactions

Red circles were used to mark shared spiritual connections. We hoped to capture traditional religious affiliations and activities as well as broader, more difficult to define spiritual experiences. The use of prompts such as the following were employed, "Some people talk about a religious sort of connection, such as knowledge of a shared faith, attending services together, or praying with or for each other. Others talk about a less definable, more ethereal kind of connection or closeness with other beings or even finding a peaceful place within oneself. Are any of these important to you?"

Conclusion of CEGRM Process

At the conclusion of the CEGRM exercise, we asked each participant if there was anything else that she wished to add, and to make an interpretation of the CEGRM pattern, by asking such questions as: "Is there anyone or anything that we missed?" "How would you describe your social world as it appears on your CEGRM?" The total time required to complete the CEGRM was recorded.

Outcomes

The results of this expanded study are summarized in three categories: compliance, feasibility and utility. *Compliance* was scored as the percent of breast imaging study participants among all those invited, who agreed to attempt collaborative construction of the CEGRM. *Feasibility* was assessed by the participants using Likert scales (1–10; 1 = best, 10 = worst) for each of the following outcomes: understandability, comfort, ease of use, ease of talking, success in eliciting narratives, and perceived proportion of time client talked. The authors evaluated time to completion and all other measures. Inferences regarding the *Utility* of doing a CEGRM for assessing social context and facilitating mutually interactive and sometimes healing counseling process were derived from observation and the open-ended responses during conversation between the participant and investigator in the course of constructing the CEGRM.

RESULTS

Population Demographics

The mean age of participants was 39 years (range: 22 to 56). Participants were all Caucasian, with one participant noting additional American Indian heritage and two women self-identifying as Hispanic. This was a well-educated group: the majority were college graduates; many had attended graduate school and had masters or doctoral degrees. The majority [100/150 = 67%] were married, 13 (9%) reported a steady partner, six (4%) were separated or divorced, thirty women (20%) were never-married, and one had unknown marital status.

Of the 150 participants, all had received prior genetic education and counseling. Of these, 141 (94%) knew their clinical *BRCA1/2* genetic testing results prior to entering the Breast Imaging study; 9 (6%) did not. Of the nine women who did not know their status, two had had genetic counseling and had blood samples drawn, but did not seek disclosure of results.

Three of nine had blood specimens for testing drawn at study entry (concurrent with doing the CEGRM), while two other women had CLIA genetic testing after study entry and CEGRM. Finally, two have remained clinically untested. Interviewers were aware of test status if revealed by the participants.

Compliance

Each of the 150 participants who were a part of the current cohort completed the CEGRM co-construction willingly. Two women missed their CEGRM interview on their initial Breast Imaging Study visit and therefore, were seen for their baseline CEGRM on a subsequent visit.

CEGRM FEASIBILITY RESULTS

Feasibility

The aggregate results from the exploratory ($N = 20$) and current ($N = 150$) samples are presented in Table I. A brief summary is provided below.

Beginning with a previously-constructed genetic pedigree, it took between 13–60 min to complete each CEGRM (mean = 30 min). Most participants quickly and easily grasped the concept and process of constructing the CEGRM with the scores on the "Understanding" question ranging from 1 to 5 (mean = 1.4) and indicated that they were comfortable with the process of constructing the CEGRM (range: 1–7; mean = 1.5).

While most participants rated ease of use of the colored stickers at 1 or 2 (mean = 1.9), the range (1–10) was wider than for other feasibility measures. Most women (146/150) successfully placed all of the stickers during CEGRM construction without assistance from the interviewer; the remaining four women (all with long synthetic fingernails) required some help or chose to use colored pencils instead.

Table I. Feasibility Measures

Variable	Exploratory Study Means ($N = 20$)	Updated Means ($N = 150$)
Duration	28 min	30 min
Understanding[a]	1.8	1.4
Comfort[a]	1.9	1.5
Ease of media[a]	2.3	1.9
Ease talking[a]	1.9	1.8
Narratives[a]	2.3	2.2
% *P* talked	76%	65%

[a]Likert scale: 1 = best; 10 = worst.

Nearly all participants (139/150) reported that they perceived that they had talked for at least half the total duration of the visit (mean: 65%). These subjective estimates, made by the participants, were not timed because the question is intended to measure their perceptions of being listened to.

The range of scores for self-rated ease of talking about family and other relationships was 1–10 (mean = 1.8). The score variations seemed to be largely a function of the personality types, which ranged from gregarious to private, by informal investigator impressions. Most women were eager to talk about cancer risk with respect to their family and friends. Some women indicated during the evaluation period that it was more difficult to talk when the content of the stories was sad or upsetting, e.g., one woman said that talking about family losses made her "feel raw." In a related measure, the range of scores regarding women's comfort with disclosing to researchers detailed information about their interactions with family and friends was 1–10 (mean = 2.2). The participants' stories helped to frame the issues addressed in the *Utility* and *Discussion* sections.

Utility

As in the exploratory study, the CEGRM once again proved useful in assessing social context of the female participants in the breast imaging study. Most women reported sharing genetic information with multiple people both within and outside the family, and they were able to readily describe the details of information exchange and to identify sources of tangible, emotional and spiritual support.

Information Exchanges

We found that respondents shared health information, e.g., the results of their genetic testing, with a variety of people. Some participants or their family members took on specialized roles of information gatherer and/or disseminator. These roles were sometimes determined by family values such as authority, respect and gender roles. Additionally, many women identified one or more persons within the family who seemed to block the flow of genetic information.

We attempted to gain insight into the details of communication patterns/styles by requesting specific

examples regarding how information moved within subjects' network of support. Participants reported frequent phone conversations, e-mail exchanges, and in-person meetings focused on cancer/genetic testing information and support. For example, some women described meeting their sisters or women friends for lunch to talk about testing and/or treatment options.

Many participants reported feeling responsible for informing women *outside* their families about the new facts they had learned regarding breast and/or ovarian cancer. In this way, they became strong advocates for screening and preventive healthcare.

When we asked how participants knew that individuals to whom they gave red stars did not want to talk about genetic testing and cancer risk, we found that there were both direct and indirect impediments to social exchanges as well as self-censored communications as classified by Kenen and colleagues (Kenen *et al.*, 2004). Specific examples that participants gave of direct blocks to cancer information exchange included some relatives' refusal to discuss cancer, conflicted relationships with particular relatives, and tacit agreements not to talk about painful topics. Examples of indirect information blocks included their relatives' passive refusal to talk, their acting uncomfortable or unresponsive, stating that they were too busy, and using intermediaries to communicate. Finally, self-censored communications included participants reporting someone pulling back because of fear of causing anxiety, feeling protectiveness, and distancing oneself from having to deal with personal risk.

Communications were reported as more open between female relatives, e.g., sisters and female cousins than with male relatives, e.g., fathers and brothers. These communication styles were not consistently predictive of other domains of social support, e.g., a brother reported as appearing closed and unresponsive about health information might also be described as providing significant tangible or emotional support.

Tangible Services Exchanges

Geographical distribution, gender, and marital status seemed to be the main determinants of help-seeking. Because this was largely a healthy group of women in the prime of life, they did not require significant tangible support. For those who were married, the spouse was typically the first person from whom they would seek help when needed, with nuclear family members a close second. Those with children at home accessed babysitting favors from relatives or exchanged childcare or carpooling with friends. One woman with prior breast cancer provided many examples of friends accompanying her to chemotherapy treatment, taking care of her children, preparing meals, and flying in from another state to stay with the family during the treatment period. Those undergoing risk-reducing surgeries, mainly salpingo-oophorectomies, accepted help during surgery and the short recovery period.

Emotional Exchanges

Most mental health professionals believe that it is important to have at least one confidante, a person with whom a participant could speak freely and openly about her own feelings about her experiences with the cancer in the family, fears of being affected or dying, figuring out what she could do to protect herself and her relatives, relationship issues and other matters of deep concern. All participants had at least one major source of emotional support, with most having multiple sources both within and outside the family. Friends featured prominently in this domain, although there was substantial heterogeneity regarding whether family members, friends, or a combination of both provided the bulk of emotional support. The mix appeared to vary, depending on situational specifics.

Religious/Spiritual Exchanges

In early 2005, we modified the CEGRM to capture information regarding religious/spiritual exchanges. This information was collected from 35 of the 150 initial study participants. These new data seemed to complement and enrich the questions about emotional closeness. During the portion of the CEGRM that focused on religious/spiritual support, participants were asked whether or not they felt that religion and/or spirituality were an important part of their social world, and whether there were any individuals with whom they felt spiritually connected. We allowed a broad range of responses characterizing the full spectrum of experiences that our participants considered relevant to capturing these complex, multi-dimensional concepts. Many women did describe a spiritual connection with members of their family or a close group of friends, e.g., attending the same church or synagogue or praying together;

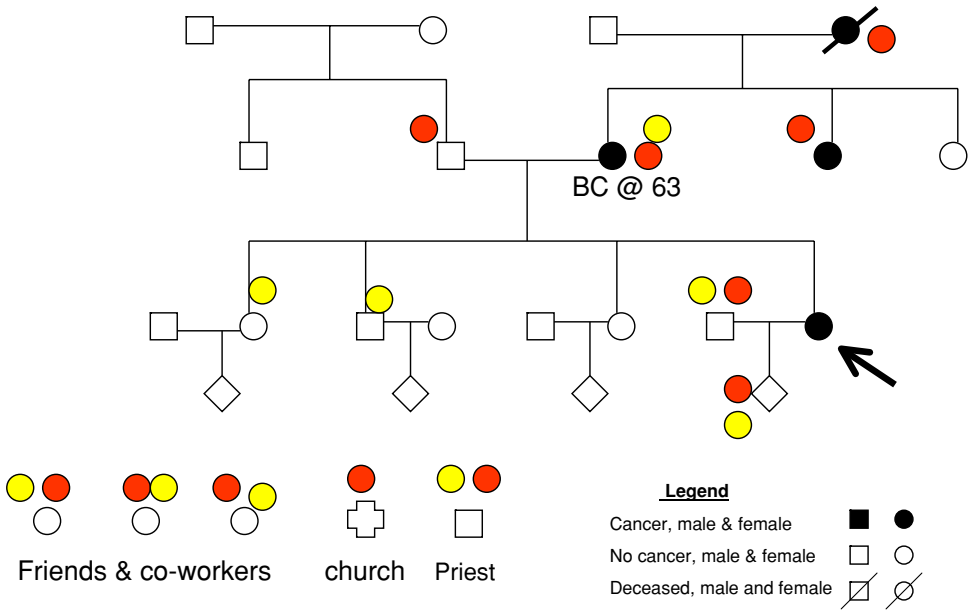

Fig. 3. CEGRM focusing an spiritual & emotional support.

sharing the same faith between blood relatives and spouses; perceiving a spiritual connection with relatives, church members, or a deceased parent or grandparent; receiving messages or signs from God or deceased relatives (see Fig. 3); connecting philosophically and empathically with close friends who "see things the same way I do" or "just get it"; connecting meaningfully with pets; and finding an internal spirituality with comfort and peace in solitude.

DISCUSSION

Our expanded experience with the CEGRM confirms the feasibility and high compliance rates observed in our original exploratory study (Peters *et al.*, 2004). Furthermore, we corroborated the CEGRM's potential for more comprehensively assessing the psycho-social milieu of the patient, and using that information to formulate effective interventions. This tool provided valuable insight into the structure and nature of the social worlds in which women at high risk of cancer exist. Families clearly differed with regard to closeness and distance between family members, the frequency with which various kinds of support were utilized, and the types of support provided by diverse support network members, e.g. spouses, parents, friends, children, co-workers, etc.. Importantly, the CEGRM process allowed *participants* themselves to achieve valuable insight into their social worlds; there were a number of "ah-ha" moments, in which a woman came to a new realization about herself or her relationships, as a direct result of the CEGRM process.

The CEGRM has evolved over time, as a consequence of what we have learned in the course of its development and refinement. A few of these insights and evolutionary steps are discussed below.

Family Structure and Roles

Family therapists and social scientists have proposed many different definitions of family and ways to organize families and distribute family roles (Richards, 1996; Patenaude, 2005; McDaniel *et al.*, 1992; Rolland, 1994). The CEGRMs revealed that direct family interactions regarding information such as genetic mutation status is pragmatically bounded by the nuclear family in most cases, either the nuclear family of origin (parents and sibs), the current nuclear family (spouse and children), or both. For example, while we observed a few exceptional cases of cousins being very close and interacting directly with one another, it was much more common for communications to proceed sequentially from patient to a parent, to a parental sibling and, finally, to the intended cousin.

Friends, neighbors, old school chums, and coworkers all received varying degrees of recognition as sources of significant support, most frequently when sharing information about genetic testing or when seeking emotional support. The women appear to have a more encompassing view of family than the more traditional one based on blood relationships. For example, "in-laws," i.e., family members not in the bloodline at risk of familial cancer, were frequently identified as major social supports, sometimes even after a couple had divorced.

The bulk of the cancer burden in these families is borne by female family members. Gender also appears to modify individuals' ability to provide various types of support to participants. For example, although many women identified their husbands and/or fathers as frequent sources of emotional and sometimes informational support, we informally observed that the vast majority of support persons identified were female, an observation we have not yet quantified.

These observations regarding the support role of the male partner have some precedence in the breast cancer literature (Lugton, 1997; Pistrang *et al.*, 1997). Pistrang *et al.* point out that the personal meanings of the interactions between the couple needed to be placed in the context of the couple's relationship in order to understand how support attempts are delivered effectively and how they sometimes fail. Kenen's interviews with at-risk women in the UK corroborated our findings that expectations regarding men's roles differed, e.g., "It was expected that men did not like to talk about illness and death, and a couple of women brought up the point that their male partners felt vulnerable when thinking about the possibility of their primary significant other dying at a relatively young age. Most of the women expected to be the ones to broach the familial breast/ovarian cancer subject and initiated the discussion at a deeper level. If their male partners listened, then they considered them to be supportive" (Kenen *et al.*, 2004). This in no way implies that the men are not supportive, only that what is expected and delivered differs between men and women.

In studying women with breast cancer, Kayser and colleagues point out what is emotionally supportive is not only what a woman receives from her partner but also what she experiences as giving to her partner (Kayser *et al.*, 1999). We also found evidence of mutuality in all the supportive relationships that women described to us (Peters *et al.*, 2004).

Health Communication

In order for genetic counselors and other health care providers to facilitate families' optimal utilization of hereditary cancer risk information, it is important that they understand to whom, how, when, and why family members convey genetic information (Green *et al.*, 1997; Bowen *et al.*, 2001; Bowen *et al.*, 2004; Koehly *et al.*, 2003). The CEGRM helps capture these complex interactions.

For example, in CEGRMs completed prior to 2005, the two communication roles of collecting and disseminating health information were considered as one role represented by the green star. We expanded this conceptualization into separate roles in 2005 after hearing about the family communication pattern in a particular family. In this family, a participant noted that while her mother took the task of disseminating cancer and genetic testing information to the family, it was the participant herself who gathered that type of information. Since that time, many other participants have differentiated between these two information-based roles. Sometimes each role is described as being filled by more than one person in the family; other times, one person does it all. Therefore, we subsequently made a permanent change to our CEGRM process and added a silver star to represent an information gatherer and maintained the green star as a symbol for an information disseminator. This refinement to our data collection strategy has increased the utility of the CEGRM in further clarifying our understanding the nature of health information exchanges in families.

Peterson and colleagues observed, "When individuals seek genetic counseling and genetic testing [for HNPCC], current standards of practice encourage and rely on those persons to communicate information about hereditary cancers to their relatives" (Peterson *et al.*, 2003)(p. 79). Yet, we found that conveying a message of genetic risk to more distant relatives was sometimes experienced as a burden, in keeping with other research (Forrest *et al.*, 2003; Hallowell *et al.*, 2004). A few participants specifically mentioned that they did not wish to burden or worry others with their troubles. Some women were conflicted as they tried to balance their own autonomy and responsibility to the family with feeling protective and not wanting to be the bearer of bad news. However, these dilemmas were not voiced to us with the same frequency or poignancy as to Hallowell (2004), perhaps due to cultural differences regarding

notions of privacy and decorum between women in the UK vs. US.

We also saw an intersection of gender with the duty to disclose genetic information, with both the benefits and burdens of this task falling primarily on women, a finding in agreement with others' research (d'Agincourt-Canning, 2001).

It appears that communication about genetic risk is more multi-faceted and culturally situated than previously appreciated. There have been numerous other studies focused on family communications that go into more depth on many of these issues, and we hope to add to that literature in subsequent publications based on our study cohort.

Religiosity and Spirituality

As is being recognized in a variety of counseling professions, including genetic counseling, consideration of spiritual and religious beliefs and attitudes is important in understanding the client (Knox *et al.*, 2005). We found that our CEGRM assessment benefited from the addition of this domain, by enriching our understanding of their social context as well as helping participants feel understood in a holistic way that promotes healing, as defined by Egnew to relate to the personal, subjective experience involving reconciliation of the meaning an individual ascribes to distressing events with her perception of wholeness as a person (Egnew, 2005).

A full review of assessment of religious practices and spirituality is beyond the scope of this paper. Most readers will be familiar with the general concept, although perhaps not with how complex this assessment might be. Domains that might be included are such phenomena as daily religious practices (e.g., prayer and attending services), moral values, religious beliefs, ethical behavior, practice of forgiveness, religious coping, support, personal and community historical precedents, commitment, and organizational affiliation (Rippentrop *et al.*, 2005). Generally, "religion" is the term reserved for institutional and structural aspects of faith practices, whereas "spirituality" applies to the more existential or inner feelings of connection with something outside or larger than oneself and one's tangible world. A detailed review of studies of religion and spirituality with respect to cancer was recently completed (Stefanek *et al.*, 2005).

CEGRM as a Psychosocial Intervention

During the two-day, research protocol-driven visit, the CEGRM session and a visit with a licensed clinical social worker were the participants' only non-medically oriented appointments. Constructing the CEGRM was a welcome break from the often anxiety-provoking clinical research protocol, offering respite and an opportunity for reflection and discussion of loved ones and important relationships.

The following observations support our belief that the CEGRM can be an effective psychosocial counseling intervention tool. During the CEGRM process, the participants were transformed from passive information recipients into active, dynamic team members. The participants came to recognize that *they* were the experts in the room, and that *they* were responsible for teaching the investigator about their social world. This participant-empowering arrangement leveled traditional hierarchical power differentials that often exist between investigators and participants in medical and research settings, and facilitated the participant's willingness to share more emotionally charged material.

Participants were actively engaged in the assessment/counseling process both by personally modifying/updating the pedigree and by actively placing CEGRM symbols onto the pedigree document. Current psychosocial research has demonstrated the personal and therapeutic benefits of collaboratively engaging participants in the counseling process (Gordon *et al.*, 2005; Schneider, 2003). In the context of seeking insight into one's social milieu relative to understanding and acting upon genetic information, this strategy seems to facilitate tapping under-utilized internal resources for healing and implementing core change. In fact, many family therapists find that attending to the relational context is essential for the successful therapeutic process (Rober, 2005).

Emotional expressiveness on the part of the participants was promoted through the bonding, mutuality, and empathy that are fostered during the CEGRM process. As the counselor and participant worked through the CEGRM process together, the counselor continually prompted the participant to share information by giving empathic, engaging responses and by eliciting narratives from the participant. As participants found themselves relating stories about their relationships with friends

and family members, new insight occurred into inter-generational patterns of relationship dynamics and awareness of one's own role and its implications. We suggest that the strong mutual empathy that may develop during this interactive process between participant and investigator also influences the quality of research findings by influencing which stories participants will tell and which not, with more vulnerable material emerging only in the context of a trusting, mutually empathetic relationship.

This empathic framework also increases patient's willingness to share strong private feelings which might underlie personal issues. These underlying issues constitute an important focus of the counseling process. For example, we frequently encountered unresolved grief and ongoing mourning during the CEGRM process. This often occurred when women were "reminiscing about" their relationships with their mothers, sisters, aunts, and grandmothers who had experienced breast or ovarian cancer, particularly if they had died. As Wellisch pointed out over a decade ago, adolescent women experience significant long-term emotional sequelae when their mothers develop or die from breast cancer (Wellisch *et al.*, 1992). Uncovering these unresolved feelings creates a valuable therapeutic opportunity for the counselor and the client. The CEGRM process provides an indirect entry point into these important emotional issues; by contemplating the loss of important social contacts that were imbedded in the role of the deceased relative, the larger issues of unresolved grief are unexpectedly encountered.

Comparison of the CEGRM with other existing tools

We see the CEGRM as complementary to the standard genetic counseling, psychiatric or clinical social work interviews, as well as to the standard pedigree and genogram or to standardized questionnaires. The pedigree is the foundation of the CEGRM because it is routinely available for our study participants, is universally used in cancer genetic counseling and it already includes key blood relationship and health information. While the genogram evolved from practices in family psychotherapy (with its emphasis on diagnosis and tracking of dysfunctional family patterns), the CEGRM was designed for practice with normative families, seeking to identify what works well socially for a given individual. Unlike the genetic pedigree, the CEGRM gives equal weight to unrelated individuals outside the family circle. While both the CEGRM and genogram depict close relationships within the family, only the CEGRM elicits and illustrates the full range of social support and inter-connections, especially the functional. While several standardized questionnaires existed for assessing social support, in our assessment, none included all of the components of the CEGRM, had the flexibility to deal with variations of responses and special situations, nor provide sufficient depth of information on certain issues related to genetic testing (Sarason *et al.*, 1983; Weissman *et al.*, 2001). On the other hand, the CEGRM interview, as currently constituted, sometimes fails to detect other unrelated stressors in the participants' lives, e.g., work tensions, events in the partner's family, natural disasters, etc. Thus we now ask participants directly at the conclusion of the process whether they have other important, active stressors in their lives.

This extended study was also designed to evaluate whether the CEGRM was operator-specific: Could counselors other than the originator use the CEGRM process successfully? To date, twenty-two CEGRMs have been co-constructed by two other investigators, seven by a genetic counseling graduate student, and fifteen by a marriage and family therapy graduate student. Both were as, or more, successful than the originator in helping participants construct and interpret their CEGRMs. We would welcome other properly trained students doing replication studies. Some participants mentioned that it was the investigator's welcoming manner that encouraged candid story-telling rather than the CEGRM *per se*. Thus both participants' and our own experiences suggest that, in addition to participant willingness, the main ingredients required to successfully construct a CEGRM are openness and the ability to establish rapport, as well as good interviewing and counseling skills, characteristics shared by all three investigators. In fact, the CEGRM may be useful in counseling training programs to facilitate development of these counseling skills.

Study Limitations

The fact that ours is a descriptive, cross-sectional study of mostly white, married, highly-educated, motivated women participating in a longitudinal breast imaging clinical trial is one of the major limitations of the current study. We do not know how generalizeable these observations would be to a less highly-selected population. The potential bias

of social desirability should be mentioned, since the evaluative research questions were administered by those who were also providing clinical service. Further, we have not yet validated the CEGRM in relation to other standardized measures of family functioning, although this would be difficult since the CEGRMs broad content and interactive information acquisition process is not captured by these more traditional tools. It is reassuring that the CEGRM seems to yield reliable impressions with a meaningfully sized study population and in the hands of different investigators. We see the CEGRM as complementary to other assessment modalities such as genograms, interviews, and questionnaire based data, rather than as a stand-alone tool.

Future Directions

The longitudinal nature of the Breast Imaging Study, of which the CEGRM project has been a component, provides us with an opportunity to follow-up CEGRM-specific parameters annually, and to monitor how diffusion of genetic information and support related to the stresses accompanying increased genetic risk of cancer change over time; data collection during follow-up visits is ongoing. We are now completing CEGRMs for both men and women participating in a familial testicular cancer protocol, in order to assess the feasibility of using this instrument in male respondents, and to clarify gender issues in family communication and support. We are also considering undertaking formal social network analysis with our data.

It has been suggested that genetic counseling training programs formally introduce the CEGRM model of the "expanded pedigree" into the genetic counseling curriculum. This could be useful in training students how to think about and conduct social assessments. Such customized psychosocial training could be a precursor to inviting genetic counselors in specialty clinics, especially in pediatric settings or research studies with long term follow-up and case management, to adopt this or similar family systems tools to track important family issues and to facilitate enhanced conversations among interdisciplinary team members managing families with complex genetic conditions.

Potential Clinical Applications

Genetic counseling involves both the provision of genetic information about a given inherited condition and support for at-risk individuals as they integrate new genetic information, adjust to their risk status emotionally and socially, and struggle to make informed decisions regarding healthcare, lifestyle and reproductive choice (Weil, 2000). The CEGRM can reveal areas troubling the client, e.g., unresolved grief or marital discord. In such cases, the genetic counselor can briefly discuss these issues with the counselee and ask whether she would be interested in a referral to a family therapist or other support/therapeutic professional.

Our work with the CEGRM demonstrates that people coping with the challenges of integrating their genetic risk status into their lives turn to family and friends for informational, tangible, emotional and spiritual support. Advances in genomic medicine will undoubtedly require an interdisciplinary approach combining the skills of medical and mental health professionals for the management of cancer-prone family members, e.g., to assist at risk individuals with family communications and medical decision making (Guttmacher *et al.*, 2001; Patenaude *et al.*, 2002; McDaniel *et al.*, 1992; McDaniel, 2005).

In the early years of clinical cancer genetics, genetic counselors focused their energy on *educating* their clients regarding general genetics concepts and syndrome-specific risk, medical management and genetic testing information. Our experience developing the CEGRM serves as a reminder of the broader psychosocial and behavioral context in which the genetic risk assessment activity takes place. It is time to reaffirm the "counseling" aspects of genetic counseling. To provide high-quality, comprehensive care to our patients, we must assess their personal, social, and emotional concerns, and consider the impact of receiving genetic test results, the challenges of family interactions and communications, the stress related to making wrenching medical decisions, and the social consequences of being designated "at increased genetic risk of cancer."

In summary, completing the CEGRM with women from hereditary breast/ovarian cancer families provides a concise, graphic means of assessing and displaying the social interaction domains of information, tangible, emotional, and spiritual exchanges in a broader social theory context than do assessment techniques currently in clinical use. This process provides insight into how, why, when, whether and with whom genetic information is shared and how this information is integrated into health decisions. The CEGRM seemed to provide a focus or a framework for putting into words the

participants' thoughts regarding complex social interactions with their family and friends. Additionally the CEGRM offers opportunities to engage therapeutically with participants about issues that arise in the mutually interactive CEGRM process.

Ultimately, all of these assessment and intervention strategies contribute to improving the health and quality of life of individuals living with increased cancer risk. With a deeper understanding of these issues, we will be better able to develop constructive interventions which facilitate incorporation of genetic information into one's sense of self, improve the effectiveness of communication with family and friends, and facilitate mobilization of needed support, as high-risk women share their deeper feelings with significant others.

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