

Exploratory Study of the Feasibility and Utility of the Colored Eco-Genetic Relationship Map (CEGRM) in Women at High Genetic Risk of Developing Breast Cancer

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We report here the results of an exploratory feasibility study of the colored eco-genetic relationship map (CEGRM), a novel, recently-developed psychosocial assessment tool, which incorporates features of the genetic pedigree, family systems genogram, and ecomap. The CEGRM presents a simple, concise, visual representation of the social interaction domains of information, services, and emotional support through the application of color-coded symbols to the genetic pedigree. The interactive process of completing the CEGRM was designed to facilitate contemporary genetic counseling goals of: (a) understanding the client in the context of her/his social milieu; (b) bolstering client self-awareness and insight; (c) fostering active client participation and mutuality in the counseling interaction; (d) eliciting illuminating social narratives; and (e) addressing outstanding emotional issues. Twenty women participating in a breast imaging study of women from families with *BRCA1/2* mutations completed and evaluated various aspects of the CEGRM. We found that efficient construction of the CEGRM was feasible, and that compliance was excellent. Participants developed insights into their social milieu through observing the visual pattern of relationships illustrated by the CEGRM. The process of co-constructing the CEGRM fostered the participant's active involvement in the session, marked by mutuality and increased empathy. In this clinical research context, the participants felt free to share poignant stories about their friends and families. Further studies are planned to refine the CEGRM and to examine its utility in cancer genetics research. Published 2004 Wiley-Liss, Inc.[†]

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

In this study, we report the results of an exploratory study of the feasibility and acceptability of a new graphic tool, the colored eco-genetic relationship map (CEGRM), which helps the clinically-oriented researcher visually and conceptually organize information about study participants' social interactions. This study was undertaken in the context of a familial cancer genetics research setting.

Familial cancer risk counseling is a communication process between a health care professional and an individual concerning the occurrence or risk of occurrence of cancer in an individual's family [Peters, 1994a,b]. The service, often seen as a variation on genetic counseling, is comprehensive in scope and includes a strong emphasis on the familial nature of cancers [Peters and Stopfer, 1996; Richards, 1996]. Components of the genetic cancer risk clinic usually involve provisions for management of psychosocial issues as well as management of medical and genetic risk [Biesecker et al., 1993; Eeles and Murday, 1996; Peters et al., 1999b; Schneider, 2001; Evans and Lalloo, 2002].

Although genetic counseling, which is often associated with genetic testing, has been offered for several decades, there is no consensus regarding the specific ingredients required for successful counseling outcomes [Resta, 1997; Biesecker and Marteau, 1999]. In part, this is due to the multi-purpose nature of the activity. Genetic counseling involves not only the provision of genetic information about a given condition and its inheritance pattern; it also is intended to help at-risk individuals integrate the new genetic information, adjust to it emotionally and socially, and make informed decisions about healthcare, lifestyle and other important matters [Ad Hoc Committee of the American Society of Human Genetics (ASHG), 1975; Weil, 2000]. The optimum strategy to accomplish these goals remains undefined.

The practice of cancer genetic counseling includes components of both the educational and counseling models of genetic counseling [Peters and Stopfer, 1996; Peters et al., 1999b]. The goal of the educational model is to inform counselees about medical and genetic factors pertinent to their family situation, based on the assumptions that they come for information and that they will be able to make their own decisions, given the right information. In the expanded genetic counseling model, the goal is to understand the client, bolster their inner sense of competence, promote a greater sense of self esteem and control over their lives, relieve distress, optimize social support, assist them in finding solutions to psychosocial problems related to the genetic disorder, and help them make difficult decisions about medical management of risk [Kessler, 1997; Peters et al., 1999a; Resta and Kessler, 2000]. These counseling tasks require significant levels of client self-awareness and mutual exchange within the context of a helping relationship. Variations on the counseling approach that also foster client

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empowerment and interaction include the mutual participation model and the life history narrative model [Kenen and Smith, 1995].

To further these goals, the CEGRM was conceived to incorporate the most helpful aspects of the genogram, ecomap, and genetic pedigree [Kenen and Peters, 2001]. The genogram is a tool used by psychotherapists, primary care providers, genetic counselors and researchers to capture historical inter-generational psychosocial information along with the usual family structure data [Rolland, 1989; McDaniel et al., 1992; Eunpu, 1997; Daly et al., 1999; McGoldrick et al., 1999]. The genogram has been further developed and customized for use in various clinical settings [De Maria et al., 1999].

The ecomap, which can stand-alone or used as a supplement to the genogram, is a tool used to illustrate how the family system is currently connected to outside resources, organizations, and agencies [Hartman, 1978]. The ecomap has been used to assess marital and family spirituality [Dunn and Dawes, 1999; Hodge, 2000]. The family map proposed by De Maria et al. [1999] is similar, as it tracks both dysfunctional as well as nurturing and supportive relationships within and outside the family.

The genetic pedigree is a nearly universally accepted graphic method among genetics professionals of recording genetic and medical family history data [Bennett et al., 1995; Bennett, 1999]. The emphasis is on accurate tracking of medical conditions as they are passed on through biological relationships.

While each of these recording systems has its advantages, none is completely satisfactory in the context of the contemporary genetic counseling goals of: (a) understanding the client in the context of her/his social milieu; (b) bolstering client self-awareness and insight; (c) fostering active client participation and mutuality in the counseling interaction; (d) eliciting illuminating family history social narratives; and (e) addressing outstanding emotional issues. We chose the genetic pedigree as the foundation of the CEGRM because of its familiarity to both cancer genetics counselors and to people who have already undergone genetic counseling, thus possibly easing the shift to the CEGRM.

METHODS

Design

This is a cross-sectional exploratory study of the social exchanges of women at high genetic risk of breast cancer in a breast imaging clinical research study.

Participants

The study participants were comprised of 20 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. Each woman was between 25–56 years of age, came from a family with a known deleterious germline *BRCA1* or *BRCA2* mutation, and had a first-degree or second-degree relative with a *BRCA*-associated malignancy, but was herself cancer-free. Each woman had undergone prior genetic education, counseling, and *BRCA1* or *BRCA2* genetic testing for the family's mutation.

Procedure: Constructing the CEGRM

Upon entry into this IRB-approved breast and ovarian imaging study, each woman gave written informed consent for a battery of psychosocial evaluations, along with the medical evaluations they were receiving. The CEGRM was part of this battery. Each woman verbally re-affirmed her wish to proceed with the CEGRM immediately prior to beginning the imaging study research process. Only the CEGRM exploratory study results are being reported here (Fig. 1).

After completing informed consent, the participant and the researcher together then constructed the CEGRM, using the participant's computerized genetic pedigree as a template. We added symbols for meaningful non-kin relationships. The researcher then used a semi-structured interview to guide the participant through the process of placing various color-coded symbols on the pedigree, at the appropriate location. The three research domains—information, services, and emotional interactions—were represented by blue, green, and yellow circles, respectively. Sample questions are indicated in the

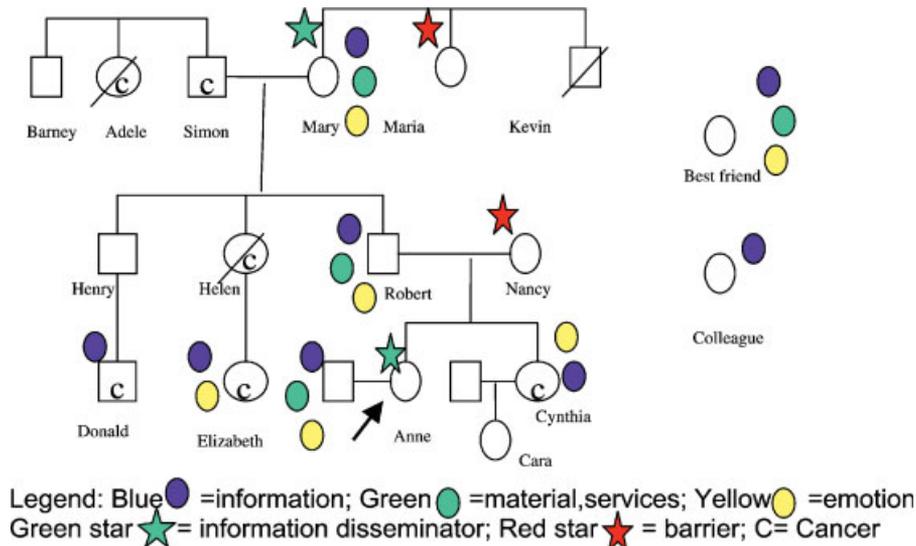


Fig. 1. Sample hypothetical colored eco-genetic relationship map (CEGRM).

specific domain sections below. The participants were queried regarding the mutuality of these relationship interactions, and departures from mutuality were noted. As the participant placed the color-coded stickers onto the pedigree, creating the CEGRM, the researcher recorded as much as possible of the participant's verbal comments, in blank space provided on the interview guide.

Information interactions. The "information 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?" Two additional information issues were also explored, "dissemination" and "blocking." Green stars (green for "go") were used to represent people who were key disseminators of cancer genetics and related health information within the family and friendship networks. Red stars (red for "stop") represented those who prefer to avoid health information or whose need for privacy might present barriers to genetic and cancer information being freely discussed and transmitted within the family.

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

Emotional interactions. Yellow circles represented emotional interactions in response to the question "With whom would you share your feelings about being at increased cancer risk?"

At the conclusion of the 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 in looking at your CEGRM?" The start and ending times were noted, so that the total time required to complete the CEGRM could be determined.

Procedure: Evaluation of the CEGRM Process

The results of this exploratory 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 construction of the CEGRM. Feasibility was assessed for each of the seven outcomes: time to completion, understandability, comfort, ease of use, ease talking and perceived proportion of time client talked, and success in eliciting narratives. In consultation with a research psychologist, the investigator devised a multi-dimensional Likert scale rating system. In this system, 1 was the best possible score and 10 the worst. The scores of the individual evaluation items were entered into an Excel database, and the responses were summarized in tabular and graphic form using SPSS version 11.5. Inferences about the utility of doing a CEGRM were derived from 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 44 years (range: 29–56). Participants were all Caucasian, with one participant noting additional American Indian heritage. This was a well-educated group, with the majority (15/20 or 75%) being college graduates; many had attended graduate school, had masters or doctoral degrees. The majority of the women (15/20 or 75%) were married, three women (15%) were separated or divorced, and two women (10%) were single.

Compliance

All twenty participants (100%) whom we approached about participating in the CEGRM exploratory study agreed to attempt to do so.

Feasibility

The aggregate results are presented in Table I. Each of the outcome variables is discussed separately below.

Length of time required to complete a CEGRM. Beginning with a previously-constructed genetic pedigree, it took between 13–50 min to complete each CEGRM (mean: 28 min.), with most women taking about 20–30 min.

Understanding. Most participants quickly and easily grasped the concept and process of constructing the CEGRM. The scores on the "Understanding" question ranged from 1 (best) to 5 (neutral), with a mean of 1.8. Since each participant had undergone genetic education and counseling prior to being enrolled in the parent breast imaging study, they were familiar with the concepts and appearance of the pedigree, and found it easy to understand how to transform it into a CEGRM.

Comfort. Most women were comfortable with the process of constructing the CEGRM. These distribution of scores ranged from 1 to 5 with a mean of 1.9. Most of the women seemed relaxed; they smiled and joked, and appeared to enjoy the process of CEGRM construction.

Ease of use of the media. The ease of using the color-coded adhesive symbols to construct the CEGRM was measured in two ways: (1) the participant's rating of ease of use on the 1–10 Likert scale; and (2) the proportion of placement attempts made in which the subject placed the color-coded stickers on the CEGRM, without assistance.

While most participants rated ease of use at 1 or 2, the range was wider than on other feasibility measures, with one participant scoring ease as 5, and another of 10 (mean: 2.3). Sixteen of the 20 women (80%) were able to place all of the stickers during CEGRM construction without assistance from the interviewer; the remaining four women required some help.

Stickers were selected to have a non-permanent adhesive, which permitted them to be lifted off the CEGRM and moved.

TABLE I. Results of Quantitative Feasibility Measures

Item	Variable	Number	Minimum	Maximum	Mean	SD
1	Time to complete	20	13	50	27.6	8.6
2	Understanding	20	1	5	1.8	1.2
3	Comfort	20	1	5	1.9	1.1
4	Ease of media	20	1	10	2.3	2.2
5	Ease of talking	20	1	10	1.9	2.0
6	Narratives	20	1	7.5	2.3	1.8
7	Perceived time talk	20	50%	90%	71%	14

This proved useful on a number of occasions when participants wished to alter the sticker location or to clarify ambiguous sticker placement. It became obvious through their comments and changing placement of symbols, that participants were considering the nature of their relationships as they were completing the CEGRM, literally thinking with their hands. A permanent means of placing the symbols such as colored marker pens would not have permitted such changes to be easily made.

Ease of talking about family relationships in the CEGRM context. The CEGRM seemed to facilitate participants talking about the nature of their social interactions (or lack thereof) with family and friends. The “ease of talking” scores ranged from 1 to 10, with all but one rating in the strongly positive range (mean: 1.9). The woman who scored 10 on this scale was not the same person with a 10 on the ease of use scale. 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.

Usefulness of the CEGRM in eliciting family narratives. There was a continuum (range: 1–8) with regard to women’s comfort with disclosing to researchers detailed information about their interactions with family and friends (mean: 2.3). In the process of constructing the CEGRM, some participants frequently told stories about one person or another, as they thought about their relationship with that person, or if they were trying to illustrate a particular point about a social exchange. One woman who scored higher (worse) on the narratives scale identified herself as being more private and reserved in talking about family and friends. Another woman told few stories in general.

Proportion of time that the participants perceived that they talked during CEGRM construction. All participants perceived that they talked for at least half the total duration of the visit, with some speaking almost all of the time (mean: 76%). This figure was based on a subjective estimate made by the participant and the researcher together; it was not objectively timed.

Utility

Along with evaluating whether it was possible to construct the CEGRM simply and efficiently, we wanted to determine whether additional useful psychosocial information might be gleaned from this process. The various ways in which the CEGRM proved useful are covered in greater detail below and in the “Discussion.”

The CEGRM proved useful in assessing social exchanges of information and emotional support among participants and those with whom they frequently interacted. Most participants reported sharing medical and genetic information with a variety of people including spouse, family, and friends via a variety of communication methods, e.g., telephone, in person, mail, and e-mail. The majority readily identified more information disseminators than blockers within their social networks. The pattern of information dissemination varied from family to family and also by gender, generation, among siblings, and by mutation status. For example, some women reported that they did less sharing of genetic information with male relatives. This is in keeping with gender differences noted by other investigators and makes sense given the skewed gender distribution of cancers in families with HBOC [Green et al., 1997; Costalas et al., 2003].

Responses to inquiries about sources of tangible support depended on the gender and geographical distribution of family and friends. For those who were married, the spouse was typically the first person they would turn to for help of any sort, with immediate family members such as parents or

siblings a close second. Other participants’ networks were primarily friendship-based.

All the women in this study reported having significant emotional support, as reflected by the many yellow circles they placed. However, the breadth, depth, range, and intensity of their emotional ties varied widely. Some women could identify one or two individuals with whom they felt closest and who demonstrated most signs of emotional caring. Others described concentric circles of intimacy with relatives and friends about their health concerns. The stories often reflected an ebb and flow of emotionally important relationships over time. As with information sharing, there were significant differences in patterns of emotional support by gender, generation, and side of the family.

Many women spontaneously told stories during construction of the CEGRM. There were stories of relatives who were ill and needed caretaking, as well as tales about the people with whom the participant talked about health matters. In fact, one woman added her physician to her CEGRM as she described how it felt to talk with him about her family history.

DISCUSSION

This exploratory project demonstrated that nearly all of the women we studied in a high-risk breast imaging research study found the CEGRM to be feasible, comfortable to do and efficiently accomplished. The CEGRM took a relatively short time to complete, usually less than 30 min. This time should be considered in addition to the time it takes to construct the genetic pedigree, often 10–15 min. in clinical settings, longer in genetic research studies. Thus, the CEGRM might not be suitable to clinical genetic counseling settings with severe time constraints.

The CEGRM, as an adjunct to the pedigree, is useful in updating or correcting genetic and/or medical information in the pedigree as occurred in several instances. It also makes broader social assessment possible, in that it includes both biological and non-biological social connections. Like pedigrees which make inheritance patterns of disease more recognizable, the CEGRM displays patterns of social networks in a visible gestalt that is readily comprehensible.

Because the CEGRM construction is interactive and non-threatening, it was largely engaging and enjoyable for both participants and researcher. This had the positive effect of lowering participant psychological defensiveness, leveling power differentials inherent in medical settings, and increasing empathetic connections. These qualities are desirable in a counseling encounter because they have the effect of promoting emotional expressiveness, bonding, mutuality and empathy.

The CEGRM procedure promoted participant self-awareness, insight, and integration. More specifically, several participants spontaneously reported finding it helpful to see visual documentation of their social support network. Viewing the CEGRM enabled them to summarize their social networks succinctly in their own minds, and to feel reassured by having the researcher confirm their perceptions of social reality. For example, one woman observed that constructing the CEGRM allowed her to see (literally) that she had more extensive support than she had previously realized. Another woman observed that her sources of support were more diverse than she had expected.

The CEGRM illustrated the importance of spouses and children to the well-being of the women in this study. Spouses were the main source of emotional, informational and tangible support for the married women, as has been reported by other researchers [Bluman et al., 2003; Wylie et al., 2003]. Some of the women talked with their children about genetic and cancer information and genetic testing, and some derived significant emotional and tangible support from their children. The

CEGRM study adds to the literature on communication of genetic results in a breast and ovarian inherited cancer family [Richards, 1996; Lerman et al., 1998; Lindberg and Wellisch, 1999; Smith et al., 1999; Foster et al., 2000; Julian-Reynier et al., 2000; Lehmann et al., 2000; Claes et al., 2001; Kenen et al., 2001; Michie et al., 2001; Claes et al., 2003; Costalas et al., 2003; Forrest et al., 2003; Peterson et al., 2003].

Friends, in-laws, and small cohesive groups, e.g., close neighbors, church members, and co-workers, were also clearly important to the women in this study. Our results support findings of Kenen et al. [2001] from a UK study. The researchers found that almost all the women had close women friends with whom they shared everything. Some of them were more open with these friends than with relatives regarding their genetic risk and breast cancer concerns.

One hypothesis we had entertained prior to this feasibility study was that the CEGRM might identify participants with inadequate social support. This pre-conceived notion was not confirmed. Rather, we found that each woman was satisfied with her own social world as represented in the CEGRM, regardless of how sparse, dense, intense, estranged or far-ranging the social network might seem to the outside observer.

The process of constructing the CEGRM elicited rich social narratives from most participants. As McDaniel et al. [1997] point out, "In the narrative of every human life and every family, illness is a prominent character." It is an essential part of the role of the genetic counselor to bear witness to life's hard stories about illness and suffering, to honor them by listening and to help our clients make meaning of them. The CEGRM seemed to aid in those processes.

The theme of mutuality arose in two ways in this project: (1) mutuality was an important quality of the relationships that the participants were reporting and (2) mutuality became manifest in the CEGRM construction process itself.

Mutuality of relationships is an under-studied aspect of the cancer genetics social support literature, although it is reported as a significant component of healthy relationships in the psychological literature [Jordan, 1991; Jordan et al., 1991; Genero et al., 1992; Miller and Stiver, 1997]. In one small study, mutuality was also an important predictor of adjustment to breast cancer [Kayser et al., 1999]. Most participants in the present study reported that the majority of their important social relationships were mutual. In fact, their comments suggested that mutuality may be one of the criteria that women use in deciding to include a given person in their health-related social networks as depicted in the CEGRM, with few non-mutual relationships reported. This has implications for evaluating women in cancer genetics clinical practice in that the genetic counselor might identify those who lack mutually satisfying relationships as potentially in need of referral.

There was mutuality embedded in the CEGRM process itself, in that the counselor and participant constructed the CEGRM together, each taking a very active role in transforming the pedigree from a biomedical document into a psychosocial one. The active CEGRM process thus affords women the opportunity to actively and tangibly think through their methods and motivations of sharing or not sharing the genetic information that they were provided through genetic testing; thereby, allowing them to better integrate the genetic information into their thinking and into the social fabric of their lives.

The CEGRM also provided an opportunity to deal therapeutically with unresolved grief and mourning issues commonly encountered in this high risk population. For example, one participant reported that completing the CEGRM led to a new insight regarding the long-term effects of early losses due to cancer in her family, especially the death of her mother. She noted that this had not only a personal emotional effect, but also a social one, by restricting contact with relatives on the

maternal side of the family. Thus, the CEGRM may also be useful in on-going genetic counseling interactions dealing therapeutically with families with other inherited disorders and chronic conditions such as Huntington disease, Duchenne muscular dystrophy, sickle cell disease, and cystic fibrosis as well as cases involving therapeutic abortions or continuing pregnancies of fetuses with congenital anomalies.

Limitations

The present study has several limitations. This was an exploratory, cross-sectional study of a small population of mostly white, married, highly-educated, highly-motivated women in a breast imaging research study. The high level of functioning of the study participants provided less information regarding exchanges of tangible support regarding health, not through any CEGRM deficiencies, but because the participants in this study were largely healthy, self-sufficient women in the prime of life, who seemed not to need extensive tangible support with respect to coping with cancer risk. Thus, the results cannot yet be generalized to other clinical or general populations.

While we did note that information obtained by CEGRM generally matched the informal impressions of other clinicians on the study team, we did not institute formal procedures to assess reliability and validity at this time. We view the CEGRM primarily as a qualitative tool to help systematically identify and elucidate key social issues in individuals. With consultation, we hope to address utility in our future efforts through a variety of means including extending the use to men, repeating the CEGRM at annual follow-up appointments to capture longitudinal impressions of our participants' social lives, comparing the CEGRM to semi-structured interviews and perhaps other measures of social functioning.

Despite the high compliance rate, constructing the CEGRM was not an entirely successful exercise with all participants. A few women had technical problems with specific aspects of constructing the CEGRM (e.g., were unable to manipulate the small stickers due to having long finger nails), felt uncomfortable in talking about their family and friends with the researcher, or were distracted by medical concerns about breast imaging procedures scheduled before or after the CEGRM. While it is possible that some patients may have felt compelled to cooperate with the CEGRM sub-study because of their desire to participate in the breast imaging project, the latter was not contingent upon the former. Patients were invited to take part in the CEGRM evaluation only after they had already enrolled in the breast imaging project.

There were other limitations of the CEGRM as a stand-alone record of the subject's social system. These pictorial representations proved insensitive to some of the nuances of social dynamics. For example, women talked about differences in timing, intensity, or compartmentalization of social interactions that were difficult to capture with the CEGRM's current design. While these were not indicated pictorially, they were captured through ancillary notes. Thus, we would recommend using the CEGRM to generate qualitative as well as graphic data, much as the multi-focused family genograms supplement basic genogram information with more detailed family maps, timelines and notes.

CONCLUSIONS

This small study contributes to filling a research niche of assessing the long term social status of people undergoing cancer genetic testing. There has been a call for such research in the literature [Bowen et al., 2001; Forrest et al., 2003; Sorenson and Botkin, 2003]. Despite its limitations, and given the very preliminary nature of the evidence from this

exploratory study, the CEGRM appears to be a feasible tool in the research setting for studying social interactions in women who come from families with hereditary breast and ovarian cancer susceptibility due to *BRCA1* or *BRCA2* mutations. It was well tolerated and there were no adverse psychosocial effects.

The CEGRM presents a simple, concise, visual representation of the social interaction domains of information, services, and emotional support through the application of color-coded symbols to the genetic pedigree. The process seemed to facilitate contemporary genetic counseling goals of understanding the client in the context of her social milieu; bolstering client self awareness and insight; fostering active client participation and mutuality in the counseling interaction; eliciting social narratives and addressing emotional issues. More specifically, in order to understand why, and whether, genetic information is likely to be passed on, the counselor/researcher must consider a variety of cultural and familial factors such as the nature of pre-existing relationships, patterns of interaction, tensions and rifts that may promote or hinder communication of important health information [Forrest et al., 2003]. Thus, the CEGRM has the potential to serve both as a tool for assessing social networks, as well as an opportunity for therapeutic psychosocial intervention.

Given the encouraging results from this preliminary study, we are continuing to explore the utility of the CEGRM and considering applications in other medical or epidemiological research studies which target members of families with a hereditary predisposition to cancer.

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