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Communication Patterns in Korean Families during BRCA Genetic Testing for Breast Cancer

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Purpose: The purpose of this micro-ethnography is to examine whether science and societal changes impact family communication patterns among a convenience sample of 16 Korean women. **Methods:** The authors observed family communication in the context of a new breast cancer genetic screening and diagnostic testing program to detect BRCA gene mutations in Korean women at highest risk. **Results:** Analysis of in-depth interviews and field notes taken during participant observation illustrated that communication patterns in families vary according to a woman's position in the family. If a grandmother tests positive for a gene mutation, her daughters make decisions on her behalf; they open and maintain the communication channel among family members. If a housewife is diagnosed with cancer and a genetic mutation, she immediately consults her husband and her sisters. The husband creates an open communication channel between his wife, his parents and his siblings. As a result, a woman's cancer is a concern for the whole family not merely a woman's secret or crisis. **Conclusion:** Cultural differences are important to consider when designing new genetic service programs in different countries.

Key Words: *Breast Neoplasms, Genes, Genetic Counseling, Health Communication, Cultural Anthropology*

INTRODUCTION

Women with a family history of early-age onset breast cancer due to an inherited BRCA1/ 2 gene mutation are at increased risk because the probability for developing a malignant tumor, depending on age, is 60% to 80%.[1)] A deleterious BRCA gene mutation is known to increase susceptibility to breast cancer in women of any ethnicity at a rate of 5-7% of all breast cancers.

The incidence of breast cancer in Korea and among Korean immigrants in the US has been steadily increasing over the last 25 years.[2)]

In terms of the genetic counseling in Korea, it can be said that from early 1980s, few pediatricians who studied at the U.S. introduced this concept to the pediatric clinics for treating rare genetic diseases. Recently, lots of physicians in oncology have paying attention to genetic counseling. Especially Korean Breast Cancer Society (KBCS) has been undertaking nationwide KOHBRA (Korean Hereditary Breast Cancer) study funded from government from 2007.[3,4)] While doing this project, breast cancer surgeon hired nurse to provide genetic counseling before BRCA1/BRCA2 tests. The results of this study suggest that the prevalence of BRCA mutations in Korean subjects is similar to the prevalence reported among Western cohorts. However, weak family history and non-familial early-onset of breast cancer were significant factors associated with carrying the BRCA mutation in Korea breast cancer patients. Recent report after completing KOHBRA study has confirmed these findings.[3)]

KOHBRA study team[3)] reported the prevalence of BRCA1/BRCA2 mutations and ovarian cancer among a high-risk group of patients with hereditary breast cancer and their families. Between May 2007 and May 2010, the KOHBRA study enrolled up to 2000 subjects. An interim analysis of the prevalence of BRCA1/2 mutations and ovarian cancer in Korean subjects was determined from the initial 975 patients who presented to 33 centers. As a result, by the April 2009, a total of 167 mutation carriers among 853 probands were identified. The prevalence of the

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BRCA mutation was as follows: 24.8% (106/428) for breast cancer patients with a family history of breast/ovarian cancers; 11.3% (24/212) for patients with early-onset (< 35 yr) breast cancer without a family history; 22.1% (15/68) for patients with bilateral breast cancer; male breast cancer in 8.3% (1/12); and 33.4% (1/3) for patients with breast and ovarian cancer.

Factors associated with highest risk include: early-age onset breast cancer in at least one female relative and one of the following additional risks: 1) early-age onset breast cancer diagnosed before age 35 in the proband or a relative, 2) bilateral breast cancer, or 3) a male breast cancer diagnosed in the family.[4,5]

The concept of coping with risk information in families is recognized as an essential counseling intervention.[6-8] Rothemund et al.[1] investigated risk, anxiety, psychological distress, and early detection behavior in 23 women with a family history and 21 women without a family history of breast cancer who attended genetic counseling. Thirty-nine percent of the women with a family history of breast cancer correctly identified their risk while 48% overestimated. Despite genetic counseling, many women continue to perceive their own lifetime risk of breast cancer inaccurately.

As cancer genetic screening becomes incorporated into Korean healthcare, nurses are being trained by physicians to collect family history information and to examine family dynamics that might influence decisions about testing or coping with a genetic mutation. The authors examine the effect of the first cancer genetic risk assessment and counseling program offered in Korea. Nurses help patients and family members work through their emotions and reactions. Consequently, it is necessary to understand family communication patterns in the context of Korean genetic services.

1. Aims of the study

The researchers examine how genetic information is communicated in Korean families when women undergo BRCA genetic risk assessment, counseling and genetic testing. In order to understand the impact of genetic testing on individuals, families, and Korean society as a whole, this study is aimed to describe communication patterns and how Korean family structure influences the dissemination of genetic information. This is clinically significant because it provides understanding about how to deliver comprehensive genetic services to Korean women and their families during a time of rapid social, cultural, and family change among many cultures worldwide.

RESEARCH DESIGN

This is the second study in a research series aimed at better understanding family communication of genetic health information. Former study was published the experiences of high-risk breast cancer women undertaking genetic test.[9] We used micro-ethnography methodology, which is focused on understanding how patients in the clinical setting interact with health professionals and family members about this type of testing in Korean culture. The cultural norms, meanings and patterns of communication, and interactions are best understood when they are observed in a real context. Social interaction theory underpins the type of knowledge this methodology can generate.[10]

1. Gaining access to the setting and informed consent

The hospital where the informants were recruited is the first to integrate BRCA1/2 testing into a clinical service in Korea. Before starting the clinical fieldwork, an author submitted research proposal to both the administrative director of the nursing department and the breast cancer clinic in the hospital and got permission to observe and evaluate patients' reaction to this new service. Hospital administrators, the medical director, two breast surgeons, the nurses, and every patient who participated were informed about the study and they gave their oral permission to be observed and to have data recorded. All the patients signed a consent form, which was recorded on the audiotape before starting each field observation session and formal interview.

2. A description of the clinical breast cancer genetics service program

All breast cancer patients who fit into one of the following categories were recommended by the breast surgeon to undergo BRCA testing during hospitalization after breast surgery.

- a family history of breast cancer among first or second degree relatives,
- a diagnosis of early-age onset (under age 35) breast or ovarian cancer,
- any male breast cancer diagnosed in the family,
- any breast or ovarian cancer and any other type of cancer,
- any bilateral breast cancer.

In this setting, the process of giving cancer genetic information occurred over several months. At the outpatient clinic a family history was taken and each patient was given information about genetic risk for cancer. Patients were encouraged to bring a relative to every session. After

obtaining informed consent, blood was drawn for BRCA1/2 testing. The test results became available about two to three months later. In phase II of the program, patients were given their test results by the breast surgeon. At least two communication sessions occurred after disclosure of test results.

The first communication session focused on giving the test results; this occurred between either the doctor, or the breast cancer nurse specialist and the patient. If a patient tested positive, the patient was advised to adhere to a vigilant surveillance program and to inform other family members about their risk and the possibility of taking a genetic test. The second communication was a follow-up session. The health care professionals made it clear that other relatives should be alerted about their familial and hereditary breast cancer risks. Patients should make relatives aware of the importance of attending an early cancer prevention program.

3. Sampling frame

Twelve Korean women were selected for the first phase of this study and they were observed during the inpatient clinic phase of the genetic counseling program at one breast cancer clinic in Seoul. In the second phase, four additional patients seen at the same breast clinic volunteered for one formal face to face private interview after hearing genetic test results. During the interview they were asked, "How was genetic information exchanged in your family?" and "How would you describe your family relationships and communications during the BRCA counseling and testing period?"

The age of informants ranged from 31 to 73. Of the 16 patients who volunteered, three tested negative and one patient declined the offer of testing. Twelve women tested positive for a BRCA gene mutation. Eleven women were diagnosed with breast cancer. One woman was the unaffected at-risk daughter of another affected woman who carried a gene mutation and who volunteered for this study. Younger and older aged participants represent both nuclear two-parent and traditional three-generation extended families.

4. Data collection methods

All interviews and research took place in one Korean breast cancer clinics from June, 2003 to March, 2008. The type of the participant observation was participants as an observer. The role of the participants was the nursing professor as a learner who was learning the new counseling technique in genetic services. In this setting, breast cancer nurse specialist was taking the role of the mentor.

Fieldnotes were written during clinic observations of 12 patient/provider interactions and during interactions between the patient and her relative(s). After qualitative analysis of theses observational fieldnotes, formal patient interviews were arranged with four additional key informants who were interviewed after giving informed consent to participate. The formal interviews with these key informants were voice recorded and transcribed verbatim into a computer text file. Care was taken to assure all informants that neither their personal information nor their work place would be identifiable. After the final research report was written, the interview tapes were erased.

5. Data analysis methods

The entire set of 100 pages of hand written field note were transcribed into computer text files. Two Korean speaking nurse researchers then sorted field notes into naturally occurring categories. All four 90 minute interviews were transcribed verbatim and de-identified copies of the interview texts were analyzed. The Korean speaking researchers read each transcript. Interview data were coded following a style of ethnographic analysis described by Agar.[11] Major themes were derived from the fieldnotes and the formal interview data. Two additional researchers were asked to verify independently the accuracy of the categorical analysis and the systematic process of generating themes. Categories focused on communication patterns and were derived from analysis of influencing factors, roles taken by different relatives, involvement in testing and treatment decisions, and motives discussed by patients and relatives. Our major analysis method can be qualitative content analysis.

The entire research team discussed transcripts separately and as a set in order to assess the authenticity of the analytic scheme, themes, and the communication patterns that emerged. After analysis and deriving research framework, only texts supporting analytic scheme, theme, and research assertion have translated in order to be included in this study. Translation was done by the authors and reviewed by the Korean professor who is teaching English in Korea.

FINDINGS

Data were analyzed by ethnographic qualitative methods in order to understand the components of symbolic interactionism in this new cultural context.

Our interpretation of the data discovered that during cancer risk assessment, counseling, and BRCA testing, communication patterns in

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families vary according to the woman's position in the family. Two types of communication patterns were discovered based on the position of the woman in the family structure and the type of family structure (nuclear or traditional). In this study, family structure means either a nuclear two-parent family that exemplifies a Gesellschaft social dynamic or a traditional multi-generational family that emphasizes a Gemeinschaft social dynamic. In terms of a woman's position in the family, in this study, a woman is classified as a mother/housewife or an elderly woman or grandmother. The reason why this classification is important is that depending on a woman's position, her role expectations in a Korean family differ greatly. These two conceptualizations of family structure including women's position represents a shift from traditional to modernized nuclear family structures that are typical features of the current social structure in Korea. Data from these 16 women enabled us to better understand cultural transformations as they are naturally occurring in Korean society. In the following section, these two types of communication patterns are described using excerpts and interpretation. An overall, finding is that these Korean families (nuclear and traditional) shared their family member's genetic information.

1. When the woman is elderly or a grandmother

When the women with breast cancer is of an old age, the nurse's genetic education session before the testing procedure was given to her grown-up daughter or daughter-in law, not directly to the elderly woman.

(The breast cancer nurse specialist explained her rationale to the researcher before entering the room to obtain written permission for a BRCA 1/2 test)

Nurse: If the patient is an old woman, I prefer the evening time for asking them to attend pre-test education because usually the family members, especially grown-up children, sit by the patient in the evening. Usually, the elderly woman cannot decide to take test due to the economic burden on her grown-up children. Most of the time, the grown-up children have to hear the BRCA test education before signing written consent form for testing.

Patient: (She had stomach surgery five days ago. She looked feeble and regretful for inflicting burden on her grown-up children for a second cancer surgery. She smiled weakly and stared at the nurse and researcher without any words)

Nurse: (Saying to patient's daughter and daughter-in law)
I need to explain to you one test for your mother. Would you follow me to the nurses' station? (They moved to nurse station and carried on the conversation.)

Daughter-in-law: When will the pathologic test report be back?

Nurse: After discharge, when the patient comes back for a follow-up check, the physician will tell you. Now I will explain to you about the genetic test. (Pretest education took about 40 minutes). Do you have any question about this test? How do you feel?

Daughter: Thank you for your kind explanation... My mother needs to take this test... but I am getting nervous... from when I heard this recommendation the first time, to have the test...I feel somewhat scary...have been anxious...

Daughter-in-law: (thinking rationally... showing calm attitude) ...Is there a possibility that the stomach cancer is related to the breast cancer? My elder sister had stomach surgery before...

Nurse: (giving additional education to them)

Daughter: This test is necessary...But...

Nurse: For the test results, do you want to put in a contact address or telephone number for your mother's...for informing test result?

Daughter: Yes... yes.

Daughter-in-law: But it would be better to put in yours (indicating the patient's grown-up sister) for later...It will be best for you to hear test result from the hospital call.

(From a field note describing pre-test education for a 73-year-old woman with breast cancer)

After hearing her genetic test results, the grandmother concentrated her discussions mainly with her closest daughters; then her husband. Other grown-up daughters or sons are informed later. The elderly woman's daughter(s) subsequently disseminated this information to other first-degree relatives. If a grandmother proves to be positive for a gene mutation, her daughters open and maintain a major communication channel among all the extended family members but mainly female relatives. Even though the risk of transmitting a deleterious mutation also applies to male siblings or male children and grandchildren, they tend to be excluded from this communication pattern.

Patient: I said that [you need to be tested] to my younger sister... She told me she would take test later... if she could have opportunity to take test...I didn't tell my younger brother about my test result... Because I think he is not grown-up enough to understand

this fact... and he is male.... His children are still young ... When they go to high school and University... In future...later... I will tell my sister-in law that I got a positive test result... so I will tell her "you must be cautious about your children's health..."Because they have two daughters... and one son... Because of their daughters...I will tell.

(From interviewing data of a 45-year-old woman with breast cancer who is positive for a BRCA gene mutation)

Daughters always stay beside the old age woman and give direct care during her hospitalization period. Both, the patient's daughters and daughters-in-law decide on their mother's treatment or care planning. The elderly woman was also entirely dependent on them to pay for all the costs associated with diagnosis and treatment. She gave them, the right to make all decisions about her health. Her daughters create a major communication channel among the old age woman's extended family members. In this style of communication, most of the family members were concerned about the children and grandchildren's health.

When listening to the nurse's pre-test education session, there was a difference between daughters and daughters-in-law in their response and attitude. Daughters were serious and anxious, but daughters-in-law were calm and somewhat indifferent. Daughters discussed the cost of the test with the patient's grown-up sons. Traditionally, sons still are responsible for supporting their parent's costs for living, including health. Daughters-in-law were reluctant to pay for the test.

A major focus is on the economic burden involved in the cost of a genetic test, cancer treatment, or future surveillance requirements. When a patient's position in the family is a grandmother, with a positive test result, she too is focused on the economic burden and she feels guilty for carrying a hereditary cancer gene mutation. The grandmothers express less worry about their own health compared to a mother or middle-aged housewife who is diagnosed with breast cancer. Grandmothers concentrate their concern on children and grandchildren.

Nurse: This gene is affected with not only patient's children but also grandchildren...

Grandmother: Oh!... Grandchildren... too... (she looked so surprised...concerned) ...male grandchildren too...(she whispered very anxiously)

(From observational field note of 73-year-old grandmother with breast cancer)

2. When a woman is a mother and a housewife

In Korea, a housewife is a married woman who is working or not working. She is expected to take care of her nuclear family as well as her husband's nuclear and extended family. When the patient's position in the family is mother or housewife, a positive test result makes her focus on her current diagnosis and her fear of cancer recurrence. She like the grandmother also feels guilty about carrying a deleterious mutation. The housewife who has a mutation immediately consults her mother, husband and her sisters.

Nurse: After knowing your positive test result, for the first time, with whom did you consult?

At –risk unaffected Daughter: When I accompanied my mother (carrier of a positive gene mutation) to hospital, I was advised to take this test. So I talked with my mother, the first time, and then I talked with my husband....

Nurse: What was your husband's response at that time?

Daughter: My husband also seemed to consider a positive result as a serious problem. All the family members are now thinking that it would be safe if I be sure to take part in a rigorous screening program... They all are supportive for me.

(Field note describing a 31-year-old unaffected daughter of a 51-year-old woman with breast cancer. Both of them had positive test results)

If the woman is a mother/housewife, she does not want to disclose her genetic test results to her husband's in-laws. Her husband then takes over the role as a communication facilitator between his wife, his parents, and his siblings. As a result of the husband's communication, his extended family pays attention to and advocates for a housewife's cancer surveillance behaviors. They considered her disease a concern for the whole family.

Patient: I told my mother and sister, you need to take the genetic test... as soon as possible... but they did not respond... (laughing... in a feeble voice)

Nurse: Did you tell your positive test result to your mother-in-law or sister-in-law?

Patient: No

Nurse: Didn't you tell them about testing?

Patient: No.

Nurse: What did they do?

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Patient: They did not talk at all about that even though they know that.

(From field note describing one 39-year-old breast cancer women with mutation)

The husband acts on behalf of his wife by establishing and orchestrating an open communication channel among his relatives during the time of diagnosis and testing (Figure 2). The following excerpt shows that the husband creates a communication channel among his family members; however, his wife does not understand why.

Nurse: Do your family members-in-law know you have this mutation?

Patient: Yes...They all know it.

Nurse: Who told them this information?

Patient: My husband said that... One day I realized that all parents and sister-in-law knew it. My husband himself said it to them when I was not there because they were concerned over my health.

Nurse: What did they say to you after knowing that?

Patient: They say ..."Take care of your health..."

(From field note describing 35-year-old breast cancer women who had a mutation.)

These Korean women known to carry a hereditary breast cancer gene mutation wanted neither husbands nor health providers to give this information to their children. They want to disclose genetic information to their young age children when the timing is right. They want to keep test results a secret until their young daughters grow up and prepare for marriage. They want to protect their children from worrying about it before adulthood. They describe how they stressed to their young daughters that they should start a regular breast health surveillance program at an early age, but not why.

Nurse: And your children are still young... 8-year-old? 3-year-old?

Patient: Yes...

Nurse: When do you want to tell them... you mean after they grow up... Do you prefer who tells them this test result, me or yourself?

Patient: (with a very firm and slight trembling voice): I will... (Brusque reply) After she would grow up ... sometime... I will tell them they need to take test... Myself will ... (Saying definitely).. When they would be an adult... it would be time to take test... I will tell them you need to take test...

(From a field note describing 35-year-old women with breast cancer and a gene mutation)

Even though husband family and the housewife knew the housewife's genetic mutation, they did not openly communicate directly their concern in front of the housewife because they wanted to avoid imposing housewife's emotional burden or current stress after breast cancer diagnosis. They wanted to protect housewife from further emotional hurt.

Researcher: Does your husband know that?

Patient: Yes. Basically he is taciturn. When I was in hospital... He did not say any comments even though about my disease.

Researcher: Just before you took genetic test, did you and your husband together listen to pre-test explanation from the clinical nurse practitioner?

Patient: Yes. That time one patient said to me that since having breast cancer surgery fist her concern had been about how her husband did think about her. I was same with her. I was too concerned about my husband more than other person. After hearing the pre-test explanation, I did not say no more till now return to home.... My husband has not given any comment about that and he is doing same as before. He pretends no to know anything. He never mention about that. Even though I asked him whether would be better to buy artificial breast form for lost my breast he answered, "Do anything as you want, do what you feel good"

Researcher: Does your husband family know your genetic test results?

Patients: I did say nothing to them but my husband said them. .....

Researcher: Didn't your husband informed your condition to your husband family?

Patient: Certainly he told them, but I don't know exactly to say about my husband family's response... My mother-in law never touches on the daughter-in law's weak point if her concern will make daughter-in law get nervous.

(From interview data of 34-year-old breast cancer women with positive mutation)

One woman's husband revealed to her that he was especially worried about the possibility of his children "catching" breast cancer due to ma-

ternal heredity. Consequently, she felt sad and disappointed that her husband's primary concern was on their children, and not her. She wanted her husband to worry about recurrence of her breast cancer and her future health.

> Patient: After hearing my positive test result, he did not worry about me... only worry about our children... He did not regret my taking test... Rather.... Today morning, when we have seen doctor, he asked him about our children's risk... I thought he should have asked him what would be necessary to prevent me from recurrence... Rather ... he only asked about the risk of our children...
>
> (From Interview data of 35-year-old, breast cancer woman having mutation)

From this ethnography, it is possible to see the significance of traditional extended family relationships and women's role expectations that foster sharing genetic information to benefit patients and other family members. Even though nuclear families are more common due to rapid social changes in Korea, the benefit of the traditional three-generation extended communication pattern is recognized. Our data illustrate the advantages of communicating genetic information among all family members as a means to understanding genetic self- and family-identity, and the need for altering women's traditional roles at this crucial time when they need to take care of their own health.

DISCUSSION

We interpret that the role of a housewife in the family structure is more valued now than previously in Korean society. Since Westernization of Korean culture, housewives' roles have increased to include: child rearing, child education, money-making, decision making about household matters in addition to traditional care giving roles. Sacrificing herself for her children, her nuclear and her extended relatives is considered a virtue. As a remnant of Confucianism, there are family reunions like memorial services for ancestors in the husband's extended family. Whenever family members gather, housewives assume a great deal of responsibility for the family's well being, such as preparing traditional meals, ceremonies and costumes.

When Park[12] reports that Korea seems to emphasize family solidarity more than in Western countries, he attributes this to familism. In Confucian societies people are obligated to try to become close and take care of people with whom they are related. According to Confucianism human relationship among family members is essential and fundamental to social harmony. Park[12] defines family support as members who share resources and foster cooperation with each other to achieve common health and human goals.

Our findings confirm that the concept of familism in Korea exists in nuclear and traditional family structures and this is why husbands facilitate communication between the wife and his family members. Familial intimacy and kinship are important and carry more respect than private or selfish concerns. Disclosure of genetic information not only to the woman's nuclear family but also the husband's extended family is especially important in traditional and nuclear communication patterns. Korean family's responses to genetic testing illustrate the importance of family identification and family support to strengthen relationships among relatives. These values are fostered by communicating private and emotionally charged information, by re-examining women's roles within the family structure, and by promoting family solidarity.

We can see numerous roles related to communication among family members in other genetic studies. DudokdeWit et al.[13] report "utilizers" who use DNA-testing for Hereditary Breast and Ovarian Cancer. They report two important roles within families. One member becomes "the messenger of the news" informing the relatives of the hereditary character of cancer in the family. Another is "the first utilizer" of the new science: namely, DNA-testing and prophylactic surgery. Grown-up daughters or sisters of an affected woman, or the mother of an unaffected daughter, in this study, would be the "messenger" or "first utilizer" of the BRCA test. Richards[14] claims that "women are often the genetic housekeepers for the kinship" and "they are likely to recognize patterns of inheritance so that these may become part of a family culture without any professional knowledge or advice". In a Korean culture, this appears to be true. The researchers discovered that, male relatives, especially brothers and male cousins, are less frequently informed of the genetic test and its result than female relatives. This is similar to other studies.[15,16]

In contrast, Koreans husbands can also be messengers. In both types of family structures, during the disclosure of genetic information, the woman and her nuclear relatives do not want to tell any of the facts to the relatives-in-law. A breast cancer diagnosis and treatment schedule prevents her from giving services to her own or his family, or keeping in close (daily) relationship with them. The husband's extended family members are afraid that the housewife could become further diseased.

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A housewife's diagnosis and illness impedes traditional family functioning. When she becomes ill, she must be excused from her husband's extended family's expectations. They must be informed about a housewife' s health situation in order to avoid unnecessary misunderstanding about her absence from family obligations. His communication generates support for his wife by his extended family members and this leads to increased intimacy and harmony among all family members.

This explains why a housewife's breast cancer can be discussed openly among relatives and regarded as a whole family's disease. Concern over privacy issues that arise with family communication as discussed in Western literature does exist in Korean families. However, traditional family structure meaning extended family communication patterns promote functional family dynamics that support rather than inhibit sharing private information. Ethical issues over privacy and autonomous decisions appear to be less problematic in this culture. However, this and other Western cultural concerns remain unanswered following this study. Future investigation is required in Korean and other diverse cultures.

The communications of secrete genetic information something like stigma among the family members can neither be really revealed through the quantitative research methodology nor measured quantitatively. Also there will be profound different cultural meaning according to different countries. Not until now, anyone tried to explain the cultural meaning of the exchanging genetic information in Korea. Without understanding of the in-depth understanding of the context of the Korean family culture, culturally sensitive cancer genetic counseling services can not be produced.[2)]

When Gu1[7)] conducted a cross sectional survey on knowledge about hereditary breast cancer according to the risk of hereditary breast cancer in Korean women with beast cancer surgery, she found 48.9% of all the patients shared their disease information related to breast cancer with their spouses. Also in the case of the patient with positive mutation, only 8.9% did not share their cancer information with others and 13.3% shared disease information only with medical practitioners.

People's behavior related to the exchanging genetic information can be best understood from their individual cultural background. Ethnographic research method can be the best to understand cultural meanings, common practices, and psychological experiences of the genetic mutated women in Korean setting.[10)]

Based on this study, it can be interpreted that, although Korean family structure is changing, the communication pattern of three-generation traditional extended family structure still has a great effect on communication patterns in families. Korean sociologists argue that with nuclear families and modernization in Korea, people are suffering from a lack of affectionate relationships that large families have provided in the pre-industrial era.[12)] Our data do not support this concern. However, further research with a larger sample that clearly distinguishes nuclear versus traditional family structures is warranted as Westernization of Korean culture deepens.

1. Study limitations

Two main limitations exist in this study. Foremost, the study is based on a small sample size and the findings are not generalizable. The second limitation is that our sample of women appears to represent a traditional extended family structure. Only two women were under the age of 35 therefore the nuclear family structure may be under represented. Further research with younger aged women who represent the nuclear family structure will clarify whether different types of family communication patterns exist as a consequence of Westernization of Korean family life.

2. Implications for health care professionals

DudokdeWit et al.[13)] suggest that practical family issues should be discussed with individuals at-risk to protect their privacy. We recommend that genetic health care professionals evaluate and supervise possible conflicts due to the intertwinement of individual self-interest versus family solidarity motives for testing. Caution is necessary to maintain confidentiality when families have young aged children. Privacy about disease information in the community should be protected while encouraging open exchange and communication among nuclear and extended family members.

Friesen et al.[18)] describe the experiences of 8 families when a member is diagnosed with cancer through a descriptive, qualitative study. The researchers conclude that interactive family learning is a valid mode of learning and a form of support in which the whole family may participate early, in the process of learning to live with cancer. By including families in teaching sessions as well as facilitating communication between patients, families, physicians, and nurses, it is possible to facilitate sharing in respectful ways. This will help all of them cope with the situation and be supportive of each other.

Claes et al.[15)] point out that usually disclosure of a cancer diagnosis and gene mutation status is mainly to first-degree female relatives. As observed in this study, this is true for both elderly Korean grandmothers and housewives. Female relatives of elderly grandmothers are the first

and often the only confidant where as husbands serve as confidents and the voice of the housewife for his extended family. These communication patterns need to be supported by professionals; however, they need to be sensitive to the fact that men's needs are largely neglected.[16]

Elderly relatives or sisters of the woman diagnosed with breast cancer tend to be reluctant to take the BRCA gene mutation test. Some elderly relatives expressed cancer fatalism as described by Powe and Finnie.[19] They define cancer fatalism as the belief that death is inevitable. That belief is a barrier to participation in cancer screening, detection and treatment. From the literature review, Powe and Finnie[19] conclude that cancer fatalism develops over time and is most frequently reported among medically underserved persons. It also occurs when people have limited knowledge of cancer.[9] Cancer fatalism can be modified through culturally relevant education programs and family-oriented interventions. Future research is needed to explore why elderly relatives might believe in cancer fatalism and how it impacts efficacy of genetic testing and counseling services.

Physicians in Western countries are limited in how much genetic information they can share with relatives because of ethical concerns[20] over autonomy, confidentiality, and privacy.[21] Medical genetics upholds a "historical tradition and currently popular, starkly individualistic model of ethics"[22] in determining who has control over information and health care decisions. It can be construed that all except the patient and the physician can be excluded from decision making. However, in many cultures, the family has traditionally played a central role-not only in the ultimate decision, but, perhaps more importantly, in the information given to the patient.[23] Claiming that only the patient should control what happens to the information is a means of excluding family from the discussion and the decision making process. Legal concerns inhibit clinicians from initiating family-oriented communication and decision making about genetic risks and how to prevent disease.[24-28]

Even though rapid industrialization, family communication is still important in Korea. Through interpersonal communication they keep going to share family information and to help reducing family member's conflict or stress and to expand the mutual understanding

From this understanding, we can conclude that communication pattern occurring furtively is distinct to Korean family and that it must be respected. This communication style can be effective to exchange burdensome information, finally leads to familial solidity in Korea.

CONCLUSION

This study illustrates differences in family communication patterns in Korea compared to Westernized family norms. In Korea, a woman's breast cancer experience becomes a disease of the whole family, not merely a woman's secret or crisis. Professionals in any culture can learn from the Korean phenomena where a woman who has a BRCA mutation must take advantage of her own and her husband's extended family to maximize different kinds of support and relief from usual role expectations. Nuclear versus traditional extended communication patterns in Korean families may be informative to international audiences who seek new ways of understanding and practicing family-centered genetic services.

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