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The Impact of Social Roles on the Experience of Men in *BRCA1/2* Families: Implications for Counseling

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Abstract

Recent advances in genetics have identified several genes associated with inherited susceptibility to breast and ovarian cancer and have led to the commercial availability of mutation analyses. Although the majority of cancers associated with *BRCA1/2* mutations are seen in women, men with *BRCA1/2* mutations are at increased risk for male breast cancer, prostate cancer, pancreatic cancer and melanoma. Limited data available on the response of men in *BRCA1/2* families suggest that the majority do not pursue genetic counseling, thus they may forgo the opportunity to improve health practices and to pass on valuable cancer risk information to offspring. The patterns of relationships of men within the family and society can pose challenges to their recognition of genetic health threats and the need for preventive interventions. Genetic counselors are in a position to inform at-risk males of their genetic risk, and to help them explore their personal health options.

Keywords

Hereditary cancer; *BRCA1/2* mutations; genetic counseling; male family members

Introduction

As genetic testing for germline cancer susceptibility genes reaches clinical practice, differential rates of dissemination of the information within the family and differential rates of testing uptake are being observed (Finlay et al., 2008). This paper explores the experience of men in families in which a *BRCA1* or *BRCA2* mutation has been identified, offers some potential explanations for their lower rates of testing uptake, and suggests some implications for the genetic counseling situation. It is divided into five sections (Table I). First, data on the penetrance of *BRCA1/2* mutations in men and women are presented. Second, the patterns of uptake of *BRCA1/2* testing within families is discussed. Third, the experience of men in *BRCA1/2* families is highlighted. Fourth, some potential reasons for the observed gender differences in response to genetic risk are explored. Finally, some practice implications for the genetic counseling setting are suggested. Most of the studies cited are limited by small sample sizes, under representation by males, and a variety of financial and logistical barriers to the testing process. Many are qualitative and do not necessarily represent the full spectrum of men's experience. This discussion is also challenged by the constantly evolving status of genetic risk information as it is understood both by the general public and by health care providers over the past 15 years. Despite these limitations in the available research, it is timely to initiate a dialogue to begin to elucidate the information and counseling needs of men in *BRCA1/2* families.

Prevalence and Penetrance of *BRCA1* and *BRCA2* Mutations

Recent advances in molecular genetics have identified a number of genes associated with inherited susceptibility to breast and ovarian cancer. Building on the results of genetic linkage analysis, investigators have identified two breast/ovarian cancer predisposition genes, referred to as *BRCA1* and *BRCA2* (Hall et al., 1990; Wooster et al., 1995). It has been estimated that about 5 to 10% of female breast and ovarian cancer cases may be due to the autosomal dominant inheritance of a mutated copy of one of these two genes. In these families, the cumulative risk for breast cancer in women with an altered *BRCA1* gene is estimated to be between 56% and 87% by age 70 with approximately half of the cancers occurring by age 50 (King, Rowell, & Love, 1993; Struwing et al., 1997). A second breast cancer gene, *BRCA2*, accounts for 35% of multiple-case breast and ovarian cancer families (Gayther et al., 1997). More than 900 different mutations in each gene have been described to date, and work is ongoing to characterize the penetrance and expressivity of each. Three particular mutations, the 185delAG and 5382insC mutations in the *BRCA1* gene and the 6174delT mutation in the *BRCA2* gene, have been observed in 2.3% of Ashkenazi Jewish individuals, indicating an especially high risk for developing breast and/or ovarian cancer in this population (Struwing et al., 1997). Mutation analyses for *BRCA1* and *BRCA2* are commercially available and are being incorporated into cancer risk counseling protocols for families with a strong history of breast and/or ovarian cancer. The pursuit of *BRCA1/2* testing is thought to provide the benefit of allowing individuals to choose the surveillance and preventive strategies that are most appropriate for their level of hereditary risk.

These genes are transmitted in an autosomal dominant pattern, resulting in both male and female offspring of a mutation carrier having a 50% chance of inheriting the mutated gene. Little attention, however, has been given to the implications of *BRCA1/2* carrier status among male members of affected families. Although the majority of cancers associated with *BRCA1/2* mutations are seen in women, men with *BRCA2* mutations have a cumulative lifetime risk of 6.9% for male breast cancer (Thompson & Easton, 2001). The majority of hereditary male breast cancer cases have been associated with mutations in the *BRCA2* gene, which have been reported in anywhere from 4 to 40% of men with breast cancer (Friedman et al., 1997). Male breast cancer has also been linked to *BRCA1* mutations, with an estimated 5.8% cumulative lifetime risk (Brose et al., 2002; Ottini et al., 2003). Two percent of men with prostate cancer occurring before the age of 65 years have been found to have deleterious *BRCA2* mutations, and the relative risk associated with *BRCA2* mutations is approximately 4.6 (Horsburgh, Matthew, Bristow, & Trachtenberg, 2005). Similarly, men with deleterious *BRCA1* mutations have an elevated risk for prostate cancer, particularly before the age of 65 (Edwards et al., 2003; Liede, Karlan, & Narod, 2004). The Breast Cancer Linkage Consortium has published increased risks for other cancers, including pancreas and melanoma, among both men and women with *BRCA1/2* mutations (Thompson & Easton, 2001; Thompson & Easton, 2002). These findings, coupled with the potential for paternal transmission of a mutated gene to offspring, makes knowledge of risk status relevant to male as well as female members of suspected hereditary families.

Uptake of Testing for *BRCA1/2* within Families

In the decade since the discovery of the *BRCA1* and *BRCA2* genes, there has been variable uptake by at-risk individuals and variable patterns of sharing genetic information with other family members (DeMarco & McKinnon, 2006; Julian-Reynier et al., 2000). Women from multi-case families of breast and ovarian cancer have been the most likely to choose genetic testing for *BRCA1/2* (Claes et al., 2003; Wagner Costalas et al., 2003). Other correlates of testing include higher socioeconomic status, higher levels of education and higher self-perceived risk of cancer (Welkenhuysen et al., 2001). Reasons for undergoing testing include

gaining information to guide clinical screening and prevention decisions, obtaining information of value to other family members, particularly children, and peace of mind (Daly et al., 2003; Foster et al., 2002). Fear of genetic discrimination by insurers and/or employers has been a major reason for lack of uptake of genetic testing (Pfeffer, Veach, & LeRoy, 2003). Other reasons cited are concern about the psychologic impact of genetic risk information on the individual and other family members, and cost of the testing (Harris, Winship, & Spriggs, 2005; E. A. Peterson et al., 2002).

The decision to undergo genetic testing for a cancer susceptibility gene has broad implications, not only for the individual being tested, but for other family members. When a genetic mutation is isolated in an individual, it automatically implicates one of the parents as the transmitter of the mutation. It also identifies the proband's siblings and children as having a 50% risk of also carrying the mutation, and second-degree relatives in the affected lineage of having a 25% risk of carrying the mutation. Given these circumstances, the proband, who visits a high-risk cancer program and receives genetic test results, becomes a conduit of cancer risk information for the rest of the family. Several studies have documented a strong sense of responsibility among both men and women undergoing genetic testing for breast/ovarian cancer to share their results with their families (d'Agincourt-Canning, 2001; Julian-Reynier et al., 2000; Liede et al., 2000). However, data are beginning to emerge which identify several limitations to the process of family communication. A study from the Cancer Family History Clinic in Cambridge, United Kingdom found that communication with relatives was often impeded by adoption, divorce, remarriage, family disharmony and large age gaps (Green et al., 1997). Open-ended interviews with 29 probands from *BRCA1/2* families described selective sharing of information with family members based on the proband's assessment of their relatives' perceived vulnerability and receptivity (Hamilton, Bowers, & Williams, 2005). Other studies have cited emotional distance, familial conflict and fear of causing alarm as barriers to communication (Hallowell et al., 2003; Hughes et al., 2002; Klitzman et al., 2007; van Oostrom et al., 2007). Individuals receiving positive genetic test results in particular have expressed reluctance to share bad news with other family members, and a sense of guilt in the possibility of passing on a mutation to their children (d'Agincourt-Canning, 2001).

The Experience of Men in *BRCA1/2* Families

It is also becoming clear that male members of breast/ovarian cancer families are less likely to participate at every level of the communication, counseling and testing process. Several studies of patterns of communication of genetic test results within families have found that probands undergoing testing are less likely to inform their male relatives than their female relatives (Beery & Williams, 2007; Claes et al., 2003; Hallowell et al., 2003). Men are less likely to be included in family conversations about familial cancer risk and less likely to be informed of test results received by their female relatives (McAllister, Evans, Ormiston, & Daly, 1998; Patenaude et al., 2006). One study that demonstrated more frequent communication of test results to female relatives suggested that the need for social support within the family determined the pattern of communication (Bowen et al., 2004). One measure of the proband's level of success in communicating genetic risk to family members is reflected by the subsequent uptake of cancer risk counseling by the at-risk relatives. In the few studies available on this issue, younger age, being affected with cancer, higher educational level, and female gender are consistently associated with uptake of counseling and testing (Hagoel et al., 2000; Julian-Reynier et al., 2000).

Some degree of exclusion from the genetic testing process may derive from the male family members themselves. A survey of 22 men from breast cancer families found that while a majority of the men were aware at some level of the hereditary nature of the cancer in their families, and had significant concerns about their own cancer risk, they admitted to preferring

avoidance and denial strategies to cope with the cancer risk in the family (McAllister et al., 1998). A study which offered genetic counseling and testing free of charge to first and second degree relatives of *BRCA1/2* positive individuals found that while disclosure of test results to male and female relatives was similar, uptake of genetic testing was significantly higher for female relatives. The men in this study reported significantly more difficulty in discussing *BRCA1/2* results than the women, suggesting that discomfort with the genetic information may create a barrier to pursuit of testing (Finlay et al., 2008). There is also limited data which suggest that men who do pursue testing may be acting under pressure exerted by other family members, and not necessarily for their own benefit. A qualitative study of 17 men undergoing genetic testing for *BRCA1/2* mutations in the UK found that while the primary motivation for all of them was a desire for information for their children and a sense of parental responsibility, the majority reported that their decision was strongly influenced by other family members, primarily their partners (Hallowell et al., 2005a). Another small qualitative study among men and women receiving *BRCA1/2* test results in Canada found that when men are informed and/or tested themselves, they are more reluctant than women to exchange information with other family members, even when the mutation originates from their lineage (d'Agincourt-Canning, 2001). A qualitative study of 59 male carriers of *BRCA1/2* mutations in Canada and the US found that while the majority of men appreciated their increased risk for cancer, and had intrusive cancer-related thoughts, a minority initiated any change in their cancer surveillance patterns (Liede et al., 2000). Men in a large extended *BRCA1* positive family in the Netherlands found that while the majority harbored fears of cancer for themselves and experienced intrusive thoughts about cancer, they tended to minimize the emotional impact of the test results and to avoid discussions of their personal risk (Dudok De Wit et al., 1996). Another study in the Netherlands found that men who actually did seek *BRCA1/2* testing for themselves reported an absence of any adverse psychological consequences of the test result, suggesting the creation of an emotional distance between the genetic information and its implications (Lodder et al., 2001). In depth interviews with Australian men testing positive for a *BRCA1/2* mutation found that they tended to distance themselves from the possibility of genetic transmission to their offspring by constructing fatalistic or deterministic explanations of inheritance (Hallowell et al., 2006).

There are some limited data regarding communication patterns along gender lines seen in other hereditary conditions. No gender difference was found in intention to be tested for hereditary colorectal cancer among predominantly Japanese patients diagnosed with early onset (less than 60 years) colon cancer in Hawaii, although overall intention was low (26%) (Glanz et al., 1999). A cohort study of 111 first degree relatives from US families identified with hereditary nonpolyposis colorectal cancer (HNPCC) conducted between 1996 and 1999 found similar results. A minority of both men and women chose to undergo genetic testing. However, male family members were significantly more likely than female family members to identify concerns about the effect the test result would have on other family members (Hadley et al., 2003). Another cohort study of 208 members of 4 extended HNPCC families interviewed between 1996 and 1998 found similar rates of test uptake among men and women. In this study, the presence of depression resulted in a significant decrease in test use among women only, suggesting that women were more attentive to psychosocial stressors than men, especially those affecting family relationships (Lerman et al., 1999). A more recent qualitative study among 39 members of 5 families offered testing for HNPCC found a significantly higher uptake of counseling and testing among female relatives (S. K. Peterson et al., 2003). Similarly, a study from Australia in which relatives in HNPCC families were offered genetic testing reported higher uptake of testing among women, who also had higher levels of cancer-related distress (Meiser et al., 2004). The different findings in these studies may be related to the fact that the earlier cohorts were members of large extended families which had been extensively studied and selected for interest in genetic research. Other studies from the neurologic literature have found that interest in and uptake of testing for Huntington's Disease, which has a 100%

penetrance, is consistently higher in women than men (Creighton et al., 2003; Maat-Kievit et al., 2000; Taylor, 2005).

Explaining Gender Differences in Sharing Genetic Information

Several reasons have been proposed for the gender differences in sharing *BRCA1/2* information within families and within society. Women have traditionally assumed the role of health maintenance within the family. Studies have consistently shown that women bear the responsibility for maintaining the health of their spouse and children, and for communicating health information to the extended family, including information about genetic status (d'Agincourt-Canning, 2001; Hallowell et al., 2005b). In the case of the *BRCA1/2* genes, because of the predominance of female cancers (breast and ovarian cancer) among individuals with *BRCA1/2* mutations, it is considered a female condition with little or no relevance to the health of male mutation carriers. Women with *BRCA1/2* mutations may preferentially interact with their female relatives because of closer emotional ties and their need to seek their support and/or medical advice (Hughes et al., 2002). Men on the other hand who are traditionally more likely to minimize or deny health threats, may be less likely to seek social support, and more likely to resort to avoidance strategies (Nicholas, 2000).

The general experience of health and disease as well as patterns of health-related behavior are often described in the context of socially defined gender roles, which are stereotypes used by society to characterize the relationships between men and women (Courtenay, 2000). Health practices have been reported to differ significantly between men and women, and may shed some light on the situation of genetic testing. Several studies have documented global gender differences in response to health threats, with women expressing a higher perception of health risk and vulnerability to health hazards than men, resulting in more proactive health protective behaviors, both for themselves and for other family members (Marteau, Dundas, & Axworthy, 1997). Participation in the genetic counseling and testing process is an example of women's socialization to actively seek health promoting behaviors. On the other hand, men at every age are more likely to engage in risky behaviors, have higher rates of suicide, and are less likely to participate in routine health care visits (Courtenay, 2000; Schofield et al., 2000).

The rejection of health behaviors construed as “feminine” and the adoption of practices that demonstrate fearlessness, independence and self-reliance may be considered a stereotype of masculinity which is reinforced as an ideal by social and cultural institutions and norms, and which can predispose men to behaviors which threaten their physical and mental health (Brooks, 2001; Courtenay, 2000; Hong, 2000; White, 2002). This idealized notion of masculinity can inform the way men relate to others in social interactions and thus perpetuate the stereotype of profound gender differences (Connell & Messerschmidt, 2005; Hyde, 2005). The perception of illness as a personal weakness by men can lead to avoidance of the health care system and delays in diagnosis (Beare & Priddy, 1999). A study among college men identified their socialization to be independent and invulnerable as the greatest barrier to the use of campus health services (Davies et al., 2000). A study which followed men through the diagnosis and treatment for prostate cancer found characteristic patterns of emotional withdrawal, avoidance of support and a struggle to maintain self-reliance as common coping mechanisms (Gray et al., 2000). Furthermore, studies have shown that male encounters within the health care setting are characterized by less time spent, less sophisticated information sharing, and fewer recommendations for preventive health compared to women's health encounters (Roter & Hall, 1992).

Even the media perpetuates the stereotype of masculinity, portrays the sports hero as the model of manliness, and perceives men as disinterested in health concerns and unwilling to engage in health-seeking behaviors (Gough, 2006; Schofield et al., 2000). In the context of genetic

risk assessment and testing, the socialization of men to value physical strength above all else can pose challenges to the recognition of genetic health threats and the need for preventive health behaviors. Those men who do choose to undergo testing are predominantly motivated to provide information for their daughters. And even in those families where men consider the sharing of genetic information with their children as their parental responsibility, there is evidence that the actual communication is more likely to be initiated by their partners (Hallowell et al., 2005b). By focusing on the needs of their children, men may not perceive the relevance of the test results to their own health, thus creating an emotional distance for their personal cancer risk, as well as minimizing the potential implications for their male offspring (Liede et al., 2000; Lodder et al., 2001).

In summary, while our understanding of the experience of men in *BRCA1/2* families is limited by the few studies addressing this issue, the small sample sizes studied, and the complexity of variables which are likely to influence the communication of genetic information within families, some common themes are beginning to emerge. Common to both men and women is a strong sense of responsibility to inform other family members about genetic risk, and a concern with the implications of their test results for other family members. However, there are still significant differences in the involvement with and response to genetic risk information between the men and women within a family. Because the overwhelming majority of cancers associated with *BRCA1/2* predominantly affect females, the significance of a positive genetic test result for women is naturally more evident than that for men. Men and their health care providers may be unaware of the health implications associated with being a *BRCA1/2* mutation carrier. Social role differences also appear to play a part in the differences in how men and women experience the risk *BRCA1/2* mutations. One component of this is the traditional acceptance by women of their role as primary care giver in the family, both in terms of their own health as well as that of their children, their partners and their extended family. Another component is the socially and culturally bound gender roles which affect the patterns of family dynamics and the way men and women understand and respond to health threats. These complex dynamics have practical implications for genetic health care providers.

Practice Implications

The health care system is one of many institutions which can cultivate and reinforce gender stereotypes by the enactment of power relationships and the control of resources (Courtenay, 2000). Genetic counseling and testing for *BRCA1/2* is an example of the interaction of social roles with the medical establishment. The complex and interwoven factors involved are likely to be relevant to the experience of men in *BRCA1/2* families and have implications for their counseling. To date, the majority of men in *BRCA1/2* mutation positive families do not pursue genetic counseling or testing, and may thus *forgo* both the opportunity to make appropriate changes in their health practices, as well as the chance to pass on valuable cancer risk information to their children. Genetic counselors are in a position to inform all at-risk family members of the broad relevance of genetic risk information within the family.

First, by carefully explaining the autosomal nature of inheritance for *BRCA1* and *BRCA2* they can emphasize the implications of a positive test result for both men and women. As men become more knowledgeable about their own genetic risk, they may be more eager to explore health options for themselves. Second, when counseling men at risk for a *BRCA1/2* mutation counselors can explore their personal experiences with health and disease, their perceptions of their own cancer risk, and their methods of coping with a health threat. This will help counselors design and tailor education and counseling materials to match the stage of life and unique life experiences of each counselee. Third, the realization that the denial-avoidance coping strategies employed by some men may lead to an underestimation of their psychological distress can be addressed in the genetic counseling process. It is important for the counselor to establish an

empathic connection by recognizing and validating the male counselee's perspective, and in that context, affirming the acceptability of talking openly about health conditions, and thus normalizing cancer prevention as a routine behavior (Dube & Fuller, 2003). The fact that most genetic counselors are women from whom a caring role is expected and endorsed may actually be an advantage in this context. An appreciation of the role of social dynamics and perceived moral obligations within the family and their impact on decisions made by men regarding genetic testing is also likely to improve the counseling process (Hallowell et al., 2005b). By recognizing the sense of familial obligation cited by those men who do consider genetic testing, counselors can at the same time draw attention to the personal implications of their test result. Because the health implications of genetic test results for men are likely to be less immediate than those for women, counselors should be sure to present the potential harms and benefits in a balanced manner without any suggestion of coercion.

This paper provides an overview of the experience to date of men in *BRCA1/2* families. It highlights the intersection of the increasing application of new genetic technologies to the health care setting with the impact of sociocultural roles of both men and women in responding to health information. While only one example, this experience may serve as a guide to some of the important issues which genetic counselors face in the delivery of sensitive health information within a familial context. As health care consumers continue to assume a more active role in health care decisions, and as gender roles continue to evolve, it will be increasingly important to understand and respond to the distinct informational needs of each member of a family with a hereditary condition.

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Table I
Major Factors Addressed

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- The prevalence and Penetrance of *BRCA1* and *BRCA2* Mutations
  - The Uptake of Testing for *BRCA1/2* within Families
  - The Experience of Men in *BRCA1/2* Families
  - Explaining Gender Differences in Sharing Genetic Information
  - Practice Implications
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