A comparison of male attendees and nonattendees at a familial cancer clinic

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Purpose: This retrospective descriptive Australian study aimed to determine predictors of nonattendance at a familial cancer clinic by men from high-risk breast/ovarian cancer families. **Methods:** Two hundred twenty-six men from families with a known *BRCA1* or *BRCA2* mutation were recruited through an epidemiological database of high-risk breast cancer families and completed a self-administered questionnaire. **Results:** Multivariate analyses using binary logistic regression showed that nonattendance at a familial cancer clinic by men from high-risk breast/ovarian cancer families was associated with younger age (51 vs. 55 years) (odds ratio = 1.03, $P = 0.04$) and lower cancer burden (one relative diagnosed versus two relatives diagnosed) (odds ratio = 2.6, $P = 0.04$). **Conclusion:** Compared with men who attended a familial cancer clinic, nonattendees were younger and had fewer relatives diagnosed with breast/ovarian cancer. Unlike previous findings, cancer-specific worry, in particular avoidance was not associated with nonattendance. The number, age, and sex of biological children were not associated with attendance or nonattendance. Hence, some of the assumptions about what makes information on *BRCA1* or *BRCA2* status salient to men and may therefore influence their attendance at a cancer genetic clinic are not borne out in this study. ***Genet Med* 2009:11(11):806–811.**

Key Words: *BRCA1, BRCA2, men, familial cancer clinics*

Extensive data from surveys conducted in Canada,[1] the Netherlands,[2,3] the United Kingdom,[4,5] and France[6,7] detail the characteristics of women who attend familial cancer clinics (FCCs) and who decide to have genetic testing. Self-reported reasons cited by many women in different countries for attending FCCs include desire to know personal and family risk, awareness of family history, need for reassurance, desire for genetic testing, and to find out about breast cancer screening or prevention.[5,6,8,9] A strong motivating factor seems to be concern about personal risk triggered by the diagnosis of (or death from) breast cancer in a first-degree relative.[4,10] A recent review indicates that women who attended and choose to have genetic testing were more likely to be affected with cancer, have higher levels of cancer anxiety and perceived risk, and larger numbers of relatives diagnosed with cancer.[11]

Less data are available on men's motivations for attending genetic counseling. Fewer men than women are referred and accept genetic counseling.[9,12] Men who do take up genetic counseling have a tendency to miss appointments, drop out of testing protocols,[13] and experience difficulties in establishing appropriate post-test care.[14] Hallowell et al.[15] reported that men's decisions to have genetic testing were motivated by a desire to obtain information for their kin and a sense of obligation to determine the carrier status of their children. Their decision to undergo testing was also influenced by family members such as partners and adult children.[15] Studies also report that men from families with hereditary breast/ovarian cancer fear that they will develop breast cancer, are aware that they are at increased risk of prostate and bowel cancer, and have intrusive thoughts about this increased risk.[14,16,17] It has also been reported that men admit to preferring avoidance and denial to cope with their cancer risk,[16,18] avoid discussing their emotions,[16,17] have unresolved grief about past and future losses, and experience guilt about passing on a potentially lethal gene mutation to their future offspring.[17,19,20]

Very little is known about men who do not attend FCCs because of difficulties in ascertaining these individuals and/or a lack of interest in participating in research studies. Indeed, we are not aware of any published research on the characteristics of men from hereditary breast/ovarian cancer or from families with other hereditary cancer syndromes who opt not to attend FCCs.

Moreover, almost all previous studies have focused on men who attended FCCs who may, or may not, be representative of the larger population of at-risk men. They may represent a socially advantaged and psychologically resourceful group. Alternatively, they may be more distressed than those who do not attend. Thus, it is important to ascertain the attitudes toward management options of men who have not attended specialist clinics. This study aimed to fill these gaps in the literature by recruiting men from high-risk breast cancer families through a population-based epidemiological study and comparing attendees at FCCs with nonattendees.

Hypotheses

On the basis of the literature exploring attendance in women, it was hypothesized: (i) that nonattendance at FCCs would be influenced by demographic variables, such as marital status, lower education, and nonprofessional employment; (ii) that nonattendance would be significantly associated with lower levels of cancer-related anxiety and lower levels of cancer burden (i.e., the number of male and female family members who have been diagnosed with, or who have died of, cancer);

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(iii) that nonattendance would be associated with having fewer biological children or young children.

MATERIALS AND METHODS

Men from families with a known *BRCA1* or *BRCA2* mutation who were 18 to 80 years, not suffering from a mental illness, and could read English proficiently were invited to join the study. Only men at 50% a priori risk of having inherited a breast cancer gene mutation, that is men whose closest affected relative was a first-degree relative, were included. Men who had a diagnosis of cancer other than nonmelanocytic cancer were excluded.

Participants were recruited through the Kathleen Cuningham Consortium into Familial Breast Cancer (kConFab), a research database of high-risk breast cancer families. kConFab is an Australian study established to co-ordinate the collection of genetic, epidemiological, and clinical data in Australian families with a dominantly inherited susceptibility to breast cancer.[21] All family members, i.e., those who carry the family mutation and those who do not, who are registered and consented to the kConFab study are sent a letter when a mutation has been detected in the family, inviting them to attend a FCC for genetic counseling, and if they wish genetic testing.

Apart from a study-specific newsletter that is mailed to all study participants once a year, participants are not provided with any educational materials. This newsletter includes information about breast cancer genes, FCCs, surveillance, genetic testing, surgical options, personal risk as well as information specifically intended for a male audience, such as the possibility of paternal inheritance of breast cancer gene mutations and the increased risk of prostate cancers in *BRCA1/2* carriers.

All kConFab participants who were eligible for this study were sent a letter inviting them to participate. An opt-out card was included with a reply paid envelope for those who did not wish to participate or be contacted regarding this study. If the opt-out card was not received within 2 weeks, a self-report questionnaire was mailed with an information sheet and consent form with a stamped addressed envelope for return. If the questionnaire was not returned within 2 weeks, a reminder letter and a second questionnaire were mailed. Ethics approval was obtained from 17 institutional human research ethics committees.

Data collection and measures

A self-reported questionnaire was completed. The questionnaire included both previously validated and new purposively designed items. All questionnaires were given a code and only this code appeared on the database. To protect the confidentiality and anonymity of study participants, the list of names and addresses of participants was kept in a locked filing cabinet, separate to the coding list. Any computers used for analysis were password protected. Research data will be stored on a computer and paper documents filed for the required time. After this time, all irrelevant material will be disposed of by shredding and erasure of computer-generated data. Only the chief investigators had access to the data.

Predictor variables

Demographic characteristics

Age, educational level, marital status, employment status, occupation, number and sex of biological children, and number of relatives who have been diagnosed with, or died from, breast/ovarian cancer were assessed.

Information preference style

This scale assesses information preference style and is based on a measure adapted from the Cassileth Information Styles Questionnaire.[22] Participants are asked to indicate whether they (i) only want information needed to deal with the immediate issues related to their own chance of developing cancer or their family's chance of developing cancer; (ii) additional information only if it is good news; or (iii) as much information as possible, good or bad.

Decision-making preference style

This item assesses participants' preferences for participation in treatment decisions.[23] Participants are asked to indicate whether they prefer (i) a passive role in decision making (e.g., "I would like the genetics cancer specialist to make the decision" [about genetic testing or screening]) using all that is known about breast cancer genetics; or (ii) a transitional role between passive and collaborative (e.g., I would like the genetics cancer specialist to make the decisions after considering my needs and opinions); (iii) a collaborative role (e.g., I would like the genetics cancer specialist and I to make the decisions together) or (iv) an active role (e.g., I would like to make the decision using all I know or have learnt about breast cancer genetics or I would like to make the decision, after considering the specialist's opinion). Although the decision-making styles were conceptualized as being on a continuum, for analysis purposes the preference styles were collapsed into passive, collaborative or individual.

Breast cancer genetics knowledge

An 11-item true-false measure assessed knowledge about breast cancer genetics. The scale is a revised version of a measure previously used in a study on the psychological impact of *BRCA1* testing.[24] In this study, the scale had high internal consistency with a Cronbach's coefficient alpha of 0.79.

Cancer burden

Three items assessed the number of family members diagnosed with breast/ovarian cancer, their year of diagnosis (or death if applicable), and their age at the time of diagnosis or death.[25–27]

Cancer-specific worry

This was measured using the Impact of Events Scale, a 15-item validated scale measuring intrusion and avoidance thoughts in relation to a specific stressor.[28] In this study, the particular stressor was concern about the family history of breast/ovarian cancer and the intrusion and the avoidance subscales were highly consistent with Cronbach's coefficient alpha of 0.90 and 0.89. Scores above 20 on either scale indicate a significant stress response.[29]

Statistical analysis

Tests of association among demographics (age, educational level, marital status, occupation, and number and sex of biological children), levels of cancer-specific worry (intrusive thoughts and avoidance), decisional and informational preferences, and cancer genetics knowledge were carried out using χ^2 tests and Fisher exact tests for categorical variables, *t* tests and analysis of variance for normally distributed continuous variables and Mann-Whitney and Kruskal-Wallis tests for ordinal or non-normally distributed continuous variables. All variables with a bivariate association with $P < 0.25$ were then entered into a linear regression model and progressively eliminated until

Table 1 Demographics

Variables	Nonattenders (n = 126)	Attenders (n = 100)	Nonresponders (n = 253)
Age	Mean 52 yrs (SD = 14.6, range = 25–86 yrs)	Mean 55 yrs (SD = 12.4, range = 27–83 yrs)	Mean 49 yrs (SD = 15.8, range = 19–89 yrs)
Marital status (%)			
Married/partnered	75	84	58
Not married/partnered	25	16	41
Children (%)			
Yes	88	88	No data available
No	12	12	
Sex			
Female	72	73	
Male	62	67	
Age (yr)			
Mean age first child	26 (SD 15.0)	29 (SD 13.7)	
Mean age second child	25 (SD 14.3)	27 (SD 14.0)	
Mean age third child	24 (SD 15.1)	26 (SD 14.8)	
Mean age fourth child	30 (SD 14.9)	30 (SD 14.7)	
Education (%)			
Below Year 12	47	42	58
Year 12 and higher	53	58	40
Employment (%)			
Professional	58	42	No data available
Nonprofessional	42	58	
Mutation status (%)			
Mutation +ve	39	46	41
Mutation −ve	61	54	57[a]

[a]Does not add up to 100% because of uninformative mutation test results.

the only remaining variables were those with $P < 0.05$, or those which confounded the association of interest.[30]

RESULTS

Four hundred seventy-nine men from families with a known *BRCA1* or *BRCA2* mutation were approached through the kConFab National Research Database in December 2005. Two hundred twenty-six questionnaires were returned (47% response rate), and of these, 100 men (44%) had previously attended a FCC (attendees) and 126 men (56%) had not attended (nonattendees).

Two hundred fifty-three men either did not respond to the invitation to participate or choose to opt-out of the study (nonresponders). Table 1 shows the sociodemographic characteristics of the respondents and nonrespondents. Nonresponders were significantly more likely to be younger ($\chi^2 = 12.7$, $P < 0.001$, 49 vs. 54 years) and less likely to be married ($\chi^2 = 15.6$, $P < 0.001$, 58% vs. 76%). There were no significant differences between nonresponders and responders in terms of mutation status or number of first- and second-degree relatives with a *BRCA1* or *BRCA2* mutation identified.

Almost half of the attendees (49%) reported that they had genetic testing. Fifty-four percent of attendees were mutation negative and 46% were mutation positive. We asked the men who had not attended a FCC if they were interested in having genetic testing. Fifty-two percent of men said "definitely yes," 29% said "probably yes," 10% "probably not," and 1% "definitely not" and 9% were "uncertain."

Decision-making preferences

Around half of the men preferred a collaborative decision-making style (50% nonattendees vs. 43% attendees). Nineteen percent of nonattendees preferred the genetics specialist to make medical decisions on issues such as genetic testing or screening compared with 6% of men who had attended. Approximately 31% (one third) of nonattendees wanted to make decisions themselves after a specialist opinion, when compared with 29% of attendees.

Table 2 Cancer-specific worry and cancer burden

	Nonattenders (n=126)	Attenders (n=100)
Cancer-specific worry		
Intrusion Scale	8 (4.5, 2–27)	9 (4.4, 6–27)
Avoidance Scale	9 (5.05, 2–28)	11 (5.2, 8–29)
Total Intrusion and Avoidance Scale	17 (9.45, 2–55)	21 (9.2, 15–53)
Cancer burden		
Relatives diagnosed	1 (1.07, 1–8)	2 (0.96, 1–5)
Relatives died	2 (1.32, 1–7)	2 (1.54, 1–8)

Values are given as median (SD, range).

Information preferences

Just more than half of the men (58%) who had not attended a FCC reported that they preferred to receive all information relating to their own chance of developing cancer or their family's chance of developing cancer, regardless of whether it was good or bad, compared with 70% of men who had attended. Less than half of the men wanted information to deal with immediate issues only (41% of nonattendees vs. 30% of attendees).

Cancer burden

Men who had not attended a FCC reported having one family member who had been diagnosed with breast/ovarian cancer and were still alive (SD = 1.2, range = 1–8) compared with a median of two family members (SD = 0.94, range = 1–5) reported by men who had attended (Table 2).

Cancer-specific worry

The majority of men did not show significant levels of cancer-specific worry with fewer than 10 men in either group scoring more than 20 on both intrusion and avoidance scales (Table 2).

Breast cancer genetics knowledge

Men who had never attended a FCC scored a median of 7 correct answers on the 11 breast cancer genetics knowledge scale (SD = 2.87, range = 0–11) compared with a median of 8 correct answers (SD = 2.34, range = 0–11) for men who had attended. Areas where fewer nonattendees gave correct answers concerned the role of male inheritance with 58% of men unaware that they have an increased risk of developing other cancers; 51% were unaware that their sons could inherit a faulty gene; and the majority (92%) were unaware that not every person with a strong family history can be offered genetic testing (Table 3).

Predictors of nonattendance at familial cancer clinics

Bivariate analyses showed men's decision-making styles, cancer-specific worry (avoidance), total cancer-specific worry (intrusion and avoidance), and knowledge were significantly associated with nonattendance at the FCC (Table 4).

Multivariate analyses using binary logistic regression showed that nonattendance at a FCC was associated with younger age (51 vs. 55 years) (odds ratio = 1.03, P = 0.04) and lower cancer burden (one relative diagnosed vs. two relatives) (odds ratio = 2.6, P = 0.04).

Table 3 Breast cancer genetics knowledge

True/false statement	Nonattenders (% correct)	Attenders (% correct)
Breast cancer is always inherited	64	68
Men can carry a faulty breast/ovarian cancer gene	74	91
All men who have a faulty breast/ovarian cancer gene will get breast cancer	73	81
Men who have a faulty breast/ovarian cancer gene can be at risk of other cancers	42	60
Daughters of men who have a faulty breast/ovarian cancer gene can inherit that faulty gene from their fathers	60	86
Sons of men who have a faulty breast/ovarian cancer gene can inherit that faulty gene from their father	49	70
A man who does not have a faulty breast cancer gene can still get breast cancer	61	73
In a family where a faulty breast cancer gene has been found, all members of the family will have the faulty gene	77	86
There is more than one breast/ovarian cancer gene	38	59
In a family where a faulty breast cancer/ovarian cancer gene has been found, those without the faulty gene have the same risk of getting cancer as people in the general population	56	63
Not every person with a strong family history of breast cancer can be offered a genetic test	8	10

DISCUSSION

To our knowledge, no previously reported study has effectively dealt with the potential ascertainment bias associated with recruiting men through specialist clinics. This study addressed this issue by identifying predictors of nonattendance at a FCC in a population-based sample of high-risk men recruited through an epidemiological study.

We found that younger men and men with fewer relatives who had been diagnosed with breast/ovarian cancer were less likely to have attended a FCC. It is of interest to compare these findings to those from studies that examined the predictors of genetic testing uptake, as there is evidence that people attending FCCs are self-selected for interest in genetic testing. Indeed, such studies show an association between strength of family history and uptake of testing[24,31]; however, findings on the association between age and test uptake are mixed.[32,33]

The uptake of genetic counseling (44%) and testing (49%) in our sample is comparable with that reported for women from high-risk breast cancer families recruited through the same

Table 4 Bivariate associations with non-attendance at the familial cancer clinic

	Nonattenders (n=126)	Attenders (n=100)	P
Decision-making style—Dr. only	19%	9%	0.02
Information preferences—to deal with immediate issues only	41%	30%	0.15
Avoidance	Median 9	Median 11	0.04
Intrusion	Median 8	Median 9	0.08
Total avoidance and intrusion	Median 17	Median 21	0.03
Knowledge	Median 7	Median 8	<0.001
Not married	25%	16%	0.14
Age	Median 51	Mean 55	0.10
Total no, relatives diagnosed	Median 1	Median 2	0.08

Australian population-based epidemiological database (kConFab), where 59% were reported to have attended a FCC and 49% to have had genetic testing.[34]

The only difference in terms of decision-making preferences between men who attended and men who did not attend was that more nonattendees preferred the genetics specialist to make medical decisions on issues such as genetic testing or screening (19%), (vs. 6% of men who had attended). This could be attributed to attendee's experiences of familial cancer services and the active role they may have been encouraged to play by these services in decision-making around issues such as genetic testing and screening. In addition, almost half of the nonattendees (41%) only wanted information to deal with immediate issues. This suggests that avoidance as a coping style may be present in these men; however, our data did not show clinically significant or indeed high levels of cancer-specific worry (avoidance or intrusion). The men in this study had similar low levels of psychological distress as reported for women recruited through the same population-based epidemiological study of high-risk breast cancer families.[3]

We observed a lack of knowledge among nonattendees about some specific issues, including their risk of developing cancers other than breast cancer and the risk that their sons could inherit a faulty breast cancer gene. Given that kConFab newsletter includes articles that are specifically targeted for a male audience, these gaps in knowledge among nonattendees suggest that the newsletter is either not read by all men or that the information needs to be personalized during a visit at a FCC to be understood.

It could be assumed that men with children, particularly daughters might be more motivated to attend for genetic testing; however, this was not borne out by the data. There were no significant differences in the number or age of biological children between attendees and nonattendees with ages of children ranging between 26 and 30 years. Hence, we cannot argue that men did not attend because they had fewer or younger children. Both groups had children within the age groups for whom knowledge of their genetic status and a screening program may be appropriate.

There was no significant difference between men who attended a FCC and men who did not according to their mutation status (mutation positive or mutation negative). This is not surprising given that men do not know their status before testing and men in the study were at a 50% risk of inheriting a *BRCA1* or *BRCA2* mutation. More surprisingly, the majority of men who did not attend a FCC were interested in genetic testing (81%). The data on knowledge, above, suggest that men might not be aware of the relevance of genetic testing for their own health, however, other explanations are possible. For instance, failure to have testing may relate to limited access or awareness of services, which offer genetic testing. Men may be "deferring" testing rather than making a decision not to proceed or their perceived risk may be lower as nonattendees had a significantly lower cancer burden.

The strengths and limitations of our study should be mentioned. This study assessed 226 men, and to our knowledge, this is the largest sample of men from hereditary breast/ovarian families with a known mutation, who were assessed in relation to their psychosocial adjustment. The sample size was sufficient to detect a small to medium effect size (0.4) difference in characteristics between attendees and nonattendees; we consider this difference to be clinically meaningful and an adequate sample size to confirm our hypotheses. The strength of the study is that men were ascertained through a large breast cancer genetics registry, where participants were recruited through a diversity of sources of index case ascertainment and subsequent systematic recruitment, leading to as representative a sample as is realistically possible without a population-based survey.

Furthermore, just more than half of the men in both groups were educated above Year 12 compared with 54% in the general Australian population.[35] These sample characteristics suggest that our sample is representative of, and our findings able to be generalized to, the larger population of high-risk men. Conversely, it should be noted that participation in a breast cancer genetics study and access to the study newsletter might have altered attitudes and knowledge levels, and a population-based survey of participants would have been ideal. Finally, the response rate was only 47%, which is lower than the 67% response rate to questionnaires reported in a study of women drawn from the same population-based study,[36] and there was some indication of response bias in that nonresponders were more likely to be younger and less likely to be married. Finally, this is a retrospective study, which means that men's recollection of their decision making may be biased by their subsequent experiences.

None of our hypotheses were confirmed with nonattendance being unrelated to demographics (apart from age) or psychological variables. A lower cancer burden was associated with men's nonattendance. Having more affected family members and as Hallowell et al.[15,20] suggested perhaps persuasion by a family member for men to go for genetic counseling and testing may explain attendance.

In conclusion, some of the assumptions we may have about what makes information on *BRCA1* or *BRCA2* status salient to men and may therefore influence their attendance at a cancer genetic clinic is not borne out. For example, most studies in men from high-risk breast cancer families show that men attend cancer genetic services because of their concern for their children. However, we have found no difference among the number, age, and sex of biological children and between attendees and nonattendees. In addition, cancer-specific worry (avoidance) was not related to nonattendance. In our earlier study, we found that men go to a cancer genetic service because they are asked to attend by a female family member.[37] Other studies suggest that social desirability and men's sense of obligation within the family are the major factors determining their attendance at a cancer genetic clinic.[15,38]

Being aware of men's sense of obligation[38] within the family, that their attendance is not contingent on having daughters, and that younger men are less likely to attend a FCC is useful in tailoring information and communication messages that raise the awareness and meet the needs of men from high-risk breast cancer families.

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