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Testicular Cancer and Genetics Knowledge Among Familial Testicular Cancer Family Members

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Abstract

Purpose—It was our aim to determine baseline levels of testicular cancer and genetics knowledge among members of families with Familial Testicular Cancer (FTC).

Methods—This is a sub-study of an ongoing National Cancer Institute (NCI) multidisciplinary, etiologically-focused, cross-sectional study of FTC. We evaluated 258 male and female participants including testicular cancer (TC) survivors, blood relatives and spouses to assess

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factors associated with a Genetic Knowledge Scale (GKS) and Testicular Cancer Knowledge Scale (TCKS).

Results—Knowledge levels were generally low, with genetic knowledge lower than TC knowledge ($p<0.01$). Men with a personal TC history scored highest on TC knowledge, while gender, age and education differentially influenced knowledge levels, particularly among unaffected relatives.

Conclusions—Prior to identifying FTC susceptibility genes, we recommend tailoring FTC genetic education to the different informational needs of TC survivors, their spouses and relatives, in preparation for the day when clinical susceptibility testing may be available.

Keywords

Testicular cancer; Knowledge; Genetic counseling; Genetic education; Familial; Hereditary

Introduction

Rationale and Background

While major hereditary contributions to conditions such as breast, ovarian, renal and colon cancers have been discovered over the past decade, there is still much to be learned about familial clusters of other cancers, such as testicular cancer (TC).

Testicular Cancer

Human germ cell tumors are heterogeneous in terms of their histology, etiology, anatomy, clinical and genetic features. In men, these germ cell tumors include tumors within the testis, and at various sites along the midline of the body, including retroperitoneal, mediastinal and hypo-thalamus/pineal gland regions that follow the migration route of primordial germ cells from the yolk sac to the genital ridge (Looijenga and Oosterhuis 2002; Oosterhuis *et al*. 2003; Oosterhuis and Looijenga 2003, 2005). Application of newer molecular methodologies is helping to define precursor states and the role of adjacent tissue (Oosterhuis *et al*. 2003).

Although rare in general, with less than 10,000 cases per year in the USA, testicular germ cell tumors are important due to rising incidence and being the most common malignancy in males between ages 15 and 45 years (Hayat *et al*. 2007; Jemal *et al*. 2007). There is considerable international variation (Purdue *et al*. 2005). There are a few known TC risk factors such as urogenital malformations, undescended testes (cryptorchidism), gonadal dysgenesis, previous TC, and positive family history. (Kramer *et al*. 2006). The practical importance of TC is that it strikes men in the prime of their lives, used to be fatal before major advances in chemotherapy treatment, may be associated with significant treatment-related toxicities or psychosocial sequelae, and is on the rise in Western Europe and the U.S. (Al Tourah *et al*. 2004; Bergstrom *et al*. 1996; Bloom *et al*. 1993; Kramer *et al*. 2006; Purdue *et al*. 2005).

The Hereditary Burden of Familial Testicular Cancer

Familial testicular cancer (FTC), i.e., having two or more affected men in the same bloodline, is uncommon but known to occur in about 2–3% of families (Heimdal *et al*. 1996a). Even in these FTC families, the number of affected cases is low, with the majority of FTC families having affected brothers (Crockford *et al*. 2006). Interestingly, brothers of affected men have a higher relative risk (eight to ten times) of developing TC than do sons of affected fathers (RR=four to six times; Heimdal *et al*. 1996a, b).

There are known hereditary disorders or constitutional chromosomal anomalies, e.g., Klinefelter and Down syndromes, that have been reported in patients who developed seminomatous or non-seminomatous TC (Holzik *et al*. 2004). However, cases due to cytogenetic abnormalities are individually rare and recognizable such that the majority of familial cases in otherwise normal men are probably due to other causes. In support of this contention, we have performed cytogenetic analyses on the first 28 consecutive TC participants in our study and found no disease-associated cytogenetic abnormalities in our 28 cases nor have other investigators in 17 previously-reported cases evaluated cytogenetically (Mueller *et al*. 2007).

The search for non-syndromic genetic causes of FTC has been difficult despite a decade of research by the International Testicular Cancer Linkage Consortium (ITCLC), a collaboration that was established to perform linkage studies for FTC. The increased relative risk for brothers could represent any of the known inheritance patterns as well as shared environmental exposures. Autosomal dominant and recessive as well as X-linked genes may all be implicated in the etiology of FTC (E. Rapley *et al*. 1998). At the time we began this study, there was considerable excitement about positive linkage to an Xq28-linked locus, which has not been confirmed in subsequent analyses (Crockford *et al*. 2006; Rapley *et al*. 2003, 2000). Indeed, segregation analysis and most recent linkage studies suggest that there are a number of loci of interest but that no single gene accounts for all familial risk and that multiple susceptibility loci with weak effects also contribute to the disease (Crockford *et al*. 2006; Heimdal *et al*. 1997).

Rationale for the Value of Genetic Education and Counseling

While genetic mechanisms are being elucidated, we have a window of opportunity to learn a great deal about the families who participate in linkage studies, with an eye towards developing targeted educational strategies which will contribute to the overall management of TC in affected families. Several authors have spoken to the importance of genetic education to empower counselees to better understand the condition in the family, its causes, sequelae and implications and to acquire knowledge required for their active partnering with healthcare providers in the informed decision-making process (Smith 1998; Weil 2000).

The relationship of education and counseling to knowledge and behavior is complex. In one of the early psychosocial studies associated with *BRCA1* testing using a randomized controlled trial of pretest education-only vs. education-plus-counseling, Lerman and colleagues found that the educational and counseling approaches both led to significant increases in knowledge, relative to the control condition (Lerman *et al*. 1997). However, only the education-plus-counseling approach produced increases in perceived limitations and risks of testing and decreases in perceived benefits leading to more realistic views about testing. Neither approach changed the stated intention to have *BRCA1* testing. The authors go on to argue that optimal decision-making requires not only knowledge, but also a reasoned evaluation of the positive and negative consequences of alternative decisions, apparently best achieved with the education-plus-counseling approach. Factors such as attitudes, beliefs, perceptions, motivation, self-efficacy, gender, educational level and a variety of interpersonal, institutional, community and public policies also influence health behaviors (Glanz *et al*. 1997; Lerman *et al*. 1999). Other studies confirm that psychological and social variables have been shown to impact reactions to genetic information and the family's importance in genetic testing decisions (Biesecker *et al*. 2000a; Peterson *et al*. 2003; Vadaparampil *et al*. 2005). We have reported our initial observations regarding FTC family attitudes about genetic testing in a separate analysis (Peters *et al*. 2006).

Our FTC research population offers a unique opportunity to assess genetic knowledge in a little-studied syndrome, before a clinical genetic susceptibility test becomes available.

Surveys have shown that knowledge of genetic principles is poor in relation to multiple cancer types, both in the general public (Bluman *et al*. 2003; Bottorff *et al*. 2002; Magnus 2004; Mesters *et al*. 2005), and among persons seeking pre-test *BRCA1/2* genetic counseling (Bluman *et al*. 1999; Lerman *et al*. 1996). Most cancer genetic knowledge studies have focused on syndromes for which genetic testing was already being offered, e.g., Hereditary Breast-Ovarian Cancer (HBOC) and Hereditary Non-Polyposis Colorectal Cancer (HNPCC). More recent studies of cancer genetic knowledge and attitudes in the general population have shown higher cancer genetic knowledge accuracy scores than some of the earlier studies mentioned above (Rose *et al*. 2005).

Aims

The aims of our exploratory study were: (1) to determine the levels of knowledge about testicular cancer and general genetic principles among FTC family members, and (2) to assess the specific variables associated with levels of knowledge within specific study sub-groups.

Materials and Methods

Study Population

The current study was conducted among members of families enrolled in an IRB-approved, NCI-sponsored multidisciplinary etiologic study of Familial Testicular Cancer (NCI Protocol #02-C-0178). Men with sporadic bilateral testicular cancer without a TC family history were eligible for the parent FTC study, but were excluded from this analysis. Three hundred and three members of 51 multiple-case testicular cancer families were eligible for the current analysis. A subset of this group has been described in more detail elsewhere (Peters *et al*. 2006). We excluded 45 study participants who were missing data on one or more of the variables of interest. The excluded participants did not significantly differ ($p<0.05$) from the rest of the sample with respect to any of the study variables.

Data Collection

Data for this analysis were collected via a mailed, self-administered questionnaire called the Lifestyle and Attitudes Questionnaire (LAQ). The present analyses were limited to those LAQ items pertaining to knowledge about testicular cancer and genetics, plus relevant independent variables. Three different versions of the LAQ were developed to accommodate our data collection requirements for three specific sub-sets of participants: (1) LAQMH for *M*en with a *H*istory of prior TC (affected); (2) LAQMR for *M*en at *R*isk (unaffected); and (3) LAQF for *F*emale family members (mothers, sisters, daughters, spouses).

Measures

We chose standardized, validated measures of independent variables of interest whenever possible, based on the literature related to genetic knowledge and our clinical experience. The TC and genetic knowledge scales were developed specifically for this study, since no suitable examples of validated measures for either exist in the medical literature.

Dependent Variables: Testicular and Genetic Knowledge

Testicular Cancer Knowledge Scale: The TCKS is a ten-item scale reported as the proportion (range 0–1) of questions answered correctly for participants who answered at least five items (TCKS questions appear in Appendix 1). Response options included *correct*, *incorrect*, and *don't know*, with one point given for each correct answer (TCKS in Appendix 1). The TCKS is based on an instrument developed by Katz and colleagues (Katz *et al*. 1995) to assess TC-related knowledge among young adults; it has acceptable internal

consistency (Cronbach's alpha, original scale=0.70; Cronbach's alpha, present study=0.81). The TCKS includes items regarding TC etiology, timing and method of testicular self examination (TSE), and the sequelae of TC. We looked at both total scores and individual questions.

Genetic Knowledge Scale: The GKS is a nine-item scale reported as the proportion (range 0–1) of questions answered correctly for participants who answered at least five items (GKS questions appear in Appendix 1). Response options included *correct*, *incorrect*, and *don't know*, with one point given for each correct answer (GKS in Appendix 1). The GKS was developed specifically for this study to assess understanding of basic biology, different patterns of inheritance and genetic principles. The questions in the GKS are similar to those used in evaluating knowledge of other cancer genetics susceptibility syndromes (Green *et al*. 2001; Hughes *et al*. 1997; Lerman *et al*. 1997; Teague *et al*. 1996). However, our GKS is more complex than other cancer genetics knowledge tools because of the genetic heterogeneity likely to be involved in FTC, i.e., that there are probably at least three different possible monogenic inheritance patterns of FTC in addition to multifactorial; whereas, all other existing cancer genetic knowledge scales target only autosomal dominant inheritance due to known inheritance patterns. Internal consistency for the GKS in the present study was high (Cronbach's alpha=0.85).

Demographic Characteristics—We used the following demographic variables: (1) Age (collapsed into three categories to produce adequate subgroup sizes for meaningful statistical analyses: 18–39, 40– 49, and 50+); (2) Education (three levels: ≤High School, College, Graduate training); (3) Have Children (Yes, No); (4) Clinical/Familial Status (Affected male, Unaffected male, Female relative/spouse); and (5) Marital Status (Yes, No).

Psychological and Social Variables—To assess whether measures of emotional and social functioning were associated with knowledge, three standard instruments were administered:

Impact of Events Scale (IES): The IES (Horowitz *et al*. 1979) measures the subjective impact, i.e., cancer-related distress, of a specific event, e.g., TC diagnosis, on an individual by quantifying intrusive thoughts and avoidance responses to stressful events. *Intrusion* (scores 0–35) is characterized by repetitive thoughts, mental images, disturbing dreams, and repetitive behavior. *Avoidance* (scores 0–40) is associated with denial of consequences from an event, blunted feelings, and emotional numbness. The psychometric properties have been established as satisfactory with mean Cronbach's alpha of 0.86 for the intrusion scale and 0.82 for the avoidance sub-scale (Stephen 2000; Sundin and Horowitz 2002). The scale has been used in previous cancer genetics research (Bresser *et al*. 2007).

Brief Symptom Inventory 18 (BSI-18): This is a standardized, validated 18-question instrument; its *Global Severity Index* (*GSI*) quantifies overall levels of current psychological distress (Derogatis 2001). Three subscales (somatization, depression, and anxiety) of six questions each (sub-scale range: 0–24) are summed to compute the *GSI* (published Cronbach's alpha=0.89).

Duke Social Support and Stress Scale (DUSOCS): The standardized *DUSOCS* (Parkerson *et al*. 1991) measures levels of family and non-family social support and stress. It focuses on the quality rather than the quantity of support in four domains: family and non-family support, family and non-family stress. Each domain is comprised of the sum of nine four-point Likert questions (range=9–36). Published Cronbach's alpha coefficients range from 0.53 to 0.70. Only family and non-family support domains were used in the present study.

Health Belief Model (HBM) Variables—We evaluated concepts central to the HBM, including perceived susceptibility and perceived severity of TC, as well as perceived benefits and barriers to TSE. In each of the following scales, higher scores indicated greater perceived susceptibility, severity, perceived benefits or barriers.

Perceived Susceptibility to Testicular Cancer Scale: Perceived susceptibility was assessed using modifications of previously-validated items associated with developing breast cancer (Champion 1999) and testicular cancer (Blesch 1986), by summing responses to three five-point Likert scale items (range 3–15; Cronbach's alpha=0.76).

Perceived Severity of Testicular Cancer Scale: Perceived severity was assessed by summing responses to four five-point Likert scale items (range 0–20) derived from previous research examining health beliefs associated with developing testicular cancer (Blesch 1986; Cronbach's alpha= 0.43).

Perceived Benefits of TSE: Perceived benefits were assessed by summing responses to six five-point Likert scale items (range 0–30) derived from previous research examining health beliefs associated with developing breast cancer (Champion 1999) and testicular cancer (Blesch 1986; Cronbach's alpha=0.77).

Perceived Barriers to TSE: Perceived barriers were assessed by summing responses to seven five-point Likert scale items (range 0–35) derived from previous research examining health beliefs associated with developing breast (Champion 1999) and testicular cancer (Blesch 1986; Cronbach's alpha=0.61).

Data Analysis

The main outcomes of interest in the present study were percent of correct responses on the Testicular Cancer Knowledge (TCKS) and Genetic Knowledge Scales (GKS). Bivariate analyses examined associations between each knowledge type and other study variables. Bivariate analyses of knowledge by age and of knowledge by education were further stratified by LAQ group. Associations with $p<0.25$ were entered into multivariate models (Hosmer and Lemeshow 2000). Multivariate linear regression was used to model TC and genetic knowledge separately. We included interactions between LAQ group and both age and education to examine whether knowledge associations were consistent in study sub-groups.

Although the individual was the unit of analysis in this study, the familial nature of the cohort raised concerns regarding the assumption of independence of observations. Therefore, all analyses were conducted with SPSS Version 15.0, Complex Samples Application that accounted for possible clustering within families (SPSS 2006). All *p*values are two-sided.

Results

Response Rates and Respondent Characteristics

As of May, 2007, 78% of participants in the parent epidemiological FTC study had completed the LAQ. Table 1 describes demographic characteristics of the study sample, comprised of 106 women and 152 men, including 76 men with a prior history of TC and 76 unaffected men. Seventeen women were spouses of either affected men or of first-degree relatives. The mean age of participants was 49 years (range 18–88). The majority of participants were non-Hispanic whites, middle-aged, well-educated, and married with children. Twenty percent of study families had more than two confirmed TC cases.

Aim 1 Results: Testicular Cancer Knowledge (TCKS) and Genetic Knowledge (GKS)

For the whole sample, knowledge levels were low on average, both for genetics and testicular cancer; on the average, 50% of the TCKS questions were answered correctly, compared with 41% of the GKS questions (Table 2). The difference between TCKS and GKS mean scores was largest for affected males ($p<0.01$), intermediate for the men at risk ($p<0.05$); and not statistically significant among women. Nearly 80% of respondents answered correctly those TCKS items which related to early age-at-onset for TC, and normal sexual/reproductive function after TC treatment.

We sought to discover whether low scores were due to *mis-information* (incorrect responses) or *missing* knowledge (*Don't Know (DK)* responses). We found that there was more *mis-information* about TC than about genetics, i.e., there were significantly more '*incorrect*' responses in the overall sample on the TCKS than the GKS (18% *versus* 12%, $p<0.01$). The TCKS question most often answered *incorrectly* was the recommended TSE frequency which, by expert consensus, is generally recommended to be once a month, rather than once a week as prompted in the TCKS (question 4 in Appendix 1).

The pattern of *missing* knowledge, i.e., *DK* responses, also differed between the TCKS and GKS, with more *DK* responses on the GKS (47%) than the TCKS (32%), a difference which was consistent across LAQ groups. No TCKS question elicited greater than 50% '*don't know*' responses. In contrast, most GKS questions elicited a 40% or higher '*don't know*' response frequency. There were ≥ 50% '*don't know*' responses to GKS questions about the normal male and female chromosome complement, definition of a gene mutation, and frequency of inherited cases of TC.

In comparing TCKS and GKS knowledge for the full sample and by LAQ group, we found that TCKS and GKS were positively correlated with each other for the whole sample. Thus, for the whole sample and within each LAQ group, those who knew more about testicular cancer also knew more about genetics ($p<0.01$).

Aim 2 Results: Variables Associated with Levels of Knowledge

Responses to individual questions are listed in Appendix 1. Table 3 summarizes non-stratified data for Testicular Cancer (via TCKS) and Genetic Knowledge (via GKS) mean scores by demographic variables Age, Education, Marital Status, Having Children as well as LAQ group version. TC knowledge was significantly associated with age, education, and LAQ group (all at $p<0.01$). Older participants (>50) had significantly lower TCKS and GKS scores compared with younger participants (<40; $p<0.01$). TCKS and GKS knowledge scores increased with level of education ($p<0.01$). Knowledge level was associated with LAQ sub-group: Men with TC history had significantly higher TCKS ($p<0.01$) and GKS ($p<0.05$) scores than did at-risk male or female participants. Neither marital status nor having children was significantly associated with knowledge scores on either scale.

To further assess the correlates of knowledge in the different study groups, in our next analyses of associations between age and knowledge and between education and knowledge, we stratified by LAQ group (Table 4). For affected men with TC History, higher education was associated with higher TCKS and GKS scores (both $p<0.01$). No statistically significant differences between age groups were seen in men with TC history on either the TCKS or GKS. For the unaffected men at risk, those men in their 40s scored highest on the GKS ($p<0.01$), with no age or education effect on TCKS. Among female participants, there was a strong association of TCKS and age ($p<0.01$), with the oldest and youngest women having lower TCKS scores than those aged 40–49 years. For the women, there was also a significant association of education with knowledge, with higher GKS scores in the women with college or graduate training ($p<0.01$).

We analyzed the bivariate associations between both knowledge scales and the continuous variables of psychosocial function, social support and health beliefs/attitudes (Table 5). Higher TCKS scores were associated with more reported TSE Benefits and fewer TSE Barriers. Genetic knowledge on GKS was also significantly and positively associated with TSE Benefits and marginally negatively associated with TSE Barriers. None of the other psychological or social support variables (e.g., distress, intrusive thoughts, avoidance, social support, perceived TC susceptibility or TC severity) were significantly associated with knowledge scores.

The study variables which were significantly associated with TCKS and GCKS at $p<0.25$ were entered into the multivariate linear regression model. For the TCKS, the variables that remained statistically significantly associated with knowledge were Age ($p<0.05$), TSE Benefits ($p<0.01$), and the interaction between Age and LAQ group ($p<0.05$) (Table 6).

Due to the interaction effect between age and LAQ on TCKS, we ran the regression stratified by LAQ. Although affected men had the highest TCKS score, knowledge did not reach significance in this small sample ($p=0.06$) as a function of age. For men at risk, the difference in scores was significant ($p=0.03$) only for the 50 and older age group who had worse knowledge than the other age groups. For women, those aged 40 and older had significantly better testicular cancer knowledge than women under 40 ($p<0.05$).

Similarly, for the GKS, we fitted a multivariate linear regression model in which TSE benefits were again found to be significantly associated with GKS scores; those who reported more TSE benefits had higher GKS scores ($p<0.01$).

Although we saw a plausible trend toward an association of lower genetic knowledge with the lowest educational level, this finding did not reach significance ($p=0.07$) in contrast to the bivariate analyses which did suggest that education was associated with higher TCKS and GKS scores ($p<0.01$ for men with TC history; and $p<0.01$ for females on GKS only). The interactions between LAQ group and education and LAQ group and age were not significant (Table 7).

Discussion

This study represents the first systematic analysis of knowledge of testicular cancer and general genetic principles in survivors of FTC and their family members. Overall, we found that knowledge regarding TC and genetics was low. Not surprisingly, the testicular cancer survivors had better knowledge of TC than their relatives and spouses, presumably reflecting their greater exposure to TC-related information and education during disease treatment and follow-up.

The mean GKS scores were statistically significantly lower than mean TCKS scores and the patterns of responses differed on the two scales. We found that more people chose '*don't know*' (rather than guessing at a true/false response) on the genetics compared with the TC questions. It is unclear whether respondents were less confident about committing to a true/false answer to genetic questions than to TC questions, or whether there was more mis-information available to participants about TC than about genetics. This distinction between *missing* information and *mis-information* is pertinent when considering public and patient-oriented education strategies; filling knowledge gaps may require different genetic education approaches than revising or changing entrenched mis-information (Gaff *et al*. 2006). This hypothesis requires focused further research.

Understanding the associations between TC knowledge and genetics knowledge with other variables was complicated in this exploratory, hypothesis-generating study. Although the

sample size is relatively large, compared to similar studies, the cross-sectional design prevented definitive decisions regarding whether the patterns seen were plausible in a specific psychosocial/behavioral framework, or whether they represented false-positive findings resulting from the many questions posed. For example, while age was associated with TC knowledge in the entire cohort, this relationship differed for the three different groups of study participants with lowest TC knowledge among older men and younger women.

Our results suggest that genetic knowledge is primarily gained through formal education, in which more years of education offer more opportunities to acquire genetic information. Formal education was strongly, positively correlated with knowledge in both TC and genetics in bivariate analyses, with the association being more consistent for knowledge about genetics. While families affected by TC may have had opportunities to learn about the clinical aspects of TC from their doctors, genetic knowledge is unlikely to be acquired through healthcare encounters. Low levels of genetic knowledge have also been documented among health care professionals: physicians (including urologists), nurses, medical students and residents reproducibly demonstrate poor knowledge of genetic principles, low confidence in ability to offer full genetic education and counseling, and low referral rates to local genetic counseling programs (Acton *et al*. 2000; Baars *et al*. 2005; Bottorff *et al*. 2005; DeWitt *et al*. 2001; Freedman *et al*. 2003; Mehnert *et al*. 2001, 2003). Our findings highlight the need for continued incorporation of practical genetics knowledge into science curricula and for more intensive health education efforts aimed at those with less formal education.

The TCKS and GKS associations that were strongest, persisting in multivariate models adjusted for other potential confounders, were that higher scores were positively correlated with the belief in the benefits of TSE. Of course, the direction of this association cannot be determined from this cross-sectional study; however, to the extent that promotion of TSE is viewed as a desirable health policy goal, efforts to elevate cancer and genetics-related knowledge may be worthwhile along with teaching TSE.

Applications of Results

So what can be done about the low levels of FTC and genetic knowledge? For patients and their families, one possibility is to imbed genetic risk assessment in a context of thorough genetic education and counseling, so that those open to genetic testing will have the opportunity for adequate informed consent when testing becomes available. There are a number of papers documenting that genetic education and counseling may improve genetic knowledge, at least for those at risk of HBOC (Biesecker *et al*. 2000b; Meiser *et al*. 2001). A meta-analysis of 25 controlled trials confirmed that genetic education and counseling improves knowledge of cancer genetics (Braithwaite *et al*. 2004).

There are a number of educational strategies available (Kelly 1992; Schneider 2001, 1994). These have become somewhat more standardized over the years culminating in the publication of clinical cancer genetic counseling guidelines (Berliner and Fay 2007; Trepanier *et al*. 2004).

Communication aids for cancer genetic counseling are common in the context of HBOC due to *BRCA1/2* mutations (Lobb *et al*. 2006), and presumably, such learning aids will eventually become available for FTC and other cancer susceptibility syndromes. Group cancer genetic education and counseling sessions are also being explored by us and elsewhere (Calzone *et al*. 2005).

In a different approach to streamlining patient genetic education, Green and his collaborators have developed an educational CD-ROM to augment cancer genetic counseling for HBOC (Green *et al*. 2001, 2004, 2005).

Currently, many people obtain their health information from the Internet. Although the Internet is more often used to retrieve health information, there is a preference for and higher trust in the health care provider as a source of health information among American adults (Hesse *et al*. 2005). This point was confirmed in an Australian study of familial prostate cancer in which unaffected relatives expressed a clear preference for obtaining information about their situation directly from a health professional, with urologists being the most preferred type (Gaff *et al*. 2006).

The NIH FTC Genetic Education Program

In our clinical research program, we have taken a staged approach to FTC genetic education, combining research interests and clinical care in assessing and educating patients and their families. Recognizing that people learn through repeated contact and build on prior knowledge to facilitate new facts, (Gagne 1985; Kendall *et al*. 2007), we offer basic FTC and genetic education to our research cohort, providing authoritative information on current FTC knowledge, while setting the stage for future genetic counseling efforts.

Possible Outcomes of Increasing TC and Genetic Knowledge

What benefits might accrue if we succeeded in increasing knowledge of TC and genetics principles? Improved genetic and TC knowledge may increase the likelihood of improving certain health behaviors, such as increasing compliance with TSE recommendations (Vadaparampil *et al*. submitted 2008). While there is no compelling evidence that widespread use of TSE would reduce TC mortality (particularly since treatment even for advanced disease is so effective), early detection could significantly reduce the morbidity associated with TC treatment, by reducing the need for aggressive, platinum-based, combination chemotherapy regimens. It seems likely that for TC, as in breast cancer, fostering active coping and informed decision-making by becoming familiar with one's normal anatomy is a desirable health behavior outcome. Knowledge may also increase satisfaction with participation in clinical research or even with quality healthcare delivery (Bernhardt *et al*. 2000). Finally, knowledge may motivate and empower FTC families to contribute to debates about public health and public policy issues concerning use of genetic information (Burke *et al*. 2002, 2006).

Study Limitations

There are a number of limitations to this current study, the first exploratory study to investigate knowledge about TC and genetics in an understudied high risk population. Future studies should include larger samples with different FTC populations to confirm the present findings. Our analyses were stratified by LAQ group; consequently, some of the analyses, based on small sample sizes, had low statistical power. Further, the study design was cross-sectional; therefore no inferences regarding causality or directionality of associations are possible. We have no post-education follow-up assessment of changes in knowledge levels after our brief genetic educational intervention. Further research will be necessary to determine whether the pattern of associations that we observed between variables, for example, age and knowledge across LAQ groups are reproducible. Once more is known about the genetic bases of FTC, more research will be required to formulate the most effective means of genetic education.

Future Directions

What, then, comprises an ideal genetic education and counseling session for Familial Testicular Cancer? The current situation for testicular, prostate and other cancers in which major susceptibility genes have not been identified is analogous to the era before *BRCA1/2* testing was available for suspected HBOC, or mismatch repair gene testing for HNPCC. At that time, there was a small cadre of genetics, oncology and other healthcare professionals evaluating high-risk patients and their family members, and offering management suggestions based on best available evidence and expressed family needs. Cancer genetic counseling sessions included assessing cancer and psychosocial risk, providing background information regarding cancer etiology and genetic principles, facilitating decision-making about cancer prevention, screening, and diagnosis, referring families to research studies and cancer registries, and offering psychosocial support for patients and relatives. The post-genome era and changes in healthcare delivery systems and staff availability are already expanding the traditional models of cancer genetic education and counseling to other settings, formats and practitioners (Eeles *et al*. 2007). We hope that our efforts to understand the genetic and TC informational needs of FTC family members will enhance the current quality of care we deliver, and facilitate the adaptation of current cancer genetic counseling guidelines to TC survivors and their families, once FTC susceptibility genes have been identified (Berliner and Fay 2007; Trepanier *et al*. 2004).

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Appendix 1

TCKS and GKS Questions and Scores by Study Sub-group

Question	Affected (%)	At-risk (%)	Female (%)	Total (%)
Testicular Cancer Knowledge Questions				
1. "Men between the ages of 20 and 34 have the highest risk of TC among all men."				
Agree	*91*	*71*	*68*	*75*
Disagree	5	3	6	5
DK	4	26	26	20
2. "TC is the most common cause of cancer among men of all ages."				
Agree	26	15	20	20
Disagree	*65*	*40*	*43*	*48*
DK	9	45	37	32
3. "The doctor or other health care provider discovers most TC."				
Agree	20	18	21	20
Disagree	*71*	*55*	*57*	*60*

Question	Affected (%)	At-risk (%)	Female (%)	Total (%)
DK	9	27	22	20
4. “Testicular self examination should be done once a week.”				
Agree	56	56	47	52
Disagree	*36*	*14*	*21*	*23*
DK	8	30	32	25
5. “The best time to do testicular self-examination is after a warm shower.”				
Agree	*78*	*63*	*51*	*62*
Disagree	9	1	2	3
DK	13	36	47	35
6. “The right way to do a testicular self-exam is by pulling the scrotal sac tight and visually inspecting for nodules.”				
Agree	10	16	14	14
Disagree	*75*	*35*	*17*	*38*
DK	15	49	69	48
7. “Sexual problems are a common symptom of TC.”				
Agree	8	6	7	7
Disagree	*77*	*41*	*38*	*50*
DK	15	53	55	43
8. “If a man gets TC, and the malignant testicle is removed, the remaining testicle usually produces enough sperm and hormones for normal sexual and reproductive functions.”				
Agree	*90*	*66*	*74*	*76*
Disagree	4	3	2	3
DK	6	31	24	21
9. “Men who have had cancer in one testicle are more likely to develop a new cancer in the other testicle.”				
Agree	*38*	*16*	*21*	*24*
Disagree	42	29	27	32
DK	20	55	52	44
10. “Trauma or injury to the testicle can cause a cancer to develop.”				
Agree	38	14	22	24
Disagree	*33*	*26*	*29*	*29*
DK	29	60	49	47
Genetic Knowledge Questions				
1. “The chromosomes of men and women look similar except for one pair.”				
Agree	*59*	*41*	*44*	*47*
Disagree	4	4	6	5
DK	37	55	50	48
2. “Cells in various organs in the body have different genes.”				
Agree	30	20	25	25
Disagree	*38*	*41*	*25*	*33*
DK	32	39	50	42
3. “Genetic changes (also known as mutations or alterations) in the information carried by a gene can occur when a specific part of the DNA is changed, increased, or decreased.”				
Agree	*58*	*39*	*40*	*44*
Disagree	1	3	3	3

Question	Affected (%)	At-risk (%)	Female (%)	Total (%)
DK	41	58	57	53
4. “Some mothers may pass on certain genetic diseases only to their sons.”				
Agree	*53*	*34*	*45*	*43*
Disagree	10	5	6	7
DK	37	61	49	50
5. “For some disorders to be inherited a mutation must come from both parents.”				
Agree	*24*	*16*	*24*	*22*
Disagree	37	32	31	33
DK	39	52	45	45
6. “Most cases of TC occur as a result of inherited cancer risk.”				
Agree	25	20	22	22
Disagree	*21*	*17*	*10*	*15*
DK	54	63	68	63
7. “Some genetic disorders occur when a child inherits one copy of an abnormal gene from either his or her mother or his or her father.”				
Agree	*73*	*51*	*60*	*61*
Disagree	1	1	1	1
DK	26	48	39	38
8. “If a person has an altered gene for a disorder, then the person will definitely get the disorder.”				
Agree	2	2	2	2
Disagree	*69*	*44*	*50*	*53*
DK	29	54	48	45
9. “Once an altered gene for a disorder is identified in a person, the disorder can be cured.”				
Agree	11	5	5	7
Disagree	*56*	*41*	*43*	*46*
DK	33	54	52	47

DK=Don’t Know

Italic typeface indicates correct answer

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Table 1

Demographic and Familial Characteristics of Participants

Characteristic	*N*	%
Number of individuals	258	100
Number of families	51	100
Age		
18–39	80	31.0
40–49	57	22.1
50+	121	46.9
Gender, male	152	58.9
LAQ version		
Affected males	76	29.5
Unaffected males at risk	76	29.5
Female relatives and spouses	106	41.1
Married, Yes	173	67.1
Have children, Yes	210	81.4
Education		
≤HS	45	17.4
Some college, technical school, or college graduate	127	49.2
Graduate level and above	86	33.3
Race, Caucasian/White	250	96.9
Relationship to case		
Case	76	29.5
First degree relative	125	49.1
Second degree relative	39	15.1
Spouse	12	4.7
Spouse of first degree relative of case	5	1.2
Third degree relative	1	0.4
Number of families with >2 cases in family	10	19.6

Legend: LAQ=Lifestyle and Attitudes Questionnaire

Table 2

Associations between Testicular Cancer Knowledge Scale (TCKS) and Genetic Knowledge Scale (GKS) Scores for Study Sample and By LAQ Group

		Mean (SE)	*p* for Difference
Whole sample	TCKS correct	0.50 (0.02)	*<0.01*
	GKS correct	0.41 (0.02)	
LAQMH	TCKS correct	0.65 (0.03)	*<0.01*
	GKS correct	0.49 (0.04)	
LAQMR	TCKS correct	0.43 (0.03)	*0.04*
	GKS correct	0.36 (0.04)	
LAQF	TCKS correct	0.44 (0.02)	0.15
	GKS correct	0.39 (0.03)	
Whole sample	TCKS incorrect	0.18 (0.01)	*<0.01*
	GKS incorrect	0.12 (0.01)	
LAQMH	TCKS incorrect	0.22 (0.02)	*<0.01*
	GKS incorrect	0.14 (0.02)	
LAQMR	TCKS incorrect	0.16 (0.01)	0.12
	GKS incorrect	0.11 (0.01)	
LAQF	TCKS incorrect	0.17 (0.01)	*0.02*
	GKS incorrect	0.12 (0.01)	
Whole sample	TCKS DK	0.32 (0.02)	*<0.01*
	GKS DK	0.47 (0.03)	
LAQMH	TCKS DK	0.13 (0.02)	*<0.01*
	GKS DK	0.39 (0.04)	
LAQMR	TCKS DK	0.41 (0.03)	*<0.01*
	GKS DK	0.53 (0.05)	
LAQF	TCKS DK	0.39 (0.02)	*<0.01*
	GKS DK	0.50 (0.03)	

Values in italics denote p≤0.05.

LAQMH Lifestyle and Attitudes Questionnaire for Men with History of Testicular Cancer; *LAQMR* LAQ for Men at Risk; *LAQF* LAQ for Female Relatives and Spouses; *TCKS* Testicular Cancer Knowledge Scale; *GKS* Genetic Knowledge Scale; *DK* Don't Know

Table 3

Non-Stratified Associations of Demographic Characteristics of Participants with Testicular Cancer Knowledge Scale (TCKS) or Genetic Knowledge Scale Scores (GKS) (*N*=258)

	Score on TCKS Mean (SE)	***p***	**Score on GKS Mean (SE)**	***p***
Overall Scores for total sample	0.50 (0.02)		0.41 (0.02)	
Age				
18–39	0.52 (0.03)	*<0.01*	0.46 (0.03)	*<0.01*
40–49	0.58 (0.03)		0.47 (0.04)	
50+	0.44 (0.02)		0.35 (0.03)	
Education				
≤HS	0.40 (0.03)	*<0.01*	0.24 (0.04)	*<0.01*
Some college or college graduate	0.48 (0.02)		0.39 (0.02)	
Graduate level and above	0.57 (0.03)		0.52 (0.03)	
LAQ version				
Affected males	0.65 (0.03)	*<0.01*	0.49 (0.04)	*<0.05*
Unaffected males at risk	0.43 (0.03)		0.36 (0.04)	
Female relatives and spouses	0.44 (0.02)		0.39 (0.03)	
Married				
Yes	0.52 (0.02)	0.08	0.40 (0.02)	0.88
No	0.46 (0.03)		0.41 (0.03)	
Have children				
Yes	0.50 (0.02)	0.54	0.40 (0.02)	0.62
No	0.47 (0.04)		0.43 (0.04)	

Values in italics denote $p \leq 0.05$.

LAQ Lifestyle and Attitudes Questionnaire

Table 4

Associations between Age and Knowledge and Education and Knowledge *Stratified* by LAQ Group

	Score on TCKS Mean (SE)	***p***	**Score on GKS Mean (SE)**	***p***
Affected males				
Age				
18–39 (*n*=33)	0.69 (0.04)	0.31	0.54 (0.05)	0.36
40–49 (*n*=25)	0.61 (0.04)		0.42 (0.06)	
50+ (*n*=18)	0.64 (0.04)		0.49 (0.07)	
Education				
≤HS (*n*=10)	0.47 (0.05)	*<0.01*	0.26 (0.08)	*<0.01*
Some college or college graduate (*n*=35)	0.63 (0.03)		0.41 (0.04)	
Graduate level and above (*n*=31)	0.73 (0.03)		0.65 (0.04)	
Unaffected males at risk				
Age				
18–39 (*n*=24)	0.47 (0.04)	0.07	0.38 (0.06)	*<0.01*
40–49 (*n*=8)	0.56 (0.09)		0.57 (0.08)	
50+ (*n*=44)	0.39 (0.03)		0.30 (0.04)	
Education				
≤HS (*n*=10)	0.38 (0.05)	0.15	0.21 (0.07)	0.06
Some college or college graduate (*n*=40)	0.39 (0.04)		0.33 (0.05)	
Graduate level and above (*n*=26)	0.52 (0.06)		0.44 (0.06)	
Female relatives and spouses				
Age				
18–39 (*n*=23)	0.33 (0.03)	*<0.01*	0.42 (0.05)	0.12
40–49 (*n*=24)	0.57 (0.05)		0.48 (0.06)	
50+ (*n*=59)	0.43 (0.03)		0.33 (0.04)	
Education				
≤HS (*n*=25)	0.38 (0.04)	0.27	0.24 (0.05)	*<0.01*
Some college or college graduate (*n*=52)	0.46 (0.03)		0.41 (0.03)	
Graduate level and above (*n*=29)	0.45 (0.05)		0.46 (0.06)	

Values in italics denote $p \leq 0.05$.

TCKS Testicular Cancer Knowledge Scale; *GKS* Genetic Knowledge Scale; *HS* high school

Table 5

Bivariate Associations between Psychological, Social Support and Health Belief Continuous Study Variables and Testicular Cancer Knowledge Scale (TCKS) or Genetic Knowledge Scale (GKS)

	TCKS		GKS		Mean (SE)
	Parameter Estimate (SE)	*p*	Parameter Estimate (SE)	*p*	
GSI	0.000 (0.001)	0.70	0.001 (0.002)	0.53	6.11 (0.60)
Intrusive Thoughts	0.003 (0.004)	0.46	−0.001 (0.004)	0.85	9.60 (0.31)
Avoidance	0.000 (0.003)	0.99	−0.001 (0.004)	0.81	11.64 (0.34)
TSE Benefits	0.03 (0.003)	*<0.01*	0.021 (0.005)	*<0.01*	24.53 (0.20)
TSE Barriers	−0.01 (0.002)	*<0.01*	−0.006 (0.003)	0.06	21.66 (0.31)
TC Susceptibility	−0.004 (0.007)	0.61	−0.003 (0.008)	0.75	9.40 (0.17)
TC Severity	0.008 (0.012)	0.49	0.014 (0.012)	0.247	7.19 (0.10)
Family Support	0.039 (0.072)	0.59	−0.025 (0.097)	0.80	0.48 (0.01)
Non-family Support	0.010 (0.060)	0.87	0.094 (0.078)	0.23	0.39 (0.02)

Values in italics denote $p \leq 0.05$.

TCKS Testicular Cancer Knowledge Scale; *GKS* Genetic Knowledge Scale; *GSI* Global Severity Index on the BSI-18 scale; *TSE* Testicular Self Examination; *TC* testicular cancer

Table 6

Multivariate Linear Regression Model of Testicular Cancer Knowledge Scale (TCKS) Scores

Model R^2=0.33	**Parameter Estimate (SE)**	***p***
Age		
18–39	Reference	
40–49	0.12 (0.05)	*0.03*
50+	0.14 (0.07)	0.06
Education		
≤HS	−0.05 (0.11)	0.68
Some college or college graduate	−0.01 (0.07)	0.92
Graduate level and above	Reference	
LAQ version		
Affected males	Reference	
Unaffected males at risk	−0.11 (0.08)	0.20
Female relatives and spouses	−0.12 (0.09)	0.19
Marital status		
Married	Reference	
Not married	−0.05 (0.03)	0.10
TSE benefits (continuous)	0.02 (0.003)	*<0.01*
TSE barriers (continuous)	−0.003 (0.003)	0.40
Age × LAQ	−0.04 (0.02)	*0.02*
Education × LAQ	0.02 (0.03)	0.40

Values in italics denote $p \leq 0.05$.

TCKS Testicular Cancer Knowledge Scale; *TSE* Testicular Self Exam; × “interaction”

Table 7

Multivariate Linear Regression Model of Genetic Knowledge Scale (GKS) Scores

	Parameter Estimate (SE)	*p*
Age		
18–39	Reference	
40–49	0.01 (0.06)	0.91
50+	−0.05 (0.10)	0.64
Education		
≤HS	−0.20 (0.11)	*0.07*
Some college or college graduate	−0.10 (0.06)	0.12
Graduate level and above	Reference	
LAQ version		
Affected males	Reference	
Unaffected males at risk	−0.08 (0.10)	0.43
Female relatives and spouses	0.02 (0.09)	0.80
TSE benefits (continuous)	0.02 (0.01)	*<0.01*
TSE barriers (continuous)	0.000 (0.005)	0.96
TC severity (continuous)	0.01 (0.01)	0.40
Non-family support (continuous)	0.004 (0.076)	0.95
Age × LAQ	−0.009 (0.024)	0.70
Education × LAQ	0.015 (0.027)	0.58

GKS=Genetic Knowledge Scale; *TSE*=Testicular Self Examination; *TC*=testicular cancer; × "interaction"; *LAQ*=Lifestyle and Attitudes Questionnaire; Italic denotes $p \leq 0.10$