A DESCRIPTIVE STUDY OF THE GENETIC COUNSELING ENVIRONMENT OF MEN WITH BREAST CANCER IN THE UNITED STATES

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ABSTRACT

In society, breast cancer is erroneously considered to be a female disease. Information regarding the psychosocial, sociocultural, and familial experiences of men diagnosed with breast cancer remains scant. Given the low incidence of male breast cancer in the general population, all diagnosis are considered as an indication for referral for genetic counseling and /or testing. Thus, counselors are often involved in the care of men with breast cancer and assist patients in understanding and adapting to the medical and psychosocial implications of genetic contributions to disease. Genetic counselors are in a position to inform not only men with breast cancer, but also all at risk family members of the implication of genetic risk information. Because of the broad reach of counselors to many individuals, which makes it relevant to public health, it is important to get a baseline picture of the current state of the counseling environment so that potential issues can be identified that might inadvertently perpetuate the stereotypes surrounding these men. It is also important for counselors to be aware of their own beliefs about the process of counseling men with breast cancer as such beliefs can influence assumptions made about the counselee and therefore can potentially affect the dynamics of the counseling session. We conducted a survey study of genetic counselors in the United States to assess these issues.

The majority of respondents are female with 1-5 years' experiences in cancer genetic counseling and reported seeing an average of 1-5 males breast cancer patient per year. The genetic counseling environment appears to be supportive for men with breast cancer. Gender does not play a role in the comfort level of either the counselor or counselee. Men appear to pay a more active role in the genetic counseling process than the literature suggests. This may be due to the fact that counselors consider themselves to be an important source of support for these men and often take a proactive approach in the assessment of psychosocial needs. In conclusion, more research is needed to determine specific informational and psychosocial needs of men with breast cancer so that counselors can tailor a session which will assist men to make optimal health care choices.

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1.0 INTRODUCTION

This descriptive study was undertaken to supplement the current literature regarding the genetic counseling of men diagnosed with breast cancer. Genetic counselors are in a position to both inform men with breast cancer of their genetic risks and to help them explore personal health care options. Genetic counselors are also in the position to inform at-risk family members of the implications of genetic risk information concerning a diagnosis of breast cancer in males within a given family by directly counseling those affected or by assisting the individual to relay cancer risk to their families. Because of the broad reach to many individuals, it is particularly important that the genetic counseling environment be supportive of the unique issues surrounding men who are diagnosed with breast cancer. It is important to get a baseline picture of the current state of the genetic counseling environment so that we can identify any issues that may adversely affect the relationship between the counselor and the man. These issues, as proposed by the literature, include both a lack of dedicated support systems and dedicated research for men with breast cancer, and a sense that breast cancer is a gendered disease. New research ideas into the male experience of breast cancer may also be generated It is also important for counselors to be aware of their own beliefs concerning counseling men with breast cancer to avoid any disruptions in the working relationship which can result when a counselor's beliefs influence the assumptions made concerning a counselee. For the purposes of this research, the environment is defined as the physical environment in which genetic counseling takes place (i.e. office.

counseling room, conference room, etc.) and the values and beliefs of genetic counselors concerning the sociocultural, psychosocial, and familial influences that men with breast cancer experience in society.

1.1 SPECIFIC AIMS

Aim 1 To provide a description of the genetic counseling environment that men diagnosed with breast cancer experience in the United States.

Aim 2 to provide genetic counselors with an opportunity to increase self- awareness about counseling men with breast cancer.

2.0 BACKGROUND

Male breast cancer (MBC) is a rare disease. It occurs when malignant cells form in the tissues of the breast. MBC is uncommon because male breasts have ducts that are less developed and are not exposed to growth - promoting female hormones; however, any man can still develop breast cancer. Like most cancers, MBC is a disease of aging. Age frequency distribution for males is unimodal with peak incidence in the late sixth and early seventh decade (Contractor 2008). The mean age of diagnosis for men is 67 years (Giordano 2005). There are factors other than age that can increase the risk for breast cancer in men such as excessive alcohol consumption, radiation exposure, certain diseases, obesity and genetic factors. The typical presentation of MBC in 75-95% of men is a hard non-tender mass with a predilection for the left side in a ratio of 1.07-1 (Contractor 2008). Nipple involvement manifesting itself as retraction, nipple discharge, fixation, or eczema occurs in 40-50% of patients (Contractor 2008). The cancer is often initially detected by the man himself. Mammography, ultrasound tests and cytology tests if nipple discharge is present may be utilized in the process of detection. A biopsy is used to make a definite diagnosis of breast cancer which will include the type and stage. Knowledge of the etiology, pathology, and clinical management of male breast cancer is not as well understood as that of female breast cancer. There is a need to better understand this disease. Because of its rare nature, large randomized trials have not been done and are not practical. Consequently, most of the available

information has been based on small, individual retrospective studies and extrapolation from female studies.

2.1 PATHOPHYSIOLOGY

All of the histological variants of breast cancer have been seen in men. Infiltrating ductal carcinoma is the most predominant subtype in men with an incidence ranging from 64-93% (Contractor 2008). The second most common type is papillary which is seen in 2.6-5% of all male breast cancer cases followed by medullary, tubular, small cell and mucinous carcinomas which together constitute less than 15% of cases (Contractor 2008). Lobular cancer is extremely rare in males. This is logical as the male breast tissues lacks terminal lobules unless exposed to exogenous estrogen. Estrogen appears to have a role in the development of breast cancer in men as it does in women; therefore, a discussion of the sources of estrogen in men under normal conditions is appropriate and might help to understand how some diseases and environmental exposures can increase the risk of breast cancer in men.

Sources of endogenous estrogen in men can be classified into gonadal and extragonadal. The testes produce only 15% of the circulating estrogen in the body (Pant 2007). Extragonadal sources of estrogen production include the mesenchymal cells of the adipose tissue or skin, osteoblasts in the bone, vascular endothelial and aortic smooth muscle cells, medial preoptic/anterior/basal hypothalamus, and the amygdale (Pant 2007). The third source of estrogen in males arises from the aromatization of the androgen testosterone which is dependent upon the enzyme aromatase encoded by the CYP19 gene. This conversion takes place in peripheral adipose tissue. In addition to testosterone, androstenedione can also be converted to

estrogen specifically estrone. Since men have less adipose tissue in the breast, the local estrogen production is much lower than that for women which might be one of the reasons for the lower breast cancer rates in men as compared to women.

Molecular markers are important in the study of breast cancer in that they can give information as to what therapeutic strategy to utilize in caring for the patient. These markers can also provide clues as to the prognosis of the patient. Several molecular markers have been studied and identified in male breast cancer some of which include the estrogen receptor, progesterone receptor, Human Epidermal Growth Factor Receptor-2, androgen receptor, P 53 gene, and MLB-1 index. Approximately 64 to 85% of breast cancers in men are estrogen receptor positive and more than 70% are progesterone receptor positive. Such high levels of positivity may be due to low estrogen levels leaving receptors available for binding (Contractor 2008). Androgen receptor status varies in the literature from negative to 95% and it is not well understood in terms of its role in pathology and survival of breast cancer in men (Contractor 2008). P 53 gene is a tumor suppressor gene that regulates cell growth by inducing blockage in the cell cycle. Its overexpression has been correlated with recurrence and poorer prognosis in some patients, whereas no such correlation has been found in others. It remains unknown as to how overexpression of this gene contributes to the prognosis of breast cancer cases in men. Human Epidermal Growth Factor-2 or Her2neu is a proto-oncogene that codes for a tyrosine kinase transmembrane receptor. Her2Neu is rarely overexpressed in MBC. Increased gelatinolytic activity of the enzymes MMP-2 and MMP-9 is related to an increased tendency for metastasis and poor prognosis. Tumor expression of the proliferation marker MIB-1 and the cell cycle protein p27 have been shown to be good predictors of lymph node metastasis in MBC.

2.2 EPIDEMIOLOGY

The lifetime risk of breast cancer in men has been estimated at about 1 in 1000 (NCCN 2013).The American Cancer Society estimates that about 2,240 new cases of invasive cancer will be diagnosed among men in 2013 (ACS 2013). The American Cancer Society estimates that approximately 410 men will die from breast cancer in 2013 (ACS 2013). Little is known about the etiology of male breast cancer. The rare nature of male breast cancer limits the application of epidemiologic methods making it difficult to establish associations between potential risk factors and disease occurrence. In addition, breast tumors in men are often small which limits the amount of tissue available for research after the requisite pathology and molecular studies. Nevertheless, there exists evidence in the literature for both genetic and epidemiologic risk factors for MBC.

Any environmental factor or disease that increases the level of circulating estrogen increases the risk of breast cancer in men. There are some known risk factors and some risk factors that have merely been implicated in the risk of breast cancer in men. Obesity is a known risk factor that leads to higher levels of estrogen due to large amounts of adipose tissue that facilitates the conversion of steroid androgens to estradiol and estrone. Trans-sexuality is factor that has been implicated in the etiology of male breast cancer in that the treatment often includes both prolonged female hormone exposure to stimulate development of a female breast and surgical castration which together creates a high estrogen to androgen ratio by lowering androgen levels. Prostate cancer whose treatment can also expose men to high levels of estrogen might be a risk factor. Another possible risk factor is liver cirrhosis that produces excessive levels of estrogen and a reduction in free testosterone due to an elevation of sex binding steroids. Testicular disorders such as undescended testes, mumps orchitis, congenital inguinal hernia and

testicular injury are known to increase the risk of breast cancer in men. These disorders are associated with low levels of androgens which have consistently been associated with an increased risk of breast cancer. Gynecomastia may be associated with breast cancer in men, but this association remains unclear in healthy men who exhibit gynecomastia. Gynecomastia may occur both with exposure to estrogen and certain classes of non-hormonal drugs such as digitalis, cimetidine, reserpine, thiazide, and tricyclic antidepressants (Weiss 2005). Gynecomastia is seen in men over 50 as a consequence of the natural decline in testosterone levels accompanied by constant level of estradiol which results in an estradiol testosterone imbalance. Gynecomastia can also be present in healthy young men.

There is some evidence that electromagnetic field exposure may be a risk factor for breast cancer in men. It has been hypothesized that electromagnetic field exposure may affect the pineal gland leading to decreased levels of melatonin. There is in vitro evidence that melatonin blocks estrogen-induced proliferation of human breast cancer cells. High temperature is a suggested risk factor in that heat leads to testicular damage, consequently altering levels of circulating estrogen and androgen. Radiation exposure is considered to be a known risk factor for breast cancer in men. Some examples of radiation exposure are chest fluoroscopy and repeated chest x-rays. Though studies are few in number, there is evidence that polycyclic aromatic hydrocarbons or PAH may be a risk factor for breast cancer in men. An increase in risk has been found in workers exposed to PAH as opposed to those not exposed in some studies. These results can be considered to be inconsistent as some studies have not found such as association.

In general, there is little evidence to suggest dietary factors such as meat consumption and alcohol play a role in the development of breast cancer. Evidence for a protective effect of fruits and vegetables remains inconsistent (Weiss 2005).

2.2.1 Genetics

There are both chromosomal and molecular genetic factors that can lead to an increased risk for breast cancer in men. Klinefelter syndrome is defined by the karyotype 47XXY and occurs in approximately 1 n 1000 men (Weiss 2005). It is usually not recognized until after puberty. Patients exhibit a eunuchoid habitus, gynecomastia, small and firm testes, low testosterone concentrations, and increased secretions of follicular secreting hormone. A high estrogen to androgen ratio exists. When compared with the frequency of the disorder in the general population, it seems that breast cancer might be at least 20 times more common in males with Klinefelter syndrome compared with males without this condition (Weiss 2005). Some possible explanations for this increased risk include abnormal hormonal stimulation of cell proliferation in mammary ductal epithelium and treatment with exogenous testosterone which is converted to estrogens in peripheral adipose tissues.

At the molecular level, the tumor suppressor genes BRCA1 and BRCA2 have been found to play an important role in breast cancer in both males and females. The BRCA1 gene is located on chromosome 17q21 and spans 5.6 kilobases of genomic DNA, comprising 1,863 amino acids; whereas, the BRCA2 gene is located on chromosome 13q12 and codes for 3,418 amino acids (Peshkin 2005). Both of these genes maintain genomic integrity by encoding nuclear proteins that help repair double-stranded DNA breaks which can occur during homologous recombination or as a result of DNA damage. Germline mutations in either of these genes can predispose an individual to an increased risk of certain types of cancer. These genetic mutations are transmitted in an autosomal dominant fashion in affected families. Offspring of carriers have a 50% chance of inheriting the mutation and a 50% chance of not inheriting the mutation. Tumor formation in carriers of BRCA1 or BRCA2 germline mutations follows the two- hit

hypothesis in that both alleles of BRCA1 and BRCA2 lose function in tumor cells (Nussbaum 2007).

2.2.1.1 Hereditary Breast and Ovarian Cancer Syndrome (HBOC)

Hereditary breast and ovarian cancer syndrome is a genetically determined cancer syndrome that is caused by mutations in BRCA1 and BRCA2. BRCA gene mutations account for about 50% of predisposition to inherited breast cancer (Euhas 2013). The following criteria are suggestive of an HBOC syndrome (NCCN Version 2013):

- Personal History of breast cancer plus one or more of the following:
  - diagnosed less than or equal to age 45
  - diagnosed at any age with 1 or more close blood relative (first, second or third degree)with breast cancer less than or equal to age 50 and/or 1 or more close relative with epithelial ovarian cancer at any age
  - two breast primaries when first breast cancer diagnosis occurred less than or equal to age 50
  - diagnosed less than or equal to age 60 with a triple negative breast cancer
  - diagnosed at less than or equal to age 50 with a limited family history such as fewer than 2 first or second degree female relatives or female relatives surviving beyond 45 years in either lineage
  - diagnosed at any age with two or more close blood relatives with pancreatic cancer or aggressive prostate cancer (Gleason score greater than or equal to 7) at any age
  - diagnosed at any age with 2 or more close blood relatives with breast cancer at any age

- close male blood relative with breast cancer
- ethnicity associated with higher mutation frequency e.g. Ashkenazi Jewish ancestry

- Personal history of male breast cancer
- Known deleterious BRCA1/BRCA2 familial mutation
- Personal history of pancreatic cancer or aggressive prostate cancer at any age with 2 or more close blood relatives with breast and /or ovarian and /or pancreatic or aggressive prostate cancer (Gleeson score greater or equal to 7) at any age
- Family history of a first or second degree relative meeting any of the above criteria or a third degree blood relative with breast cancer and/or ovarian cancer with 2 or more close blood relatives with breast cancer (at least one with breast cancer greater than or equal to 50 years) and/or ovarian cancer

Both BRCA1 and BRCA2 germline mutations confer increased cancer risks for men as well as women. Men with mutations in BRCA1 are at increased risk for cancers of the prostate and breast. Lifetime breast cancer risk is estimated at 1.8% for men with BRCA1 mutations (Euhus 2013). BRCA2 gene appears to be the more important gene for cancer susceptibility in men in that there is a wider spectrum of cancer risks mainly breast, prostate, pancreas and melanoma of skin and eye (Liede 2004). It is estimated that 4% to 16% of male breast cancers are associated with a BRCA2 mutation (Coffy 2013). Friedman et al. analyzed a population-based series of 54 male breast cancer cases from the US for mutations in BRCA1 and BRCA2. They found that 3% of the male breast cancer cases with no family history carry a BRCA2

mutation, whereas 11% of cases with an affected first- degree relative carry a BRCA2 mutation. Couch et al. analyzed germline DNA from 50 males with breast cancer unselect4ed for family history and 26 individuals from site-specific female breast and breast-ovarian cancer families for mutations in BRCA2. They found that BRCA2 mutations account for 14% of male breast cancer, all but one of which had a family history of male and/or female breast cancer. The lifetime breast cancer risk for males with a BRCA2 mutation has been estimated at 8.3% (Euhas 2013). Male BRCA2 germline mutation carriers may also be at risk for stomach cancer, gallbladder cancer although reports are very rare and magnitude of risk is poorly defined (Leide 2004).

BRCA1 and BRCA2 mutations are rare in most populations, occurring in approximately 1 of 400 individuals, but much more common in Ashkenazi Jewish populations in which 1 of 40 individuals carries 1 of 3 main disease-causing mutations: 2 in BRCA1 (185delAG and5382 insC) and the 6174delT mutation in BRCA2 (Shannon 2012). There are differences in the distributions of certain mutations in varied ethnic populations which suggest a founder effect. Other founder mutations have been identified, but the utility of these in the US population is minimal (Shannon 2012).

2.3 DIAGNOSIS AND TREATMENT

The typical clinical presentation of breast cancer in 75-95% of men is a hard non-tender mass with a predilection for the left side in a ratio of 1.07-1 (Contractor 2008). Nipple involvement manifesting itself as retraction, nipple discharge, fixation, or eczema occurs in 40-50% of patients (Contractor 2008). Ductal Carcinoma *In Situ (*DCIS) is rarer in men than women. The staging in male breast cancer is similar for female breast cancer and follows the same TNM

classification. Despite the fact that male breast cancer is less aggressive than that found in women, axillary node involvement is common. This paradox is believed to be due to lack of awareness and delayed diagnosis.

The small amount of breast tissue in men makes it difficult to perform and interpret common diagnostic tools such as ultrasound and mammography. Routine screening is not recommended for men due to its low incidence of male breast cancer. Because of the rare nature and lack of standardization of imaging strategies, there is less familiarity with the imaging features of cancer in the male breast. However, mammography and ultrasound are acceptable imaging modalities. Mammography has a sensitivity and specificity for diagnosing MBC of 92% and 90%, respectively (Colfry 2013). There are limitations to these techniques as diseases such as gynecomastia can mask malignant disease. Also, as male breast cancer usually occurs in the subareolar region, evaluations of lesions are made difficult by the shadowing of the nipple. If a lesion is discovered, stereotactic or ultrasound guided biopsy should be used (Colfry 2013). In recent years, core needle biopsies or CNB are being used over fine needle aspirations due to the idea that CNB provides a more specific or definite diagnosis as well as an assessment of prognostic/ predictive factors (Rosa 2010). MRI is increasingly being used in imaging of the male breast, mainly for imaging of the contralateral breast following initial diagnosis to establish extent of disease prior to surgery.

The current surgical approach for men with localized breast cancer is the same for females with localized breast cancer. Although for many years radical mastectomy was the standard of treatment for MBC, modified radical mastectomy or simple mastectomy followed by sentinel node biopsy/axillary lymph node dissection has become the standard surgical therapy (Colfry 2012). Lumpectomy for men is generally not considered due to the lower volume of

breast tissue and more centralized location of the cancer; however, some men with breast cancer do have sufficient breast tissues to permit breast conservation.

Lymph node statuses along with tumor stage are considered to be independent prognostic factors for survival in men. Sentinel lymph node biopsy (SNL biopsy) which predicts status of regional lymph node involvement can be inappropriate as men are often diagnosed at an advanced stage. As for those men who are clinically node negative, retrospective studies have suggested that axillary staging for these men may be reliable. No prospective studies currently exist which demonstrates the sensitivity and specificity of sentinel node biopsy in male breast cancer. Despite the limited amount of data, an expert panel convened by the American Society of Clinical Oncology concluded that the use of SLN biopsy for men with breast cancer was acceptable (www.uptodate.com).

An unanswered question is whether MBC has a molecular profile similar to that of estrogen-positive breast cancer in women or whether men develop a unique subtype of estrogen-positive breast cancer. Another factor that complicates this issue is that we cannot assume the hormonal milieu of men is the same as that of postmenopausal women. Hormonal therapy can be divided into two functions. The first function is blocking, downgrading or destroying the ER receptor, while the second is to inhibit any mechanism involving estrogen production and release. Tamoxifen is the gold standard for treatment of ER positive metastatic breast cancer in men. The use of Tamoxifen avoids the surgical morbidity associated with such procedures as orchiectomy, adrenalectomy, and hypophysectomy which all have been used in the past to decrease the estrogen levels in men with metastatic breast cancer. Normally estrogen binding to a receptor facilitates translation. Tamoxifen is a non-steroidal anti-estrogen that binds the estrogen receptor in tumor cells and could initiate the death of the cell or an end to cell

replication. The side effects include hot flashes, weight gain, deep vein thrombosis, decrease in libido, and sexual dysfunction. The 5 year duration is extrapolated from studies using female breast cancer patients. Fulvestrant used in the treatment of MBC, albeit rarely. This drug binds equally to both types of ER receptors, thereby destroying the receptor. It has a long elimination half-life so a monthly dose will be sufficient to maintain a therapeutic plasma concentration. Side effects involve the GI tract and vasodilation which are considered to be tolerable. Due to the lack of information, the role of Fluvestrant in MBC treatment remains unclear (Sousa 2013). Another class of drugs used as part of hormonal therapy is aromatase inhibitors such as anastrozol, letrozol and exemestane. This action is reversible i.e. when use is discontinued estrogen levels return to normal. Aromatase inhibitors specifically decrease estrogen and do not affect the synthesis of other steroid hormones. In the clinical setting, aromatase inhibitors have been used to treat some patients with metastatic disease progressing to Tamoxifen and chemotherapy, but only small case series are available (Sousa 2013). It is believed that the target male population should be 65 years of age or older as there is less free testosterone available for conversion. Aromatase inhibitors are unable to inhibit the testicular production of estrogen that is regulated by both the Luteinizing hormone (LH) which is sensitive to the feedback effects of testosterone and the follicle stimulating hormone (FSH) which appears to stimulate the aromatization of androgens to estrogen in Sertoli cells. Also, the suppression of estrogen from this class of drugs can cause an increase of LH and FSH, resulting in a paradoxical increase in substrate for aromatase conversion. Therefore, monotherapy with aromatase inhibitors alone may not be optimal. In the clinical setting, aromatase inhibitors have been used to treat some patients with metastatic disease progressing toe Tamoxifen and chemotherapy, but only small case series are

available (Sousa 2013). There remains insufficient data to support the use or aromatase inhibitors as routine hormonal therapy for MBC.

The role of adjuvant therapy in male breast cancer has not been well established. The general consensus gleaned from small retrospective studies and anecdotal observation is that adjuvant chemotherapy should be used with node-positive disease. It is also currently accepted that chemotherapy can provide palliation in patients with early to advanced disease, patients who have not done well with hormonal manipulation, or in those who have hormone receptor negative tumors. An optimal chemotherapy regime for men has not been defined.

Case and population data from the National Cancer Institute's Surveillance Epidemiology and End Result or SEER program for breast cancer diagnosed between 1973 and 2005 was studied in an attempt to compare and contrast both male and female breast cancer (Anderson2010). This was one of the largest comparative studies of male versus female breast cancer and is considered to be an important source of information in the absence of randomized clinical trials for men. A major strength was the supplementation of standard descriptive epidemiology with age-period- cohort models adjusted for period and cohort effects and survival analysis adjusted for age, stage and grade. (Anderson 2010). Period effects are associated with such thing as changing treatment or screening patterns and cohort or generational effects are associated with such thing as lifestyle changes or risk factors. Both period and cohort effects can vary between men and women. In general, breast cancer develops at a later age in men than women. Early onset breast cancer are generally female specific (pre menopause) and somewhat uncommon in men (Anderson 2010). Anderson et al. defines early onset for men as that occurring before age 67. As with women, early onset breast cancer in men most likely has a genetic component, i.e. Klinefelter and BRCA mutations. The results revealed age- specific

incidence patterns which suggested that the biology of male breast cancer resembled that of late –onset (post menopause) and ER positive female breast cancer. The similarity of both age-standardized and age-specific incidence trends over time suggest that there are environmental and/or other nonhormonal risk factors for breast cancer, such as diet .and obesity to name a few, that are common to both men and women (Anderson 2010). Both men and women with breast cancer were found to have improved mortality and survival rate over time; however, progress for men lags behind that of females. Declining female mortality rates are attributed to adjuvant therapy, screening mammography and reduction in hormone replacement therapy. By contrast, any decline in male mortality rate is likely a reflection of adjuvant therapy alone as the other two factors are not common to the male experience. The smaller improvement in mortality for men versus women might be a reflection of the underutilization of adjuvant therapy specifically Tamoxifen in men or non-compliance on the part of the man due to adverse side effects of certain treatments.

2.4 PSYCHOSOCIAL EXPERIENCES

There is scant information on the psychosocial effects of breast cancer in men as opposed to female breast cancer which is considered to be the most studied malignancy in terms of psychological effects (Donovan 2007). Men with breast cancer have a unique experience in society in that they have a disease considered by society to be female. The issue of gender permeates all aspects of the male experience from diagnosis to treatment. Men who are diagnosed with breast cancer report feelings of shame and confusion. An exploration of the lived experience of men with breast cancer in the United Kingdom found that men viewed a diagnosis

of breast cancer as an intrinsic defect which can lead to questions about sexual orientation and masculinity (Donovan 2007). A mastectomy is considered to be a significant alteration in male self- image, thereby having the potential to impact male sexuality. Mastectomy scars are concerning to men in that they feel that it will be seen by society as a mark of femininity. In reporting survivor stories by men with breast cancer, the media tends to stress their masculinity by referring to these men as " regular" or "normal" men which paradoxically can reflect the view that breast cancer is gendered (Donovan 2007). In society, masculinity is often affirmed through sexual function. The treatment of male breast cancer can also exacerbate the gendered views of breast cancer in that the treatment can interfere with male sexual function.

Men with breast cancer have reported that health professionals are unaware of the specific psychosocial and informational needs of men with breast cancer. A study which focused on the gender differences in psychosocial adjustment to a diagnosis of cancer found that the support of health professionals contributed more to the adjustment of men whereas the support of family contributed more to the adjustment of women (Fife 1994). A possible reason for this may be related to the fact that mend tend to associated illness with weakness, thereby making it difficult for men to solicit support from their family for fear that this may be seen as a flaw in masculinity. This can also be a reflection of a man's tendency to have a task oriented approach to problem solving. The support from health professionals can be seen as a component of a working relationship with these professionals to solve problems. Avoidance and denial are defense mechanisms often used by these men who tend to present to the health care system at a more advanced stage than their female counterparts. One explanation might be that the use of the health care system does not fit into the concept of masculinity. Also, a period of concealment

might be necessary for the man to assimilate all of the unique issues surrounding the fact that he is diagnosed with a gendered illness.

2.4.1 Genetic counseling

As defined by the American Society of Human Genetics in 1975, Genetic counseling is a communication process which deals with the occurrence or risk of occurrence of a genetic disorder in a family (Baker et al. 1998). A definition of genetic counseling as per the National Society of Genetic Counselors follows:

- Genetic counselors are health professionals who help people understand and adapt to the medical and psychological implications of genetic contributions to disease. Genetic counselors interpret family and medical histories to assess the chance of disease occurrence. They also educate individuals about such areas as inheritance, testing, management, prevention, resources, and research. In addition, genetic counselors counsel patient so that they are able to make informed decisions about their personal health care and to also adapt to the risk or condition\

The American Society of Clinical Oncology recommends that genetic testing be offered when 1) the individual has personal or family history features suggestive of a genetic cancer susceptibility condition, 2) the test can be adequately interpreted, and 3) the results will aid in the diagnosis of influence the medical or surgical management of the patient or family members at hereditary risk of a cancer mutation. The selection of appropriate candidates for genetic testing is based on the personal and familial characteristics that determine the individual's prior probability of being a mutation carrier, and on the psychosocial degree of readiness of the person to receive

genetic test results (NCCN 2013). In population-based series of men with breast cancer unselected for family history, 0 to 4% have BRCA1 mutations, while between 5 and 15% have BRCA2 mutations, depending on ethnicity and the strength of the family history ; therefore, all men with breast cancer are candidates for genetic counseling and BRCA testing (www.uptodate.com 2013). Germline genetic testing is performed on DNA isolated form leukocytes obtained from a venous blood sample of from oral epithelial cells obtained from a salvia sample (Euhus 2013). Blood samples would be contraindicated in those who have had allogeneic hematopoietic stem cell transplantation. In such cases, DNA of the individual being tested should be extracted from a fibroblast culture. If this is not possible, buccal cells may be considered; however, genetic testing using buccal cells may be limited in this population as buccal epithelia cells may be replaced by donor-derived cells over time. When testing is indicated, BRCA1 and BRCA2 mutations are identified through either targeted mutation analysis or sequence analysis in combination with deletion/duplication analysis. Targeted mutations analysis is useful when searching for known specific genetic mutations suspected to be present from prior family testing or because the population at risk is known to possess certain mutations at higher frequencies, such as 187delAG, and 5385insC in BRCA1 and 6174delT in BRCA2 in patients of Ashkenazi Jewish heritage (Gage 2012). Full sequencing plus deletion/duplication analysis is recommended when the suspected mutation in BRCA1 or BRCA2 in a given family is previously unidentified. Mutation detection frequency was > 88% when comprehensive analysis was done on individuals with families with demonstrated linkage to BRC1 or BRCA2 (Gage 2012). NCCN currently recommends for all individuals undergoing BRCA analysis a test called the BRCAnalysis Large Rearrangement Test or BART which provides a more comprehensive analysis test for large rearrangements in BRCA1 and BRCA2. These large rearrangements

account for up to 17% of deleterious BRCA gene mutations in individuals of Near-East/Middle East ancestry and up to 22 % for individuals with Latin American /Caribbean ancestry (Euhus 2013).

2.4.1.1 Possible Genetic testing outcomes

Genetic counseling is highly recommended by a qualified health professional with expertise and experience in cancer genetics such as a genetic counselor, medical geneticist, oncologist surgeon or oncology nurse during the process of genetic testing and after the result are disclosed (NCCN 2013). The possible testing outcomes are 1) positive for familial mutation and 2) negative for familial mutation 3) variant of unknown clinical significance (NCCN 2013).

In those affected probands with no known familial BRCA1/BRCA2 mutation, comprehensive genetic testing, which includes full sequencing of BRCA1/BRCA2 and testing for large genomic rearrangements, may be offered (NCCN 2013). If the proband is unaffected, testing of family members with highest likelihood of a BRCA1BRCA2 mutation should be performed (NCCN 2013). If more than one family member is affected, first consider: youngest age at diagnosis, bilateral disease, multiple primaries, ovarian cancer and most closely related to the proband (NCCN 2013). If no living family member with breast or ovarian cancer, consider testing first- or second-degree family members affected with cancers thought to be related to BRCA1/BRCA2 such as prostate, melanoma, pancreas (NCCN 2013). In those individuals with a known familial mutation, it is recommended that BRCA1/BRCA2 testing for the specific familial mutation be offered (NCCN 2013).

Even if no mutation is identified, it is possible that the cancer in the proband is due to another gene that may or may not yet be identified. Testing for other hereditary breast syndrome should be considered. The decision to test other genes should be guided by both paternal and

maternal family history and phenotypic clues. Also, current available gene tests are not capable of identifying every deleterious mutation. The sensitivity of BRCA gene testing is estimated at 80% to 90% (Euhus 2013). Attempts to contact patients with these noninfomative negative gene tests to offer retesting should be done as new technology becomes available. If a noninfomative test result cannot be resolved, then recommendations for medical management should be based on the individual's personal and family history of breast cancer.

Another uninformative result is the variant of unknown significance or VUS. For BRCA1 and BRCA2, it is estimated that in the Caucasian population 2.9% of identified mutations fall into this category (Euhus 2013). Work is continually ongoing to definitively classify these variants as deleterious or nondeleterious. A record of the genetic test result and patient contact information needs to be maintained so that these individuals can be contacted when the VUS is classified as deleterious or nondeleterious (Euhus 2013). Testing family members for the VUS should not be used for clinical purposes. Referrals to research protocols can be considered. As with the other type of noninfomative test result, medical management should be based on the individual's personal and family history of breast cancer.

For both affected and unaffected individuals of Ashkenazi Jewish decent with no known familial mutation, first test for the three most common mutations (NCCN 2013).Then, if negative for the three mutations and ancestry also includes non-Ashkenazi Jewish relatives or other HBOC criteria is met, consider comprehensive genetic testing,

2.4.1.2 Medical management for positive test results

The recommendations for those men found to have a deleterious BRCA mutation are as follows (NCCN 2013):

- Breast self-exam training and education starting at age 35.
- Clinical breast exam, every 6 – 12 months, starting at age 35.
- Consider baseline mammograms at age 40; annual mammograms if gynecomastia or parenchymal/ glandular breast density on baseline study.
- Adhere to screening guidelines for prostate cancer – baseline digital rectal examination and PSA at age 40.

2.4.1.3 Psychosocial issues relating specifically to genetic counseling

Some factors in the literature associated with greater uptake of genetic testing include the following: women from multi-case families, higher economic status, higher levels of education and higher self-perceived risks of cancer (Daly 2009). Reasons for undergoing testing for BRCA1/2 include: surgical decision making, gaining information to guide screening and preventive practices, obtaining information for family members and peace of mind (Daly 2009).

Despite the fact that the information is sparse, there are some unique themes emerging from the research about the experiences of men with breast cancer and genetic testing. Fewer men than women come forward for predictive BRCA1/2 testing and men who do proceed with genetic testing have a tendency to miss appointments, drop out of testing protocols and experience difficulties establishing appropriate posttest care (Lobb 2009). There is limited data that suggests that men who do pursue testing may be acting under pressure exerted by family members and not necessarily for their own benefit (Daly 2009). Also, there is evidence in the literature that just knowing their mutation status is not sufficient motivation for a man to pursue genetic testing (Lobb 2009). Concern for their offspring plays a role in the decision to pursue genetic testing: men tend to view the decision to pursue testing out of concern for their family

rather than as a benefit to themselves. Men feel that they have a responsibility to get testing not only for optimal health practices for themselves, but also so that their children can make informed health care choices. Men can experience a conflict between the sense of duty to warn their children and the sense of duty to protect them.

Women are emerging as strong influential figures for men in the total process of genetic counseling from decision making to communication of risk information to family members. Women have been found to be the initiators of genetic testing of the male. This can be a reflection of the fact the women often play the main role in both providing health care and communicating with health care systems on behalf of their husband and children. (Strosvik 2009). It can also be a reflection of the different support systems that men and women have which can influence the number of people considered to be a confidant. Men regard their wives or significant other as their closest personal contact and support system compared with women who tend to have a broader support system which may include other women and health professionals as well as their husband/partner. Also, health practices have been found to differ between men and women. Women express a higher perception of health risk and vulnerability to health hazards than men, resulting in more proactive health care practices which may include genetic testing. Social stereotypes of masculinity equate illness with personal weakness and may result in an avoidance of the health care system by the male. Men's health behaviors are influenced by the social context in which they live. In other words, a male's perception of male behavior forms his own behavior in terms of health care practices. Women might play a role in the formation of male health care practices in two different ways. Men's fear of being perceived as feminine leads them to define themselves in opposition to woman (Mahalik 2007). If a man constructs his identity in contrast to women, he may do the opposite of what he perceives as

normative for this group (Mahalik 2007). Alternatively, men may view women as a salient reference group because they also provide important information about health behavior (Mahalik 2007).

There is evidence that men may be more willing to take a more active role in the process of genetic testing. A pilot study conducted by Juan et al. in 2008 showed evidence that men may be more willing to take a more active role in the genetic testing process. Juan et al. developed an aid to help men with a strong family history of breast and/or ovarian cancer in decision making with regards to genetic testing. The aid included background information on BRCA genes, a description of the testing process and possible test results, and a discussion of the impact of testing on the man and his children. All of the men in the study would recommend the aid to others and 96% reported that they were satisfied with the aid (Juan 2008). Despite the avoidance denial coping mechanism found upon the diagnosis of breast cancer described in the literature, men do report a strong sense of duty to inform other family members of the genetic testing results. Men have reported both a need to be informed as to which family members need to be aware of testing results and a need to learn how to better communicate genetic risk to these family members. Still within the family, women often take on the role of the disseminator of risk information, even for those family members of their partner whom they do not know well. From the limited body of research, men are also 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 (Daly 2009).

Genetic testing may affect family dynamics through the identification of at-risk relatives who may adopt their carrier status as a component of their identity. For both carriers and non-carriers, genetic information becomes a component of their sense of self and family. A study of

at risk male responses to BRCA1/2 testing was undertaken by conducting interviews with at risk men by Hallowell et al. in 2006. The study population was men over the age of 18 with no previous diagnosis of cancer or mental illness who had previously received a BRCA testing result. They conducted interviews with 5 BRCA positive males and 12 males who were found not to have a BRCA mutation (Hallowell 2006). BRCA negative men were found to willingly accept responsibility for disrupting the family dynamics in the period in which the test results were unknown. In other words, they accepted responsibility for the fact that their offspring remained at risk while the results of the testing remained unknown. This is theorized to be a way of both reaffirming not only their obligation to the family as a responsible parent, but also their role in fixing any breaks in family dynamics that have occurred during the testing process (Hallowell 2006). In addition, BRCA negative men stated that they would have taken responsibility for the transmission of increased risk had they tested positive. This could be another example of a man strengthening his position in the family as a responsible parent. Among the BRCA negative men, there was relief for their children, but also evidence of survivor's guilt. Some of the men expressed the sentiment that it would have been better for them to have a mutation rather than their female sibling as the risk of cancer is lower for men. BRCA positive men in this study felt the transmission of the gene was a chance event over which they had no control. This view is such that it exonerates them from blame and in a sense helps them to come to terms with putting their children at risk. Both examples can be viewed as evidence that both BRCA negative and BRCA positive males attempt to reconcile their genetic makeup with their sense of self and family and all the responsibilities that come with being a member of a family.

2.4.2 Transference and Countertransference

Transference and countertransference are present in a variety of relationships including genetic counseling. Transference is defined as an unconscious transference of experiences from one interpersonal relationship to another (Jones 2004). Thoughts and feelings about past situations are projected onto current relationships. Transference serves as a means for alleviating anxiety by preserving the past and has the potential to prevent self-development. Countertransference is a response to transference that can complicate the working relationship. Two types have been found in genetic counseling. Associative countertransference arises when a patient shares an experience that brings the counselor back in time to her memories of a similar experience (Baker 1998). The second type of countertransference is called projection in which a counselor makes an assumption about the experiences of a counselee based on his or her own past experiences (Baker 1998). As professionals, genetic counselors have a responsibility to identify any process which can affect the genetic counseling process. We must be aware of our vulnerabilities, countertransference triggers and abilities to take in the experiences of the counselee (Baker 1998). This self-awareness can be achieved through discussions with colleagues, case discussions in which psychological issues are considered and sometimes therapy (Baker 1998).

2.5 SOURCES OF PATIENT SUPPORT AND RESOURCES

The following are some resources for men with breast cancer:

- American Cancer Society. Breast Cancer in Men: Detailed Guide

  www.cancer.org/Cancer/BreastCancerinMen/DetailedGuide/index

- John W. Nick Foundation

  www.malebreastcancer.org

- Mayo Clinic. Male Breast Cancer

  www.mayoclinic.com/health/male-breast-cancer/DS00661

- Menstuff, The National Men's Resource. Breast Cancer in Men.

  www.menstuff.org/issues/byissue/breastcancer.html

- National Cancer Institute. Male Breast Cancer Treatment PDQ

  www.cancer.gov/cancertopics/pdq/treatment/malebreast/Patient

  www.cancer.gov/cancertopics/pdq/treatment/malebreast/HealthProfessional

2.6 CURRENT RESEARCH

The European Organization for Research and Treatment of Cancer is coordinating a global effort, which joins forces from the Breast International Group and the North American Breast Cancer Groups, called International male Breast Cancer Program (Sousa 2013). This Program is composed of three parts: 1) retrospective joint analysis of all male breast cancer cases diagnosed in the last 20 years in the participating institutions, evaluating the biology of male breast cancer in detail with central pathology review of tumor blocks and analysis of biological characteristics and promising biomarkers; 2) prospective international registry of all male breast cancer cases diagnosed in the participating institutions for a period of 2 years which is about to be launched and will provide valuable insight into the current treatment decisions as well as ensure that the

network in place can effectively recruit the needed patients for part 3 of the Program; 3) conduct of a prospective randomized trial (Sousa 2013).

3.0 METHODS

3.1 PARTICIPANTS

The target population for this study is genetic counselors who currently counsel cancer patients in the United States. Data on those counselors who work outside of the United States was also collected as this additional data might provide valuable information regarding ideas for future research. The counselors must belong to either the Familial Cancer Risk Counseling special interest group of the National Society of Genetic Counselors (NSGC) or the general listserv of the NSGC (Appendix A). The total amount of counselors who belong to the Familial Cancer Risk Counseling special interest group is 490. It is unknown how many genetic counselors belong to the general listserv and not the special interest group. As per the National Society of Genetic Counselors, the listserv is an electronic open forum discussion group only open to NSGC members and serves as one avenue of communication among members. It has been described by the NSGC organization as an electronic bulletin board i.e. one member can post a message for all other members to read and respond to if applicable. As per the NSGC, the listserv also helps to develop supportive professional relationships, address questions relevant to the genetic counseling community, and disseminate pertinent updates or changes in practice methods. It was felt that members would be familiar with this approach for recruitment into a study as such recruiting practices have been used in the past.

3.2 PROTOCOL

A review of literature regarding familial, genetic and psychosocial issues was done via PubMed. Genetic, familial and psychosocial issues were reviewed. The survey was conducted at the University of Pittsburgh. SurveyMonkey was responsible for collecting the data. After obtaining IRB approval from the University of Pittsburgh, an invitation to participate was sent in January 2011 via a posting sent to the listserv of both the Familial Cancer Risk Counseling special interest group of the National Society of Genetic Counselors (NSGC) and the general listserv of the NSGC (Appendix A). To ensure confidentiality, the survey was encrypted during transmission to the target audience as well as their responses back to the Survey Monkey account. Also, the survey was distributed through a web collector that tracks respondents using cookies on their individual computers rather than a unique ID attached to the link. Subjects were evaluated with a 31 question survey utilizing both nominal and ordinal measurements (Appendix B). For ordinal measurements, the level of disagreement or agreement was measured via a 5 level Likert scale defined as follows:

- 1 - strongly disagree
- 2 – disagree
- 3 – neither agree nor disagree
- 4 - agree
- 5 – strongly agree

Nominal measurements utilized yes/no or true false responses. The survey gathered information on such topics as the counselor's experiences counseling men with breast cancer as well as their beliefs concerning the sociocultural, psychosocial, and familial issues impacting these men. Information on demographic variables concerning the respondent such as gender, years of

experience, work setting, number of cases per year and geographic area of practice was also gathered. The majority responded within one month. No reminders were sent to the counselors. Data collection ended in March 2011.

3.3 DATA ANALYSIS

Data analysis consisted of descriptive statistics displayed in graph form This type of analysis will give us measure of central tendency of which the mode will be most useful to fulfilling the aims of the study. The percentages of each answer option will give us an idea of the range across the responses.

4.0 RESULTS

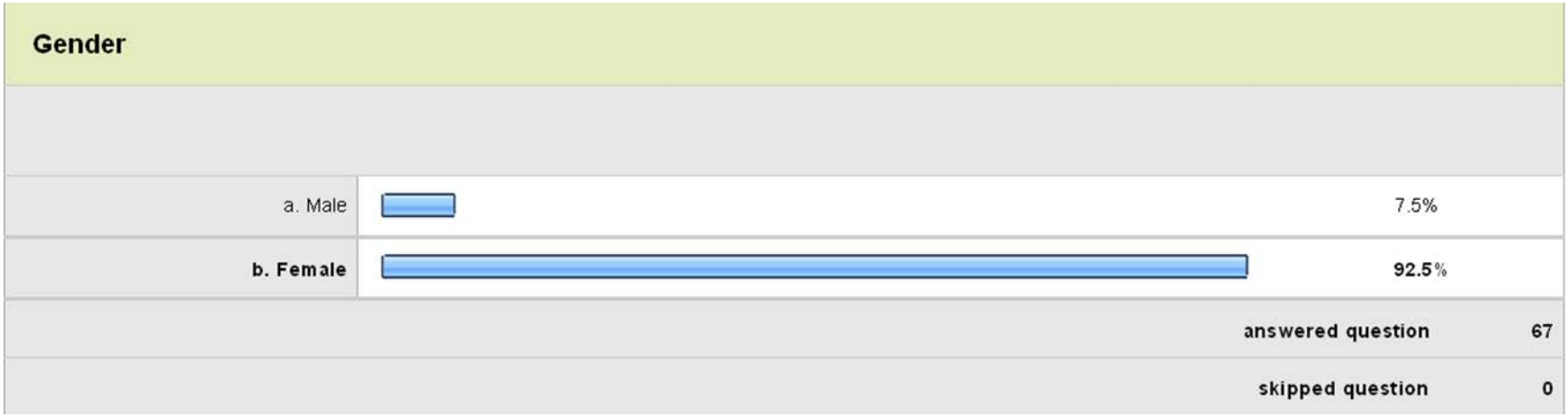

Figure 1-Gender

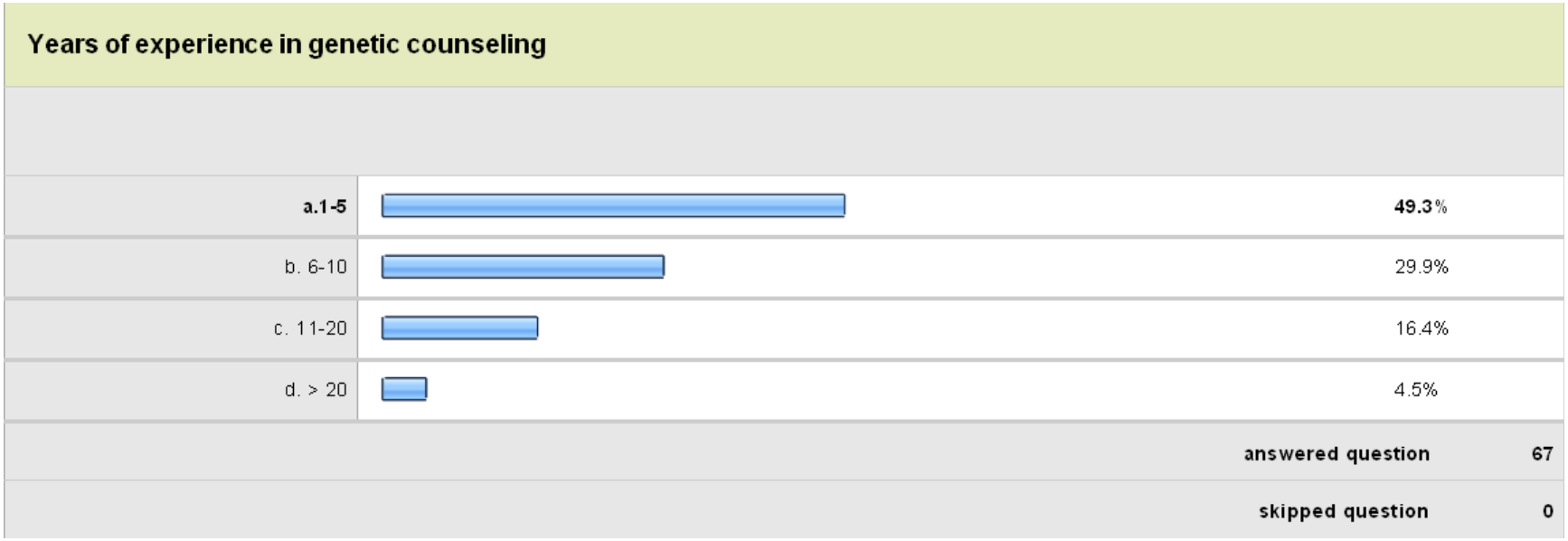

Figure 2-Years of Experience

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Primary work setting		
a. University Medical Center		**41.8%**
b. Private Hospital/Medical Facility		28.4%
c. Public Hospital/ Medical Facility		29.9%
d. Physician's Private Practice		0.0%
e. University/Non- Medical Center		0.0%
f. Private Practice/Self- Employed		0.0%
	answered question	**67**
	skipped question	**0**

Figure 3-Primary Work Setting

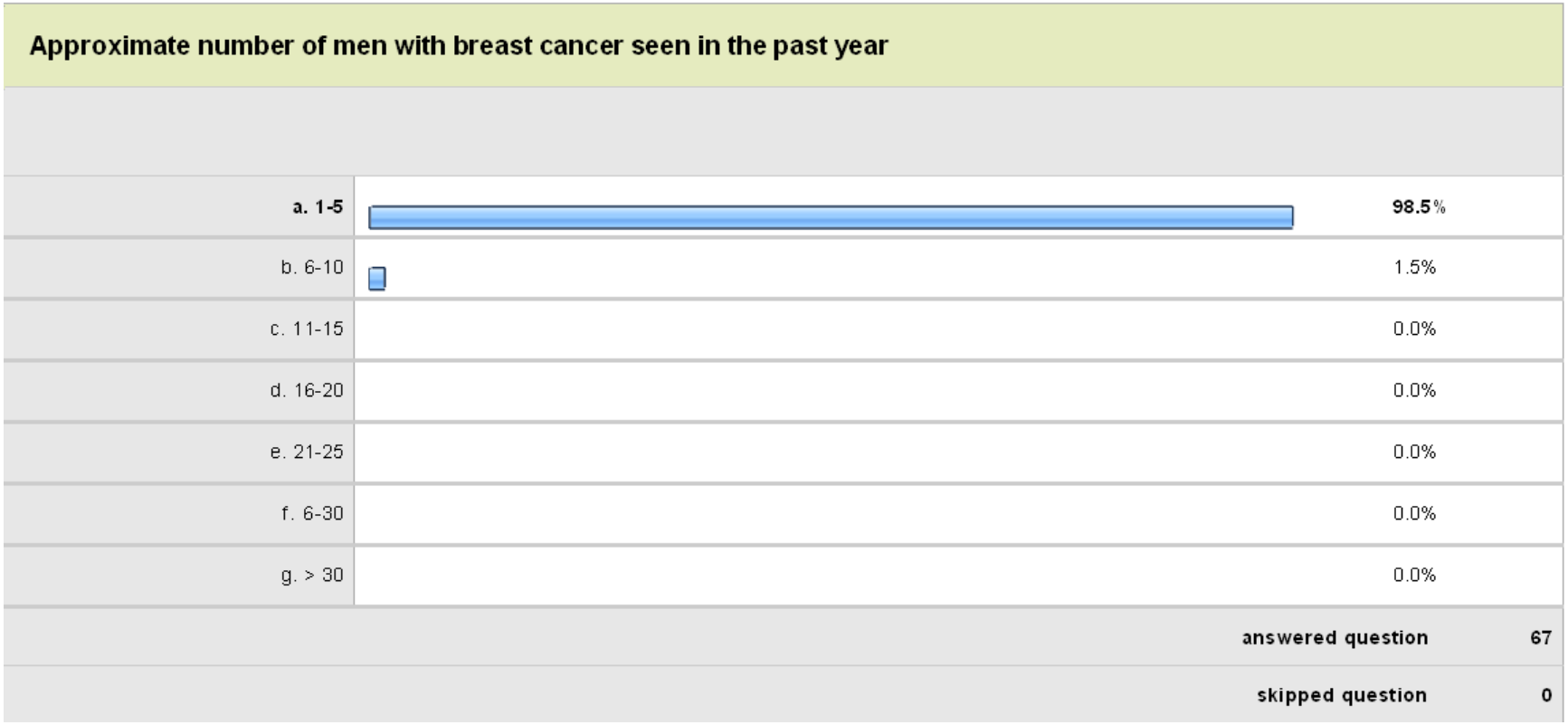

Figure 4-Number of Men Affected

Area of practice		
a. United States		**100.0** %
b. Canada		0.0%
c. United States and another country		0.0%
d. Other – Please specify		0.0%
	answered question	**67**
	skipped question	**0**

Figure 5-Area of Practice

Please choose which statement best describes your current practice:		
a. The percentage of men diagnosed with breast cancer who choose BRCA testing is greater than the percentage of women with breast cancer who choose BRCA testing.		**53.2%**
b. The percentage of men with breast cancer who choose BRCA testing is equal to the percentage of women with breast cancer who choose BRCA testing.		40.3%
c. The percentage of men with breast cancer who choose BRCA testing is less than the percentage of women with breast cancer who choose BRCA testing.		6.5%
	answered question	**62**
	skipped question	**5**

Figure 6-Percent Choosing Testing

Please choose which statement best describes your current practice:		
a. In general, the BRCA counseling session is shorter in time for men than for women.		29.0%
b. In general, the BRCA counseling session is equal in time for both men and women.		**71.0%**
c. In general, the BRCA counseling session is greater in time for men than for women.		0.0%
	answered question	**62**
	skipped question	**5**

Figure 7-Length of Session

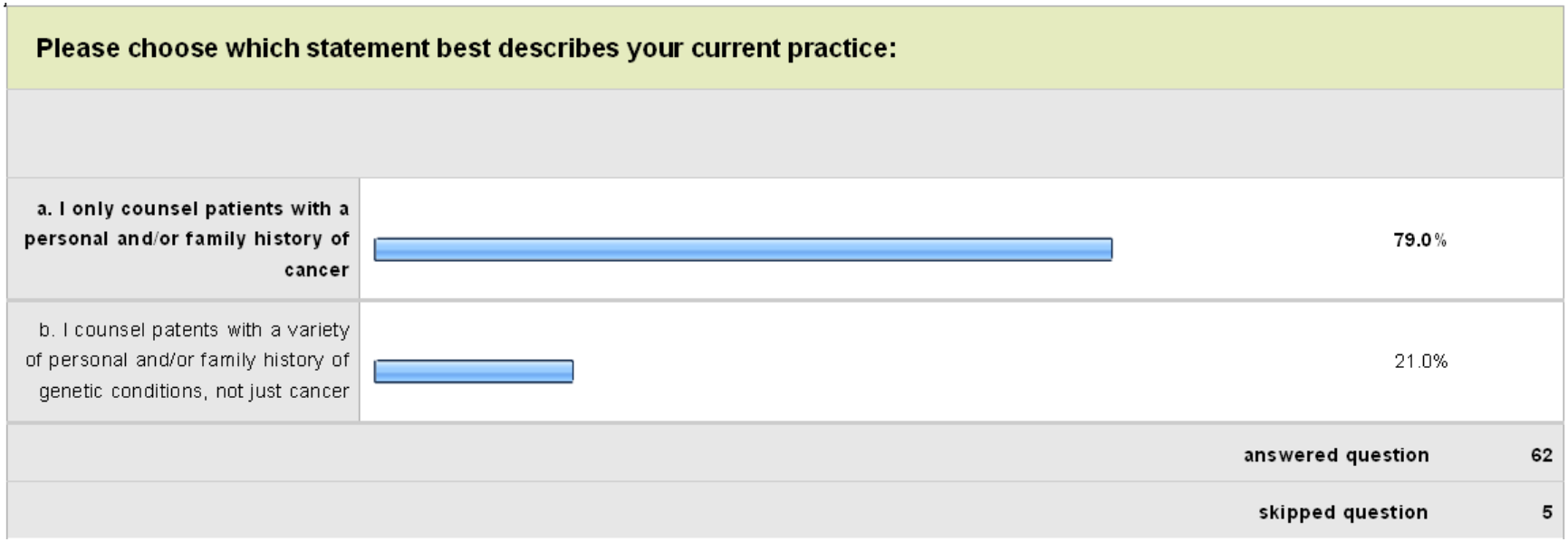

Figure 8-Types of Patients in Practice

Please choose which statement best describes your current practice:		
a. Most of the men who attend counseling sessions are referred by their doctors.		**96.8%**
b. Most of the men who attend counseling sessions are referred by their spouse/partners.		1.6%
c. Most of the men who attend counseling session are referred by their children.		1.6%
d. Most of the men who attend counseling sessions are referred by a friend.		0.0%
e. Most men who attend counseling sessions are not referred by anyone.		0.0% 0
	answered question	**62**
	skipped question	**5**

Figure 9-Description of Practice

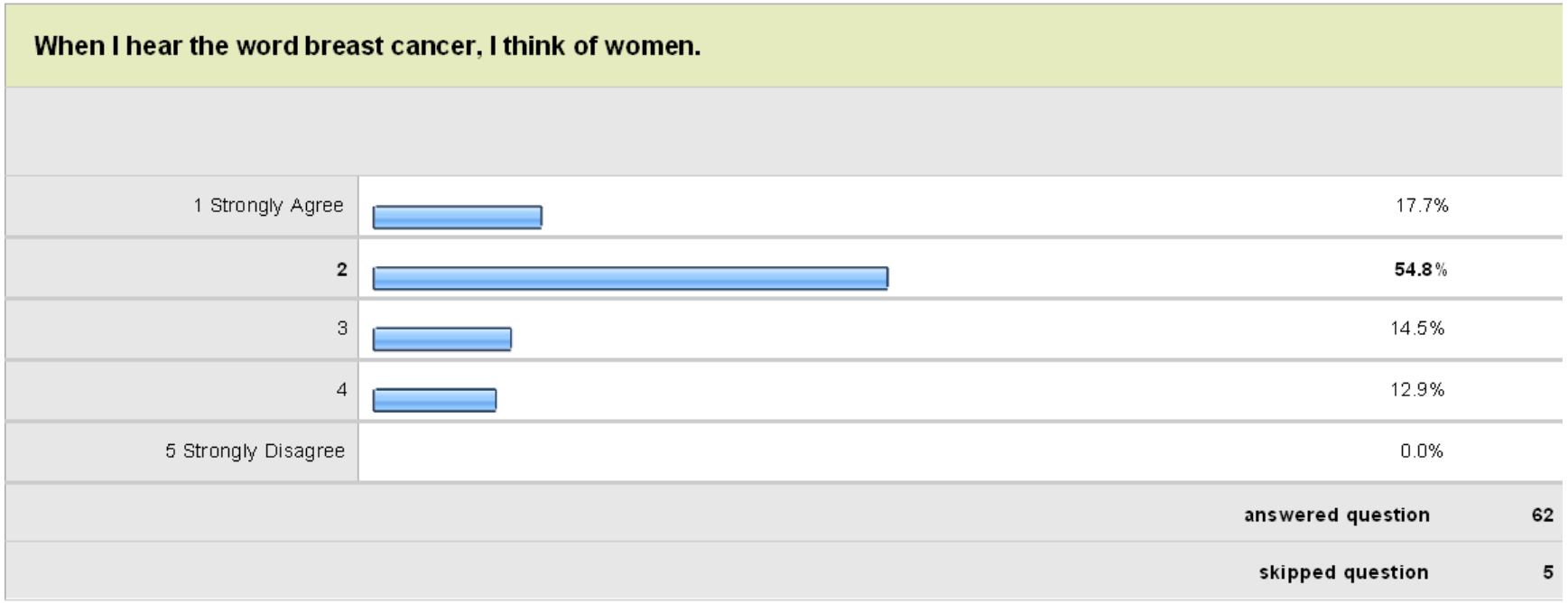

Figure 10-Perception of Breast Cancer

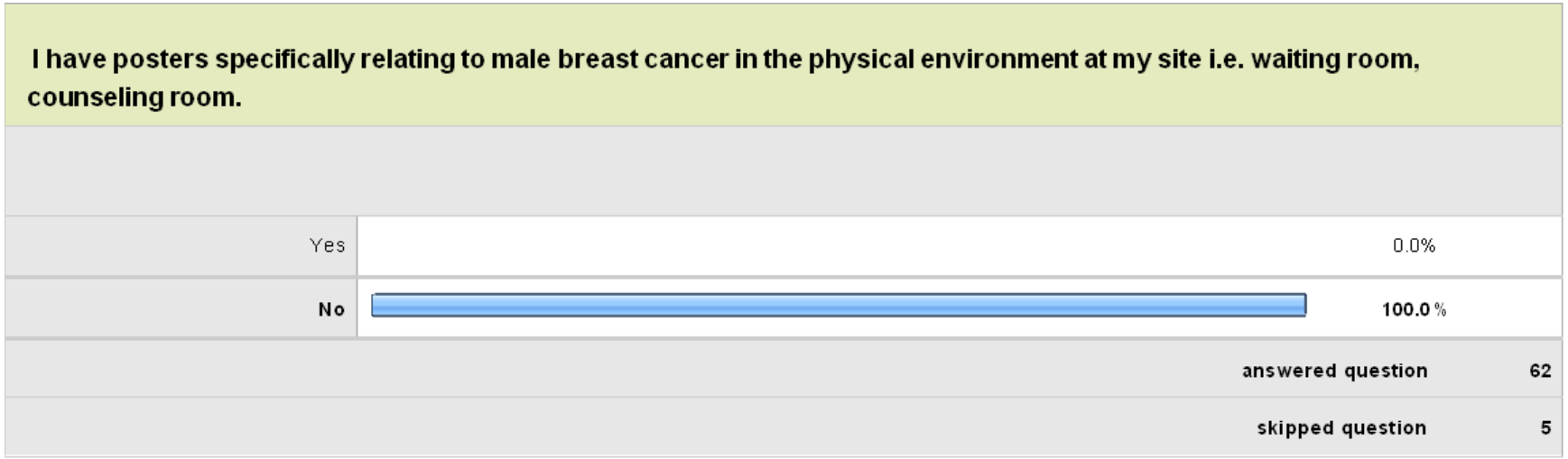

Figure 11-Posters in Counseling Room

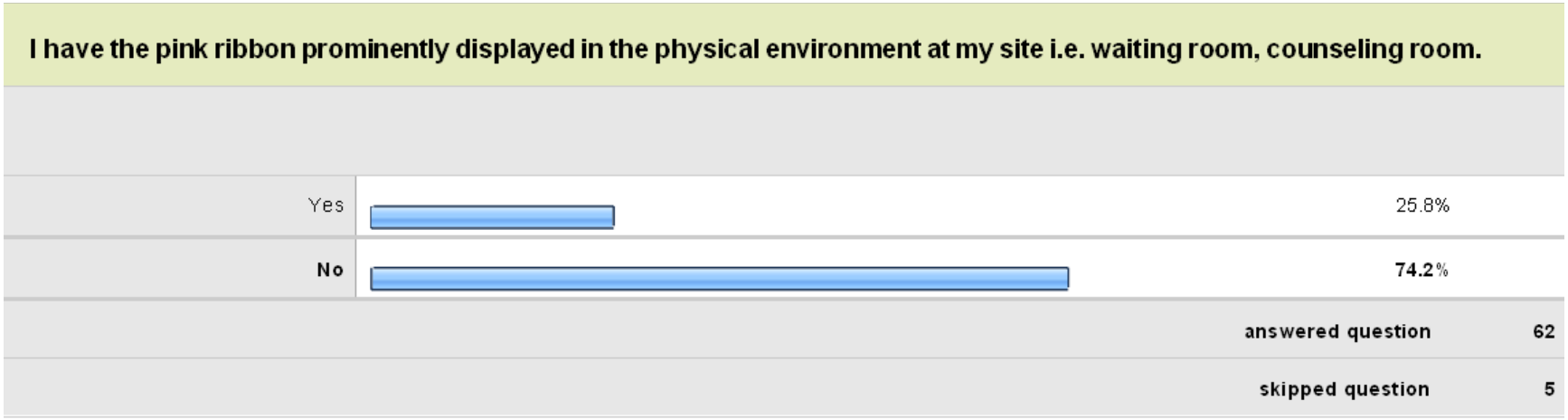

Figure 12-Presence of Pink Ribbon

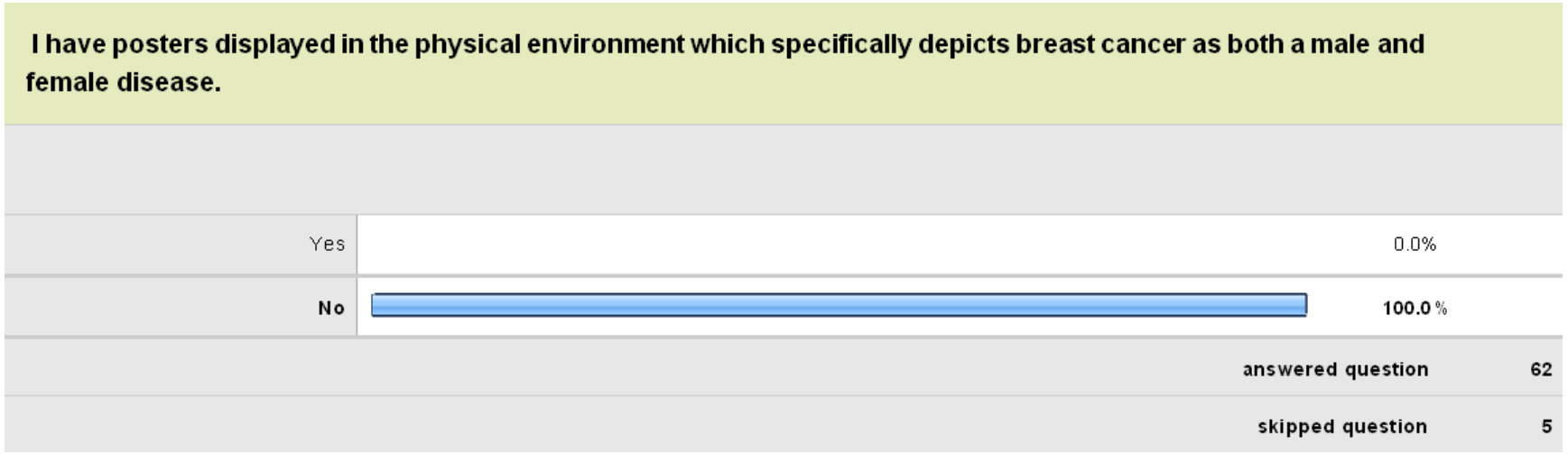

Figure 13-Presence of Posters Depicting Breast Cancer as both a Male and Female Disease

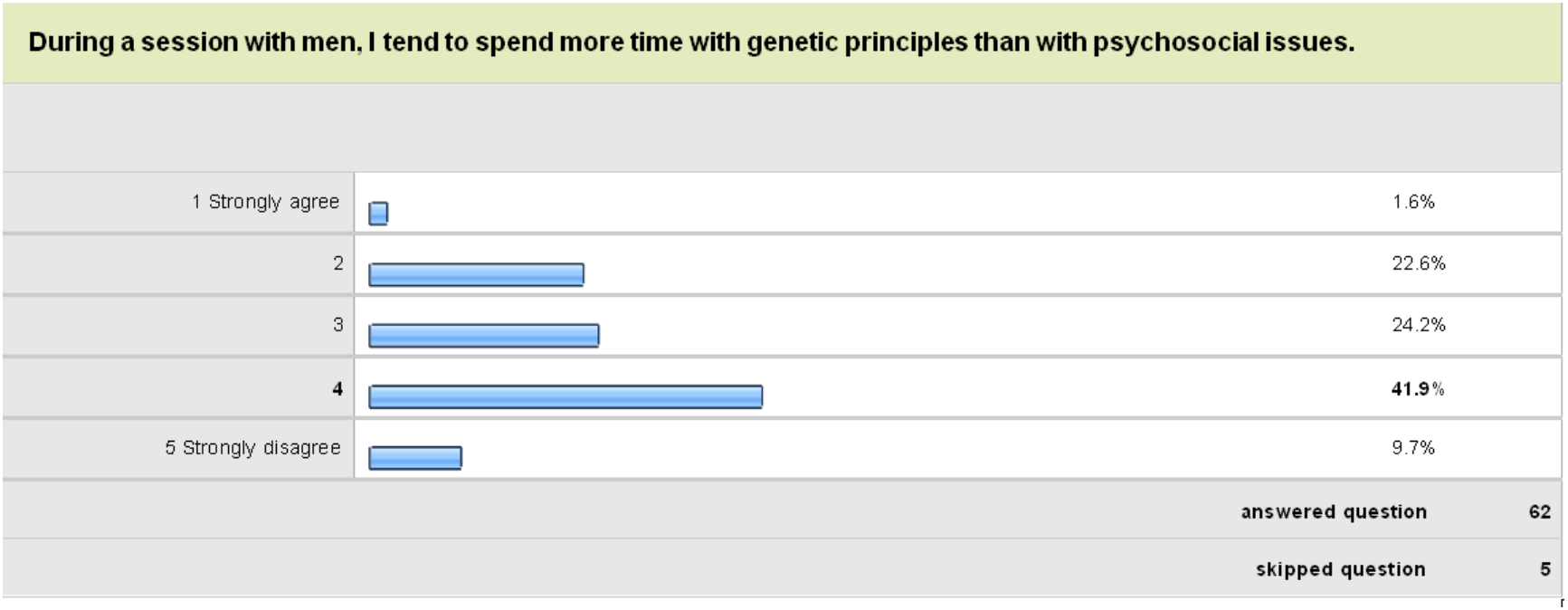

Figure 14-Time Spent on Genetic Principles versus Psychosocial Issues

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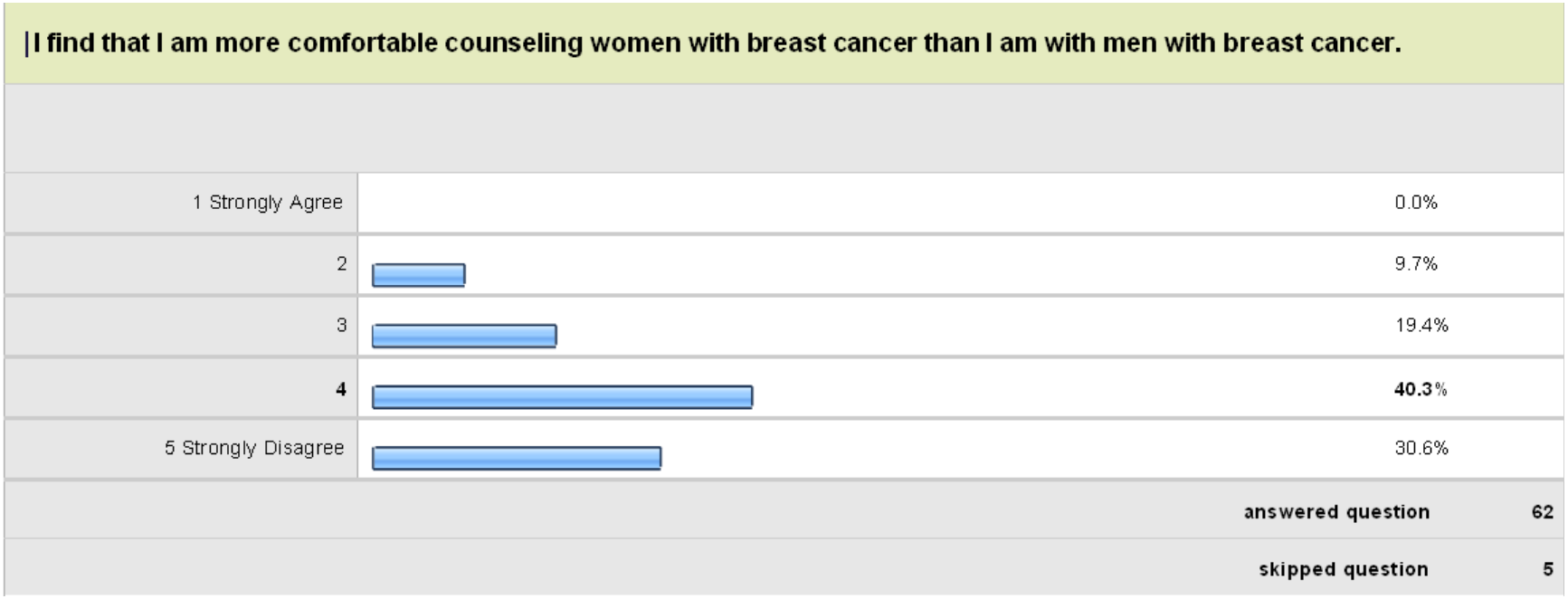

Figure 15-Comfort Level Counseling Women versus Men

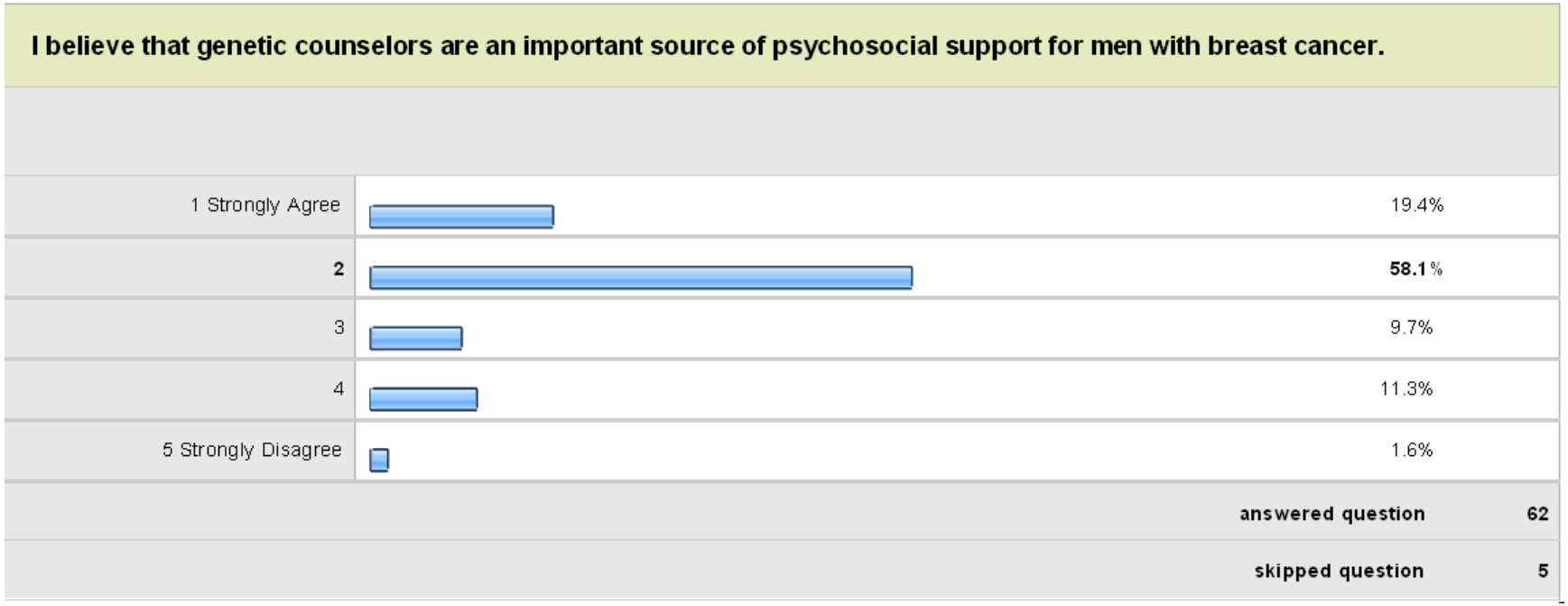

Figure 16-Belief that Counselors are an Important Support System for Men

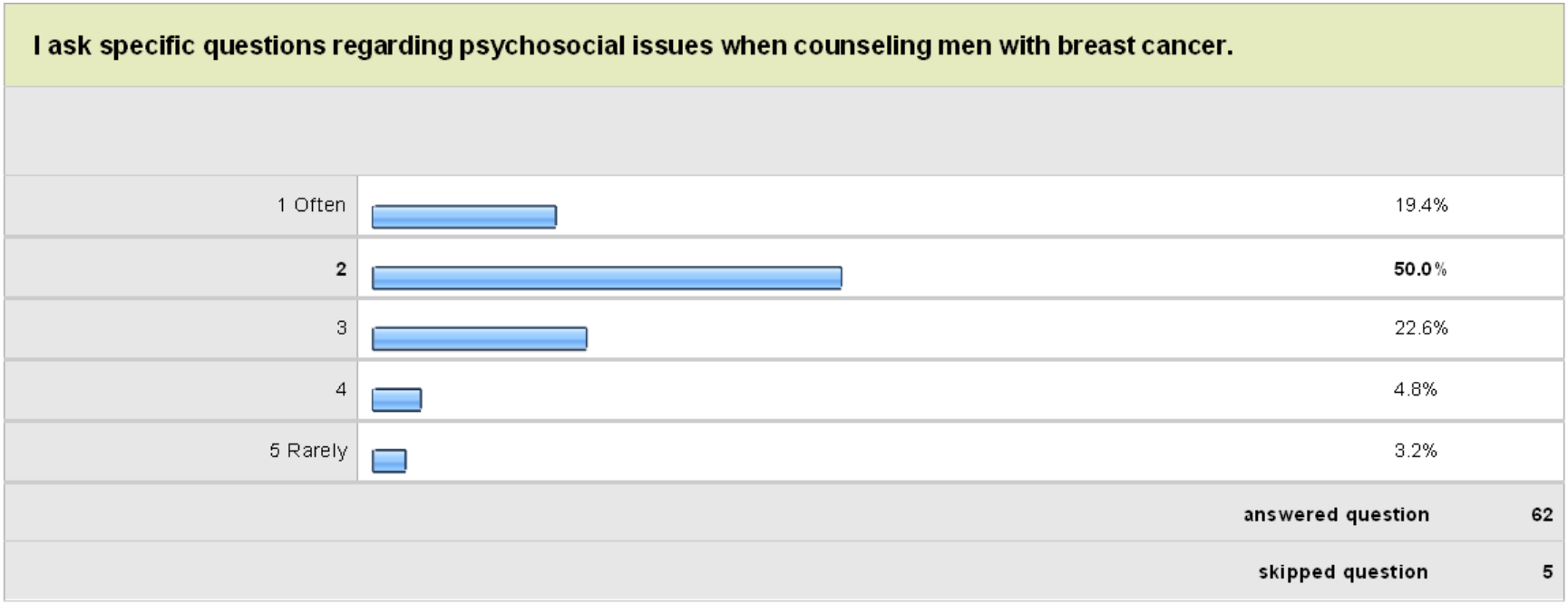

Figure 17- Psychosocial Questions during a Counseling Session

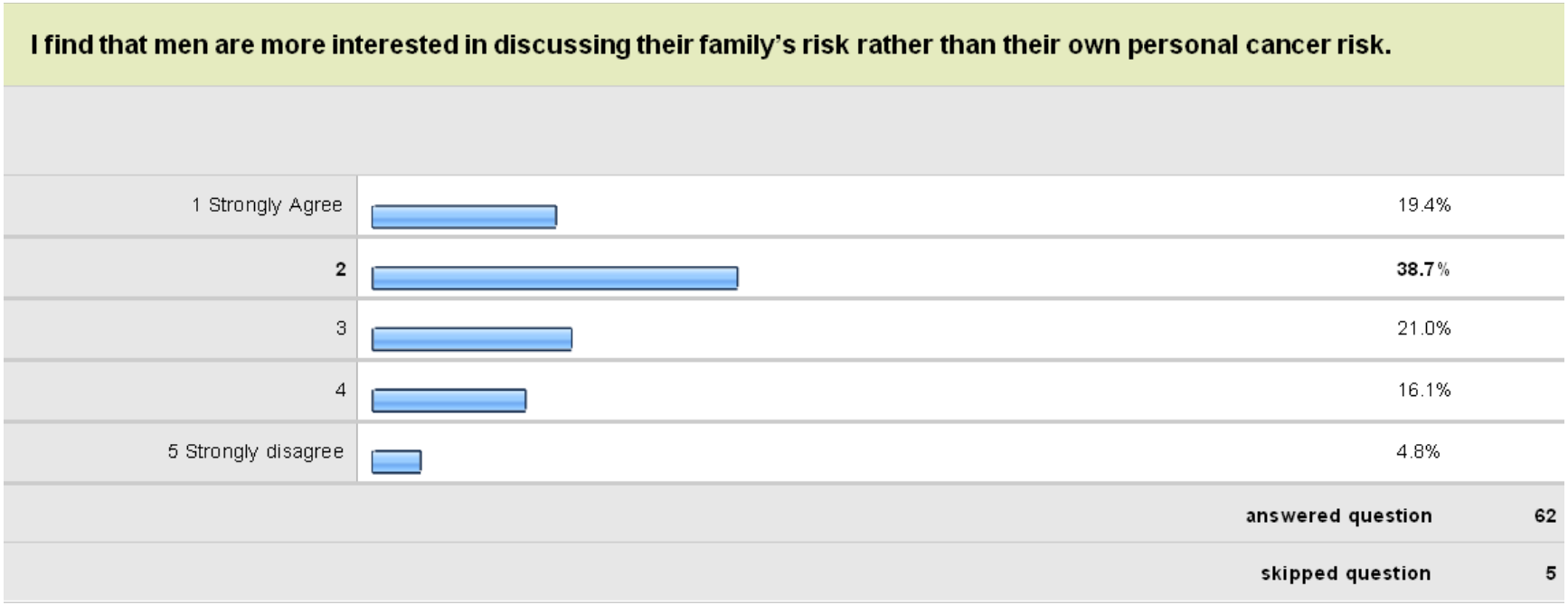

Figure 18- Male Interest in Family Risk versus Personal Risk

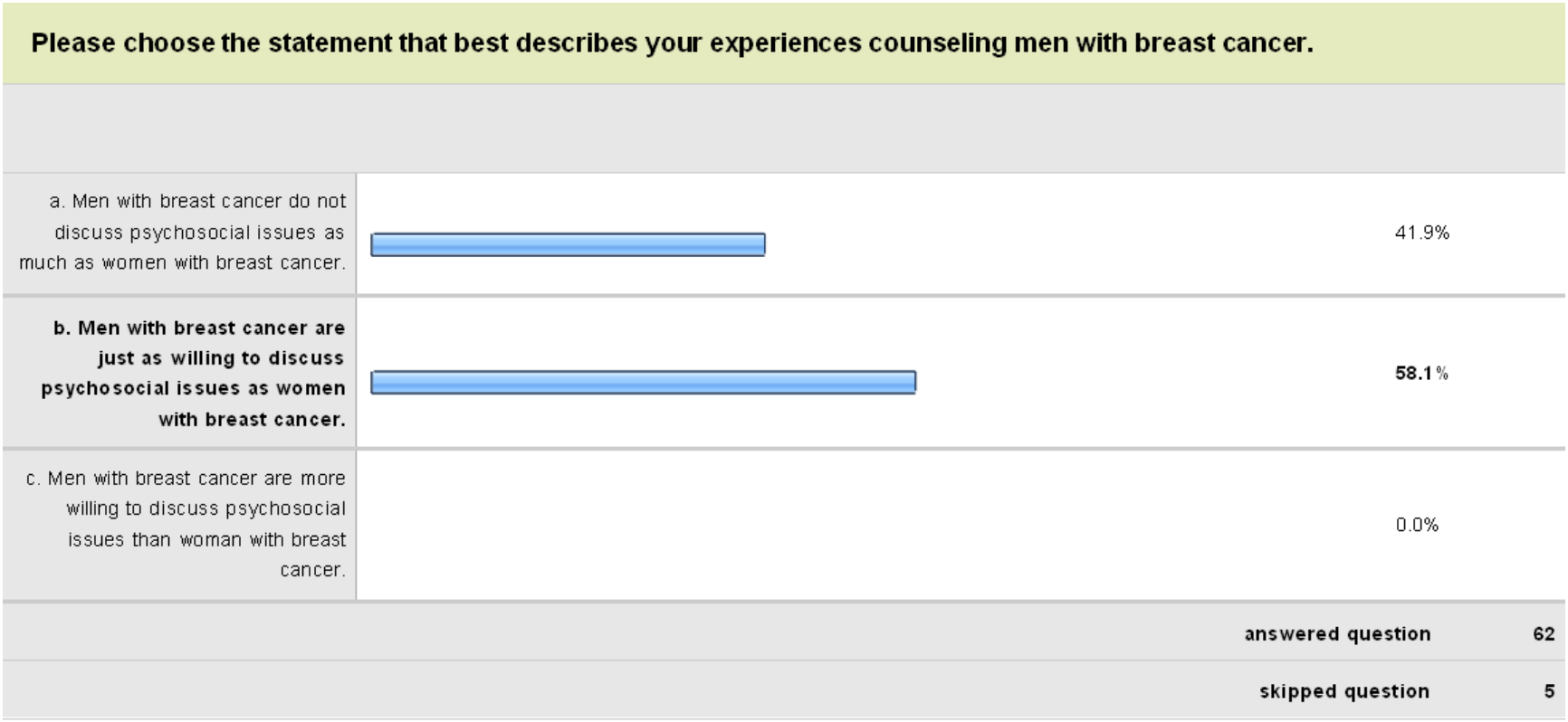

Figure 19- Male Willingness to Discuss Psychosocial Issues

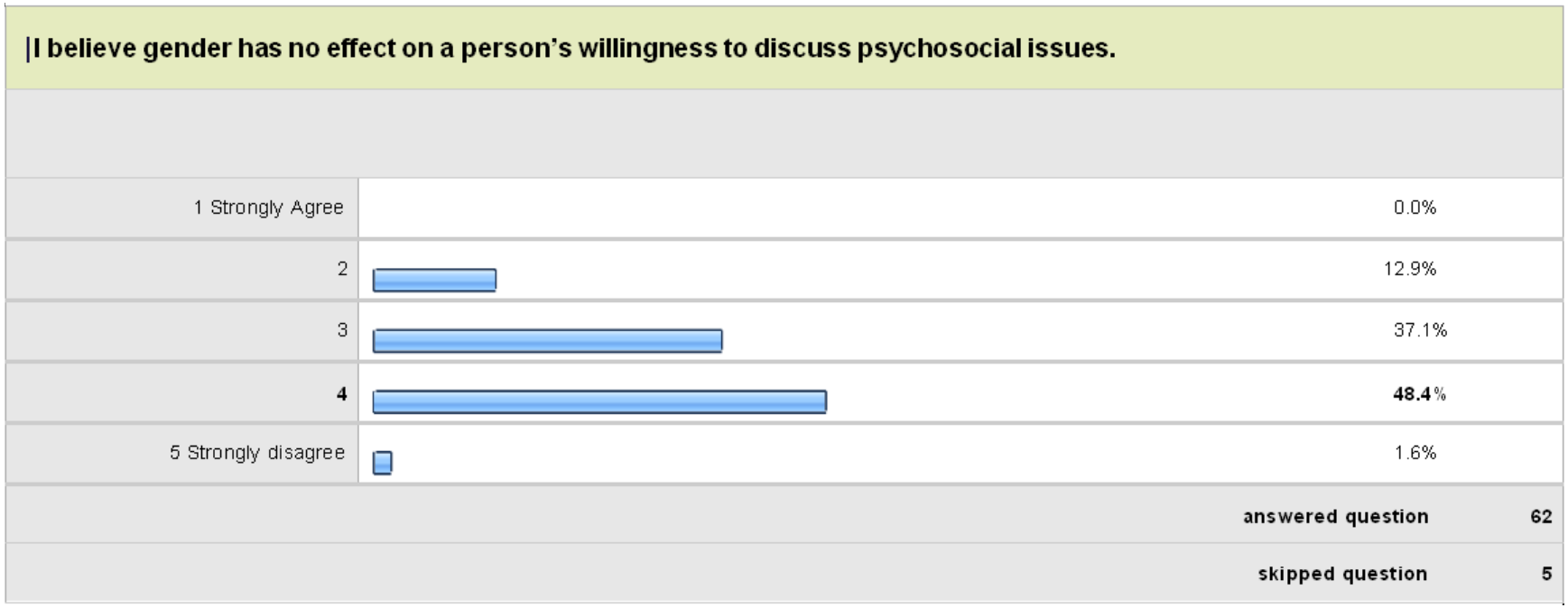

Figure 20- Effect of Gender on Willingness to Discuss Psychosocial Issues

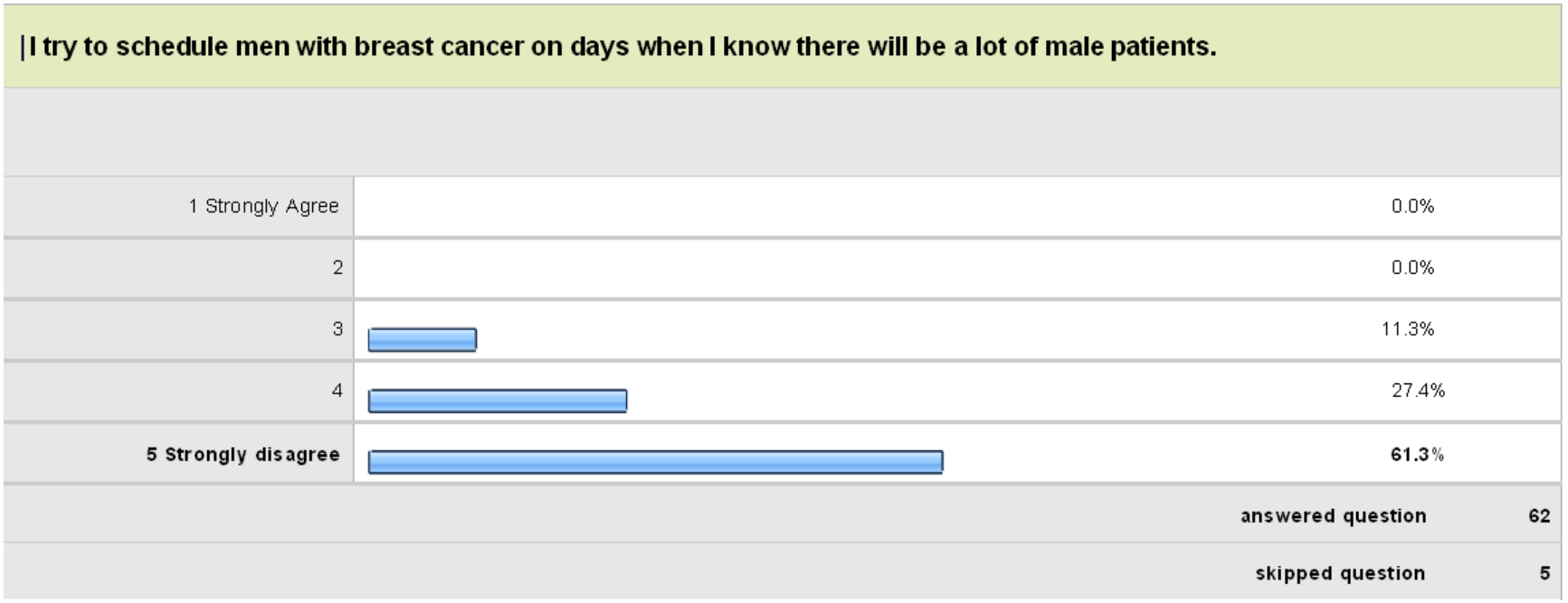

Figure 21-Scheduling Men with Breast Cancer

I believe that men with breast cancer would be more comfortable with a male genetic counselor than with a female genetic counselor.

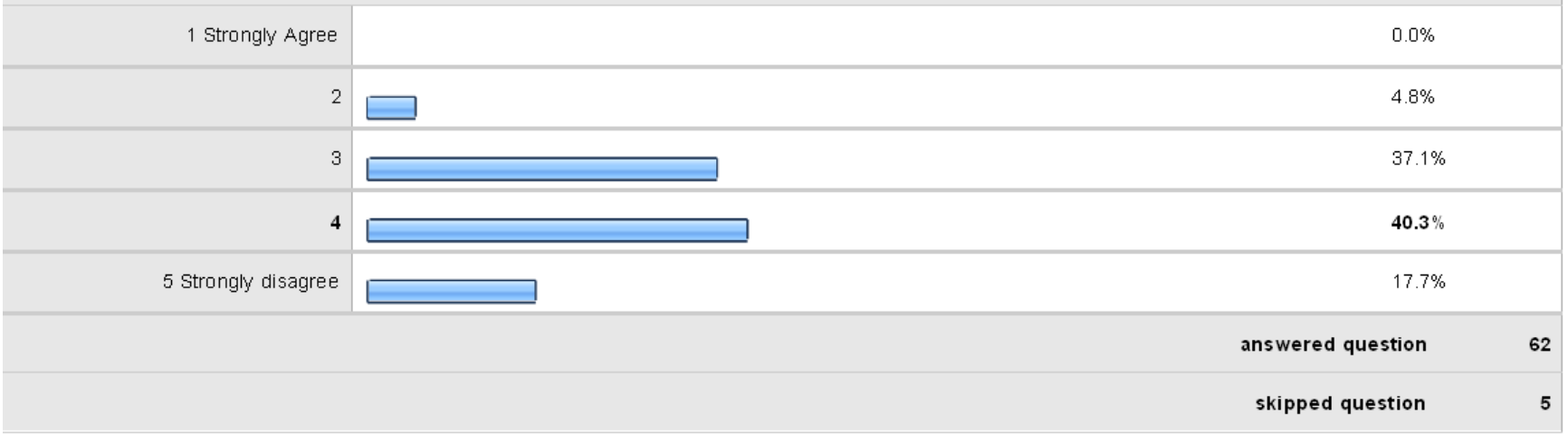

Figure 22-Confort Level of Men with a Male versus Female Counselor

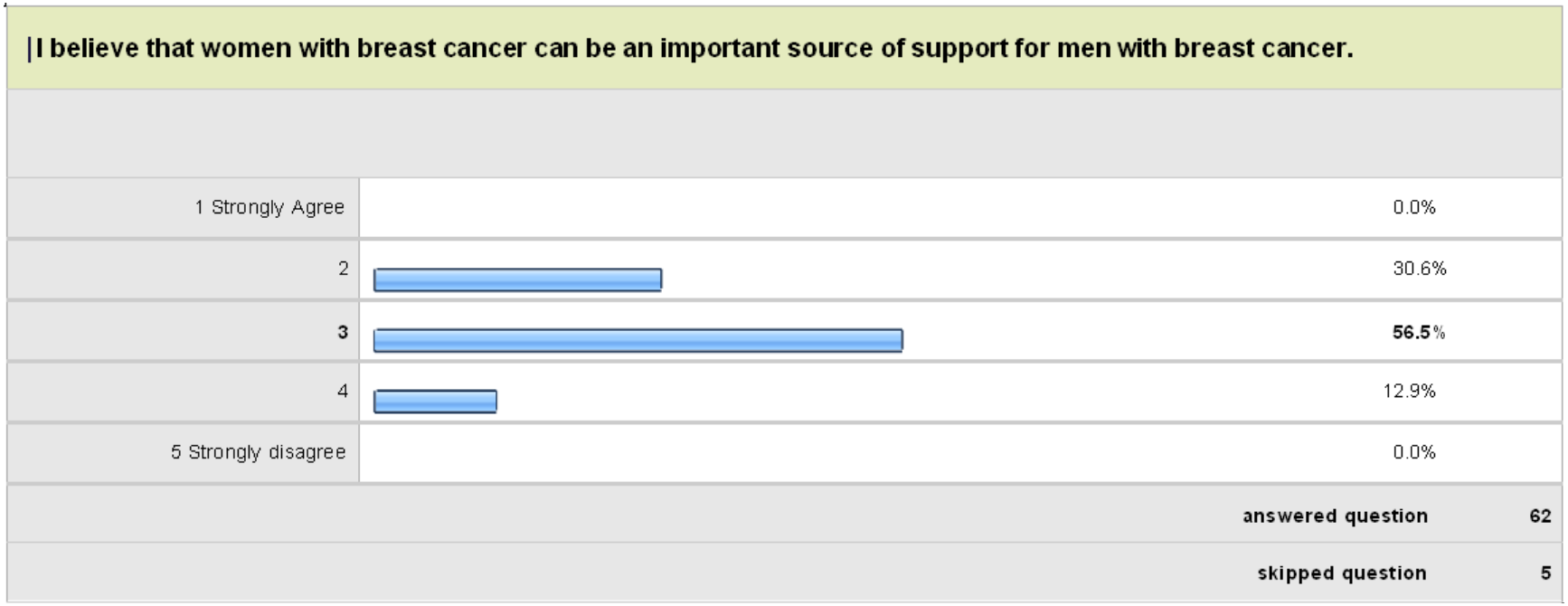

Figure 23-Women as a Source of Support

Which of the following statements best describes your beliefs:		
a. A breast cancer diagnosis is a more traumatic event for men than for women.		9.7%
b. A breast cancer diagnosis is an equally traumatic event for both men and women.		**82.3%**
c. A breast cancer diagnosis is not as traumatic for men as it is for women.		8.1%
	answered question	**62**
	skipped question	**5**

Figure 24-Breast Cancer as a Traumatic Event for Men versus Women

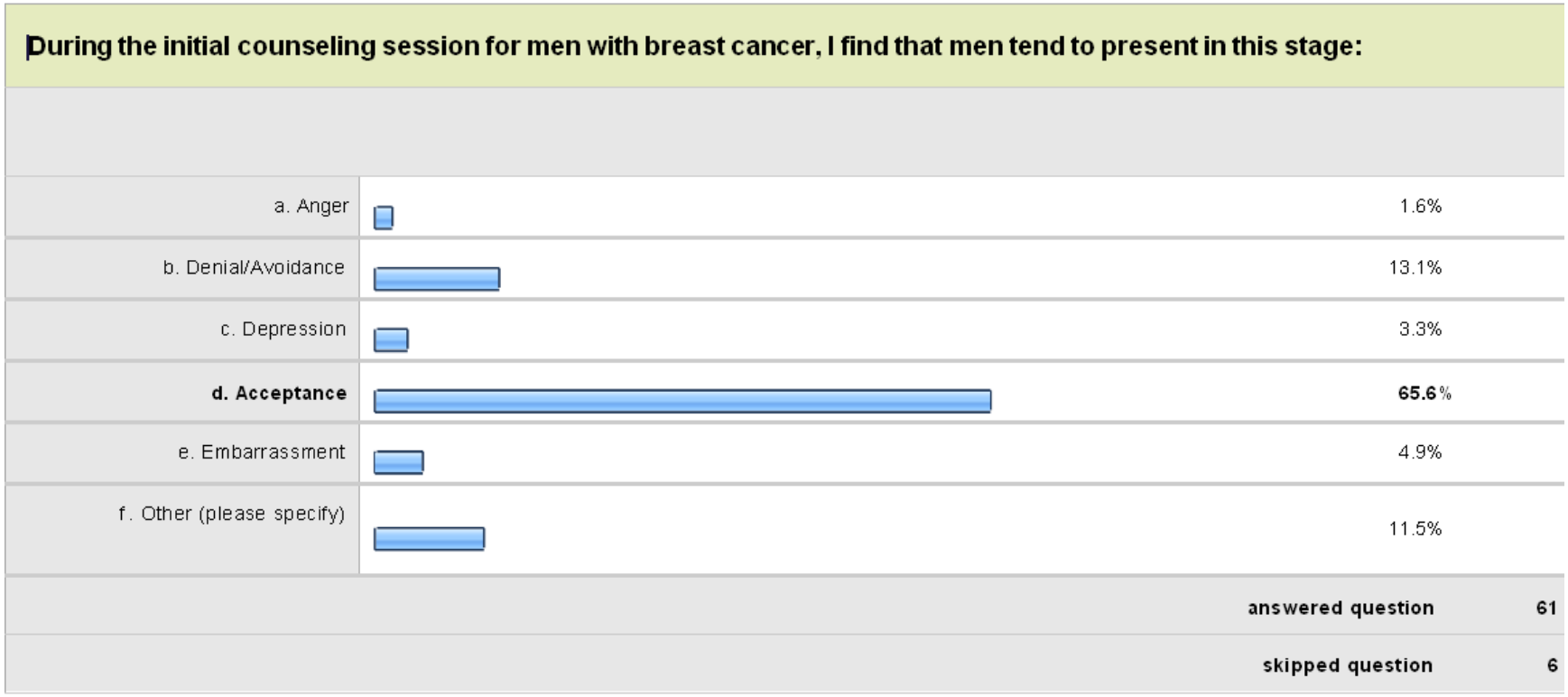

Figure 25- Stage of Grief at Initial Counseling Session

Table 1-Additional Thoughts on Initial Stage of Grief

	During the initial counseling session for men with breast cancer, I find that men tend to present in this stage:
1	a variety of emotions just like my female breast cancer patients
2	It really does vary. I don't feel comfortable picking just one answer.
3	It really depends on how long ago the diagnosis was. It also seems to be very person-dependent. I don't think I could generalize.
4	hard to say - everyone is so different
5	Each of my situations with men having breast cancer have been very different so it is hard to generalize. one man was embarrassed and would only say he had lung cancer (breast mets to lung) - another was interviewed by a newspaper to raise awareness of male brest cancer, so he was very willing to talk.
6	There is no way to generalize this - it often depends on how long ago the man was diagnoses.
7	None of the men I have seen with breast cancer seem embarrassed in the least. I generally don't see them at the time of dx, so many of your questions don't apply. I do see women at the time of their diagnosis, because their treatment decisions depend on testing, whereas for men, that's not so much the case.

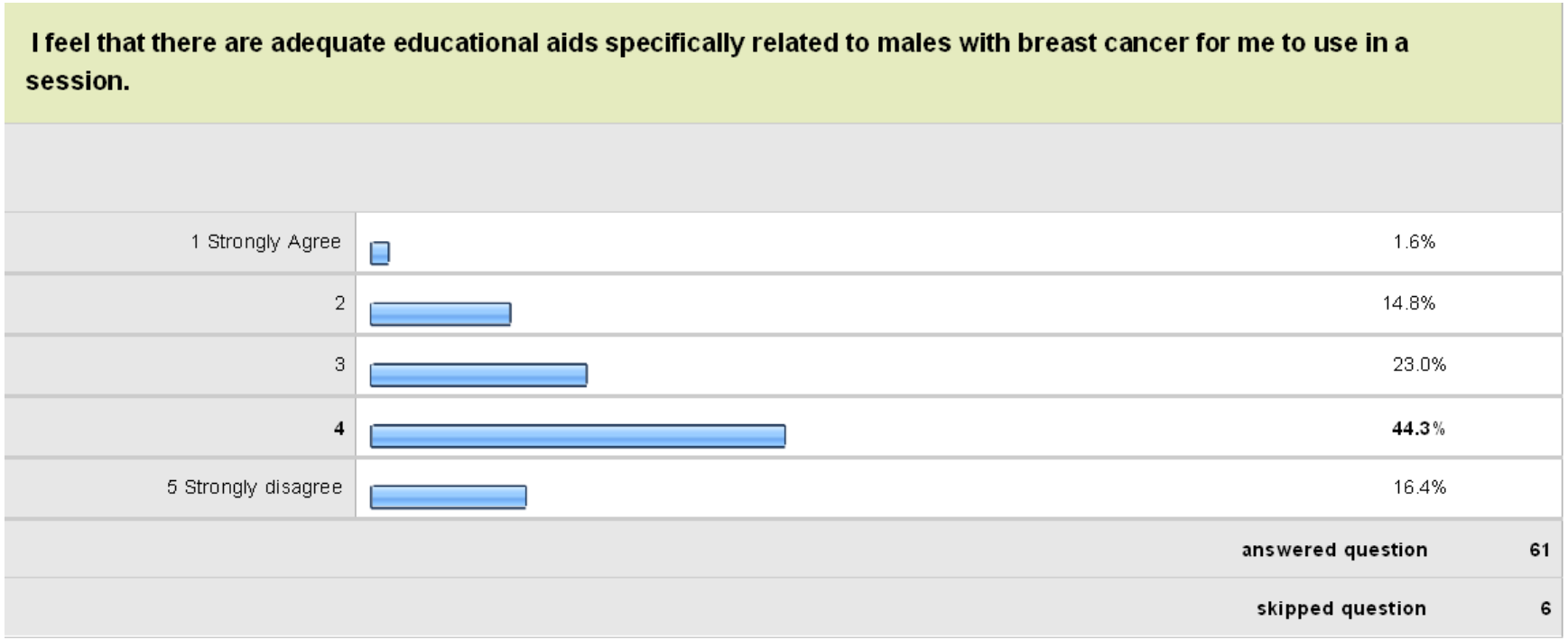

Figure 26- Adequacy of Educational Aids for Men with Breast Cancer

Which of the following statements best describes your beliefs:

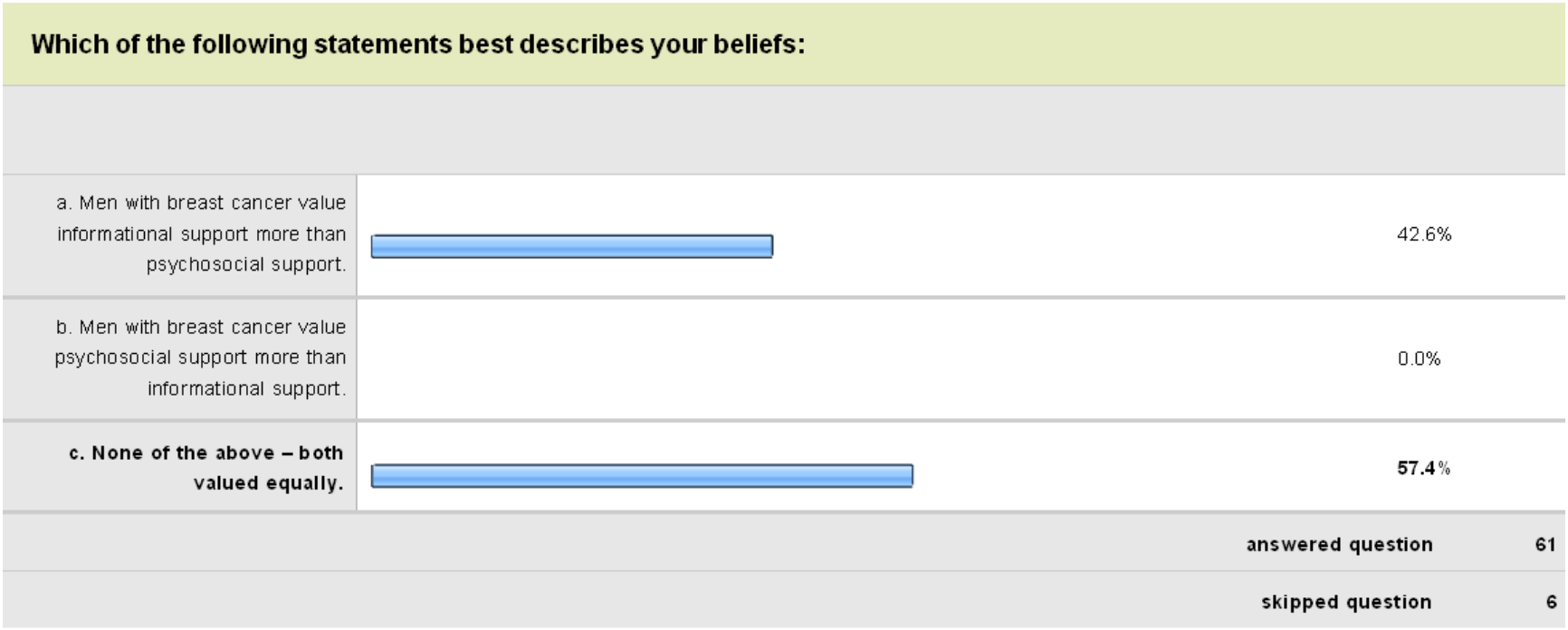

Figure 27- Informational Support versus Psychosocial Support

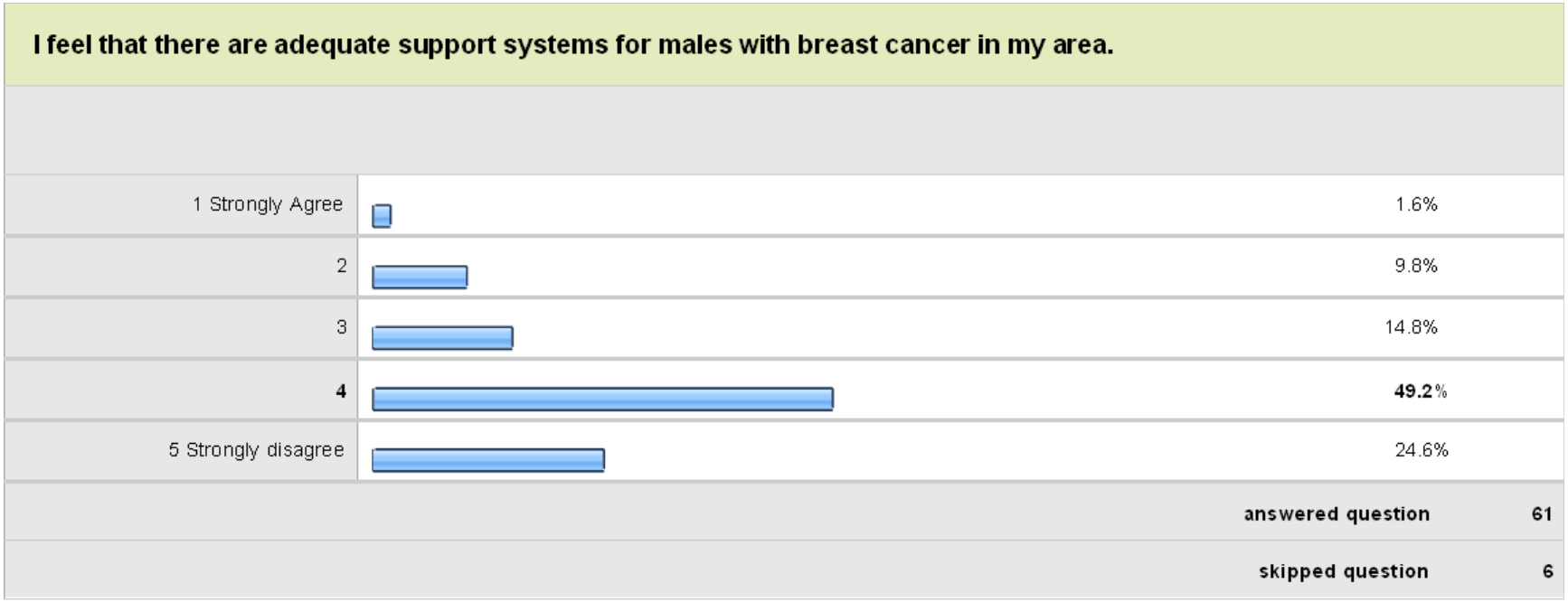

Figure 28-Adequacy of Support Systems

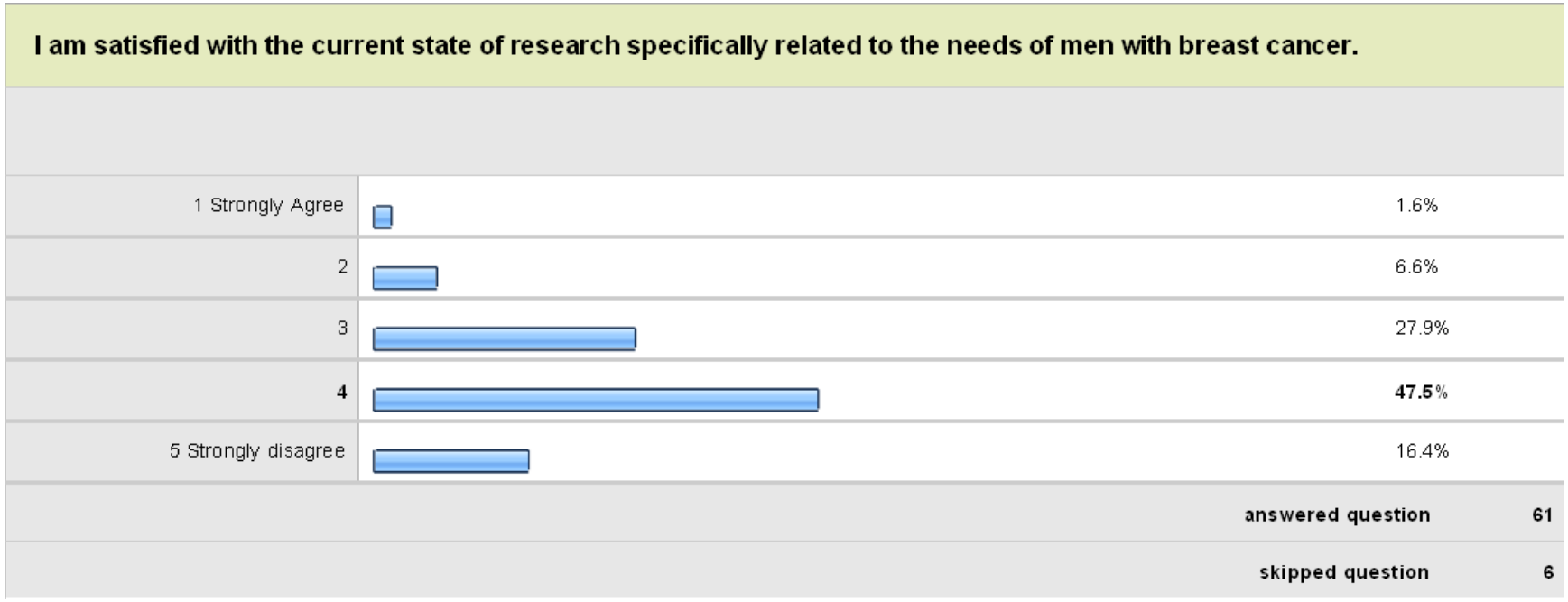

Figure 29-Satisfaction with Research

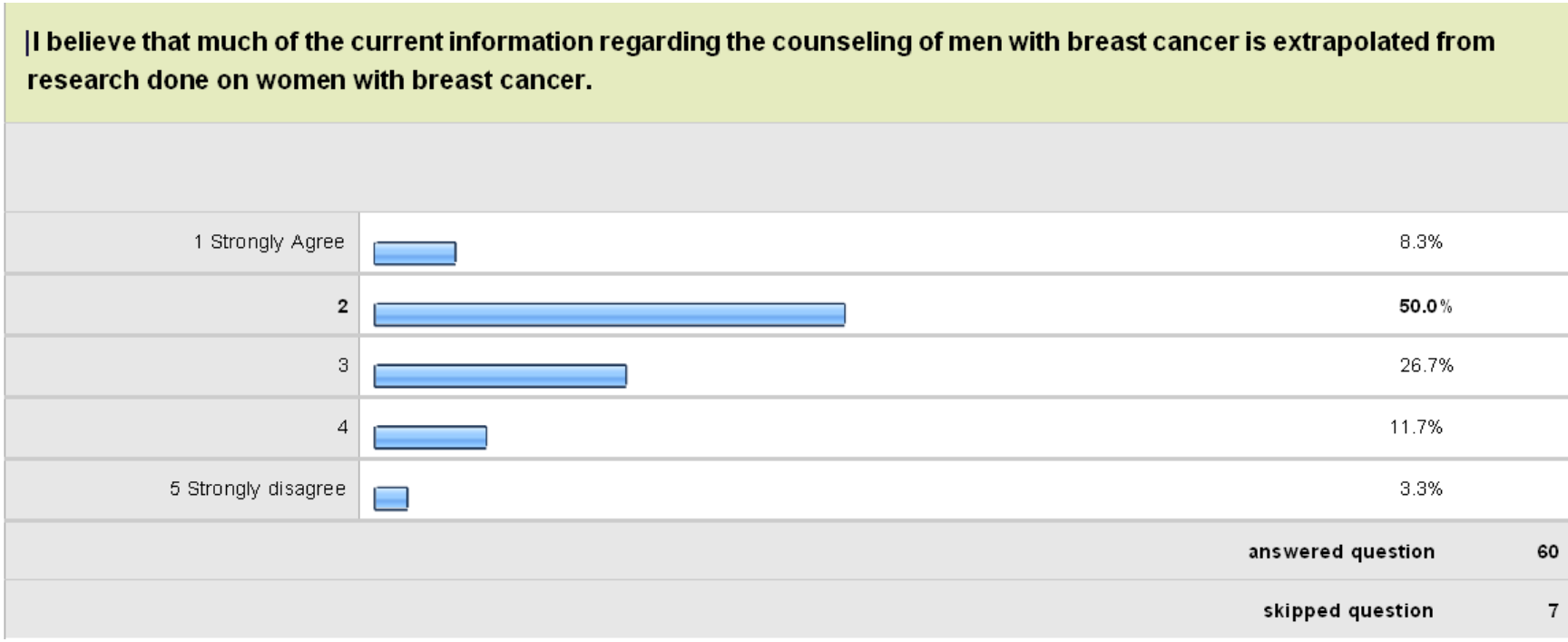

Figure 30-Belief that Research on Men is Extrapolated from Women

Figure 31-Individual Primarily Responsible for Disclosing Genetic Risk

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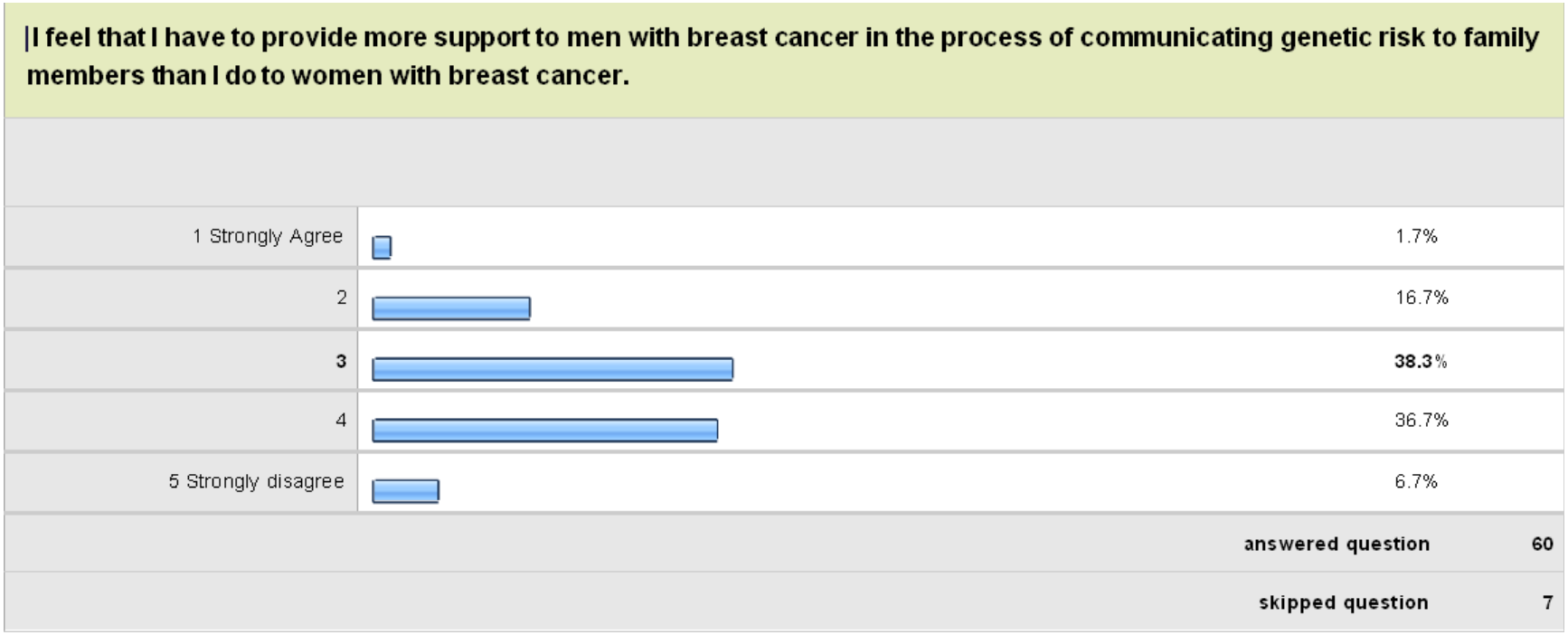

Figure 32-Support Needed by Men versus Women in Disclosing Genetic Risk to Family

Men differ in the type of support needed in the counseling session to enable them to disclose genetic risk information to family members. For the purposes of this survey, support can be defined as psychosocial in nature and /or any tools provided to assist in communicating risk to family members

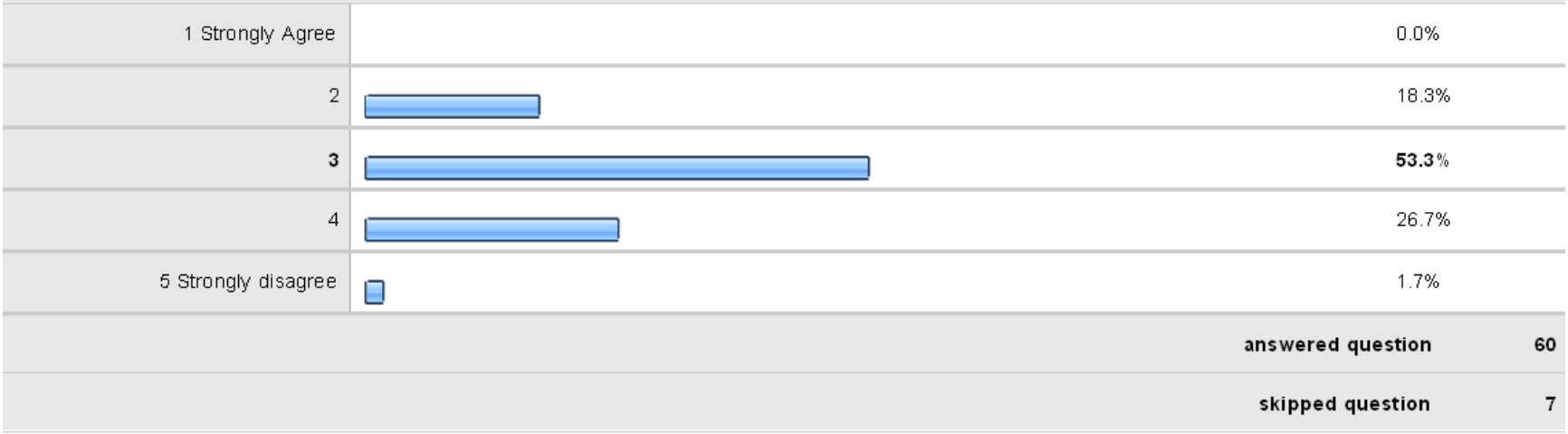

Figure 33-Difference in Support Needed by Men for Disclosure of Genetic Risk

Table 2-Additional Thoughts on Support Needed to Disclose Risk to Family

If you answered 1 or 2, please provide more information on the support that you provide:	
1	I have had to write mock letters that they can use to send or email to their family members, although I have also had to do this with women. I find that when I mention such mock letter, men are more likely to follow-up on it than women are; which makes me feel that they need it more than the women do.
2	introduction of strategies to share information with their relatives, reassurance and support regarding "blaming" of selves for passing to daughters, letters to family members, offer of family appointments
3	Sample letters to use to send to relatives.
4	Men are more likely to request information to provide to family members rather than guidance in how to talk to them.
5	We specifically discuss each relative he should contact and what their risks are. We also give extra brochures for genetic counseling that he can provide and offer to talk with each of them individually by phone or discuss information with a female relative who has open communication with multiple relatives. We do much of this for women also, but in more detail and depth for men.
6	I have found that sometimes men need more assistance with the actual 'language' used to disclose information to family members. They have also been more willing to use a letter template provided by our clinic.
7	Men seem to be less likely than women to come up with a disclosure plan on their own. In general, they seem to need to be more often led through the steps of creating a plan to share this information than their female counterparts.

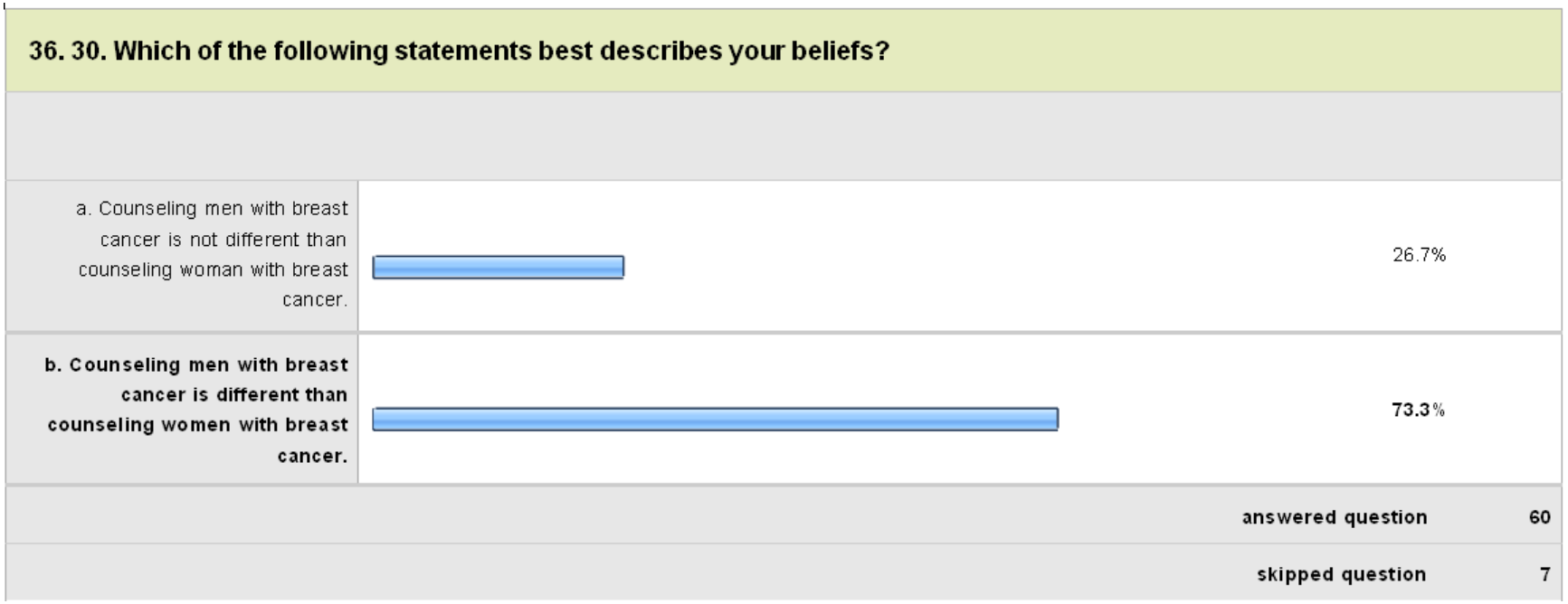

Figure 34-Diffenece in Counseling Men versus Women

Table 3-Additional Thoughts on Differences between Counseling Men and Women

	Please state how you feel counseling men diagnosed with breast cancer is different compared with women
1	Because male breast cancer is so rare, men with breast cancer often express feelings of isolation and frustration with the lack of information and support available for men with breast cancer. Addressing this is very important and I spend more time helping them accept their diagnosis for what it is or exploring how they have coped
2	In my somewhat limited experience of counseling men with breast cancer, I find the single most motivating factor for them to consider BRCA testing is whether they have daughters or not. Women, on the other hand, may have this as a motivator, but are also very often interested in the information this provides them regarding their future cancer risks.
3	their cancer risks and screening options are different if BRCA1/2 positive
4	I think every man is different. I don't go into a session with a man planning to do anything different than I would do in a session with a female patient. With both men and women, I respond to the specific needs of the individual patient.
5	It is true that men tend to be externally less emotional and less open to psychosocial exploration. However, those who have been diagnosed with breast cancer are also often taken by surprise by the diagnosis and may feel more vulnerable and willing to discuss their emotions than usual. I find that I sometimes have to be more subtle in my approach to the psychosocial evaluation.
6	I find myself talking more in detail about the scenarios of "if the test comes back positive, then..." with men. For example, I find men want to talk about their sisters and daughters risks more so than their own clinical implications.
7	Different, but not much different. I do make a point of recognizing in the conversation that a man with breast cancer can feel awkward in an environment of predominantly female patients.
8	Much less risk to develop cancer in the future, and no recommendations for prophylactic surgery
9	Most of the men I have seen have completed their treatment and don't view the genetic information as directly affecting their own medical management. They primary motivation is typically to get information about cancer risk for their family members, particularly their daughters.

Table 3 continued

10	Higher chance of brca mutation
11	I have seen so few men with breast cancer, it is hard to make an assessment of this. The few male patients with breast cancer that I have seen have been fairly similar to one another, while I have seen a greater variety in my female patients. The counseling sessions with the male patients were similar to the sessions with some of my female patients, but different from sessions with the majority of my female patients, so overall I checked different. I feel that there are differences in the amount of available information regarding male and female breast cancer, which necessarily changes the counseling session. The medical recommendations for men with BRCA mutations are less clear than those for women, so that conversation is often more general with men. In addition, the fact that men with BRCA mutations do not have ovarian cancer risk makes a huge difference in the way the session goes. Many female patients cannot get past the fear of ovarian cancer leading to a greater portion of the session being psychosocial. Finally, my male patients have all been quite curious about the technical information, and ask technical questions. I think this may represent an intellectualizing coping strategy to some extent, which I think is more prevalent in men in general (I see this in my general genetics patients and non-breast cancer patients as well). I also think it might have to do with the lack of available information for men with breast cancer on the internet.
12	Each patient is different but I believe men tend to come in for their daughters and sisters with less personal interest. Women come in for their daughters and sisters too, however believe that testing will clarify their chances for second cancer or ovarian cancer
13	Lack of sufficient data supporting increased screening and prevention in positive men reduces ability to focus on patient when discussing genetic testing, focus has to shift primarily to focusing on their family/ daughters
14	management (future) shorter and simpler due to no discussion of oophorectomy or contralateral preventive mastectomy
15	personal risks are different, issues are different
16	It's important to acknowledge the things they are most likely feeling and going through, because they are less likely to bring them up than a woman.
17	It is a different disease with different implications. There are also fewer support resources to offer.
18	Emotionally/psychosocially--more difficult for men to accept the diagnosis and many are embarrassed.

Table 3 continued

19	They often have different emotion and psychological issues related to their diagnosis
20	I find informational, technical needs may be higher, more emphasis in placed on the benefits to family rather than self, less need for psychosocial support than women.
21	There is no risk for ovarian cancer
22	medical management issues are different
23	Overall I don't think there is a major difference, but I think it is important to think about who you are counseling and modify the session accordingly. There are different concerns for men than for women and although I don't think these are specific to psychosocial issues, I think there are some differences.
24	The personal cancer risks for men with BRCA mutations is different than for women with BRCA mutations.
25	I feel that men are less likely to bring up psychosocial issues on their own. I also feel, that in general, they seem to know less about their family histories than women.
26	The information provided is different in terms of risks of a second primary cancer, risks to other family members if no mutation is found, and screening recommendations for male breast cancer.
27	They often has less information about the medical history of their relatives and less knowledge of relatives in general. The family history takes less time and we spend more time discussing genetic testing details (depending on the education level of the patient) and we spend more time emphasizing the importance of sharing information with family and the potential benefit if they are tested. We discuss more the inability to control what we pass on and the ability to benefit from knowledge of this information.
28	Biggest difference I have seen is rapport. I can generally actually more easily build rapport with male breast cancer patients than with female ones. However, I believe this may be a reflection of my personality more than anything else.
29	they tend to be more focused on their families, are embarrassed/upset that they are living in a woman's world, feel more guilt about possibility of passing gene mutation on to their daughters
30	Different risks, gender roles/expectations, less scientific information/certainty, limited support community
31	The risks for additional malignancies with BRCA positive males versus females is different. Women often experience more changes in their medical management than men, thus changing some of the relevance of information from the pt to the family.

I believe this questionnaire is an effective tool for self reflection concerning my experiences counseling men with breast cancer.

		Response Percent	Response Count
1 Strongly Agree		5.0%	3
2		**38.3%**	**23**
3		30.0%	18
4		25.0%	15
5 Strongly disagree		1.7%	1
		answered question	**60**
		skipped question	**7**

Figure 35-Belief that Questionnaire is an Effective Tool for Self Reflection

For the discussion of the results from the questions utilizing the Likert scale, levels one and two will be combined to get the total percentage of those who agree, and levels 4 and 5 will be combined to get the percentage of those who disagree. Only the findings of the majority of counselors will be discussed.

From the results of the questionnaire, the majority of counselors can be described as follows: 92.5% are female, 49.3% have between 1-4 years experience, 78% are dedicated cancer counselors, 41.8% work in a University Medical Center and 98.5% see approximately 1-5 men in a year (Figure 1-4, Figure 8)

In the work setting, none have posters in the physical environment that either depicts breast cancer as a male disease or as both a male or female disease (Figure 11, Figure 13). In fact, 74.2% do not have a pink ribbon displayed in the physical environment (Figure 12). The majority at 89.7% disagree with the statement that they try to schedule men with breast cancer on days where there will be a lot of male patients (Figure 21).

The questionnaire results revealed that 82.3% of counselors believe that a breast cancer diagnosis is an equally traumatic event for both men and women (Figure 24). Yet, 73.8% do not agree that there are adequate support systems for men with breast cancer and 63.9% are not satisfied with the current state of research specifically related to the needs of men with breast cancer (Figure 28, Figure 29). Half of the counselors disagree with the statement that gender has no effect on a person's willingness to discuss psychosocial issues and the majority at 56.5% chose level 3 in response to the statement that women with breast cancer can be an important source of support for men (Figure20, Figure 23).

In a genetic counseling environment, 72.5% of counselors reports that the words breast cancer evoke thoughts of women (Figure 10). Despite this, 58% do not agree that men would be

more comfortable with a male genetic counselor and 70.9% do not agree that they are more comfortable counseling women with breast cancer as compared to men (Figure 22, Figure 15). In fact, 77.5% agree that genetic counselors are an important source of psychosocial support for men with breast cancer (Figure 16). The vast majority of counselors at 96.8% report that men who attend counseling session are referred by their doctors and 65.6% believe men are in the acceptance stage at the time of the initial counseling session (Figure 9, Figure 25). The percentage of men diagnosed with breast cancer who choose BRCA testing is greater than the percentage of their female counterparts as reported by 53.2% of the counselors (Figure 6). An assessment of the psychosocial issues during a counseling session from the counselor's perspective revealed the following: 51.6% disagree with the statement that more time is spent on genetic principles than with psychosocial issues, 69.4% agree that specific questions are asked regarding psychosocial issues, 58.1% believe men are just as willing to discuss psychosocial issues as their female counterparts and 57.4% believe men value information and psychosocial support equally (Figure 14, Figure17, Figure 19, Figure 27).

During the process of risk discussion, 58.1% of counselors agree that men are more interested in discussing their family's risk rather that personal risk (Figure 18). Half of the counselors believe that men perceive themselves as primarily responsible for disclosure of genetic risk to family; alternately, the rest of the counselors believe that men rely on a close female relative for this task (Figure 31). For the disclosure process, 43.4% do not agree that men need more support in communicating genetic risk to family members (Figure 32). The majority of counselors at 53.3% chose level 3 in response to the question that men differ in the type of support needed in the counseling session (Figure 33).

During the counseling session, 60.7% of counselors did not feel there are adequate educational aids specifically related to men with breast cancer (Figure 26). Further, 58.3% believe that the current information regarding counseling men with breast cancer is extrapolated from research done on women with breast cancer (Figure 30).

The length of the counseling session was reported by 71% to be equal in time for both men and women (Figure 7). Counseling men is different than counseling women as reported by 73% of counselors (Figure 34). The main differences reported are the following: focus on familial risk rather than personal risk, feeling of isolation and frustration with the lack of support and information available for men with breast cancer, and different medical management issues (Table 3).

The majority of counselors at 43.3% reported that they believed the questionnaire is an effective tool for self-reflection (Figure 35).

5.0 DISCUSSION

5.1 AIM 1

The total number of respondents was 67(13.6%). As it is unknown how many genetic counselors belong to the general listserv and not the special interest group, this rate may not be entirely accurate. The majority of cancer genetic counselors who responded to this survey are females with 1-5 year of experience who practice in a University Medical Center. The approximate number of men seen in a year ranges from 1 to 5 (Figures 1-4 and Figure 8).

The counselors work in a physical environment that can be characterized as neutral in that there is not representation of cancer in terms of posters or symbols (Figures 11- 13).None of the counselors try to schedule patients on days when male patients are present (Figure 21). The gender of other patients does not appear to enter into the act of scheduling patients.

The majority of counselors feel that a breast cancer diagnosis is equally traumatic for men and women (Figure 22). This recognition validates the literature which reports men can experience feelings of shame and confusion and will even question their masculinity upon a diagnosis of breast cancer. Half of the counselors do not agree that gender has no effect on a person's willingness to discuss psychosocial issues (Figure 20). This is surprising as this response seems to contradict the responses of the counselors to other questions and might be due to poor design of the question. For example, the majority of counselors believe that men value

informational and psychosocial support equally (Figure 27) and are just as willing to discuss psychosocial issues (Figure 19). Also, the counselors do not feel that more time is spent on genetic principles versus psychosocial issues (Figure 14). It is very encouraging to see such an emphasis on psychosocial issues and the positive responses of men to such issues during a session. The finding in this survey that the majority of counselors are proactive in that they ask specific questions about psychosocial issues might explain such a response (Figure 17).

Counselors agree that the words breast cancer evoke thoughts of women (Figure 10). This is understandable as the incidence of breast cancer is higher in women. A concern, based on the theory of projection countertransference, would be that these feelings could exacerbate the feelings of shame and confusion that men can experience with a disease considered to be gendered i.e. feminine. It is unlikely that this would occur as counselors report that they are not more comfortable counseling women with breast cancer (Figure 15), nor do they feel that men would be more comfortable with a male genetic counselor (Figure 22). In addition, counselors also recognize that counseling men with breast cancer is different from counseling women (Figure 34).

Counselors feel they are an important source of psychosocial support for men. This is extremely important as men value the support of health professional in the process of adjusting to their diagnosis. Counselors feel there is a lack of dedicated support systems for men with breast cancer (Figure 28) which makes the support of counselors crucial.

Much of the research on men with breast cancer has been extrapolated from women most likely due to the small incidence of MBC which makes prospective studies highly impractical. The experiences of genetic counselors appear to support this finding. Counselors are not satisfied with the current state of research relating to the needs of men with breast cancer (Figure 29).

They feel there is a lack of educational aids dedicated to the needs of men (Figure 26). In general, the counselors feel that much of the information concerning the counseling of men is extrapolated from research done on women (Figure 30).

Studies often report that men present in the denial stage regarding their diagnosis of breast cancer. Most counselors report that men are in the acceptance phase (Figure 25). One of the reasons could be that men who choose genetic testing share common factors such as education level or cultural issues. A question assessing the demographics of men who choose genetic testing would have been informative. Also, some reports suggest that men need a period of concealment to adjust to the unique issues associated with a diagnosis of breast cancer. This period of concealment, considered to be beneficial, can be misinterpreted as denial.

Surprisingly, counselors feel that the number of men who choose BRCA testing is higher than the percentage of women. The literature reports that fewer men than women chose genetic testing (Figure 6). A possible explanation could be that all men who present for counseling are qualified given that male breast cancer is a rare disease unlike female breast cancer. In other words this high percentage may be due to the fact that more men qualify for genetic counseling rather than due to a man's willingness to accept counseling which is what the question was intended to measure.

As the literature reports, counselors feel men are more interested in discussing their family's risk rather than their own personal cancer risk (Figure 18). Studies have reported that a close female relative takes on the role of disseminating risk information to the family. Half of the counselors find this to be true. The other half believes that men perceive themselves as responsible for disseminating risk in formation to their family. In an attempt to clarify the reason for this deviation from the literature, it would be interesting to compare demographics between

the men who are counseled by those who believe a close female relative discloses risk and those who believe that men disclose risk to detect any significant differences between the two groups or significant patterns within each group.

5.2 AIM 2

In general, counselors felt the survey was an effective tool for increasing self-awareness concerning their belief and valise about counseling men with breast cancer (Figure 35).

5.3 LIMITATIONS

There are biases that exist in this study that could affect the generalization of the results to the general population of men with breast cancer. In the design of the study, the category 3 on the Likert scale should have been defined in the recruiting letter. It is not possible to determine if the counselors who choose the level 3 agree a little, disagree a little or are not sure /have no opinions on the question which could be a valid interpretation. The majority of counselors chose level 3 in response to the statement that men differ in the type of support needed for disclosure of genetic information (Figure 33). They also chose level 3 in response to the statement that women with breast cancer can be an important source of support for men with breast cancer (Figure 23) and also in response to the statement that more support is needed for men in the process of communicating genetic risk to family members (Figure 32). The findings for these three questions are difficult to determine due to the vague definition of level 3 mentioned earlier.

The study population may not be representative of the target population which is all genetic counselors in the United States. Due to financial constraints obtaining a list of all genetic counselors in the United States was not possible. Time constraints prevented the research needed to determine which of these counselors have experience in counseling those with a family or personal history of breast cancer. Recall bias could also exist. Because of the rare nature of the disease, it is conceivable that the lack of experience could affect a counselor's interpretation of their experiences. Also, counselors may not adequately recall experiences if a long time has elapsed since counseling a man with breast cancer which is reasonable to consider as the average number of males seen in a year is 1-5. A desire to answer the questions in a way which reflects positive experiences for men may be another bias present in this study

5.4 CONCLUSION

Despite the lack of dedicated resources and research, the genetic counseling environment of men in the United States appears to be supportive of the needs these men face in their experience of breast cancer. Gender does not appear to affect the comfort level of the counselee or the counselor. This is important as the majority of counselors are female. Counselors recognize that such a diagnosis is traumatic for men as it is for women. Counselors view themselves as an important source of support for these men. In fact, the assessment of psychosocial needs is just as much a part of the session as the assessment of informational needs. Men are more concerned about their family's risk versus their own risk; however, they appear to pay a more active role in the dissemination of risk than what the literature suggests. This may be due to the proactive approach taken during the session in the assessment of psychosocial needs.

5.5 FUTURE RESEARCH

Future research should focus on an assessment of the specific educational and psychosocial needs of men with breast cancer as well as their experiences as a patient in the medical community and as a member of society. Cooperative groups could be formed throughout not only the United States, but also other countries which would provide clues as to the effects of culture on the male experience. This could also be useful in the US as the population is culturally diverse. This information could provide counselors with the opportunity to better tailor a counseling session to meet the unique needs of men with breast cancer. It is important to recognize the individuality of each male breast cancer patient. It is equally important to recognize that there are shared experiences that men with breast cancer experience in society. The challenge is to incorporate knowledge of these shared experiences with each man's unique personality and life experience to devise a plan which will enable each man to make the best decision not only for his family, but also for him as a unique person.

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APPENDIX A

RECRUITMENT LETTER

Greetings,

My name is Elizabeth Hight. I am a genetic counseling student at the University of Pittsburgh. I would like to extend to you an invitation to participate in a survey entitled A Survey of the Genetic Counseling Environment for Men Diagnosed with Breast Cancer which will serve as my thesis project. This is a descriptive survey designed to give information about the environment men with breast cancer experience in a genetic counseling session. The survey is being performed for research purposes. I have defined the environment as not only the physical setting of the session, but also the values and beliefs of genetic counselors concerning the sociocultural, psychosocial and familial influences that men with breast cancer experience in society. This survey has the potential to identify further areas of research as well as providing an opportunity for self-reflection concerning your experiences counseling men with breast cancer. It is 31 questions and will take approximately 30 minutes to complete.

To participate, you must currently have experience counseling men with breast cancer. Although for the purposes of my thesis. I will be focusing on those responses from the United States, I would like to extend the invitation to those who participate outside of the United States

as this could provide valuable information for future research. The study is IRB approved, voluntary and the responses will be anonymous. There are no identifiable risks associated with this survey. If you have questions for the IRB, please contact them at irb@pitt.edu. If you have any questions about the study, please email me at eah15211@hotmail.com.

APPENDIX B

QUESTIONNAIRE

1. Please provide the following demographic information:

Gender

- a. Male
- b. Female

Years of experience in genetic counseling

- a.1-5
- b. 6-10
- c. 1-20
- d. > 20

Primary work setting

- a. University Medical Center
- b. Private Hospital/Medical Facility
- c. Public Hospital/ Medical Facility
- d. Physician's Private Practice
- e. University/Non- Medical Center
- f. Private Practice/Self- Employed

Approximate number of men with breast cancer seen in the past year

- a. 1-5
- b. 6-10
- c. 11-15
- d. 16-20
- e. 21-25
- f. 6-30
- g. > 30

Area of practice

- a. United States
- b. Canada
- c. United States and another country
- d. Other – Please specify

If you selected answer C in the question above, please specify what other country :

2. Please choose which statement best describes your current practice:

- a. The percentage of men diagnosed with breast cancer who choose BRCA testing is greater than the percentage of women with breast cancer who choose BRCA testing.
- b. The percentage of men with breast cancer who choose BRCA testing is equal to the percentage of women with breast cancer who choose BRCA testing.
- c. The percentage of men with breast cancer who choose BRCA testing is less than the percentage of women with breast cancer who choose BRCA testing.

3. Please choose which statement best describes your current practice:

- a. In general, the BRCA counseling session is shorter in time for men than for women.
- b. In general, the BRCA counseling session is equal in time for both men and women.
- c. In general, the BRCA counseling session is greater in time for men than for women.

4. Please choose which statement best describes your current practice:

- a. I only counsel patients with a personal and/or family history of cancer
- b. I counsel patents with a variety of personal and/or family history of genetic conditions, not just cancer

5. Please choose which statement best describes your current practice:

- a. Most of the men who attend counseling sessions are referred by their doctors.
- b. Most of the men who attend counseling sessions are referred by their spouse/partners.
- c. Most of the men who attend counseling session are referred by their children.
- d. Most of the men who attend counseling sessions are referred by a friend.
- e. Most men who attend counseling sessions are not referred by anyone.

6. When I hear the word breast cancer, I think of women.

1 Strongly Agree	2	3	4	5 Strongly Disagree

7. I have posters specifically relating to male breast cancer in the physical environment at my site i.e. waiting room, counseling room.

- Yes
- No

8. I have the pink ribbon prominently displayed in the physical environment at my site i.e. waiting room, counseling room.

- Yes
- No

9. I have posters displayed in the physical environment which specifically depicts breast cancer as both a male and female disease.

- Yes
- No

10. During a session with men, I tend to spend more time with genetic principles than with psychosocial issues.

1 Strongly agree	2	3	4	5 Strongly disagree

11. I find that I am more comfortable counseling women with breast cancer than I am with men with breast cancer.

1 Strongly Agree	2	3	4	5 Strongly Disagree

12. I believe that genetic counselors are an important source of psychosocial support for men with breast cancer.

1 Strongly Agree	2	3	4	5 Strongly Disagree

13. I ask specific questions regarding psychosocial issues when counseling men with breast cancer.

1 Often	2	3	4	5 Rarely

14. I find that men are more interested in discussing their family's risk rather than their own personal cancer risk.

1 Strongly Agree	2	3	4	5 Strongly disagree

15. Please choose the statement that best describes your experiences counseling men with breast cancer.

- a. Men with breast cancer do not discuss psychosocial issues as much as women with breast cancer.
- b. Men with breast cancer are just as willing to discuss psychosocial issues as women with breast cancer.
- c. Men with breast cancer are more willing to discuss psychosocial issues than woman with breast cancer.

16. I believe gender has no effect on a person's willingness to discuss psychosocial issues.

1 Strongly Agree	2	3	4	5 Strongly disagree

17. I try to schedule men with breast cancer on days when I know there will be a lot of male patients.

1 Strongly Agree	2	3	4	5 Strongly disagree

18. I believe that men with breast cancer would be more comfortable with a male genetic counselor than with a female genetic counselor.

1 Strongly Agree	2	3	4	5 Strongly disagree

19. I believe that women with breast cancer can be an important source of support for men with breast cancer.

1 Strongly Agree	2	3	4	5 Strongly disagree

20. Which of the following statements best describes your beliefs:

- a. A breast cancer diagnosis is a more traumatic event for men than for women.
- b. A breast cancer diagnosis is an equally traumatic event for both men and women.
- c. A breast cancer diagnosis is not as traumatic for men as it is for women.

21. Which of the following statements best describes your beliefs:

- a. Men with breast cancer value informational support more than psychosocial support.
- b. Men with breast cancer value psychosocial support more than informational support.
- c. None of the above – both valued equally.

22. During the initial counseling session for men with breast cancer, I find that men tend to present in this stage:

- a. Anger
- b. Denial/Avoidance
- c. Depression
- d. Acceptance
- e. Embarrassment
- f. Other (please specify)

23. I feel that there are adequate educational aids specifically related to males with breast cancer for me to use in a session.

1 Strongly Agree | 2 | 3 | 4 | 5 Strongly disagree

24. I feel that there are adequate support systems for males with breast cancer in my area.

1 Strongly Agree | 2 | 3 | 4 | 5 Strongly disagree

25. I am satisfied with the current state of research specifically related to the needs of men with breast cancer.

1 Strongly Agree	2	3	4	5 Strongly disagree

26. I believe that much of the current information regarding the counseling of men with breast cancer is extrapolated from research done on women with breast cancer.

○ 1 Strongly Agree ○ 2 ○ 3 ○ 4 ○ 5 Strongly disagree

27. Which of the following statements best describes your experiences counseling men with breast cancer:

○ a. Men perceive themselves as primarily responsible for disclosing genetic risk information to family members.

○ b. Men rely on a close female relative such as spouse/ partner/ daughter to disclose information to other family members.

28. I feel that I have to provide more support to men with breast cancer in the process of communicating genetic risk to family members than I do to women with breast cancer.

○ 1 Strongly Agree ○ 2 ○ 3 ○ 4 ○ 5 Strongly disagree

29. Men differ in the type of support needed in the counseling session to enable them to disclose genetic risk information to family members. For the purposes of this survey, support can be defined as psychosocial in nature and /or any tools provided to assist in communicating risk to family members

○ 1 ○ 2 ○ 3 ○ 4 ○ 5 Strongly disagree

If you answered 1 or 2, please provide more information on the support that you provide:

30. Which of the following statements best describes your beliefs?

- a. Counseling men with breast cancer is not different than counseling woman with breast cancer.
- b. Counseling men with breast cancer is different than counseling women with breast cancer.

If you have answered b, How so?

31. I believe this questionnaire is an effective tool for self reflection concerning my experiences counseling men with breast cancer.

1 Strongly Agree | 2 | 3 | 4 | 5 Strongly disagree

Comments regarding the questionnaire, if any.

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