Decision Making for Bilateral Mastectomy in Women Newly Diagnosed with Breast Cancer

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Abstract

Women diagnosed with breast cancer who carry a mutation in the genes BRCA1/2 are at an increased risk of developing cancer in the contralateral breast. Undergoing bilateral mastectomy significantly reduces the risk of developing second primary breast cancer in these women. Rapid genetic counseling and testing can provide newly affected women the opportunity to know their carrier status before undergoing any primary surgery so they can avoid an additional second surgery.

Method: Forty-four women newly diagnosed with breast cancer were offered rapid genetic testing and counseling. Several psychological factors were measured at baseline and during follow-up in order to investigate the influencing factors on decision-making to undergo bilateral mastectomy in newly diagnosed women.

Result: Seven out of 44 participants were identified as mutation carriers. All of the carriers underwent prophylactic surgery. Results showed no difference in cancer-related stress and general anxiety in patients opting for bilateral mastectomy compared to those who did not. All of the women were satisfied with undergoing rapid genetic counseling and testing and thought that it was offered to them at an appropriate time.

Conclusion: Carrier status knowledge plays a determining role on decision-making for undergoing bilateral mastectomy. Participating in genetic testing right after diagnosis does not impose an additional distress on women.

Résumé

Les femmes diagnostiquées d'un cancer du sein qui portent une mutation dans les gènes BRCA1/2 sont à risque accru de développer un cancer du sein controlatéral. La mastectomie bilatérale réduit significativement le risque de cancer du sein chez ces femmes. Des tests ainsi qu'un conseil génétique rapide peuvent fournir aux femmes nouvellement affectées la possibilité de connaître leur statut de porteur avant de subir une intervention chirurgicale primaire afin qu'elles puissent éviter une deuxième intervention chirurgicale supplémentaire.

Méthode: Quarante-quatre femmes nouvellement diagnostiquées d'un cancer du sein ont été rencontrée a fin de leurs offrir un conseil génétique. Plusieurs facteurs psychologiques ont été mesurés au départ et pendant le suivi, afin d'étudier les facteurs influençant la prise de décision concernant l'ablation des deux seins chez les femmes nouvellement diagnostiquées.

Résultat: Sept des 44 participantes ont été identifiées comme porteuses d'une mutation. Toutes les porteuses ont subi la chirurgie prophylactique. Les résultats ont montré aucune différence dans le stress lié au cancer et l'anxiété générale chez les patientes qui ont optées pour la mastectomie bilatérale par rapport à celles qui ne l'ont pas subie. Toutes les femmes étaient satisfaites de subir les tests ainsi que le conseil génétique rapide et étaient de l'avis que ces derniers leurs ont été offerts en un temps opportun.

Conclusion: la connaissance du status de porteur joue un rôle principal dans la prise de décision pour subir une intervention chirurgicale. Participer à des tests génétiques immédiatement après le diagnostic n'impose pas d'inquiétude supplémentaire chez ces femmes.

Introduction

Breast cancer epidemiology

Breast cancer is the most commonly diagnosed cancer in Canadian women over the age of 20 and accounts for 26 percent of all the newly diagnosed cancers. Breast cancer is also known as the second leading cause of cancer death after lung cancer and is responsible for 14 percent of all cancer-related deaths in Canada (Canadian Cancer Society, 2013). Some of the known risk factors for breast cancer are family history, obesity, alcohol consumption, hormone replacement therapy, an early age at menarche, and late menopause (McPherson, Steel, & Dixon, 2000). Genetic factors also play a role in developing breast cancer. Approximately five to ten percent of breast cancer cases are due to hereditary pre-disposition. The majority of the hereditary cases are attributed to mutation in the genes BRCA1 and BRCA2 (Ford et al., 1998). The risk of developing hereditary breast cancer is higher in women with a history of breast or ovarian cancer in first and second degree relatives; women with a first degree male relative diagnosed with breast cancer at any age, and individuals with a known mutation in a family member or personal or family history of familial cancers attributable to the BRCA1/2 mutation (e,g pancreatic cancer and early onset prostate cancer). Furthermore, it is known that the probability of carrying a genetic mutation is higher in women belonging to certain ethnicities such as Eastern European, Ashkenazi Jewish and French-Canadians (Narod, 2010; Ghadirian et al., 2009; Levy-Lahad & Freidman, 2007; McPherson, Steel, & Dixon, 2000) or in women who are diagnosed with a triple-negative breast cancer, defined by the absence of estrogen receptor, progesterone receptor, and HER-2 expression (Hartman et al., 2012) .

Breast cancer and genetic Testing

The discovery of the BRCA1 and BRCA2 genes (Miki et al., 1994; Wooster et al., 1995) has led to the gradual introduction of genetic testing for breast cancer in the clinical context. In many countries, there are established guidelines in order to identify individuals at increased risk of developing hereditary cancer (Gadzicki et al., 2011). Currently, several Canadian provinces (such as British Colombia and Ontario) have developed specific criteria based on which individuals are referred for BRCA1/2 testing (BC Cancer Agency, 2012; Ontario Medical Association, 2001). According to the Ontario Medical Association individuals with the following criteria should be referred for genetic counseling and testing: those who have a family member with both breast and ovarian cancer; a family member with breast cancer diagnosed before age 35; a family member with ovarian cancer; a family member with primary cancer in both breasts especially if diagnosed before age 50; a family member with an identified BRCA1 or BRCA 2 mutation; multiple cases of breast or ovarian cancer on same side of the family; and Ashkenazi Jewish heritage. However, currently there are no published provincial guidelines describing the eligibility criteria for referral to genetic services in Québec.

The early identification of carriers has important clinical implications for the individual as well as family relatives as they can benefit from obtaining information regarding their future risk of cancer. It is known that BRCA1/2 carriers not already affected by cancer have an elevated risk of developing cancer in the future compared to the general population. For example, lifetime risk of developing breast cancer is at 85% among BRCA1 mutation carriers and at 75% in BRCA2 mutation carriers. Furthermore, it has been shown that female BRCA1/2 mutation carriers have up to 60% risk of

developing ovarian cancer in their lifetime. There is also a heightened risk of developing prostate cancer among male BRCA2 carriers (Antoniou et al., 2003; Ford et al, 1998; Edwards et al., 2003).

While non-affected individuals can benefit from genetic testing, there are also potential benefits of testing for those who are already affected by cancer. There is evidence that the clinical and behavioral patterns of the tumor in BRCA-related cases are different from the non-hereditary cases. For example breast cancer patients carrying mutation in the genes BRCA1/2 are at increased risk of developing cancer in the contralateral breast (Malone et al., 2010; Graeser et al., 2009). Furthermore, BRCA-associated tumors have a high sensitivity to some chemotherapy agents such as poly (ADP-ribose) polymerase inhibitors (PARP), platinum agents and taxanes (Price & Monteiro, 2010; Silver et al., 2010; Tutt & Ashworth, 2008). Therefore, carrier status identification has great clinical significance even for the individuals diagnosed by cancer and can guide the management of future risk in context of current treatment regiments.

Psychosocial aspects of genetic testing

I. Psychological impact

A growing body of literature assessed the psychological consequences of undergoing BRCA1/2 genetic testing in women. Smith et al. (2008) evaluated general distress level in a group of women with personal or family history of breast cancer and found no increase in long-term distress level of these women. However, a positive carrier status was associated with a short-term increase in anxiety among carriers. In another study by Schlich-Bakker et al. (2006) no additional psychological burden was reported in

women receiving genetic counseling and testing shortly after surgery. In fact, findings from a study by Coyne et al. (2003) showed that the majority of the affected women rated being a mutation carrier less distressing than the cancer diagnosis itself.

The situation may be different in unaffected women. The majority of the studies showed differences in psychological outcomes for unaffected mutation carriers as compared to unaffected non-mutation carriers. There is evidence that genetic testing is associated with psychological benefits among unaffected non-mutation carriers (Lerman et al., 1996; L. Lodder et al., 2001; Meiser et al., 2002; Schwartz et al., 2002). However, several studies indicated short-term increases in breast cancer anxiety among unaffected mutation-carriers. (Watson et al., 2004; Van Roosmalen et al., 2004; Meiser et al., 2002).

II. Cancer risk estimate

The identification of the genes BRCA1/2 and the use of genetic testing in clinical practice created the general public's impression that BRCA testing can be used as a method for early detection and prevention of breast cancer (Freedman, 1997). However, it is known that 90%-95% of all breast cancer cases are not hereditary and the vast majority of cases can not be predicted by genetic testing (Wevers et al., 2012). Therefore, a negative test result does not guarantee a future free of breast cancer and a non-carrier woman remains at risk similar to the general population. Furthermore, test results could be inconclusive. An inconclusive test result occurs when no deleterious BRCA1/2 mutation is identified while there is a strong family history of breast or ovarian cancer. Hence failure in detecting a mutation in BRCA1/2 does not necessarily provide reassurance of not developing hereditary cancer because an undetected mutation in

BRCA1/2 or a mutation in an unknown gene may be present (Gayther & Ponder, 1997; Zilliacus et al., 2012).

III. Genetic discrimination

Genetic discrimination may occur when employers or insurance companies treat people who are at risk of developing hereditary diseases differently from those who are not at risk. The fear of health insurance discrimination may influence women's decision-making when deciding whether to undergo genetic testing for breast cancer. Armstrong and colleagues (2000) conducted a study in order to examine the factors affecting decision-making about BRCA1/2 testing in unaffected women who underwent genetic counseling. Results showed that 47% of participants declined BRCA testing only due to their concerns of insurance discrimination. In a similar study, patients diagnosed with breast or ovarian cancer who requested coverage for BRCA testing reported having unusual difficulty in obtaining insurance. In the same study, fifteen percent of the participants chose the private pay option because of their concerns regarding insurance and/or future employment discrimination (Peterson, Milliron, Lewis, Goold, & Merajver, 2002).

Recently, heightened public concern against genetic discrimination has led to new policies in the United States. These policies prohibit health plans and health insurers to refuse coverage or charge higher premiums to a healthy individual because of a genetic predisposition to develop a disease in the future (Genetic Information Nondiscrimination Act 2008). However, in Canada there is still no legislation specifically prohibiting

insurance companies from genetic discrimination (Canadian Coalition for Genetic Fairness 2009).

Risk Management strategies

Individuals who are identified as BRCA1/2 mutation carriers confront different choices that can help them manage their future cancer risk. Risk management strategies commonly used among these patients include cancer surveillance of the breasts (e.g. breast self-examination, clinical breast examination, screening by mammography and magnetic resonance imaging of breast), or ovaries (e.g. trans-vaginal ultrasound scanning and serum CA125), chemoprevention (tamoxifen or raloxifen) and prophylactic surgery (mastectomy and/or salpingo-oophorectomy). These strategies have different effectiveness and the range in which they can increase life expectancy differs from a few months to a few years (Salhab, Bismohun, & Mokbel, 2010; Howard et al., 2009; Jatoi & Anderson, 2008).

Surveillance

Surveillance is used for early detection of cancer rather than prevention of the disease. Canadian Cancer Society guideline (2014) suggests women aged 50-74 with an average risk of breast cancer to undergo breast screening every 2 to 3 years. Screening can be done with either digital or film mammography. Women at moderately increased risk of breast cancer are suggested to start annual screening by 40 years of age using both mammography and clinical breast examinations. This guideline recommends women at

high risk of breast cancer to begin annual screening by 30 years of age using magnetic resonance imaging, mammography and clinical breast examination.

Currently, the Quebec Breast Cancer Screening Program offers a mammography every two years to women with an average risk of breast cancer aged between 50 to 69 years in Quebec. Women at higher than average risk of breast cancer are suggested to undergo mammography more often or earlier than people with average risk (Ministère de la santé et de services sociaux 2014; Canadian Cancer Society, 2013).

Regarding ovarian cancer, surveillance methods commonly used for early detection, such as serum CA125 measurement, pelvic examination and trans-vaginal ultrasound, cannot detect tumors at a sufficiently early stage before they metastasize. Thus, they are considered to be ineffective methods for detecting ovarian cancer because they have no significant impact on the disease prognosis and overall survival (Stirling et al., 2005; Salhab et al., 2010). However, a recent study by Nolen and Lokshin (2013) demonstrated that diagnostic tests measuring biomarkers alternative to CA125 might be able to detect ovarian cancer at an early stage.

Chemoprevention

There is evidence that estrogen plays an important role in mammary carcinogenesis through its effect on cellular DNA and it is necessary for the growth and development of some breast carcinomas (Subramanian, Salhab, & Mokbel, 2008). This finding has led to the use of chemotherapy agents targeting the estrogen receptors as an effective risk-reducing strategy. One agent widely used in order to prevent developing of breast cancer in high-risk population is a Selective Estrogen receptor Modulator (SEM)

called *Tamoxifen* (Jatoi & Anderson, 2008; Howard et al., 2009). An overview of several randomized trials showed that the use of *tamoxifen* is associated with about 38% reduction in the incidence of invasive breast cancer (Cuzick et al., 2003). Furthermore, *tamoxifen* prevented the development of secondary and contralateral breast cancer in BRCA1/2 carriers already diagnosed with cancer (Calderon-Margalit & Paltiel, 2004; K. Metcalfe et al., 2004). However, it seems that women taking *tamoxifen* have an increased risk of endometrial cancer and thromboembolism by twofold or more (Fisher et al., 2005). *Raloxifen* is another SEM used to decrease the risk of breast cancer in high-risk postmenopausal women with a better safety profile and fewer side effects than *tamoxifen*. However, *tamoxifen* is a better choice in high risk premenopausal women (Vogel et al., 2006).

Prophylactic Surgery

Prophylactic mastectomy is a surgical procedure involving the removal of one or both breasts in order to reduce future cancer risk. There is increasing evidence that prophylactic bilateral mastectomy or prophylactic BLM is an effective method in decreasing the risk of breast cancer among carriers (Ray, Loescher, & Brewer, 2005). Findings from a case-control study by Rebbeck and colleagues (2004) revealed that subsequent development of breast cancer was two percent among carriers who underwent prophylactic BLM compared to 49% among those who did not. In another study by Meijer-Hejboer and colleagues (2001) a group of women were observed. Results revealed that the incidence of breast cancer was significantly lower in women carrying a BRCA1/2 mutation who underwent prophylactic BLM compared to those who underwent targeted surveillance. Furthermore, it is known that contralateral prophylactic mastectomy (CPM)

is associated with 94% to 96% decrease in the risk of developing contralateral breast cancer (Evans et al., 2005, McDonell et al., 2001) and it may also reduce breast cancer-specific mortality (Herrinton et al., 2005; Van Sprundel et al., 2005).

Despite the well-known impact of prophylactic BLM in reducing risk of breast cancer, it is still considered a controversial procedure for several reasons. Firstly, there is the potential for surgical complications such as infection, pain syndromes and lymphadenopathy (Bebbington Hatcher & Fallowfield, 2003; Bjorkman, Arner, & Hyden, 2008). Secondly, it could influence a woman's self-identity, body image, and sexual relationship, which might consequently impact on her quality of life (Hallowell, 1998; McCullum, Bottorff, Kelly, Kieffer, & Balneaves 2007). Furthermore, surgery does not guarantee a total elimination of cancer risk and there remains a risk of developing cancer in the residual tissue (Petit & Greco, 2002; Ray et al., 2005). Lastly, the possibility for developing cancer is not certain, therefore questioning the necessity of surgery for this population (Ray et al., 2005).

For many women, the decision to undergo bilateral mastectomy is a complex decision. So far, numerous studies have tried to explore various factors that influence this process. The majority of these studies have found a positive association between anxiety, distress and worry, and uptake of prophylactic mastectomy (Antill et al., 2006; L. N. Lodder et al., 2002; van Dijk et al., 2003; Meiser et al., 2000; Unic, Verhoef, Stalmeier, & van Daal, 2000; M. E. Stefanek, Helzlsouer, Wilcox, & Houn, 1995). Several other factors such as BRCA1/2 mutation status, previous cancer diagnosis, perceived cancer risk, and young age have been also found to be influential in decision-making regarding BLM (van Dijk, van Roosmalen, Otten, & Stalmeier, 2008; Uyei et al., 2006; Scheuer et

al., 2002). Nonetheless, there is evidence of an increasing trend in women's acceptance of prophylactic surgery as a risk-reducing option (King et al., 2013; Metcalfe, Werrett, Burgess, Chapman, & Clifford, 2009; Arrington, Jarosek, Virnig, Habermann, & Tuttle, 2009; Graves et al., 2007)

Timing of BRCA1/2 genetic testing

Traditionally, genetic counseling and testing is offered to women diagnosed with breast cancer after completion of their primary treatment and the results can be used for managing their future risk of a new primary breast cancer (Meiser et al., 2012; Zilliacus et al., 2012). Recently, the advancement in genetic testing technologies has made it possible for women newly diagnosed with breast cancer to know their test results within 1 or 2 weeks. The process of quick turn-around of test results, which is also called *Treatment-Focused Genetic Testing* (TFGT) or *Rapid Genetic Counseling and Testing* (RGCT) in the literature, can help patients to know their carrier status at the time of diagnosis and enables them to make an informed decision regarding treatment (Zilliacus et al., 2012, Wevers et al., 2012). It has been argued that TFGT is far more important in guiding risk management of cancer than traditional genetic testing for different reasons. First, determining the carrier status right after the diagnosis and before undergoing a primary surgery gives women who are carriers this option to undergo immediate BLM and therefore avoid dispensable radiotherapy used for local control of disease, which interferes with surgical reconstruction of the breast. Second, the BLM prevents the patients from needing to undergo an additional second surgery at a later date (Meiser et al., 2012; Schwartz et al., 2004).

However, TFGT has some disadvantages as well. For example, undergoing genetic testing during the vulnerable time right after cancer diagnosis might pose additional stress on patients. Furthermore, the time necessary for disclosure of test results could cause a delay in definitive surgical treatment (Schwartz et al., 2004). Besides, such as is the case for traditional genetic testing; there is a possibility of inconclusive test result in TFGT as well.

Considering all the advantages and disadvantages, the optimum time for offering genetic counseling and testing remains controversial. Yet, there is growing evidence of willingness in women newly diagnosed by breast cancer to undergo TFGT if it is available. In a qualitative study by Zilliacus et al. (2012) a semi-structured interview was conducted with newly diagnosed women in order to explore their attitudes toward TFGT. Results revealed that majority of women had positive attitudes toward TFGT and believed it can help them in managing their future cancer risk. Also, most of the participants felt that undergoing TFGT at the time of diagnosis would not be an additional psychological burden. In a similar study, Meiser and colleagues (2012) conducted an interview with newly diagnosed women regarding their views of TFGT. They also found that majority of the women had a positive outlook toward TFGT and were ready to be informed about their genetic risk around the time of diagnosis. In the same line, Wevers and colleagues (2012) asked 26 women who had received TFGT at the time of diagnosis about their perceived psychosocial impact of genetic testing as well as their level of distress at the time of the study. Findings revealed that TFGT was associated with short-term psychological stress in the majority of the women without causing any long-term distress and it did influence their surgical decision-making.

However, the study conducted by Ardern-Jones and colleague (2005) demonstrated different findings. They interviewed 13 young women with breast cancer who underwent genetic testing post breast cancer treatment to explore their attitudes toward rapid genetic testing if it was available to them right after the diagnosis. Most of these participants believed that taking the test at the time of diagnosis would have been "too much too soon" and would impose an informational and emotional overload on them.

A growing body of literature demonstrates that undergoing TFGT affects women's decision-making regarding treatment leading to an increasing rate of BLM as a risk reducing option among newly diagnosed breast cancer patients. In a recent randomized control trial two groups of women received either traditional genetic testing or rapid genetic testing. According to the results, the rate of BLM was significantly higher in women who had rapid testing (Wevers et al., 2014). In a similar study by Schwartz et al. (2004), TFGT was offered to 194 newly diagnosed breast cancer patients and the majority of the participants (86%) chose to receive the test results. Also, 48% of the mutation carriers opted for bilateral mastectomy. According to the results, 24% of patients with uninformative test results and 4% of test decliners chose to undergo BLM as well. Weitzel and colleagues (2003) performed another study in which 32 of the participants with breast cancer received genetic cancer risk assessment at peri-diagnosis and seven of them were identified as carriers. According to the results, all of the carriers, as well as two of the non-carriers, chose to undergo BLM.

TFGT has been recently introduced as an available option for newly diagnosed women. Nevertheless, factors that influence decision-making for BLM among newly

diagnosed women are not fully understood. Also, little is known about the psychological impact of offering genetic testing to women affected by breast cancer shortly after being diagnosed. Not all patients elect to have prophylactic BLM at the time of diagnosis. This illustrates that despite potential benefits of BLM at the time of diagnosis deciding to undergo BLM at this time is not a straightforward procedure and different factors might influence it. According to Howard et al., (2011) unaffected women with positive test results feel threatened in different dimensions of self such as self-identity, physical and emotional well-being and relationship with others. Therefore, decision-making process in these women focuses mainly on *preserving the self*. Contextual factors such as health service characteristics might also influence this process. In a review study by Howard et al., (2009) she summarized that medical, psychological, and social factors were influential factors on decision-making for risk reducing surgery in women carrying a BRCA1/2 mutation. Today, with technological advances, rapid genetic counseling and testing is becoming readily available to aid in treatment-based decision making in newly diagnosed women. However, the impact of genetic testing at the time of diagnosis in women with breast cancer is largely unknown. This study aimed to assess the psychological determinants in decision-making for bilateral mastectomy in women newly diagnosed with breast cancer who underwent rapid genetic testing and evaluated the psychological impact of receiving their test result at the time of diagnosis.

Objectives

The goal of the present study was to determine the role of TFGT (Rapid genetic counseling and testing) in decision-making for undergoing bilateral mastectomy in women newly-diagnosed by breast cancer and to identify the role of psychological factors in their decision. In order to achieve these goals, the decision regarding the surgery was compared among carriers and non-carriers. In addition, different psychological variables were measured and were compared between the carrier and non-carrier groups and between the two groups who opt for or against risk reducing surgery. The psychological characteristics evaluated in this study included *cancer-specific distress* and *general distress* level which were assessed by valid and reliable questionnaires at baseline and during the follow-up. Information-seeking style, control preference scale, health locus of control and decision-making style were also measured. Also, participants were given a questionnaire regarding their satisfaction about rapid genetic counseling and testing.

Hypothesis

1. The patients who carry a mutation in the genes BRCA1/BRCA2 are more likely to opt for bilateral mastectomy compared to those without any mutation.
2. Women who decide to undergo bilateral mastectomy have a higher level of general anxiety and a higher level of cancer-related stress.
3. More intrusive thoughts regarding the cancer are associated with a higher rate of risk reducing surgery among patients.
4. Participants with more internal locus of control and high monitoring information-seeking style are more likely to decide to undergo bilateral mastectomy.

Materials and Methods

Participants

Eligible participants comprised of women newly diagnosed with breast cancer attending Segal Cancer Center at the Jewish General Hospital in Montreal from June 2012 till December 2013. Given the current high cost of genetic testing and the publicly funded health-care system, eligible participants were purposely selected according to the following criteria: (a) age at diagnosis is less than 65 years of age (b) self-report being of an ethnic group (French Canadians, Ashkenazi Jews and Eastern European) where a founder mutation panel in BRCA1/2 is available (c) agreed to have genetic testing. Complete analysis of BRCA1/2 was offered to those women who were affected under the age of 35, or who developed a triple negative breast cancer or who had a significant family history of breast and/or ovarian cancer. Women were excluded from the study if (a) they had a previous history of breast or ovarian cancer (b) previously received genetic counseling or testing for breast cancer susceptibility (c) previously had bilateral mastectomy (d) or had knowledge of the existence of a BRCA1/2 mutation already in their family. All potential participants were Quebec residents who were fluent in either French or English. Forty-four women were enrolled in the study. Two women died prior to completion of the study.

Procedure

Potential participants who had been offered rapid genetic counseling and testing were invited to participate in the study by their genetic counselor. Participants completed two questionnaires. The first questionnaire was implemented at baseline (prior to receiving genetic test results) and a follow-up questionnaire was given post disclosure of

genetic test results. Participants' medical charts were reviewed to collect information related to their surgical choice of treatment. For compensation, participants were given the option of having their name entered in a lottery to win one of four 50$ gift certificates. The research protocol and consent forms were approved by the research ethics review board of the university-affiliated health center.

Measures:

Sociodemographics. Age, ethnicity, marital status, number of children, level of education and family history of cancer were assessed at the baseline questionnaire. A positive family history was defined as having a first, second, or third degree relative diagnosed by breast or ovarian cancer.

Psychological variables:

Cancer-specific distress. The Impact of Event Scale was used to assess the level of cancer specific distress among participants. This instrument is a reliable measure (Cronbach's α coefficient = .82) with 15 items and consists of *avoidance* and *intrusion* subscales (Horowitz, Wilner, & Alvarez, 1979). The avoidance subscale entails eight items that measure the extent in which the respondent tries to avoid feelings and thoughts about the stressful event i.e., breast cancer diagnosis in this study. An example of an avoidance item is: "I feel as if it (cancer) had not happened or it was not real". The intrusion subscale entails seven items that evaluate the extent to which the respondent is overwhelmed by feelings and thoughts regarding the stressful event. An example of an intrusion subscale is: "Any reminder brought back feelings about it". Francophone participants received a validated French version of this questionnaire (Guay, 2002).

Distress Level. The Brief Symptom Inventory 18 (BSI-18) was used to evaluate the level of general distress. BSI-18 is a reliable psychometric instrument (Cronbach's α coefficient = .79) including 18 items on a 5-point Likert scale and it has three 6-items subscale for measuring *anxiety*, *depression* and *somatization*. BSI -18 is measured as an overall score called General Severity Index and three subscales scores (Derogatis, 2001). The BSI-18 is a brief version of the Symptom Checklist-90-R (SCL-90-R) and SCL-90-R has already been validated for a Montreal French-speaking population of women (Derogatis, 1977; Fortin, Coutu-Wakulczyk, & Engelsmann, 1989).

Health Locus of Control (HLC): Locus of control refers to the extent to which individuals believe that their health is or is not controlled by their behavior. In this study, Form C of Multidimensional Health Locus of Control (MHLC) was used to measure this characteristic. MHLC, which was originally developed by Wallston et al. (1978), consists of three scales (Form A, B and C). Form A and B measure what is called "general" health locus of control (Wallston, Wallston, & DeVellis, 1978). Form C (Wallston, Stein & Smith, 1994) is a "condition-specific" form with a high internal consistency (Cronbach's α of each subscale > = 0.70). This form can be used instead of form A and B when the individuals under study have an existing health issue. In the present study the form C was used and term "condition" was replaced by "cancer". A French version of this questionnaire was made cancer-specific by altering the French-Canadian adaptation of MHLC (Talbot, 1996) such that items referred to general health were replaced by cancer. This form has 18 items on a 6-point Likert scale and consists of *internal*, *chance*, *other people* and *doctors'* subscales. The internal subscale includes six items and measures the extent to which individuals believe that their health status is determined by internal

factors. An example of an internal item is: “Whatever goes wrong with my cancer is my own fault”.

The chance subscale also entails six items and measures the extent to which individuals believe that chance affects their health status. An example of a chance item is: “If my cancer worsens, it’s a matter of fate”. The other people’s subscale measures the extent to which individual believes that other people can influence their health condition and it includes three items. An example of this subscale is: “The type of help I receive from other people determines how soon my condition improves”. The doctors’ subscale shows the extent to which the individual believes that their doctor can influence their health outcome. An example of this subscale is: “If I see my doctor regularly, I am less likely to have problems with my condition”.

Information Seeking Style: An abbreviated version of the Miller Behavioral Style Scale (MBSS) was used in order to assess the information seeking style of the participants (Steptoe, 1989). Francophone participants received a validated French version of this questionnaire (Jacques et al., 1999). According to Miller (1987) individuals develop two main information-processing styles when facing stressful situations such as medical threats. *Monitors* are those who seek for information and emotionally amplify threatening cues. On the other hand, *Blunters* try to avoid any information regarding the situation and distract from such cues. MBSS, which is a highly valid questionnaire, explains four stressful scenarios and participants are asked to identify which one of the eight potential responses would describe their reaction in each scenario. Four of the eight answers indicate high monitoring style and four of them indicate low monitoring style. In the abbreviated MBSS only two stressful situations are described. The two scenarios include

threat of job lost and phobia of going to dentist. For instance, in the dentist scenario, the individual is asked to imagine he/she has dentist phobia and needs some dental work. An example of the blunting reaction is that "I would try to sleep" however a monitoring reaction might be "I would ask the dentist exactly what he was going to do". Based on their level of blunting and monitoring, participants can have a dominant monitor, dominant blunter, or mixed copying style or they might not to belong to any specific coping style (Nikoletti, Kristjanson, Tataryn, McPhee, & Burt, 2003).

Control Preference: Control preference is the extent to which individuals prefer to have control over decision-making with regard to medical treatment. It is commonly measured by control preference scale (CPS), which consists of five cards illustrating five different decision-making roles in health-related situations using text and pictures. These roles include *Active*, *Passive* and *Collaborative* roles (Degner, Sloan, &Venkatesh, 1997). In this study, a question with five possible answers was asked instead of cards in the interest of feasibility. According to Degner et al. (1997), CPS is a valid and reliable measure of preferred roles in medical decision-making.

Satisfaction: Participants completed a questionnaire regarding their satisfaction about rapid genetic counseling and testing on average 10 months after filling out the baseline questionnaire. Appendix E.

Genetic test-related distress: The Impact of Event Scale was used in the follow-up to assess the level of distress associated with taking genetic test among participants. In the follow-up questionnaire taking genetic test was considered as the stressful event. Appendix A.

Treatment Choice:

Treatment choice was collected from reviewing patients' medical records. Based on their choice of treatment participants divided to two groups. One group consisted of those patients who underwent surgery to remove both the affected and contralateral breast. The other group included the participants who did not undergo total mastectomy.

Results

Sample characteristics

In the course of this study, 87 women were diagnosed by breast cancer at Segal Cancer Center in Montreal. Seventy four of these women were referred to get genetic counseling out of which 72 were tested. A total of 44 women agreed to complete the questionnaire and were enrolled in the study. As seen in Table 1, the majority of participants were of French-Canadian or Ashkenazi Jewish descent. Seventy percent of the participants had a positive family history of breast or ovarian cancer. Most of the participants had university-level education (57%), had children (82%) and were married or partnered (77%). Fifty-four percent of the women were between 41-60 years of age. Seven of the 44 participants were identified as carrying a BRCA1/2 founder mutation. All seven carriers opted for bilateral mastectomy whereas in the non-carrier group only one out of 37 women decided to undergo this procedure. Statistical analysis did not show any correlation between the collected demographic variables and choice of surgery.

Decision-making and health locus of control

Results from the control preference scale indicated that when it comes to decision-making regarding participating in a genetic test, the majority of participants

(61%) preferred to be actively involved in the decision-making process, 29% preferred to share responsibility for deciding with their doctor and only 7% preferred a passive role in decision-making. Also, there was no difference in the average scores of the subscales of health locus of control between the breast conservation and BLM groups.

Psychological variables

As seen in Table 4, the average score on the IES questionnaire at baseline was 35 (*SD =8.8*). The mean score on the avoidance subscale was 17 (*SD =5.1*) and the mean score on the intrusion subscale was 17 (*SD = 5.3*). Sixty-six percent of the women had an IES score ranging from 26 to 43, which indicated that the diagnosis of cancer was powerful stressor. Sixteen percent of the participants were severely impacted by cancer diagnosis (IES > 44). According to the statistical analysis the mean avoidance score was significantly lower in patients who underwent BLM compared to those who did not ($p < 0.05$). However, no statistical difference was found in the intrusion subscale between the two groups. See Table 5.

The average score on the BSI-18 scale was 12 (*SD =9.9*) with a mean of 5 (*SD =4.5*) on the anxiety subscale, a mean of 3 (*SD =3.2*) on the somatization subscale and a mean of 4 (*SD =4.3*) on the depression subscale. The mean score of the BSI-18 questionnaire and related subscales (anxiety, somatization, depression) were not significantly different in the patients who chose BLM versus those who did not (See Table 4 and 5). The IES and the BSI-18 were significantly correlated to each other ($r = 0.55, p < 0.01$) however no significant correlation was found between them and decision to have the surgery to reduce the risk for future breast cancers.

Participants completed the follow-up questionnaire on average 10-months after completion of the baseline questionnaire. Follow-up questionnaire consisted of the IES and the BSI-18 scale. The IES was included twice in the follow-up questionnaire; one of the IES scales measured cancer-specific distress and the other one evaluated stress associated with having genetic testing. Twenty patients out of 44 returned the follow-up questionnaire in which three were mutation carriers. Findings from the follow-up questionnaire showed an average score of 30 (*SD* = 9.2) for the cancer-related stress with a mean of 13 (*SD* = 5.9) on the intrusion subscale and a mean of 17 (*SD* =5) on the avoidance subscale. The mean score of IES and Intrusion was significantly lower in about one year after the diagnosis ($P < 0.05$) however, the average level of cancer avoidance remained about the same level. See Table 6.

The average score of BSI-18 on the follow up questionnaire was 27 (*SD* =10.4) with a mean of 9 (*SD* = 4.2) on the depression subscale, a mean of 9 (*SD* = 4.1) on the anxiety subscale and a mean of 9 (*SD* = 4) on the somatization subscale. Interestingly, the average level of BSI-18 and all the related subscales were significantly higher than baseline level ($p > 0.05$). However, the average BSI-18 score was not significantly different between non-carriers and carriers in the follow-up group. Also, the changes in the IES and BSI-18 score 10 months after the baseline measurement were not significantly different in carriers and non-carriers. See Table 6.

Five out of twenty patients showed a severe level of stress related to undergoing genetic testing however the average level of stress associated with genetic testing was not different among carries and non-carriers.

Twenty patients completed the satisfaction questionnaire and the majority of them thought that genetic testing was offered to them at the appropriate time. All the twenty patients were at least to some degree satisfied with their decision regarding undergoing to genetic test. Forty percent of the patients said that having genetic test was to some level stressful for them and their family. Four patients mentioned that test results affected their relationship with their family and relatives even though 3 of them were not carriers.

Overall, 32 out of 44 participants filled out the MBSS questionnaire. According to the results, 41 percent of the participants were both low monitors and low blunters and therefore did not belong to any of the coping style categories. Twenty-eight percent of the participants were dominant monitors, 16% were dominant blunters and 16% had a mixed copying style. No correlation was found between monitoring or blunting score and surgery status. See Table 7.

Table 1. *Sociodemographics and Clinical Characteristics of Patients*

Characteristic	Total Sample	Percentage (%)
Age		
< 40	9	20
41- 60	24	54
> 60	11	25
Education		
University level	25	57
No University	18	41
Marital status		
Married or partnered	34	77
No partner	10	23
Children status		
Children	36	82
No child	8	18
Carrier status		
Carrier	7	16
Non-carrier	37	84
Surgery		
BLM	8	18
No BLM	36	82
Ethnicity		
French-Canadian	16	36
Ashkenazi Jewish	11	25
Anglo-Saxon	5	11
Greek	4	9
Russian	4	9
Polish	4	9
Sephardi Jewish	2	5
Irish	2	5
Hungarian-Magyar	1	2
Italian	1	2
Other	7	16
Family history		
Positive	31	70

Negative	13	30
Breast	41	93
Ovarian	3	7

Table 2. Descriptive Data for the Control Preference Scale

Preferred Role in Decision-making	Participants number (n = 43)	Percentage (%)
Active		
I prefer to make the final decision	8	18
I prefer to make the final decision considering my doctor's opinion	19	45
Collaborative		
I prefer that my doctor and I share responsibility for deciding	13	29
Passive		
I prefer that my doctor makes the final decision seriously considering my opinion	2	5
I prefer to leave all decisions to my doctor	1	2

Table 3. Health Locus of Control and Surgery Choice

Health Locus of Control (HLC)	Surgery Group (n=8)		Non Surgery Group (n=34)		t-test (p)
	Mean	*SD*	Mean	*SD*	
Internal HLC	17	5.5	14	5.1	-1.1 (ns)
Doctor HLC	15	1.7	15	2.3	0.2 (ns)
Chance HLC	17	9.2	19	8.3	0.7 (ns)
Other HLC	13	3.1	10	4.4	-1.5 (ns)

Table 4. Descriptive Data for Impact of Event scale (IES) and Brief Symptom Inventory-18 (BSI-18) at baseline

Variable	Mean (n = 44)	*SD*
IES	35	*8.8*
Intrusion	17	*5.3*
Avoidance	17	*5.1*
BSI-18	12	*9.9*
Somatization	3	*3.2*
Anxiety	5	*4.5*
Depression	4	*4.3*

Table 5. Psychological Variables and Surgery Choice

Variable	BLM Group (n=8)		Non BLM Group (n=36)		t-test (p)
	Mean	*SD*	Mean	*SD*	
IES(Cancer-specific Distress)	32	6.7	35	9.0	1.0 (ns)
Intrusion	16	5.3	17	5.3	0.5 (ns)
Avoidance	15	2.3	18	5.5	1.3 (P <0.05)
BSI-18	9	10.2	12	10.0	0.8 (ns)
Somatization	2	2.4	3	3.3	0.2 (ns)
Anxiety	5	5.3	6	4.3	0.5 (ns)
Depression	2	3.2	4	4.4	1.2 (ns)

Table 6. Descriptive Data for Impact of Event Scale (IES) and Brief Symptom Inventory-18 (BSI-18) at baseline and follow-up

Variable	Baseline (n = 20)		Follow-up (n = 20)		t - test (*p*)
	Mean	SD	Mean	SD	
IES (Cancer-specific Distress)	35	9.6	*30*	*9.2*	*4* (*p < 0.05)*
Intrusion	17	5.9	13	5.9	4.7 (*p < 0.05*)
Avoidance	18	5.4	17	5.0	1.4 (*ns*)
BSI-18	11	8.6	27	10.4	*9.4* (*p < 0.05)*
Somatization	2.4	2.6	9	3.4	11.4 (*p < 0.05*)
Anxiety	5	4.5	9.5	4.1	5.7 (*p < 0.05*)
Depression	4	3.3	9	4.2	5.3 (*p< 0.05*)

Table 7. Copying style and Surgery Choice

Copying Style	Participants Number (%) (n = 32)	BLM (%)	No BLM (%)
Dominant Monitor	9 (28)	2	7
Dominant Blunter	5 (16)	3	2
Mixed Style	5 (16)	0	5
No Style	13 (41)	1	12

Discussion

The first hypothesis in this study was that the BRCA1/2 carriers are more likely to choose bilateral mastectomy compared to non-carrier women. This hypothesis is supported since all of the seven identified carrier women in our study opted for the surgery as opposed to only one of the 29 non-carrier women. As much as this is a very striking finding it should be noted that the dominant effect of positive carrier status on decision-making in this particular project led to lack of a possible comparison group consisting of carrier women not undergoing breast ablation. This was a limitation in testing of the hypothesis in a more meaningful way.

It was also hypothesized that the rate of BLM would be higher in women with a higher level of general anxiety and cancer-specific anxiety. According to the results, no association was found between IES or general anxiety and surgery choice. Also, there was no association between having intrusive thoughts regarding breast cancer diagnosis and the likelihood of undergoing BLM. However it was found that women who opted for BLM have significantly lower avoidant thoughts than those who decline the surgery.

One important finding of this study was the observed 100 percent uptake rate of BLM among carriers. This observed high rate might have occurred because of the small sample size of the study. Nevertheless it highlights the significant impact of genetic testing at the time of diagnosis on treatment choice. Similar findings reported by other researchers also demonstrated a high rate of risk reducing mastectomy in women receiving rapid genetic counseling and testing (Coretsi et al., 2014; Wevers et al., 2014; Wevers et al., 2012; Schwartz et al., 2004; Weitzel et al., 2003). Therefore, it seems that

rapid genetic testing has an important impact on treatment choice and was an acceptable and an appropriate option for women who were willing to receive information regarding their carrier status at the time period between diagnosis and the primary surgery.

The majority of the women who underwent BLM also had a positive family history of cancer. This finding is supported by results of a previous qualitative study (McQuirter et al., 2010) in which knowledge of a positive carrier status or a cancer diagnosis in the family were found to be pivotal points in making a definitive decision for undergoing risk reducing mastectomy. Theory of preserving-the-self proposed by Howard et al (2011) provides support for this outcome as well. According to this theory carrier women feel threatened in different dimensions of the-self such as physical and emotional health, self-identity and interpersonal relationship. So they are motivated to undergo prophylactic bilateral mastectomy to protect their physical health. Also, worry and distress associated with witnessing relatives with cancer or caring for affected family members directs them towards making a decision that maintains their emotional-health. Therefore, as discussed in previous studies (Howard et al., 2011; McQuirter et al., 2010) decision-making for undergoing BLM is a complex process resulting from interaction between two different modes of thoughts which can be explained through dual-process theory of thinking. Based on this theory people rely on two fundamentally different system when confront risks; experiential mode-which is based on affective cues- and analytical mode which is reason oriented. In order to make a sound decision, appropriate input of both modes is required (Slovic, Finucane, Peters, & MacGregor, 2004; Epstein 1994).

Furthermore, the results revealed a lower level of avoidant thoughts in patients who opted for risk reducing surgery than those who did not. A lower level of avoidant thoughts in carriers was also found (compared to non-carriers). Considering the small sample size of this study, it is not clear whether having less avoidant thoughts plays a role in choosing BLM beyond being a mutation carrier. Interestingly, one of the non-mutation carriers with a negative family history decided to undergo BLM. This finding suggests some other factors might also be involved in decision-making process given that BLM is not routinely offered as standard care to non-carrier women. As discussed by Guth et al., (2012), patients receive an overwhelming amount of information right after diagnosis that might prevent them from making a complex decision during this stressful time. Furthermore, misperception about the risk and benefits of surgery may direct patients to make a radical decision (Tracy, Rosenberg, Dominici, & Patridge, 2013). Thus, patients can benefit from receiving decision aids to make an informed decision and therefore the increasing trend of prophylactic BLM in recent years can be controlled (Tuttle et al., 2009; Jones et al., 2009; Kurian et al., 2012). In the present study, BLM was not offered as a standard procedure to women newly diagnosed with breast cancer otherwise there might have been a higher rate of BLM in non-carrier women.

This study addresses the remaining concern about offering rapid genetic testing and counseling, that is the possible additional psychological burden of undergoing the genetic test at the stressful time of cancer diagnosis. The results reveal that the majority of the participants did not show a high level of distress related to genetic testing. This finding indicates that rapid genetic testing per se does not impose a clinically relevant distress on patients and is similar to findings from previous studies, which did not report

additional anxiety due to undergoing traditional genetic counseling and testing (A. W. Smith et al., 2008; Schlich-Bakker et al., 2006). Therefore, it can be argued that participants may have considered rapid genetic counseling and testing as a regular medical test and part of the standard therapeutic procedure as it might be the case for traditional genetic testing. Although it should be noted that most of the patients who filled out the IES regarding genetic testing were non-carrier women and test results revealing non-hereditary nature of the cancer might have been reassuring for them. These patients would probably perceive higher level of genetic-testing related anxiety if they were carriers.

Regarding the satisfaction with genetic testing, all of the twenty patients who completed the follow-up questionnaire mentioned that they were satisfied with their decision about undergoing genetic testing and that they think genetic testing was offered to them at an appropriate time. This result is similar with findings of a study by Cortesi et al. (2014). In this study women receiving TFGT who underwent BLM were interviewed and all of them were satisfied with their decision to undertake surgery. Similarly, the results of another study by Wevers and colleague (2012) revealed that 90% of the women were satisfied with undergoing rapid genetic testing and would recommend it to the other patients. Along the same line, Zilliacus and colleagues (2012) reported a high acceptance rate of rapid genetic counseling and testing among women who underwent this test. Conversely, a qualitative study conducted by Ardern-Jones and colleagues (2005) demonstrated different results. In that study the majority of the women already diagnosed by cancer who were asked about offering genetic testing right after diagnosis believed that it would be an emotional overload. However, it should be noted the hypothetical

situation in the interview might have impacted their answers. Also, some women in this study indicated a preference for the testing at the time of diagnosis. On the other hand, there is a possibility of biased finding in this study regarding participants' satisfaction in considering that half of the patients did not complete the follow-up questionnaire. According to a study by Mazor et al, (2002) response bias in the satisfaction surveys may lead to a significant overestimation of satisfaction level among the overall study sample.

There was no association between the baseline level of general or cancer-specific distress and decision-making for BLM. This finding again emphasizes carrier status identification as the main predictor of undergoing BLM. However, there is a possibility that patients with the highest cancer-related distress are among those who actually declined undergoing rapid genetic testing despite having a referral. For instance two of the referred patients declined genetic testing and 13 of the newly diagnosed women were not referred to the genetic counseling service. However, it is not clear if the decision was physician or patient driven. The importance of cancer-specific and general distress in decision to undergo testing should not be ignored during this sensitive period if the decision is patient-driven. A qualitative study conducted by Vadaparampil and colleagues (2009) supports this explanation. Their study was comprised of women with breast cancer who did not have genetic testing at the time of diagnosis despite receiving a referral letter. Participants of their study mentioned that it would be emotionally overwhelming to take the test at that time. Therefore, it seems that further studies are needed to elucidate the role of psychological factors that influence decision-making for receiving rapid genetic counseling and testing at the time peri-diagnosis.

This study revealed a significantly lower level of cancer-specific distress as well as a higher general distress level (BSI-18) in patients ten months after the diagnosis of cancer. A significant increase in the anxiety and depression subscales of the BSI-18 ten months after the diagnosis was found which is consistent with results of previous studies. A review study by Howard-Anderson and colleagues (2012) demonstrated that patients are very prone to developing long-term psychological consequences of the disease following the completion of breast cancer treatment. According to this study, concerns regarding treatment-induced menopause and infertility as well as weigh gain and physical inactivity during treatment play a role in increased distress after treatment. Furthermore, some studies reported an elevated rate of depression in breast cancer survivors (Zainal, Nik-Jaffar, Baharudin, sabki, & Ng, 2013; Begovic-Juhant, Chmielewski, Iwuagwu, & Chapman, 2012; Rabin et al., 2009). Post-treatment depression and anxiety were associated with poor quality of life (Ho, So, Leung, Lai, & Chan, 2013; Chen et al., 2009; Rabin et al., 2009). One study by Groenvold and colleagues (2007) revealed that psychological distress might affect the overall survival rate in breast cancer patients. In this study the anxiety level in a group of patients with breast cancer was measured two months after their primary surgery. Based on the results, lower level of anxiety predicted a longer recurrence-free survival. Association between distress level and overall survival could be linked to the effect of psychological distress on immunological function and cancer resistance. Also, low level of stress might be a reflection of both mental and physical health which lead to cancer resistance (Groenvold et al., 2007; Garssen & Goodkin, 1999). These findings emphasize the need for further screening for psychological problems post-treatment. Providing psychological support and

pharmacological intervention at this sensitive time point may reduce long-term psychological consequences of breast cancer.

There are several limitations to this study that should be noted. First, the small sample size limits the statistical power of the study such that certain effects might not be detected. It should be especially noted that not all the participants filled-out the MBSS questionnaire. This limits the study power in that it could not detect a possible association between copying style and surgery choice. Therefore, the study results are not generalizable to the population. Second, this study did not include women who were referred but declined genetic testing. It is possible that the women who did not pursue the referral had elevated avoidant thought, a very high level of anxiety or were low monitors. All of these characteristics might interact with their level of engagement in health-related behaviors such as taking a genetic test or undergoing risk-reducing surgery. Therefore participants of this study may not be representative of women at high-risk of hereditary breast cancer. Third, the treating physicians for the patients were not the same across the sample and they possibly had different approaches regarding mastectomy. Thus, it is not clear the extent in which decision-making for surgery was patient-driven or influenced by the physician.

Despite these limitations, the present study provides useful data on the predictive value of carrier status determination at the time of diagnosis in surgical treatment. Yet, more studies are needed to evaluate the long-term psychological impact of rapid genetic testing on newly diagnosed women as well as satisfaction with their treatment choice. It is also very important to assess the influencing factors in decision-making for undergoing genetic testing at the time of diagnosis. Psychological issues that might prevent patients

from undertaking the test must be determined if testing is going to be incorporated in clinical management of newly diagnosed women.

Conclusion

This study evaluated the role of rapid genetic counseling and testing in opting for bilateral mastectomy in women newly diagnosed by cancer. According to the results, all of the identified carriers decided to undergo prophylactic surgery. Also, offering the test at the time of diagnosis did not impose any additional stress on the patients. The majority of the women in the study were satisfied with their treatment of choice as well as the timing of the test. No association was found between the baseline level of general and cancer-specific distress and their surgery choice. The findings of this study reflect the significant impact of carrier status knowledge at the time of diagnosis on surgical therapy as well as high acceptability of rapid genetic testing among newly diagnosed women. Further research on predictive factors involved in taking rapid genetic counseling and testing is suggested before it is implemented in standard clinical setting.

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APPENDIX A: Impact of Event Scale (IES)

INSTRUCTIONS: Below is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how frequently these comments has been true for you during the past seven days. If they did not occur during that time, please mark the "not at all" column.

0 = Not at all
1 = rarely
2 = Sometimes
3 = Often

1. I thought about it when I didn't mean to.

2.I avoided letting myself get upset when I thought about it or was reminded of it.

3. I tried to remove it from my memory.

4. I had trouble falling asleep or staying asleep, because of pictures or thoughts about it that came to my mind.

5. I had waves of strong feelings about it.

6. I had dreams about it.

7. I stayed away from reminders of it.

8. I felt as if it hadn't happened or wasn't real.

9. I tried not to talk about it.

10. Pictures about it popped into my mind.

11. Other things kept making me think about it.

12. I was aware that I still had a lot of feelings about it, but I didn't deal with them.

13. I tried not to think about it

14. Any reminder brought back feelings about it.

15. My feelings about it were kind of numb.

APPENDIX B: Brief Symptom Inventory 18 (BSI-18)

Here I have a list of problems people sometimes have. As you read each one, please answer HOEW MUCH THAT PROBLEM HAS DISTRESSES OR BOTHERED YOU DURING THE PAST 7 DAYS INCLUDING TODAY. Theses are the answers I want you to use:

0= Not at all
1= a little bit
2= Moderately
3= Quite a bit
4= extremely

DURING THE PAST 7 DAYS, how much were you distresses by:

1-Faintness or dizziness	0	1	2	3	4
2-Pains in the heart or chest	0	1	2	3	4
3-Nausea or upset stomach	0	1	2	3	4
4-Trouble getting your breath	0	1	2	3	4
5-Numbness or tingling in part of your body	0	1	2	3	4
6-Feeling weak in parts of your body	0	1	2	3	4

DURING THE PAST 7 DAYS, how much were you distresses by:

1-Feeling no interest in things	0	1	2	3	4
2- Feeling blue	0	1	2	3	4
3-Feeling of worthlessness	0	1	2	3	4
4-feeling hopeless about the future	0	1	2	3	4
5-Thoughts of ending your life	0	1	2	3	4
6-Feeling lonely	0	1	2	3	4

DURING THE PAST 7 DAYS, how much were you distresses by:

1-nervousness or shakiness inside	0	1	2	3	4
2-Feeling tense or keyed up	0	1	2	3	4
3- Suddenly scared for no reason	0	1	2	3	4
4- Spells of terror or panic	0	1	2	3	4
5- Feeling so restless that you couldn't sit still	0	1	2	3	4
6- Feeling fearful	0	1	2	3	4

APPENDIX C: Form C Multidimensional Health Locus of Control (MHLC-C)

Instructions: Each item below is a belief statement about your medical condition with which you may agree or disagree. Beside each statement is a scale, which ranges from strongly disagree (1) to strongly agree (6). For each item we would like you to circle the number that represents the extent to which you agree or disagree with that statement. The more you agree with a statement, the higher will be the number you circle. The more you disagree with a statement; the lower will be the number you circle. Please make sure that you answer **EVERY ITEM** and that you circle **ONLY ONE** number per item. This is a measure of your personal beliefs; obviously, there are no right or wrong answers.

1=STRONGLY DISAGREE **(SD)** 2=MODERATELY DISAGREE **(MD)** 3=SLIGHTLY DISAGREE **(D)**	4=SLIGHTLY AGREE **(A)** 5=MODERATELY AGREE **(MA)** 6=STRONGLY AGREE **(SA)**

		SD	**MD**	**D**	**A**	**MA**	**SA**
1	If my cancer worsens, it is my own behavior which determines how soon I will feel better again.	1	2	3	4	5	6
2	As to my cancer, what will be will be.	1	2	3	4	5	6
3	If I see my doctor regularly, I am less likely to have problems with my cancer.	1	2	3	4	5	6
4	Most things that affect my condition happen to me by chance.	1	2	3	4	5	6
5	Whenever my cancer worsens, I should consult a medically trained professional.	1	2	3	4	5	6
6	I am directly responsible for my cancer getting better or worse.	1	2	3	4	5	6
7	Other people play a big role in whether my cancer improves, stays the same, or gets worse.	1	2	3	4	5	6
8	Whatever goes wrong with my cancer is my own fault.	1	2	3	4	5	6
9	Luck plays a big part in determining how my cancer improves.	1	2	3	4	5	6
10	In order for my cancer to improve, it is up to other people to see that the right things happen.	1	2	3	4	5	6
11	Whatever improvement occurs with my cancer is largely a matter of good fortune.	1	2	3	4	5	6
12	The main thing which affects my cancer is what I myself do.	1	2	3	4	5	6
13	I deserve the credit when my cancer improves and the blame	1	2	3	4	5	6

	when it gets worse.						
14	Following doctor's orders to the letter is the best way to keep	1	2	3	4	5	6
14	Following doctor's orders to the letter is the best way to keep my cancer from getting any worse.	1	2	3	4	5	6
15	If my cancer worsens, it's a matter of fate.	1	2	3	4	5	6
16	If I am lucky, my cancer will get better.	1	2	3	4	5	6
17	If my cancer takes a turn for the worse, it is because I have not been taking proper care of myself.	1	2	3	4	5	6
18	The type of help I receive from other people determines how soon my cancer improves.	1	2	3	4	5	6

PPENDIX D: Abbreviated Version of Miller Behavioral Style Scale

Different people tend to respond in different ways when faced with difficult or threatening situations. The following four questions describe possible difficult situations, which you may encounter. Please consider each scenario and indicate how you think you would react.

1- Vividly imagine that you are afraid of the dentist and have to get some dental work done. Which of the following would you do? Tick **All** of the statements that might apply to you.

_____ I would ask the dentist exactly what he was going to do.

_____ I would take a tranquilizer or have a drink before going.

_____ I would try to think about pleasant memories.

_____ I would want the dentist to tell me when I would feel pain.

_____ I would try to sleep.

_____ I would watch all the dentist's movements and listen for the sound of the drill.

_____ I would watch the flow of water from my mouth to see if it contained blood.

_____ I would do mental puzzles in my mind.

2- Vividly imagine that, due to a large drop in sales, it is rumored that several people in your department at work will be laid off. Your supervisor has turned in an evaluation of your work for the past year. The decision about lay-offs has been made and will be announced in several days. Tick all of the statements that might apply to you."

_____ I would talk to my fellow workers to see if they knew anything about what the supervisor's evaluation of me said.

_____ I would review the list of duties for my present job and try to figure out if I had fulfilled them all.

_____ I would go to the movies to take my mind off things.

_____ I would try to remember any arguments or disagreements I might have had with the supervisor that would have lowered his opinion of me.

_____ I would push all thoughts of being laid off out of my mind.

_____ I would tell my spouse that I'd rather not discuss my chances of being laid off.

_____ I would try to think which employees in my department the supervisor might have thought had done the worst job.

_____ I would continue doing my work as if nothing special was happening

APPENDIX E: Patient Satisfaction regarding Genetic Testing

Please select the response that represents the extent to which you agree or disagree with the following statements:

1=Agree 2=Slightly agree 3=Slightly disagree 4=Disagree

I was given adequate information about the genetic test.

It was important to me to have received adequate information about the test.

I was satisfied with the information I received about the genetic test.

It was important to me to be satisfied with the information about the genetic test.

I am satisfied with my decision in having the genetic test.

I am satisfied with the way the results were disclosed to me.

Genetic testing had an impact on my treatment.

My genetic test result has affected my family planning (e.g. having children or marriage).

Having genetic testing was stressful for my family and me.

Was genetic testing offered at the appropriate time to you?

Yes No