J Genet Counsel (2009) 18:303–312
DOI 10.1007/s10897-009-9227-y

COMMENTARY

Risk Perception Among Women at Risk for Hereditary Breast and Ovarian Cancer

Robert Pilarski

Received: 11 December 2008 / Accepted: 18 February 2009 / Published online: 10 April 2009

Abstract This paper is a summation of selected history and literature on risk perception as it pertains to genetic counseling and testing, with a focus on hereditary breast and ovarian cancer, the area which has seen the greatest focus of research. Risk perception is a complex and incompletely understood concept which seeks to capture the myriad meanings that an individual attaches to the experience of being at increased risk. It is now evident that "risk", as perceived by the patient, is different from the objective, quantifiable risk estimate often provided to them during genetic counseling. What is also clear is that the complicated set of factors influencing risk perception are not yet well understood, nor are the mechanisms the lead from perceived risk to behavioral change in the patient. In situations where specific behavioral changes such as increased cancer screening are an inherent goal of the genetic risk assessment and counseling process, gaining a better understanding of the specific factors motivating change will be essential.

Keywords Risk perception · Risk construction · Hereditary breast cancer · Genetic counseling

Introduction

Since the identification in the mid 1990s of the *BRCA 1* and *2* genes, which are responsible for the Hereditary Breast and Ovarian Cancer syndrome, numerous genetic counseling clinics have been developed to assess, counsel, test and offer management guidelines to women with a possible hereditary predisposition to these cancers. Risk assessment is a major component of the services offered by these clinics: by assessing aspects of the family history, such as number of affected relatives, ages of diagnosis, and types of cancer, as well as pathological features of the cancers themselves, estimates can be made as to the probability that the cancers in the family are caused by mutations in one of the *BRCA* genes (Berliner and Fay 2007). Numeric risk is usually the focus in these assessments, with a number of tabular and computer models being available which can quantitate the chance of having a mutation (Antoniou et al. 2008). Women with approximately a 10% chance or greater of having a mutation are usually offered genetic testing.

Since women who inherit *BRCA* mutations have a 50–85% lifetime risk of developing breast cancer and a 20–40% risk of developing ovarian cancer (Levy-Lahad and Friedman 2007), aggressive management guidelines have been developed (National Comprehensive Cancer Centers, 2008). For breast cancer risk these include annual mammograms and breast MRI beginning at age 25, and consideration of preventive methods such as chemopreventive drugs (e.g., tamoxifen) and prophylactic mastectomy. Given that there are no effective screening methods for ovarian cancer (which is thus usually diagnosed at an untreatable stage), management recommendations call strongly for removal of the ovaries between ages 35 and 40 in order to prevent the disease. A growing body of data supports the effectiveness of breast MRI combined with mammography (Granader et al. 2008) and preventive measures such as prophylactic surgery (Bermejo-Perez et al. 2007).

An underlying assumption of hereditary cancer risk assessment and testing programs is that women at "high enough" objective risk for cancer will tend to comply with

R. Pilarski (✉)
Clinical Cancer Genetics Program,
James Comprehensive Cancer Center, Ohio State University,
2250 Kenny Road, Room 808,
Columbus, OH 43221, USA
e-mail: robert.pilarski@osumc.edu

recommendations for increased screening. Yet the relationship between objective risk and risk as it is perceived by patients is complex and not completely understood. And even less is often understood by practitioners in clinical practice about how women interpret their risk, and how this risk perception affects screening behaviors and compliance with screening recommendations. Nonetheless there is some data, reviewed below, to suggest that perceived risk may influence a number of psychosocial factors for those at-risk for genetic diseases, and may also affect choices to access genetic testing and preventive care; inaccurate risk perceptions may also lead to inappropriate choices regarding potentially risky preventive surgeries such as mastectomy and oophorectomy (see Sivell et al. 2008, Heshka et al. 2008). The importance of perceived risk has been highlighted by its critical placement in a number of theoretical constructs addressing health behaviors, such as the Health Belief Model (Rosenstock 1966).

This paper summarizes a selected set of articles on risk perception in the context of women at increased risk for breast and ovarian cancer, and what is known about determinants of screening behavior.

Methodology

The published literature was surveyed using searches of electronic databases including Medline, the ISI Citation Databases covering psychology and the social sciences, EBSCOhost social work abstracts, and PsycINFO (1967 — present). Search keywords included combinations of heredity/hereditary, family history, genetics, counseling, breast cancer, BRCA1/2, risk perception, perceived risk, model (s), screening and behavior. Additional articles were found through searches of references cited in the articles identified through the database searches. Articles were included if they specifically and significantly addressed the topic of risk perception in the context of hereditary risk (particularly as related to the risk for breast cancer) and built upon other findings in the literature. Articles covering primary research, literature reviews and conceptual modeling were included. This paper was not designed to be an exhaustive analysis of the literature but rather a focused summary of key concepts in the area of interest.

Historical Overview of the Concept of "Risk" in a Genetic Counseling Context

Just prior to the identification of the BRCA genes, Palmer and Sainfort (1993) reviewed the history of the conceptualization and operationalization of "risk" in the context of genetic counseling. They noted that prior to 1979 genetic risk was usually defined and operationalized simply as the objective probability of that risk. During this era the focus for genetic risk assessment was on the possibility that a child (or another child) that a couple might have would be affected with a genetic disease — i.e., the chance that a genetic event would occur/recur. Genetic counseling was seen, in part, as the provision of that occurrence/recurrence risk probability, and the risk probability was felt to be the primary component of the person or couple's decision-making process. "The cornerstone of this characterization was the belief that the magnitude of the recurrence risk had an inherent meaning of high, medium, or low, which was invariant across observers and diseases" (Palmer and Sainfort 1993, p. 276). The general assumption was that genetic counseling promoted *rational* decision-making by counselees regarding their reproductive choices — choices which were based on the quantitative risk level. Couples with a high numerical risk were generally expected to avoid having further children, while those with low numerical risks were not. During this period Leonard et al. (1972) did find evidence that the "burden" of the disease was a separate variable impacting decision-making. For the most part, however, this was addressed by controlling for "burden" in research studies by only studying a single (or similar) disease at a time. Even with burden controlled for, studies from this period failed to show a clear relationship between risk level and reproductive choices. This eventually led to a re-evaluation and refocusing of the practice of genetic counseling to emphasize its role in helping couples make the *best decision for their situation,* rather than a "correct", *rational* decision.

Beginning with a seminal series of papers in 1979 by Lippman-Hand and Fraser (1979a, b, c, d) the practice of genetic counseling (and the published literature) began to incorporate the counselee's perspective as the field began to emphasize the psychosocial aspects of genetic risk. The focus of research increasingly came to be on *how* counselees arrived at their reproductive decisions. Lippman-Hand and Fraser noted that counselees often converted risk figures into subjective categories of high, medium and low. They also suggested that counselees often used heuristics to simplify the complicated probability information they were given and thus interpreted their risks in binary form — either it will happen or it won't. They could then mentally construct the worst-case scenario of the risk event occurring, and gauge the acceptability of this to themselves. This and subsequent work led to a better understanding that the same quantitative risk could be interpreted in different ways by different subjects, which in turn led to efforts to understand the determinants of risk interpretation. After 1979 "risk perception"— the patient's *subjective* interpretation of risk — increasingly became the focus of research in the field of genetic counseling. This

work has focused on achieving a better understanding of the relationship between objective risk and perceived risk, and of how people process risk information, how they arrive at a personal risk perception, and how this perception influences subsequent decisions and health behaviors. It should also be noted that since the 1980s the identification of the genes for an ever increasing number of adult onset conditions has expanded the focus of genetic counseling from reproductive decision-making regarding risks for birth defects to a host of medical management decisions that can impact the chance of developing adult onset diseases. These include the hereditary cancer syndromes such as the Hereditary Breast/Ovarian Cancer syndrome, the focus of this paper.

How is Hereditary Cancer Risk Perception Constructed?

> Understanding the meanings people attribute to genetic predisposition to cancer requires an analysis of the ways in which genetic risk information affects people individually, within their families and communities and in their social lives. (d'Agincourt-Canning, 2005, p. 55).

There is now ample evidence that for members of high-risk families genetic risk is not a simple, objective, numerical value but rather it is an evolving, subjective, experienced reality. In a qualitative study of women with family histories of breast cancer Chalmers and Thomson (1996) and Chalmers, Thomson and Degner (1996) found evidence that living with risk was an ongoing experience which led over time to a subjective development of one's sense of risk. They identified three phases that women go through in forming a personalized view of their risk for breast cancer: 1) living the breast cancer experience through the affected relative's experience; 2) developing a risk perception; and 3) putting risk in its place:

> In the first phase…, the woman vicariously lived the cancer illness through her relative's experience. … Resolution allowed the woman to personally separate from her relative's experience and begin to shape an articulation of her own vulnerability to breast cancer... [In] the second phase… the woman attempted to articulate her personal vulnerability to breast cancer by assessing the significance of her biology (i.e., age, family history, etc.) and by appraising her own threatening experiences with breast lumps or other bodily abnormalities... In the third and final phase…, the perception of cancer risk was integrated into the woman's sense of self. Cancer risk was acknowledged and managed mentally and practically by exerting control through cognitive processes (such as mentally rehearsing her possible future breast cancer experience) and self-care practices (e.g., BSE). Putting risk in its place was not a permanent state, nor was it experienced by all women. Women with unresolved issues from the earlier phases… experienced difficulty putting risk in its place. Adapting to the threat of breast cancer was a complex process of constructing, and coping with, a personal sense of vulnerability to breast cancer (Chalmers et al. 1996, p. 206).

In this context, numerous investigators have explored risk perception in genetic contexts in general, and in the context of hereditary breast and ovarian cancer risk specifically. As noted by Sivell et al. (2008) in their systematic review of the literature on perceived genetic risk, however, the definition and operationalization of "perceived risk" has varied across studies, as did the ways in which it was measured. In the vast majority (35 of 38) of the studies they reviewed, the nature and accuracy of perceived risk was assessed in quantitative terms, usually by comparing the patient's numerical estimate of their risk to the objective risk estimate calculated by the genetic counselor or physician. Risk perception was assessed at varying time points in different studies, and in some cases it was assessed only once, making it difficult to draw causal inferences.

Bottorff et al. (1998) noted that while "risk" is operationalized in medicine as the statistical measure of the chance of an event occurring, in reality it is not a unidimensional concept and the general public attaches many meanings to the term. A qualitative study by Parsons and Atkinson (1992), for example, found that women in families with Duchene Muscular Dystrophy tended to reduce numerical risk information into ordinal or categorical terms ("high"/"low", "bad"/"not so bad", etc.), with risks below 5% seen as low, and risks above 20% seen as high. They noted that women tended to transform their risk information in the direction of greater certainty, turning the probabilistic risk figures they were given into definitive categories by conceptualizing themselves, for example, as "being a carrier" or "not being a carrier", or "being able to have boys" or "not being able to have boys". For those women who did state a numerical risk their recall of it was frequently inaccurate. Similarly, Lippman-Hand and Fraser (1979a), as noted above, found risk information to be transformed into dichotomous terms (either "it will happen" or "it won't happen"). As noted by Parsons and Atkinson, "It is not often that the interpretation of levels of measurement, and the translation of one level into another, is a problematic issue for the social actors who are the

subject matter of the research. In the case of genetic risk, however, it is especially pertinent" (Parsons and Atkinson 1992, p. 453). The interpretation of one's risk level as "high' or "low" thus lies within the subject themselves, but in the process of transforming numeric to subjective risk, information is lost, and the perceived risk may not necessarily correspond with the objective risk. Sivell et al. (2008), for example, found that in most studies they reviewed the majority of the participants overestimated their risk of developing cancer.

Bottorff et al. (1998) reviewed the literature addressing factors which can influence a person's perception of risk, including cognitive and social biases. *Cognitive biases* which affect risk perception may include the person's prior assumptions about their risk status, their general emotional outlook (e.g., pessimistic vs. optimistic), and their sense of "locus of control" (e.g., whether they feel that they may be able to modify their lifestyle to overcome genetic risk or whether they view genetic risk as a destiny that they cannot alter). This has been framed as: "risks that are viewed as controllable or voluntary are viewed as more acceptable and less risky than involuntary, uncontrollable exposures. The public is more willing to tolerate far greater risks or hazards when their own choice is involved, as in smoking cigarettes or climbing mountains" (Jacobs 2000, p. 3). *Social biases* which may also affect risk perception include one's family history (having seen loved ones struggle and perhaps die with cancer), causal schemas of one's own and one's family's vulnerability (feeling doomed by one's family legacy), and one's understanding of the level of risk in the general population. As noted by Jacobs (2000):

> Risk is a social and cultural construct. The selection of risks deemed to be hazardous to a population is a social process. These risks may have no relation to real danger, but they are culturally identified as important. Cultural systems create collective notions of risk and play an important role in evaluating which risks are worth taking (gamble), who should take them, who is accountable for them, and whether a specific danger is possible to control. (p. 13)

The experience of living with a family history of cancer has been shown in a number of qualitative studies to have a highly significant impact on one's perception of risk. Kenen et al. (2003) studied 21 women from families with breast and/or ovarian cancer who presented for evaluation at hereditary cancer clinics. Their findings indicated that women filtered and integrated the risk information they were given in the clinic with their prior beliefs and feelings about their risks. These beliefs and feelings were derived from their experiences with their family history and the individuals in it who had had cancer, which served as reference points for their integrated risk perception. Both the number of relatives affected with cancer and the nature of the women's experiences with their relative's cancer impacted on their perception of their own risk. McAllister (2003) discussed how "lay models of inheritance" are commonplace in society and often provide schemas to explain the transmission of physical and behavioral traits within families (e.g., "she takes after…"). Working with individuals at 25 to 50% risk for another hereditary cancer syndrome (Hereditary Nonpolyposis Colon Cancer), she found that one-third of these family members, going beyond these socially constructed lay models of inheritance, drew on their own life experiences to form a "personal theory of inheritance". These personal theories were used by women to explain their own beliefs that they either did or did not carry the family's gene mutation. She noted that "their personal experience was what made certain aspects of the family history more salient to them in constructing an explanation of the family history that was meaningful to them" (McAllister 2003, p. 185). The personal theories of inheritance that the women developed included beliefs that the syndrome was co-inherited with either some other physical characteristic, a specific gender, birth order, a shared blood group, etc. These personal beliefs played a significant role in women's risk perceptions despite the fact that they at times contradicted established biological patterns of inheritance. The power of the family history experience in shaping risk perceptions was further demonstrated by Geller et al. (1997) through their focus groups with women concerning testing for hereditary breast and ovarian cancer. They too noted that women's personal experiences with cancer in their family significantly impacted their perception of their risk. Importantly, they noted that some women were unwilling to accept the objective risk estimate given them if it was not consistent with their experience of their personal and/or family history of cancer.

d'Agincourt-Canning (2005) reviewed the literature suggesting that women with family histories of cancer have high levels of anxiety and distress, persistent and intrusive thoughts about developing breast cancer, and an increased sense of vulnerability to the disease, and that family history shapes women's attitudes and motivations toward genetic testing. She then used qualitative research methods to study the experiences of 45 subjects at risk for hereditary breast and ovarian cancer. She sought to explore how family history and subjective experiences create "experiential knowledge" which impacts women's perceptions of their cancer risk. Experiential knowledge is thus defined as "not just an abstract product based on rationality and objective determination of truth, but is a process that emerges and is shaped by the identity, circumstances, experiences and interests of the knower" (d'Agincourt-Canning 2005, p. 57). Building on prior work in the field, she used the

division of experiential knowledge into two types. *Empathetic* knowledge is derived from close association with others going through an experience — in this case from experiencing a relative having cancer, which might range in intensity from direct caregiving for a loved one who dies to having only heard family stories about the affected person's experience. *Embodied* knowledge is derived from actually going through the experience yourself — in this case being diagnosed with cancer and going through the experience of treatment. For a disease like breast cancer, the empathetic knowledge gained by caring for a sister or mother fighting breast cancer can be just as powerful as the embodied knowledge gained from fighting cancer yourself. d'Agincourt-Canning found that both types of experiential knowledge were important, with both family history and personal cancer experiences impacting on a woman's risk perception. In these families with potentially hereditary cancer, many women equated a cancer diagnosis with death, but this was often based more on their family's experience with cancer than on the existing medical statistics regarding breast cancer survival. On the other hand, other women might develop a more optimistic outlook on breast cancer based on having seen multiple family members survive their diagnosis. As with Geller et al. (1997), d'Agincourt-Canning's work indicated that knowledge derived from experience often took precedence over the objective clinical estimates of cancer risk provided through genetic counseling, suggesting that counseling approaches which are grounded in the patient's own experience of the disease may lead to more effective communication of genetic risk.

The Use of Heuristics and Other Factors in the Processing of Genetic Risk Information

Genetic risk estimates are complex and are based on probabilistic information which most people have little experience processing. A number of studies indicate that women have difficulty understanding the probabilistic risk information they are given in genetic counseling (see for example Lippman-Hand and Fraser, 1979a and 1979b; Kenen et al. 2003). A number of authors have used the concept of heuristics to explain the actual processes that individuals go through in constructing their own risk perceptions under these complicated circumstances (Wertz et al. 1986; Rees et al. 2001; Palmer and Sainfort 1993; Shiloh 1994; Kenen et al. 2003; Gerund et al. 2004; Peters et al. 2006). As defined by Peters et al. (2006), heuristics are mental shortcuts or "rules of thumb" that people consciously or unconsciously use to help themselves simplify and expedite decision-making processes when faced with complex and ambiguous or uncertain information. "People are limited by time, their cognitive and computational abilities… and their environment... [B]ecause people often do not know what they value or prefer, they tend to construct judgments 'on the spot'…" (Peters et al. 2006, p. 46). Research on decision-making suggests that people tend to process information using two distinct modes: deliberative (which is analytical, reason-based, and slower) and experiential (which is automatic, based on associations, and faster). It is the experiential mode of thinking that relies on heuristics to simplify and highlight important information. While the deliberative mode may seem to be more accurate, "research suggests that intuitive processes… may have greater influence when deliberative capacity is diminished because of cognitive constraints…" such as are faced when dealing with complicated genetic risk information (Peters et al. 2006, p. 46).

Peters et al. (2006), Kenen et al. (2003), Rees et al. (2001) and others have all reviewed the heuristics commonly used in the context of genetic risk. The *Affect* heuristic addresses the feeling of "goodness" or "badness" associated with an experience, and the strength of that feeling. The mind relies on these associated feelings to assign importance and simplify complex decisions and judgments. Because cancer is a dreaded disease the strong affective reaction to it (especially by those who have experienced cancer themselves or in their family) may thus overshadow a relatively low objective cancer risk; i.e., the low affect associated with the statistical information given in genetic counseling is unable to override the high affect associated with the woman's risk perception based on her lived experience. "Genetic risk counseling has been shown to improve significantly the accuracy of risk perception, but up to… two-thirds of US women continue to report exaggerated risks of cancer" (Hopwood 2000, p. 388). The affect heuristic also implies that how risk is framed and communicated may impact risk perception. As shown by Slovic et al. (1982), for example, a person is much more likely to be concerned with being told that their risk is 30% higher than an average person, than by being told that their risk is 1.3 per 10,000 compared to 1 per 10,000 in the general population. Watson et al. (1998) found that in genetic counseling for breast cancer risk, risk figures given as an odds ratio were recalled better than risk figures given in other forms.

With the second heuristic, *Representativeness*, people assess their risk for something based on their perception of their similarity (or difference) to their stereotype of the type of person who they think typically has that experience. In the case of breast cancer, Gerund et al. (2004) found that women's perceived risk to get breast cancer was gauged in part (along with their perceived prevalence of the disease) by their sense of how similar they were to the "typical" woman who gets breast cancer. It is important to note that

this heuristic could apply to perceptions of who usually gets breast cancer in the general population as well as to who they think usually gets breast cancer within their family.

The *Availability* heuristic refers to the fact that a person's estimate of the probability of an event is related to the ease with which they can recall or picture from memory an occurrence of that event. Playing into this is the vividness or intensity of the event, which makes it easier to be recalled. Women with a close family history of breast cancer are thus more likely to perceive themselves to be at increased risk (often well above their objective risk) than women without a close affected relative (McCaul et al. 1998). It also explains why people are often more concerned about their chance of developing a particular disease after the extensive media coverage that often follows when a well known celebrity has been diagnosed with that disease.

The final heuristic, termed *Anchoring and Adjustment*, refers to the tendency for decision-makers to be affected by available (but not necessarily relevant) numbers that they consciously or subconsciously have associated with the event in question. Their risk perception is adjusted relative to the "anchor" of that associated statistic or risk. In the context of genetic risk, for example, this could mean that an overly high prior risk perception based on one's family history experience affects the woman's perception of a much lower objective risk estimate given during genetic counseling, to the extent that the objective risk estimate is heard but not accepted. Ekwo et al. (1985) and Watson et al. (1998), for example, both found little or no relationship between the accuracy of the objective risk recalled by a person and their subjective perception of their risk.

In addition to the use of heuristics, a number of other factors have been suggested to impact the construction of risk perception. Schwartz et al. (1995) found that among first degree relatives of patients with ovarian cancer, a higher monitoring attentional style (the tendency to scan the environment for information relevant to a perceived threat) was associated with both higher perceived risk and higher levels of psychological distress and intrusive thoughts. These results were felt to parallel the findings from research in other settings and were consistent with expectations from the Monitoring Process Model. Rees, Fry and Cull (2001) discussed how two other phenomenon may also impact risk perceptions. Misunderstandings about genetics are common, with many women expressing a sense that they are more likely to get breast cancer because they are "just like" a relative who also developed it, whether that be physical resemblance, similar personality traits, closeness to the age that their relative was diagnosed, birth order, or otherwise. The nature of peoples' beliefs and perceptions about the illness itself can also impact risk perception. These "illness representations", according to Leventhal's Common Sense Model of self-regulation of health and illness (Leventhal et al. 1980), mediate our reactions to perceived health threats. Such illness representations are developed from a range of influences, including personal experiences, media, family, friends, and culture. Five dimensions of illness representation have been identified, including the nature of the threat, its cause, its timeline (duration and progression), its consequences, and its controllability. For genetic risks, family history experiences can play a major role in the development of all five of these dimensions of illness representations. Sivell et al. (2008) found that, although most studies on cancer risk perception were not grounded in a theoretical framework, there was greater evidence supporting the Common Sense Model in the published literature than for any other model. Decruyenaere et al. (2000) and Marteau and Weinman (2006) have both used the model in theoretical discussions of how genetic risk information might be expected to motivate behavior changes aimed at reducing risk.

Why is Risk Perception Important?

Far from being an isolated, objective variable in the genetic decision-making process, perceived risk has been shown to impact a range of psychosocial factors for those at-risk for genetic diseases, and may also impact whether individuals access genetic testing and health/preventive services and comply with screening recommendations. There is also evidence that inaccurate risk perceptions may lead to inappropriate health management choices, such as decisions to pursue potentially risky preventive surgeries (mastectomy and oophorectomy) despite a low objective risk. The importance of perceived risk has been highlighted by its critical placement in a number of theoretical constructs addressing health behaviors, many of which assume that individuals make decisions regarding health-related behaviors based on rational analyses of risks and benefits. One of the best known of these is the Health Belief Model (HBM), initially proposed by Rosenstock (1966) and further modified over time. The HBM proposes that one's likelihood of adopting a health behavior aimed at preventing an illness or threat is related to four variables: 1) the perceived susceptibility to that threat; 2) the perceived severity/burden of that threat; 3) the perceived benefits of adopting the preventive behavior; and 4) the perceived costs of adopting the behavior. If the perceived susceptibility (risk) and severity of the illness are high, while the perceived benefits of adopting the behavior are seen to be greater than the perceived costs, the behavior is more likely to be adopted. Once these factors are in place, however, the actual behavior is felt to be triggered by cues to action, which could be anything from personal symptoms or a

relative being diagnosed to health messages received through providers or the media.

The relationship between perceived risk (susceptibility) and cancer-related distress or anxiety has also been explored by a number of investigators. Cancer-related distress, worry or anxiety can be seen as part of the perceived severity of being at-risk for the disease, while its reduction can be seen as part of the perceived benefit of undertaking a risk-reducing behavioral change. van Dooren et al. (2004), in studying women at increased risk for breast cancer, distinguished between cognitive risk (the numerical risk that subjects would quote) and affective risk (how they felt about their risk). They found that affective risk had a greater impact on distress than cognitive risk, and that women with a higher affective risk perception had higher general and cancer-specific distress. Similarly, Lloyd et al. (1996) and Watson et al. (1998) both found that cancer worry was more strongly associated with perceived risk than objective risk. Katapodi et al. (2004), in a meta-analysis of the literature, found that in all seven studies in which it was addressed, higher perceived risk was associated with a higher negative emotional response (worry, anxiety, concern) to breast cancer. More recently, however, Price et al. (2007) found that although perceived risk acted independently of other factors in determining cancer worry, it was not the primary determinant and in fact was only one of many factors (including family experiences with breast cancer) that together influenced cancer worry. In fact, level of general anxiety (which in turn was correlated with perceived risk and other factors) was the single strongest predictor of cancer worry in their cohort.

The relationships between cancer worry, perceived risk, and screening compliance are complicated. Sivell et al. (2008) reviewed twelve studies that addressed the effect of perceived risk on use of services (genetic testing, screening and surveillance, and prophylactic surgery) and concluded that the existing evidence was weak and sometimes contradictory. Some studies have suggested that increased levels of cancer-related distress or worry are actually associated with decreased levels of screening compliance (see for example, Kash et al. 1992; Lerman and Schwarz 1993). Heshka et al. (2008) also reviewed the literature on the impact of genetic testing (primarily for hereditary cancer syndromes and Alzheimer disease) on perceived risk, emotional state, and health behaviors. They concluded that the current evidence suggests that genetic testing did not change perceived risk and had little or no long term impact on psychological outcomes or health behaviors. On the other hand Meiser et al. (2000) found that among high-risk women the intention to undergo prophylactic mastectomy was highly associated with higher cancer anxiety and perceived risk, but not with objective risk. Fang et al. (2003) found a similar association between higher perceived risk and intention to undergo preventative removal of the ovaries. Similarly, Metcalfe and Narod (2002) found that almost all women (except those with *BRCA* gene mutations) who chose to undergo prophylactic mastectomy significantly overestimated their objective risk of developing breast cancer, both before and after their surgery, suggesting that the surgical decision was driven by a higher perceived risk. The meta-analysis by Katapodi et al. (2004) found that while most studies showed a positive association between perceived risk and mammographic screening, the association with breast self-examination was less clear, with two studies finding a positive association and two a negative one. Overall they felt that the literature showed inconsistent findings regarding the relationship between risk perception and use of screening and preventive services.

While the Health Belief Model has been shown to predict many health-related behaviors, its effectiveness in predicting breast cancer screening behaviors in high risk women has been mixed, as reviewed by Rees et al. (2001). These authors suggested that this may be because it is the subjective experience of cancer in the family, rather than the mere presence of a family history of cancer, that is correlated with adopting screening behaviors. Marteaux and Lerman (2001) conducted a review of the literature on behavioral responses to genetic risk information. They noted that changing health-related behavior is difficult, and is rarely accomplished simply by informing people that they are at increased genetic risk. In some cases it may even backfire if it leads people to feel that there is nothing that they can do to alter their genetic destiny. Furthermore, interventions that are designed to induce behavioral change are seldom effective. They concluded that people's motivation to change behavior could best be increased by both strengthening their belief that the behavior change would reduce risk (i.e., increasing the perceived benefit) and strengthening their belief in their own ability to make that behavioral change. Similarly, Shiloh and Ilan (2005) investigated interest in genetic testing among women at risk for hereditary breast cancer and found evidence that perceived risk is necessary, but not sufficient, to motivate health behaviors. Their work suggested that health behaviors can be motivated by convincing the participant that the behaviors will both reduce risk and reduce the fear the person faces — i.e., that it will provide both prevention and reassurance.

The Effect of Genetic Counseling on Perceived Risk

While one of the goals of genetic counseling is to impart accurate risk information to the counselee, the data are mixed as to how effectively this is achieved. As noted above, an analysis of the literature by Sivell et al. (2008) found that most people overestimate their risk to develop breast cancer. Although they found some evidence in the

literature that genetic counseling did move patients' self-reported risk estimates closer to their true objective risk, the finding was not consistent. They also found that overall patients had a poor recall of the objective risk figure given to them in the counseling session. Butow et al. (2003) reviewed the literature on risk perception after genetic counseling for breast cancer risk. They found that although genetic counseling and testing appeared to produce short term improvement in the accuracy of risk perception, 22–50% of women still overestimated their risk immediately after counseling; longer term follow-up tended to show no changes in accuracy or maintenance of improvement. They concluded that genetic counseling was "reasonably successful" in educating women about their risk. Watson et al. (1998) found that women overall had a poor recall of the objective breast cancer risk they were given during their genetic counseling sessions, despite being given audiotapes of their actual sessions. In addition, they found a poor correlation between the objective risk level a woman recalled and her own perceived risk of developing breast cancer, such that accurate recall of the numerical risk didn't mean that the woman had an accurate perception of the magnitude of her risk. The authors felt that while the assumption of the genetic counselor or physician is that patients want risk levels given, the actual evidence suggests that what patients want from the session is quite different. They surmised that having a precise risk figure is less important to women than having a general perception of their risk and a sense that a system is in place to manage their risk. Interestingly, Bjorvatn et al. (2007), studying individuals at risk for colon, breast or ovarian cancer, found that patients and counselors had fairly close agreement after counseling as to the patient's numerical risk level. However they significantly differed on how they verbally rated the patient's risk relative to an average person of the same age and gender. Patients more often underestimated their relative risk, and did so somewhat more after genetic counseling than before. Highlighting again the difference between objective and perceived risk, various patients associated a perceived numerical risk of a 50% lifetime risk for cancer with all the verbal risk categories offered, ranging from "unlikely" to "no doubt" that cancer would occur. "This suggests that a counselor will not really know what is meant by "high risk", even if the patient provides the counselor with a percentage risk figure" (Bjorvatn et al., 2007, p. 218).

Conclusions

> Risk magnitude is only one characteristic of risk assessment… It is important to incorporate this with individuals' understanding of risk information, their beliefs about risk, perceived risk factors, and emotional aspects related to their risk status… (Sivell et al. 2008, p. 56).

Risk perception is a complex and incompletely understood concept which seeks to capture the myriad meanings and weights that an individual attaches to the experience of being at increased risk. While genetic counseling can now fairly easily provide the objective risks estimates for women at risk for hereditary breast cancer, the patients themselves must use their own cognitive and emotional resources to determine what that objective risk means to them — i.e., how they will perceive that risk. What is increasingly clear is that it is the woman's perceptions — of her degree of risk for cancer, and the implications of developing cancer — that most impact her psychological reactions and resultant health behaviors.

An accurate perception of risk is felt to be important for motivating appropriate screening and prevention behaviors in at-risk women. Metcalfe and Narod (2002) found that 24% of their cohort of women who had undergone preventive mastectomy were not considered to be at high objective risk. All of these women had overestimated their risk for developing cancer. Yet the literature suggests that accurate risk perceptions are hard to achieve. Individuals are generally inaccurate in their numerical estimate of their objective cancer risk, and in any case this estimate, whether accurate or not, correlates poorly with how they perceive their risk relative to others in the population. Objective risk estimates are inconsistently influenced by genetic counseling, and people often have poor recall of the objective risk estimates given to them in the counseling session.

The literature also suggests that the perception of risk may have broad impact on both psychological parameters (anxiety, worry, distress) and risk management behaviors (preventive measures such as surgery, health screening, and lifestyle changes) for those at risk. It is thus the key role of the counseling component of cancer genetic counseling to carefully address the process of risk construction with individual patients, with the goals of both addressing the resulting psychological needs, and of guiding and influencing subsequent risk-reducing behaviors. There is some information in the literature to guide those working with this patient population, suggesting that we should be focusing less on numeric risk levels and more on assessing and understanding how each individual patient is perceiving and acting on that risk. Simply getting the patient to state their numeric risk as they understand it is not the answer, however, since patients have been shown to attribute widely varying subjective risk levels to the same degree of numeric risk. A more affective approach will be to ascertain what that level of risk means to each particular patient, and how they plan to act upon it.

While we have come a long way since the days when risk was seen simply as a static, objective, numerical figure, clearly much still remains to be determined about the process of constructing risk perception, and how that can be influenced when necessary. Areas for future research in this area should include:

- Identifying better ways to measure or assess perceived risk consistently and accurately so that findings may be compared and correlated across studies.
- Identifying ways to assess individual patients to determine which method to use to present risk information in a way that they will best understand it.
- Developing a better understanding of the relationships between perceived risk and resultant patient health behaviors.
- Identifying better ways to influence perceived risk when it contradicts objective risk and may lead to inappropriate medical decisions.
- Determining how best to influence health behaviors through utilization of the patient's risk perception.

As noted by Sivell et al. (2008): "Understanding the ways in which perceived risk acts as a motivator will help to tailor risk communication and genetic counseling appropriately, particularly for individuals whose pre-conceived perceptions of risk may be resistant to the standard education and counseling approaches undertaken in clinical genetics" (p. 31).

References

Antoniou, A. C., Hardy, R., Walker, L., Evans, D. G., Shenton, A., Eeles, R., et al. (2008). Predicting the likelihood of carrying a BRCA1 or BRCA2 mutation: validation of BOADICEA, BRCAPRO, IBIS, Myriad and the Manchester scoring system using data from UK genetics clinics. *Journal of Medical Genetics*, *45*(7), 425–431. doi:10.1136/jmg.2007.056556.

Berliner, J. L., & Fay, A. M. (2007). Risk assessment and genetic counseling for breast and ovarian cancer: recommendations of the National Society of Genetic Counselors. *Journal of Genetic Counseling*, *16*, 241–260. doi:10.1007/s10897-007-9090-7.

Bermejo-Perez, M. J., Marquez-Calderon, S., & Llanos-Mendez, A. (2007). Effectiveness of preventive interventions in BRCA1/2 gene mutation carriers: a systematic review. *Journal of Cancer*, *121*(2), 225–231.

Bjorvatn, C., Eide, G. E., Hanestad, B. R., Oyen, N., Havik, O. E., & Carlsson, A. (2007). Risk perception, worry and satisfaction related to genetic counseling for hereditary cancer. *Journal of Genetic Counseling*, *16*(2), 211–222. doi:10.1007/s10897-006-9061-4.

Bottorff, J. L., Ratner, P. A., Johnson, J. L., Lovato, C. Y., & Joab, S. A. (1998). Communicating cancer risk information: the challenges of uncertainty. *Patient Education and Counseling*, *33*, 67–81. doi:10.1016/S0738-3991(97)00047-5.

Butow, P. N., Lobb, E. A., Meiser, B., Barratt, A., & Tucker, K. M. (2003). Psychological outcomes and risk perception after genetic testing and counseling in breast cancer: a systematic review. *The Medical Journal of Australia*, *178*, 77–81.

Chalmers, K., & Thomson, K. (1996). Coming to terms with the risk of breast cancer: perceptions of women with primary relatives with breast cancer. *Qualitative Health Research*, *6*, 256–282. doi:10.1177/104973239600600207.

Chalmers, K., Thomson, K., & Degner, L. F. (1996). Information, support, and communication needs of women with a family history of breast cancer. *Cancer Nursing*, *19*(3), 204–213. doi:10.1097/00002820-199606000-00007.

D'Agincourt-Canning, L. (2005). The effect of experiential knowledge on construction of risk perception in hereditary breast/ovarian cancer. *Journal of Genetic Counseling*, *14*(1), 55–69. doi:10.1007/s10897-005-1500-0.

Decruyenaere, M., Evers-Kiebooms, G., Welkenhuysen, M., Denayer, L., & Claes, E. (2000). Cognitive representations of breast cancer, emotional distress and preventive health behaviour: a theoretical perspective. *Psycho-Oncology*, *9*, 528–536. doi:10.1002/1099-1611(200011/12)9:6<528::AID-PON486>3.0.CO;2-#.

Ekwo, E. E., Seals, B. F., Kim, J.-O., Williamson, R. A., & Hanson, J. W. (1985). Factors influencing maternal estimates of genetic risk. *American Journal of Medical Genetics*, *20*, 491–504. doi:10.1002/ajmg.1320200310.

Fang, C. Y., Miller, S. M., Malick, J., Babb, J., Engstrom, P. F., & Daly, M. B. (2003). Psychosocial correlates of intention to undergo prophylactic oophorectomy among women with a family history of ovarian cancer. *Preventive Medicine*, *37*, 424–431. doi:10.1016/S0091-7435(03)00163-4.

Geller, G., Strauss, M., Bernhardt, B. A., & Holtzman, N. A. (1997). "Decoding" informed consent. Insights from women regarding breast cancer susceptibility testing. *The Hastings Center Report*, *2*(2), 28–33. doi:10.2307/3527625.

Gerund, M. A., Aiken, L. S., West, S. G., & Erchull, M. J. (2004). Beyond medical risk: investigating the psychological factors underlying women's perceptions of susceptibility to breast cancer, heart disease and osteoporosis. *Health Psychology*, *23*(2), 247–258. doi:10.1037/0278-6133.23.3.247.

Granader, E. J., Dwamena, B., & Carlos, R. C. (2008). MRI and mammography surveillance of women at increased risk for breast cancer: recommendations using an evidence-based approach. *Academic Radiology*, *15*(12), 1590–1595. doi:10.1016/j.acra.2008.06.006.

Heshka, J. T., Palleschi, C., Howley, H., Wilson, B., & Wells, P. S. (2008). A systematic review of perceived risks, psychological and behavioral impacts of genetic testing. *Genetics in Medicine*, *10*(1), 19–32. doi:10.1097/GIM.0b013e31815f524f.

Hopwood, P. (2000). Breast cancer risk perception: what do we know and understand? *Breast Cancer Research*, *2*, 387–391. doi:10.1186/bcr83.

Jacobs, L. A. (2000). An analysis of the concept of risk. *Cancer Nursing*, *23*(1), 12–19. doi:10.1097/00002820-200002000-00003.

Kash, K. M., Holland, J. C., Halper, M. S., & Miller, D. G. (1992). Psychological distress and surveillance behaviors of women with a family history of breast cancer. *Journal of the National Cancer Institute*, *84*, 24–30. doi:10.1093/jnci/84.1.24.

Katapodi, M. C., Lee, K. A., Facione, N. C., & Dodd, M. J. (2004). Predictors of perceived breast cancer risk and the relation between perceived risk and breast cancer screening: a meta-analytic review. *Preventive Medicine*, *38*, 388–402. doi:10.1016/j.ypmed.2003.11.012.

Kenen, R., Ardern-Jones, A., & Eeles, R. (2003). Family stories and the use of heuristics: women from suspected hereditary breast and ovarian cancer (HBOC) families. *Sociology of Health & Illness*, *25*(7), 838–865. doi:10.1046/j.1467-9566.2003.00372.x.

Leonard, C. O., Chase, G. A., & Childs, B. (1972). Genetic counseling: a consumer's view. *The New England Journal of Medicine*, *287*, 433–439.

Lerman, C., & Schwarz, M. (1993). Adherence and psychological adjustment among women at high risk for breast cancer. *Breast Cancer Research and Treatment*, *28*, 145–155. doi:10.1007/BF00666427.

Leventhal, H., Meyer, D., & Nerenz, D. (1980). The common sense representation of illness danger. In S. Rachman (Ed.), *Contributions to medical psychology*. Oxford: Pegamon.

Levy-Lahad, E., & Friedman, E. (2007). Cancer risks among BRCA1 and BRCA2 mutation carriers. *British Journal of Cancer*, *96*, 11–15. doi:10.1038/sj.bjc.6603535.

Lippman-Hand, A., & Fraser, F. C. (1979a). Genetic counseling: provision and reception of information. *American Journal of Medical Genetics*, *3*, 113–127. doi:10.1002/ajmg.1320030202.

Lippman-Hand, A., & Fraser, F. C. (1979b). Genetic counseling — The postcounseling period: I. Parents' perceptions of uncertainty. *American Journal of Medical Genetics*, *4*, 51–71. doi:10.1002/ajmg.1320040108.

Lippman-Hand, A., & Fraser, F. C. (1979c). Genetic counseling — The postcounseling period: II. Making reproductive choices. *American Journal of Medical Genetics*, *4*, 73–87. doi:10.1002/ajmg.1320040109.

Lippman-Hand, A., & Fraser, F. C. (1979d). Genetic counseling: parents' responses to uncertainty. *Birth Defects Original Article Series*, XV(5C), 325–339.

Lloyd, S., Watson, M., Waites, B., Meyer, L., Eeles, R., Ebbs, S., et al. (1996). Familial breast cancer: a controlled study of risk perception, psychological morbidity and health beliefs in women attending for genetic counseling. *British Journal of Cancer*, *74*, 482–487.

Marteau, T. M., & Lerman, C. (2001). Genetic risk and behavioural change. *British Medical Journal*, *322*, 1056–1059. doi:10.1136/bmj.322.7293.1056.

Marteau, T. M., & Weinman, J. (2006). Self-regulation and the behavioral response to DNA risk information: a theoretical analysis and framework for future research. *Social Science & Medicine*, *62*, 1360–1368. doi:10.1016/j.socscimed.2005.08.005.

McCaul, K. D., Branstetter, A. D., O'Donnell, S. M., Jacobson, K., & Quinlan, K. B. (1998). A descriptive study of breast cancer worry. *Journal of Behavioral Medicine*, *21*, 565–579. doi:10.1023/A:1018748712987.

McAllister, M. (2003). Personal theories of inheritance, coping strategies, risk perception and engagement in hereditary non-polyposis colon cancer families offered genetic testing. *Clinical Genetics*, *64*, 179–189. doi:10.1034/j.1399-0004.2003.00133.x.

Meiser, B., Butow, P., Friedlander, M., Schnieden, V., Gattas, M., Kirk, J., et al. (2000). Intention to undergo prophylactic bilateral mastectomy in women at increased risk of developing hereditary breast cancer. *Journal of Clinical Oncology*, *18*, 2250–2257.

Metcalfe, K. A., & Narod, S. A. (2002). Breast cancer risk perception among women who have undergone prophylactic bilateral mastectomy. *Journal of the National Cancer Institute*, *94*, 1564–1569.

National Comprehensive Cancer Centers. (2008). NCCN Clinical Practice Guidelines in Oncology: Breast Cancer. v.2.2008. Retrieved August 1, 2008 from http://www.nccn.org/professionals/physician_gls/PDF/breast.pdf

Palmer, C. G. S., & Sainfort, F. (1993). Toward a new conceptualization and operationalization of risk perception within the genetic counseling domain. *Journal of Genetic Counseling*, *2* (4), 275–294. doi:10.1007/BF00961576.

Parsons, E., & Atkinson, P. (1992). Lay constructions of genetic risk. *Sociology of Health & Illness*, *14*, 437–455. doi:10.1111/1467-9566.ep10493083.

Peters, E., McCaul, K. D., Stefanek, M., & Nelson, W. (2006). A heuristic approach to understanding cancer risk perception: contributions from judgment and decision-making research. *Annals of Behavioral Medicine*, *31*(1), 45–52. doi:10.1207/s15324796abm3101_8.

Price, M. A., Butow, P. N., Lo, S. K., & Wilson, J. (2007). Predictors of cancer worry in unaffected women from high risk breast cancer families: risk perception is not the primary issue. *Journal of Genetic Counseling*, *16*, 635–644. doi:10.1007/s10897-007-9105-4.

Rees, G., Fry, A., & Cull, A. (2001). A family history of breast cancer: women's experiences from a theoretical perspective. *Social Science & Medicine*, *52*, 1433–1440. doi:10.1016/S0277-9536(00)00248-3.

Rosenstock, I. M. (1966). Why people use health services. *The Milbank Memorial Fund Quarterly*, *44*, 94–127. doi:10.2307/3348967.

Schwartz, M. D., Lerman, C. L., Miller, S. M., Daly, M., & Masny, A. (1995). Coping disposition, perceived risk, and psychological distress among women at increased risk for ovarian cancer. *Health Psychology*, *14*(3), 232–235. doi:10.1037/0278-6133.14.3.232.

Shiloh, S. (1994). Heuristics and biases in health decision-making: Their expression in genetic counseling. In L. Heath, R. S. Tindale, J. Edwards, E. J. Posavac, F. B. Bryant, E. Henderson-King, Y. Suarez-Balcazar, & J. Myers (Eds.), *Applications of heuristics and biases to social issues*. London: Plenum Press.

Shiloh, S., & Ilan, S. (2005). To test or not to test? Moderators of the relationship between risk perceptions and interest in predictive genetic testing. *Journal of Behavioral Medicine*, *28*(5), 467–479. doi:10.1007/s10865-005-9017-4.

Sivell, S., Elwyn, G., Gaff, C. L., Clarke, A. J., Iredale, R., Shaw, C., et al. (2008). How risk is perceived, constructed and interpreted by clients in clinical genetics, and the effects on decision-making: systematic review. *Journal of Genetic Counseling*, *17*, 30–63. doi:10.1007/s10897-007-9132-1.

Slovic, P., Fischoff, B., & Lichtenstein, S. (1982). Fact versus fears: understanding perceived risk. In D. Kahneman, P. Slovic, & A. Tversky (Eds.), *Judgment under uncertainty: heuristics and biases* (pp. 464–489). Cambridge: Cambridge University Press.

van Dooren, S., Rijnsburger, A. J., Seynaeve, C., Duivenvoorden, H. J., Essink-Bot, M.-L., & Tilanus-Linthorst, M. M. A. (2004). Psychological distress in women at increased risk for breast cancer: the role of risk perception. *European Journal of Cancer*, *40*, 2056–2063. doi:10.1016/j.ejca.2004.05.004.

Watson, M., Duvivier, V., Wade Walsh, M., Ashley, S., Davidson, J., Papaikonomou, M., et al. (1998). Family history of breast cancer: what do women understand and recall about their genetic risk? *Journal of Medical Genetics*, *35*, 731–738. doi:10.1136/jmg.35.9.731.

Wertz, D. C., Sorenson, J. R., & Heeren, T. C. (1986). Clients' interpretation of risks provided in genetic counseling. *American Journal of Human Genetics*, *39*, 253–264.