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Assessment of genetic testing and related counseling services: current research and future directions

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Abstract

With the recent completion of the sequencing of the Human Genome, genetic testing will increasingly become available for a greater number of medical conditions, many of which are those that manifest in adulthood (e.g., various cancers, cardiovascular disease, diabetes) or for which little or no treatments are available (e.g., Alzheimer disease). Genetic services, defined here as those relating to genetic testing and counseling, will be with helping more individuals deal with medical information that affects their health directly, as opposed to affecting primarily the health of their offspring. This paper reviews the existing research in the genetic testing and counseling literature and presents an evaluation framework outlining the intended outcomes of genetic services. The purpose of this framework is to provide an overview of the potential outcomes of these services and highlight constructs for future research in this area. In addition, other issues that will affect the assessment of genetic services are raised, using examples from the existing literature. Ultimately, the goal of this paper is to highlight and suggest directions researchers can take to produce the information needed to guide genetic testing and counseling practice. Moreover, as genetic knowledge is increasingly applied towards the prevention and treatment of various common, chronic disease conditions, genetic information will have implications for providers outside of the traditional medical genetics realm, such as primary care providers and public health practitioners. A better understanding of the outcomes of genetic testing and counseling will provide a basis from which to ensure an appropriate application of genetic information by all those who eventually provide care and "genetic" services.

Keywords: Genetic counseling; Genetic testing; Outcomes research; Doctor–patient communication

Introduction

With the recent completion of the sequencing of the Human Genome (Collins, Green, Guttmacher, & Guyer, 2003, The International Human Genome Mapping Consortium, 2001; Venter et al., 2001) genetic testing will increasingly become available for a greater number of medical conditions, many of which manifest in adulthood (e.g., various cancers, cardiovascular disease, diabetes) or for which little or no treatment is available (e.g., Alzheimer disease) (Bell, 1998; Biesecker & Marteau, 1999; Marteau & Croyle, 1998). Genetic services, defined here as those relating to genetic testing and counseling, will be helping more individuals deal with medical information that affects their health directly, as opposed to affecting primarily the health of their offspring.[1] As the realm of genetic testing continues

[1] The latter is the case for both prenatal (e.g., amniocentesis) and carrier testing (e.g., Tay-Sachs, cystic fibrosis). Genetic counseling that is offered in conjunction with genetic testing has evolved from tests that focus on reproduction and/or diagnosis of rare genetic diseases to tests that now identify individuals at increased susceptibility for common diseases.

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to expand, so do the implications of ensuring that these testing and related counseling services meet the needs of an increasingly diverse clientele (Biesecker & Marteau, 1999; Guttmacher, Jenkins, & Uhlmann, 2001; Orr, 1993; Sorenson, 1993).

Definitions of genetic counseling have existed for decades (American Society of Human Genetics Ad Hoc Committee on Genetic Counseling, 1975). Inherent in these definitions are the goals of these services. However, what constitutes actual "success" for genetic services has rarely been explicitly stated. In addition, much of what has been proposed as a desired outcome of genetic services has been vague, nonspecific, and difficult to assess.

Efforts to facilitate the much-needed research in this area will need to begin by clarifying the intended outcomes of genetic services. A better understanding of the intended outcomes will also become ever more important for those outside of the traditional medical genetics field (e.g., primary care, public health), as genetic knowledge is applied towards the prevention and treatment of various common, chronic disease conditions. Consequently, as the use of genetic information in health care grows and the demand for those who practice "genomic medicine" increases (Guttmacher et al., 2001), so does the need to determine the outcomes we are trying to achieve.

The purpose of this paper is to present a framework for evaluating genetic services. To do so, we begin by reviewing the goals and desired outcomes of genetic services. Moreover, we highlight the challenges and limitations that have affected the literature to date, such as goals that have not been operationalized and outcome studies that have been limited in focus, and suggest other potential outcomes for consideration. Upon presenting this framework, we also raise other issues that have been problematic or have complicated the evaluation of genetic services. These issues include the variation of genetic conditions, methodological considerations, and unintended effects of genetic technologies.

Our definition of genetic services focuses on genetic testing and related services, such as genetic counseling.[2] We refer to genetic counseling as pertaining to the actual education and counseling provided, both before and after (if tested) the receipt of genetic test results. In contrast, we refer to genetic services as an all-encompassing term that pertains to genetic counseling as well as genetic testing, which can occur in the absence of counseling. Throughout this paper, we focus on predictive testing—that is, genetic testing to learn about one's risk for a disease that develops later in life. However, we draw from the existing counseling literature that includes extensive work in both prenatal and carrier testing contexts. As such, much of the information we present on counseling outcomes is relevant to these other areas of testing.

[2] It should be noted, however, that our focus is but a subset of all that can be considered under the rubric of genetic services. Others have also specified distinctions between genetic counseling, genetic testing/screening, and genetic services and we direct readers to their work for further discussion (see Biesecker & Marteau, 1999).

What are the goals of genetic services?

Most of what has been written about the goals of genetic services has focused on the specific goals of genetic counseling. The definitions and goals of counseling, however, have recently come under increased scrutiny (Bernhardt, Biesecker, & Mastromarino, 2000; Biesecker, 2001; Biesecker & Peters, 2001; Clarke, Parsons, & Williams, 1996; Emery, 2001; Pilnick & Dingwall, 2001; Walker, 1998). Most commonly cited is the definition put forth by the American Society of Human Genetics (ASHG) in 1975 which states:

> "Genetic counseling is a communication process which deals with the human problems associated with the occurrence, or the risk of an occurrence, of a genetic disorder in the family. This process involves an attempt by one or more appropriately trained persons to help the individual or family to (1) comprehend the medical facts including the diagnosis, probable course of the disorder, and the available management; (2) appreciate the way heredity contributes to the disorder, and the risk of recurrence in specified relatives; (3) understand the alternatives for dealing with the risk of occurrence; (4) choose the course of action which seems to them appropriate in view of their risk, their family goals, and their ethical and religious standards, to act in accordance with that decision; and (5) to make the best possible adjustment to the disorder in an affected family member and/or the risk of recurrence of that disorder" (pp. 240–241).

This definition, however, is most suited for the types of genetic conditions seen at the time the definition was put forth; namely, reproductive conditions. For example, Tay-Sachs is a degenerative, neurological condition that manifests in infancy and results in death by the age of 5. Couples who are both mutation carriers for the disease face the dilemma of wanting to have children but are concerned about the 1 in 4 probability of having an affected child. Genetic counseling, in accordance with the above noted definition, would focus on helping a couple understand the condition, how it is inherited, and the risk of having an affected child. Options, such as prenatal testing, would be presented and discussed to allow the couple to make reproductive decisions and to

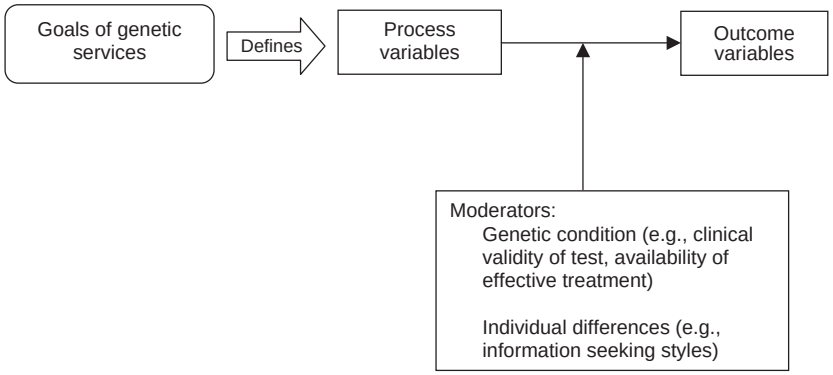

Fig. 1. Framework for evaluating genetic services. The identification of goals is a precursor for determining which processes to examine. The impact of processes on outcomes must be examined taking into consideration potential moderators, such as the genetic condition itself and individual differences. A breakdown list of goals and variables included in the framework is provided in Table 1.

help them cope with the outcomes of their decision (e.g., possible abortion, referral to support services).

Definitions of genetic counseling that have followed suit over the years have yielded similar goals pertaining to decision-making (Soldan, Street, Gray, Binedell, & Harper, 2000; White, 1997). For example, some definitions have focused on a "good decision" as a goal, which occurs when one's values and goals are in equilibrium (White, 1997).[3] Others have suggested that genetic counseling should aim to help patients make informed decisions and prepare for the result (Soldan et al., 2000). This would entail a form of stress inoculation, where clients experience smaller doses of stress in order to promote coping with upcoming stress.

Given the greater number of genetic conditions being seen by various medical genetics professionals, the need to refine and update the definition of counseling has become more apparent. Recently, Biesecker and Peters (2001) presented a working definition of genetic counseling that emphasizes a therapeutic relationship between provider and client. Specifically, they propose that genetic counseling be seen as a "dynamic *psychoeducational* process centered on genetic information… clients are helped to personalize technical and probabilistic genetic information, to promote self-determination and to enhance their ability to adapt over time. The goal is to facilitate clients' ability to use genetic information in a personally meaningful way that minimizes psychological distress and increases personal control." (p. 194).

Two key conclusions can be deduced from these genetic counseling definitions. First, the goals of genetic counseling are broad and encompass several distinct areas. A way to categorize these goals is to organize them into three overarching areas: (1) to educate and inform clients of the genetic condition, (2) to provide support and help them cope (psychological, social—e.g., support to families, referral to appropriate support services), and (3) to facilitate informed decision-making. Second, the effectiveness and success of genetic services will depend on the extent to which these goals are attained. As the framework in Fig. 1 illustrates, the identification of goals is a precursor for determining which processes to examine. The goals specified for genetic testing and counseling, therefore, have implications for the criteria chosen to evaluate these services (see Table 1).

The literature examining outcome criteria for genetic services, however, is problematic. Much of what has been proposed as an important goal (e.g., informed decision-making) has not been clearly spelled out or operationalized and this has been a limiting factor in evaluating genetic services. Moreover, outcome criteria, often specified in advance of clarifying goals and objectives of genetic counseling, run the risk of limiting what research eventually examines. As we elaborate on in the next section, the most commonly examined criteria of existing studies have focused on knowledge acquisition and risk comprehension, psychological distress, patient satisfaction, and reproductive decision-making (Bernhardt et al., 2000; Kessler, 1989; Pilnick & Dingwall, 2001). However, this list is a narrow range of outcomes when we take into consideration the goals of genetic counseling that have been put forth.

[3] A distinction should be made between a good decision and a good outcome. A good decision, based on a formal decision analysis, does not ensure that a good outcome will result. Or, more specifically, this does not rule out the possibility that a bad outcome (due to bad luck) could ensue. For example, a father may go ahead with the decision to test for Huntington's disease, which results in learning that he carries the gene for the condition. Testing positive for the Huntington gene could be considered a bad outcome, but this is independent of the decision to test which may have been made after significant consideration and scrutiny of the choice. (For a different viewpoint, see Yates, Veinott, & Patalano, 2001).

Table 1
Breakdown of goals and variables included in framework for evaluating genetic services

Goals of genetic services	Process variables	Outcome variables
Counseling		
Educate and inform	Genetic counselor competencies (ability to listen/clarify client values) Communication between counselor and client Format/style of counseling (individual, group, video, interactive multimedia)	Knowledge Risk comprehension (incl. recall) Satisfaction with information provided Time spent counseling
Provide support and help cope	Problem solving (enhanced coping) Anticipatory guidance Social support Feelings of connectedness to counselor	Psychological distress Satisfaction with consultation Perceived personal control Meeting patient expectations Uncertainty reduction Quality of life
Facilitate informed decision-making	Analytic vs. automatic Values clarification Knowledge of pros vs. cons Anticipatory guidance	Actual decisions (e.g., having genetic test) Decisional conflict Decision satisfaction Informed choice Regret Decision persistence vs. change in decision Adherence to chosen therapy
Testing		
Subsequent decisions	Intention	Treatment Preventive/prophylactic surgery Reproduction
Health behaviors	Behavior change counseling (directive) Motivation Self-efficacy Intention Skills	Screening frequency/adherence Lifestyle behaviors (smoking, diet, exercise)
Heath status		Morbidity/mortality

Our framework for evaluation of genetic services thus begins with the goals of these services. This framework was established, in part, to help identify additional constructs that could be used to evaluate genetic services. As we have specified, goals define the desired outcomes of genetic services. More specifically, goals provide a starting point from which to consider how a program may be assessed and evaluated.

What are the desired outcomes of genetic services?

Based on the definitions of genetic counseling and the goals that have been specified in the literature, what can be concluded about the desired outcomes of genetic services? Traditionally, genetic services have been assessed at two different time points: (1) following the genetic counseling encounter, or (2) following genetic testing. This distinction is made here because genetic counseling and genetic testing are not necessarily offered together. Thus, genetic counseling does not always lead to genetic testing, and genetic testing is not always preceded by genetic counseling.

Studies examining *counseling* outcomes have focused on the impact of counseling on outcomes that may be considered indicative of counseling "effectiveness" (Pilnick & Dingwall, 2001). These outcomes have included educational variables such as knowledge acquisition and risk comprehension or recall, which have been rigorously studied across many settings including various reproductive scenarios (Evers-Kiebooms & van den Berghe, 1979; Leonard, Chase, &

Childs, 1972; Lippman-Hand & Fraser, 1979; Somer, Mustonen, & Norio, 1988; Wertz, Sorenson, & Heeren, 1986) and breast cancer (Evans, Blair, Greenhalgh, Hopwood, & Howell, 1994; Meiser et al., 2001; Watson et al., 1998). Other indicators of counseling have included patient anxiety levels (Bish et al., 2002; Julian-Reynier et al., 1999) and satisfaction with either the information provided or the consultation (Clark et al., 2000; Shiloh, Avdor, & Goodman, 1990; Tercyak, Bennett Johnson, Roberts, & Cruz, 2001), although these outcome variables have not necessarily been found to be associated with information recalled (Michie, McDonald, & Marteau, 1997b). Decisions, such as having children following genetic counseling (Evers-Kiebooms & van den Berghe, 1979; Frets, Duivenvoorden, Verhage, Niermeijer, van de Berge, & Galjaard, 1990; Somer et al., 1988), or the decision to undergo genetic testing (Craufurd, Dodge, Kerzin-Storrar, & Harris, 1989; Evans, Maher, Macleod, Davies, & Craufurd, 1997; Julian-Reynier et al., 2000; Patenaude et al., 1996) have also been extensively studied.[4] More recently, adherence to breast cancer screening behaviors has been examined as an outcome of genetic counseling (Meiser, & Dunn, 2001; Schwartz, Rimer, Daly, Sands, & Lerman, 1999).

Studies examining the outcomes following genetic *testing* have been increasingly reported, reflecting the growing availability of predictive testing for various adult-onset conditions. The majority of these studies have focused on psychological reactions to testing (i.e., distress) (Broadstock, Michie, & Marteau, 2000b; Dudok de Wit, Duivenvoorden, Passchier, Niermeijer, & Tibben, 1998; Lerman et al., 1996; Lodder et al., 2001; Marteau & Croyle, 1998). However, the decisions following testing (i.e., reproductive or treatment decisions) (Kessler, 1989; Lerman et al., 2000; Lerman et al., 1996; Lynch et al., 1999a; Miron et al., 2000) and subsequent health behaviors (Lerman et al., 2000; Plon, Peterson, Friedman, & Richards, 2000) are beginning to be examined.

Although there are a multitude of studies examining outcomes of genetic testing and counseling, those that have been presented reflect only a narrow spectrum of desired outcomes. This has been a central criticism of prior research (Berkenstadt, Shiloh, Barkai, Katznelson, & Goldman, 1999). Based on our framework for evaluating genetic services, the goals of genetic services may serve as a useful guide to enable researchers to identify other outcome areas to examine. What follows are some suggested areas that may be examined, which stem from the goals of testing and counseling, and may help provide for a more comprehensive evaluation of genetic services. We acknowledge at the outset that these areas are by no means an exhaustive list of outcomes to examine. However, they are a starting point from which to consider the possibilities. The areas were chosen for their relevance to predictive testing and for their potential impact on research. An overview of six of these areas will now be presented. The six areas are perceived personal control, meeting patient expectations, genetic counseling processes, informed decision-making and decision processes, system-based outcomes, and health status.

Perceived personal control

In light of the limited criteria used to evaluate genetic counseling, Berkenstadt et al. (1999) introduced the concept of perceived personal control (PPC) to be used as an outcome variable. This concept refers to the belief that one can control the threat of a stressor. PPC encompasses three dimensions, all of which can be considered outcomes of genetic counseling: (1) cognitive control—the ability to mentally process and cope with an event in a manner that reduces its perceived threat; (2) behavioral control—the ability to alter the physical characteristics of the stressful event, thereby altering its actual threat; and, (3) decision control—the opportunity to choose among options. Moreover, perceived personal control is found to correlate with knowledge, satisfaction, and general evaluations of the genetic counseling session (Berkenstadt et al., 1999).

Overall, there is strong support for the usefulness of this concept as an outcome of genetic counseling. First, definitions and goals of genetic counseling emphasize the importance of coping and adaptation to genetic risk (Biesecker, 2001; Biesecker & Peters, 2001). The notion of perceiving that one can control the threatening nature of a stressor (secondary appraisal) has been an important hallmark of research on stress and coping (Lazarus & Folkman, 1984). Moreover, a central motive for pursuing genetic testing is to reduce uncertainty about an event, in efforts to cope with the threat of the disease in the family (Baum, Friedman, & Zakowski,

[4] Although the decision to undergo testing has often been examined as an outcome of genetic counseling, there are several drawbacks to its use. Most importantly, the decision to test in the majority of cases cannot necessarily be deemed as right or wrong and is, therefore, considered value-laden (O'Connor, 1995). In addition, the central tenet of "nondirectiveness" in genetic counseling, which precludes the counselor from encouraging a particular course of action (see Walker, 1998), suggests that the "best option" depends on the preferences of the individual. This tenet is analogous to the informative or consumerist model in the patient–provider literature, in which the emphasis is on preserving patient autonomy and where the primary role of the provider is that of information sharing (Charavel, Bremond, Moumjid-Ferdjaoui, Mignotte, & Carrere, 2001; Charles, Gafni, & Whelan, 1997; Roter & Hall, 1997). However, like the informative model in the patient–provider literature, the notion of nondirectiveness in genetic counseling has recently been challenged (Elwyn et al., 2000).

1997; Clark et al., 2000; Croyle & Lerman, 1995; Decruyenaere, Evers-Kiebooms, & Van den Berghe, 1993). As such, measures like the one developed by Berkenstadt et al. (1999), which capture the perception of control one has over a threat, may reflect how effectively one is coping with the situation at hand.

Meeting patient expectations

Patients' expectations and the extent to which counseling has met expectations have also been suggested as an important area to study (Bernhardt et al., 2000). Studies undertaken to examine patients' expectations of genetic counseling have reported a range of expectations, which vary by timing of counseling (pre- vs. post-testing) (Audrain et al., 1998; Hallowell, Murton, Statham, Green, & Richards, 1997). For example, prior to genetic testing, women at high risk for breast cancer considered the essential elements of counseling to primarily include information on risks, benefits, and limitations of testing (Audrain et al., 1998). The discussion of personal goals and values and possible emotional responses to testing was considered less essential but endorsed by approximately half of the women surveyed. In contrast, others in the area of cancer genetics have argued that because individuals undergoing genetic counseling already perceive their risk to be high, the main motivation for attending counseling is not to obtain information about their risk per se, but rather to learn what actions they can take to reduce their risk (e.g., prophylactic surgery or chemoprevention in the case of breast cancer) (Hallowell & Richards, 1997; Richards, Hallowell, Green, Murton, & Statham, 1995).

Following testing, there are high expectations of social support and the provision of options (e.g., for dealing with a positive testing result) (Jay, Afifi, & Samter, 2000). For example, women at high risk for breast cancer considered it essential to receive information on the meaning of the test result and recommendations for screening and prevention following testing for hereditary breast–ovarian cancer (Audrain et al., 1998). Many of these women also believed that emotional support and counseling was a necessary component of posttest counseling.

Some retrospective studies have reported that patients often have few expectations of genetic counseling and are unsure of the role of the genetic counselor (Bernhardt et al., 2000; Macleod, Craufurd, & Booth, 2002). Although in some circumstances, the lack of expectations resulted in a positive surprise because counseling was much more comprehensive than expected (Bernhardt et al., 2000), other studies have suggested that not having certain expectations may have negative consequences (Collins, Halliday, Warren, & Williamson, 2000; Hallowell et al., 1997). Hallowell et al. (1997) noted that although women attending genetic counseling for hereditary breast–ovarian cancer expected to discuss their family history, their personal and family risks, and options for risk management, they did not have expectations regarding the process of counseling. As a consequence, many women did not feel adequately prepared for the counseling session and expressed disappointment with some aspect of genetic counseling (e.g., not drawing blood for testing during the visit). This occurred in spite of the high levels of overall satisfaction expressed with the consultation.

Although studies reporting on patient expectations assume that it is important to meet patients' needs, few report the impact of meeting patients' expectations or identify the most essential needs to target during the counseling session. One study, however, has attempted to identify the impact of meeting patients' expectations on various psychological outcomes (Michie, Marteau, & Bobrow, 1997a). In their study, Michie et al. focused on outcomes including anxiety, concern about the medical problem, and satisfaction with information provided. Patient expectations during counseling were classified into five areas: information, explanation, reassurance, advice, and help in making decisions. Although meeting patients' expectations for information, explanation, and help in decision making was not associated with better outcomes, meeting expectations for reassurance and advice was associated with improved outcomes. More specifically, greater reductions in concern and anxiety levels were noted when patients' expectations for reassurance and advice were met. The association between meeting various patient expectations and satisfaction, however, was not consistent. Further advances in this area should focus on identifying predictors of patient expectations or of having expectations met in the counseling session.

Genetic counseling processes

Limitations in counseling effectiveness may occur due to deficiencies in process areas—i.e., *how* genetic counseling is provided. Several articles have recently stressed the importance of process variables in genetic counseling studies (Biesecker & Peters, 2001; Pilnick & Dingwall, 2001). Process areas that have been highlighted for further research include genetic counselor competencies (e.g., ability to listen or clarify client values), communication between counselor and client, formats or styles of counseling (e.g., video, group, individual), and therapeutic approaches used to help patients cope and problem-solve (Biesecker & Peters, 2001; Geller et al., 1997). Genetic counseling research has traditionally focused more on outcome variables rather than process aspects of counseling, which limits the applicability of the research findings to identify ways to specify areas of counseling for improvement (Pilnick & Dingwall, 2001).

Although research is needed to determine the processes by which counseling is provided, even more important is the need to examine how specific component parts of the counseling process are associated with the outcomes of genetic counseling. For example, genetic counselors will often indicate that getting their clients to anticipate what may happen or how they will feel in future (anticipatory guidance) is an important aspect of genetic counseling (Bernhardt et al., 2000). However, experimental studies in this area have demonstrated that the manner in which we have individuals focus and think about the issues at hand can modify and systematically bias their decisions about genetic testing (Wroe & Salkovskis, 1999). As illustrated in this example, a better understanding of the association between how counseling is provided and its outcome (testing decisions in this case) will enable researchers to identify important areas for further study and intervention. Table 1 presents a list of process variables that stem from the goals of genetic services and their associated outcomes that may be examined.

Research from traditional patient–provider communication literature may shed light on some of the processes that would be crucial in genetic counseling effectiveness. For example, some aspects of the patient–provider interaction that have been deemed to be important for patient satisfaction include information giving, partnership building, positive talk, and social talk (Hall, Roter, & Katz, 1988; Roter & Hall, 1997). Amount of information has been found to be the strongest predictor of satisfaction; however, this may not only be attributed to patients' desire for more information, but to their associating positive qualities with doctors who provide more information.

The patient–provider communication literature can also provide further insight into techniques used to study interaction between counselor and client. For example, the Bales Interaction Process Analysis, developed as a method to code group interactions, has been applied to study the impact of doctor–patient interactions on functional and physiological health outcomes (see Kaplan, Greenfield, & Ware, 1989). Specific aspects of the interaction such as control (doctor vs. patient), communication and information exchange, and affect are particularly relevant. Another technique that has been suggested is the Roter Interaction Analysis System (RIAS) (Biesecker & Peters, 2001; Roter, 1995). Recently applied to study of the communication processes within genetic counseling (see Ellington et al., 2003), the RIAS codes for both task-related (e.g., information giving) and socioemotional categories (e.g., agreements, reassurance), and has been used extensively to evaluate patient–provider interactions (Hall et al., 1988; Roter & Hall, 1997).

Two other novel approaches have recently been applied to study genetic counseling processes: (1) sociolinguistic discourse analysis (Benkendorf, Prince, Rose, De Fina, & Hamilton, 2001) and (2) interpretative phenomenological analysis (IPA) (Chapman & Smith, 2002; Macleod et al., 2002; Smith, Michie, Stephenson, & Quarrell, 2002). Both are qualitative approaches. Sociolinguistic discourse analysis examines how language choice and speech patterns can influence the counseling process. For example, Benkendorf et al. (2001) noted that genetic counselors will often use indirect speech in efforts to provide nondirective counseling for decision-making, which may result in leaving clients confused or without further exploration of the underlying values or motives for their choices.

IPA aims to help the researcher explore the phenomenon of interest rather than test specific hypotheses. For example, Macleod et al. (2002) used this approach to examine those aspects of genetic counseling that patients perceived as useful for them. In their study, certain process issues were identified as important including the need to offer preparatory information in advance to inform patients of what to expect. In addition, IPA may also be used to examine decision processes (see Smith et al., 2002), which is also a key outcome to examine and discussed in the next section.

Informed decision-making and decision processes

A central facet of genetic counseling, in the context of genetic testing, is to facilitate the decision-making process and to enable informed decision-making. Enabling informed decision-making rests primarily on the notion that individuals need to possess complete and accurate information in order for decisions to be "informed" (Geller et al., 1997; Lerman & Croyle, 1995). Some researchers, however, have challenged whether certain elements of counseling (i.e., precise recall of factual details and probabilities) are necessary for decision-making (Kessler, 1989).

Although the essentialness of informed decisions or informed choice is rarely disputed, there are few who have attempted to define it. Two notable exceptions come from O'Connor (1995) and Marteau, Dormandy, and Michie (2001). Marteau et al., referring to the work by O'Connor on effective decisions, proposes that informed choice encompasses three main characteristics: (1) the decision is based on relevant, high quality information, (2) reflects the values of the person making the decision, and (3) is behaviorally implemented. According to this definition, the decision to undergo testing is considered informed if an individual is knowledgeable about the test, holds a positive attitude toward undergoing testing, and goes ahead with the procedure. Conversely, a choice is uninformed if an individual makes a decision without full knowledge of the procedure or that is in contrast with his or her attitudes. A measure of informed choice, based on the

above-noted definition, has been developed and holds promise as a useful tool to evaluate the effectiveness of genetic counseling (Marteau et al., 2001).

Understanding the processes of decision-making (i.e., how individuals are making decisions) may help us to understand the extent to which a counselor is successful in helping a client make decisions. Decision processes can be described as one of two types: analytic vs. automatic (Broadstock & Michie, 2000). Analytic processes, which have been described as normative/classic models of decision-making, suggest that individuals are motivated to make rational choices with the goal to maximize benefit or utility (i.e., make the best choice). Most often, this consists of assessing the product of the probability of various outcomes and the value attached to each. This approach, however, has been criticized for failing to incorporate contextual factors that are important to decision makers (Ubel & Loewenstein, 1997) and is often considered unnatural and not representative of how individuals actually make decisions. In contrast, automatic processes or the naturalistic decision making paradigm suggest that individuals rely on "rules of thumb" or gut instincts when making decisions, with the goal of achieving a satisfactory, rather than an optimal outcome (Broadstock & Michie, 2000; Griffin, Gonzalez, & Varey, 2001).

What processes are used to make genetic testing decisions? Most often, strategies inherent in analytical approaches to decision making, such as deliberating between the pros and cons of a decision, are believed to be essential aspects of informed decision-making (Lerman et al., 1997a). To date, however, little is known about how patients make decisions about genetic testing. As indicated earlier, genetic counselors often use strategies such as anticipatory guidance to help patients to work through the decisions they face (Bernhardt et al., 2000; Walker, 1998). It is unclear, however, to what extent these processes are useful in helping clients make decisions.

Research has suggested that patients may make complex medical decisions without relying extensively on analytic strategies. For example, qualitative studies describing breast cancer treatment decisions have shown that deliberative, analytic processes are least used (Pierce, 1993). Moreover, when they were used, they required the most resources (i.e., time, energy) and were associated with the greatest levels of psychological distress. Studies from the genetic counseling and other literature have also demonstrated that individuals tend to simplify genetic risk estimates into a binary format (i.e., event will or will not happen), suggesting the possibility that individuals naturally take 'short cuts' when processing information for decision-making (Lippman-Hand & Fraser, 1979; Tversky & Kahneman, 1974; Vlek, 1987).

Measures assessing some of the processes involved in decision making may prove useful in gaining a better understanding of the role of genetic counseling in facilitating informed decisions. For example, the Decisional Conflict Scale has been widely utilized in the decision aid literature to study the impact of decision supporting interventions (O'Connor, 1995). Inherent in decisional conflict (defined as a state of uncertainty about the course of action to take) are modifiable factors that contribute to uncertainty: lack of information, unclear values, and inadequate social support. Although this instrument does not purport to measure all of the processes involved in decision-making, studying whether counseling influences these factors may shed light on how clients are making genetic testing decisions.

System-based outcomes

In the past decade, there has been a steady increase in the number of adults being seen in genetic services for hereditary cancer syndromes and neurological conditions. Average genetic clinic encounters last between 1 to 2 hours and often require more than one session (Guttmacher et al., 2001; Schneider & Marnane, 1997). The intensity of these sessions along with the limited number of trained genetic counselors in general raises concerns about the availability of qualified personnel to provide the needed genetic services. As such, there is a growing concern for the need to modify the present model of genetic service delivery, especially if genetic technologies are to be eventually applied to a large portion of the population (Guttmacher et al., 2001; Suchard, Yudkin, & Sinsheimer, 1999).

Research is needed to identify ways to efficiently expedite the counseling process and help alleviate the strain of the extensive education that is often needed to convey difficult genetic concepts. The total amount of time spent with patients or time spent on discussing with patients topics that are more personal and individualized are potential outcomes to examine.

Efforts have begun to determine ways that genetic counselors can become more efficient without compromising the quality of care. One area of focus has been on identifying alternatives for educating patients on the basis of inheritance—something that is time consuming and considered a standard component of care. Various technologies including videos (Cull et al., 1998) and CD ROM computer programs (Green, Biesecker, McInerney, Mauger, & Fost, 2001a) have already shown promise as effective aids to supplement counseling services. Moreover, these alternative education programs have been shown to reduce the amount of time patients spend with experts (Cull et al., 1998) and patients appear to be satisfied with them (Green, McInerney, Biesecker, & Fost, 2001b).

Health status

Ultimately, the goals of genetic services should emphasize long-term health status and improvements in public health. To help frame the broader public health implications of genetic advances, it may be useful to examine health outcomes in terms of primary or secondary prevention of disease, or tertiary intervention of disease complications and suffering. In the case of genetic testing for chronic diseases, the focus rests upon identifying individuals at increased risk so that they may take preventive actions (e.g., lifestyle modification) to reduce their risk. However, because chronic diseases are usually attributed to both genetic and environmental factors, research efforts must first strive towards identifying critical gene-environment interactions prior to widespread implementation of population level interventions (Evers-Kiebooms, Welkenhuysen, Claes, Decruyenaere, & Denayer, 2000; Khoury, 1996).

Nonetheless, researchers should examine the impact of genetic services on the modifiable risk factors that are implicated in disease manifestation. This is especially the case for circumstances in which the genetic test is clinically valid and for which an effective treatment is available (Burke, Pinsky, & Press, 2001). For example, those who undergo genetic testing for familial adenomatous polyposis (FAP) and are identified at increased risk for colorectal cancer can benefit from intensified screening and removal of detected polyps, which are precursors to disease onset. These individuals can also greatly reduce their risk by undergoing a prophylactic colectomy (Lynch et al., 1999a). The integration of knowledge about the effectiveness of different medical options can be presented to patients as a part of genetic services and evaluated accordingly.

Genetic services should also be evaluated on the extent to which they help individuals reduce the risk of conditions for which there is not an effective treatment available. Initial studies for hereditary breast cancer have focused on screening adherence as a desirable outcome of genetic testing and counseling (Lerman et al., 2000; Meiser et al., 2001; Plon et al., 2000; Schwartz et al., 1999). Interestingly, others have shown that risk factors such as poor diet and physical inactivity may be prevalent among this high-risk population (Emmons et al., 2000). As such, the identification of these at-risk populations presents a unique opportunity for behavioral risk factor counseling and highlights a priority for incorporating effective behavior change strategies into genetic services (Marteau & Lerman, 2001).

Other issues to consider when evaluating genetic services

In this section, we raise some other issues that have been problematic or have complicated the evaluation of genetic services. The purpose of raising these issues is to provide the reader with a more detailed context within which research in this area has taken place. We focus on three issues in particular: complexities associated with different genetic conditions, methodological limitations of prior research, and unintended effects of genetic technologies.

Complexities associated with different genetic conditions

Any discussion of genetic testing outcomes necessitates a preliminary discussion of the possible test results, which vary in their interpretation depending on the genetic condition. For example, the interpretation of test results for genetic conditions such as Huntington's disease is relatively straightforward. A positive test denotes there is 100% chance the disease will occur while a negative test indicates there is 0% chance the disease will occur. Although there are unclear issues relevant to the patient, such as age of disease onset or severity of the condition, the test is definitive with regards to disease occurrence, if death from other causes does not occur first.

In contrast, interpretation of test results for hereditary breast–ovarian cancer syndromes is much less straightforward. A positive test means that a known deleterious mutation has been detected and that breast and ovarian cancer are more likely to occur. The specific risk for cancer depends on the penetrance of the mutation (i.e., likelihood that a mutation will lead to clinical disease). A negative test, however, can mean one of several things. First, in the situation where a familial mutation is known, a negative test indicates that the person does not carry the mutation that is suspected to be responsible for the excess of cancers seen in that family. However, this does not mean that the person will not develop cancer (since most cancers are sporadic in nature), but rather, that his or her risk is reduced to that of the general population. Second, if a familial mutation has not previously been identified, a negative test result is often considered uninformative because several possible interpretations: (a) the person does not have a mutation, (b) testing procedures did not pick up the genetic aberration (i.e., false negative), or (c) a mutation may exist on a gene that has not been found yet to be associated with the hereditary cancer syndrome. Consequently, distinctions are often made in the literature between "uninformative" and "true" negatives (Friedman et al., 1999; Schwartz et al., 2002). Finally, to further complicate interpretation, genetic test results for hereditary cancer syndromes can be deemed uninformative because the significance of the mutation or variant detected is unknown (often because it has not previously been seen). The evaluation of genetic services must take this variability into account as they likely have different psychological implications.

In addition to differences in test interpretation, genetic testing for different conditions can vary according to their clinical validity (i.e., positive test confers great risk) and the extent to which an effective treatment is available (Burke et al., 2001). Distinguishing between genetic conditions accordingly may prove useful when evaluating outcomes of genetic services. For example, as previously discussed, long-term health status should be an assessed outcome when a clinically valid genetic test is available for a condition in which an effective treatment is available (e.g., FAP). In contrast, for conditions in which a valid test is available yet an effective treatment is not (e.g., Huntington disease), the most appropriate outcome of genetic counseling may be the process by which counseling is delivered (Bernhardt et al., 2000). For example, was the information effectively conveyed by the genetic counselor? Or, did the individual feel that he or she was listened to? Studies focused on the outcomes of genetic services should differentiate between conditions of varying treatment availability and examine the moderating effect of genetic condition (see Fig. 1).

The distinctions as to whether there are effective ways of treating or preventing a condition may explain some of the variability seen on the uptake rates of genetic testing (Marteau & Croyle, 1998; Patenaude et al., 1996). Uptake of testing for Huntington disease, which may offer relief from not knowing (i.e., uncertainty) and allow some to prepare for the future (i.e., childbearing decisions, purchasing adequate health/life insurance), has been approximately 15% (Bloch, Fahy, Fox, & Hayden, 1989; Craufurd et al., 1989). In contrast, uptake of testing for hereditary breast cancer, which cannot only clarify uncertainty about risk but also motivate a woman to consider strategies that may reduce her risk, ranges from 43% to 80% (Lerman et al., 1997a, 1996; Loader, Levenkron, & Rowley, 1998; Patenaude et al., 1996).[5]

Variations between genetic conditions also have implications for how some counseling outcomes are interpreted. For example, in most cases, the decision to undergo genetic testing is left to the client. However, circumstances may exist in which changing an individual's interest in testing could be considered a desirable outcome. Let us take the example of genetic testing for hereditary breast–ovarian cancer. Many women who are interested in BRCA1/2 testing are not considered at high risk (i.e., they lack a suggestive family history) (Andrykowski, Lightner, Studts, & Munn, 1997; Bottorff et al., 2000). Testing in these circumstances may not be deemed as warranted given the low probability of finding a mutation and the limitations of interpreting test results for unaffected women without a known mutation in the family. Several studies in this area have reported a decline in interest to test following genetic counseling (Burke et al., 2000; Green, Biesecker, McInerney, Mauger, & Fost, 2001a).[6] Further consideration is necessary to clarify the possible range of desired outcomes for genetic services.

Finally, the variability across genetic conditions highlights the recent perspectives in the literature surrounding the central tenet of "nondirectiveness" in genetic counseling (Bernhardt, 1997; Biesecker, 2001; Biesecker & Marteau, 1999; Elwyn, Gray, & Clarke, 2000; Fine, 1993; Greendale & Pyeritz, 2001; Sorenson, 1993). Although the definition of what is nondirective counseling has been subject to debate in the literature (see Kessler, 1997), its basic premise rests on the notion of providing information (including facts, alternatives, anticipated consequences) devoid of coercion (National Society of Genetic Counselors, 1992). Often viewed as a goal of genetic counseling (Fine, 1993), the notion of nondirectiveness has recently been challenged in light of circumstances in which there is obvious clinical benefit to either the patient or family members (Elwyn et al., 2000). For example, when an effective treatment is unavailable or ethically controversial (i.e., abortion following prenatal testing), the use of a nondirective approach is highly appropriate to avoid unduly influencing these value-laden decisions. In contrast, remaining nondirective when effective treatments are available raises concerns about the clinical (and legal) obligation to ensure the most appropriate standard of medical care to the patient as well as the patient's family. With the recent legal decisions going in favor of plaintiffs claiming wrongful practice for not being made aware of certain heritable risks (see Severin, 1999, for a review), it becomes increasingly critical to examine the role of nondirectiveness in genetic counseling across different genetic conditions.

Methodological limitations of previous studies

Prior studies in the genetic counseling literature have faced several methodological limitations. The primary limitation has been the excessive use of cross-sectional study designs to answer questions that require longitudinal study designs. For example, studies looking at predictors of genetic testing decisions have been conducted by examining correlations between various psychological variables and interest/intention to test (Glanz, Grove, Lerman, Gotay, & Le Marchand, 1999; Jacobsen, Valdimarsdottir, Brown, & Offit, 1997; Vernon et al., 1999). Interest in genetic testing, however, does not necessarily translate into actual test use (Bloch

[5] It should be noted that these estimates are based on US data in the context of research settings.

[6] Other researchers did not find changes in intention to test in women at low to moderate risk following genetic counseling (see Lerman et al., 1997a).

et al., 1989; Craufurd et al., 1989). Prospective studies of actual testing behavior are very much needed.

Studies in genetic counseling have also lacked generalizabity due to the selection bias of participants. For example, data on individuals undergoing genetic testing for hereditary breast cancer syndromes have been primarily on high-risk, cancer registry families who are mostly Caucasian and from a higher socioeconomic background (Biesecker et al., 2000; Lerman et al., 1996; Lerman, Schwartz, Lin, Hughes, Narod, & Lynch, 1997c; Lynch et al., 1999b). The unique barriers facing individuals who do not come from these families (e.g., ability to interpret a negative test result, cost of testing), however, suggests that the earlier findings on testing decisions must be carefully interpreted until more evidence is gathered on a broader spectrum of the population.

A related issue of concern centers on the type of individuals who seek out genetic services. In reviews of psychological consequences of testing information, distress levels following testing were not found to be higher than they were at baseline (Broadstock, Michie, & Marteau, 2000b). This finding may be partly attributed to the characteristics of this self-selected population presenting for testing (Coyne, Benazon, Gaba, Calzone, & Weber, 2000). Most often, those distressed at baseline are those who are distressed following testing (Lodder et al., 2001). Others have also noted a tendency of those who present for presymptomatic testing for Huntington's disease to be a self-selected group who are better emotionally equipped to deal with genetic test results (Meiser & Dunn, 2001). As such, the findings on the psychological consequences of testing also need to be interpreted with caution. Additional research with different populations (e.g., clinic populations, general public) will help to clarify the external validity of existing findings.

Unintended effects of genetic technologies

Research findings are beginning to surface that raise concerns about the unintended effects of genetic information. A novel application of using genetic risk information has been in smoking cessation interventions with the intent to increase motivation for behavior change. Initial findings, however, suggest that incorporating feedback on genetic susceptibility may have negative effects. Subjects randomized to a smoking cessation arm that included genetic susceptibility information were no more likely to quit smoking, yet were more depressed and had higher levels of fear than subjects who did not receive genetic information (Lerman et al., 1997b). This may, in turn, cause some smokers to deny their smoking problem and raises the concern of greater resistance to future cessation attempts.

Unintended outcomes have also been noted in studies of screening behaviors of women at risk for hereditary breast–ovarian cancer. For example, Schwartz et al. (1999) found that among those with lower education levels, mammography adherence at one-year follow-up was worse for those who had undergone individualized risk counseling compared to women who had undergone general health counseling. In another study, Meiser et al. (2001) also examined breast cancer screening behaviors following genetic counseling and observed a significant decline in clinical breast examinations at 12-month follow-up. The researchers did not find, however, any detrimental impact of counseling on mammography adherence at follow-up.

The decline in screening behaviors noted in both the aforementioned studies may be due to a decline in breast cancer anxiety and distress following learning about one's risk, which is often overestimated by women (see Croyle & Lerman, 1999). Women in this situation may mistakenly equate the result to no longer being at risk for hereditary cancer and may develop a false sense of reassurance about their risk resulting in reduced screening vigilance (Cummings, 2000). These explanations must be cautiously interpreted until the effects are replicated and alternative explanations are ruled out.

Unintended effects may also occur with ambiguous test results. Qualitative data have repeatedly demonstrated that women perceive the reduction of uncertainty as a major advantage to undergoing genetic testing (Bernhardt et al., 1997; Tessaro, Borstelmann, Regan, Rimer, & Winer, 1997). However, when uncertainty cannot be reduced, such as when a genetic test comes back ambiguous or inconclusive, the outcome is often greater distress than if the test outcome was either positive or negative (Wiggins et al., 1992). Moreover, in situations where a genetic test is still in its early research stage and development, lengthy waiting times are common, and a test result is not guaranteed; individuals without any results may experience increases in general distress, which may reflect the continuing uncertainty about their genetic status (Broadstock, Michie, Gray, MacKay, & Marteau, 2000a).

The role of uncertainty reduction, or lack thereof, may also explain why increased rates of depression have been observed among individuals with high baseline stress levels who declined genetic testing for hereditary breast cancer, compared to those who tested positive and showed no changes in depression (Lerman et al., 1998). This raises concerns about reasons why genetic testing is not undertaken and identifies possible subgroups that may be at greater risk for adverse outcomes. For example, those who are interested in genetic testing but deemed ineligible (i.e., due to limitations in genetic testing technology) have displayed negative reactions (Bottorff et al., 2000). Other barriers to testing, such as insurance and cost concerns, may also place individuals

at risk for negative outcomes (Peterson, Milliron, Lewis, Goold, & Merajver, 2002; White, 1997).

Conclusion

This paper set out to present a framework for evaluating genetic services. Several issues were addressed within this framework, including the importance of clarifying and operationalizing the range of testing and counseling goals such that they are applicable across the spectrum of genetic conditions. Although the goals most readily specified in the literature have tended to focus on immediate outcomes, the ultimate goal for many conditions will be long-term health status. Efforts to work towards this will be difficult unless we begin by changing our views of what entails a "genetic" condition.

Also, traditional practice philosophies that have been longstanding in the genetic counseling discipline are being re-conceptualized to accommodate the shifts in genetics research brought about by the Human Genome Project. Decisions that clients must face are often multiple and sequential (Emery, 2001) and the decision to test is usually just the catalyst that brings about more decisions to be made. As such, approaches to counseling (directive vs. nondirective) should not be thought of as mutually exclusive but rather along a *"directiveness continuum"* depending on the purpose of the counseling interaction and the decision at hand.

Researchers will need to implement more sophisticated research methods to help overcome some of the existing limitations in the literature. Methods traditionally employed in other disciplines including patient–provider communication and health education, such as the Bales Interaction Process analysis, may prove to be useful. A better understanding of these various processes will help identify areas for intervention.

Variability between genetic conditions must be identified so that counseling approaches may be matched accordingly. Just as no one would question matching counseling to meet the needs of different cultural groups, we should also be mindful of differences between genetic conditions. In addition, identifying individual differences in reactions to genetic information should also be a priority. For example, differences in information seeking may lead people to prefer different types of information (Miller, 1987; Miller, Fang, Diefenbach, & Bales, 2001). Tailored counseling programs can subsequently be developed based on these differences and may offer a way to increase the relevance of genetic information and minimize adverse outcomes.

Finally, efforts should be undertaken to screen for and identify possible unintended outcomes of genetic services. Some of these already identified, such as declines in cancer screening behavior, reinforce the need to follow subjects longitudinally to gain a fuller understanding the impact of genetic services. Although genetic technology has the potential to offer new ways to manage and decrease disease risk, such applications will not be deemed successful if they are carried out at a cost to patients or their families.

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References

American Society of Human Genetics Ad Hoc Committee on Genetic Counseling. (1975). Genetic counseling. *American Journal of Human Genetics, 27*, 240–242.

Andrykowski, M. A., Lightner, R., Studts, J. L., & Munn, R. K. (1997). Hereditary cancer risk notification and testing: How interested is the general population? *Journal of Clinical Oncology*, *15*(5), 2139–2148.

Audrain, J., Rimer, B., Cella, D., Garber, J., Peshkin, B. N., Ellis, J., Schildkraut, J., Stefanek, M., Vogel, V., & Lerman, C. (1998). Genetic counseling and testing for breast–ovarian cancer susceptibility: What do women want? *Journal of Clinical Oncology*, *16*(1), 133–138.

Baum, A., Friedman, A. L., & Zakowski, S. G. (1997). Stress and genetic testing for disease risk. *Health Psychology*, *16*(1), 8–19.

Bell, J. (1998). The new genetics: The new genetics in clinical practice. *British Medical Journal*, *316*, 618–620.

Benkendorf, J. L., Prince, M. B., Rose, M. A., De Fina, A., & Hamilton, H. E. (2001). Does indirect speech promote nondirective genetic counseling? Results of a sociolinguistic investigation. *American Journal of Medical Genetics*, *106*, 199–207.

Berkenstadt, M., Shiloh, S., Barkai, G., Katznelson, M. B., & Goldman, B. (1999). Perceived personal control (PPC): A new concept in measuring outcome of genetic counseling. *American Journal of Medical Genetics*, *82*, 53–59.

Bernhardt, B. A. (1997). Empirical evidence that genetic counseling is directive: Where do we go from here? *American Journal of Medical Genetics*, *60*, 17–20.

Bernhardt, B. A., Biesecker, B. B., & Mastromarino, C. L. (2000). Goals, benefits, and outcomes of genetic counseling: Client and genetic counselor assessment. *American Journal of Medical Genetics*, *94*, 189–197.

Bernhardt, B. A., Geller, G., Strauss, M., Helzlsouer, K. J., Stefanek, M., Wilcox, P. M., & Holtzman, N. A. (1997). Toward a model informed consent process for BRCA1 testing: A qualitative assessment of women's attitudes. *Journal of Genetic Counseling*, *6*(2), 207–222.

Biesecker, B. B. (2001). Goals of genetic counseling. *Clinical Genetics*, *60*, 323–330.

Biesecker, B. B., Ishibe, N., Hadley, D. W., Giambarresi, T. R., Kase, R. G., Lerman, C., & Struewing, J. P. (2000). Psychosocial factors predicting BRCA1/BRCA2 testing decisions in members of hereditary breast and ovarian cancer families. *American Journal of Medical Genetics*, *93*, 257–263.

Biesecker, B. B., & Marteau, T. M. (1999). The future of genetic counselling: An international perspective. *Nature Genetics*, *22*, 133–137.

Biesecker, B. B., & Peters, K. F. (2001). Process studies in genetic counseling: Peering into the black box. *American Journal of Medical Genetics*, *106*, 191–198.

Bish, A., Sutton, S., Jacobs, C., Levene, S., Ramirez, A., & Hodgson, S. (2002). Changes in psychological distress after cancer genetic counselling: A comparison of affected and unaffected women. *British Journal of Cancer*, *86*, 43–50.

Bloch, M., Fahy, M., Fox, S., & Hayden, M. R. (1989). Predictive testing for Huntington disease: II. Demographic characteristics, life-style patterns, attitudes, and psychosocial assessments of the first fifty-one test candidates. *American Journal of Medical Genetics*, *32*(2), 217–224.

Bottorff, J. L., Balneaves, L. G., Buxton, J., Ratner, P. A., McCullum, M., Chalmers, K., & Hack, T. (2000). Falling through the cracks: Women's experiences of ineligibility for genetic testing for risk of breast cancer. *Canadian Family Physician*, *46*, 1449–1456.

Broadstock, M., & Michie, S. (2000). Processes of patient decision making: Theoretical and methodological issues. *Psychology and Health*, *15*(2), 191–204.

Broadstock, M., Michie, S., Gray, J., MacKay, J., & Marteau, T. M. (2000a). The psychological consequences of offering mutation searching in the family for those at risk of hereditary breast and ovarian cancer - A pilot study. *Psycho-Oncology*, *9*, 537–548.

Broadstock, M., Michie, S., & Marteau, T. (2000b). Psychological consequences of predictive genetic testing: A systematic review. *European Journal of Human Genetics*, *8*, 731–738.

Burke, W., Culver, J. O., Bowen, D., Lowry, D., Durfy, S., McTiernan, A., & Andersen, M. R. (2000). Genetic counseling for women with an intermediate family history of breast cancer. *American Journal of Medical Genetics*, *90*, 361–368.

Burke, W., Pinsky, L. E., & Press, N. A. (2001). Categorizing genetic tests to identify their ethical, legal, and social implications. *American Journal of Medical Genetics*, *106*, 233–240.

Chapman, E., & Smith, J. A. (2002). Interpretative phenomenological analysis and the new genetics. *Journal of Health Psychology*, *7*(2), 125–130.

Charavel, M., Bremond, A., Moumjid-Ferdjaoui, N., Mignotte, H., & Carrere, M. O. (2001). Shared decision-making in question. *Psycho-Oncology*, *10*, 93–102.

Charles, C., Gafni, A., & Whelan, T. (1997). Shared decision-making in the medical encounter: What does it mean? (Or it takes at least two to tango). *Social Science & Medicine*, *44*(3), 681–692.

Clark, S., Bluman, L. G., Borstelmann, N., Regan, K., Winer, E. P., Rimer, B. K., & Skinner, C. S. (2000). Patient motivation, satisfaction, and coping in genetic counseling and testing for BRCA1 and BRCA2. *Journal of Genetic Counseling*, *9*(3), 219–235.

Clarke, A., Parsons, E., & Williams, A. (1996). Outcomes and process in genetic counselling. *Clinical Genetics*, *50*, 462–469.

Collins, F. S., Green, E. D., Guttmacher, A. E., & Guyer, M. S. (2003). A vision for the future of genomics research. *Nature*, *422*(6934), 835–847.

Collins, V., Halliday, J., Warren, R., & Williamson, R. (2000). Assessment of education and counselling offered by a familial colorectal cancer clinic. *Clinical Genetics*, *57*, 48–55.

Coyne, J. C., Benazon, N. R., Gaba, C. G., Calzone, K., & Weber, B. L. (2000). Distress and psychiatric morbidity among women from high-risk breast and ovarian cancer families. *Journal of Consulting and Clinical Psychology*, *68*(5), 864–874.

Craufurd, D., Dodge, A., Kerzin-Storrar, L., & Harris, R. (1989). Uptake of presymptomatic predictive testing for Huntington's disease. *Lancet*, *2*(8663), 603–605.

Croyle, R. T., & Lerman, C. (1995). Psychological impact of genetic testing. In R. T. Croyle (Ed.), *Psychosocial effects of screening for disease prevention and detection* (pp. 11–37). New York: Oxford University Press.

Croyle, R. T., & Lerman, C. (1999). Risk communication in genetic testing for cancer susceptibility. *Journal of the National Cancer Institute. Monographs*, *25*, 59–66.

Cull, A., Miller, H., Porterfield, T., Mackay, J., Anderson, E. D. C., Steel, C. M., & Elton, R. A. (1998). The use of videotaped information in cancer genetic counseling: A randomized evaluation study. *British Journal of Cancer*, *77*(5), 830–837.

Cummings, S. (2000). The genetic testing process: How much counseling is needed? *Journal of Clinical Oncology*, *18*(21s), 60s–64s.

Decruyenaere, M., Evers-Kiebooms, G., & Van den Berghe, H. (1993). Perception of predictive testing for Huntington's disease by young women: Preferring uncertainty to certainty? *Journal of Medical Genetics*, *30*, 557–561.

Dudok de Wit, A. C., Duivenvoorden, H. J., Passchier, J., Niermeijer, M. F., & Tibben, A. (1998). Course of distress experienced by persons at risk for an autosomal dominant inheritable disorder participating in a predictive testing program: An explorative study. *Psychosomatic Medicine*, *60*, 543–549.

Ellington, L., Roter, D., Beveridge, R., Upchurch, R., Baty, B., Smith, K., Biesecker, B., & Botkin, J. (2003). Communication analysis of BRCA1 genetic counseling sessions. *Annals of Behavioral Medicine*, *25*(suppl), S185.

Elwyn, G., Gray, J., & Clarke, A. (2000). Shared decision making and non-directiveness in genetic counselling. *Journal of Medical Genetics*, *37*(2), 135–138.

Emery, J. (2001). Is informed choice in genetic testing a different breed of informed decision-making? A discussion paper. *Health Expectations*, *4*, 81–86.

Emmons, K. M., Kalkbrenner, K. J., Klar, N., Light, T., Schneider, K. A., & Garber, J. E. (2000). Behavioral risk factors among women presenting for genetic testing. *Cancer Epidemiology, Biomarkers and Prevention*, *9*, 89–94.

Evans, D. G. R., Blair, V., Greenhalgh, R., Hopwood, P., & Howell, A. (1994). The impact of genetic counselling on risk

perception in women with a family history of breast cancer. *British Journal of Cancer*, *70*, 934–938.

Evans, D. G. R., Maher, E. R., Macleod, R., Davies, D. R., & Craufurd, D. (1997). Uptake of genetic testing for cancer predisposition. *Journal of Medical Genetics*, *34*, 746–748.

Evers-Kiebooms, G., & van den Berghe, H. (1979). Impact of genetic counseling: A review of published follow-up studies. *Clinical Genetics*, *15*, 465–474.

Evers-Kiebooms, G., Welkenhuysen, M., Claes, E., Decruyenaere, M., & Denayer, L. (2000). The psychological complexity of predictive testing for late onset neurogenetic diseases and hereditary cancers: Implications for multidisciplinary counselling and for genetic education. *Social Science & Medicine*, *51*, 831–841.

Fine, B. A. (1993). The evolution of nondirectiveness in genetic counseling and implications of the Human Genome Project. In D. M. Bartels, B. S. LeRoy, & A. L. Caplan (Eds.), *Prescribing our future: Ethical challenges in genetic counseling* (pp. 101–117). New York: Aldine de Gruyter.

Frets, P. G., Duivenvoorden, H. J., Verhage, F., Niermeijer, M. F., van de Berge, S. M. M., & Galjaard, H. (1990). Factors influencing the reproductive decision after genetic counseling. *American Journal of Medical Genetics*, *35*, 496–502.

Friedman, L. C., Webb, J. A., Richards, C. S., Lynch, G. R., Kaplan, A. L., Brunicardi, F. C., & Plon, S. E. (1999). Psychological impact of receiving negative BRCA1 mutation test results in Ashkenazim. *Genetics in Medicine*, *1*(3), 74–79.

Geller, G., Botkin, J. R., Green, M. J., Press, N., Biesecker, B. B., Wilfond, B., Grana, G., Daly, M. B., Schneider, K., & Kahn, M. J. E. (1997). Genetic testing for susceptibility to adult-onset cancer: The process and content of informed consent. *Journal of the American Medical Association*, *277*(18), 1467–1474.

Glanz, K., Grove, J., Lerman, C., Gotay, C., & Le Marchand, L. (1999). Correlates of intentions to obtain genetic counseling and colorectal cancer gene testing among at-risk relatives from three ethnic groups. *Cancer Epidemiology, Biomarkers and Prevention*, *8*(4), 329–336.

Green, M. J., Biesecker, B. B., McInerney, A. M., Mauger, D., & Fost, N. (2001a). An interactive computer program can effectively educate patients about genetic testing for breast cancer susceptibility. *American Journal of Medical Genetics*, *103*, 16–23.

Green, M. J., McInerney, A. M., Biesecker, B. B., & Fost, N. (2001b). Education about genetic testing for breast cancer susceptibility: Patient preferences for a computer program or genetic counselor. *American Journal of Medical Genetics*, *103*, 24–31.

Greendale, K., & Pyeritz, R. E. (2001). Empowering primary care professionals in medical genetics: How soon? How fast? How far? *American Journal of Medical Genetics*, *106*, 223–232.

Griffin, D., Gonzalez, R., & Varey, C. (2001). The heuristic and biases approach to judgment under uncertainty. In A. Tesser, & N. Schwartz (Eds.), *Blackwell handbook of social psychology: Intraindividual processes* (pp. 207–235). Malden, MA: Blackwell Publishers.

Guttmacher, A. E., Jenkins, J., & Uhlmann, W. R. (2001). Genomic medicine: Who will practice it? A call to open arms. *American Journal of Medical Genetics*, *106*, 216–222.

Hall, J. A., Roter, D. L., & Katz, N. R. (1988). Meta-analysis of correlates of provider behavior in medical encounters. *Medical Care*, *26*(7), 657–675.

Hallowell, N., Murton, F., Statham, H., Green, J. M., & Richards, M. P. M. (1997). Women's need for information before attending genetic counselling for familial breast or ovarian cancer: A questionnaire, interview, and observational study. *British Medical Journal*, *314*, 281–283.

Hallowell, N., & Richards, M. P. M. (1997). Understanding life's lottery: An evaluation of studies of genetic risk awareness. *Journal of Health Psychology*, *21*(1), 31–43.

Jacobsen, P. B., Valdimarsdottir, H. B., Brown, K. L., & Offit, K. (1997). Decision-making about genetic testing among women at familiar risk for breast cancer. *Psychosomatic Medicine*, *59*, 459–466.

Jay, L. R., Afifi, W. A., & Samter, W. (2000). The role of expectations in effective genetic counseling. *Journal of Genetic Counseling*, *9*(2), 95–116.

Julian-Reynier, C., Eisinger, F., Chabal, F., Aurran, Y., Bignon, Y., Machelard-Roumagnac, M., Maugard, C., Nogues, C., Vennin, P., & Sobol, H. (1999). Cancer genetic consultation and anxiety in healthy consultees. *Psychology and Health*, *14*, 379–390.

Julian-Reynier, C., Sobol, H., Sevilla, C., Nogues, C., Bourret, P., & Network, T. F. C. (2000). Uptake of hereditary breast/ovarian cancer genetic testing in a French national sample of BRCA1 families. *Psycho-Oncology*, *9*, 504–510.

Kaplan, S. H., Greenfield, S., & Ware, J. J. E. (1989). Impact of the doctor–patient relationship on the outcomes of chronic disease. In M. Stewart, & D. Roter (Eds.), *Communicating with Medical Patients* (pp. 228–245). Newbury Park, CA: Sage.

Kessler, S. (1989). Psychological aspects of genetic counseling: VI. A critical review of the literature dealing with education and reproduction. *American Journal of Medical Genetics*, *34*, 340–353.

Kessler, S. (1997). Psychological aspects of genetic counseling. XI. Nondirectiveness revisited. *American Journal of Medical Genetics*, *72*, 164–171.

Khoury, M. J. (1996). From genes to public health: The applications of genetic technology in disease prevention. *American Journal of Public Health*, *86*(12), 1717–1722.

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer.

Leonard, C. O., Chase, G. A., & Childs, B. (1972). Genetic counseling: A consumers' view. *New England Journal of Medicine*, *287*(9), 433–439.

Lerman, C., Biesecker, B., Benkendorf, J. L., Kerner, J., Gomez-Caminero, A., Hughes, C., & Reed, M. M. (1997a). Controlled trial of pretest education approaches to enhance informed decision-making for BRCA1 gene testing. *Journal of the National Cancer Institute*, *89*(2), 148–157.

Lerman, C., & Croyle, R. T. (1995). Genetic testing for cancer predisposition: Behavioral science issues. *Journal of the National Cancer Institute. Monographs*, *17*, 63–66.

Lerman, C., Gold, K., Audrain, J., Lin, T. H., Boyd, N. R., Orleans, C. T., Wilfond, B., Louben, G., & Caporaso, N. (1997b). Incorporating biomarkers of exposure and genetic susceptibility into smoking cessation treatment: Effects on smoking-related cognitions, emotions, and behavior change. *Health Psychology*, *16*(1), 87–99.

Lerman, C., Hughes, C., Croyle, R. T., Main, D., Durham, C., Snyder, C., Bonney, A., Lynch, J. F., Narod, S. A., & Lynch, H. T. (2000). Prophylactic surgery decisions and surveillance practices one year following BRCA1/2 testing. *Preventive Medicine*, *31*, 75–80.

Lerman, C., Hughes, C., Lemon, S. J., Main, D., Snyder, C., Durham, C., Narod, S., & Lynch, H. T. (1998). What you don't know can hurt you: Adverse psychologic effects in members of BRCA1-linked and BRCA2-linked families who decline genetic testing. *Journal of Clinical Oncology*, *16*(5), 1650–1654.

Lerman, C., Narod, S., Schulman, K., Hughes, C., Gomez-Caminero, A., Bonney, G., Gold, K., Trock, B., Main, D., Lynch, J., Fulmore, C., Synder, C., Lemon, S. J., Conway, T., Tonin, P., Lenoir, G., & Lynch, H. (1996). BRCA1 testing in families with hereditary breast–ovarian cancer: A prospective study of patient decision making and outcomes. *Journal of the American Medical Association*, *275*(24), 1885–1892.

Lerman, C., Schwartz, M. D., Lin, T. H., Hughes, C., Narod, S., & Lynch, H. T. (1997c). The influence of psychological distress on use of genetic testing for cancer risk. *Journal of Consulting and Clinical Psychology*, *65*(3), 414–420.

Lippman-Hand, A., & Fraser, F. C. (1979). Genetic counseling: Provision and reception of information. *American Journal of Medical Genetics*, *3*, 113–127.

Loader, S., Levenkron, J. C., & Rowley, P. T. (1998). Genetic testing for breast–ovarian cancer susceptibility: A regional trial. *Genetic Testing*, *2*(4), 305–313.

Lodder, L., Frets, P. G., Trijsburg, R. W., Meijers-Heijboer, E. J., Klijn, J. G. M., Duivenvoorden, H. J., Tibben, A., Wagner, A., van der Meer, C. A., van den Ouweland, A. M. W., & Niermeijer, M. F. (2001). Psychological impact of receiving a BRCA1/BRCA2 test result. *American Journal of Medical Genetics*, *98*, 15–24.

Lynch, H. T., Watson, P., Shaw, T. G., Lynch, J. F., Harty, A. E., Franklin, B. A., Kapler, C. R., Tinley, S. T., Liu, B., & Lerman, C. (1999a). Clinical impact of molecular genetic diagnosis, genetic counseling, and management of hereditary cancer. Part II: Hereditary nonpolyposis colorectal carcinoma as a model. *Cancer*, *86*(11), 2457–2463.

Lynch, H. T., Watson, P., Tinley, S., Snyder, C., Durham, C., Lynch, J., Kirnarsky, Y., Serova, O., Lenoir, G., Lerman, C., & Narod, S. A. (1999b). An update on DNA-based BRCA1/BRCA2 genetic counseling in hereditary breast cancer. *Cancer Genetics and Cytogenetics*, *109*, 91–98.

Macleod, R., Craufurd, D., & Booth, K. (2002). Patients' perceptions of what makes genetic counseling effective: An interpretative phenomenological analysis. *Journal of Health Psychology*, *7*(2), 145–156.

Marteau, T. M., & Croyle, R. T. (1998). The new genetics: Psychological responses to genetic testing. *British Medical Journal*, *316*(7132), 693–696.

Marteau, T. M., Dormandy, E., & Michie, S. (2001). A measure of informed choice. *Health Expectations*, *4*, 99–108.

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

Meiser, B., Butow, P. N., Barratt, A. L., Schnieden, V., Gattas, M., Kirk, J., Gaff, C., Suthers, G., Tucker, K., (The Psychological Impact Collaborative Group). (2001). Long-term outcomes of genetic counseling in women at increased risk of developing hereditary breast cancer. *Patient Education and Counseling, 44*, 215–225.

Meiser, B., & Dunn, S. (2001). Psychological impact of genetic testing for Huntington's disease: An update of the literature. *Journal of Neurology, Neurosurgery, and Psychiatry*, *69*(5), 574–578.

Michie, S., Marteau, T. M., & Bobrow, M. (1997a). Genetic counselling: The psychological impact of meeting patients' expectations. *Journal of Medical Genetics*, *34*(3), 237–241.

Michie, S., McDonald, V., & Marteau, T. M. (1997b). Genetic counseling: Information given, recall, satisfaction. *Patient Education and Counseling*, *32*, 101–106.

Miller, S. M. (1987). Monitoring and blunting: Validation of a questionnaire to assess styles of information seeking under threat. *Journal of Personality and Social Psychology*, *52*(2), 345–353.

Miller, S. M., Fang, C. Y., Diefenbach, M. A., & Bales, C. B. (2001). Tailoring psychosocial interventions to the individual's health information-processing style. In A. Baum, & B. L. Anderson (Eds.), *Psychosocial Interventions for Cancer* (pp. 343–362). Washington, DC: APA.

Miron, A., Schildkraut, J. M., Rimer, B. K., Winer, E. P., Skinner, C. S., Futreal, P. A., Culler, D., Calingaert, B., Clark, S., Marcom, P. K., & Iglehart, J. D. (2000). Testing for hereditary breast and ovarian cancer in the southeastern United States. *Annals of Surgery*, *231*(5), 624–634.

National Society of Genetic Counselors. (1992). *Code of ethics*, available: www.nsgc.org/about/code_of_ethics.asp.

O'Connor, A. M. (1995). Validation of a decisional conflict scale. *Medical Decision Making*, *15*, 25–30.

Orr, H. T. (1993). The impact of the Human Genome Project for genetic counseling services. In D. M. Bartels, B. S. LeRoy, & A. L. Caplan (Eds.), *Prescribing our future: Ethical challenges in genetic counseling* (pp. 97–99). New York: Aldine De Gruyter.

Patenaude, A. F., Schneider, K. A., Kieffer, S. A., Calzone, K. A., Stopfer, J. E., Basili, L. A., Weber, B. L., & Garber, J. E. (1996). Acceptance of invitations for p53 and BRCA1 predisposition testing: Factors influencing potential utilization of cancer genetic testing. *Psycho-Oncology*, *5*, 241–250.

Peterson, E. A., Milliron, K. J., Lewis, K. E., Goold, S. D., & Merajver, S. D. (2002). Health insurance and discrimination concerns and BRCA1/2 testing in a clinic population. *Cancer Epidemiology, Biomakers and Prevention*, *11*, 79–87.

Pierce, P. F. (1993). Deciding on breast cancer treatment: A description of decision behavior. *Nursing Research*, *42*(1), 22–28.

Pilnick, A., & Dingwall, R. (2001). Research directions in genetic counselling: A review of the literature. *Patient Education and Counseling*, *44*, 95–105.

Plon, S. E., Peterson, L. E., Friedman, L. C., & Richards, C. S. (2000). Mammography behavior after receiving a negative BRCA1 mutation test result in the Ashkenazim: A community-based study. *Genetics in Medicine*, *2*(6), 307–311.

Richards, M. P. M., Hallowell, N., Green, J. M., Murton, F., & Statham, H. (1995). Counseling families with hereditary breast and ovarian cancer: A psychosocial perspective. *Journal of Genetic Counseling*, *4*(3), 219–233.

Roter, D. L. (1995). *The roter interaction analysis system (RAIS) coding manual*. Baltimore, MD: Johns Hopkins School of Hygiene and Public Health.

Roter, D. L., & Hall, J. A. (1997). Patient–provider communication. In K. Glanz, F. M. Lewis, & B. K. Rimer (Eds.), *Health behavior and health education* (2nd ed.) (pp. 206–226). San Francisco: Jossey-Bass.

Schneider, K. A., & Marnane, D. (1997). Cancer risk counseling: How is it different? *Journal of Genetic Counseling*, *6*(2), 97–109.

Schwartz, M. D., Peshkin, B. N., Hughes, C., Main, D., Isaacs, C., & Lerman, C. (2002). Impact of BRCA1/BRCA2 mutation testing on psychologic distress in a clinic-based sample. *Journal of Clinical Oncology*, *20*(2), 514–520.

Schwartz, M. D., Rimer, B. K., Daly, M., Sands, C., & Lerman, C. (1999). A randomized trial of breast cancer risk counseling: The impact on self-reported mammography use. *American Journal of Public Health*, *89*(6), 924–926.

Severin, M. J. (1999). Genetic susceptibility for specific cancers: Medical liability of the clinician. *Cancer*, *86*(11), 2564–2569.

Shiloh, S., Avdor, O., & Goodman, R. M. (1990). Satisfaction with genetic counseling: Dimensions and measurement. *American Journal of Medical Genetics*, *37*, 522–529.

Smith, J. A., Michie, S., Stephenson, M., & Quarrell, O. (2002). Risk perception and decision-making processes in candidates for genetic testing for Huntington's disease: An interpretative phenomenological analysis. *Journal of Health Psychology*, *7*(2), 131–144.

Soldan, J., Street, E., Gray, J., Binedell, J., & Harper, P. S. (2000). Psychological model for presymptomatic test interviews: Lessons learned from Huntington disease. *Journal of Genetic Counseling*, *9*(1), 15–31.

Somer, M., Mustonen, H., & Norio, R. (1988). Evaluation of genetic counselling: Recall of information, post-counselling reproduction, and attitude of the counsellees. *Clinical Genetics*, *34*, 352–365.

Sorenson, J. R. (1993). Genetic counseling: values that have mattered. In D. M. Bartels, B. S. LeRoy, & A. L. Caplan (Eds.), *Prescribing our future: Ethical challenges in genetic counseling* (pp. 3–14). New York: Aldine De Gruyter.

Suchard, M. A., Yudkin, P., & Sinsheimer, J. S. (1999). Are general practitioners willing and able to provide genetic services for common diseases? *Journal of Genetic Counseling*, *8*(5), 301–311.

Tercyak, K. P., Bennett Johnson, S., Roberts, S. F., & Cruz, A. C. (2001). Psychological response to prenatal genetic counseling and amniocentesis. *Patient Education and Counseling*, *43*, 73–84.

Tessaro, I., Borstelmann, N., Regan, K., Rimer, B. K., & Winer, E. (1997). Genetic testing for susceptibility to breast cancer: Findings from women's focus groups. *Journal of Women's Health*, *6*(3), 317–327.

The International Human Genome Mapping Consortium. (2001). A physical map of the human genome. *Nature, 409*, 934–941.

Tversky, A., & Kahneman, D. (1974). Judgment under uncertainty: Heuristics and biases. *Science*, *185*, 1124–1131.

Ubel, P. A., & Loewenstein, G. (1997). The role of decision analysis in informed consent: Choosing between intuition and systematicity. *Social Science Medicine*, *44*(5), 647–656.

Venter, J. C., Adams, M. D., Myers, E. W., Li, P. W., Mural, R. J., & Sutton, G. G., et al. (2001). The sequence of the human genome. *Science*, *291*, 1304–1351.

Vernon, S. W., Gritz, E. R., Peterson, S. K., Perz, C. A., Marani, S., Amos, C. I., & Baile, W. F. (1999). Intention to learn results of genetic testing for hereditary colon cancer. *Cancer Epidemiology, Biomarkers and Prevention*, *8*(4), 353–360.

Vlek, C. (1987). Risk assessment, risk perception and decision making about courses of action involving genetic risk: An overview of concepts and methods. *Birth Defects: Original Article Series*, *23*(2), 171–207.

Walker, A. P. (1998). The practice of genetic counseling. In D. L. Baker, J. L. Schuette, & W. R. Uhlmann (Eds.), *A guide to genetic counseling* (pp. 1–26). New York: Wiley-Liss, Inc.

Watson, M., Duvivier, V., Wade Walsh, M., Ashley, S., Davidson, J., Papaikonomou, M., Murday, V., Sacks, N., & Eeles, R. (1998). Family history of breast cancer: What do women understand and recall about their genetic risk? *Journal of Medical Genetics*, *35*, 731–738.

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.

White, M. T. (1997). "Respect for Autonomy" in genetic counseling: An analysis and a proposal. *Journal of Genetic Counseling*, *6*(3), 297–313.

Wiggins, S., Whyte, P., Huggins, M., Adam, S., Theilmann, J., Bloch, M., Sheps, S. B., Schechter, M. T., & Hayden, M. R. (1992). The psychological consequences of predictive testing for Huntington's disease. *New England Journal of Medicine*, *327*, 1401–1405.

Wroe, A. L., & Salkovskis, P. M. (1999). Factors influencing anticipated decisions about genetic testing: Experimental studies. *British Journal of Health Psychology*, *4*, 19–40.

Yates, J. F., Veinott, E. S., & Patalano, A. L. (2001). Hard decisions, bad decisions: On decision quality and decision aiding. In S. L. Schneider, & J. Shanteau (Eds.), *Emerging perspectives on judgment and decision research*. New York: Cambridge University Press.