

### Meeting Report

## Current Research Promises and Challenges in Behavioral Oncology: Report from the American Society of Preventive Oncology Annual Meeting, 2002

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### Abstract

**The Behavioral Oncology Interest Group of the American Society of Preventive Oncology held a Roundtable session on March 10, 2002, at the American Society of Preventive Oncology annual meeting in Bethesda, Maryland, to discuss the current state-of-the-science in behavioral approaches to cancer prevention and control and to delineate priorities for additional research. Four key areas were considered: (a) behavioral approaches to cancer genetic risk assessment and testing; (b) biological mechanisms of psychosocial effects on cancer; (c) the role of risk perceptions in cancer screening adherence; and (d) the impact of tailored and targeted interventions on cancer prevention and control research. The evidence reviewed indicates that behavioral approaches have made significant contributions to cancer prevention and control research. At the same time, there is a need to more closely link future investigations to the underlying base of behavioral science principles and paradigms that guide them. To successfully bridge the gap between the availability of effective new cancer prevention and control technologies and the participants they are meant to serve will require the development of more integrative conceptual models, the incorporation of more rigorous methodological designs, and more precise identification of the individual and group characteristics of the groups under study.**

### Introduction

Behavior has been shown to play a key role in many aspects of cancer prevention and control from disease risk through treat-

ment through survivorship. Indeed, behavioral science has emerged as one of the key priorities at the National Cancer Institute and a rapidly growing area for funded research (1). Yet, behavioral science is not always well integrated with other research areas; for example, behavioral research is often not coordinated with the clinical research agenda of the nation's cancer centers and investigations. In 2000, we therefore established a Behavioral Oncology Interest Group, nested within the existing umbrella organization of the American Society of Preventive Oncology. To date, the Behavioral Oncology Interest Group Steering Committee, comprised of behavioral scientists, has brought together a group of ~200 investigators who all share ongoing interests and active research programs at the interface of behavioral science and oncology. The mission of this group is to provide a structured forum for behavioral interactions and collaborations, with a view to addressing basic unresolved issues in psychosocial assessment and intervention approaches to cancer prevention and control.

To further this mission, we arranged a preconference session at the March 2002 meeting of American Society of Preventive Oncology, held in Bethesda, Maryland, with the goal of conducting a state-of-the-science evaluation of current areas of research focus in behavioral oncology. Four areas of research interest were chosen by the Behavioral Oncology Steering Group via a series of telephone conference calls before the annual meeting. These areas were as follows: (a) behavioral approaches to cancer genetic risk assessment and testing; (b) biological mechanisms of psychosocial effects on cancer; (c) the role of risk perceptions on cancer screening adherence; and (d) the impact of tailored and targeted interventions on cancer prevention and control research. The four topics were judged to be sufficiently well established in the behavioral oncology field to have generated an impressive and tantalizing array of research findings. The overarching goal of the roundtables was to provide an overview of what is known, what is suspected, and what is still unknown or unexplained to delineate priorities for research concentration and collaboration.

Two behavioral science leaders were selected to lead each roundtable based on their expertise in the field. One recorder supported the work of each roundtable. Discussions lasted on average one and one-half hours and were tape recorded. Participants were comprised mainly of behavioral scientists and self-selected into a roundtable based on interest and/or expertise. The specific objective of each roundtable was to summarize the current state of the field and to recommend potential directions and areas for future research. In this article, we highlight the key conclusions of the four roundtable discussions. For each topic area, we present the conclusions in terms of: (a) key findings and goals of the research area; (b) strengths of the research area; (c) weaknesses of the research area; and (d) directions for future research.

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### Behavioral Oncology Roundtable 1: Behavioral Approaches to Cancer Genetic Risk Assessment and Testing

**Introduction.** The development and clinical use of genetic mutation testing for cancer risk has provided unprecedented opportunities for a new area of research: the behavioral and psychological antecedents and consequences of genetic risk assessment and testing. Although genetic testing has been used medically in prenatal settings and in the identification of risk for various diseases such as Huntington's disease (2), the incorporation of genetic risk information into the field of cancer prevention and control is relatively new.

**Key Findings and Goals of the Research Area.** One of the main research goals has been to design effective methods of providing support to individuals undergoing genetic mutation testing. In-person genetic counseling has been the main focus of research to date. Other methods such as telephone, CD-ROM, and web-based modalities are beginning to be evaluated (3–6). The model of genetic counseling for cancer susceptibility was adapted from the prenatal genetic counseling field and modified to be more relevant for a chronic disease setting. Testing for *BRCA1/2* genetic mutations has been a main cancer model for mutation testing, but others such as testing for colon cancer mutations have also received research attention as well. (*e.g.*, Refs. 8–12). The focus has generally been on screening/testing rates among genetically high risk patients (13), effects of genetic counseling and testing participation on short- and long-term psychosocial functioning (14, 15), and psychological variables that predict reactions to testing and the sequelae of testing (14, 15). With the identification of these variables, the design of counseling interventions that are tailored to the individual's needs and issues has become a focus of research (16, 17).

In addition to facilitating decision-making regarding initial testing, the patterns and factors that determine subsequent decisions about the uptake of surveillance (*e.g.*, mammography or ovarian ultrasound) and preventive (*e.g.*, chemoprevention or prophylactic surgery) regimens are a developing focus in this area (18, 19). An additional, but similarly less well researched, goal is to identify the effects of the testing process on family members. Family communication during the testing process has received attention among high-risk families (20, 21). Issues of informing families of the mutation status of the index patient and subsequent actions of family members regarding their own risk are new areas of current study (22).

A few target groups have been studied, with more proposed. The most common target of study is the high-risk patient and/or family member, specifically the first-degree relative. Some research has explored ethnic or cultural differences in these samples, finding distinctive patterns in beliefs and approaches across cultures (23–25). Providers that act as gatekeepers to risk assessment have been subjects in studies, with findings suggesting that providers are underinformed about genetic testing (26–28). Finally, some studies have included persons at multiple levels of risk and are more generalizable, but few interventions have targeted this public health sample (29, 30).

**Strengths of the Research Area.** The strengths of this field include a multidisciplinary approach to the research questions, a focused line of research directed at high-risk patients and their families, the use of data from other areas as it applies to the study of issues in genetics, and consideration of a broad range of ethical, social, and legal issues in the current studies. Furthermore, multiple methodologies have been used to study the process of genetic risk information and testing, including qual-

itative methods, quantitative survey research, and randomized and nonrandomized intervention designs.

**Weaknesses of the Research Area.** This field is relatively new, and therefore, there is not a critical mass of studies to be reviewed. There is often less use of existing theoretical approaches to guide the study of the psychosocial correlates and consequences of genetic risk assessment and testing. Noteworthy exceptions include the Cognitive-Social Health Information Processing model (15, 31, 32) and self-regulation theory (33, 34). Additional development and consolidation of the available theoretical base is an area of clear research need.

Measurement approaches have grown with the field, but there are key gaps in the published literature on this topic. First, target study outcomes are difficult to define given the current scientific knowledge base. For example, it is unclear whether actually undergoing testing should be the desired outcome or whether satisfaction with one's testing decision is the more appropriate (and ethical) target outcome. Recently, articles have begun to address the difficulties in identifying outcome variables and have presented alternate strategies (*e.g.*, the use of process research) to assess counseling effectiveness (35–37). Related to this concern is the fact that most studies rely on short-term outcomes and fail to take a systematic longitudinal or developmental perspective on genetic risk decisions, correlates, and consequences (38).

An additional measurement issue relates to the potentially unique role of genetic risk as a risk factor, relative to other risk factors. It is unclear whether genetic risk is in some ways qualitatively different in its impact from other risk factors and, if so, why. An additional question that arises is whether genetic-specific measures of variables such as satisfaction, quality of care, and negative affect are more appropriate than general measures that have been developed for a broad range of health situations. Measurement of risk perceptions, one of the key short-term outcomes in this field, is fraught with measurement problems and is in need of research attention (32).

Finally, a key design weakness in this area is the reliance on self-selected sampling from high-risk clinics and from volunteer samples. Self-selected samples may be more resilient to adverse outcomes, and this may account for the lack of adverse psychological reactions noted in the literature (39). Alternatively, these reactions may well exist but are rare, even in samples that are generalizable to the geographical area of recruitment. A population-based sample can be defined as a sample that has known properties and that can be compared with the population from which it is recruited. The consistent differences observed in health and psychological functioning between volunteer and population-based samples in other research areas highlights the need to broaden our sampling methods and to pay attention to the impact of different referral and recruitment methods in the outcomes under study. The use of population-based sampling, which is the collection of data from a population with defined characteristics, will increase our ability to interpret and generalize study results.

**Directions for Future Research.** Four main areas of research priorities were identified. Some of these priorities can be addressed through "quick fix" remedies and accomplished in the context of existing studies. However, most of these priorities require more innovative scientific approaches, including conceptual and methodological development.

First, more integrative and comprehensive models of risk communication and risk information provision are needed, beyond the traditional genetic counseling approach. Greater attention needs to be given to theory-based and hypothesis-driven

research and to more precise identification and measurement of target outcomes.

Second, research addressing the long-term consequences of counseling, testing, and choices after testing is needed. These studies should include follow-up of existing cohorts and registry samples to identify any long-term adverse effects or difficulties with current models, as well as the testing of innovative and more conceptually based models of information and support provision, including the application of new media approaches. Identification of the appropriate outcome variables and the potential mediator and moderator variables also needs to be a part of this agenda. Related to this, greater attention needs to be given to the familial and developmental context in which genetic assessment and testing decisions unfold.

Third, research in this field has to use care when recruiting participants and not draw conclusions based solely on volunteer samples from high-risk families. Cultural and ethnic differences have been identified in the few studies that have focused on diverse target groups (*e.g.*, Refs. 22, 24). A range of socioeconomic barriers and issues is just now being identified, and the meaning and import of those differences needs to be explored. In the past 5 years, we have obtained an emerging outcome database on high-risk, volunteer individuals. However, we are still not in a position to generalize these findings to a defined population because of the focus on potentially biased, self-selected samples. Encouragingly, the sampling issues that exist are ultimately easily addressable through more carefully designed research protocols. The research infrastructures funded by the National Cancer Institute to recruit population-based samples of high- and average-risk patients and family members could provide a fresh source of ideas, collaborators, and research participants in this area. For example, the Cancer Genetics Network (CGN) is a national network of centers specializing in the study of inherited predisposition to cancer. The CGN consists of eight centers and an Informatics Technology Group, which provides the supporting informatics and logistics infrastructure. The CGN enrolls individuals who have a personal or family history of cancer and who may be interested in participating in studies about inherited susceptibility to cancer. Enrollees provide information about their health and family history of cancer, in addition to information about sociodemographic factors. The CGN supports collaborative investigations on the genetic basis of cancer susceptibility, as well as mechanisms to integrate this new knowledge into medical practice. The CGN also addresses the associated psychosocial, ethical, legal, and public health issues by providing the enrollment data to qualified investigators or by providing study subjects from its registry information about more specialized research by approved investigators.

Finally, on the structural and political level, more must be done to consider other models of delivering genetic testing information besides the for-profit company-driven model. The modus operandi of the few biotechnology companies currently involved in producing and marketing genetic tests to healthcare providers and to consumers must be shaped by data and policy on what is appropriate, health promoting, and adaptive for the target groups. To accomplish this task requires that we consider alternatives to existing policy and practice in the monitoring of genetic testing.

## Behavioral Oncology Roundtable 2: Biological Mechanisms of Psychosocial Effects on Cancer

**Introduction.** There is increasing interest among the scientific community and the lay public in how mind-body interactions

influence disease processes. This interest has been driven partly by empirical evidence suggesting that psychological factors are associated with cancer outcomes and by claims that psychosocial interventions can increase survival. Over the past 20 years, a growing body of research has attempted to identify the biological mechanisms of psychosocial effects on cancer and to delineate the potential pathways through which psychosocial factors might influence cancer outcomes. Specific targets of study vary depending upon the nature of the research question and include healthy people at average or increased risk for cancer and cancer patients.

**Key Findings and Goals of the Research Area.** Whether psychosocial factors (such as psychological stress and adjustment, social support, and depression) are associated with cancer onset or progression remains an area of scientific inquiry and controversy (*e.g.* Refs. 40, 41). The biological mechanisms by which psychosocial factors might influence tumor development, growth, and metastases are currently under investigation. To date, the majority of studies of psychosocial effects on cancer, many of which were based on Burnet's immune surveillance theory (42), have focused on psychoimmunological pathways. In general, studies have reported an inverse relationship between stress and various indices of *in vitro* immune activity [*e.g.*, natural killer cell functional activity, lymphocyte proliferative response to mitogens, numbers and percentages of specific immune cell subsets (*e.g.*, Ref. 43)]. However, this relationship has not been consistently found across all studies. In other work (*e.g.*, Refs. 44–46), social support has generally been shown to be positively associated with greater natural killer cell functional activity, and depression has been consistently associated with immune dysregulation, primarily reflected by lower numbers of natural killer and helper T cells (47, 48) and higher levels of interleukin 6 (49).

In addition to observational studies, randomized clinical trials that explore the impact of psychosocial interventions (*e.g.*, cognitive-behavioral stress management, or group psychotherapy) have been used to test psychoimmunological pathways in cancer patients. Overall, the efficacy of psychosocial interventions in producing immunological change has been mixed, with some studies reporting results demonstrating enhanced immune activity (*e.g.*, Refs. 50–53) and other studies showing no effect (*e.g.*, Refs. 54–56).

On the basis of the existing data, there are three main goals for research. First, there is a need to identify and assess biological markers that have prognostic value and are associated with cancer risk, progression, or other clinically relevant outcome (*e.g.*, increased morbidity). For example, an increasing awareness of the role of cytokines in infectious processes and cancer-related morbidity calls for the measurement of biological markers beyond the repertoire of immune outcomes that have been historically used (*e.g.*, natural killer cell activity). In addition, recent studies (*e.g.*, Refs. 56–58) illustrate the importance of considering neuroendocrine mechanisms in cancer risk and progression. To date, biobehavioral research has had a limited impact in the cancer context, primarily due to a failure to demonstrate that the biological pathways or mechanisms assessed are of clinical relevance. Thus, behavioral researchers need to be aware of and familiarize themselves with the latest advances in relevant related fields, including immunology, genetics, molecular biology, and endocrinology, to incorporate appropriate biological markers into their research.

A second goal is to expand the research domain to include patient outcomes other than survival. Historically, studies have attempted to delineate the pathways between psychosocial fac-

tors and a given biological marker, with the ultimate goal of predicting survival as an end point. However, because survival is influenced by a multitude of factors, building a research agenda that is focused solely on this end point will inevitably predispose many studies to failure. Thus, cancer outcomes in addition to survival (*e.g.*, disease progression, patient response to treatment, cancer-related morbidity, and recurrence) should also be considered as viable endpoints in this research area.

A third goal is to understand the biobehavioral bases of risk behaviors that lead to cancer. For example, research has identified individual differences in genetic predisposition to cigarette smoking (*e.g.*, Refs. 59, 60), substance abuse, and risk-taking behaviors (*e.g.*, Ref. 56). Particular genetic polymorphisms have been linked to certain personality traits (*e.g.*, poor impulse control and novelty seeking) that are associated with a predisposition toward these behaviors (*e.g.*, Ref. 58). In addition, affective disorders (such as depression) are often associated with tobacco and alcohol use (*e.g.*, Ref. 59). A greater comprehension of the biobehavioral bases of risk behaviors would contribute to our ability to successfully modify or treat these risk factors through behavioral intervention and/or pharmacotherapy.

**Strengths of the Research Area.** There are a number of strengths that define this research area. First, this multidisciplinary field draws upon diverse areas of cancer research to inform its hypotheses and research questions. Second, when properly designed and conducted, this research can identify key biological mechanisms of action underlying psychosocial effects, which can then be rigorously tested in randomized intervention studies. Finally, appropriate treatment or modification of psychosocial or behavioral risk factors may yield significant positive effects on patient clinical outcomes such as cancer-related fatigue and treatment response.

**Weaknesses of the Research Area.** This field of study has been limited by conceptual weaknesses. In some cases, intervention studies have been carried out prematurely, without being guided by theory-based hypotheses, thereby hampering an understanding of the potential processes involved.

The impact of study findings has also been undermined by methodological weaknesses. The most common study design flaw is the failure to include an appropriate or relevant control group. To date, many observational studies and several intervention studies have used a repeated measures design in which psychosocial and immunological factors are assessed across various time points and the patient serves as his or her own control. The findings from these studies have contributed immensely to our understanding of potential biobehavioral pathways. However, the gold standard in determining causality and the directional nature of these pathways is the utilization of a randomized experimental design that compares the treatment condition to an appropriate control group. Although this has been difficult to achieve for many studies, thereby limiting the potential impact of research findings in the field, current studies are meeting this standard.

In addition, the selection and measurement of biological markers is often determined by what can easily be measured (*e.g.*, markers in peripheral blood or saliva) and when it can be measured (*e.g.*, during a clinic visit), rather than assessing the most relevant measures at optimal time points for understanding the mechanisms involved. Too often, logistical constraints in obtaining biological measures and methodological limitations such as small sample size lessen the resulting data's potential contribution to the field. Furthermore, replication of key findings is not commonly observed, although it is important

to note that a failure to replicate is not specific to this particular field.

Finally, a salient weakness that needs to be addressed is the selection of appropriate patient samples. Psychoimmunological effects may be more relevant to and more likely to be observed among people with highly immunogenic tumors (*e.g.*, basal cell carcinoma, renal cell carcinoma, and cervical cancer). In these individuals, where the psychosocial-immune-tumor response link is definable, psychosocial intervention is more likely to yield discernable effects. Furthermore, stage of disease is an important factor to consider when testing psychosocial interventions, which tend to produce small to moderate immune effects. Interventions directed at individuals with late-stage tumors are less likely to demonstrate any significant biological changes as a result of the overwhelming effects associated with tumor biology.

**Directions for Future Research.** The accumulating data suggest that additional exploration of the role of psychosocial factors on cancer outcomes (*i.e.*, disease- and treatment-related morbidity, tumor progression, and survival) is warranted. A growing awareness of the complexity of biological measures and the bi-directional influence of the central nervous system and immune system illustrates the need for multidisciplinary perspectives. The field needs to continue to focus on promising areas of research by defining immunogenic cancer sites for studies relating to cancer progression, regression, and survival, as well as to expand the current research domain to include other cancer outcomes such as disease- and treatment-related morbidity (*e.g.*, fatigue and infection). Finally, there is a clear need to explore health disparities within this area of research and to extend research beyond the focus on more selected samples to include more population-based studies.

Three main research directions would significantly contribute to the existing knowledge and database in this field. First, there is a conceptual need to identify appropriate biomarkers and to extend biological assessments beyond the immunological to include genetic, neuroendocrine, and physiological measures. Assessments of functional activity such as DNA repair mechanisms and apoptosis may also provide insight into the various pathways underlying psychosocial effects on cancer outcomes. Incorporation of these types of assessments would require that investigators have multidisciplinary training and/or a multidisciplinary team of collaborators. In addition, research teams should develop a closer interface with clinicians to gain a greater understanding of the clinical relevance of these types of biomarkers.

Second, there is a need to strengthen study design and methodology. Findings are often limited by the use of nonexperimental research designs or by sample size constraints. Moreover, choosing the appropriate group is crucial. A greater focus on at-risk individuals (*e.g.*, intraepithelial neoplasia or precancers) may translate into clinical benefits in terms of prevention and regression of precancerous lesions (*e.g.*, Ref. 60). Biobehavioral studies that are conducted within the context of a chemoprevention trial may provide the most pertinent and timely information.

Third, additional research on health disparities is needed to shed light on the potential biobehavioral mechanisms that may account for differential incidence and mortality rates across groups. Findings from other research domains (*e.g.*, cardiovascular disease) have demonstrated ethnic and racial differences in stress reactivity that, by extension, may also contribute to discrepancies in cancer outcomes. Some prior studies may not have adequately controlled for socioeconomic differences

across racial or ethnic groups. Therefore, it has been difficult to determine whether observed differences are because of biological or socioenvironmental factors. Nevertheless, differences in physiological responses to stress, whether because of biological mechanisms, socioeconomic factors, or some combination of the two, can result in differential uptake of health behaviors (e.g., tobacco use, diet, or exercise), with subsequent effects on cancer risk, treatment response, and cancer-related morbidity and mortality.

### Behavioral Oncology Roundtable 3: The Role of Risk Perceptions in Cancer Screening Adherence

**Introduction.** Cancer risk perceptions represent a core construct in cancer prevention and control research. Perceptions of one's own risk for cancer appear in most behavioral models are researched in multiple patient and nonpatient settings, and risk estimates are given by providers as potential motivators for behavior change.

**Goals of the Research Area and Key Findings.** Studies that explore the role of risk perceptions in health behavior have involved selected groups such as high-risk individuals (e.g., participants in a genetic testing program; Refs. 30, 61, 62) and have focused on detection behaviors (e.g., prostate and colon cancer screening; Refs. 63, 64). The majority of these studies have found that the individual's perception of cancer risk is only a moderate predictor of screening behavior (65), which often disappears in final measurement models (e.g., Refs. 66, 67). The emerging data suggest that cancer risk perceptions need to be considered as one component of a greater constellation of inter-related disease-specific cognitions and affects (32, 68–70).

**Strengths of the Research Area.** Cancer-related perceptions of risk are multifaceted constructs that may be interpreted in several ways for any one individual. For example, perceived risk for cancer may be associated with the risk of developing disease, the risk of side effects associated with treatment of the disease, or the risk of disease recurrence. Accumulating evidence over the past years supports the multifaceted nature of the risk perception construct (e.g., Refs. 71–74). Such an interpretation is additionally supported by recent cognitive-affective theoretical perspectives (e.g., Refs. 68, 75), which stipulate that a complex pattern of cancer-relevant beliefs and expectations (i.e., disease representations) influence a person's overall risk perception.

To date, the strengths of this research area can be seen not so much in the answers that it has yielded across studies, but in the questions that have been raised. The heterogeneous results obtained with the risk perception construct underscores the need to examine issues such as how individuals process and understand risk-related information, how they react effectively to risk feedback, and how best to communicate risk information. The findings additionally emphasize the need to imbue the perceived risk construct in current theories of health and behavior. In particular, the study of risk perceptions needs to go beyond the reliance on the perceived risk variable as the single predictor of behavior or adjustment in different adherence contexts (32).

**Weaknesses of the Research Area.** There are a number of possible explanations for the weak effects of the risk perception construct. First, limitations in the way in which risk is currently measured may act to minimize or mask the actual effects of this variable. In general, there is little variation in the measurement of risk, with two main commonly used approaches: (a) as an estimate of the percentage likelihood of developing the cancer

type, ranging from 0 to 100% (e.g., Refs. 63, 76); and (b) as a Likert-type scale, with descriptions of the likelihood of developing the disease ranging from very low to very high (e.g., Refs. 64, 77, 78).

Individuals may have difficulty interpreting these questions because of differing basic conceptualizations or grounding points, from which they estimate risk (79). Researchers usually do not assess how participants interpret closed-ended questions such as the ones just described. However, such assessments are warranted because individuals differ predictably in their personal experiences, beliefs, expectations, and somatic experiences related to cancer, which in turn affect personal risk assessments (68, 75).

It could be the case that inaccurate personal risk perceptions (too high or too low) are related to lack of information about disease incidence rates. However, research has repeatedly demonstrated that individuals often persist in their inaccurate risk beliefs, even after extensive counseling (80). The cognitive-affective, self-regulatory framework offers an explanation for these findings: because risk perceptions result from stable individual belief systems, are grounded in personal experiences, and are connected to somatic events, they become deeply embedded in a person's representation of the self (32). Consequently, the addition of new information that does not address long-held beliefs, expectations, and somatic experiences or that contradicts these existing belief structures will not be potent modifiers of the individual's risk perceptions.

**Directions for Future Research.** A growing awareness of the limitations of current approaches to the assessment of cancer risk perceptions and the acknowledgment of the complexity of the risk construct literature illustrate the need for a multidisciplinary perspective in this area. Researchers must begin to adopt a conceptually grounded multidisciplinary approach, to integrate advances in theory model building from diverse sub-areas of social and cognitive science, and to embrace novel methodologies for assessing this construct.

On the basis of the existing data, four main directions for additional research can be identified. These directions include the expansion of the overall scope and depth of cancer risk investigations, with a specific focus on groups that have been otherwise neglected. Most importantly, we need to expand the conceptual domain to include a wider perspective on subjective interpretations and definitions of risk. There is a need to move beyond the current unidimensional measurement paradigm to supplement existing methods of risk assessment with multidimensional methods used in areas such as social psychology, cognitive psychology, and marketing. For example, risk perceptions may be influenced by heuristics and biases as described by Kahneman (81), by information processing tendencies (68), and by different mood states (82).

A second direction is to develop more sophisticated measurement tools for assessing risk perceptions. Applying a broader theoretical and empirical base from diverse disciplines will help to not only fine-tune existing survey-type measures of risk assessment but also to use more diverse approaches to risk assessment through the use of qualitative methodologies. Qualitative methods would greatly elucidate what we know about how individuals think and how they react emotionally when responding to perceived risk questions. Information from these studies could then be used to develop more rigorous quantitative assessment tools.

Third, to date, few studies assessing risk have used an experimental design; thus, the causative role of risk perceptions in relation to cancer screening behaviors has not been ade-

quately delineated. In addition to fully develop a broad-ranging understanding of risk perceptions, cancer researchers need to extend their research perspectives to include what is already known about risk-related adherence behaviors from other disease contexts such as HIV/AIDS (*e.g.*, Refs. 83, 84) and cardiovascular disease (*e.g.*, Refs. 85, 86).

Finally, there is a need to identify the role of background factors (such as gender, ethnicity, age, culture, disease site, and socioeconomic status) as they relate to risk perceptions. As such, the analysis of risk needs to encompass the broader social/disease context because it is not clear to what extent risk perceptions are stable across different situations, disease models, and population-based settings. For example, research to date has focused primarily on risk perceptions for a specific cancer type (87–90). A thorough understanding of cancer risk will require an exploration of how individuals encode their vulnerability across a number of different cancer sites. Similarly, the specific stage within the cancer continuum may differentially influence an individual's risk perceptions. For example, perceptions of cancer risk for an individual contemplating participation in a chemoprevention trial may be quantitatively and qualitatively different from the perceived risks associated with participation in a cancer treatment trial.

#### **Behavioral Oncology Roundtable 4: The Contribution of Tailored and Targeted Interventions to Cancer Prevention and Control Research**

**Introduction.** Research increasingly points to the importance of health behaviors in the primary prevention and early detection of cancer and other chronic diseases. A growing body of research has demonstrated that tailored and targeted interventions are generally more effective than one size fits all behavior change programs. Many unanswered questions remain, however, such as the relative effectiveness of tailored communications compared with other state-of-the-art intervention approaches, the circumstances under which tailoring *versus* targeting should be used, and the mediators of the effectiveness of tailored communications.

In terms of definitions for this article, the term targeting (based on social marketing principles) refers to audience segmentation and analysis using formative research that leads to interventions designed to appeal to group-level characteristics such as demographics or other shared characteristics (*e.g.*, cultural beliefs). The term tailoring, on the other hand, is used to describe interventions that vary according to individual-level characteristics. Tailored communications are assessment based and should include personalized information that is relevant to the identified psychosocial constructs, as well as providing behavioral feedback (90).

**Key Findings and Goals of the Research Area.** Several recent review articles have summarized the evidence for the effectiveness of computer-tailored communications (92–94). Skinner *et al.* (92) reviewed the first 12 published studies, which spanned a variety of health behaviors, including diet, physical activity, smoking, and mammography screening. Findings showed that tailored print materials outperformed nontailored information in terms of process (*e.g.*, attention, recall, readership, or perceived relevance) and outcome (*e.g.*, fat intake or obtaining a mammogram) measures. Furthermore, a review of tailored smoking cessation interventions showed generally favorable outcomes of tailoring, especially among precontemplators and when combined with nicotine replacement therapy (95).

The evidence has been less clear when tailored materials

have been compared with other intervention modalities such as telephone counseling. Additional discussion of mixed findings can be found in the review of Rimer and Glassman (94) and in a recent experimental study with nicotine replacement and computer-tailored materials (96). Additional limitations noted in the articles included relatively short follow-up periods and lack of standardization of many elements of tailoring methods, including differing theoretical frameworks, number and choice of tailoring variables, decision rules and algorithms, and process and outcome measures.

Currently, tailoring research includes a continued focus on the effectiveness of print communications, as well as the use of new media such as the Internet, CD-ROM, and automated telephone systems (97–99). Although the bulk of the evidence supports the efficacy of tailoring, some studies have shown no added effects of tailored messages over well-designed nontailored information (100, 101). Studies have begun to investigate mediating steps in the process between exposure to tailored information and behavior change such as the role of cognitive processing of messages, effects of tailoring to specific psychological characteristics, and the relative impact of varying message sources and characteristics (102–105). In addition, Kreuter (91) have suggested that targeted materials can perform as well as tailored information when there is a good match between participant characteristics and group-level targeting variables (*e.g.*, when there is a relatively high degree of homogeneity in behavioral determinants in the group under study).

**Strengths of the Research Area.** Several strengths of the research on tailored interventions can be identified. First, based on well-designed randomized trials, there is a growing body of evidence demonstrating that tailored interventions can achieve health behavior changes, including diet, physical activity, smoking, and screening behaviors such as mammography (106). Second, there is evidence to suggest possible mechanisms whereby tailoring may exert its effects based on theories of information processing, social psychology, and persuasion (32, 102–104, 106, 107). Third, more recent research indicates that tailored interventions are effective for minority and lower income groups, thereby offering a potential avenue to reduce health disparities (98, 108). Finally, with the growing use of and access to innovative technologies such as the Internet, new opportunities are emerging for broad dissemination and testing of tailored health behavior change interventions.

**Weaknesses of the Research Area.** Studies that have directly compared the efficacy of tailored interventions to other strategies such as telephone counseling have produced inconsistent results (92). It is important to note, however, that traditional interventions such as in-person and telephone counseling, by definition, constitute tailored modalities of information provision. In contrast to programmed tailored messages, however, the counselor is able to provide on-the-spot, spontaneous individualization of information to the participant's personal and situational characteristics. One might expect, therefore, an equivalent or superior outcome from highly trained, skilled counselors who can deliver the message in a dynamic interactive fashion that takes advantage of social and nonverbal cues, rather than drawing from predetermined message libraries and algorithms to provide the feedback. In addition, computer-tailored interventions rely on assessment of psychosocial and behavioral construct measures to determine tailored feedback. However, many of these measures have never been subjected to psychometric testing or validation in diverse groups and cultures.

Follow-up periods generally have been short (several

months), and many studies have relied on self-report information to assess outcomes. More evaluative research is also needed regarding the relative impact of tailoring using new technologies such as the Internet. In addition, most tailored communications generally have focused on individual-level behavior change, whereas many health behaviors are strongly influenced by other levels of change in the socioecological model such as social and community norms and environmental factors (109). Greater attention needs to be paid to multilevel interventions that incorporate tailoring as one of a number of coordinated and integrated interventions (108). There is also a need to more systematically extend tailoring studies beyond screening and behavioral change outcomes to provide a greater focus on decision-making and long-term adjustment.

**Directions for Future Research.** Tailored and targeted cancer communications have shown promise for cancer prevention and control research. Future studies should be designed so that theories, measures, and mechanisms can be elucidated and so that efficacious interventions can be compared and replicated. There are three broad directions for future research. First, there is a need to specify and study the relative efficacy of differing amounts of tailoring and targeting in intervention studies. Because many interventions include both individualized tailoring and group-level targeting, researchers should specify which parts of the interventions are tailored *versus* targeted and the rationale for those choices.

Second, research is needed to understand the “black box” of unanswered questions that could explain whether and why tailored interventions are effective. To advance the field, it is vitally important to foster the next generation of studies that can add to our understanding of the factors that explain or mediate the processes and outcomes of tailored interventions, including greater specification of presumed underlying mechanisms, theories, and contextual factors.

The key research questions under this goal include the following.

1) What variations between groups or individuals are most predictive of who will—or will not—benefit from tailored and/or targeted communications (110)? Some research suggests that variation is greater within than between cultures, arguing for tailoring as well as targeting. Different cultural groups and individuals within those groups may vary on many issues such as trust, access to information and media/technology, literacy, language, beliefs, and cultural and ethnic identity; however, it is not clear whether tailoring to some or all of these variations will increase efficacy (111).

2) What are the contextual factors that may explain under what circumstances or situations tailoring may be most effective? This may include recognizing the influence of factors such as teachable moments; for example, diagnosis of an illness such as cancer in oneself or a family member may heighten motivation for health behavior change (112, 113). Affective states such as depression or anxiety as well as situational, environmental, and developmental factors all may play a powerful role in determining a person’s ability to comprehend, process, and act on health information.

3) What are the basic mechanistic factors underlying tailored communications? Understanding of mechanisms will require laboratory studies of communication and information processing, qualitative studies to observe the processes by which people receive, process, use, and incorporate tailored information into their behavior change efforts, and dose and timing studies to determine the amount of intervention necessary to produce change. In addition, in studies where multiple

behaviors are included in interventions (e.g., diet and physical activity), research should address how individuals choose and prioritize among these behaviors and how best to design and evaluate communications to facilitate these decisions (114).

4) What media are most effective and cost-effective? Studies are needed to evaluate the appropriateness, understandability, and usability of different media used for tailoring, including the Internet and interactive technologies such as handheld computers and automated voice recognition, as well as more traditional media such as print and telephone counseling (115).

5) What theories and models should underlie tailored and targeted communications? Most research studies of tailoring to date have been based on a relatively small number of health behavior theories based in cognitive psychology, including the transtheoretical model or stages-of-change model, Health Belief Model, and Social Cognitive Theory (116–118). We know relatively little regarding the relative mediating effects of these variables and constructs in tailored interventions or how many variables is the optimal number for tailoring (32).

**General Conclusions.** There is remarkable consensus regarding future directions in the four areas of research. The areas of priority revolve around three key issues: (a) incorporation of more comprehensive and integrative conceptual models; (b) greater sophistication and advances in methodological approaches; and (c) identification of the individual and group characteristics of the target population. First, all four areas call for the further development of more integrative and overarching conceptual models to systematically assess and address the phenomena under study. Greater theoretical consistency and richness would be invaluable for accomplishing a number of goals, including the use of more comprehensive, unifying, and predictive models; the formulation of more hypothesis-driven research questions; the resolution of methodological confusions; as well as the design and evaluation of more refined measurement approaches and more effective intervention strategies.

Second, there is a uniform need for the application of sound methodological research principles. In particular, all four areas would benefit from more precise measurement of the key constructs under consideration, as well as greater rigor in study design, including long-term evaluation. Measurement improvements are particularly important for the areas of Behavioral Approaches to Cancer Genetic Assessment and Testing (Roundtable 1) and the Role of Risk Perceptions in Cancer Screening Adherence (Roundtable 3). Advances in study design and selection of appropriate control groups are critical for the areas of Biological Mechanisms of Psychosocial Effects of Cancer (Roundtable 2) and the Contributions of Tailored and Targeted Interventions to Cancer Prevention and Control Research (Roundtable 4).

Finally, a key agenda for future research is to delineate the characteristics of target populations that need to be considered. This agenda requires greater attention to the sample selection procedures in terms of such factors as the inclusion of disadvantaged individuals into research projects, the use of population-based recruitment, and more precise characterization of the target samples as predictors and influences on outcomes.

The outcomes of the roundtables show the breadth, as well as the depth of behavioral contributions to cancer prevention and control. Furthermore, they point to the importance of linking psychosocial investigations to the broader behavioral science base that guides them and of achieving more seamless collaboration between behavioral science investigators and their public health and medical science collaborators.

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