A Model of Health Behavior to Guide Studies of Childhood Cancer Survivors

Cheryl Lorane Cox, RN, PhD

The rates of disease-free survival at five years for most childhood cancers now exceed 70%, and 1 in 900 adults from 20–45 years of age in the United States is a childhood cancer survivor (Ries et al., 1999). An array of potential late effects of radiation therapy and chemotherapy renders this population vulnerable to long-term health problems, such as second cancers (Bhatia et al., 1996; Black, Straaten, & Gutjahr, 1998; Swerdlov et al., 1997), cardiovascular problems (Green, Hyland, Chung, Zevon, & Hall, 1999; Hudson et al., 1998; Hudson, Jones, Boyett, Sharp, & Pui, 1997; Wolden, Lamborn, Cleary, Tate, & Donaldson, 1998), osteoporosis (Atkinson, Halton, Bradley, Wu, & Barr, 1998; Hoorweg-Nijman et al., 1999; Vassilopoulou-Sellin et al., 1999), and obesity and its sequelae (e.g., hypertension, diabetes, dyslipidemia) (Oeffinger et al., 2001; Sklar et al., 2000; Talvensaari, Lanning, Tapanainen, & Knip, 1996).

In the general population, sound dietary practices, breast and testicular self-examination, and aerobic and resistance exercise are behaviors known to reduce the risk of cardiovascular disease, diabetes, osteoporosis, obesity, and cancer (U.S. Department of Health and Human Services, 2000). These self-care behaviors are especially important to the long-term health and well-being of cancer survivors given their treatment-related risks. However, studies have documented that adolescent and young adult survivors choose not to engage in these health-promoting behaviors; instead, they practice high-risk behaviors (e.g., tobacco use, recreational drug use, unprotected sexual activity, alcohol consumption) at a rate equal to or exceeding that of their healthy peers (Corkery et al., 1979; Haupt et al., 1992; Hollen & Hbbie, 1996; Tao et al., 1998; Troyer & Holmes, 1988; Tye, Hudson, & Hinds, 1999). Only recently have investigators begun to develop and test interventions designed to reduce risk behavior and increase health-protective behavior in young cancer survivors (Hudson et al., 2002). For the most part, these interventions have focused on changing survivors’ beliefs about treatment-related risks and the efficacy of health-protective behaviors in reducing those risks. Providers present risk and risk-modification and well-being of cancer survivors given their treatment-related risks. However, studies have documented that adolescent and young adult survivors choose not to engage in these health-promoting behaviors; instead, they practice high-risk behaviors (e.g., tobacco use, recreational drug use, unprotected sexual activity, alcohol consumption) at a rate equal to or exceeding that of their healthy peers (Corkery et al., 1979; Haupt et al., 1992; Hollen & Hbbie, 1996; Tao et al., 1998; Troyer & Holmes, 1988; Tye, Hudson, & Hinds, 1999).

Only recently have investigators begun to develop and test interventions designed to reduce risk behavior and increase health-protective behavior in young cancer survivors (Hudson et al., 2002). For the most part, these interventions have focused on changing survivors’ beliefs about treatment-related risks and the efficacy of health-protective behaviors in reducing those risks. Providers present risk and risk-modification

Purpose/Objectives: To describe the Interaction Model of Client Health Behavior (IMCHB) and its application to health promotion in childhood cancer survivors.

Data Sources: Periodical literature about cancer survivors, health behavior models, and the IMCHB.

Data Synthesis: Childhood cancer survivors are at risk for various late complications of treatment. The primary goal of intervention is the modification of health-related behavior. Conceptual models that extend beyond health beliefs are needed to guide explanatory and intervention studies in this group.

Conclusions: The IMCHB identifies background, cognitive, affective, motivational, and contextual variables that explain health-related behaviors. The model defines the interactive and collective contributions of a survivor, family, and provider to adherence to protocols, reduction of risk behavior, and promotion of health-protective behavior.

Implications for Nursing: This model may identify new determinants of health-related behavior that can be targeted by specific inter- or intrapersonal interventions to protect the health of childhood cancer survivors and reduce their risk of late sequelae.

Key Points . . .

➤ Survivors of childhood cancer engage in health-risk behaviors at a rate comparable to or exceeding that of their healthy peers, despite their increased risks for treatment-related complications.

➤ Documentation is limited or nonexistent regarding the antecedents of participation in risk behaviors or health-protective behaviors for this vulnerable group.

➤ New conceptual approaches that broadly consider intrapersonal and contextual determinants of health-related behavior are needed to direct explanatory and intervention studies of childhood cancer survivors.

➤ The Interaction Model of Client Health Behavior has the potential to identify new targets for behavioral intervention.

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Digital Object Identifier: 10.1188/03.ONF.E92-E99
information by combining patients’ goal selection and a classical health education approach. Survivors choose a behavior on which to focus (e.g., stopping smoking, initiating an aerobic exercise program), and behavior-specific information is provided during the patient-provider encounter.

This cognitive processing approach, which uses only knowledge to inform beliefs and attitudes, has shown limited success in reducing health-risk behaviors or increasing health-enhancing behaviors; therefore, survivors’ behavioral choices are likely to reflect factors other than beliefs and attitudes toward their disease and knowledge about treatment-related risks and risk modification. Multiple intrapersonal variables (e.g., perceived current and future health status, perceived sense of self, developmental status, diagnosis and treatment experiences, affective responses to their disease and its treatment, demographic factors) that extend beyond health beliefs and attitudes may influence survivors’ behavior choices.

Family, social, and healthcare contexts are equally important influences on behavior (Gochman, 1997). Family and peer responses to survivors’ disease and treatment and to their health-related behaviors may significantly influence whether they follow prescribed or proscribed regimens. The preliminary findings of a recent qualitative study suggested that the disease-related behavior of childhood cancer survivors is affected strongly by providers’ communication style, the relationships between providers and patients, and the extent to which providers recognize their patients’ autonomy in choice of behavior (Crom, Hinds, Gattuso, Tyc, & Hudson, 2002). The inclusion and documentation of these intrapersonal and contextual variables in explanatory studies of childhood cancer survivors’ health-related behaviors offer an opportunity to design risk-targeted, multifocal interventional interventions to decrease the late complications of treatment.

Prior Applications of the Interaction Model of Client Health Behavior

The Interaction Model of Client Health Behavior (IMCHB) (Carter & Kulbok, 1995; Cox, 1982, 1984, 2000) was developed to describe the multiple interacting antecedents of health-protective and risk-taking behavior and to identify provider behaviors that affect health outcomes. This model has served as the basis for a variety of health behavior studies in which the uniqueness of each patient was used to explain variances in health outcomes. Studies have focused on adult health behaviors, such as prenatal diagnostic testing (Cox & Roghmann, 1984), smoking cessation (Solheim, 1989), employee fitness (Cox & Montgomery, 1991), health-promotion behavior in military personnel (Troumbley & Lenz, 1992), practitioner-patient interaction in prenatal care (Brown, 1992), condom use among separated and divorced women (Marion & Cox, 1996), and reproductive decision making (Read, 2002). The IMCHB has guided explanatory studies in pediatric and adolescent health behavior, such as adolescent violence (DiNapoli, 2000), contraceptive use among adolescents (Aruda, 2002), and children’s health-promotion behaviors (Farrand & Cox, 1993).

A number of instruments have been designed to measure specific concepts within the IMCHB: self-determination in the health behaviors of adults (Carter & Kulbok, 2002; Cox, 1985) and children (Cox, Cowell, Marion, & Miller, 1990), satisfaction with care (Bear & Bowers, 1998), self-determination in sexual risk-taking behavior (Abel, Marion, & Sera-}

**Structure of the Interaction Model of Client Health Behavior**

The framework of the IMCHB (see Figure 1) incorporates physical, social, cognitive, motivational, affective, and environmental antecedents to health behavior. The model gives a prominent contextual role to the provider or clinician in effecting positive and negative health outcomes. The original empirical support for the concepts and their relationships in the IMCHB is reported in detail elsewhere (Cox, 1982, 1984). Briefly, the model comprises three elements: client singularity (the unique intrapersonal and contextual configuration of the individual), client-professional interaction (the therapeutic content and process that occurs between a clinician and patient), and health outcomes (the behavior or behaviorally related outcome subsequent to a client-professional interaction). The basic assumptions of the model (described in detail in Cox [1984]) recognize the role of choice and self-determination in health behavior, the ability of the clinician’s interaction style and intervention approach to support or discourage health behavior, and the dynamic impact of the client’s singularity.

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**Figure 1. Interaction Model of Client Health Behavior**
profile on health outcomes. The model’s working hypothesis is that the potential for positive patient health outcomes increases as the provider intervention or interaction is tailored to the uniqueness of each patient (i.e., background and cognitive, affective, and motivational manifestations).

A reciprocal relationship (as noted in Figure 1) has been found between the dynamic variables of client singularity and the four concepts that constitute the client-professional interaction element. Briefly, the intervention must address the unique configuration of the client’s singularity to maximize positive health outcomes. Over time, the health outcomes element exerts a feedback effect that can influence both the background and dynamic variables of the client singularity element.

The model was intended to accomplish two sequential purposes: to guide the inclusion of client singularity variables in studies that may explain health-related behaviors and their associated health outcomes and to lead the design of interventions that target these identified variables.

Client Singularity

This element of the model comprises two different sets of factors: background variables (e.g., gender, religion, health history) and dynamic variables (e.g., motivation, knowledge, fear). These variables can be defined and measured in terms of many different factors. Together, these sets of factors can define the uniqueness of every young cancer survivor (client singularity) at a given point in time on the basis of intrapersonal and socioenvironmental contextual characteristics.

Background Variables of Client Singularity

Factors such as demographic characteristics, social influence (e.g., culture, religion, peer influences, social network, social support), previous healthcare experiences (e.g., health history, developmental status, objective health data), and environmental resources (e.g., access to health care, barriers to health care, personal resources) are relatively static variables at any single point in time (i.e., the time at which the patient-provider encounter occurs). Selected background variables may change over time, but such change tends to be subtle. For example, a young survivor’s treatment history and response to that treatment remain relatively stable as perceived experiences within a given developmental stage. The impact of the change in these background variables on motivated behavior, in most cases, will not be immediate because health-promoting and health-risking behaviors are largely under the control of the patients.

Unique to survivors of pediatric cancer are the influences of developmental status. Developmental status is treated as a background variable within the IMCHB in that, at any given point in time, a child’s developmental status is an important consideration in explaining health behavior. The inclusion of developmental status within the background variables category does not imply that it is a static variable; indeed, over time, developmental status will change. Although interventions to modify behavior must incorporate an understanding of a child’s development, developmental status itself is not altered by the intervention, thus making developmental status a stable rather than a modifiable model characteristic.

Background variables are posited to have a direct influence on some health outcomes (e.g., sex and income may weakly predict adherence or utilization) (Cockerham, 1997); however, they mainly serve as explanatory antecedents to the dynamic variables of client singularity. For example, a survivor whose family has a limited income (demographic characteristic), no health insurance (environmental resource), and members who fear the worst when a new symptom arises (social influence) may decide (intrinsic motivation, as a dynamic variable) against making an appointment for a follow-up medical evaluation.

The background variables are assumed to be interrelated. Demographic characteristics certainly influence the cultural factors of social influence (e.g., racial, ethnic, and cultural connections). Demographic characteristics and social influence often are tied to health history, health status, and experience. Demographic characteristics and other background variables are connected similarly to the availability and nature of environmental resources.

Multiple interrelated indicators, such as those described by the background variables, can make a conceptual model cumbersome. However, because the IMCHB was developed to guide clinical practice through research, the model attempts to articulate all potentially important direct and indirect conceptual classes of correlates of health-promoting and risk behaviors.

If the background variables that are most important in identifying individuals at risk or in explaining individuals’ cognitive appraisal, motivation, or affective responses are identified, interventions can be tailored specifically to them. For example, interventions that target young male and female survivors separately may be optimal if sex is strongly explanatory of a given health behavior or is a strong determinant of the dynamic variables of client singularity (Farrand & Cox, 1993). A recent study demonstrated distinctive patterns between adolescent cultural and ethnic groups and risk-taking behaviors; consequently, interventions may need to be tailored specifically to cultural and ethnic survivor groups to maximize their impact (Kulbok & Cox, 2002).

Dynamic Variables of Client Singularity

Cognitive appraisal, affective response, and motivation are dynamic variables (see Figure 1 and Table 1). These variables would be affected by an intervention more immediately than would background variables (which tend to be more static) (Wilbur, Miller, Chandler, & McDevitt, 2003). Cognitive appraisal comprises such factors as patient knowledge, beliefs, and attitudes toward the illness and treatment. These factors (knowledge, beliefs, and attitudes) correspond to those previously used in studies of interventions in childhood cancer survivors (Hudson et al., 2002). Affective response factors are based on emotion and ultimately contribute to behavioral decision making. Fear, anxiety, anger, joy, sadness, and uncertainty can be very strong predictors of behavior that are independent of other cognitively based variables (attitudes, knowledge, and beliefs) (Deci & Ryan, 2002).

Motivation in the IMCHB is defined according to the concept of intrinsic and extrinsic motivation derived from the Theory of Self-Determination (Deci & Ryan, 1985). Briefly, the motivation for a behavior is based on two major operative factors: the content of a patient’s behavioral goals (intrinsic versus extrinsic) and the regulatory processes (autonomous versus controlled) through which these goals are pursued. Both content and process affect goal-directed behavior (Deci & Ryan, 2002).
The dynamic client singularity variables (i.e., motivation, cognitive appraisal, and affective response) influence one another. Attitudes, knowledge, and beliefs (factors of cognitive appraisal) contribute to motivation and emotions (affective response). Similarly, emotions can influence motivation and beliefs. For example, consider a young cancer survivor who recently discovered a mass in her breast. The discovery generates overwhelming fear of recurrent or new disease (affective response); this fear, in turn, generates a fear-controlled goal not to seek medical attention (motivation). Alternatively, another young female survivor on making the same discovery might act on her knowledge (cognitive appraisal) that not all breast masses are cancerous. This leads to the self-determined intrinsic goal (motivation) to seek evaluation to reduce her anxiety (affective response).

Although cognitive appraisal, motivation, and affective response all are cognitively based, the IMCHB proposes that the behavioral impact of each of these constructs can be very different, thus creating the need for conceptual specificity and distinction. The IMCHB conceptually separates and distinguishes each of the concepts to enable the development of more focused interventions. Use of the model to pinpoint the

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**Table 1. Correspondence of the Interaction Model of Client Health Behavior Labels With Descriptors Relevant to Childhood Cancer Survivors**

<table>
<thead>
<tr>
<th>Labels</th>
<th>Conceptual Definition</th>
<th>Childhood Cancer Survivor Descriptors</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Client Singularity</strong></td>
<td>Unique intrapersonal and contextual configuration of an individual based on background variables, motivation, cognitive appraisal, and affective response</td>
<td></td>
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<tr>
<td>• Background variables</td>
<td></td>
<td></td>
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<tr>
<td>– Demographic characteristics</td>
<td>Relatively nonmodifiable influences on health behavior</td>
<td>Age, education, race or ethnicity, family income</td>
</tr>
<tr>
<td>– Social influence</td>
<td>Client characteristics</td>
<td>Variation in amount and consistency (religiosity; family, peer, and cultural influences)</td>
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<tr>
<td>– Previous healthcare experience</td>
<td>Health history (objective and subjective), current physiologic health status, and developmental status</td>
<td>Diagnosis and treatment history or experience, response to treatment, dexamethasone levels</td>
</tr>
<tr>
<td>• Environmental resources</td>
<td>Availability of informational, people, financial, and geographic resources to facilitate health behavior</td>
<td>Access to oncology providers, other providers, insurance, transportation, and informational resources</td>
</tr>
<tr>
<td>• Dynamic variables</td>
<td>Modifiable targets for intervention</td>
<td></td>
</tr>
<tr>
<td>– Affective response</td>
<td>Emotional response to a health concern</td>
<td>Fears about the future, health, fertility, and interactions with peers, family, and teachers; depression; anxiety over loss of contact with oncology providers and adequacy of generalist’s care</td>
</tr>
<tr>
<td>– Motivation</td>
<td>Intrinsic or extrinsic motivation, self-determination</td>
<td>Feelings of competency related to disease course, treatment, or new behaviors; health behaviors based on intrinsic (self-determined) versus extrinsic (non–self-determined) goals</td>
</tr>
<tr>
<td>– Cognitive appraisal</td>
<td>Cognitive representation of a health concern</td>
<td>Knowledge; attitudes; beliefs about health, cancer, treatment, and health behaviors</td>
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<td><strong>Client-Professional Interaction</strong></td>
<td>The extent to which the provider attends to a client’s singularity and tailors the intervention approach to that singularity</td>
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<tr>
<td>• Affective support</td>
<td>The process of attending to a client’s level of emotional arousal and building an affiliative bond with the client</td>
<td>The bond with the survivor, acknowledgement of survivor’s feelings about disease and treatment</td>
</tr>
<tr>
<td>• Provision of health information</td>
<td>The process of providing useful health information to a client</td>
<td>Timing, content, quantity, method of delivery, validation of learning</td>
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<tr>
<td>• Decisional control</td>
<td>The process of creating a healthcare climate that is supportive of autonomy rather than controlling</td>
<td>Supporting a survivor to participate in his or her own healthcare decision making, avoiding controlling statements</td>
</tr>
<tr>
<td>• Professional or technical competencies</td>
<td>Therapeutic skills of the provider</td>
<td>The ability of the provider to tailor the intervention to the uniqueness of each survivor</td>
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<tr>
<td><strong>Health Outcomes</strong></td>
<td>Health behavior or health state that is behaviorally related</td>
<td></td>
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<tr>
<td>• Healthcare utilization</td>
<td>The extent to which an individual seeks out and uses available healthcare resources</td>
<td>Follow-up appointments, participation in support groups</td>
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<tr>
<td>• Health status indicators</td>
<td>Physiologic, psychological, social health, and well-being parameters</td>
<td>Fitness levels, well-being measures</td>
</tr>
<tr>
<td>• Problem-severity indicators</td>
<td>Disease progression, stabilization as a function of measures of disease or treatment sequence</td>
<td>Symptoms, fatigue, appetite, quality of life</td>
</tr>
<tr>
<td>• Adherence to the recommended care regimen</td>
<td>Extent to which a patient engages in care regimens, behaviors, or treatments that are necessary to ensure optimal health</td>
<td>Use of sunscreen, takes prescribed medications</td>
</tr>
<tr>
<td>• Satisfaction with care</td>
<td>Client’s appraisal of adequacy of a provider’s response to a healthcare problem and extent to which the patient’s expectations are or are not met</td>
<td>Perceived adequacy of care, satisfaction measures</td>
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descriptive factors that explain young survivors’ health-related behaviors would allow for interventions targeted at these factors. The greater the precision with which an intervention is targeted to the multiple explanatory contributing factors of a behavior, the greater the likelihood that the intervention will be effective.

The importance of paying attention to the uniqueness of each patient was supported in a recent focus group study of young female survivors of childhood cancer. When asked what providers could do to support survivors’ health-protective behaviors, they responded resoundingly and unanimously, “Listen to my story.” They wanted providers to listen to and address their fears, their specific knowledge deficits, and internal and external factors that supported or negated positive health behaviors (Crom et al., 2002). These young patients articulated their need for providers to recognize their singularity and to address that singularity in interactions and interventions. This study was conducted without any knowledge of the IMCHB, yet the patient data strongly support multiple concepts within the model.

Client-Professional Interaction

Four factors define the client-professional interaction element: affective support, provision of health information, decisional control, and professional or technical competencies. Affective support means attending to a survivor’s level of emotional arousal and building an affiliative bond with the client (Cox, 1984). These two aspects of affective support are related in complex ways (see Cox [1984] for a more detailed discussion) and have particular relevance to childhood cancer survivors. During treatment, pediatric patients with cancer develop very strong bonds with their oncology care providers. After completion of therapy, patients often are returned to generalist providers for continuing care and follow-up. The loss of relationships with oncology care providers and worry that the generalists may not provide adequate cancer follow-up can be powerful determinants of subsequent behavioral choices.

The provision of health information to cancer survivors can be examined from multiple perspectives: the nature (specific versus abstract) and content (the message) of information provided, the manner in which the information is conveyed (written, audio, video, or one-on-one interaction), the affective state of patients when the information is offered, and the quantity of information provided. Health information varies in type and function. Some health information is useful in informing survivors’ cognitive appraisal (e.g., didactic content on treatment-related complications and risks). Other health information can be used to promote intrinsic motivation (e.g., positive feedback on survivor-initiated health-protective behavior). Some information can focus on altering the affective response (e.g., specific information about how a treatment will feel to lessen patient anxiety).

Decisional control conceptually represents providers’ recognition of patients’ ability to participate in decision making related to their own health care. Although most healthcare professionals would insist patients’ input into healthcare decision making is normative, it still is often overlooked as a specific intervention strategy (Gochman, 1997). Providers can limit patients’ sense of control by failing to provide useful information and using coercive tactics (e.g., provider addresses parents versus patients). These factors reduce patients’ sense of competency, self-determination, and responsibility for their own health care. Decisional control describes the extent to which the healthcare climate is supportive of autonomy or is controlling. During treatment, survivors have limited opportunities to participate fully in their care; after they gain “survivor status,” they may seek opportunities to exert their decisional control, even if that control means participating in health-risking behaviors. Adolescents, in particular, look for opportunities to gain control. The more their autonomy in decision making is supported, the less likely they are to behave in a reactive manner and the more open they are to making positive health choices. Over time, they internalize the responsibility for health-protective behaviors.

Professional or technical competencies refer to the ability of a provider to interact with a client in ways that are appropriate to the client’s singularity and appreciation of the patient’s technical versus interpersonal needs in light of the healthcare problem. For example, the newly hospitalized child who is in crisis, being managed by protocol, and minimally responsive to external stimuli has needs that are different from those of the adolescent childhood cancer survivor whose greatest therapeutic need is skilled behavioral assessment and intervention. With the former, provider skills are oriented very much to the physiologic and technical aspects of care; with the latter patient, skills are needed that can facilitate patient decision making relative to new behaviors to support health. Skills and abilities at both extremes are important. Behavioral assessment and intervention skills are as important as acute care technologic intervention skills. A single provider may not be expert in both areas but should be able to recognize the need for a given intervention and find appropriate resources to meet a patient’s needs.

Factors within the element of client-professional interaction influence one another. The relationship component of affective support is the primary foundation on which all other intervention and interaction factors are built. Even the most advanced therapies and elaborate health education programs can be unsuccessful without effective communication, the ability to deliver a message of caring and concern, and attention to a patient’s affective response. For example, a 16-year-old boy post-treatment for acute lymphocytic leukemia who is depressed (affective response) by the impact of his disease and its treatment may not be attentive to provider recommendations relative to exercise and diet to decrease his risks for treatment-related problems. Failure to address his affective response may result in his noncompliance with therapeutic health-protective recommendations. Alternatively, recognition of his affective state (affective support); pharmacologic treatment of depression, if needed; and information that helps him cope with his concerns about his disease (health information) may enhance his adherence to treatment.

Decisional control is related strongly to affective support and provision of health information. In a healthcare climate that is supportive of autonomy, providers can assist young cancer survivors on many levels. Providers can aid survivors to become aware of their health-related behaviors, help to formulate standards against which survivors can compare their behavior and set goals, foster a sense of self-efficacy that stresses survivors’ capacity to make decisions about their health, assist survivors to see the relationship between their behaviors and specified outcomes, and help survivors to understand what can and cannot be changed about their health.
status. By supporting survivors’ self-determination, this approach ultimately strengthens survivors’ feelings of self-efficacy and promotes the internalization of responsibility for health-related behavior.

The client-professional interaction or intervention is dictated by survivors’ singularity profiles. The patient-provider encounter can provide many clues that can help to guide the intervention approach. Clearly, what survivors know and believe (cognitive appraisal) and survivors’ emotional state (affective response) are targets for intervention in terms of affective support and the provision of health information. The need for autonomy can be assessed simply by asking survivors how they relate to a care provider, to what extent they want to be involved in decision making, and to what extent they are willing to be full participants in their care.

Survivors constantly offer clues to their sense of efficacy and competency related to their illness and treatment. The extent to which survivors initiate questions and want information about progress and setbacks is a clear indicator of whether they want an active role in their care and whether they feel competent to make choices (Deci & Ryan, 2002). Such behavior is highly indicative of an intrinsically motivated survivor. Such survivors, when they need to stop smoking and begin an aerobic exercise regimen, are more likely to respond to an autonomy-supportive intervention strategy (“I personally would like to see you stop smoking and begin an exercise program; however, that is your choice. If you decide you would like some help to do both or either of these things, I am here to help you.”) than one in which the provider is controlling (“You should stop smoking and start exercising.”). Conversely, when survivors indicate overtly or covertly that they prefer that the provider be the decision maker, interventions that emphasize closer contact and external reinforcement from the provider (e.g., more frequent visits, regular telephone contact) are appropriate.

Health Outcomes

The element of health outcomes consists of healthcare utilization, health status indicators, problem-severity indicators, adherence to recommended care regimens, and satisfaction with care. The broad array of behaviorally related conceptual outcomes allows the specification of a measured outcome that is sufficiently sensitive to the explanatory singularity factors and to the variables manipulated as part of an intervention. The outcomes are not limited to behavior, although behavior certainly is implied in each of the outcomes, and can be measured directly or indirectly as a function of any of the outcomes. For the most part, health outcomes are related logically and conceptually. The relationships among outcome measures, however, may or may not be interrelated, depending on the specific operationalization of the outcome and the context in which it is being evaluated. For example, common sense would dictate that satisfaction with care could be related to whether someone would adhere to a recommendation or use services in the future; similarly, adherence to a regimen may have a definitive impact on the severity of healthcare problems or clinical health status indicators. Although the potential for these interrelationships exists, theoretically, it cannot be put forward as universal for all health outcomes across all contexts. For that reason, health outcomes are presented as a collective with the potential for interrelationship; however, those relationships are not specified a priori or in the absence of a healthcare problem and context under study.

Generally, health behavior studies, for reasons of practicality, are limited to one or two outcome measures.

Healthcare utilization refers broadly to the use of health resources as a health-promoting behavior. The concept can be operationalized to measure survivors’ independent access of health information sources to inform their decisions or measure self-referred or professional-referred use of formal or informal healthcare services (e.g., frequency of visits, type and nature of services sought).

Health status indicators conceptually represent the full spectrum of clinical health outcomes (e.g., weight, objective and subjective health status, laboratory measures, well-being). Studies may seek to use self-report health status measures, physiologic or laboratory data (hematology and immunology data), or standardized measures of affective or cognitive states (depression, anxiety, or problem-solving abilities).

Problem-severity indicators can be used to evaluate progression of disease, stabilization of disease, return of function, and other end points. This category of variables enables the development of outcome measures that are based less on measures of disease and more on measures of the sequelae of disease or its treatment (e.g., fatigue, quality of life, appetite, control of nausea).

Adherence to the recommended care regimen is the extent to which the survivor engages in those behaviors or treatments that are necessary to ensure optimal health. Actual behavior (e.g., frequency of aerobic exercise sessions per week), indicators of adherence (e.g., pill counts, dexamethasone assays), and congruency measures (the correspondence between recommended and actual behavior) represent the types of measurable adherence outcomes.

Satisfaction with care directly reflects the content of the provider’s interaction or intervention and sensitivity to the client’s singularity. Although it is not a behavioral measure, satisfaction with care is a strong indicator of subsequent behavior (Kovac, Patel, Peterson, & Kimmel, 2002; Roberts, 2002). Satisfaction with care is linked very closely to whether patients follow a therapeutic protocol, use care options as suggested, and implement suggested health behaviors.

Extending the Boundaries of Survivor Behavioral Research

The IMCHB can improve childhood cancer care and research efforts in two ways. First, the conceptual breadth of the model will allow the generation of new questions incorporating new concepts, variables, and relationships heretofore unexamined. For example, in previous studies of cancer survivors (Hudson et al., 2002), after an education intervention, girls demonstrated more knowledge than boys about the risks associated with their cancer and its treatment. Increased knowledge, however, did not lead to behavior modification. The IMCHB would be a useful guide for the design of studies that include multiple questions about what modifies the knowledge and behavioral outcome link, such as to what extent is increased knowledge mediated by other demographic or social influence variables? Does fear or anxiety (affective response) modify the assimilation and application of knowledge positively or negatively? Are knowledge and affect associated with an adolescent’s motivational orientation?

The IMCHB can be used to guide the formulation of questions about the connections among affective response, moti-
vational orientation, and behavioral outcomes. How much do motivation and affect predict health-related behavior? Does fear of treatment-related complications contribute to an extrinsic motivational orientation and thereby increase participation in health-risking behaviors? Healthy adolescents whose parents are supportive of autonomy participate less in health-risking behaviors (Williams, Cox, Hedberg, & Deci, 2000), and diabetic patients whose healthcare providers are supportive of autonomy rather than controlling are more adherent to therapeutic regimens (Williams, Freedman, & Deci, 1998). Could home and healthcare contexts be influential in determining survivors’ health behavior motivation and subsequent health-related behaviors?

Second, the IMCHB can be used to test whether client singularity variables explain the health-risk and health-protective behaviors of childhood cancer survivors and how these multiple variables are related (direct or indirect influences, mediating or modifying influences). This information can be used to clearly define intervention strategies for cancer survivors. Intervention approaches broader than didactic health education may be indicated. If the healthcare climate (client-professional interaction) is found to be predictive of health behavior in this population, then interactions that are tailored to the motivational orientation of survivors should be highly effective in changing behavior. If social influences (parent-survivor interaction) predict behavior, then interventions that modify parent-survivor interaction related to health-risk behaviors may be useful. If affective responses to cancer and its treatment are related to the motivational orientation of adolescents, then interventions that directly address emotional concerns and thereby mediate the motivational response are indicated.

Conclusions

A wide variety of measures are available throughout the medical, nursing, and psychosocial literature to address the multifocal concepts within the IMCHB. Similarly, analytical strategies such as structural equation modeling and confirmatory structural factor analysis lend themselves well to the examination of models containing multiple variables with interactive moderating and mediating effects on dependent measures. Such strategies allow for examination of the structure of the IMCHB as a whole and estimation of its ability to explain behavior. The IMCHB is being used to direct a program of research targeted at explaining health promotion and risk reduction in survivors of pediatric cancers. A currently funded study will examine the ability of the IMCHB to specifically identify targets for intervention and reevaluate the impact of a previously tested intervention using reconfigured behavioral outcome measures (Cox, 2003). These studies are preliminary to intervention studies that will focus on supporting positive health-protective behaviors in young survivors.

In summary, the IMCHB offers a conceptual structure that can support explanatory studies and intervention trials in the childhood cancer survivor population. This broader conceptual framework has the potential to reveal new explanatory variables for health-protective and health-risk behaviors. Interventions that target these variables can promote behavioral changes that advance survivors’ health and well-being while reducing their risk of late sequelae.

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References


For more information...

➤ Candelighters Childhood Cancer Foundation
www.candelighters.org

➤ National Childhood Cancer Foundation
www.nccf.org

➤ The Children’s Cause
www.childrenscause.org

Links can be found using ONS Online at www.ons.org.