

CHILDHOOD CANCER SURVIVOR STUDY Analysis Concept Proposal

03-10

Title: New Approaches to Explaining Health-Protective and Health-Risk Behaviors in Childhood Cancer Survivors

Working Group and Investigators: Publications derived from the proposed work would be generated by the Cancer Control Group. Additionally, Dr. Jack McArdle of the University of Virginia, an international authority on structural equation modeling, has agreed to serve as a consultant to the project. Dr. McArdle is currently assisting me in this capacity on two funded projects.

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BACKGROUND AND RATIONALE

A wide array of late effects of radiation and chemotherapy render childhood cancer survivors vulnerable to long-term health problems: new malignancies, cardiovascular problems, osteoporosis, and obesity and its complications. After treatment, the responsibility for health protection increasingly falls to the individual patient. Important risk-avoidance behaviors (e.g. avoidance of tobacco, recreational drugs, unprotected sexual activity, and alcohol), health-protective behaviors (e.g. sound diet, breast and testicular self-exam, aerobic and resistance exercise), and adherence to prescribed medical evaluations (bone density, mammogram, Pap smear, clinical breast and testicular exam) are especially important to the long-term health and well-being of childhood cancer survivors, given their treatment-related risks. A number of studies have documented that survivors not only fail to practice health-protective behaviors, but engage in health-risk behaviors at a rate equal to or greater than that of their healthy peers. Recent CCSS reports indicate that cancer screening practices (Pap smears, breast/testicular clinical exams, mammograms) are significantly less frequent among young adult survivors than is recommended for the general population; fewer than half of the adult survivors in these studies reported having had contact with the medical system during the most recent follow-up period.

While most behavioral studies of survivors are not theory-based, a few have relied upon cognitive processing theories. Unfortunately, studies of health behavior in the general population have shown that cognitive processing theories can fail to identify important determinants of health and risk behavior. The explanatory power of these theories has been limited by their failure to incorporate intrapersonal (affective, competing needs, socio-cultural) and contextual variables (influences of family and health care providers) that may motivate health-risk and health-protective behaviors; consequently, interventions based on these studies may overlook important targets for behavior change. Interventions which have the greatest likelihood for success target those modifiable variables which have the strongest explanatory relevance for a given behavior; comprehensive, methodologically precise conceptual frameworks of health behavior have the potential to identify these variables and their interrelationships.

SPECIFIC AIMS

Reported studies relying on CCSS data have examined behavioral variables primarily as prevalence-based outcomes. In contrast, the proposed study will use a previously tested model of health behavior to examine the individual, cumulative, and interactive relationships of a broad array of variables with health-risk and health-protective behaviors as the outcomes. The study will also investigate the clustering of specific health-protective and health-risk behaviors according to gender and age groups. These clusters and their relation to intrapersonal and contextual variables may provide a basis for focused interventions that will have an improved probability of reducing survivors' risk of late sequelae. Specifically, this project proposes re-examination of

portions of 3 CCSS data sources: The **Baseline Survey** was initiated in 1994 with the majority of questionnaires returned by 1997; the **Follow-up 2000 Survey** had a start send-out date of November 2000, and the last questionnaires were sent out in October, 2002 (with an anticipated analysis-ready data file in July, 2004); The Health Care Needs Survey is derived from a CCSS ancillary study, and was sent in 2001 to a random sample of 1600 CCSS cases.

■ **Aim 1:** Document the individual, cumulative and interactive effects of selected demographic, health history, resource, social, cognitive, affective, and motivational variables on 3 individual health-risk behaviors (alcohol use, smoking, and other tobacco use) and on 9 individual health-protective behaviors (physical activity, sunscreen use, breast/testicular self exam, breast/testicular provider exam, mammogram, Pap smear, medical checkups). This analysis will identify variables that directly and indirectly affect each health-protective and health-risk behavior, and that therefore may mediate or moderate behavior.

■ **Aim 2:** Identify the factorial dimensions of health-risk and health-protective behaviors, and document how these dimensions vary within age, gender and racial sub-groups. Completion of this aim will allow for the definition of hierarchies of health risk behaviors (lower risk vs. higher risk with respect to late effects) and health-protective behaviors within a developmental and social context.

■ **Aim 3:** Construct two separate structural equation models (health-risk behavior and health-protective behavior) for survivors of childhood cancer by testing the following structural hypotheses derived from the Interaction Model of Client Health Behavior (IMCHB):

Hypothesis a) The background variables are interrelated;

Hypothesis b) The modifiable variables are interrelated;

Hypothesis c) The background variables influence the modifiable variables;

Hypothesis d) The background and modifiable variables predict childhood cancer survivors' health-related behavioral outcomes.

These models will provide a template for risk identification and the development of interventions.

METHODS

Conceptual Framework

The Interaction Model of Client Health Behavior (IMCHB) (Figure 1) incorporates both intrapersonal and contextual variables, including patient-provider interaction. While abstract, it includes variables that are intended to be measured at the level of a behavior-dependent health-related outcome. The strengths of the model rest on its inclusive configuration of variables and its' specific link to the development of prescriptive interventions.

Briefly, the IMCHB proposes that health behavior is a function of multiple, interactive intrapersonal and contextual factors; therefore, to be maximally effective, provider interventions aimed at reducing health-risk behavior and enhancing health-protective behavior must ultimately address both personal and contextual factors. As shown in Figure 1, patients are uniquely defined by **Client Singularity**, which comprises two sets of variables: **background variables** (demographics, social influences, health history and experience, environmental resources) and **dynamic** (i.e., modifiable) **variables** (motivation, affective response, and cognitive appraisal). Background characteristics are important in identifying at-risk populations and the co-variance of behavior with particular socio-economic profiles. The background variables remain relatively static over time, while the three **dynamic variables** are sensitive to outside influences. The three dynamic variables are the targets of interventions designed to modify behavior. **Client-Professional Interaction** defines the intervention resources available to the provider. **Health Outcome** comprises five broad outcome concepts, each of which can represent a wide array of outcome variables. The variables within each element (Client Singularity, Client-Provider Interaction, Health Outcomes) are assumed to be interrelated. Figure 2 and Table 1 list the CCSS data variables (Baseline, Follow-up 2000, and Health Care Needs Surveys) and their correspondence with the elements of the IMCHB.

Data

Table 2 identifies the specific questionnaire items to be examined across the three surveys.

Analysis

I will assume primary responsibility for conducting the majority of the analyses. All work will be validated with Dr. Yasui. Dr. McArdle will assume primary responsibility for supervising the structural equation modeling and for validating the confirmatory factor analysis work that I complete. Given my current program of research here at SJCRH, I am comfortable in assuming this role. Level of measurement, variance, distribution, and psychometric adequacy will guide the choice of all statistical procedures. Aim 1 allows a strictly empirical exploration (independent of a theoretical framework) of the relationships between a broad array of independent variables and the health-risk and health-protective behaviors as discrete phenomena. Aim 2 allows for the development of interval level behavioral outcomes while simultaneously estimating the structure of health and risk behaviors in survivors; how this structure changes within gender, age, and racial sub-samples can be evaluated. Aim 3 allows for the evaluation of the total structure of a theoretical model using higher-order latent constructs that consider related variables simultaneously. This approach will be very useful in informing the development of interventions for subsequent testing.

Analytic Strategies

Aim 1: Item response theory (IRT), log transformation, 12 separate multiple regression/logistic regression analyses, and serial linear regressions (Baron & Kenney, 1997; Holmbeck, 1997) to identify the mediating and modifying variables of health-protective and health-risk behaviors.

Aim 2: Common factor analysis (principal components), confirmatory or structural factor analysis (SFA) (McArdle, 1994, 1996). SFA will allow an assessment of the congruency of factors across age and gender sub-groups.

Aim 3: Structural equation modeling will include an evaluation of: non-normal distribution (Mardia's coefficient, non-normal fit index), all parameters and their standard errors, a complete correlation matrix and any associated discrepancies, and goodness of fit indices (GFI, AGFI, CFI, root mean squared error). Goodness of fit of the model and significant parameter estimates for each path tested in the IMCHB will provide support for the structural hypotheses.

SUMMARY

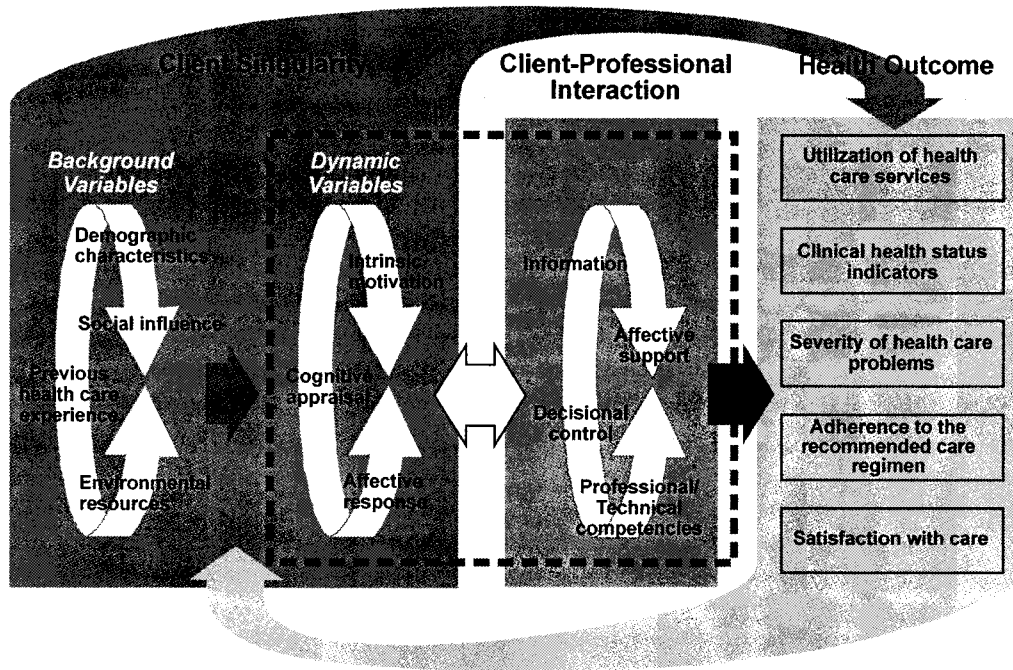
This project incorporates **4 major innovations**: (1) use of CCSS data to identify factors that facilitate or impede commitment of pediatric cancer survivors to their own health; (2) identification of behavioral patterns and dimensions in health and risk behaviors within age, racial and gender groups that can be compared with the general population; (3) the potential to offer a broader explanation of survivors' health-protective and health-risk behaviors than previously offered, while generating new hypotheses for behavioral interventions to reduce the risk of treatment-related sequelae; (4) introduction of novel approaches to the measurement of survivors' health- and risk-related behavior, aimed at producing more reliable measures, more refined analyses, and more focused interventions.

The most recent IOM report (August, 2003) challenges clinical investigators to develop and evaluate the effectiveness of interventions to ameliorate late effects in survivors of childhood cancer. Very few intervention trials for this group have been proposed, and when tested, they been disappointing in their ability to moderate health protective and health risk behaviors. Failure to account for the dimensionality of the behavioral outcomes, and theories of health behavior which are too narrow to inform intervention development for behavior change are two limiting factors which recently have been identified in our work here at St Jude Children's Research Hospital. A recent clinical trial tested the ability of a multicomponent intervention to change health and risk behaviors in adolescent survivors. The intervention showed no impact when tested on a single unidimensional behavioral outcome measure; however, when the behaviors were examined individually and then clustered into continuous negative behaviors (e.g. smoking, ETOH use, junk food consumption) and continuous positive behaviors (e.g. dental care, nutrition, breast/testicular self-exams), the intervention demonstrated a clear impact in reducing negative behaviors, increasing motivation for behavior change, and increasing perceptions related to the seriousness of late effects in the treatment group. Additionally, through application of the IMCHB to these data, important antecedent variables have been found to profile at-risk groups, and important variables, previously not addressed, are identified as targets for intervention: older adolescents practice more negative health behaviors; the practice of positive health behaviors predicts a decreased practice of negative health behaviors, and motivation, NOT KNOWLEDGE, is a strong predictor of both positive and negative health behaviors. While additional analyses are in progress, it is

clear at this point that motivation-based interventions which consider age and gender tailored approaches need to be developed for maximum effectiveness. Only through the outcome measurement approaches and the use of a more broadly configured theoretical framework, did these clear directions for intervention development emerge.

The proposed analyses will generate at least 3 published reports: (1) Predictors and mediators of health-protective and health-risk behaviors; (2) the structure, dimensionality, and consistency of health-risk and health-protective behavior by age groups and gender; and (3) theory-based explanations of health and risk behavior.

Figure 1: The Interaction Model of Client Health Behavior



Correspondence of the IMCHB Concepts with CCSS Data

Background Variables

Demographics

Highest grade
Marital status
Current employment
Date of birth
Gender
Racial Group
Current residence
Income

Social Influence

Living arrangements
Family/friend concern
Friends/spouse trust
Marital History
School history
Employment history
Religion

Previous Health

CA visits to MD,
Hep C
Sun sensitivity, Skin CADxs
Med Hx (2 yr)
CA Recurrence (2 yr)
Other Rx, Sexual Hx
Height, weight
Hospital adm.
Medical history
Surgery history

Environmental Resources

Dental care, insurance
Health care (last yr)
source, frequency
Insurance coverage
provider, exclusions
Income household
people supported on income
Personal income
Phone access to MD
Last PE, last dental visit

Dynamic Variables

Cognitive Appraisal

Health Perception
1 Year Health
Health Limitations
Functional Status Impairment
Emotional Status Impairment
Social Status Impairment
Pain Perception
Functional Status/Pain
Peer Health Comparison
Future health
Health Status
Ladder of Life
Problem-Solving Perception
Main Health Problems
Barriers to Care
7 days Sx

Motivation

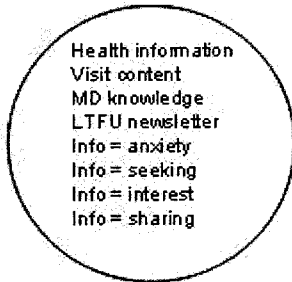
Susceptibility
Intrinsic cues
Extrinsic cues

Affective Response

Well-being
Cancer Impact
Feelings/Emotions
Feelings/Emotions Dur.
Adaptation
Worry
Mood
Anxiety
Concerns

Client-Professional Interaction

Health Information

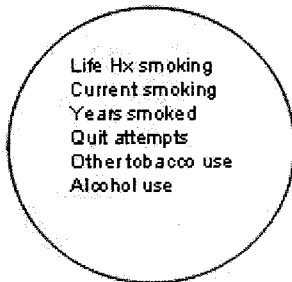


Affective Support



Health Outcome

Health Risk Behavior



Health Protective Behavior

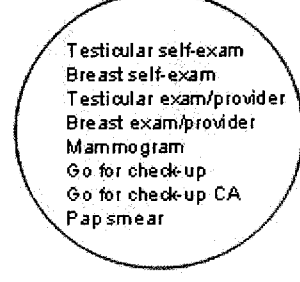
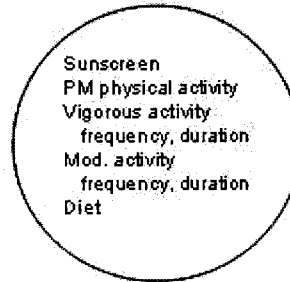


Table 1: Correspondence of the IMCHB Concepts with Proposed LTFU (CCSS) Data Sources

IMCHB CONCEPT	PROPOSED STUDY VARIABLES	LTFU Data Source
DEMOGRAPHICS	Highest grade level Marital Status Current Employment Job Title Job Description Date of Birth Gender Racial Group Current Residence Marital Hx Marital Status Income	LTFU: #1(p.3) LTFU: #2(p.3) LTFU:#3(p..3) LTFU: #4a (p..3) LTFU: #4b (p..3) BLINE: #A1 (p.2) BLINE: #A2 (p. 2) BLINE: #A4 BLINE: #A8 (p. 2) BLINE: #L1 (p. 12) BLINE: #:L2 (p. 12) BLINE: #Q8-9 (p. 23)
SOCIAL INFLUENCE	Living Arrangements Family/Friend Concern Friends/Spouse MD Trust Marriage Duration Current Relationship School History Employment/Military History Religion	LTFU: #5 (p.3) HCNS: #C1-7 (p. 5) HCNS: #C9-10 (p. 5) HCNS: #C8 (p.5) BLINE: #L6-8 (p. 12) BLINE: #L9-13 (p. 12) BLINE: #O1-4 (p. 16) BLINE: #O5-11 (p. 17) BLINE: #Q7 (p. 23)
HEALTH EXPERIENCE/HX	CA Visits to MD Medical Screening Tests Blood Transfusion Hep C Sun Sensitivity Skin Growth Removed Skin CA Dx CA Recurrence (2 yr.) Other Med. Conditions Height Weight CA Related Health Visits Hospital Admissions 2 Year Surgical Hx Medical History Surg. History 7 Day Sx 12 MO. PMH CA Recurrence History	LTFU: #5 (p.4) LTFU: #1-5 (p. 5) LTFU:#6-7 (p. 5) LTFU:#8-9 (p. 5) LTFU:#1-7 (p. 6) LTFU:#8 (p.6) LTFU:#9 (p.7) LTFU:#1-2 (p.17) LTFU:#1-2 (p. 19) BLINE: #A10 (p. 2) BLINE: #A11 (p. 2) BLINE: #B4 (p. 3) BLINE: #B6 (p. 3) BLINE: #B7 (p. 3) BLINE: #C-H (p.6-8) BLINE: #I(1-31) (p. 9) BLINE: #J (16-36) (p.10) BLINE: #J 38 (p. 11) BLINE: #K(1-8) (p. 11)
ENVIRONMENTAL RESOURCES	Dental Care Dental Insurance Health Care (last year) Source Frequency Insurance Coverage Provider Exclusions Income Household # people supported on income Personal Income Health Care (2 years) Provider Source Frequency Telephone MD Last General PE Insurance	LTFU:# 14-15(p.14) LTFU:#17 (p.14) LTFU: #1 (p.4) LTFU: #2 (p.4) LTFU: #3 (p.5) LTFU: #1 (p. 5) LTFU: #1a (p. 5) LTFU: #1b (p. 20) LTFU: #1 (p. 20) LTFU: #2 (p.20) LTFU: #3 (p. 20) BLINE: #B3 (p. 3) BLINE: #B1 (p.3) BLINE: #B2 (p. 3) BLINE: #B3 (p. 3) BLINE: #BS (p.3) BLINE: #N16 (p. 16) BLINE: #Q1-6 (p. 22-23)
MOTIVATION	Susceptibility Intrinsic/extrinsic cues	HCNS: #B1-6 (p. 4) HCNS: #E1-17 (p. 7)
COGNITIVE APPRAISAL	Health Perception 1 Year Health Health Limitations Functional Status Impairment Emotional Status Impairment Social Status Impairment Pain Perception Functional Status/Pain Peer Health	LTFU: #1 (p. 8) LTFU: #2 (p. 8) LTFU: #3-12 (p.8) LTFU: # 13-16 (p. 8) LTFU: #17-19 (p. 8) LTFU: # 20 (p. 8) LTFU: #21 (p.8) LTFU: #22 (p.8) LTFU: #10-11 (p. 10)

IMCHB CONCEPT	PROPOSED STUDY VARIABLES	LTFU Data Source
	Health Expectation Health Evaluation Ladder of Life Problem-Solving Health Status Main Health Problems Primary Care Barriers to Care Health Limitations Health Limitations (2 yr. hx) Perceived health status	LTFU: #12 (p. 10) LTFU: #13 (p. 10) LTFU: #1-3 (p. 11) LTFU: #1-25 (p. 11) HCNS: #A16 (p. 3) HCNS: #A18 (p. 3) HCNS: #A19 (p.3) HCNS: #B7-8 (p. 4) BLINE: #N 10-12 (p. 15) BLINE: #N14 (a-f) (p. 15) BLINE: #N15 (p. 15)
AFFECTIVE RESPONSE	Well-being Cancer Impact Feelings/Emotions Feelings/Emotions Dur. Worry Anxiety CA Concerns	LTFU: #1-9 (p. 10) LTFU: #14-34 (p. 10) LTFU: #1-17 (p. 12) LTFU: #18 (p. 12) HCNS: #B11-16 (p. 4) BLINE: #J37 (p. 10) BLINE: #R1-6 (p. 23)
CLIENT-PROVIDER INTERACTION	Health Information MD Knowledge Visit Content LTFU Newsletter Info=anxiety Info Seeking Info Interest Info Sharing Satisfaction with Care Check-up Cancer Docs/Time Relationship Trust MD Health Care Rating	LTFU: #6,9,10 (p. 4) LTFU: #7 (p.4) LTFU: #8 (p.4) LTFU: #1 (p. 20) LTFU: #2 (p. 20) LTFU: #3 (p. 20) LTFU: #5 (p. 20) LTFU: #6 (p. 20) HCNS: #A10 (p.3) HCNS: #A15 (p. 3) HCNS: #B9 (p. 4) HCNS: #B17-19 (p. 4) HCNS: #C8 (p. 5) HCNS: #D7 (p. 6)
HEALTH BEHAVIORS	Using Sunscreen PM Physical Activity Vigorous Physical Activity Vig. Activity Frequency Vig. Activity Duration Moderate Physical Activity Mod. Activity Frequency Mod. Activity Duration Life History Smoking Current Smoking Status # cigarettes smoked Years smoked Quit Attempts Other Tobacco Use Smoking Hx Tobacco Product Use Alcohol Use Physical Activity Monthly Testicular Exam Pap Smear Breast Exam/Provider Mammogram	LTFU: # 7 (p. 6) LTFU: #1 (p. 7) LTFU: #3 (p. 7) LTFU: # 4 (p. 7) LTFU: #5 (p. 7) LTFU: # 6 (p. 7) LTFU: # 7 (p. 7) LTFU: # 8 (p. 7) LTFU: #1 (p. 9) LTFU: #2 (p. 9) LTFU: #3 (p. 9) LTFU: #4 (p. 9) LTFU: #5 (p. 9) LTFU: #6 (p. 9) BLINE: #N1 (a-f) (p. 14) BLINE: #N2 (p. 14) BLINE: #N3-8 (p. 14-15) BLINE: #N9 (p. 15) BLINE: #N18 (p. 16) BLINE: #N19 (p. 16) BLINE: #N21 (p. 16) BLINE: #N22 (p. 16)

**TABLE 2: SPECIFIC ITEMS PROPOSED FOR ANALYSIS
BASELINE, HEALTH CARE NEEDS AND FOLLOW-UP**

BASELINE	HEALTH CARE NEEDS	FOLLOW-UP
A1-4A	A1-19	1-7 (p. 3)
A9-11	B1-19	Medical Care 1-9
B3-7	C1-10	Screening Test 1-9
C1-19	D1-17	Insurance 1-1b
D1-5	E1-17	Sun Sensitivity 1-9
E1-18		Physical Activity 1-7
F1-21		Daily Activities 1-22
G1-13		Smoking 1-6
H1-18		Health and Well-being 1-34
I1-31		Ladder of Life 1-3
J1-38		Problem Solving 1-25
K1-8		Feelings/Emotions 1-18
L1-13		
N1-22		
01-5,7,9-11		
Q1-9		
R1-6		