



Care of Patients with Heart Disease

The role of illness uncertainty in the relationship between disease knowledge and patient-reported outcomes among adolescents and adults with congenital heart disease



Steven E. Schiele^a, Charles F. Emery^{a,b,d}, Jamie L. Jackson^{a,c,e*}

^a Department of Psychology, Ohio State University, Columbus, OH, USA

^b Department of Internal Medicine, Ohio State University, Columbus, OH, USA

^c Department of Pediatrics, Ohio State University, Columbus, OH, USA

^d Institute for Behavioral Medicine Research, Ohio State University, Columbus, OH, USA

^e Center for Biobehavioral Health, Nationwide Children's Hospital, 700 Children's Drive, Columbus, OH 43205, USA

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ABSTRACT

Background: Greater general disease knowledge predicts better patient-reported outcomes (PROs) among congenital heart disease (CHD) survivors, but higher illness uncertainty is associated with elevated emotional distress and poorer well-being among patients with chronic disease.

Objectives: This study explored the relationship of illness uncertainty and disease knowledge with emotional distress and health-related quality of life (HRQoL) among patients with CHD.

Methods: Individuals with CHD (N = 169, ages 15–39) completed self-report measures of disease knowledge (general and risk-related), illness uncertainty, depressive and anxiety symptoms, and HRQoL. Pearson correlations and regressions analyses were utilized.

Results: Greater risk-related knowledge was associated with greater anxiety ($b = .41, p = .03, 95\% \text{ CI} = [.04, .77]$) and poorer emotional HRQoL ($b = -.53, p = .03, 95\% \text{ CI} = [-1.02, -.05]$) when illness uncertainty was higher.

Conclusion: When individuals with CHD feel uncertain about their disease course and outcomes, knowledge about future cardiovascular risks may result in higher levels of distress.

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Introduction

Congenital heart disease (CHD) is the most common birth defect and currently the leading birth defect-related cause of death during the first year of life.¹ Sixty years ago, the one-year survival rate for infants born with CHD was 25%,² but one-year survival rates have more recently increased to 90% (Moons, 2010). Indeed, due to advances in cardiac treatment, over 95% of CHD patients are living to adulthood.² However, CHD remains a chronic condition that requires continual surveillance of heart health with lifelong implications for health-related quality of life (HRQoL) and psychological well-being. Survivors sustain an elevated risk for additional health complications such as hypertension, stroke, and heart failure as they age.³

In addition to future cardiovascular risks, CHD survivors may also have an elevated risk of emotional distress. The estimated prevalence of elevated depressive symptoms among individuals with CHD is as high as 22–23%, and 30–34% for anxiety symptoms.^{5,6} Symptoms of depression and anxiety, in turn, are predictive of

poorer HRQoL among those with CHD.⁷ Furthermore, Bromberg and colleagues⁸ found that, among those with CHD who are considered “well-adjusted” by their cardiologists, 36.4% had a diagnosable psychiatric disorder such as anxiety or depression. Because poorer HRQoL is associated with greater mortality, worse prognosis, more hospitalizations, and poorer psychological well-being among patients with other cardiovascular diseases,^{9–12} understanding and identifying risk factors for poorer HRQoL is vital earlier in treatment.

One common factor related to HRQoL and emotional distress among patients with CHD is difficulty understanding and adapting to the variable course of CHD. Accurate knowledge of CHD among patients has been related to better emotional well-being, social support, sense of coherence and optimism, as well as HRQoL.^{4,8} Across the lifespan, CHD survivors appear to have suboptimal levels of disease knowledge, including general disease knowledge as well as knowledge about future cardiovascular risks due to their condition.^{4,13–17} Shaw and colleagues demonstrated that the way in which patients think about their illness (e.g., appraisal of illness, perceived control) as well as the type of cardiac information provided

* Corresponding author at: Center for Biobehavioral Health, Nationwide Children's Hospital, 700 Children's Drive, Columbus, OH 43205, USA.

E-mail address: jamie.jackson2@nationwidechildrens.org (J.L. Jackson).

(e.g., general vs. risk-specific) may influence the amount of knowledge acquired and the success of recovery following discharge.

In the context of illness-related beliefs, patients may experience illness uncertainty, characterized by vagueness about the illness, lack of clarity, ambiguity, unpredictability, inconsistency, and lack of information.^{20,21} Greater illness uncertainty is associated with lower disease knowledge and poorer emotional well-being and HRQoL,^{4,19,20} including a negative association with self-care behaviors possibly due to a lack of knowledge.²² In addition, greater illness uncertainty is associated with higher depressive symptoms, poorer quality of life, and more fatigue among patients with chronic illnesses, such as chronic obstructive pulmonary disease²⁴ and hepatitis C.²³ However, no prior study has examined the relationship between illness uncertainty and psychosocial variables among adolescent or adult patients with CHD.

The aims of this study were to evaluate the degree to which disease knowledge is associated with illness uncertainty, emotional distress, and HRQoL as well as to determine the role of illness uncertainty in the relationship between disease knowledge, and emotional distress and HRQoL among patients with CHD. In the current study, disease knowledge was operationalized as two types of understanding about one's illness: general disease knowledge and risk-related knowledge. It was hypothesized that (1) poorer general knowledge and risk-related knowledge would be associated with greater illness uncertainty and emotional distress, and with lower HRQoL; (2) illness uncertainty would be positively associated with emotional distress and negatively associated with HRQoL; and (3) the magnitude of the relationships between general knowledge and risk-related knowledge, emotional distress, and HRQoL would be greater in the context of higher illness uncertainty.

Methods

Participants and procedures

Participants were identified from outpatient cardiology clinic rosters at Nationwide Children's Hospital (NCH) and the Ohio State University Medical Center (OSUMC) as part of a larger study of disease knowledge and self-management among adolescents and adults with CHD. Participants were included in the study if they had a structural heart defect and were 15–39 years of age. Exclusion criteria included a diagnosis of a genetic syndrome, cognitive impairment, or absence of proficiency in English. After patients were identified, a letter was sent from their attending cardiologist notifying them that a study staff member would be contacting them about the study. An opt out number was provided in case the participant did not wish to be contacted. Approximately one week later, a study staff member called the participant by phone to obtain verbal consent (or assent if under the age of 18 along with guardian consent) to complete an online questionnaire. If participants could not be reached by phone, they were approached in clinic. Patients from pediatric and adult cardiology clinics at the pediatric hospital were initially invited to participate in a study examining disease knowledge and health-related quality of life (Phase 1). Self-report measures of depressive and anxiety symptoms and illness uncertainty were added to the study protocol after data collection was initiated at the pediatric institution, requiring participants to be re-contacted and re-consented in Phase 2 of the study. As participants from the pediatric hospital were being re-contacted, recruitment efforts began at the adult hospital. As shown in Fig. 1, of the total eligible patients who were contacted,

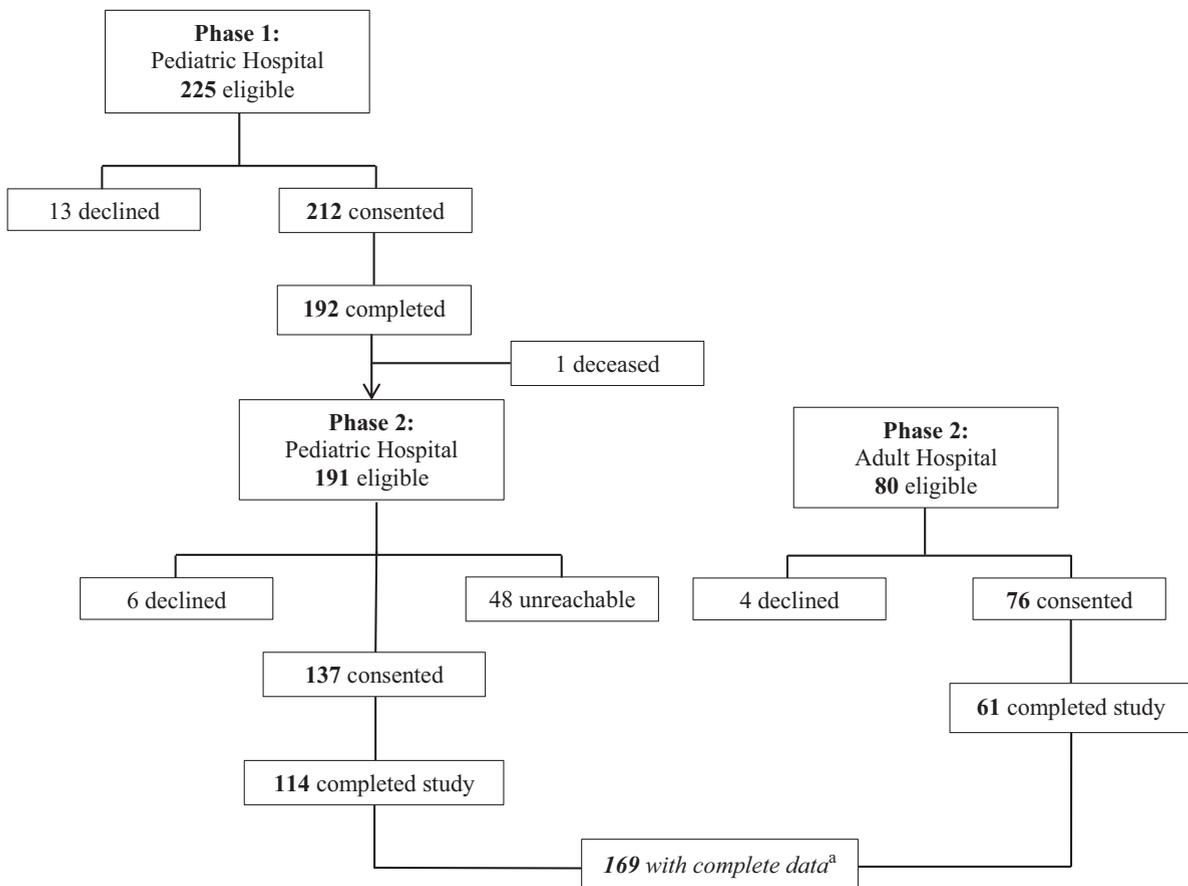


Fig. 1. Study flow diagram.

^aIncludes having data for the Medical Outcomes Study – Short Form 36, CHD-Assessment of Information Measure, Child Uncertainty in Illness Scale, and Youth Self-Report/Adult Self-Report.

Table 1
Sample characteristics.

	Mean (SD) or %	Range
Demographics		
Age	26.5 (\pm 7.3)	15–39
Sex		
Male	44.0%	
Female	56.0%	
Race		
White	88.7%	
Non-white	11.3%	
Education		
High school or technical/trade school	63.9%	
College or graduate/profession	36.1%	
Marital Status		
Never married	44.6%	
Married	43.9%	
Divorced/widowed/separated	11.5%	
Family income (dollars/year)	70,147.00 (32,059)	12,718–167,509
Lesion Severity		
Simple	29.6%	
Moderate	40.2%	
Complex	30.2%	
NYHA Class		
I	70.4%	
II, III, IV	29.6%	
Comorbid conditions	1.04 (1.09)	0.0–6.0
Number of medications	1.50 (1.84)	0.0–9.0
Patient-reported outcomes		
General knowledge (CHD-AIM)	0.83 (0.16)	0.0–1.0
Risk knowledge (CHD-AIM)	0.57 (0.28)	0.0–1.0
Illness uncertainty (CUIS)	36.8 (11.7)	16.0–62.0
Depressive symptoms (YSR/ASR)	47.2 (22.0)	5.0–100.0
Anxiety symptoms (YSR/ASR)	55.1 (7.2)	50.0–80.0
MCS (SF-36)	49.8 (10.6)	8.6–67.0
PCS (SF-36)	49.2 (9.3)	20.3–62.6

Note: CHD-AIM = Congenital Heart Disease Assessment of Information Measure; NYHA = New York Heart Association; CUIS = Child Uncertainty in Illness Scale; SF-36 = Medical Outcomes Survey Short Form-36; YSR/ASR = Youth Self-Report/Adult Self-Report; MCS = mental component scale from SF-36; PCS = physical component scale from SF-36.

23 declined participation at either phase, 48 were unreachable at Phase 2 from the pediatric hospital, 58 did not complete the study at either phase, 1 died prior to Phase 2, and 6 had missing or incomplete data at Phase 2. As a result, 169 participants were included in the current study. As shown in Table 1, mean age of the sample was 26.5 (\pm 7.3; range 15 to 39) years. The sample included more females than males (56% vs. 44%) and was mostly Caucasian (89%).

Indicators of disease severity and functional status were abstracted from participants' medical charts. Lesion severity was classified as simple, moderate, or complex.²⁶ Functional status was determined via the New York Heart Association (NYHA) functional classification system. The NYHA classification was dichotomized such that participants were classified as either not having functional limitations (I) or having at least some functional limitations due to cardiac symptoms, such as dyspnea, (II–IV) (Criteria Committee New York Heart Association, 1994). As shown in Table 1, the vast majority of participants in the study (94.1%) were classified as I or II, thus the dichotomy reflected an appropriate grouping of this sample of patients.

The following self-report questionnaires were completed by study participants.

Disease knowledge

Disease knowledge of CHD was evaluated with the 24-item CHD Assessment of Information Measure (CHD-AIM).¹⁴ Two subscales of the CHD-AIM were included in this investigation: general knowledge and future risk-related knowledge. The general knowledge subscale consists of 11 multiple choice questions related to CHD

self-care, course of illness, follow-up care, and genetic risk for offspring, healthy diet, and exercise recommendations. Two of the general knowledge questions are sex-specific; all participants completed nine common items with males completing two additional items related to erectile dysfunction and sexual performance and females completing two additional items related to pregnancy. Items were scored as either 0, "incorrect", or 1, "correct", and scores were expressed as a proportion of a maximum of 11 total points (e.g., 6/11 = 0.55). Internal consistency of the nine general knowledge items answered by both males/females was $\alpha = 0.58$. Internal consistency for the eleven items that included sex-specific items was $\alpha = 0.63$ for males and $\alpha = 0.46$ for females. Lower internal consistency on this measure was anticipated due to items reflecting disparate aspects of disease knowledge.

The risk-related knowledge subscale consists of a list of 10 relatively common cardiac-related conditions (e.g., arrhythmia, stroke, heart failure) experienced by CHD survivors across lesion types, and participants were asked to mark each condition for which they believed they were at greater risk due to their disease. Based on their diagnoses and intervention history, their accuracy was scored. A score of 0 was given if $\leq 25\%$ of the conditions were identified, 1 if 26–74% were identified, and 2 if $\geq 75\%$ were identified. Accuracy of answers was based on individual diagnoses/risk. Depending on actual risk indicated by their diagnoses, four additional questions related to symptoms and warning signs of arrhythmia, heart failure, stroke, and aortic aneurysm were included for each patient at risk for these conditions. These four additional questions were scored as either 0 = "incorrect" or 1 = "correct". Thus, risk scores were expressed as a proportion of a maximum of 2–6 total points (e.g., 1/2 = 0.50; 2/6 = 0.33). Internal consistency for risk-related knowledge could not be calculated due to the structure of the scale and differential responses. Higher scores on either subscale of the CHD-AIM suggest greater disease knowledge.

Illness uncertainty

The Child Uncertainty in Illness Scale (CUIS) is a 16-item assessment of perceptions of uncertainty in chronic illness (e.g., "I don't know why some days I feel worse"; "I know how bad my illness is").²⁷ Items are rated on a 5-point Likert scale (1 = very false, 5 = very true), and ratings are summed for a total score that ranges from 16–80 with higher scores indicating greater uncertainty. The CUIS was utilized because it was developed for use with both adolescents and young adults.²⁷ Internal consistency of the scale in the current sample was very good ($\alpha = 0.88$) and good internal consistency was maintained among participants under age 18 ($\alpha = 0.82$) as well as 18 and older ($\alpha = 0.89$).

Emotional distress

Symptoms of depression and anxiety were measured with the Adult Self-Report (ASR) and Youth Self-Report (YSR). The ASR and YSR provide a DSM-oriented assessment of problems in normal functioning that include subscales in the domains of depression (ASR = 14 items; YSR = 14 items) and anxiety (ASR = 7 items; YSR = 6 items).²⁸ Each item is rated on a 3-point Likert scale (0 = Not True, 1 = Somewhat/Sometimes True, 2 = Very True/Often True). The YSR was administered to participants 15–17 years old as well as to 18-year-olds who had not yet graduated from high school. The ASR was administered to all other 18-year-old participants as well as to participants older than 18. T-scores were calculated to facilitate interpretation of scores, with $T > 65$ indicating clinical levels of distress, and to allow inclusion of both ASR and YSR scores in data analyses. The depression/anxiety symptoms subscales of the ASR have shown good internal consistency ($\alpha = 0.88$).²⁸ Construct validity for

the ASR depression/anxiety subscales has been demonstrated in numerous studies.²⁸ Correlations of depression/anxiety subscales with other standard measures are generally high: correlations of 0.69 to 0.78 with the depression and anxiety dimensions of the Symptom Checklist-90-Revised; correlations of 0.67 with structured diagnostic interviews; correlations of -0.65 with the Global Assessment of Functioning scale; and correlations of greater than 0.50 with the MMPI-2 depression, paranoia, psychasthenia, and schizophrenia scales.²⁸ In the present study, the ASR demonstrated good internal consistency in both the depressive ($\alpha = 0.85$) and anxiety ($\alpha = 0.82$) subscales, in patients 18 years and older. The YSR also demonstrated good internal consistency in the depressive ($\alpha = 0.77$) and anxiety ($\alpha = 0.79$) subscales for patients between 15–18 years old.

HRQoL

Emotional and physical HRQoL were assessed with the Medical Outcomes Study – Short Form 36 (SF-36).²⁹ The SF-36 is a commonly used 36-item generic measure of health-related quality of life that yields an emotional summary score (MCS) and a physical summary score (PCS). Raw scores range from 0–100 and are converted to standardized scores (mean = 50; standard deviation = 10), with higher scores suggesting better HRQoL. The MCS and PCS in the present sample demonstrated good internal consistency for both adolescent (MCS: $\alpha = 0.74$; PCS: $\alpha = 0.96$) and adult (MCS: $\alpha = 0.88$; PCS: $\alpha = 0.93$) participants.

Data analyses

Analyses were conducted utilizing Statistical Analysis Software (SAS) version 9.3 and the PROCESS macro.³⁰ Pearson correlations evaluated the association among study variables. Moderation analyses were conducted with the PROCESS macro to test the conditional direct effects of risk-related knowledge and general knowledge on MCS, PCS, depressive symptoms, and anxiety symptoms by the moderating variable of illness uncertainty. A total of 8 moderation analyses were conducted. Age and NYHA were significantly correlated with outcome variables and were thus used as covariates in each moderation analysis.

Results

CHD lesion severity among participants was distributed across all three classifications: 30% simple, 40% moderate, and 30% complex. Twenty-nine percent of participants had at least minimal functional impairment (NYHA class 2 or higher). The average general knowledge score was 83% (SD = 16%) and the average risk-related knowledge score was 57% (SD = 28%). As shown in Table 1, mean T-scores for depressive and anxiety symptoms were within the normal range (< 65), and HRQoL scores were nearly identical to the population mean (PCS = 49.22 ± 15.13; MCS = 53.78 ± 13.14).³¹ As shown in Table 2, greater risk-related knowledge was associated with poorer MCS and higher depressive and anxiety symptoms. However, neither

Table 3

Illness uncertainty moderating the relationships of risk knowledge to mental component scale and anxiety symptoms with age and NYHA included as covariates.

Dependent variable MCS (n = 157)				
	Coefficient	SE	t	p
RK	-13.13	7.52	-1.75	0.08
IU	-0.08	0.12	-0.63	0.53
RK x IU	0.42	0.19	2.21	0.03
Age	0.10	0.09	1.11	0.27
NYHA	0.64	1.35	0.47	0.64
Dependent Variable Anxiety (n = 157)				
	Coefficient	SE	T	P
RK	-12.65	7.38	-1.71	0.09
IU	-0.07	0.12	-0.56	0.58
RK x IU	0.41	0.19	2.21	0.03
Age	0.09	0.08	1.11	0.27
NYHA	0.69	1.27	0.55	0.59

Note: MCS = mental component scale from SF-36; NYHA = New York Heart Association functional classification; IU = illness uncertainty; RK = risk knowledge; RK x IU = risk knowledge by illness uncertainty interaction.

general knowledge nor risk-related knowledge was associated with illness uncertainty. General knowledge was associated only with symptoms of depression. Higher illness uncertainty was associated with lower MCS and PCS, as well as with higher depressive and anxiety symptoms. CHD lesion severity was not associated with illness uncertainty or general knowledge and was only modestly associated with risk-related knowledge ($r = 0.16, p = .05$). NYHA status was associated with illness uncertainty ($r = 0.26, p < .001$) and risk-related knowledge ($r = 0.32, p < .001$) but not general knowledge.

PROCESS analyses revealed a moderating effect of illness uncertainty on the relationship between risk-related knowledge and MCS ($b = -0.53, p = .03, 95\% \text{ CI} = [-1.02, -0.05]$), as shown in Table 3. When the interaction was probed (at the mean and plus/minus one standard deviation from the mean) the effect was only present among participants scoring one standard deviation above the mean of illness uncertainty (48.79; point estimate = -9.33, $p = .02, 95\% \text{ CI} = [-17.10, -1.56]$), as shown in Fig. 2a. The interaction remained significant when NYHA status and age were included in the model. Analyses also revealed a moderating effect of illness uncertainty in the relationship between risk-related knowledge and anxiety symptoms ($b = 0.41, p = .03, 95\% \text{ CI} = [0.04, 0.77]$), as shown in Table 3. When the interaction was probed, the effect was only present among participants scoring one standard deviation above the mean of illness uncertainty (48.79; point estimate = 7.30, $p = .01, 95\% \text{ CI} = [1.45, 13.15]$), as shown in Fig. 2b. The interaction remained significant when NYHA status and age were included in the model. No interaction was found between risk-related knowledge and illness uncertainty in predicting PCS or depressive symptoms. General knowledge did not interact with illness uncertainty to predict MCS, PCS, depressive symptoms, or anxiety symptoms.

Table 2

Inter-correlations of health-related quality of life, psychological distress, illness uncertainty, and disease knowledge.

	MCS	PCS	Depressive Symptoms	Anxiety Symptoms	Illness Uncertainty	General Knowledge
PCS	.26**	–				
Depressive Sxs	-0.37**	-0.29**	–			
Anxiety Sxs	-0.56**	-0.24**	.28**	–		
Illness uncertainty	-0.51**	-0.36**	.22**	.33**	–	
General knowledge	-0.14	.05	.20**	.05	-0.13	–
Risk knowledge	-0.24**	-0.13	.28**	.20*	.14	.47**

Note: * $p \leq 0.05$; ** $p \leq 0.01$; MCS = mental component scale; PCS = physical component scale.

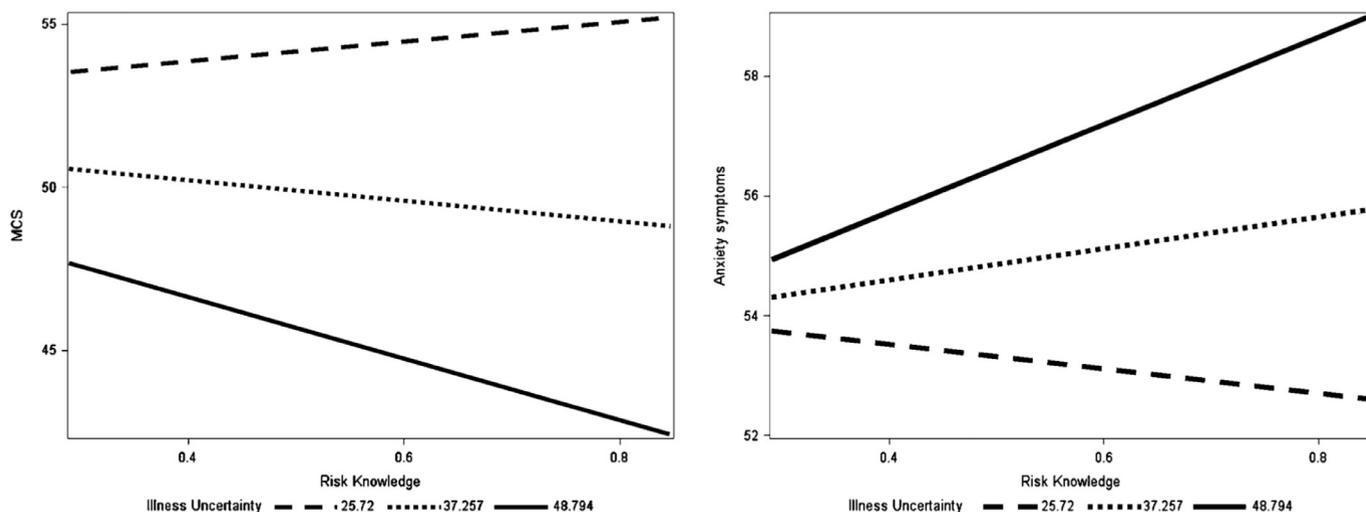


Fig. 2. a and b: The moderating effect of illness uncertainty (mean \pm 1 SD) on the relationship between risk knowledge and emotional health-related quality of life (MCS) and anxiety symptoms. Note: MCS = mental component scale from SF-36.

Discussion

Although greater disease knowledge is generally associated with better well-being in a wide range of chronic illness populations,^{4,19} the current study found that CHD patients with greater understanding of their risks for future cardiovascular complications reported greater anxiety and poorer emotional HRQoL, especially when there was uncertainty related to the CHD diagnosis. Based on the results of recent studies,^{4,19} greater disease knowledge (general and risk-related) was expected to be associated with better HRQoL and lower psychological distress. Risk-related knowledge may represent a construct distinct from general knowledge, with risk-related knowledge more likely contributing to emotional distress among patients reporting greater uncertainty. Measures of disease knowledge used in recent studies do not include items related to future risk.^{4,13,15,17,25,32–34} However, Shaw and colleagues demonstrated that information regarding risk factors may have a different influence on emotional well-being than general disease-related information, depending on patient characteristics.

Consistent with studies of other chronic diseases, illness uncertainty was associated with lower physical and emotional HRQoL as well as with greater psychological distress among patients with CHD.^{23,24} Surprisingly, there was no association between disease knowledge (general or risk-related) and illness uncertainty. As this was the first study to explore the relationship between these constructs, there is no prior research to compare with these findings. One possible explanation for the lack of a relationship between illness uncertainty and disease knowledge is that illness uncertainty is less dependent on awareness of the objective nature of the health problem (e.g., diagnosis, surgical outcome, course/timeline, future risk) because it reflects subjective perception of ambiguity and comprehension of illness-related events. Instead, illness uncertainty may be more strongly associated with individual differences, such as personality, emotional distress, cognitive functioning, and illness-related perceptions.²⁰ Thus, illness uncertainty may be experienced independent of disease knowledge among patients with CHD.

This study documents the relevance of illness uncertainty for psychosocial outcomes and the importance of distinguishing between risk-related knowledge and general knowledge among patients with CHD. The current study had several strengths, including a sample representing a pertinent developmental age range from adolescence through young adulthood when transition readiness is critical. Also, the sample was recruited from both a pediatric hospital and an adult

medical center with the goal of enhancing the generalizability of study findings to those CHD survivors who receive care in either medical setting. Despite these strengths, several limitations should be noted. This was a cross-sectional study, thereby making temporal precedence in the observed effects indeterminable. However, findings from the current study can serve as the foundation for future investigations tracking change in illness uncertainty longitudinally, as well as effects of illness uncertainty in predicting future psychosocial outcomes. Also, the need to re-contact some of the participants to complete the YSR/ASR resulted in time lag between measurement periods which could inflate measurement error. The time lag would be most likely to reduce the strength of associations between variables, rather than strengthen; therefore, the associations presented in this study may underestimate the magnitude of the effect. There were also limitations related to the measures utilized. There is currently limited psychometric data on CHD-AIM due to the nature of the item and subscale structure, making internal consistency difficult to assess. Additionally, the CUIS has not been previously used with individuals older than 18 years of age, but the current study provides evidence that the internal consistency remains intact with a sample of adults.

Disease knowledge has been a focus of research and intervention in chronic illness populations; however, results of this study do not support the notion that greater disease knowledge is consistently associated with better emotional well-being and HRQoL among patients with CHD. There is evidence that patient characteristics, such as coping style, influence the type of information desired as well as actual knowledge gained by patients with heart disease.¹⁸ For example, a patient with a denial-focused coping strategy may experience elevated distress when presented with risk-related information and may experience greater uncertainty when their actual level of risk-related knowledge is higher. Additional research is needed to assess the relationship between illness uncertainty, disease knowledge, and personality dimensions among patients with CHD.

Greater risk-related knowledge in the context of increased uncertainty may be associated with poorer psychosocial outcomes among patients with CHD. Fortunately, illness uncertainty is modifiable and can be reduced with a variety of techniques.³⁵ Mishel provides a review of several techniques used to reduce uncertainty among patients with a range of chronic illnesses.³⁵ Illness uncertainty may be reduced among patients with acute medical needs when health care providers express confidence, provide definitive diagnoses, and take an active role in formulating self-management plans with the

patient.³⁵ Conversely, proactive efforts by health care providers to display control may be counterproductive when attempting to reduce illness uncertainty among patients with chronic illness.³⁵ Mishel provides some evidence that self-management efforts are hindered by health care providers when they assume the role of “expert”. Physicians may fail to communicate with patients about the daily impact of chronic illness which could result in the patient perceiving the physician as lacking knowledge or understanding of their experience.³⁵ Thus, illness uncertainty may follow from a perceived lack of knowledge in the physician regarding the personal experiences of the patient. Uncertainty may be reduced when health care providers seek to restore perceptions of control and self-efficacy to the patient.³⁵ Several educational and cognitive-behavioral techniques are effective in reducing illness uncertainty, and may benefit patients with CHD, including 1) providing individually-tailored information; 2) helping patients build confidence with self-monitoring by identifying triggers for the onset of symptom exacerbation; 3) teaching patients to create contingency plans to accommodate unexpected illness-related events; 4) helping patients form an illness schema, including constructing a personal scenario for the illness that includes why or how the illness began, how it will progress, and how the individual will recover; and 5) train patients to challenge invalid thoughts about negative perceptions of themselves and inflexible beliefs about the future.³⁵ Many of these strategies are common tools used by mental health professionals as part of cognitive behavioral therapy.

Results of this study provide implications for future research and intervention efforts. Educational interventions among patients with CHD and their families may benefit from considering patients' level of illness uncertainty when providing disease information. Illness uncertainty may be related to individual characteristics such as personality traits, cultural differences, world view, and coping strategies,³⁵ all of which may be associated with a differential influence of disease knowledge on emotional well-being and HRQoL as well as intervention outcomes. Additional research is needed to assess the relationship between illness uncertainty and personality dimensions (e.g. need for control, spirituality), coping behaviors, and sense of self among patients with CHD. Mishel³⁵ proposed that illness uncertainty may function differently among those with chronic illness versus those with acute illness. Relatedly, the influence of illness uncertainty on emotional well-being and HRQoL may vary according to the patient's stage of illness (i. e., diagnosis, exacerbation, recurrence, or daily living). Longitudinal methods will be useful in future research to assess the chronicity of illness uncertainty as well as the relationship between illness uncertainty and disease stage among patients with CHD.

Supplementary material

Supplementary material associated with this article can be found in the online version at [doi:10.1016/j.hrtlng.2018.10.026](https://doi.org/10.1016/j.hrtlng.2018.10.026).

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