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Understanding and Promoting Medical Transition Readiness  
in Adolescents and Young Adults with Chronic Illness

A dissertation submitted in partial satisfaction of the  
requirements for the degree Doctor of Philosophy  
in Psychology

by

Kate Louise Herts

2018

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## ABSTRACT OF THE DISSERTATION

### Understanding and Promoting Medical Transition Readiness in Adolescents and Young Adults with Chronic Illness

by

Kate Louise Herts

Doctor of Philosophy in Psychology

University of California, Los Angeles, 2018

Professor Annette L. Stanton, Chair

Few psychosocial interventions for adolescents and young adults (AYAs) with chronic illness aim to promote medical transition readiness (i.e., preparation to transfer from pediatric to adult medical care), an important developmental task. Inadequate medical transition readiness can result in poor psychological, financial and health-related outcomes. Guided by research and theory in Positive Youth Development (PYD), childhood chronic illness and medical transitions, the primary goals of the studies comprising this dissertation were to identify and promote factors that contribute to medical transition readiness. First, a systematic review of the literature was conducted to identify studies that assessed self-efficacy for disease management in AYA cancer survivors. In the second study, young adults with chronic illness were randomly assigned to a Coping Skills Intervention (CSI) condition, representing a life skills intervention in line with PYD theory; or a print control condition (Informational Materials; IM). All participants received

weekly emails with information that aims to promote medical transition readiness. Participants in the CSI condition also attended an eight-week cognitive behavioral therapy group. Findings from the systematic review indicated 1) that self-efficacy for disease management is positively associated with health-promoting behaviors and inversely related to physical and mental health problems; and 2) that behavioral and educational interventions have the potential to increase self-efficacy. Results of the randomized controlled trial demonstrated that at two months (immediately post-intervention), CSI (vs. IM) participants were significantly more likely to have initiated the transition to adult medical care. There was no significant impact of group assignment on disease-related skills and knowledge, medical regimen adherence, quality of life, or depressive symptoms. CSI (vs. IM) group members demonstrated significantly higher illness-related benefit finding, self-efficacy and approach-oriented coping, as well as lower anxiety and perceived illness-related threat. Future research and clinical intervention refinement should build on the current findings by incorporating additional components of Positive Youth Development programs and by evaluating the CSI in diverse populations and settings. Additional directions for research include the need for validated measures of self-efficacy for disease management for AYA cancer survivors, as well as interventions that target the health care team's role in promoting self-efficacy.

The dissertation of Kate Louise Herts is approved.

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## **Chapter 1: General Introduction to the Research**

### **Epidemiology and Impact of Childhood Chronic Illness**

Chronic illness is defined by the Centers for Disease Control and Prevention as a noncommunicable illness that: (1) lasts longer than three months; (2) does not spontaneously resolve; and (3) is rarely completely cured (Centers for Disease Control and Prevention, 2009). Up to 25% of U.S. children under age 17 years suffer from a chronic health problem such as type 1 diabetes, cancer, sickle cell disease or asthma (Compas, Jaser, Dunn, & Rodriguez, 2012; Newacheck, 1992). Furthermore, recent data from the National Longitudinal Survey of Youth suggests that the prevalence of childhood chronic physical conditions is on the rise (Van Cleave, Gortmaker, & Perrin, 2010).

As compared to their healthy peers, children with chronic illness are at higher risk for a range of poor psychosocial outcomes, which is evidenced in relatively low health-related quality of life (HRQoL), a construct that captures the perceived impact of disease on functioning in social, emotional, physical and other domains (Varni, Seid, & Rode, 1999). In a study comparing the HRQoL of adolescents with cystic fibrosis, diabetes or asthma to that of adolescents in a large community sample, Sawyer and colleagues (2004) found that adolescents with chronic illness had poorer HRQoL compared to healthy peers based on measures of illness interference with family, physical and school/peer activities, as well as on measures assessing general health perceptions and behavior problems. Similarly increased risk for poor HRQoL has been shown for children with other illnesses including juvenile chronic arthritis, celiac disease and cancer (Grootenhuis, Koopman, Verrips, Vogels, & Last, 2007).

Poor HRQoL also is reflected in reports of academic and social difficulties. Children with chronic illness have higher rates of school absence than their healthy peers (Suris, Michaud, &



Viner, 2004; Thies, 1999; Taras & Potts-Datema, 2005; Wodrick & Cunningham, 2008). They may miss up to three times as many school days as their peers, and 10% of children with chronic illness miss more than 25% of the school year (Newacheck, 1998; Thies, 1999). School absences can increase risk for poor academic performance (Thies, 1999). Absenteeism can also disrupt peer relationships. In an age- and gender-matched study of children with sickle cell disease, Noll, Vannatta, Koontz, Kalinyak, Bukowski, and Davies (1996) found that girls (but not boys) with sickle cell disease were perceived by their classmates to be less sociable and well accepted. Notably, disruptions in peer relationships may vary by diagnosis. Children with illnesses associated with cognitive impairment, such as epilepsy and sickle cell disease, face increased risk for social difficulties compared to children with other illnesses such as cancer and diabetes; in contrast, children in the latter category experience similar risk for social problems as their healthy peers (La Greca, Bearman, & Moore, 2002).

Chronic illness has consistently been shown to put children at increased risk for emotional and behavioral problems (Cadman, Boyle, Szatmari, & Offord, 1987; Cohen, Pine, Must, Kasen, & Brook, 1998; Hysing, Elgen, Gillberg, Lie, & Lundervold, 2007; Lavigne & Faier-Routman, 1991; Pinquart & Shen, 2011). Meta-analyses demonstrate that children with chronic illness have higher rates of both internalizing symptoms, such as anxiety and depression, and externalizing symptoms, such as aggression and hyperactivity (Lavigne & Faier-Routman, 1991; Pinquart & Shen, 2011). Children and adolescents with chronic illness also demonstrate poorer self-concept (i.e., self-evaluation of physical appearance, social acceptance, academic competence, athletic competence and behavior) compared to healthy controls (Ferro & Boyle, 2013). Prospective studies in healthy samples have found that low self-concept in adolescence is associated with increased risk for psychological disorders, physical health problems and poor

educational attainment in adulthood (Pelkonen, Marttunen, Kaprio, Huurre, & Aro, 2008; Trzesniewski, Donnellan, Moffitt, Robins, Poulton, & Caspi, 2006), domains in which children with chronic illness are already at risk for poor outcomes.

In sum, children with chronic illness are at increased risk for poor health-related quality of life, academic outcomes and psychological health when compared to their healthy peers. They may also be more vulnerable to difficulties with peer relationships. These risk factors pose challenges for adolescents with chronic illness as they enter young adulthood and attempt to establish independence. Accordingly, the primary goals of the two projects for this dissertation were to identify and to promote factors that contribute to positive psychosocial adjustment for adolescents and young adults (AYAs) with chronic illness.

### **Chronic Illness During the Transition to Adulthood**

As a result of advances in medical treatments over the past half century, 90% of children born with a chronic illness will now survive into adulthood, and an estimated 500,000 youth with special health care needs (YSHCN) turn 18 each year (Maslow, Haydon, McRee, Ford, & Halpern, 2011). The transition to adulthood represents a vulnerable time for AYAs with a history of childhood chronic illness. Disruption in established routines, relationships, diet and other lifestyle factors when AYAs leave their family home can make them more vulnerable to medical non-adherence, an important factor influencing health outcomes. Typical developmental processes may limit rates of medical adherence in adolescence. For example, one key developmental task of adolescence is the development of an independent identity; adolescents might have trouble incorporating illness into their emerging sense of self and thus engage in non-adherence as a form of denial (Taddeo, Egedy, & Frappier, 2008). They may also engage in non-adherence to test limits with their parents and doctors, or to gain a sense of control over their

illness (Taddeo et al., 2008). Rates of adherence to medical regimens vary by chronic illness, but AYAs report low rates of adherence in several illness samples. For example, rates of non-adherence to treatment of 50% or more have been reported in samples of AYAs with cancer and sickle cell disease (Kondryn, Edmondson, Hill, & Eden, 2011; Walsh, Cutrona, Kavanagh, Crosby, Malone, Lobner, & Bundy, 2014). Non-adherence can increase symptomatology, which may in turn hinder the development of independence.

In addition to the need to maintain medical adherence, AYAs with chronic illness face a myriad of other unique challenges to maintaining physical and psychosocial health as compared to their healthy peers. For example, the transition from a pediatric oncology treatment setting to adult medicine for childhood cancer survivors is complicated and often delayed for several reasons, including that adult specialists may lack the necessary knowledge to provide adequate follow-up care or that family members may be overprotective (Henderson, Friedman, & Meadows, 2010). Additionally, for young adults with type 1 diabetes, challenges to self-care (i.e., lack of social support, erratic schedules) that are common in young adulthood can lead to an increase in serious complications including mortality (Weissberg-Benchell, Wolpert, & Anderson, 2007). Difficulty with navigating these challenges is reflected in poor young adult outcomes across several domains for those with a history of childhood chronic illness. Young adults with childhood-onset chronic illness have been shown to have lower odds of college graduation or employment, lower health-related quality of life, higher odds of receiving public assistance and higher perceived loneliness as compared to healthy peers (Herts, Maslow, & Wallis, 2014; Maslow et al., 2011).

**Medical transition readiness.** One important developmental task AYAs with chronic illness must undertake is preparation to transition from pediatric to adult-oriented medical care.

Preparedness for this transition, termed *medical transition readiness*, is a modifiable factor that predicts successful outcomes in adult medical care such as health maintenance and autonomous disease management (Wood, Sawicki, Miller, Smotherman, Lukens-bull, Livingood... & Kraemer, 2014). Medical transition readiness is defined as “the capacity of the adolescent and those in his or her primary medical system of support (family and medical providers) to prepare for, begin, continue and finish the transition process” (Schwartz, Tuchman, Hobbie, & Ginsburg, 2011; p. 885). The American Academy of Pediatrics, Department of Health and Human Services and other professional societies identify medical transition readiness as an important focus of research attention (McManus, Pollack, Coolet, McAllister, Lotstein, Strickland, & Mann, 2013; Schwartz et al., 2011). Yet, many AYAs struggle to achieve the level of autonomy in disease self-management skills required by the adult healthcare system (Wood et al., 2014). Further, data from the 2009-2010 National Survey of Children with Special Health Care Needs (CSHCN) suggest that only 40% of families of CHSN receive adequate guidance from medical providers in preparing for the transition to adult care (e.g., advice about maintaining health insurance coverage; McManus et al., 2013). As a result, AYAs with chronic illness often experience a decline in important health indicators such as decreased glycemic control in diabetics or increased life-threatening complications in young adult cancer survivors (Wood et al., 2014). Poor transition planning can also result in poor psychological and financial outcomes, such as increased use of expensive emergency healthcare in young adulthood (Schwartz et al., 2011). Promoting medical transition readiness among AYAs with chronic illness is thus an important target for intervention that holds serious implications for psychosocial and physical health.

### **Conceptualizing Medical Transition Readiness**

The Social Ecological Model of AYA Readiness for Transition (SMART) was designed to facilitate understanding and promotion of medical transition readiness (Schwartz et al., 2011). SMART identifies seven components of medical transition readiness that are amenable to intervention: 1) developmentally appropriate level of autonomy; 2) disease knowledge; 3) skills/self-efficacy for disease management; 4) beliefs and expectations about transition; 5) transition-related goals; 6) relationships among patients, parents and providers; and 7) psychosocial functioning (Schwartz et al., 2011). Prior studies have commonly assessed only age and disease-related skills and knowledge as criteria for medical transition readiness, which may not translate into successful transition (e.g., engagement with adult medical providers) in the absence of the other important factors, such as self-efficacy for and a social support system to promote transition (Schwartz et al., 2011). By examining several modifiable components of medical transition readiness in samples of AYAs with chronic illness, the current research contributes to the understanding and application of this comprehensive conceptualization of medical transition readiness.

### **Psychosocial Interventions for AYAs with Chronic Illness**

Though psychosocial or transition-focused medical interventions for AYAs with chronic illness are numerous, few have strong empirical support. Results from a recent systematic review of transition care programs demonstrated that only six empirically supported programs have demonstrated positive effects on health outcomes for AYA patients; these consisted mainly of patient education in the context of a joint pediatric-adult medical care clinic and all were for patients with diabetes (Crowley, Wolfe, Lock, & McKee, 2011). In a recent systematic review of psychological interventions for AYAs with chronic illness, Sansom-Daly, Peate, Wakefield, Bryant and Cohn (2012) identified 25 studies that used two-group quantitative designs and

measured at least one psychosocial outcome; similarly, most were for AYAs with diabetes. The authors found that successful interventions for AYAs alone (vs. with a family component) were commonly group-based and included the teaching of cognitive behavioral skills. None specifically set out to measure the impact of the intervention on medical transition readiness, though all targeted at least one component of medical transition readiness (e.g., psychosocial functioning; Sansom-Daly et al., 2012). These reviews demonstrate a need for rigorously evaluated transition-focused interventions for AYAs with chronic illness, particularly outside of the diabetes population. Many transition-related challenges are common across illness populations, such as the need to transfer to an adult medical provider. As such, the effective interventions for AYAs with diabetes described above have the potential to foster positive psychosocial and physical health outcomes in other disease populations.

**Positive Youth Development programs.** Positive Youth Development (PYD) programs hold promise for promoting medical transition readiness in AYAs with chronic illness. PYD programs aim to promote strengths in youth by: 1) providing leadership opportunities; 2) building life skills; and 3) establishing caring, sustained adult-child mentoring relationships (Maslow & Chung, 2013). In line with the SMART, PYD programs aim to promote the development of competence (SMART construct: disease management skills), confidence (SMART construct: self-efficacy) and social connection (SMART construct: relationships among patients, parents and providers; Catalano, Berglund, Ryan, Lonczak, & Hawkins, 2002; Schwartz et al., 2011). In prior research, PYD programs have been shown to promote positive outcomes for diverse groups of healthy adolescents (Catalano et al., 2002). Recently, PYD programs for AYAs with chronic illness have demonstrated positive effects on components of medical transition readiness including social connection, disease knowledge and self-advocacy

skills (Maslow, Adams, Willis, Senouillet, Herts, Froehlich, Calleson... & Rickerby, 2013; Maslow & Chung, 2013). However, all data are based on pre- and post-reports from program participants, and thus the impact of the interventions cannot be distinguished from normal developmental changes. Further, only one program evaluation has included quantitative analyses (Maslow et al., 2013), limiting the conclusions that can be drawn from the other evaluations in terms of detecting significant effects of the program.

### **Aims of the Current Research**

As described above, inadequate medical transition readiness can result in poor psychological, financial and health-related outcomes for AYAs with chronic illness, a group that is already vulnerable to poor psychosocial adjustment. To date, few psychosocial interventions for AYAs with chronic illness have strong empirical support and fewer still specifically aim to promote medical transition readiness. Guided by research and theory in positive youth development, childhood chronic illness and medical transitions, the current research aims to help address this gap in the literature by identifying and promoting mechanisms underlying positive psychosocial adjustment and adaptation to illness for AYAs with chronic illness, with a primary focus on modifiable components of medical transition readiness.

**Study 1.** The aim of the first study was to identify factors that promote self-efficacy for disease management (SEDM) in AYA cancer survivors. SEDM is a causal factor underlying medical adherence and a modifiable component of medical transition readiness per the SMART model. A systematic review of the literature was conducted to identify cross-sectional and intervention studies that assessed SEDM. Factors associated with SEDM in cross-sectional analyses and interventions that have been shown to promote SEDM are identified. Additionally,

measurement issues and directions for future research are discussed. Results will help inform future intervention work to promote SEDM.

**Study 2.** In light of the need for empirically supported psychosocial interventions to facilitate the transition to adulthood for AYAs with chronic illness, the current randomized controlled trial evaluated the efficacy of a Coping Skills Intervention (CSI) as compared to a print control condition (Informational Materials; IM) in a sample of young adults with chronic illness. All participants received weekly emails with information that aims to promote medical transition readiness. Participants who were assigned to the CSI also attended an eight-week cognitive behavioral therapy group, representing a life skills intervention in line with Positive Youth Development theory. Medical transition behavior and SMART-congruent indicators of medical transition readiness were assessed as outcomes, including psychosocial adjustment (e.g., anxiety symptoms), illness-related adjustment (e.g., medical regimen adherence), competence/disease-related skills (i.e., approach-oriented coping), confidence (i.e., self-efficacy for disease management), and social connection (i.e., loneliness). A cognitive behavioral skills-based group intervention was chosen in light of evidence that similar interventions have yielded positive effects on psychosocial outcomes for AYAs with chronic illness. Further, in testing an intervention to build life skills, this trial provides the first step in a program of research designed to conduct a rigorous components test of a PYD program for AYAs with chronic illness. Understanding the contribution of core PYD components will allow for refinement of the intervention to improve efficacy and feasibility.



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## **Chapter 2: Correlates of self-efficacy for disease management in adolescent/young adult cancer survivors: A systematic review (Study 1)**

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### **Abstract**

**Objective:** The primary objective of this review was to summarize the literature regarding factors associated with self-efficacy for disease management (SEDM) in cross-sectional studies and the efficacy/effectiveness of psychosocial interventions that are designed to improve SEDM in adolescent and young adult (AYA) cancer survivors. The secondary aim was to assess the quality of included studies.

**Methods:** We conducted a systematic review using PsycInfo and PubMed to identify studies for review. Eligible studies were conducted in AYA cancer survivors ages 15 – 39; included a measure of SEDM assessed as an outcome or in a cross-sectional analysis; and were published in a peer-reviewed, English-language journal.

**Results:** From the 2,910 records screened, 7 cross-sectional studies and 4 intervention studies met criteria for inclusion. Eleven of the 12 SEDM measures in the studies were author-constructed, limiting the ability to draw conclusions across studies. All cross-sectional studies met at least 21 of 26 relevant quality assessment criteria, and intervention studies met between four and 11 of 14 criteria. Cross-sectional findings indicate that SEDM is positively associated with health-promoting behaviors and inversely related to physical and mental health problems. The intervention studies demonstrated that behavioral and educational interventions have the potential to increase SEDM.

**Conclusions:** Directions for research include the need for validated measures of SEDM for AYA cancer survivors, as well as interventions that target both the health care team's and the patient's role in promoting SEDM.

## **Correlates of self-efficacy for disease management in adolescent/young adult cancer survivors: A systematic review**

Cancer is the leading disease-related cause of death among adolescents and young adults (AYAs) aged 15 – 39 years in the United States (Ward, DeSantis, Robbins, Kohler, & Jemal, 2014). Approximately 70,000 AYAs are diagnosed with cancer each year (National Cancer Institute [NCI], 2014). After completion of cancer treatments, AYA survivors have a significantly higher prevalence of chronic health conditions, as well as a higher prevalence of obesity and current smoking as compared to healthy peers (Tai et al., 2012). One in 530 young adults between the ages of 20 and 39 years is a childhood cancer survivor (CCS; Ward et al., 2014), a different albeit overlapping group from survivors of cancers diagnosed while AYAs. Data from the CCS Study demonstrate an increased risk of mortality for CCSs as compared to healthy peers up to 30 years after diagnosis (Ward et al., 2014). These data also indicate that CCSs are 3.3 times more likely to have a chronic health condition as compared to healthy peers (Oeffinger et al., 2006).

In light of increased risk for mortality and chronic disease, it is vitally important that AYAs adhere to established guidelines for cancer treatment and follow-up care. However, a review indicated that 27% to 63% of teenagers and young adults with cancer were not adherent to oral medications, and 14% to 24% of patients failed to seek medical care for a raised temperature, diarrhea, or bleeding, all of which are symptoms that can signal life-threatening consequences in the absence of medical treatment (Kondryn, Edmondson, Hill, & Eden, 2011).

A small body of research has focused on identifying factors that influence adherence in AYAs with cancer (Buchanan, Block, Wilder Smith, & Tai, 2014; Butow, et al., 2010; Kato, Cole, Bradlyn, & Pollock, 2008; Kondryn et al., 2011; Trevino, Fasciano, & Prigerson, 2013)



and that are associated with survivorship care participation and engagement in healthy behaviors in CCSs (Casillas et al., 2011; Emmons et al., 2002; Hocking et al., 2013; Hudson et al., 2002; Klosky et al., 2008). Findings from review articles identify family relationship factors (e.g., family environment; Butow et al., 2010) and psychological factors (e.g., emotional functioning; Kondryn et al., 2011) as predictors of treatment adherence. Empirical studies demonstrate that adherence to treatment and health behaviors are associated with demographic factors (e.g., age at diagnosis; Emmons et al., 2002); health status (Casillas et al., 2011); and psychological symptoms (Emmons et al., 2002). Finally, intervention studies have found a positive effect of a behavioral, cancer-specific video game intervention (Kato et al., 2008) and no effect of a multi-behavioral educational intervention (Hudson et al., 2002) on adherence to treatment. One common avenue through which these diverse factors can be theorized to influence adherence is through their impact on *self-efficacy for disease management (SEDM)*, the focus of the present review.

### **Self-Efficacy for Disease Management**

SEDM is a modifiable psychological factor that is theorized (Bandura, 1977) and demonstrated (Kato et al., 2008; Strecher et al., 1986) to be associated with adherence to medical treatment and other health behaviors. Social-cognitive theory posits that self-efficacy is a causal psychological mechanism underlying behavior change (Bandura, 1977). *Self-efficacy* refers to one's belief that he or she can successfully engage in a behavior needed to produce a desired outcome (Bandura, 1977). For example, AYAs might believe that taking a medication daily will improve their health. In this case, a lack of self-efficacy for taking the medication constitutes a barrier to adherence, even if they have a strong desire to improve their health. Low self-efficacy is associated with engagement in many unhealthy behaviors including cigarette smoking, alcohol

abuse, and lack of exercise (Strecher et al., 1986). Moreover, improving self-efficacy through intervention predicts positive health behavior change (Strecher et al., 1986).

*Disease management* is comprised of at least three sets of tasks: 1) adherence to medical regimens; 2) adapting meaningful behaviors or life roles to accommodate illness; and 3) managing negative disease-related emotions (Lorig & Holman, 2003). A review of treatment non-adherence in AYAs with various cancer diagnoses who were on active treatment revealed that commonly assessed disease management tasks include adhering to daily oral medications, seeking medical help when needed, and attending medical appointments (Kondryn et al., 2011). In contrast, CCSs must engage in disease management tasks and health behaviors that mitigate risk for late effects (e.g., cardiac and pulmonary problems), which include attending and coordinating follow-up care, regularly engaging in physical activity, and avoiding smoking (Nathan, Hayes-Lattin, Sisler, & Hudson, 2011). Drawing from the definitions of self-efficacy (Bandura, 1977) and disease management (Lorig & Holman, 2003), we defined *SEDM* as a patient's belief that she or he can adhere to the prescribed health care regimen, use coping strategies to manage negative disease-related emotions, and find ways to engage in valued behaviors.

## **Objectives**

At present, the literature lacks a comprehensive review of contributors to *SEDM* in AYAs. To address this limitation, we aimed to provide summaries of factors associated with *SEDM* in cross-sectional studies and the efficacy/effectiveness of psychosocial interventions designed to prospectively predict *SEDM*. When examining cross-sectional studies, we detail which factors are hypothesized to be predictors vs. outcomes of *SEDM*, as understanding these theoretical relationships will facilitate the development of interventions targeting *SEDM*.

Furthermore, in order to contextualize the findings about factors associated with SEDM, we aimed to assess the quality of both cross-sectional and intervention studies regarding SEDM.

### **Method**

This review was conducted and reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009). Below, we describe operationalizations of key constructs, the literature search procedure and study inclusion criteria, the article screening process, and the article review process that allowed for data extraction.

#### **Construct Definition**

**SEDM.** Self-efficacy was operationalized to include constructs labeled “self-efficacy” or “confidence” by the studies’ authors. The term “confidence” was included because SEDM questionnaires often ask about confidence in one’s abilities to perform health behaviors (Heitzmann et al., 2011; Lorig et al., 1996; Nicholas, 2007). In order to improve the ability to draw conclusions across studies, research that assessed related constructs (e.g., empowerment, locus of control, perceived behavioral control) were not included. Perhaps the most closely related construct excluded from the review is perceived behavioral control, which refers to one’s perception of control over a particular behavior (Ajzen 1991). Perceived behavioral control differs conceptually from one’s confidence in the ability to engage in a behavior (i.e., self-efficacy). Indeed, research demonstrates that although the two constructs are correlated, they are distinct in their ability to predict intentions to engage in or actual engagement in health behaviors (Motl et al., 2005; Myers & Horswill, 2006; Norman & Hoyle, 2004).

Social cognitive theory posits that self-efficacy is tied to specific behaviors (Bandura, 1977), and as such, studies that assessed only general self-efficacy were excluded. *Disease*

*management* was defined to include behaviors intended to: 1) adhere to medical treatment regimens; 2) adapt life roles to accommodate illness; and 3) manage negative disease-related emotions.

**AYAs.** We adopted the he NCI’s definition of AYAs as cancer survivors aged 15 – 39 years (Adolescent and Young Adult Oncology Progress Review Group, 2006). Therefore, we included samples with an average age between 15 and 39 years. Of note, we also follow the NCI definition of cancer survivors. Specifically, the NCI classifies patients as survivors from “the time of diagnosis until the end of life” (National Cancer Institute, 2016).

### **Literature Search Procedure**

A systematic search was conducted using PsycInfo and PubMed. Searches were inclusive of studies published from each database’s inception through December of 2014 and used the following search terms: 1) “cancer” AND “self efficacy;” 2) cancer AND “self efficacy” AND confidence; 3) cancer AND [confident OR confidence in title]. Studies were screened according to the following inclusion criteria: 1) mean age between 15 and 39 years; 2) sample consists of individuals ever diagnosed with cancer; 3) SEDM is measured as a longitudinal outcome or in a cross-sectional design; 4) empirical study published in a peer-reviewed, English-language journal. Studies of adult samples that did not report a mean age for participants and that did not have an age range falling primarily within the NCI’s AYA age range were excluded. In the second stage of the literature search, the reference lists of included studies were screened for eligible studies.

### **Article Screening Strategy**

Reference management software was used to remove duplicates automatically. Records were first screened by abstract according to the inclusion criteria. For studies included at the

abstract level, full articles were obtained and screened. Next, all records and the full text of articles included at the abstract level were independently screened for inclusion by the first author. The second author independently screened 68% of the records and full-text articles returned from the search. Inter-rater agreement was 93%. A research assistant (RA) screened the remaining 32% of the records and articles returned from the cancer search. Inter-rater reliability regarding agreement between the first author and the RA was 96%. Discrepancies were resolved through discussion among the screeners.

### **Article Review Strategy**

Included studies were independently coded by the first author on predetermined categories to detail data relevant to the interpretation of findings: 1) SEDM measures, means, standard deviations, and internal consistency estimates of reliability; 2) primary study purpose; 3) sample characteristics: sample size; mean age and age range; time elapsed since diagnosis; percent currently in treatment; time since treatment completion; percent each of two most highly represented ethnic/racial groups; percent female; education level; 4) study methods: study design and SEDM analyses; if applicable, type of intervention, intervention leaders, control conditions, and length of follow-up; and 5) factors associated with SEDM and indicators of effect size when available. In detailing the results, factors associated with SEDM were characterized as belonging to one of the following categories: participant characteristics, social relationships, physical health status, mental health status, health beliefs, health behaviors, and intervention status. Half of the included intervention studies ( $k = 2$ ) and half of the included cross-sectional studies ( $k = 4$ ) were coded for agreement by the second author. Inter-rater reliability was above 95% for both. Discrepancies in these codes and in those described below were resolved through discussion between the authors.

To facilitate understanding of how SEDM is currently measured for AYA cancer survivors, the first author independently coded the domains of disease management assessed by each self-efficacy measure used in the included studies. Half of the SEDM measures ( $k = 6$ ) were coded for agreement by the second author. Inter-rater reliability was 99%.

We selected distinct scales to evaluate the quality of intervention vs. cross-sectional studies in order to allow for the assessment of components of intervention studies that are irrelevant to cross-sectional studies (e.g., random assignment). Cross-sectional studies were evaluated for quality by the second author using the Strengthening the Reporting of Observational studies in Epidemiology (STROBE) checklist for cross-sectional studies (Vandenbroucke et al., 2007). Four of the seven included cross-sectional studies were coded for agreement by the first author. Inter-rater agreement was 96%. Intervention studies were assessed for quality by the first author using a modified version of the PEDro scale, which evaluates studies for internal validity and interpretability (Center for Evidence Based Physiotherapy, 2009). The scale was modified to provide information about generalizability of findings (Hart et al., 2012). Half the included intervention studies ( $k = 2$ ) were coded for agreement by the second author. Inter-rater agreement was 100%.

## **Results**

Figure 1 illustrates the number of references excluded at each stage of the screening process. From 2,910 references screened, 11 studies met inclusion criteria: seven cross-sectional studies and four intervention studies.

### **Quality Assessment**

In order to contextualize our findings, we aimed to assess the quality of the included cross-sectional and intervention studies. Results of the STROBE quality assessment are detailed

in Tables 1 and 2. All seven studies satisfied at least 21 of the 26 broadly applicable criteria (range = 21 - 24 out of 26 criteria met), suggesting generally sound reporting of the cross-sectional studies.

Findings from the PEDro criteria quality coding of the four intervention studies are included in Table 3. Two intervention studies for AYAs diagnosed with cancer in adulthood both met at least 10 of 14 possible criteria (Jones et al., 2010, 11 criteria; Kato et al., 2008, 10 criteria). Two studies in CCSs did not employ control groups; one study met five criteria (Eiser, Hill, & Blacklay, 2000), and one met four criteria (McLaughlin et al., 2012; Song et al., 2012).

### **Disease Management Domains Assessed by Self-Efficacy measures**

All SEDM measures were designed to capture patients' (vs. parents' or others') reports. Information about the specific self-efficacy constructs assessed is displayed in Table 4. In total, 12 different SEDM measures were used. Eleven were author-constructed or adapted from existing measures, such as the Chronic Disease Self-Efficacy Scales (Lorig et al., 1996), which are not cancer-specific. Although the majority of studies assessed at least one construct that reflects self-efficacy for adhering to medical recommendations ( $k = 10/11$ ), only one study each assessed self-efficacy for adapting life roles and managing negative disease-related emotions, and none assessed all three domains relevant to disease management.

### **Factors Associated with SEDM in Cross-Sectional Studies**

Details regarding each study's purpose, sample characteristics, SEDM measures, and correlates of SEDM measures in cross-sectional studies are presented in Table 5.

**Demographics, social support, health status and cancer- and treatment-related variables are conceptualized as predictors of SEDM.**

***Demographic factors are inconsistently associated with SEDM.*** Three studies examined demographic factors associated with SEDM (Casillas et al., 2011; Emmons et al., 2003; Keats et al., 2007), with mixed results. In one sample of CCSs, men (vs. women; Cohen's  $d = .23^1$ ) and those diagnosed at a younger age (continuous increasing age variable Cohen's  $d = -.02^1$ ) reported higher self-efficacy for quitting smoking (Emmons et al., 2003). In a second, self-efficacy for physical activity was not associated with age (Keats et al., 2007). Finally, Casillas et al. (2011) found that racial/ethnic minorities who were young adult cancer survivors had higher odds of falling in a low (vs. high) SEDM group (Cohen's  $d = .28^1$ ).

***Social support is positively associated with SEDM.*** Emmons et al. (2003) found that CCSs who reported receiving a lot of (vs. little or no) support for smoking cessation had higher self-efficacy for quitting (Cohen's  $d = .31^1$ ).

***Cancer- and treatment-related variables are not associated with SEDM.*** One study found that time since diagnosis and length of adjuvant therapy were not associated with self-efficacy for physical activity in adolescents (Keats et al., 2007).

***When an association is found, poor health predicts poor SEDM.*** Indicators of physical health problems, i.e., self-reported health status (Cohen's  $d = .43^1$ ; Casillas et al., 2011) and late effects (Cohen's  $d = -.68^1$ ; Taylor et al., 2012), were inversely associated with SEDM in one study of CCSs (Taylor et al., 2012) and in one study of AYAs diagnosed in adulthood (Casillas et al., 2011). In addition, self-efficacy for physical activity was not associated with Body Mass Index in a study of CCSs (Keats et al., 2007).

**Mental health symptoms and health beliefs are conceptualized as having a reciprocal relationship with SEDM.**

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<sup>1</sup> Effect size statistics were calculated by the authors from data given in the original papers.



***Mental health symptoms are consistently inversely associated with SEDM.*** Severe psychological symptoms (Cohen's  $d = -.31^1$ ; Emmons et al., 2003) and post-traumatic stress symptoms (Cohen's  $d = -1.12^1$ ; Taylor et al., 2012) were inversely correlated with self-efficacy in two studies of CCSs.

***Disclosure ability is positively associated with SEDM.*** Emotional self-efficacy was associated with disclosure ability (e.g., ability to talk about cancer with others; Cohen's  $d = 1.35^1$ ) in a study of young adult men with testicular cancer (Hoyt, Cato, Saigal, & Stanton, 2013).

***Health beliefs are consistently associated with SEDM.*** Findings from three studies examining the associations between health beliefs and SEDM suggest that SEDM is positively associated with perceived behavioral control and positive and normative beliefs about the cancer experience. Keats et al. (2007) demonstrated that physical activity self-efficacy was positively associated with perceived behavioral control (Cohen's  $d = 2.49^1$ ), normative beliefs (Cohen's  $d = .98^1$ ), and affective attitude (e.g., enjoyableness; Cohen's  $d = .93^1$ ) in AYAs diagnosed between the ages of 11 and 19. In cross-sectional analyses of a social networking intervention for CCSs (see below), SEDM was positively correlated with participants' reports of positive cancer stereotypes such as new appreciation of life ( $r = .45$ , Cohen's  $d = 1.01^1$ ; Song et al., 2012). Additionally, higher perceived vulnerability to smoking was associated with higher SEDM in CCSs (Cohen's  $d = .08^1$ ; Emmons et al., 2003).

**Health behaviors are conceptualized as outcomes of SEDM.**

***SEDM predicts multiple positive health behaviors.*** The association between self-efficacy and health behaviors was examined in three cross-sectional studies of CCSs. Overall, findings suggest that SEDM predicts positive health behaviors including physical activity and intent to

seek healthcare. Butterfield et al. (2004) found that AYAs who had lower self-efficacy to avoid smoking in high-risk situations reported drinking more (vs. less) than the recommended amount of alcohol (Cohen's  $d = -.42$ ) and were not (vs. were) physically active (Cohen's  $d = -.29$ ); self-efficacy and other risky health behaviors (e.g., red meat consumption, Cohen's  $d = .04^1$ ) were not significantly correlated. Finnegan et al. (2007) and Keats et al. (2007) both found that higher physical activity self-efficacy was associated with higher likelihood of being physically active (Cohen's  $d = 1.01^1$  [Keats et al., 2007]; Cohen's  $d = .66^1$  [Finnegan et al., 2007]).

***SEDM predicts intent to engage in treatment and engagement in a cancer-related psychosocial intervention.*** One cross-sectional study of AYAs diagnosed in young adulthood (Milam et al., 2015) yielded a positive association between SEDM and intent to seek follow-up care (Cohen's  $d = .28^1$ ). In cross-sectional analyses of the social networking intervention for CCSs, SEDM was significantly inversely correlated with intervention blog participation (Cohen's  $d = -1.28^1$ ; McLaughlin et al., 2012).

### **Interventions to Improve SEDM: Prospective Studies**

Detailed information about the study purpose, sample characteristics, SEDM measures and correlates of SEDM measures in intervention studies are presented in Table 6.

**Intervention methods.** One clinic-based intervention and three computer-based interventions were described. The clinic-based intervention for CCSs consisted of written educational materials targeted to individual patients' needs, and a treatment summary, explained by physicians during a single session of routine follow-up care (Eiser et al., 2000). The computer-based interventions consisted of a social networking blog site for CCSs (McLaughlin et al., 2012; Song et al., 2012); an interactive, educational CD-ROM for AYAs diagnosed with cancer in adolescence (Jones et al., 2010); and a behavioral, cancer-specific video game for

AYAs in current treatment for cancer (Kato et al., 2008). Participants in the social networking intervention attended an orientation session where they learned how to use the social networking site, which included avenues to create a profile, share social media, blog and message other participants (McLaughlin et al., 2012). Participants received periodic text messages prompting them to create video blogs about particular topics (e.g., reflection on cancer survivorship; McLaughlin et al., 2012). Content and design of the CD-ROM intervention were developed to address information needs of adolescents with cancer (Jones et al., 2010). The CD-ROM includes information about treatments, side effects, late effects and other resources, as well as opportunities for participants to test their knowledge about side effects via a quiz and to learn about tumors by blasting cancer cells to score points (Jones et al., 2010). Drawing from theories including social cognitive theory and learning theory, the cancer-specific video game intervention was designed to impact treatment-related health behaviors by providing vicarious practice of desired behaviors, contingency-based learning of health information, problem-solving and practice of procedural knowledge (Kato et al., 2008). For example, participants had to take oral chemotherapy virtually to combat cancer cells (Kato et al., 2008).

The clinic-based and social-networking interventions employed single-group, pre/post assessment designs, whereas the two other computer-based interventions were evaluated in randomized controlled trials. The control group for the educational CD-ROM intervention received a handbook with comparable information, and the control group for the video game intervention played a commercial video game. The clinic-based intervention had a two-week follow-up, whereas the computer-based interventions all had follow-ups of at least three months.

**Interventions' effects on SEDM.** Two studies demonstrated a positive impact of interventions on SEDM. Participants in the clinic-based intervention ( $p < .01$ ; Eiser et al., 2000)

and the video game intervention demonstrated increased SEDM at follow-up, with participants in the video game intervention group (Cohen's  $d = .36$ ) vs. control group (Cohen's  $d = .08$ ) demonstrating significantly greater increases in SEDM ( $p = .01$ ; Kato et al., 2008). Further, changes in SEDM and cancer knowledge together fully mediated the effect of the video game intervention on adherence to oral antibiotics assessed via objective dose count data (Kato et al., 2008). Participants in the CD-ROM intervention failed to demonstrate significant pre/post intervention changes in SEDM (Cohen's  $d = .15$ <sup>1</sup>; Jones et al., 2010). To our knowledge, no prospective findings of the social networking intervention have been provided to date (McLaughlin et al., 2012; Song et al., 2012).

In sum, a clinic-based educational intervention (Eiser et al., 2000) and a behavioral video game intervention were shown to have a positive impact on SEDM. However, an interactive, educational CD-ROM intervention did not demonstrate significant effects on SEDM (Jones et al., 2010). Notably, due to the small sample size ( $n = 30$  participants in intervention group, 35 participants in control group) this study had insufficient power to detect a moderate effect of the intervention. To achieve power of .80 to detect a difference between groups when there is a moderate effect size (Cohen's  $d = .5$ ), the authors would have needed at least 80 participants per group.<sup>2</sup> Alternatively, the failure of the CD-ROM intervention to promote SEDM might be explained by the drastically more limited opportunity for virtual practice of health behaviors as compared to the video game intervention. Though the CD-ROM and clinic-based interventions both provided disease-related education, the follow-up of the CD-ROM intervention (3 months) was considerably longer than that of the clinic-based intervention (2 weeks), suggesting that the effects of an educational intervention may not endure for three months. As the video game

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<sup>2</sup> We would like to thank an anonymous reviewer for drawing our attention to this important point.

intervention showed a positive impact on SEDM at three-month follow-up (Kato et al., 2008), it is possible that behavioral interventions are more effective than educational interventions at promoting enduring SEDM.

## **Discussion**

The aims of the present review were to summarize factors associated with SEDM in AYA cancer survivors, detail which factors are conceptualized as predictors vs. outcomes of SEDM, and to assess the quality of included studies regarding SEDM. Eleven studies met inclusion criteria. The included studies used 12 different measures of SEDM, 11 of which were author constructed or adapted from existing measures, making it difficult to draw strong conclusions across studies. Additionally, none of the measures assessed all three domains of SEDM, indicating a pressing need for the development of psychometrically sound SEDM measures for this population. When examining associations between SEDM and other factors in cross-sectional studies, we found mixed evidence for an association between SEDM and participant demographics. We found largely consistent evidence that when an association exists, SEDM is positively associated with positive health behaviors (e.g., physical activity), perceived behavioral control, and positive and normative beliefs about the cancer experience, whereas SEDM is inversely associated with physical health and mental health problems. Because the majority of the included studies are cross-sectional in design ( $k = 7 / 11$ ), conclusions regarding causal directions are not possible. The small number of included intervention studies suggest that educational and behavioral interventions have the potential to improve SEDM. However, the intervention studies for CCSs ( $k = 2$ ) were of poor quality because they failed to employ control groups, making it impossible to distinguish the impact of the interventions from normal developmental changes. The included cross-sectional studies were of relatively sound quality.

## **Limitations**

The current findings should be interpreted in light of several limitations. First, the literature search was limited to empirical articles in peer-reviewed, English-language journals, which may reflect publication bias towards significant findings. However, some studies did report null results. Second, there was considerable variability in terms used to describe SEDM, suggesting that our search may not have captured all such variants. Third, the narrow focus of this review on AYA cancer survivors limits the generalizability of findings to AYAs with other illnesses. To our knowledge, no similar reviews exist of factors associated with SEDM in AYAs with other chronic illnesses including diabetes, asthma or juvenile arthritis.

The included studies also have considerable limitations. Most used author-constructed or adapted SEDM measures that varied greatly in how they assessed SEDM, limiting the comparison of findings across studies and thus our ability to draw strong conclusions from the present review. Similarly, a recent systematic review of psychosocial, health-promotion and neurocognitive interventions for CCSs is limited by the large proportion of included studies that employed new measures, which lacked population norms or clinical cutoffs (Brier, Schwartz, & Kazak, 2015). However, there is a considerable benefit to using an author-constructed measure of SEDM, specifically that authors can tailor the measure to the specific process under investigation. Notably, none of the measures accounted for who (patient, parent or doctor) is perceived to be or is actually responsible for a given aspect of disease management. For samples that include a substantial number of teenagers (e.g., Jones et al., 2010), participants may well perceive some disease management tasks (e.g., scheduling appointments, communicating with physicians) to be the responsibility of their parents. If this is the case, young teenagers who report low SEDM may not evidence similarly poor mental or physical health as compared to

young adults with low SEDM. Further limiting our ability to draw conclusions about the relationships between SEDM and other factors, more than two-thirds of the included studies were cross-sectional in design. Though a small number of studies ( $k = 3$ ) assessed intervention effects on SEDM, they rarely reported mediators or other longitudinal predictors of SEDM. Thus, we are unable to draw strong conclusions about prospective predictors of SEDM.

### **Directions for future research**

**Measurement issues.** The present findings demonstrate the need for development, evaluation and wide dispersal of SEDM measures for AYA cancer survivors. The Cancer Behavior Inventory is a validated measure of self-efficacy for coping with cancer that has been widely used in studies of adults with cancer (e.g., Collie et al., 2005; Howsepian & Merluzzi, 2009; Schofield et al., 2008). Items from this or other existing measures of SEDM for adults with cancer can inform development of measures for AYAs. Separate SEDM measures should be developed for AYA cancer survivors who are and are not in current treatment. An SEDM measure for AYAs in treatment should emphasize self-efficacy for managing daily symptoms and negative emotions, whereas a measure for AYAs who have completed treatment should emphasize self-efficacy for effectively engaging in survivorship care.

**Areas for future intervention and longitudinal research.** All interventions were directed toward AYAs themselves. The limited research on interventions to help medical providers promote patients' SEDM signifies an important gap in the literature. Only the clinic-based educational intervention for childhood cancer survivors included medical providers, and in this case the provider's role was limited to providing disease-related education (Eiser et al., 2000). Interventions that target the physician's role in doctor-patient communication may serve to promote patients' SEDM. In a sample of adolescents with diabetes, Croom and colleagues

(2011) found that adolescents' perceptions of doctors' use of patient-centered communication techniques during a clinic visit predicted improvements in adolescents' SEDM six months later. Patient-centered communication describes a collaborative style of interaction between doctors and patients that includes empathy and partnership building (Croom et al., 2011). Results indicate that interventions to help doctors engage in patient-centered communication might have long lasting, beneficial effects on SEDM in AYAs.

None of the included intervention studies assessed cognitive behavioral interventions, and all were designed for individual patients. Findings from a recent systematic review of psychological interventions for AYAs with chronic illness demonstrated that skills-based interventions that were successful at promoting positive psychosocial outcomes were commonly group- or family-based interventions that taught cognitive behavioral therapy skills (Sansom-Daly, Peate, Wakefield, Bryant, & Cohn, 2012). Indeed, Cognitive Behavioral Therapy (CBT) group-based interventions for adolescents with diabetes (Rosselló & Jiménez-Chafey, 2006) and family- (Barakat, Schwartz, Salamon, & Radcliffe, 2010) and group-based (Thomas, Dixon, Milligan, & Thomas, 1999) CBT interventions for AYAs with sickle cell disease have demonstrated positive effects on SEDM. Thus, future research should include tests of CBT interventions in both group and family formats for AYA cancer survivors.

None of the included studies involved longitudinal assessments of SEDM outside of the context of an intervention study. Longitudinal research can facilitate the identification of prospective predictors of SEDM and of mechanisms of change in interventions that promote SEDM. Notably, Brier et al. (2015) found that there is limited process analysis conducted in existing intervention studies for CCSs., indicating a pressing need for studies to identify mediators of intervention effects. Identifying mediators of change can contribute to amplification



of effective ingredients of interventions (Kazdin, 2007). Another important aim for future research is to identify potential moderators of intervention effects on SEDM. Large studies can provide the power needed to detect differences in the predictors and correlates of SEDM in diverse groups and in doing so, inform the identification of subgroups that might benefit most from particular interventions. For example, the finding that poorer health is associated with lower SEDM (e.g., Casillas et al., 2011) may reflect higher complexity of disease management regimens for patients with poorer health, perhaps necessitating a greater focus on daily management issues in interventions for those with poor vs. better health, or even indicating that some extremely ill patients may not be able to benefit from SEDM interventions.

Finally, longitudinal research presents an opportunity to improve understanding of the impact of SEDM on salient outcomes including adherence to medical regimens and psychological and physical health. As in the study by Kato et al. (2008), future studies should employ objective measures of adherence to medical regimens (e.g., pill counts) in order to facilitate understanding of the impact of SEDM on adherence. Longitudinal studies should also examine the impact of SEDM on psychological adjustment, in line with the theory that managing negative emotions is a core component of disease management (Lorig & Holman, 2003). Further, longitudinal research should examine the impact of SEDM on physical health outcomes in order to help assess whether SEDM translates into more effective disease management that can improve long-term health.

## **Conclusions**

The current review adds to the literature by providing a comprehensive assessment of research on factors underlying SEDM in AYA cancer survivors. This group is at increased risk for mortality as compared to their healthy peers, yet many do not adhere to their medical

treatment regimens. SEDM is a modifiable psychological factor that is associated with adherence to treatment and other health-promoting behaviors, yet cross-sectional study designs limit our ability to identify factors that prospectively predict SEDM. The current findings indicate that behavioral and educational interventions have the potential to promote SEDM. Future intervention trials and longitudinal studies are needed to facilitate understanding of avenues for promoting SEDM in AYAs.

Table 1

*STROBE Statement Checklist of Cross-Sectional Studies - AYAs with Cancer and AYA Cancer Survivors Diagnosed in Adulthood*

	<b>Recommendation</b>	<b>Casillas et al., 2012</b>	<b>Hoyt et al., 2013</b>
<b>Title and abstract</b>	1(a). Indicate the study's design with a commonly used term in the title or the abstract	N	Y
	1(b). Provide in the abstract an informative and balanced summary of what was done and what was found	Y	Y
<b>Introduction</b>			
Background/rationale	2. Explain the scientific background and rationale for the investigation being reported	Y	Y
Objectives	3. State specific objectives, including any prespecified hypotheses	Y	Y
<b>Methods</b>			
Study design	4. Present key elements of study design early in the paper	Y	Y
Setting	5. Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	Y	Y
Participants	6(a). Give the eligibility criteria, and the sources and methods of selection of participants	Y	Y
Variables	7. Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	Y	Y
Data sources/ Measurement	8. For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	Y	Y
Bias	9. Describe any efforts to address potential sources of bias	N	Y
Study size	10. Explain how the study size was arrived at	Y	Y
Quantitative variables	11. Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	Y	Y
Statistical methods	12(a). Describe all statistical methods, including those used to control for confounding	Y	Y
	12(b). Describe any methods used to examine subgroups and interactions	- <sup>a</sup>	-
	12(c). Explain how missing data were addressed	N	N

Table 1

*STROBE Statement Checklist of Cross-Sectional Studies - AYAs Diagnosed in Adulthood (Continued)*

	<b>Recommendation</b>	<b>Casillas et al., 2012</b>	<b>Hoyt et al., 2013</b>
	12(d). If applicable, describe analytical methods taking account of sampling strategy	-	-
	12(e). Describe any sensitivity analyses	N	N
<b>Results</b>			
Participants	13(a)*. Report numbers of individuals at each stage of study – e.g., numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analyzed	N	Y
	13(b)*. Give reasons for non-participation at each stage	N	Y
	13(c)*. Consider use of a flow diagram	N	N
Descriptive data	14(a)*. Give characteristics of study participants (e.g., demographic, clinical, social) and information on exposures and potential confounders	Y	Y
	14(b). Indicate number of participants with missing data for each variable of interest	Y	N
Outcome data	15*. Report numbers of outcome events or summary measures	Y	Y
Main results	16(a). Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (e.g., 95% confidence interval). Make clear which confounders were adjusted for and why they were included	Y	Y
	16(b). Report category boundaries when continuous variables were categorized.	Y	-
	16(c). If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	-	-
Other analyses	17. Report other analyses done – e.g. analyses of subgroups and interactions, and sensitivity analyses	-	-

Table 1

*STROBE Statement Checklist of Cross-Sectional Studies - AYAs Diagnosed in Adulthood (Continued)*

<b>Recommendation</b>		<b>Casillas et al., 2012</b>	<b>Hoyt et al., 2013</b>
<b>Discussion</b>			
Key results	18. Summarize key results with reference to study objectives	Y	Y
Limitations	19. Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	Y	Y
Interpretation	20. Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	Y	Y
Generalizability	21. Discuss the generalizability (external validity) of the study results	Y	Y
<b>Other information</b>			
Funding	22. Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	Y	Y
<b>Total Number of Items Satisfied</b>		<b>21</b>	<b>23</b>

Note. An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at [www.strobe-statement.org](http://www.strobe-statement.org).

<sup>a</sup> A dash “-“ indicates that the item is not applicable.

\*Give information separately for exposed and unexposed groups.

Table 2

*STROBE Statement Checklist of Cross-Sectional Studies - AYAs with Cancer and AYA Cancer Survivors Diagnosed in Childhood*

	<b>Recommendation</b>	<b>Butterfield et al., 2004; Emmons et al., 2003</b>	<b>Finnegan et al., 2012</b>	<b>Keats et al., 2007</b>	<b>Milam et al., 2015</b>	<b>Taylor et al., 2012</b>
<b>Title and abstract</b>	1(a). Indicate the study's design with a commonly used term in the title or the abstract	N	Y	N	N	N
	1(b). Provide in the abstract an informative and balanced summary of what was done and what was found	Y	Y	Y	Y	Y
<b>Introduction</b>						
Background/rationale	2. Explain the scientific background and rationale for the investigation being reported	Y	Y	Y	Y	Y
Objectives	3. State specific objectives, including any prespecified hypotheses	Y	Y	Y	Y	Y
<b>Methods</b>						
Study design	4. Present key elements of study design early in the paper	Y	Y	Y	Y	Y
Setting	5. Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	Y	Y	Y	Y	Y
Participants	6(a). Give the eligibility criteria, and the sources and methods of selection of participants	Y	Y	Y	Y	Y
Variables	7. Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	Y	Y	Y	Y	Y
Data sources/ Measurement	8.* For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	Y	Y	Y	Y	Y
Bias	9. Describe any efforts to address potential sources of bias	N	N	Y	Y	Y
Study size	10. Explain how the study size was arrived at	Y	Y	Y	Y	Y
Quantitative variables	11. Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and	Y	Y	Y	Y	Y
Statistical methods	12(a). Describe all statistical methods, including those used to control for confounding	Y	Y	Y	Y	Y
	12(b). Describe any methods used to examine subgroups and interactions	-	Y	-	-	-
	12(c). Explain how missing data were addressed	N	N	N	N	Y

Table 2

*STROBE Statement Checklist of Cross-Sectional Studies - AYAs Diagnosed in Childhood (Continued)*

<b>Recommendation</b>		<b>Butterfield et al., 2004; Emmons et al., 2003</b>	<b>Finnegan et al., 2012</b>	<b>Keats et al., 2007</b>	<b>Milam et al., 2015</b>	<b>Taylor et al., 2012</b>
	12(d). If applicable, describe analytical methods taking account of sampling strategy	-	-	-	-	-
	12(e). Describe any sensitivity analyses	N	N	N	N	N
<b>Results</b>						
Participants	13(a)*. Report numbers of individuals at each stage of study—e.g. numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analyzed	N	Y	Y	Y	Y
	13(b)*. Give reasons for non-participation at each stage	N	Y	Y	Y	Y
	13(c)*. Consider use of a flow diagram	N	N	N	N	N
Descriptive data	14(a)*. Give characteristics of study participants (e.g. demographic, clinical, social) and information on exposures and potential confounders	Y	Y	Y	Y	Y
	14(b). Indicate number of participants with missing data for each	Y	Y	Y	Y	N
Outcome data	15.* Report numbers of outcome events or summary measures	Y	Y	Y	Y	Y
Main results	16(a). Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (e.g., 95% confidence interval). Make clear which confounders were adjusted for and why they were included	Y	Y	Y	Y	Y
	16(b). Report category boundaries when continuous variables were categorized	Y	-	Y	Y	Y
	16(c). If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	-	-	-	-	-
Other analyses	17. Report other analyses done—e.g. analyses of subgroups and interactions, and sensitivity analyses	-	Y	-	-	-
<b>Discussion</b>						
Key results	18. Summarize key results with reference to study objectives	Y	Y	Y	Y	Y

Table 2

*STROBE Statement Checklist of Cross-Sectional Studies - AYAs Diagnosed in Childhood (Continued)*

	<b>Recommendation</b>	<b>Butterfield et al., 2004; Emmons et al., 2003</b>	<b>Finnegan et al., 2012</b>	<b>Keats et al., 2007</b>	<b>Milam et al., 2015</b>	<b>Taylor et al., 2012</b>
Limitations	19. Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	Y	Y	Y	Y	Y
Interpretation	20. Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	Y	Y	Y	Y	Y
Generalizability	21. Discuss the generalizability (external validity) of the study	Y	Y	N	N	N
<b>Other information</b>						
Funding	22. Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	Y	Y	Y	Y	Y
<b>Total Number of Items Satisfied</b>		<b>21</b>	<b>24</b>	<b>23</b>	<b>23</b>	<b>23</b>

Note. An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at [www.strobe-statement.org](http://www.strobe-statement.org).

<sup>a</sup> A dash “-“ indicates that the item is not applicable.

\*Give information separately for exposed and unexposed groups.



Table 3.  
*Quality Assessment of Intervention Studies*

Modified Physiotherapy Evidence Database (PEDro) Criterion	Intervention Study			
	Eiser et al., 2000	Jones et al., 2010	Kato et al., 2008	McLaughlin et al., 2012; Song et al., 2012
Eligibility criteria were specified	Yes	Yes	Yes	Yes
Subjects were randomly assigned to treatment groups	No	Yes	Yes	No
Allocation was concealed	No	Yes	Yes	No
The groups were similar at base-line regarding most important prognostic indicators	No	Yes	Yes	No
All participants were blinded to treatment	No	No <sup>a</sup>	No	No
There was blinding of all therapists who administered the therapy	No	N/A <sup>b</sup>	N/A <sup>b</sup>	N/A <sup>b</sup>
All assessors who measured at least one key outcome were blinded to treatment information	No	No	No	No
Measures of at least one key outcome were obtained from more than 85% of the subjects initially allocated to treatment groups	No	Yes	No	Yes <sup>c</sup>
All participants for whom outcome measures were available received the treatment or control intervention as allocated or, when this was not done, data for at least one key outcome was analyzed by "intention to treat" (including imputation)	Yes	Yes	Yes	Yes
The results of between-group statistical comparisons were reported for at least one key outcome	No	Yes	Yes	No
The study provided both point measures and measures of variability for at least one key outcome	No	Yes	Yes	Yes
The study had an adequate treatment fidelity protocol, including manualized treatment	Yes	Yes	Yes	No
The study had an adequate treatment fidelity protocol, including monitoring of treatment implementation	Yes	Yes	Yes	No
Loss to follow-up information was provided	Yes	Yes	Yes	No <sup>d</sup>
<b>Total number of above criteria met</b>	<b>5</b>	<b>11</b>	<b>10</b>	<b>4</b>

<sup>a</sup>Though we expect that participants were blinded to treatment because the handbook used in the control condition contained the same information found in the CD-ROM (intervention group), this is not clearly stated in the text.

<sup>b</sup>This intervention was self-delivered (e.g., by playing a video game) and as such there were no therapists involved.

<sup>c</sup>All analyses presented were cross-sectional in nature and thus used data from all participants.

<sup>d</sup>Loss to follow-up information was not provided, however, the authors made the following statement: “we are unable to report post-test data from the conclusion of the intervention in significant numbers to make statistical analysis meaningful. Arranging for participants to return to the research site to engage in a post-intervention follow up proved to be extremely challenging” (McLaughlin et al., 2012, p. 639).

Table 4.  
*Self-Efficacy Constructs Assessed by SEDM Scales used in Included Studies*

Type of SEDM Assessed	AC <sup>a</sup>	AC <sup>b,c</sup>	AC <sup>d</sup>	AC <sup>e</sup>	AC <sup>f</sup>	AC <sup>g</sup>	AC <sup>h</sup>	AC <sup>i</sup>	AC <sup>j</sup>	AC <sup>k</sup>	AC <sup>l,m</sup>	Stanford Emotional Self-Efficacy Scale – Cancer <sup>n</sup>	Total
<b><i>Adherence to medical regimens</i></b>													
Disease-related knowledge	X	X	X	X	X	X	X	X	X	X	X		11
Manage physical symptoms	X			X				X		X	X		3
Manage treatment				X			X				X		3
Quit/avoid smoking		X	X										2
Engage in physical activity					X	X				X			3
Communicate with physicians/ask for help when needed							X	X		X	X		4
<b><i>Adapting meaningful behaviors or life roles to accommodate illness</i></b>													
Keep health problems from interfering with things you want to do									X		X		2
Talk to others about your illness									X		X		2
<b><i>Managing negative disease-related emotions</i></b>													
Emotional self-efficacy												X	1
Communicating emotions in relationships												X	1
Focusing in the present moment												X	1
Confronting death and dying												X	1

Note. AC is used to indicate an author-constructed scale or a scale adapted from an existing measure.

<sup>a</sup>Casillas et al. (2011)

<sup>b</sup>Butterfield et al. (2004)

<sup>c</sup>Emmons et al. (2003)

<sup>d</sup>DiClemente et al. (1985)

<sup>e</sup>Kato et al. (2008)

<sup>f</sup>Benisovich et al. (1998)

<sup>g</sup>Keats et al. (2007)

<sup>h</sup>Milam et al. (2015)

- <sup>i</sup>Taylor et al. (2012)
- <sup>j</sup>Jones et al. (2010)
- <sup>k</sup>Eiser et al. (2000)
- <sup>l</sup>McLaughlin et al. (2012)
- <sup>m</sup>Song et al. (2012)
- <sup>n</sup>Giese-Davis et al. (2004)

Table 5.

*Findings from Cross-Sectional Studies*

<b>Cross-Sectional Studies of AYA Cancer Survivors (Diagnosed in Adulthood)</b>			
<b>Reference</b>	<b>Primary Study Purpose</b>	<b>Sample Characteristics</b>	<b>Study Methods</b>
Casillas et al., 2011	Examine the associations between sociodemographic, cancer treatment, and care delivery factors and young adult cancer survivors' confidence in managing their survivorship care.	<i>N</i> = 376 young adult cancer survivors Mean age = 28, range 18 – 39 Mean age at diagnosis = 18 years 100% Completed active phase of treatment 74% White, 9% mixed race/ethnicity 54% Female 53% Bachelor's, graduate or professional degree	Design: cross-sectional questionnaire Self-efficacy analysis: bivariate and multivariate logistic regression analyses predicting membership in a low confidence group, defined as average confidence score that falls below scale midpoint
Hoyt et al., 2013	Develop and evaluate the psychometric properties of a measure of HRQoL, the Cancer Assessment for Young Adults, in young men with testicular cancer.	<i>N</i> = 171 young men with testicular cancer Mean age = 25.2, range 18 – 29 Mean 32.4 months since diagnosis Mean 30.1 months since treatment 46.2% White, 38% Hispanic/Latino 0% Female 47% 4-year college graduates	Design: cross-sectional questionnaire with 4 week test/retest reliability assessment Self-efficacy analysis: correlational analysis
<b>Cross-Sectional Studies of AYA Childhood Cancer Survivors (Diagnosed in Childhood)</b>			
<b>Reference</b>	<b>Primary Study Purpose</b>	<b>Sample Characteristics</b>	<b>Study Methods</b>
Butterfield et al., 2004 (1); Emmons et al., 2003 (2)	(1) Describe the prevalence of multiple risk factors for developing preventable disease among smokers who are childhood cancer survivors. (2) Evaluate demographic, psychosocial, and cancer-related factors that are associated with smoking behavior and mediators of smoking cessation.	<i>N</i> = 541 childhood cancer survivors Mean age = 30.7 years Mean age at diagnosis = 9.6 years Mean 21 years since treatment 89.5% White, 2.2% African American 46% Female 14% College graduates	Design: cross-sectional questionnaires Self-efficacy analysis: logistic regression analyses

Table 5.  
*Findings from Cross-Sectional Studies (Continued)*

<b>Cross-Sectional Studies of AYA Childhood Cancer Survivors (Diagnosed in Childhood)</b>			
<b>Reference</b>	<b>Primary Study Purpose</b>	<b>Sample Characteristics</b>	<b>Study Methods</b>
Finnegan et al., 2007	Examine correlates of regular physical activity in young adult survivors of childhood cancers	<i>N</i> = 117 childhood cancer survivors Mean age = 24 years, range 18 – 37 Mean age at diagnosis = 10 years Mean 11 years off treatment 95% White, 10% Hispanic or Latino 68% Female 40% Completed college	Design: cross-sectional questionnaires Self-efficacy analyses: logistic regression analyses
Keats et al., 2007	Apply the Theory of Planned Behavior to understanding physical activity motivation and behavior in adolescent cancer survivors.	<i>N</i> = 59 childhood cancer survivors Mean age = 17.37 years, range 15 – 20 Mean 31.7 months since diagnosis 39% Female 42% Completed high school, 22% some university/college	Design: cross-sectional questionnaires Self-efficacy analyses: multivariate analysis of variance, hierarchical regression analyses and Pearson correlations
Milam et al., 2015	Identify risk and protective factors for the receipt of follow-up care among Hispanic and non-Hispanic childhood cancer survivors in adolescence and young adulthood.	<i>N</i> = 193 childhood cancer survivors Mean age = 19.9, range 15 - 25 Mean age at diagnosis = 12.1 +/- 3 years Minimum 2 years since end of treatment 54.4% Hispanic, 28.5% White 49.7% Female 47.1% Some college or associate's/college degree	Design: cross-sectional questionnaires Self-efficacy analysis: logistic regression analyses
Taylor et al., 2012	Examine the incidence of PTSD in childhood cancer survivors, contributions of related variables to PTSD, and associations between PTSD and self-efficacy.	<i>N</i> = 118 childhood cancer survivors Mean age = 20.8, range 16.0 - 32.6 Mean age at diagnosis = 9.0 years Mean 10.5 years since end of treatment 52.8% Female	Design: cross-sectional questionnaire Self-efficacy analysis: hierarchical regression and correlational analyses

Table 5.  
*Findings from Cross-Sectional Studies (Continued)*

Cross-Sectional Studies of AYA Cancer Survivors (Diagnosed in Adulthood)		
Reference	Self-Efficacy Measures	Factors Associated with Self-Efficacy
Casillas et al., 2011	Author-constructed Items assessed confidence of survivors to manage their survivorship care, e.g., confidence in knowledge about late effects.	<i>Racial/ethnic minorities</i> had higher odds of belonging to the low confidence group as compared to non-Hispanic Whites in bivariate (Cohen's $d = .28^a$ ) and multivariate (Cohen's $d = .46^a$ ) analyses, as did survivors with <i>no survivorship care plan</i> (bivariate Cohen's $d = .57^a$ ; multivariate Cohen's $d = .54^a$ ) analyses. Survivors with <i>fair or poor self-reported health status</i> (bivariate Cohen's $d = .43^a$ ; multivariate Cohen's $d = .44^a$ ) and survivors reporting <i>lack of copies of medical records</i> (bivariate Cohen's $d = .25^a$ ; multivariate Cohen's $d = .15^a$ ) and <i>no written treatment summary</i> (bivariate Cohen's $d = .31^a$ ; multivariate Cohen's $d = .19^a$ ) had significantly higher odds of being in the low confidence group in bivariate analyses only.
Hoyt et al., 2013	Stanford Emotional Self Efficacy Scale - Cancer (Giese-Davis et al., 2004).	<i>Disclosure Ability</i> (e.g., I am able to talk about my cancer with others) was significantly correlated with emotional self-efficacy (Cohen's $d = 1.35^a$ ).
Cross-Sectional Studies of AYA Childhood Cancer Survivors (Diagnosed in Childhood)		
Reference	Self-Efficacy Measures	Factors Associated with Self-Efficacy
Butterfield et al., 2004 (1); Emmons et al., 2003 (2)	Author-constructed <i>Self-efficacy for quitting smoking</i> (1,2) was assessed by asking participants how confident they were that they could quite smoking in the next 30 days. Higher score indicates high self-efficacy. Mean = 2.21, $SD = 1.19$ , range 1 - 5 (2) <i>Situational self-efficacy</i> (1) was assessed via three questions that asked about confidence to avoid smoking in high-risk situations (DiClemente et al., 1985).	(1) Participants who <i>drank more (vs. less) than the recommended amount of alcohol</i> (Cohen's $d = -.42$ ) and who <i>were not (vs. were) physically active</i> (Cohen's $d = -.29$ ) had lower situational self-efficacy. Risk factors for developing preventable disease including consuming red meat (Cohen's $d = .04^a$ ), less than daily multivitamin use (Cohen's $d = .12^a$ ), and not having a primary care professional (Cohen's $d = .12^a$ ) were not significantly associated with situational self-efficacy, nor was total number of risk factors. No risk factors were significantly associated with self-efficacy for quitting smoking, nor was the total number of risk factors. (2) <i>Men</i> (vs. women; Cohen's $d = .23^a$ ), those who <i>received a lot of support for cessation</i> (vs. little or no support; Cohen's $d = .31^a$ ), those who were <i>diagnosed at a younger age</i> (continuous increasing age variable; Cohen's $d = -.02^a$ ), and those with <i>higher perceived vulnerability</i> (Cohen's $d = .08^a$ ) were more likely to have higher self-efficacy for quitting, and those who <i>had severe psychological symptoms</i> (vs. those who did not; Cohen's $d = -.31^a$ ) were less likely to have higher self-efficacy.

Table 5.  
*Findings from Cross-Sectional Studies (Continued)*

Cross-Sectional Studies of AYA Childhood Cancer Survivors (Diagnosed in Childhood)		
Reference	Self-Efficacy Measures	Factors Associated with Self-Efficacy
Finnegan et al., 2007	<p>Author-constructed measure (Benisovich et al., 1998) adapted from Marcus et al. (1992).            Items assessed confidence to engage in physical activities despite potential barriers (e.g., being under stress). Higher scores indicate higher self-efficacy.            Mean = 2.70, <i>SD</i> = .81, range 1 – 5,            Cronbach's <math>\alpha</math> = .94</p>	<p>Participants with higher (vs. lower) SEDM scores were more likely to be physically active (Cohen's <math>d</math> = .66<sup>a</sup>).</p>
Keats et al., 2007	<p>Author-constructed            Assessed self-efficacy for being physically active, e.g., "how confident are you that you are capable of being physically active on a regular basis?" Higher score indicates higher self-efficacy.            Mean = 5.62, <i>SD</i> = 1.47, range 1 – 7,            Cronbach's <math>\alpha</math> = .94</p>	<p>SEDM was positively correlated (<math>p &lt; .01</math>) with beliefs about physical activity, i.e., <i>perceived behavioral control</i> (Cohen's <math>d</math> = 2.49<sup>a</sup>), <i>instrumental attitude</i> (Cohen's <math>d</math> = .80<sup>a</sup>), <i>affective attitude</i> (Cohen's <math>d</math> = .93<sup>a</sup>), <i>subjective norm</i> (Cohen's <math>d</math> = .98<sup>a</sup>), <i>control beliefs</i> (Cohen's <math>d</math> = 1.09<sup>a</sup>), <i>behavioral beliefs</i> (Cohen's <math>d</math> = .72<sup>a</sup>), <i>normative beliefs</i> (Cohen's <math>d</math> = .98<sup>a</sup>), and self-reported <i>physical activity</i> (Cohen's <math>d</math> = 1.01<sup>a</sup>). SEDM was significantly positively correlated with <i>intention to quit smoking</i> (Cohen's <math>d</math> = .82<sup>a</sup>) in a bivariate model, but not in a multivariate model (<math>\beta</math> = .20, <math>p &gt; .05</math>). SEDM was not correlated with demographic (i.e., age, BMI) or medical (i.e., time since diagnosis, length of adjuvant therapy) variables. In a hierarchical regression model examining intention, perceived control and self-efficacy as predictors of <i>physical activity</i>, SEDM was a significant independent predictor (<math>\beta</math> = .42, <math>p</math> = .04).</p>
Milam et al., 2015	<p>Author-constructed measure adapted from the Chronic Disease Self-Efficacy Scales (Lorig et al., 1996).            Items assessed confidence in asking a physician about concerns, making physician's appointments and getting needed follow-up care. Higher scores indicate higher self-efficacy.            Mean = 4.1, <i>SD</i> = 1.69, range 0 – 6,            Cronbach's <math>\alpha</math> = .64</p>	<p>Participants who had <i>received cancer-related follow-up care in the past two years</i> were more likely to have higher SEDM in a univariate logistic regression analysis (Cohen's <math>d</math> = .18<sup>a</sup>), but not after controlling for covariates (Cohen's <math>d</math> = .10<sup>a</sup>). Participants who <i>intended to seek follow-up care in the next two years</i> were more likely to have higher SEDM in both univariate (Cohen's <math>d</math> = .28<sup>a</sup>) and multivariate (Cohen's <math>d</math> = .28<sup>a</sup>) logistic regression analyses.</p>

Table 5.  
*Findings from Cross-Sectional Studies (Continued)*

<b>Cross-Sectional Studies of AYA Childhood Cancer Survivors (Diagnosed in Childhood)</b>		
<b>Reference</b>	<b>Self-Efficacy Measures</b>	<b>Factors Associated with Self-Efficacy</b>
Taylor et al., 2012	Author-constructed measure adapted from the Chronic Disease Self-Efficacy Scales (Lorig et al., 1996). Sample item: How confident are you that you can ask your doctor about things that concern you? Higher scores indicate higher self-efficacy. Cronbach's $\alpha \geq 0.79$ .	SEDM was significantly inversely correlated with <i>post-traumatic stress symptoms</i> (PTSS; Cohen's $d = -1.12^a$ ) and <i>self-reported late effects</i> (Cohen's $d = -.68^a$ ). In hierarchical regression analyses, higher PTSS ( $\beta = -.47, p < .001$ ) and self-reported late effects ( $\beta = -.22, p < .05$ ) predicted lower SEDM. No significant differences in SEDM were found between PTSD diagnostic groups.

*Note.* AYA = adolescent and young adults; HRQoL = health-related quality of life; PTSD = posttraumatic stress disorder; SEDM = self-efficacy for disease management.

<sup>a</sup>This effect size was calculated by the first author and checked by the second author using data available in the manuscript.



Table 6.  
Findings from Intervention Studies

<b>Intervention Studies of AYA Cancer Survivors (Diagnosed in Adulthood)</b>			
<b>Reference</b>	<b>Primary Study Purpose</b>	<b>Sample Characteristics</b>	<b>Study Methods</b>
Jones et al., 2010	Develop and evaluate an interactive, educational CD-ROM intervention for teens with cancer.	<i>N</i> = 71 teens with cancer at baseline <i>N</i> = 65 at follow-up Mean age = 14.8, range 12-18 50% in current treatment Mean time since treatment for those not in active treatment = 14.8 months 75.3% White, 15.4% African American 36.9% Female	Intervention: interactive, multimedia CD-ROM to educate teens about their cancer Design: randomized controlled trial Control group: handbook with similar information Length of follow-up: 3 months Self-efficacy analysis: t-tests on pre-post change scores
Kato et al., 2008	Determine the effectiveness of a video game intervention for improving adherence in AYAs with cancer.	<i>N</i> = 371 AYAs with cancer at baseline <i>N</i> = 334 at 1-month, 304 at 3-months Age range 13-29 Mean 1.59 years since diagnosis 100% Currently in treatment 56.6% White, 20.5% Hispanic 32.3% Female 17.8% some college or more	Intervention: a behavioral video game; activities included destroying cancer cells and managing aversive treatment effects Design: randomized controlled trial Control group: commercial video game Length of follow-up: 1 month, 3 months Self-efficacy analysis: mixed-effect linear model analysis
<b>Intervention Studies of AYA Childhood Cancer Survivors (Diagnosed in Childhood)</b>			
<b>Reference</b>	<b>Primary Study Purpose</b>	<b>Sample Characteristics</b>	<b>Study Methods</b>
Eiser et al., 2000	Evaluate a clinic-based intervention to improve self-efficacy, attitude to follow-up and knowledge about vulnerability to future health problems	<i>N</i> = 263 childhood cancer survivors at baseline <i>N</i> = 155 at follow-up Mean age = 21, range 16 - 29 Mean time since diagnosis: 14.48 years % Female: 46	Intervention: information booklet, treatment summary and informational handouts explained by physician during routine follow-up care Design: single group, pre/post assessment Length of follow-up: 2 weeks Self-efficacy analysis: paired t-tests
McLaughlin et al., 2012 (1); Song et al., 2012 (2)	(1) Examine factors influencing participation in a videosharing social networking intervention (2) Examine how cancer survivors construct their identity and how it relates to psychological health	<i>N</i> = 14 childhood cancer survivors at baseline Age range: 18-29 <sup>b</sup> at start of study Off treatment min. 2 years Disease free min. 5 years 85.7% Hispanic/Latino, 7.1% Asian or Pacific Islander 36.7% Female 50% some college or vocational school	Intervention: a social networking video blog site tailored for young adult cancer survivors. Participants attended a single orientation session and received text messages prompting them to post on the blog. Design: single group, pre/post assessment Length of follow-up: 6 months Self-efficacy analysis: (1) OLS regression, (2) bivariate correlations

Table 6.  
*Findings from Intervention Studies (Continued)*

<b>Intervention Studies of AYA Cancer Survivors (Diagnosed in Adulthood)</b>		
<b>Reference</b>	<b>Self-Efficacy Measures</b>	<b>Factors Predicting Self-Efficacy</b>
Jones et al., 2010	Author-constructed Patients rate their confidence that they can engage in behaviors explicitly addressed in the CD-ROM. Higher scores indicate higher self-efficacy. Cronbach's $\alpha > .60$	There were no group differences in the change in pre-post SEDM (Cohen's $d = .10^a$ ) and no significant difference in pre-post SEDM in either group (intervention group Cohen's $d = .15^a$ ; control group Cohen's $d = .10^a$ ).
Kato et al., 2008	Author-constructed Higher scores indicate greater perceived self-efficacy to manage cancer and its treatment. <i>Intervention group</i> mean ( <i>SD</i> ) at baseline = 155.9 (22.3), at 3 months = 164.1 (23.4) <i>Control group</i> mean ( <i>SD</i> ) at baseline = 156.6 (21.3), at 3 months = 158.8 (23.5) Cronbach's $\alpha = .93$	There was a significantly greater increase in SEDM over time for the <i>intervention</i> group (Cohen's $d = .36$ ) vs. control group (Cohen's $d = .08$ ; group x time interaction, $p = .01$ ). Neither change in SEDM nor change in cancer knowledge alone accounted for intervention effects on adherence, but changes in SEDM and cancer knowledge together fully mediated the effect of the intervention on <i>adherence to oral antibiotics</i> .
<b>Intervention Studies of AYA Childhood Cancer Survivors (Diagnosed in Childhood)</b>		
<b>Reference</b>	<b>Self-Efficacy Measures</b>	<b>Factors Predicting Self-Efficacy</b>
Eiser et al., 2000	Author-constructed, Patients rate agreement with statements about self-rated confidence to undertake illness-related and general health behaviors. Baseline mean = 4.75, follow-up = 4.92 Cronbach's $\alpha = .74$	There was a significant increase in SEDM at follow-up ( $p < .01$ ).
McLaughlin et al., 2012 (1); Song et al., 2012 (2)	Survivorship Self-Efficacy (measure adapted from Jerusalem & Schwarzer, 1992). Cronbach's $\alpha = .89$	(1) SEDM was inversely correlated with <i>participation on the blog</i> (Cohen's $d = 1.28^a$ ). (2) <i>Positive stereotypes</i> (e.g., when describing the cancer experience, patient mentions mental strength) were positively correlated with SEDM (frequency Cohen's $d = 1.01^a$ ; percentage Cohen's $d = 1.04^a$ ). Negative stereotypes (frequency Cohen's $d = -.18^a$ ; percentage Cohen's $d = -.39^a$ ) and their antonyms (frequency Cohen's $d = .12^a$ ; percentage Cohen's $d = -.28^a$ ) were not correlated with SEDM.

*Note.* AYA = adolescent and young adults; OLS = ordinary least squares; SEDM = self-efficacy for disease management.

<sup>a</sup>This effect size was calculated by the first author and checked by the second author using data available in the manuscript

<sup>b</sup>Whenever possible, the age range of participants is provided if mean age is not available from the article.

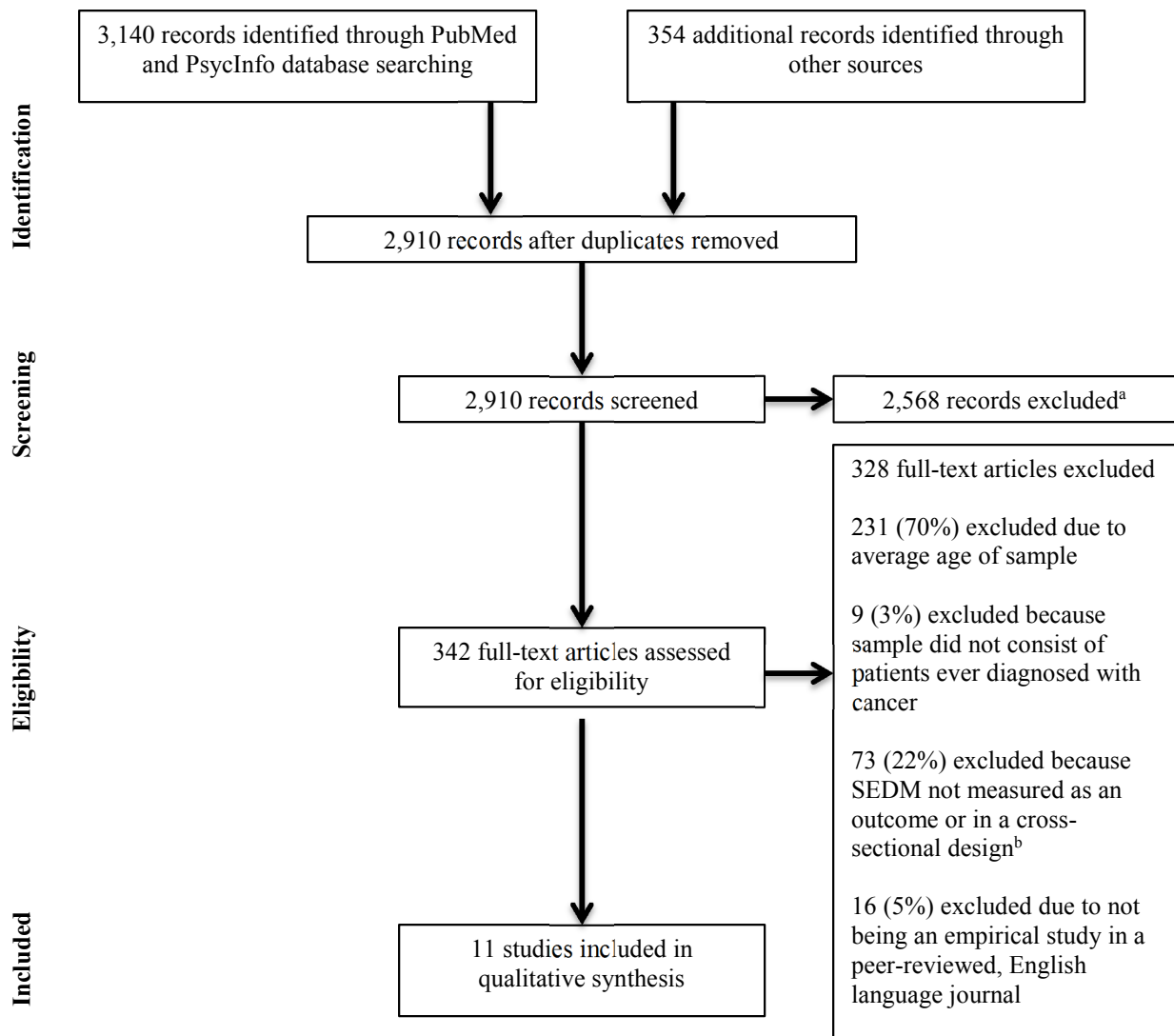


Figure 1. Flow of information through different phases of systematic literature review.

<sup>a</sup>Of the excluded records, 158 (6%) were excluded due to the average age of the sample; 1,302 (51%) were excluded because the sample did not consist of patients ever diagnosed with cancer; 347 (13%) were excluded because SEDM was not measured as an outcome or in a cross-sectional design; and 761 (30%) were excluded due to not being an empirical study in a peer-reviewed, English language journal.

<sup>b</sup>Of the 73 articles excluded because SEDM was not measured as an outcome or in a cross-sectional design: a) 54 included no measure of self-efficacy; b) 11 included a measure of general self-efficacy; and c) 8 were excluded for other reasons (e.g., two included measure of self-efficacy for social interactions, and three included a measure of SEDM but did not measure SEDM as an outcome or in a cross-sectional design).

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### **Chapter 3: A Randomized Controlled Trial of Cognitive Behavioral Group Therapy Targeting Medical Transition Readiness in Young Adults with Chronic Illness (Study 2)**

#### **Abstract**

**Introduction:** Young adults with chronic illness evidence poor psychosocial outcomes as compared to their healthy peers across multiple domains. Yet, few existing psychosocial interventions for this group have strong empirical support. Fewer still specifically aim to promote medical transition readiness (i.e., preparation to transfer from pediatric to adult medical care), an important developmental task.

**Method:** Young adults ( $N = 63$ ) with chronic illness were randomly assigned to a Coping Skills Intervention (CSI) condition, representing a life skills intervention in line with Positive Youth Development theory, or a print control condition (Informational Materials; IM). All participants received weekly emails with information that aims to promote medical transition readiness. Participants in the CSI condition also attended an eight-week cognitive behavioral therapy group. Medical transition behavior, as well as measures of general psychosocial adjustment and illness-related adjustment that are indicative of one's level of medical transition readiness, were assessed as outcomes. Participants completed assessments prior to randomization (T1) and one month (T2; mid-intervention) and two months (T3; immediately after intervention completion) later.

**Results:** At T3, CSI (vs. IM) participants were significantly more likely to have initiated the transition to adult medical care. There was no significant impact of group assignment on disease-related skills and knowledge, medical regimen adherence, quality of life, or depressive symptoms. CSI (vs. IM) group members demonstrated significantly higher illness-related benefit

finding, self-efficacy and approach-oriented coping, as well as lower anxiety and perceived illness-related threat ( $p < .05$ ). Most effects were moderated by the baseline value of the dependent variable (e.g., self-efficacy), such that participants who reported low or average (but not high) levels of favorable adjustment at baseline improved more over time if assigned to the CSI (vs. IM) group. T2 self-efficacy mediated the association between group assignment and: 1) medical regimen adherence; 2) quality of life; and 3) anxiety. Other significant T2 mediators were also identified.

**Conclusions:** The CSI positively impacted participants' likelihood of initiating the transition from pediatric to adult medical care as well as several psychosocial and illness-related factors indicative of one's level of medical transition readiness. Future research and clinical intervention refinement should build on the current findings by incorporating additional components of Positive Youth Development programs and by evaluating the CSI in diverse populations and settings.

## **A Randomized Controlled Trial of Cognitive Behavioral Group Therapy Targeting Medical Transition Readiness in Young Adults with Chronic Illness**

Children who have a chronic physical illness are at increased risk for poor psychosocial outcomes as compared to their healthy peers (Cadman, Boyle, Szatmari, & Offord, 1987; Pless, Cripps, Davies, & Wadsworth, 1989; Wallander & Varni, 1998). In adolescence, poor psychosocial adjustment can pose barriers to the successful transition to adulthood in multiple domains, including medical care and financial independence. Further, adolescents with chronic illness frequently experience medical transition practices (i.e., practices leading to the transition from pediatric to adult medical care) that are delayed, rushed, inconsistent, or leave them without a source of care (DeBaun & Telfair, 2012; Henderson, Friedman, & Meadows, 2010; Tuchman, Slap, & Britto, 2008). These practices might contribute to increased symptom severity and related psychological distress during a critical moment in development. Yet, few empirically supported psychosocial interventions exist to facilitate the transition to adulthood for adolescents and young adults (AYAs) with chronic illness (Crowley, Wolfe, Lock, & McKee, 2011; Sansom-Daly, Peate, Wakefield, Bryant, & Cohn, 2012). The present study helps address this gap in the literature by rigorously evaluating practices that may promote positive psychosocial and illness-related adjustment for young adults with chronic illness. Guided by research and theory in positive youth development, childhood chronic illness and medical transitions, the current randomized controlled trial evaluated a cognitive behavioral group therapy that targets several diverse indicators of medical transition readiness in young adults with chronic illness.

### **Childhood Chronic Illness**

Up to 25% of children under age 17 suffer from a chronic health problem that can increase risk for poor psychosocial adjustment (Compas, Jaser, Dunn, & Rodriguez, 2012;

Newacheck 1998; Piquart & Shen, 2011). For example, children with chronic illnesses including cystic fibrosis, diabetes, asthma, juvenile chronic arthritis, celiac disease, and cancer are at increased risk for low health-related quality of life (HRQoL) as compared to their healthy peers (Grootenhuis, Koopman, Verrips, Vogels, & Last, 2007; Sawyer, Reynolds, Couper, French, Kennedy, Martin.... & Baghurt, 2004). Further, meta-analyses have demonstrated that children with chronic illness have higher rates of both internalizing symptoms, such as anxiety and depression, and externalizing symptoms, such as aggression and hyperactivity (Lavigne & Faier-Routman, 1992; Piquart & Shen, 2011). Thus, children with chronic illness are at risk for poor psychosocial outcomes including compromised quality of life and psychological problems. These risk factors pose challenges for adolescents with chronic illness as they enter young adulthood and attempt to establish independence.

### **Transitioning to Adulthood with a Chronic Illness**

As a result of advances in medical treatments over the past half century, 90% of children born with a chronic illness will now survive into adulthood, and an estimated 500,000 youth with special health care needs turn 18 each year (Maslow, Haydon, McRee, Ford, & Halpern, 2011). Young adults with a history of childhood chronic illness face considerable challenges to becoming self-sufficient, including higher rates of psychosocial problems from childhood and the need to engage in disease management behaviors (e.g., adherence to medical regimens) with increasing independence. Furthermore, the need to transfer from pediatric to adult medical specialists poses a unique challenge. For instance, for young adult survivors of childhood cancer, the transition from a pediatric oncology treatment setting to adult medicine is complicated and often delayed for several reasons. For example, adult specialists may lack the necessary

knowledge to provide adequate follow-up care, or family members may be overprotective (Henderson et al., 2010).

The Department of Health and Human Services Maternal and Child Health Bureau identified the successful transition to adulthood for Youth with Special Health Care Needs (YSHCN) as a core performance outcome needed to create comprehensive services for YSHCN, defining successful transition as “receiv[ing] the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence” (McManus, Pollack, Cooley, McAllister, Loststein, Strickland, & Mann, 2013, p. 1091). Similarly, Healthy People 2020 has identified transition planning as a core performance objective to be met by increasing the proportion of YSCHN whose healthcare provider has discussed the transition from pediatric to adult-oriented medical care (“Disability and Health,” 2014). An analysis of the 2009-2010 National Survey of Children with Special Health Care Needs (McManus, Pollack, Cooley, McAllister, Loststein, Strickland, & Mann, 2013) demonstrated that only 40% of YSHCN met this national transition objective based on parents’ reports of their own or their child’s discussions with a health care provider about: switching to an adult provider (reported by 44% of parents), changing health care needs (59%), child taking increased responsibility for self-care (78%), and maintaining health insurance coverage (35%).

Difficulty with navigating the transition to adulthood is reflected in poor young adult outcomes across several domains for patients with a history of childhood chronic illness. In an analysis of the National Longitudinal Study of Adolescent Health, Maslow et al. (2011) found that young adults with childhood-onset chronic illness were less likely to graduate from college (OR = 0.49), or to have ever had a job (OR = 0.53), and more likely to have received public assistance (OR = 2.13) as compared to healthy peers. In a study of first-year students at a private



university, Herts, Wallis, and Maslow (2014) found that chronically ill students had significantly more impaired health-related quality of life and higher levels of loneliness than their healthy peers. Further, only 11% of students with chronic illness in that sample had a local physician (generalist or specialist), and only 15% were registered with the college's office of Disability Support Services, the entity charged with providing accommodations for this population. Taken together, these findings suggest that many young adults with chronic illness are socially isolated, are not connected to necessary health services, and face difficulty establishing financial independence.

### **Conceptualizing Medical Transition Readiness**

Prior studies have commonly assessed only age and disease-related skills and knowledge as criteria for medical transition readiness, which may not translate into successful transition (e.g., engagement with adult medical providers) in the absence of the other important factors, such as self-efficacy for and a social support system to promote transition (Schwartz, Tuchman, Hobbie, & Ginsberg, 2011). Indeed, a literature review of consensus reports, opinion papers, and empirical studies supported an expanded conceptualization of medical transition readiness, which resulted in development of the Social Ecological Model of AYA Readiness for Transition (SMART; Schwartz et al., 2011). SMART identifies seven components of medical transition readiness that are amenable to intervention: 1) developmentally appropriate level of autonomy; 2) disease knowledge; 3) skills/self-efficacy for disease management; 4) beliefs and expectations about transition; 5) transition-related goals; 6) relationships among patients, parents and providers; and 7) psychosocial functioning (Schwartz et al., 2011). The current study overcomes limitations of prior research by examining several of these factors as indicators of medical transition readiness in a sample of young adults with chronic illness.

## **SMART-Congruent Risk and Protective Factors for Psychosocial Adaptation**

Illness perceptions, disease management skills (e.g., approach-oriented coping skills), relationships and self-efficacy have all been identified as modifiable targets for intervention to facilitate medical transition readiness under SMART (Schwartz et al., 2011). Research suggests that these psychosocial resources might be important sources of risk or resilience for adolescents and adults with chronic illness. In a review, Compas et al. (2012) found that the self-reported use of secondary control coping strategies (i.e., efforts to adapt to the stressor, an approach-oriented coping strategy) is associated with positive psychosocial adaptation (e.g., fewer emotional/behavioral problems and better quality of life) to chronic illness in adolescents. The evidence for primary control coping strategies (i.e., approach-oriented efforts to directly mitigate the stressor) was mixed. Similarly, approach-oriented coping strategies have been shown to be adaptive in samples of adults with chronic illness (Luyckx, Seiffge-Krenke, Schwartz, Goossens, Weets, Hendrieckx, & Groven, 2008; Taylor & Stanton, 2007).

Social support and self-efficacy for disease management each are associated with both positive psychological adjustment and adherence to medical regimens in samples of adolescents and adults with chronic illness (Di Matteo, 2004; Gallant, 2003; Grey, Sullivan-Bolyai, Boland, Tamborlane, & Yu, 1998; Griva, Myers, & Newman, 2000; Ott, Greening, Palardy, Holderby, & DeBell, 2000; Symister & Friend, 2003). Finally, illness perceptions are associated with psychological symptoms, self-efficacy and medical adherence in adolescents and adults with chronic illness (Edgar & Skinner, 2003; Griva et al., 2000; Petrie, Jago, & Devcich, 2007). For example, perceived control over illness is positively associated with medical adherence in adolescents with diabetes (Griva et al., 2000). In another sample of adolescents with diabetes, Edgar and Skinner (2003) found that higher perceived disease impact was positively associated

with depressive symptoms. Notably, this association was not mediated by coping strategies (Edgar & Skinner, 2003), suggesting that illness perceptions represent an independent pathway to psychological adjustment. Illness perceptions, approach-oriented coping, social support and self-efficacy for disease management are thus important factors to consider when trying to understand and promote positive adjustment and a successful transition from pediatric to adult medical care in AYAs with chronic illness.

### **Psychosocial Interventions for AYAs with Chronic Illness**

Recent research has focused on identifying psychosocial treatments that facilitate the transition to adulthood for AYAs with chronic illness (Crowley et al., 2011; Sansom-Daly et al., 2012). However, few existing psychosocial treatments for this population have strong empirical support. Crowley et al. (2011) conducted a systematic review of transition care programs that measured health outcomes for AYAs with chronic illness in a pre- vs. post-intervention or in an intervention vs. control group design. Only 10 studies met inclusion criteria; all six programs that yielded positive effects were for patients with diabetes. These programs consisted mainly of patient education in the context of a joint pediatric-adult care medical clinic. In a recent systematic review of psychological interventions for AYAs age 10-30 years with chronic illness, Sansom-Daly et al. (2012) identified 25 studies that used two-group quantitative designs and measured at least one psychosocial outcome. Of these studies, 13 included AYAs with diabetes, 7 included AYAs with cancer, and 5 included AYAs with other illnesses. Skills-based interventions that spanned at least six sessions over three months were most likely to yield positive results, with moderate effect sizes. Successful interventions for AYAs alone (vs. with a family component) were commonly group-based and included the teaching of cognitive behavioral strategies (e.g., cognitive restructuring and communication skills). None specifically

set out to measure the impact of the intervention on indicators of medical transition readiness. These reviews demonstrate that transition-focused and psychosocial interventions for AYAs with chronic illness have the potential to yield positive effects. However, further research is needed to evaluate such programs, particularly outside of diabetes samples.

**Positive Youth Development (PYD) theory.** PYD theory provides a promising framework for future research and interventions to promote psychosocial adaptation for AYAs with chronic illness. PYD programs aim to promote strengths in youth by including the following core components: 1) providing leadership opportunities; 2) building life skills; and 3) establishing caring, sustained adult-child mentoring relationships (Maslow & Chung, 2013). These components may be implemented in many different ways. For example, PYD programs for AYAs with chronic illness have provided leadership opportunities by encouraging youth to organize fundraising and advocacy activities, serve as peer mentors and participate in program evaluations (Maslow & Chung, 2013). Similarly, varied strategies for building life skills related to illness have been employed, including providing education about health services and teaching self-advocacy and health promotion skills (Maslow & Chung, 2013). Sustained mentoring relationships are commonly established between professional staff and youth leaders, and through formal and/or informal peer mentoring (Maslow & Chung, 2013).

Under a PYD theoretical framework, positive youth outcomes include the development of competence (e.g., social, emotional, cognitive, and behavioral competence), confidence (e.g., self-efficacy, hope and optimism about the future), compassion, character, and social connection (Catalano, Berglund, Ryan, Lonczak, & Hawkins, 2002; Maslow & Chung, 2013). To date, PYD programs have been shown to be effective at promoting positive outcomes for diverse groups of healthy adolescents in community and school settings (Catalano et al., 2002). A systematic

review of PYD programs in healthy adolescents identified 25 existing PYD programs that were rigorously evaluated (i.e., in an experimental design or a quasi-experimental design with a comparison group) and had statistically significant positive effects on outcomes including interpersonal skills, frustration tolerance, substance use, aggressive behavior and academic achievement (Catalano et al., 2002). The programs were implemented in varied settings (e.g., school, community organizations, church) and with ethnically diverse samples, specifically, 28% of programs served Native American youth, half served Hispanic youth, and approximately 75% served African American and White youth (Catalano et al., 2002). Only five of 30 rigorously evaluated PYD programs identified in this review failed to show positive effects on behavioral outcomes (Catalano et al., 2002).

PYD is a relatively new framework for promoting positive psychosocial adjustment for AYAs with chronic illness. In a recent systematic review of PYD programs for adolescents with chronic illness, Maslow and Chung (2013) identified three existing, comprehensive PYD programs that included the three core components discussed above. Qualitative analyses revealed that participants in all three programs described increased knowledge of resources. One program's participants also described increased emotional support, and another program's participants also reported decreased social isolation. Though not described in the Maslow and Chung (2013) review, The Adolescent Leadership Council (TALC) of Hasbro Children's Hospital in Providence, RI is a mentoring program for teenagers with chronic illness developed using PYD principles (Maslow, Adams, Willis, Senouillet, Herts, Froehlich, Calleson...& Rickerby, 2013). In the first formal program evaluation, TALC teens evidenced statistically significant decreases in loneliness and increases in self-advocacy skills after completing one year of the program (Maslow et al., 2013).

In sum, findings from the four existing PYD programs for adolescents with chronic illness suggest that they can have positive effects on SMART indicators of medical transition readiness, such as social connectedness, disease knowledge and self-advocacy skills. However, data are based on pre- and post-reports from program participants, and thus cannot be distinguished from normal developmental changes. Further, only the TALC program evaluation included quantitative analyses, limiting the conclusions that can be drawn from the other evaluations in terms of detecting reliable effects of the program.

**The current study.** In light of the promising findings from established PYD programs, the current study serves as the first step in program of research designed to conduct a rigorous components test of a PYD intervention for AYAs with chronic illness. Understanding the contribution of core PYD components (i.e., leadership opportunities, life skills development and adult-youth mentoring relationships) will allow for refinement of the intervention to improve efficacy and feasibility. The current randomized controlled trial tested the life skills component of PYD programs by implementing and evaluating a cognitive behavioral therapy skills group for young adults with chronic illness that was specifically designed to target SMART-congruent indicators of medical transition readiness.

### **Conceptual Model**

The conceptual model guiding the current study is displayed in Figure 1. The model was developed drawing from research and theory in childhood chronic illness, positive youth development and medical transitions. Young adults with chronic illness were randomly assigned either to attend an eight-week cognitive behavioral skills group (Coping Skills Intervention – Chronic Illness edition; CSI) or to receive printed materials designed to facilitate the transition from pediatric to adult medical care (print control group). We predicted that participants in the

intervention group would experience greater improvements in outcomes (i.e., psychosocial and illness-related SMART indicators of medical transition readiness, as well as medical transition behavior) as compared to participants in the control group due to improvements in several mediational processes.

**Selection of mediators.** SMART-congruent mediators of the effects of the CSI intervention were selected with the aim of helping inform theory and knowledge underlying the development of future psychosocial interventions for AYAs with chronic illness to promote medical transition readiness. Further, identification of mediators allowed for the evaluation of whether the other core components of PYD programs (i.e., leadership opportunities, adult-youth mentoring relationships) are necessary to enhance efficacy. Hypothesized mediators included competence (i.e., approach-oriented cognitive and behavioral coping strategies), confidence (i.e., increased self-efficacy), social connection (i.e., decreased loneliness), and illness perceptions (i.e., decreased perceived illness-related threat).

**PYD constructs.** As described previously, in accordance with a PYD theoretical framework, PYD interventions can be expected to improve social connection, competence and confidence in AYAs (Catalano et al., 2002; Maslow & Chung, 2013; Maslow et al., 2013). The current intervention was designed to improve perceived social connection by bringing together peers with chronic illness in a skills group that facilitated the discussion of challenges common to young adults with chronic illness. We predicted that competence (i.e., use of approach-oriented coping strategies) and confidence (i.e., self-efficacy) would be enhanced through the teaching and practice of approach-oriented cognitive and behavioral coping strategies. We expected each of these proposed mechanisms to mediate the impact of the intervention on psychosocial and illness-related adjustment.

***Illness perceptions.*** We expected that the intervention would decrease perceived illness-related threat through the teaching of cognitive restructuring techniques, communication skills (e.g., in the context of doctor-patient communication) and adaptive health behaviors. Illness perceptions have been shown to enhance psychological health and medical adherence in adolescents and adults with chronic illness, but have not been widely examined in the context of intervention research (Edgar & Skinner, 2003; Griva, Myers, & Newman, 2000; Petrie, Jago, & Devcich, 2007).

**Selection of outcome variables.** Dependent variables for the current study were selected to examine the effects of the CSI group intervention on SMART-congruent indicators of psychosocial and illness-related adjustment. By providing a comprehensive assessment of psychosocial adjustment as well as adaptation to illness, the present study helped evaluate whether the intervention facilitates participants' ability to meet the national transition goal of transitioning to all aspects of adult life, including work, healthcare and independence (McManus et al., 2013). Additionally, participants' medical transition behavior was examined in exploratory analyses in order to determine whether improvements in psychosocial and illness-related adjustment resulted in participants taking steps towards transferring from pediatric to adult medical care providers.

***Adjustment to illness.*** Disease-related skills and knowledge, medical regimen adherence, and illness-related benefit finding were assessed as measures of illness-related adjustment.

Disease-related skills and knowledge was selected as an outcome of interest in the current study because it is one of few constructs that has been assessed in prior research as an indicator of medical transition readiness (Schwartz et al., 2011). Thus, assessing skills/knowledge as an outcome allowed for comparison with prior studies of interventions targeting medical transition



readiness. We expected that the intervention would promote disease-related skills and knowledge through teaching of coping skills, problem solving techniques and doctor-patient communication skills.

Medical regimen adherence was chosen as another valuable marker of illness-related adjustment that also reflects disease-related skills and knowledge. Rates of non-adherence to medical regimens of more than 50% in adolescence and young adulthood have been reported in several illness populations including sickle cell disease and cancer (Kahana, Drotar, & Frazier, 2008; Kondryn, Edmondson, Hill, & Eden, 2011; Walsh, Cutrona, Kavanagh, Crosby, Malone, Lobner, & Bundy, 2014). Further, cognitive behavioral therapy has been shown to influence medical adherence (Richards, Bartlett, Wong, Malouff, & Grunstein, 2007; Safren, O’Cleirgh, Tan, Raminani, Reilly, Otto, & Mayer, 2009). We expected the intervention to improve adherence through increasing self-efficacy for disease management. Improving medical adherence in young adulthood could have positive implications for health and the related development of independence.

Finally, benefit finding was chosen to serve as a marker of illness-related psychosocial adjustment in the form of personal growth. Benefit finding refers to finding good in a negative experience (Algoe & Stanton, 2009). For example, patients commonly report increased appreciation for life and enhanced relationships following a cancer diagnosis (Stanton, 2010). Prior research suggests that benefit finding might promote positive physical health outcomes in adults with chronic illness (Algoe & Stanton, 2009). The current intervention was expected to promote benefit finding attributed to illness through teaching of cognitive restructuring strategies and increasing perceived social connectedness.

***Psychosocial adjustment.*** As discussed previously, children and adolescents with chronic illness are at increased risk for internalizing symptoms (e.g., depressive symptoms) as compared to their healthy peers (Lavigne & Faier-Routman, 1992; Piquart & Shen, 2011). Thus, symptoms of anxiety and depression were assessed as markers of psychological distress. Cognitive behavioral therapy has been shown to be superior to other psychological treatments in reducing anxiety and depressive symptoms (Tolin, 2010). Additionally, health-related quality of life was assessed in light of evidence that children and young adults with chronic illness are at risk for impaired quality of life as compared to their healthy peers (Herts et al., 2014; Grootenhuis et al., 2007; Sawyer et al., 2004). Quality of life is a broad measure of functioning that facilitates understanding of wellbeing in this population. The current intervention was expected to improve quality of life through increasing perceived social connectedness, self-efficacy for disease management, and use of approach-oriented cognitive and behavioral coping strategies; and decreasing perceived illness-related threat.

***Medical transition behavior.*** Whether or not participants took steps to leave pediatric medical providers and engage in care with adult medical providers during the study period (i.e., medical transition behavior) was examined as an outcome in exploratory analyses. We expected that improvements in psychosocial and illness-related adjustment to illness would result in increased medical transition behavior among participants in the intervention (vs. control) group.

***Selection of moderators.*** Prior studies of adults with chronic illness suggest that baseline distress strongly predicts outcome distress (Linden & Satin, 2007). Furthermore, a meta-analysis of randomized controlled trials of psycho-oncologic interventions for adult patients with cancer found that levels of baseline distress moderated the impact of interventions on psychological distress and quality of life (Faller, Schuler, Richard, Heckl, Weis, & Kuffner, 2013).

Specifically, studies that enrolled participants who scored above a pre-defined cutoff for psychological distress (vs. studies that did not recruit participants based on distress levels) demonstrated a larger positive effect on emotional distress and quality of life at post-treatment (Faller et al., 2013). Similarly, a study of PYD constructs in adolescents demonstrated that greater school connectedness is associated with lower emotional distress, but only for adolescents with low or moderate (but not high) family connectedness (Wilkinson-Lee, Zhang, Nuno, & Wilhelm, 2011). Furthermore, a meta-analysis of mentoring interventions, one of the three core components of PYD programs, demonstrated that the interventions were more effective if they served youth with elevated baseline environmental risk or disadvantage (e.g., living in a low-income, urban community; DuBois, Holloway, Valentine, & Cooper, 2002; Rhodes, 1994). Taken together, these findings suggest that baseline levels of distress may moderate the impact of the CSI intervention on mediators and outcomes. As such, baseline values of the mediator and outcome variables will be evaluated as possible moderators of the associations between group assignment and these variables at one month (mid-intervention) and two months (immediately post-intervention).

### **Specific Aims**

The aims of the present research were as follows:

**Aim 1.** Conduct a randomized, controlled trial of the impact of the intervention on psychosocial adjustment (i.e., psychological symptoms and health-related quality of life) and illness-related adjustment (i.e., disease-related skills and knowledge, illness-related benefit finding and medical adherence).

*Hypothesis 1.* Compared to a print control group, participants receiving the intervention will demonstrate greater improvements in psychosocial and illness-related adjustment over time.

*Hypothesis 2.* The association between group assignment and outcomes will be moderated by the baseline value of the dependent variable, such that participants who report less favorable adjustment at baseline will benefit more from the intervention.

**Aim 2.** Examine possible mediators of the intervention effects on psychosocial and illness-related adjustment, including: illness perceptions (i.e., perceived illness-related threat), competence (i.e., approach-oriented cognitive and behavioral coping skills), social connection (i.e., loneliness) and confidence (i.e., self-efficacy for disease management).

*Hypothesis 3.* Illness perceptions, competence, social connection and confidence will independently mediate the effects of the intervention on both psychosocial and illness-related adjustment.

**Aim 3.** Explore the impact of the intervention on participant-reported medical transition behavior, i.e., leaving pediatric medical providers and initiating care with adult medical care providers.

*Hypothesis 4.* Intervention (vs. control) group participants will be more likely to take steps towards initiating the transition to adult medical care.

## **Method**

### **Participants**

Figure 3 details the flow of participants through different stages of the study. Young adults with chronic illness ( $N = 67$ ) were recruited to participate. Intent-to-treat analyses were conducted using data from the 63 participants who completed the baseline assessment and underwent random assignment; 32 participants were assigned to the Coping Skills Intervention (CSI) group, and 31 were assigned to the Informational Materials (IM) group. Sensitivity analyses using G\*Power 3.1 demonstrated that this sample size was sufficient to detect a medium

effect size ( $f = 0.25$ ) for each of the aims. This effect size was chosen due to evidence that skills-based psychosocial interventions for adolescents and young adults with chronic illness tend to yield moderate effect sizes (Sansom-Daly et al., 2012). Further, psychosocial interventions for AYAs with chronic illness also tend to have higher rates of success when there are at least 25 participants per group (Sansom-Daly et al., 2012).

Eligibility criteria included: (1) young adults age 18-22 years; (2) primary diagnosis of a chronic medical illness (e.g., cancer, diabetes, inflammatory bowel disease); (3) able to complete assessments and the intervention in English; (4) provides informed consent; (5) willing to attend eight in-person, weekly intervention sessions in Los Angeles, CA; and (6) if has serious mental illness (e.g., psychosis, schizophrenia, bipolar disorder, borderline personality disorder), signs release for principal investigator to consult with individual therapist.

Exclusion criteria included: (1) primary diagnosis of a functional illness (e.g., irritable bowel syndrome, fibromyalgia; Barsky & Borus, 1999); (2) diagnosis of HIV or AIDS; (3) psychiatric condition requiring current treatment and not receiving psychological care; (4) primary developmental delay (e.g., Autism Spectrum Disorders); and (5) if has serious mental illness, individual therapist notes that participation in CSI group is contra-indicated for potential participant or other intervention group members.

## **Procedure**

Institutional Review Board approval was obtained prior to the initiation of study recruitment procedures. Participants were recruited from a large public university in Southern California in exchange for being entered to win compensation via a raffle (e.g., gift cards) or for psychology course credit. All participants were current college students with the exception of one participant who was a recent graduate of the university. Recruitment took place through

several avenues, including (1) email listserv announcements; (2) posting to the university's undergraduate psychology subject pool; (3) direct physician or psychologist referrals; and (4) flyers distributed to locations frequented by young adults with chronic illness (e.g., the Student Health & Wellness Center and Counseling and Psychological Services at the university).

Potential participants were introduced to the trial by the principal investigator or trained research assistants following a standard verbal script. With consent, the study staff further described the trial, confirmed eligibility and discussed informed consent. Potential participants were given the opportunity to ask questions about the trial conditions and the consent form prior to signing. Once at least 10 participants were recruited, participants were sent an email with instructions to login to a secure website to complete baseline measures within one week. Participants were provided with paper measures upon request.

After baseline measures were completed, a random number generator was used to randomly assign blocks of four women or two to three men to one of the intervention conditions, such that an equal number of participants were assigned to the intervention group as to the control group. Block gender randomization was used in order to ensure that an equal number of men were assigned to each intervention condition, in light of the fact that women greatly outnumbered men in study enrollment. Upon assignment, participants were informed of their intervention status. Eligible and consenting participants were randomized to one of two intervention conditions: 1) a cognitive behavioral therapy (CBT) skills group, Coping Skills Intervention-Chronic Illness edition (CSI group); or 2) a print control group, the Informational Materials (IM) group. A CBT-based intervention was chosen to test the life skills component of Positive Youth Development due to prior research suggesting that psychological interventions that teach cognitive behavioral skills have positive effects on psychosocial outcomes for AYAs

with chronic illness (Sansom-Daly et al., 2012). Further, there is a strong literature base supporting the efficacy of CBT for reducing psychological symptoms (Hofmann, Asnaani, Vonk, Sawyer, & Fang, 2012) as well as a more modest literature suggesting positive effects of CBT on medical adherence (Richards et al., 2007; Safren et al., 2009).

One month (mid-intervention) and two months (immediately post-intervention) after the baseline assessment, participants were emailed to complete additional online questionnaires. Timing of follow-up assessments was selected to capture potential mediators (one month) and program effects (two month). This allowed for a prospective test of potential mechanisms linking preliminary and two-month indicators of psychosocial and illness-related adjustment. Treating physicians were unaware of patients' study participation.

**IM group.** Participants completed the baseline and follow-up assessments and otherwise received standard medical care, as well as weekly emails with widely available information about preparing for medical transitions. Participants could choose to receive print mailings (2 – 7 pages per week, totaling 32 pages) in place of emails. Print/email materials were adapted from resources highlighted by Got Transition, a partnership between the Maternal and Child Health Bureau and the National Alliance to Advance Adolescent Health that aims to facilitate the transition to adult health care (National Alliance to Advance Adolescent Health, 2014).

Participants assigned to the intervention condition also received these print materials via email.

**CSI group.** The CSI intervention was delivered in eight group sessions (delivered in 90-minute sessions for a total of 12 intervention hours) conducted weekly, commencing at the conclusion of the baseline assessment week. The duration of the intervention was chosen based on evidence that psychosocial interventions for AYAs with chronic illness of at least (vs. fewer than) six sessions that span a minimum of three months are more likely to yield positive

outcomes (Sansom-Daly et al., 2012). The span of the intervention was limited to two months because increasing the length of the intervention to three months would substantially decrease the feasibility of the study with undergraduate participants. Eight sessions were delivered because clinical trials demonstrating effectiveness of CBT interventions for psychological symptoms have usually included at least eight sessions (Shafran, Clark, Fairburn, Arntz, Barlow, Ehlers... & Wilson, 2009). Evidence also suggests that group-based CBT interventions of 10 hours or fewer have been effective at improving psychosocial outcomes in AYAs with specific chronic diseases (Hampel, Rudolph, Stachow, & Petermann, 2003; Thomas, Dixon & Milligan, & Thomas, 1999).

A 101-page treatment manual was developed by the first author that covers a curriculum adapted from topics and coping skills covered in the manual for The Adolescent Leadership Council of Hasbro Children's Hospital, an existing PYD program for AYAs with chronic illness (Maslow et al., 2008) and from CBT skills covered in a widely available manual for group-based CBT for depression (Muñoz, Gosh Ippen, Rao, Le, & Dwyer, 2000). The intervention curriculum is summarized in Table 1. In addition to completing the curriculum, participants were asked to complete homework each week to practice the skills learned in the CSI session.

CSI groups were led by one of four therapists who were doctoral students in clinical psychology. The first author conducted four groups, and master's level students each ran one group. Groups had three (one group), four (five groups), or five (one group) participants. Prior to administering the intervention, therapists complete a four-hour training in the psychology of chronic illness and the CSI manual co-led by a licensed clinical psychologist and the first author. Group leaders also had weekly supervision by the first author, under the supervision of the



licensed psychologist. This allowed group leaders to consult about problems that arose and plan for subsequent sessions.

## **Measures**

At baseline, demographic and illness-related variables were assessed. Outcome variables were assessed at baseline and two months (after treatment completion), while mediator variables were assessed at all three assessments. During the two-month intervention period, session attendance and homework completion were assessed for participants in the intervention group. The acceptability of the intervention was assessed after completion of the two-month intervention period. Fidelity to the intervention sessions (i.e., adherence to each session's intended delivery) was assessed using an author-constructed measure developed based on the intervention manual. Intervention sessions were audio-recorded with informed consent from participants. Research staff uninvolved in the delivery of the intervention completed the fidelity assessments based on the recordings. The measures are described in detail below.

**Demographic factors and illness-related variables.** Demographic and illness-related variables, including questions assessing medical transition behavior, were adapted from the manual for and program evaluation of The Adolescent Leadership Council (TALC), an existing PYD program for AYAs with chronic illness (Maslow et al., 2008; Maslow et al., 2013) and a descriptive study that compared the experience and psychosocial adaptation of college freshmen with chronic illness to that of their healthy peers (Herts et al., 2014). These measures can be seen in Appendix A.

**Demographic variables.** At baseline, demographic variables including age, gender, family income, race/ethnicity, and education level of parent and self were assessed via self-report. Additionally, college students were asked about their use of school-based health services

and other medical care in the city where they attended school (e.g., “Do you see a physician specialist in the same city as your school?”).

***Illness-related variables.*** At baseline, illness-related variables were assessed via self-report. The variables included current diagnoses (i.e., diagnoses of chronic physical illness, psychological disorders, documented learning disabilities, physical disabilities), and number of social ties with peers with chronic physical illness.

**Intervention attendance and homework completion.** Intervention group leaders tracked participant attendance and homework completion using a checklist of assignments (see Appendix A).

**Group acceptability.** At the two-month assessment, participants in each group completed a brief questionnaire inviting feedback about their experience in the CSI or IM group. CSI group participants rated their overall experience in the group on a scale that ranged from 1 (very negative) to 7 (very positive). IM (but not CSI) group members rated how helpful they found the weekly information provided to them on a scale that ranged from 1 (not at all helpful) to 5 (extremely helpful). Members from both groups also provided qualitative feedback about their experience in answers to free-response questions. Sample items are “*What would you like to change about the CSI group?*” and “*What did you find most helpful about the information [provided]?*” These measures can be seen in Appendix A.

**Intervention fidelity.** Trained research staff completed fidelity assessments based on audio recordings from the intervention sessions. The measure of intervention fidelity was developed by the author based on the treatment manual. An example item is “*Group leaders provided psychoeducation about the link between thoughts, behaviors and mood.*” Research staff

indicated whether or not each topic in the manual was addressed in the session. See Appendix A for the full text of the measure.

**Dependent variables.** Measures assessing psychosocial and illness-related adjustment were assessed as dependent variables at baseline and two months.

***Illness-related adjustment.*** Disease-related skills and knowledge, adherence to medical regimens, and illness-related benefit finding were assessed as indicators of illness-related adjustment. Self-reported medical transition behavior (described above) was also explored as an illness-related outcome.

***Disease-related skills and knowledge.*** The 20-item Transition Readiness Assessment Questionnaire (TRAQ) was used to assess disease-related skills and knowledge (Wood, Sawicki, Miller, Smotherman, Lukens-Bull, Livingood... & Kraemer, 2014). The TRAQ has subscales assessing perceived skill in managing medications, appointment keeping, tracking health issues, talking with providers and managing daily activities. Participants indicated their skill level with regard to each item (e.g., “Do you answer questions that are asked by the doctor, nurse, or clinic staff?”) on a scale ranging from 1 (*no, I do not know how*) to 5 (*yes, I always do this when I need to*). The TRAQ has demonstrated good internal reliability and criterion validity in samples of AYAs ages 14 – 21 years with special health care needs (Wood et al., 2014). In the present sample, internal consistency was good across both assessments (T1  $\alpha = .87$ , T3  $\alpha = .89$ ).

***Medical regimen adherence.*** Participants’ reports of medical adherence were assessed via a modified version of the 5-item General Adherence Scale from the Medical Outcomes Study (MOS GAS; DiMatteo, Hays, & Sherbourne, 1992). The scale was modified by adding questions that ask participants briefly to describe their doctor’s recommendations for taking medication, injections or engaging in other treatment; for engaging in health behaviors (e.g., checking insulin

levels); and for attending medical appointments (these introductory questions can be seen in Appendix A). Participants then rated how often during the past four weeks they were able to engage in adherence behaviors (e.g., “I found it easy to do the things my doctor suggested I do”) on a scale ranging from 1 (*all of the time*) to 6 (*none of the time*). The General Adherence Scale has demonstrated good internal consistency in past samples of adults with chronic illness (DiMatteo, Sherbourne, Hays, Ordway, Kravitz, McGlynn, . . . & Rogers, 1993), and high (T1  $\alpha = .85$ ; T3  $\alpha = .92$ ) reliability in the present sample. This self-report measure of adherence was chosen because inclusion criteria did not require that participants belong to a single illness population, which limited the feasibility of collecting a single biological or physician-reported measure of treatment adherence.

***Benefit finding.*** Perceived benefits arising from having a chronic illness were assessed via the 10-item Benefit Finding Scale for Children (BFSC; Phipps, Long, & Ogden, 2007). Participants indicated how having an illness has positively influenced them (e.g., “has helped me become a stronger person” and “has helped me know how much I am loved”) on a scale ranging from 1 (*not at all true for me*) to 5 (*very true for me*). The scale demonstrates good internal consistency in past studies of children and adolescents with cancer (Phipps et al., 2007) and high internal consistency in the present sample (T1  $\alpha = .92$ , T3  $\alpha = .91$ ). The Benefit Finding Scale for Children was chosen due to the relevance of the items for young adults, which stood in contrast to some items on benefit finding scales for adults (e.g., “having had breast cancer has made me realize the importance of planning for my family’s future;” Tomich & Helgeson, 2004).

***Psychosocial adjustment.*** Health-related quality of life, depressive symptoms, and anxiety symptoms were assessed as indicators of psychosocial adjustment.

***Health-related quality of life.*** Quality of life was assessed via the 12-item Short Form Health Survey (SF-12; Ware, Kosinski, & Keller, 1996). The SF-12 has demonstrated acceptable internal consistency in college student samples (e.g., Anders, Frazier, & Shallcross, 2012) and has been used in samples of young adults with chronic illness (e.g., Adler, Raju, Beveridge, Wang, Zhu, & Zimmermann, 2008). The measure demonstrated acceptable (T1  $\alpha = .76$ ) to good (T3  $\alpha = .81$ ) internal consistency in the present sample. Participants responded to questions about their health and daily activities during the past 4 weeks. Responses were used to form a physical health component (PCS) summary score, such that a higher score indicates better perceived quality of life (Ware et al., 1996).

***Depressive symptoms.*** Participants completed the 20-item Center for Epidemiologic Studies Depression scale (CES-D; Radloff, 1977). On the CES-D, participants indicated how they felt or behaved during the past week regarding each item (e.g., “I had crying spells”) on a scale ranging from 1 (*rarely or none of the time; less than 1 day*) to 4 (*most or all of the time; 5 – 7 days*). The CES-D is a widely used measure of adolescent and adult depressive symptoms that has demonstrated good internal consistency in young people under age 25 (Radloff, 1977). The CES-D demonstrated high internal consistency in the current sample (T1  $\alpha = .92$ , T3  $\alpha = .93$ ).

***Anxiety symptoms.*** Self-reported anxiety symptoms were assessed via the six-item Brief Symptom Inventory – Anxiety subscale (BSI-ANX; Derogatis & Melisaratos, 1983). Participants rated how much each problem had distressed or bothered them (e.g., “nervousness or shakiness inside”) during the past seven days on a scale ranging from 0 (*not at all*) to 4 (*extremely*). The BSI-ANX has demonstrated good internal consistency in past samples (Derogatis & Melisaratos, and high (T1  $\alpha = .86$ ; T1  $\alpha = .92$ ) internal consistency in the present sample. This measure was

chosen because the BSI includes separate scales for anxiety and somatization, thus helping prevent possible overlap between physical symptoms of chronic illness and anxiety symptoms.

**Medical transition behavior.** At baseline and two months, participants answered medical transition behavior questions (see Appendix A) adapted from the program evaluation of TALC (Maslow et al., 2013). The total number of participants in each condition who evidenced steps toward making the transition from a pediatric to an adult medical professional during the course of the study was calculated for analysis. These calculations were drawn from three indicators. First, participants who at baseline reported obtaining care from a pediatric generalist physician and then at two months reported obtaining care from an adult generalist physician were counted for each condition. Second, participants in each condition were counted if they: 1) reported obtaining care from a pediatric disease specialist at baseline; 2) reported that they did not see either a pediatric or adult disease specialist at two months; and 3) at two months reported that they had not yet identified an adult disease specialist to whom they planned to transfer. Third, participants who at baseline reported obtaining care from a pediatric disease specialist and then at two months reported obtaining care from an adult disease specialist were counted for each condition.

**Mediator variables.** Assessed at baseline, one and two months, mediator variables included social connection, confidence, competence, and illness perceptions.

**Social connection (loneliness).** Social connection was assessed via a 10-item version of the UCLA Loneliness Scale (ULS; Russell, 1996). Participants rated each item (e.g., “how often do you feel unhappy doing so many things alone?” and “how often do you feel shut out and excluded by others?”) on a scale from 1 (*I never feel this way*) to 4 (*I often feel this way*). The scale has demonstrated good internal consistency and construct validity in college students

(Russell, 1996) and has been used in studies of adolescents with chronic illness (e.g., Maslow et al., 2013). In the present study, the ULS demonstrated high internal consistency at all assessments (T1  $\alpha = .91$ , T2  $\alpha = .92$ , T3  $\alpha = .94$ ).

***Confidence (self-efficacy for disease management)***. Confidence was measured via three scales measuring different aspects of self-efficacy for disease management. First, participants completed the Self Efficacy for Managing Chronic Disease 6-Item Scale, which assesses self-efficacy for disease-management activities common to many chronic illnesses, including symptom control and reducing the impact of illness on everyday life (Lorig, Sobel, Ritter, Laurent, & Hobbes, 2001). Participants indicated how confident they were in their ability to do disease-management activities (e.g., “how confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?”) on a scale ranging from 1 (*not at all confident*) to 10 (*totally confident*).

Second, using the same response scale, participants also completed a shortened 10-item version of the Chronic Disease Self-Efficacy Scales comprised of three subscales: getting information about disease (one item), communication with physicians (three items, e.g., “how confident are you that you can ask your doctor things about your illness that concern you?”), and managing depression (six items, e.g., “how confident are you that you can keep from getting discouraged when nothing you do seems to make any difference?”; Lorig, Stewart, Ritter, Gonzalez, Laurent, & Lynch, 1996). The subscales have demonstrated excellent internal consistency in samples of adults with chronic illness (Lorig et al., 1996; Lorig et al., 2001).

Third, participants also completed a modified version of the self-efficacy for managing depression subscale assessing self-efficacy for managing anxiety (eight items, e.g., “how

confident are you that you can do something to make yourself feel better when you are fearful or scared?”). The Self-Efficacy for Managing Anxiety scale can be seen in Appendix A.

The three scales (Self Efficacy for Managing Chronic Disease 6-Item Scale, the Chronic Disease Self-Efficacy Scales, and the Self-Efficacy for Managing Anxiety scale) were highly correlated at all time points ( $r = .49$  to  $.78$ ,  $p \leq .01$  between all scales at all assessments).

Further, the scales use the same response format. Therefore, for the current study, items from the three scales were averaged to form a Self-Efficacy for Disease Management Composite scale (SEDMC). The SEDMC demonstrated high internal consistency at all assessments (T1  $\alpha = .95$ , T2  $\alpha = .96$ , T3  $\alpha = .97$ ).

**Competence (approach-oriented coping).** Self-reported use of cognitive (e.g., acceptance) and behavioral (e.g., seeking social support) coping strategies served as the indicator of competence. Participants completed a shortened 36-item version of the COPE (Carver, Scheier, & Weintraub, 1989) and the Emotional Approach Coping scales (EACs; Stanton, Kirk, Cameron, & Danoff-Burg, 2000). These scales assess six approach-oriented coping strategies: problem-focused coping, emotional expression, emotional processing, acceptance, seeking support, and positive reinterpretation and growth. Participants indicated to what extent they have been engaging in each item (e.g., “I get help and advice from other people”) in response to being asked what they have been doing to cope with their experience of having a chronic illness on a scale ranging from 1 (*I don't do this at all*) to 4 (*I do this a lot*). The COPE and the Emotional Approach Coping scales have demonstrated adequate internal reliability among college students (Carver et al., 1989; Stanton et al., 2000) and adults with chronic illness (e.g., Stanton, Danoff-Burg, & Huggins, 2002). In the present study, the approach-oriented coping scale demonstrated high internal consistency across assessments (T1  $\alpha = .93$ , T2  $\alpha = .94$ , T3  $\alpha = .95$ ).



**Illness perceptions.** Cognitive and emotional representations of illness were assessed via the 9-item Brief Illness Perception Questionnaire (BIPQ; Broadbent, Petrie, Main, & Weinman, 2006). Participants indicated their perceptions of control over illness (e.g., “how much control do you feel you have over your illness?”), disease impact (e.g., “how much does your illness affect your life?”) and other aspects of living with illness on a scale ranging from 0 (e.g., *absolutely no control*) to 10 (e.g., *extreme amount of control*). Scores were summed to form a total scale, with a higher total score on the BIPQ indicating higher perceived illness-related threat. The BIPQ has demonstrated good test-retest reliability and concurrent and discriminant validity in samples of adults with chronic illness (Broadbent et al., 2006). In the present study, the BIPQ total score demonstrated adequate (T1  $\alpha = .79$ , T2  $\alpha = .80$ , T3  $\alpha = .75$ ) internal consistency reliability.

### **Data Analysis Strategy**

Preliminary analyses were descriptive statistics, baseline group differences in study variables, and examination of the BIPQ in light of its items that might be confounded with outcomes. Primary analyses were tests of main effects and moderators of group assignment on mediators and outcomes (Aim 1), tests of one-month mediators of the association between group assignment and two-month outcomes (Aim 2), and a test of the impact of group assignment on medical transition behavior (Aim 3).

### **Preliminary Analyses**

Descriptive statistics (i.e., means, standard deviations) were calculated for study variables at each assessment. Using  $t$ -tests and  $\chi^2$  analyses, study completers and dropouts were assessed for differences in baseline outcome and mediator variables, as well as demographic and illness-related variables. Similarly, group equivalence on baseline variables was assessed via independent  $t$ -tests and  $\chi^2$  analyses. When significant baseline group differences in outcomes

were found, analyses assessing main effects (Aim 2), moderators, and mediators (Aim 3) of the association between group assignment and outcomes controlled for the baseline value of the outcome variables. In addition to controlling for the baseline value of the dependent variable, all mediation analyses also controlled for baseline values of any mediators with significant baseline group differences on the initial path from group assignment to the mediator being assessed (Aim 3).

Preliminary analyses included use of two different versions of the BIPQ in tests of main effects, moderation and mediation (Aims 2 and 3). Findings using the entire BIPQ were compared with findings using a modified version of the BIPQ that omitted three items that might overlap with illness-related emotional distress (e.g., “*How much does your illness affect you emotionally?*”).

### **Evaluation of Specific Aims**

To test Aim 1 and Aim 2, intent-to-treat (ITT) analyses were conducted in order to maintain the group equivalence generated by random assignment. Path analyses used the full information maximum likelihood estimation method (FIML; Enders, 2001) to account for missing data. Model fit was evaluated according to accepted criteria (Hu & Bentler, 1999); a value  $\leq .06$  for the Root Mean Square Error of Approximation (RMSEA), a value  $\geq .95$  for the Comparative Fit Index (CFI) and a value  $< .08$  for the Standardized Root Mean Square Residual (SRMR) indicate good fit. Analyses were repeated using data from study completers to allow for comparison of findings using the two methods.

**Aim 1.** Analyses evaluated the influence of group assignment (CSI vs. IM) on change in hypothesized mediators and outcomes across time, with a one- or two-month measure as the dependent variable (e.g., medical transition readiness) and group, the baseline value of

demographic and illness-related variables with significant baseline imbalance, and the baseline value of the dependent variable (to assess the impact of the intervention on change in the dependent variable over time) as independent variables. Next, baseline values of the dependent variable were tested as moderators of the associations between group assignment and each conceptual mediator and outcome. Significant interactions were plotted for the relationship between group assignment and the relevant dependent variable at low ( $\bar{x} - 1 SD$ ), mean ( $\bar{x}$ ), and high ( $\bar{x} + 1 SD$ ) levels of the moderator. We expected that participants assigned to the CSI (vs. IM) group would demonstrate greater improvements in mediators and outcomes over time (Hypothesis 1). Additionally, we expected moderation analyses to reveal that participants who reported poorer adjustment at baseline would benefit more from the intervention (Hypothesis 2).

**Aim 2.** We evaluated hypothesized mediators of the effects of the intervention using change in the hypothesized mediator (e.g., self-efficacy) from baseline to one month to predict change in outcome (e.g., health-related quality of life) from baseline to two months. We used bootstrapping to test mediation, which is recommended for small samples; indirect effects are significant if the confidence interval does not include zero (Shrout & Bolger, 2002). We expected that loneliness, approach-oriented coping, illness perceptions and self-efficacy would each independently mediate the association between CSI and the outcomes (Hypothesis 3).

**Aim 3.** A  $\chi^2$  analysis was conducted to assess whether group assignment was associated with self-reported medical transition behavior (i.e., discontinuing care with a pediatric medical care provider and initiating care with an adult medical care provider). We expected that participants who completed the CSI (vs. IM) group would be more likely to take steps towards initiating the transition from pediatric to adult medical care providers (Hypothesis 4).

## Results

## Preliminary Analyses

**Descriptive statistics and baseline group differences.** Descriptive statistics as well as the results of *t*-tests assessing between-group differences in all variables at baseline are displayed in Table 2. Graphs displaying changes in each study measure over time by group are contained in Figures 3 through 12. Due to a significant baseline group difference in depressive symptoms, analyses assessing main effects (Aim 1), moderators, and mediators (Aim 2) of the association between group assignment and outcomes controlled for baseline depressive symptoms. There were also significant group differences in two hypothesized mediators at baseline: illness perceptions and self-efficacy for communicating with physicians. As such, mediation analyses controlled for baseline values of these variables on the initial path from group assignment to the mediator being assessed (Aim 2).

**Zero-order correlations.** Table 3 displays associations between outcomes at baseline and two months (immediately post-intervention) with mediators at baseline and one month (mid intervention). Of 96 correlations tested, over one third ( $n = 36$ ) were statistically significant. Specifically, correlations were tested between each of six outcomes (i.e., disease-related skills and knowledge [TRAQ], medical regimen adherence [MOS GAS], disease-related benefit finding [BFSC], physical health-related quality of life [PCS], depressive symptoms [CES-D], and anxiety symptoms [BSI-ANX]), separately at baseline and two months, with each of four mediators (i.e., perceived loneliness [ULS], self-efficacy for disease management [SEDMC], approach-oriented coping [COPE and EAC], and perceived illness-related threat [BIPQ]), separately at baseline and one month.

At baseline, reporting greater disease-related skills and knowledge was associated with higher self-efficacy ( $r = .34, p < .05$ ) and approach-oriented coping ( $r = .31, p < .05$ ). Baseline

and two-month skills/knowledge were positively associated with one-month approach-oriented coping ( $r = .34$  to  $.37, p < .05$ ). Baseline adherence was positively associated with baseline (but not one month) self-efficacy ( $r = .31, p < .05$ ) and inversely associated with perceived threat ( $r = -.29, p < .05$ ). At two months, adherence was positively associated with one-month (but not baseline) self-efficacy ( $r = .31, p < .05$ ) and inversely associated with perceived threat ( $r = -.37, p < .05$ ). Two-month quality of life was significantly positively associated with self-efficacy at baseline ( $r = .36, p < .05$ ) and one month ( $r = .41, p < .01$ ). Additionally, at baseline and two months, better quality of life was significantly correlated with lower perceived threat at baseline and one month ( $r = -.43$  to  $-.52, p < .01$ ). Baseline benefit finding was significantly correlated with all mediators at T1 and T2 ( $|r| = .26$  to  $.65, p < .05$ ), with the exception of baseline loneliness. Two-month benefit finding was positively associated with approach-oriented coping at both assessments ( $r = .51$  to  $.60, p < .01$ ), and with self-efficacy at two (but not one) months ( $r = .37, p < .05$ ). Finally, depressive (CES-D) and anxiety (BSI-ANX) symptoms at baseline and two months were each positively associated with loneliness ( $r = .36$  to  $.59, p < .05$ ), inversely associated with self-efficacy ( $r = -.34$  to  $-.55, p < .05$ ), and positively associated with perceived threat ( $r = .28$  to  $.48, p < .05$ ) at baseline and one month.

In sum, when associations were found: 1) skills/knowledge, adherence, quality of life, and benefit finding were positively associated with self-efficacy, while depressive and anxiety symptoms were inversely correlated with self-efficacy; 2) skills/knowledge and benefit finding were positively associated with approach-oriented coping; 3) adherence, quality of life, and benefit finding were inversely correlated with perceived threat, while depressive and anxiety symptoms were positively correlated with perceived threat; and 4) benefit finding was inversely

correlated with loneliness, while depressive and anxiety symptoms were positively correlated with loneliness.

Intercorrelations between mediators at each assessment can be seen in Tables 4 through 6. All four mediators (i.e., loneliness, self-efficacy for disease management, approach-oriented coping, and perceived illness-related threat) were significantly associated at all assessments ( $p < .05$ ), with only two exceptions. At baseline, approach-oriented coping was not associated with perceived threat, and at two months, coping was not associated with loneliness. In general, greater loneliness predicted lower self-efficacy and approach-oriented coping, and higher perceived threat. Self-efficacy and approach-oriented coping were positively associated, and each was inversely associated with perceived threat.

Intercorrelations between outcomes at each assessment are displayed in Tables 7 and 8. Specifically, correlations between each of the six outcomes (i.e., disease-related skills and knowledge, medical regimen adherence, illness-related benefit finding, physical health-related quality of life, anxiety symptoms, and depressive symptoms) were tested at baseline and two months (immediately post-intervention). Of 30 correlations tested, nine were statistically significant. Depressive and anxiety symptoms were positively correlated at both assessments ( $r = .65$  to  $.69$ ,  $p < .01$ ). Depressive symptoms were inversely correlated with quality of life at both assessments ( $r = -.26$  to  $-.27$ ,  $p < .05$ ). Adherence was inversely correlated with anxiety at both assessments ( $r = -.30$  to  $-.29$ ,  $p < .05$ ), and with depression at two months only ( $r = -.27$ ,  $p < .05$ ). Adherence was positively associated with skills/knowledge at two months ( $r = .32$ ,  $p < .05$ ). Finally, anxiety was inversely associated with two-month skills/knowledge ( $r = -.27$ ,  $p < .05$ ).

**Findings using different versions of the BIPQ.** For both scoring methods, results were the same for main effects and moderator analyses (Aim 1). One significant mediation finding

became marginally significant when using the modified version of the BIPQ that omitted items related to emotional distress; this finding is described in the description of mediation findings. Due to the overall similarities in the findings and the widespread use of the original BIPQ in other studies (Broadbent, Wilkes, Koschwanez, Norton, & Petrie, 2015), results from the analyses using the entire BIPQ are presented.

**Comparison of findings in study completers, dropouts, and ITT analyses.** There were no significant differences between completers and dropouts on any baseline measure. Furthermore, no differences in results emerged when analyses were conducted in completers vs. using FIML to handle missing data, and as such, results from ITT analyses are presented.

### **Participant Characteristics**

Demographic characteristics of participants are displayed in Table 9. Participants were majority female (76%) with a mean age of 19.81 years. The sample was ethnically diverse, as was family income, ranging from below \$50,000 per year (27% of participants) to at least \$100,000 per year (37% of participants). Three-quarters of participants reported that their most highly educated parent had at least a college degree. There were no significant differences in demographic characteristics by group assignment.

All but one participant was a current college student at the time of the baseline assessment. The participant who was not in college was a recent college graduate who was working full time. Descriptive information about the current college students is displayed in Table 10. Most students were in their sophomore (32%) or junior (32%) year. Over 40% of students did not have a primary care or specialty physician in the same city as their college. Approximately half the sample (54%) used the college's health services, and over 50% were not registered with the Office for Students with Disabilities at the college, an entity charged with

serving students with chronic illness. Just over one-quarter of students used university psychological services, while less than 5% participated in a university-offered support group. There were no significant differences in characteristics of current college students by group assignment.

Table 11 displays the diseases reported by participants. The most commonly reported diseases were digestive disorders ( $n = 15$  participants, most with ulcerative colitis or celiac disease); asthma ( $n = 12$  participants); cancers ( $n = 11$  participants, most with Hodgkin's Lymphoma); and endocrine, nutritional and metabolic disorders ( $n = 11$  participants, most with type 1 diabetes or hypothyroidism). Excluded physical comorbidities reported by participants are presented in Table 12. The most commonly reported excluded diagnoses were digestive disorders ( $n = 4$ , most with Irritable Bowel Syndrome) and musculoskeletal disorders ( $n = 4$ , most found in the shoulder). Randomization was not stratified by chronic disease diagnosis due to the small number of participants with each specific diagnosis.

Additional information about participants' diagnoses is contained in Table 13. Participants reported a mean age at diagnosis of their primary chronic disease of 14 years. On average, participants indicated that they knew fewer than three peers with chronic illness, and over 30% of participants reported that they did not know any peers with chronic illness. Approximately one-third of participants reported that they still see pediatric medical providers. There were no significant differences in this medical information by group assignment.

Finally, participant-reported psychiatric diagnoses are displayed in Table 14. The most commonly reported diagnoses were depressive disorders ( $n = 15$ ) and anxiety disorders ( $n = 11$ ). Also represented were participants reporting obsessive-compulsive and related disorders ( $n = 3$ ),



eating disorders ( $n = 2$ ), attention-deficit/hyperactivity disorder ( $n = 2$ ), bipolar I disorder ( $n = 1$ ), insomnia disorder ( $n = 1$ ), and post-traumatic stress disorder ( $n = 1$ ).

### **Intervention Fidelity and Acceptability**

**CSI group.** Recordings of CSI sessions were independently rated by two trained undergraduate-level research assistants for fidelity to treatment. For each CSI group, 90 items across eight sessions were rated. Across all sessions, inter-rater agreement was 100%. Five of the seven groups were conducted with 100% fidelity to treatment (90/90 items completed). One group leader demonstrated 98.88% fidelity (89/90 items completed), and another group leader demonstrated 97.77% fidelity (88/90 items completed).

The 27 participants who completed the CSI group attended an average of 7.15/8 sessions ( $SD = .91$ , range = 5 – 8). The most common reasons given for missed sessions were illness and academic conflicts. Between sessions, participants completed an average of 8.85/11 homework assignments ( $SD = 1.73$ , range = 4 – 11), as evidenced by group leaders' reports of the total number of homework assignments completed (see CSI Group Homework Tracker, Appendix A).

Participants provided positive quantitative and qualitative feedback about their experience in the CSI group. Eighty-five percent ( $n = 23/27$ ) of CSI group participants rated their overall experience as “Very Positive,” 11% ( $n = 3/27$ ) rated their experience as “Fairly Positive,” and one participant rated the experience as “A Little Positive.” The mean overall experience rating for CSI group members was 6.81/7, where a rating of seven indicated a very positive experience. In their qualitative feedback, nearly all CSI group members ( $n = 26/27$ ) cited benefits of engaging with other young adults with chronic illness. For example, one participant noted that she was able to be open and felt accepted in the group setting:

*“What I liked the most about the group was the intimacy of the setting. Sharing details about my illness has never been something that I've been open to, mainly because of the fear of being judged or of passing a burden onto someone else. Being able to share with others and hear their*

*experiences made me feel accepted.”*

Another described the relief resulting from social connection:

*“To be able to see through new perspectives from other people who suffer from chronic illness is almost a relief in itself. In everyday life, chronic illness is relatively invisible and can make you feel isolated. To know that there are more people out there can that understand you, that's really precious.”*

Participants also described specific aspects of the intervention they found helpful, including cognitive restructuring, relationship skills practice, and expressive writing assignments. For example, the participant below described several positive aspects of the intervention:

*“[Group leader], you've changed my life. You said that you will never forget about us, but I don't think you understand the difference you've made in our lives: the confidence I've gained, the ability to recognize my own destructive thoughts and separate that from reality, the friendships I've made, the reassurance of community, the steps I've made in fixing my interpersonal problems, the ability to not only see but find solutions to issues I'm having, [and] the newly developed perspective I have about my illness. All of this and more. So, so much more... Thank you for everything.”*

When asked what they would like to change or what disappointed them about the intervention, the most common response came from nearly half of participants ( $n = 13/27$ ) who requested an increase in the intervention intensity or reach. Specifically, participants requested that the CSI group go on for longer, become more widely available (e.g., by becoming an official campus group), or cover certain topics in more depth (e.g., relationships and chronic illness). Others requested a specific avenue for increasing group member communication outside the group, such as a social media network. For example, when asked what disappointed her about the CSI group, one participant responded:

*“I wasn't disappointed with anything. I thought it was really helpful, and I wish that more young people with chronic illness could benefit from what we learned in the group.”*

In sum, qualitative and quantitative feedback suggests that participants viewed the CSI favorably.

**IM group.** The 29 participants who completed the IM group provided varied feedback

about their experiences. The mean overall experience rating for IM group members was 3.39/5 ( $SD = 1.03$ ), where a rating of three indicated that a participant found the information provided to be “Somewhat Helpful,” and a rating of five indicated that a participant found the information to be “Extremely Helpful.” In their qualitative feedback, IM group participants said they appreciated that the information provided was tailored to college students ( $n = 3$ ), and they found the information about stress management ( $n = 6$ ) and the transition from pediatric to adult medical care ( $n = 4$ ) to be helpful. When asked what they would change or what disappointed them about the information provided, participant responses included that they already knew the information ( $n = 5$ ), wished the information was more specific to their illness ( $n = 3$ ), or wanted more information about stress relief and maintaining mental health ( $n = 3$ ).

### **Aim 1. Main and Moderated Effects of the Intervention**

Table 15 displays the results of analyses assessing the impact of the intervention on mediators and outcomes, as well as the results of analyses assessing moderators of these associations.

**Intervention effects on psychosocial and illness-related adjustment.** The main or moderated effects of condition were statistically significant for two of six outcomes, although effects were not significant for the other four outcomes. Analyses assessed the main or moderated effects of condition on outcomes at two months (immediately post-intervention), controlling for the baseline value of the outcome and of depressive symptoms. As compared to IM group members, CSI group members reported significantly higher illness-related benefit finding (BFSC) at two months ( $\beta = .22, p = .03, \text{model } R^2 = .48, \text{RMSEA} < .01, \text{SRMR} = .01, \text{CFI} = 1.00, \chi^2(3) = 39.22, p \leq .01$ ). The main effect of group assignment on anxiety was not significant; however, the impact of group assignment on anxiety at two months was moderated

significantly by baseline anxiety (BSI-ANX; interaction term  $\beta = .35$ ,  $p = .05$ , model  $R^2 = .57$ , RMSEA  $< .01$ , SRMR = .02, CFI = 1.00,  $\chi^2(4) = 46.61$ ,  $p \leq .01$ ). The interaction between group assignment and baseline anxiety on two-month anxiety is displayed in Figure 13. Contrary to our hypothesis, at low levels of baseline anxiety, CSI group members had significantly lower two-month anxiety as compared to IM group members ( $p = .05$ ). Group assignment was not associated with two-month anxiety at mean or high levels of baseline anxiety ( $p > .05$ ). Group assignment did not produce changes in disease-related skills and knowledge (TRAQ), medical adherence (MOS GAS), physical health-related quality of life (SF-12 PCS), or depressive symptoms (CES-D).

**Intervention effects on social connection, confidence, competence, and illness perceptions (hypothesized mediators).** The main or moderated effects of condition were statistically significant for three of four mediators at one month (mid intervention), and for all four mediators at two months (immediately post-intervention). Analyses controlled for the baseline value of the mediator and of depressive symptoms. There was no effect of group assignment on one-month social connection, as measured by self-reported loneliness (ULS). The impact of group assignment on two-month loneliness was moderated by baseline loneliness (interaction term  $\beta = -.86$ ,  $p = .03$ , model  $R^2 = .38$ , RMSEA  $< .01$ , SRMR = .02, CFI = 1.00,  $\chi^2(4) = 26.86$ ,  $p \leq .01$ ). Figure 14 displays the interaction between group assignment and baseline loneliness. At very high levels of baseline loneliness ( $\bar{x} + 2SD$ ), CSI group members had significantly lower two-month loneliness as compared to IM group members ( $p = .05$ ). Group assignment was not associated with two-month loneliness at very low ( $\bar{x} - 2SD$ ) or mean levels of baseline loneliness.

There was a significant interaction between group assignment and baseline confidence (i.e., self-efficacy for disease management [Self-Efficacy Composite Scale]), in predicting self-efficacy at one month (interaction term  $\beta = -.96$ ,  $p < .01$ , model  $R^2 = .67$ , RMSEA  $< .01$ , SRMR =  $.02$ , CFI =  $1.00$ ,  $\chi^2(4) = 61.49$ ,  $p \leq .01$ ). This interaction is displayed in Figure 15. At low ( $p < .01$ ) and mean ( $p = .01$ ) levels of baseline self-efficacy (but not at high self-efficacy;  $p > .05$ ), CSI group members had significantly higher one-month self-efficacy as compared to IM group members. Similarly, the interaction was significant between group assignment and baseline self-efficacy in predicting two-month self-efficacy (interaction term  $\beta = -.90$ ,  $p = .01$ , model  $R^2 = .61$ , RMSEA  $< .01$ , SRMR =  $.03$ , CFI =  $1.00$ ,  $\chi^2(4) = 51.94$ ,  $p \leq .01$ ; see Figure 16). At low ( $p < .01$ ) and mean ( $p = .01$ ) levels of baseline self-efficacy, CSI group members had significantly higher two-month self-efficacy as compared to IM group members. Group assignment did not predict self-efficacy at one or two months for participants with high baseline self-efficacy ( $p > .05$ ).

As compared to IM group members, CSI group members reported significantly higher competence (i.e., approach-oriented coping; COPE and EACs) at one month ( $\beta = 1.74$ ,  $p = .05$ , model  $R^2 = .59$ , RMSEA  $< .01$ , SRMR =  $.04$ , CFI =  $1.00$ ,  $\chi^2(3) = 49.78$ ,  $p \leq .01$ ). Baseline approach-oriented coping moderated the association between group assignment and two-month approach-oriented coping (interaction term  $\beta = -1.03$ ,  $p = .02$ , model  $R^2 = .56$ , RMSEA  $< .01$ , SRMR =  $.05$ , CFI =  $1.00$ ,  $\chi^2(4) = 44.29$ ,  $p \leq .01$ ). The interaction is displayed in Figure 17. At low ( $p < .01$ ) and mean ( $p = .04$ ) levels of baseline approach-oriented coping, CSI group members had significantly higher two-month approach-oriented coping as compared to IM group members. Group assignment did not predict two-month approach-oriented coping for participants with high baseline approach-oriented coping ( $p > .05$ ).

There was a significant interaction between group assignment and baseline illness perceptions (i.e., perceived illness-related threat [BIPQ]), in predicting perceived threat at one month (interaction term  $\beta = -.92$ ,  $p < .01$ , model  $R^2 = .76$ , RMSEA  $< .01$ , SRMR = .02, CFI = 1.00,  $\chi^2(4) = 82.89$ ,  $p \leq .01$ ). This interaction is displayed in Figure 18. At high ( $p < .01$ ) levels of baseline threat, CSI group members had significantly lower one-month perceived illness-related threat as compared to IM group members. Similarly, as can be seen in Figure 19, there was a significant interaction between group assignment and baseline perceived threat in predicting two-month perceived threat (interaction term  $\beta = -.75$ ,  $p = .01$ , model  $R^2 = .69$ , RMSEA  $< .01$ , SRMR = .02, CFI = 1.00,  $\chi^2(4) = 66.22$ ,  $p \leq .01$ ). At high ( $p < .01$ ) levels of baseline threat, CSI group members had significantly lower two-month perceived illness-related threat as compared to IM group members. Group assignment did not predict perceived illness-related threat at one or two months for participants with low or mean baseline perceived threat ( $p > .05$ ).

In sum, immediately after the intervention (at the two month assessment), significant or moderated effects of the CSI (vs. IM) were apparent on all four hypothesized mediator variables. First, CSI (vs. IM) participants reported higher one-month approach-oriented coping. Additionally, among participants who had low or mean baseline scores on the relevant moderator variable, CSI (vs. IM) group members reported higher one- and two-month self-efficacy and higher two-month approach-oriented coping. Among participants who reported high perceived illness-related threat at baseline, CSI (vs. IM) group members demonstrated lower perceived one-month and two-month threat. Similarly, among participants with very high self-reported baseline loneliness ( $\bar{x} + 2SD$ ), CSI (vs. IM) group members had significantly lower two-month loneliness. There was no significant effect of group assignment on one-month loneliness.

## **Aim 2. Mediators of the Impact of Group Assignment on Two-Month Outcomes**

Displayed in table 16, results of bootstrapping analyses assessed whether changes in loneliness, self-efficacy, approach-oriented coping, or illness perceptions from baseline to one month (mid-intervention) mediated the association between group assignment and two-month (immediately post-intervention) outcomes. Additionally, the relationship between group assignment, mediators and outcomes is depicted in Figure 20.

Assignment to the CSI (vs. IM) group was associated with greater increases from baseline to one month in self-efficacy (SEDMC), which in turn predicted improvements in: (1) two-month medical regimen adherence (MOS GAS; CSI indirect effect  $\beta = 11.42$ ,  $p = .04$ , 95% CI [.74, 22.10]); (2) physical health-related quality of life (SF-12 PCS; CSI indirect effect  $\beta = 4.72$ ,  $p = .04$ , 95% CI [.16, 9.28]); and (3) anxiety (BSI-ANX; CSI indirect effect  $\beta = -.40$ ,  $p = .03$ , 95% CI [-.75, -.04]). Additionally, assignment to the CSI (vs. IM) group was associated with greater increases from baseline to one month in approach-oriented coping (COPE and EACS), which in turn predicted greater two-month benefit finding (BFSC; CSI indirect effect  $\beta = 1.31$ ,  $p = .04$ , 95% CI [.04, 2.58]).

There was a significant indirect effect of the interaction between group assignment (CSI) and change from baseline to one month in perceived illness-related threat (BIPQ) in predicting two-month adherence (MOS GAS;  $\beta = .26$ ,  $p = .04$ ), indicating that whether or not change from baseline to one month in perceived threat mediated the association between group assignment and two-month adherence was moderated by level of baseline perceived threat. Thus, the mediation model was conducted separately at low (each participants' BIPQ total score -  $\bar{x}$  -  $SD$ ), mean (BIPQ total score -  $\bar{x}$ ), and high (BIPQ total score -  $\bar{x}$  +  $SD$ ) levels of perceived threat at baseline. Results indicate that after transforming participants' scores to reflect high perceived

illness-related threat at baseline, change from baseline to one month in perceived threat mediated the association between group assignment and two-month adherence (CSI indirect effect  $\beta = 7.06$ ,  $p = .04$ , 95% CI [.24, 13.87]). Perceived threat did not mediate the association between group assignment and adherence when participants' scores were transformed to reflect low or mean levels of perceived illness-related threat (CSI indirect effect  $p > .05$ ). Notably, when the modified version of the BIPQ was used in these analyses, the indirect effect of group assignment was not significant, nor was the indirect interaction effect.

No other tests of mediation were significant. First, change from baseline to one month in self-efficacy (SEDMC) did not mediate the association between group assignment and two-month medical transition readiness (TRAQ), illness-related benefit finding (BFSC), or two-month depression (CES-D). Second, change in approach-oriented coping (COPE and EACS) from baseline to one month did not mediate the association between group assignment and two-month medical transition readiness (TRAQ), adherence (MOS-GAS), physical health-related quality of life (PCS), anxiety (BSI-ANX), or depression (CES-D). Third, change from baseline to one month in perceived illness-related threat (BIPQ) did not mediate the association between group assignment and two-month medical transition readiness (TRAQ), benefit finding (BFSC), physical health-related quality of life (PCS), depression (CES-D), or anxiety (BSI-ANX). Finally, change in loneliness (ULS) from baseline to one month did not mediate the association between group assignment and any of the six outcomes (TRAQ, MOS-GAS, PCS, BFSC, CES-D, or BSI-ANX).

### **Aim 3. Impact of the Intervention on Medical Transition Behavior**

At two months, four of the seven CSI participants and one out of eight IM group participants who reported seeing a pediatric generalist physician at baseline and who completed



the study had transitioned to an adult generalist physician. Among study completers who reported that they saw a pediatric disease specialist at baseline, one of seven of CSI participants and no IM participants (0/12) reported having transitioned to an adult disease specialist at two months, and an additional two of seven CSI participants and one of 12 IM participants reported that they no longer saw a pediatric specialist but had not yet identified an adult disease specialist to whom they planned to transfer. Of the total number of study completers who reported seeing a pediatric generalist and/or specialist physician at baseline (as discussed above), at two months significantly more CSI participants (6/10) than IM group participants (2/13) had taken steps towards completing the transition to adult medical care ( $\chi^2[22] = 4.96, p = .03$ ).

### **Discussion**

The Coping Skills Intervention (CSI) group is among the first psychosocial interventions specifically intended to promote indicators of medical transition readiness in young adults with chronic illness in a college/university setting. To our knowledge it is one of five existing interventions for adolescents or young adults with chronic illness to provide an intervention in line with Positive Youth Development theory that is rigorously evaluated in a randomized controlled trial (Daley, 1992; Powers, Turner, Eliison, & Matuszewski, 2001; Rhee, Belyea, Hunt, & Brasch, 2011; Shah, Peat, Mazurski, Wang, Sindhusake, Bruce, ... & Gibson, 2001). Furthermore, the current study is only the second of these to include participants with a variety of chronic illnesses, and the first of these to include young adult participants over the age of 18.

The CSI group did not significantly influence depressive symptoms, quality of life, medical adherence or disease-related skills and knowledge during the intervention period. In contrast, the intervention significantly and positively impacted participants' illness-related benefit finding, illness perceptions (i.e., perceived illness-related threat), confidence (i.e., self-

efficacy for disease management), competence (i.e., approach-oriented coping), and social connection (i.e., loneliness) for those with relatively poor adjustment per baseline values of these variables. Regarding hypothesized intervention effects on outcomes, at low (vs. mean or high) baseline anxiety, intervention (vs. control) group participants demonstrated greater decreases in anxiety over time. Exploratory analyses suggest that the CSI positively influenced medical transition intentions and self-reported behavior, in that at two months (immediately post-intervention), CSI (vs. IM) participants were significantly more likely to have discontinued care with their pediatric medical providers and/or identified or initiated care with an equivalent adult medical care provider (e.g., transitioned from a pediatric to adult disease specialist). Potential explanations for the current findings, strengths and limitations of the current study, and directions for future clinical interventions and research are discussed below.

### **Participant Characteristics**

**Demographic profile.** Nearly all participants were college students at the time of study participation. As compared to the demographic profile of all undergraduates at the university in fall 2016, females (76% of sample vs. 56% of undergraduates) and non-Latino whites (46% of sample vs. 27% of undergraduates) were overrepresented among study participants (UCLA Office of Academic Planning and Budget, 2017). Latino/Hispanic (17% of sample vs. 22% of undergraduates) and Asian (22% of sample vs. 29% of undergraduates) students were somewhat underrepresented (UCLA Office of Academic Planning and Budget, 2017). The median family income of undergraduate students in the class of 2013 at the university was \$104,900 (Chetty, Friedman, Saez, Turner, & Yagan, 2017), which suggests that participants in the current sample were somewhat more economically disadvantaged (only 37% reported family income of at least \$100,000) as compared to the total undergraduate population. Finally, in spring 2016, 32% of

enrolled undergraduates were first-generation college students (UCLA Student Affairs, 2017) as compared to 25% of the current sample. Published data about the percentage of undergraduate students at the university with chronic illness is not available, which limits generalizability of findings to the full population of undergraduates with chronic illness at the university.

Compared to a nationally representative sample of 230 young adults with chronic illness from the National Longitudinal Sample of Adolescent Health (Add Health), females (58.1% of Add Health sample) and Hispanics (9.5% of Add Health sample) were overrepresented, which and non-Hispanic whites (76.4% of Add Health sample) and non-Hispanic Blacks (11.0 percent of Add Health sample) were underrepresented, as were participants whose most highly-educated parent had less than a college degree (72.2% of Add Health sample; Maslow, Haydon, McRee, & Halpern, 2012). Due to these demographic differences, current findings should be generalized to other populations of young adults with chronic illness with caution.

**Illness characteristics.** The 63 participants who completed the baseline assessment reported 38 different included chronic disease diagnoses. Despite having a wide range of diseases, nearly all participants reported benefits of connecting with peers with chronic illness. This findings suggests both that it is not necessary that participants have the same diagnosis in order to promote social connection in a group-based intervention and that participants learned that they can relate to peers with chronic illness regardless of their specific diagnosis. The CSI might be particularly beneficial for young adults with relatively rare diagnoses who would have difficulty finding a comparable resource for those with their specific diagnosis. Notably, in the current study, 74% ( $n = 28/38$ ) of included disease diagnoses were reported by only one participant. Furthermore, this finding indicates that limiting the current study to participants with a single illness (e.g., diabetes) likely would have compromised the feasibility of achieving an

adequate sample size. Thus, a non-categorical approach to identifying chronic diseases in college students is recommended for future research and clinical intervention.

Data from the National College Health Assessment Undergraduate Reference Group in Spring 2016 suggest that approximately 25% of U.S. undergraduates report at least one psychiatric diagnosis (Mcbride, Van Oman, Wera, Leino, & American College Health Association Benchmarking Committee, 2016). In the current sample, 33% of participants reported at least one psychiatric diagnosis at baseline, most commonly an anxiety or depressive disorder. These data are in line with research suggesting that children and adults with chronic illness report higher rates of psychological distress and disorders as compared to healthy peers (Lavigne & Faier-Routman, 1992; Loftus, Guerin, Yu, Wu, Yang, Chao, & Mulani, 2011; Pinquart & Shen, 2011; Tai, Buchanan, Townsend, Fairley, Moore, & Richardson, 2012).

**Illness-related service use.** Though past studies have examined characteristics of college students with chronic illness (Barakat & Wodka, 2006; Bishop, 2005; Wdowik, Kendall, Harris, & Auld, 2001; Wodka & Barakat, 2007), few have set out empirically to examine university-based or local illness-related service use in this population (e.g., Herts et al., 2014; Royster, & Marshall, 2008). As compared to a prior sample of college freshman with chronic illness at a smaller private university in the northeast (Herts et al., 2014), participants in the current sample were more likely to have a local physician (generalist or specialist; over 50% in the current sample vs. 13% in the prior sample) and to use the university disability support services program (47% in the current sample vs. 13% in the prior sample). Notably, students at the large public university from which the current sample was drawn are more commonly commuters (55% of undergraduates live off campus) as compared to the small private university from which the prior sample was drawn (24% of undergraduates live off campus; U.S. News & World Report L.P.,

2017). Thus, it is possible that participants in the current sample were more likely to have local medical care providers prior to enrolling at the university. Similarly, students who live in the same city as their university might have more knowledge about the services the university offers (i.e., disability support services) prior to enrollment. In both cases, knowledge about local services prior to enrollment for commuters might help explain the discrepancies seen in these two studies.

Data from the 2010 Survey on the Utilization of Student Health Services demonstrated that 43% of eligible college students at 68 U.S. public institutions use university health services, inclusive of physical and mental health-related services (McBride et al., 2016). Data from the Center for Collegiate Mental Health 2015 Annual Report demonstrated that on average, 9.5% of college students across 93 U.S. institutions used university counseling center services in 2014 (Center for Collegiate Mental Health, 2016). A larger percentage of students in the current sample used both college health services (54%) and psychological services (27%) as compared to students in national samples (Center for Collegiate Mental Health, 2016; McBride et al., 2016). Published data on use of student health and psychological services specific to the university from which the current sample was drawn are not currently available. However, national findings suggest that the current sample evidenced a greater need for physical and mental health care as compared to healthy peers.

**Illness-related adjustment.** At baseline, participants in the current sample reported similar disease-related skills and knowledge (TRAQ  $\bar{x}$  in current sample = 4.07 vs. 3.99 in comparison sample) as compared to other samples of young adults over age 18 with chronic illness (Wood et al., 2014). Baseline illness-related benefit finding was also similar in the current sample (BFSC  $\bar{x}$  = 33.74) as compared to findings from studies of children and adolescents with

cancer (BFSC  $\bar{x}$  = 33.30, Michel, Taylor, Absolom, & Eiser, 2010; BFSC  $\bar{x}$  = 37.35, Phipps et al., 2007). Participants' baseline reports of adherence to medical recommendations (MOS GAS  $\bar{x}$  = 62.95) were lower than adults in the general population (MOS GAS  $\bar{x}$  = 74; Sherbourne, Hays, Ordway, DiMatteo, & Kravitz, 1992). This finding aligns with findings suggesting that 50% of more of AYAs with chronic illness are non-adherent to treatment (Kondryn, Edmondson, Hill, & Eden, 2011; Walsh, Cutrona, Kavanagh, Crosby, Malone, Lobner, & Bundy, 2014).

**Psychosocial Adjustment.** Participants reported similar baseline physical health-related quality of life on the SF-12 Physical Component Summary scale (PCS  $\bar{x}$  = 46.26) as compared to samples in other studies of AYAs with chronic illness (PCS  $\bar{x}$  = 48.77 in AYA cancer survivors, Kazak, DeRosa, Schwartz, Hobbie, Carlson, Ittenbach...& Ginsberg, 2010; PCS  $\bar{x}$  = 49.58 in adolescents with epilepsy, Asato, Manjunath, Sheth, Phelps, Wheless, Hovinga...& Zingaro, 2009). The mean baseline score in the current sample on the CES-D (22.28) was above the clinical cutoff for significant depressive symptoms (cutoff = 16; Radloff, 1977). Similarly, the mean baseline score on the BSI-ANX (1.07) fell above the mean for a non-patient adult sample ( $\bar{x}$  = .35 *SD* .45; Derogatis & Melisaratos, 1983). These findings are consistent with data suggesting that participants in the current sample have higher rates of psychiatric diagnoses as compared to the national population of undergraduates (McBride et al., 2016).

**Social connection.** The full-scale UCLA Loneliness Scale (ULS) has  $\bar{x}$  = 40 and *SD* = 9.5 in healthy U.S. college students (Russell, 1996). The baseline  $\bar{x}$  on the 10-item ULS used in the current sample was 24.10, suggesting that the full-scale  $\bar{x}$  would be 48.2. This finding is in line with other studies of AYAs with chronic illness demonstrating above-average self-reported loneliness on the ULS in as compared to healthy AYAs (Herts et al., 2014; Maslow et al., 2013). Furthermore, nearly one third of participants in the current study reported that they did not know

any peers with chronic illness. Similarly, in a prior study of college students with either a physical or psychiatric chronic illness, 57% of participants reported no known peers with chronic illness (Herts et al., 2014). Taken together, these findings indicate that it is not unusual for college students with chronic illness to not know any peers with chronic illness, which could contribute to observed high rates of loneliness among participants in both studies.

**Confidence.** At baseline, participants reported slightly higher confidence (i.e., self-efficacy for disease management; SEDMC  $\bar{x} = 6.65$   $SD = 1.77$ ) as compared to adult participants in a psychometric study of the Self-Efficacy for Chronic Disease 6-Item Scale ( $\bar{x} = 5.17$ ,  $SD = 2.22$ ; Lorig et al., 2001). Participants in the psychometric sample (vs. the current sample) were significantly older (mean age = 62.2 years) and on average, had not completed college (mean years of education = 14.3; Lorig et al., 2001). One possible explanation for the relatively high reported self-efficacy in the present sample is that participants were admitted to and enrolled in a highly competitive public university, perhaps a marker of pre-existing personal resources or an achievement that might bolster self-efficacy in their ability to overcome illness-related obstacles to educational success.

Comparison to reports of self-efficacy in other AYAs with chronic illness is difficult due to the fact that few other studies in this age group employ the Self-Efficacy for Disease Management 6-Item Scale or other validated self-efficacy scales that are not disease specific. Indeed, a systematic review of correlates of self-efficacy for disease management (SEDM) in AYA cancer survivors found that few studies used validated measures of SEDM and instead used author-constructed or author-adapted measures (Herts, Khaled, & Stanton, 2017). In light of the positive findings of the current study with regard to self-efficacy, future intervention trials

and other studies of participants with chronic illness could employ the SEDM 6-Item Scale and/or the Chronic Diseases Self-Efficacy Scales (Lorig et al., 1996; 2001) used in this study.

**Competence.** Mean scores at each assessment (T1  $\bar{x} = 2.72$ , T2  $\bar{x} = 2.93$ , T3  $\bar{x} = 2.93$ ) were comparable to means on the COPE and EAC scales measuring approach-oriented coping strategies in healthy undergraduate samples (Austenfeld & Stanton, 2004; Stanton et al., 2000; Yanez, Stanton, Hoyt, Tennen, & Lechner, 2011). This finding indicates that despite greater health-related challenges, young adults with chronic illness in the current sample engaged in similar levels of approach-oriented coping strategies as compared to healthy peers. This is consistent with findings in other samples of adults with chronic illness that also demonstrate comparable means on the COPE and EACs to the aforementioned healthy undergraduate samples. For example, sample means were comparable to those in a sample of young adult men with testicular cancer (approach-oriented coping  $\bar{x} = 2.85$ ; Hoyt, Gamarel, Saigal, & Stanton, 2016), and in a sample of young to middle age female adult cancer survivors (emotional processing  $\bar{x} = 2.96$ , emotional expression  $\bar{x} = 2.97$ ; Cho, Park, & Blank, 2013).

**Illness perceptions.** Mean baseline reports of perceived illness-related threat (i.e., BIPQ) in the current sample (BIPQ  $\bar{x} = 42.61$ ,  $SD = 14.23$ ) were similar to scores in a study of young adult men (BIPQ  $\bar{x} = 41.2$ ,  $SD = 11.8$ ) and women (BIPQ  $\bar{x} = 44.2$ ,  $SD = 7.7$ ) with type 1 diabetes (Kibbey, Speight, Wong, Smith, & Teede, 2013). Though more than forty studies have examined the full scale BIPQ in patients with chronic illness (Broadbent et al., 2015), only the study by Kibbey et al. (2013) has done so in young adults, thus precluding further comparisons.

In sum, compared to nationally representative samples, participants in the current sample were not demographically representative of young adults with chronic illness, reported higher rates of psychiatric disorders as compared to young adults, and were more likely to use college



health and psychological services as compared to undergraduates. Participants in the current sample reported clinically elevated levels of depressive and anxiety symptoms, above average levels of perceived loneliness, and a low rate of medical regimen adherence. Comparison of self-efficacy in the current sample vs. other samples of AYAs with chronic illness was limited by widespread use of author-constructed or author-adapted scales in other studies. Finally, as compared to samples of other AYAs and adults with chronic illness, participants in the current sample reported comparable baseline levels of disease-related skills and knowledge, illness-related benefit finding, physical health-related quality of life, approach-oriented coping, and perceived illness-related threat. Despite demographic differences as compared to a national sample of young adults with chronic illness, overall, participants in the current sample evidenced similar levels of psychosocial and illness-related adjustment at baseline as compared to other sample of AYAs with chronic illness. This suggests that current findings may be cautiously generalized to other groups of AYAs with chronic illness.

### **Intervention Effects on SMART-Congruent Indicators of Medical Transition Readiness**

The CSI (vs. the IM condition) had mixed effects on measures assessing two SMART-congruent indicators of medical transition readiness, psychosocial and illness-related adjustment. First, participants in the CSI (vs. IM) condition reported significantly greater improvements in benefit finding at two months. Additionally, in contrast to hypothesis, the intervention significantly reduced anxiety symptoms only for participants who entered with relatively low baseline anxiety. Other important indicators psychosocial adjustment (i.e., depressive symptoms and physical health-related quality of life) and illness-related adjustment (i.e., medical regimen adherence) did not improve significantly in response to the CSI relative to the IM condition.

Notably, the intervention also failed to improve a measure of disease-related skills and knowledge (i.e., TRAQ), a SMART construct that is more commonly assessed as compared to the other indicators of medical transition readiness measured in the current study (Schwartz et al., 2011). This finding stands in contrast to hypothesis and to findings from a quantitative program evaluation of TALC (Maslow et al., 2013). Specifically, TALC participants evidenced significant increases in TRAQ self-advocacy skills over the intervention period (Maslow et al., 2013). Though participants in both groups in the current study demonstrated small increases in mean TRAQ scores over the two-month intervention period, these changes were not statistically significant, nor did group assignment predict changes in disease-related skills and knowledge over time.

One possible reason for the observed discrepancies between findings from TALC and from the present study is that CSI participants were older at study entry. Specifically, TALC participants had a mean age of 15.4 years (Maslow et al., 2013), whereas participants in the current study were on average 19.81 years old. TRAQ scores are significantly associated with older age in prior studies of AYAs with chronic illness (Wood et al., 2014), as well as in the current study ( $r = .32, p = .01$ ). The TALC program evaluation used a previous version of the TRAQ that had separate scales for health care self-advocacy and chronic condition management skills (Maslow et al., 2013; Sawicki, Lukens-Bull, Yin, Demars, Huang, Livingood...& Wood, 2011). On both scales, TALC participants reported lower TRAQ scores at study entry (TALC TRAQ self-advocacy  $\bar{x} = 3.8, SD = .20$ , TALC TRAQ chronic condition management  $\bar{x} = 3.1, SD = .30$ ; Maslow et al., 2013) as compared to participants in the current study (TRAQ full scale  $\bar{x} = 4.07, SD = .56$ ), which is in line with an expected increase in scores on the TRAQ with older age. Given that participants in the current study began with higher TRAQ scores, there may have

been a ceiling effect that resulted in less room for improvement on this scale over time.

Additionally, the TALC intervention spanned ten months and did not include comparison with a control group, suggesting that the observed changes in TRAQ scores may have been due to normal developmental change over time with increasing age or other factors.

The CSI (vs. the IM) had positive effects on measures assessing four other SMART-congruent indicators of medical transition readiness, i.e., self-efficacy for disease management, disease management skills in the form of engagement in approach-oriented coping skills, illness perceptions, and social connection. In line with our hypotheses, the intervention effects on these putative mediators were greater at relatively poor levels of baseline adjustment (e.g., high perceived illness-related threat, high loneliness, low self-efficacy, and low reported use of approach-oriented coping skills).

Notably, the CSI was carried out over a shorter period of time (two months) as compared to other successful psychosocial interventions for AYAs with chronic illness, which are delivered over at least three months (Sansom-Daley et al., 2012). That the two-month assessment revealed a positive impact on putative mediators of the intervention effects on these outcomes suggests that a later assessment (i.e., a minimum of three months) might reveal a positive impact of the CSI on depressive symptoms, quality of life, and anxiety for those with high levels of baseline distress.

### **Intervention Impact on Medical Transition Behavior**

Among study completers who reported seeing a pediatric generalist or specialist physician at baseline, at two months significantly more CSI participants (6/10) as compared to IM group participants (2/13) had left their pediatric medical providers, and most had initiated care with adult medical care providers. Notably, two of the CSI participants and one IM

participant who reported changes had not been connected to an adult disease specialist at two months. Two months is a short time frame in which to identify, schedule, and attend an appointment with a new specialist. A later assessment would be needed to determine whether these participants were able to establish care with an adult disease specialist within a reasonable period (i.e., six to 12 months) and without experiencing any negative medical outcomes attributable to a gap in care. Recent reviews of the impact of transition interventions on observed transfer from pediatric to adult healthcare (e.g., clinic attendance rates) have found that most successful existing interventions involve patient education that takes place in the context of a specialty medical clinic for patients with diabetes (Chu, Maslow, von Isenburg, & Chung, 2015; Crowley et al., 2011). Current data suggest that psychosocial interventions such as the CSI group also hold promise for promoting the transition from pediatric to adult medical care.

### **Strengths and Limitations**

The current study has numerous strengths that bolster its contribution to the literature. First, this research is consistent with the Maternal and Child Health Bureau's attention to a national transition outcome (McManus et al., 2013). Second, the study design was driven by a conceptual model developed by drawing from existing research and theory in childhood chronic illness, positive youth development and medical transitions, which allows for evaluation and refinement of the model. Third, to our knowledge the intervention was the first to evaluate the life skills component of a PYD program for AYAs with chronic illness through a randomized controlled trial, which allowed for distinguishing outcomes from normal developmental change over time. Fourth, the intervention was among the first psychosocial interventions in this population to employ evidence-based practices (i.e., teaching of skills from cognitive behavioral therapy) tailored to target the preparedness for and completion of the transition from pediatric to

adult medical care. Fifth, the current study allowed for the evaluation of the impact of the intervention on multiple aspects of medical transition readiness identified by the SMART model in addition to the commonly examined construct of disease-related skills and knowledge. Sixth, the longitudinal study design allowed for evaluation of mediators of the impact of the intervention on outcomes as well as moderators of the impact of the intervention over time. Identification of mediators and moderators of change is important because it allows for optimization of interventions in future research and clinical practice (Kazdin, 2007).

Despite considerable strengths, current findings should be evaluated in light of important limitations. First, participants were not demographically representative of the national population of young adults with chronic illness, and as such, results should be generalized to young adults with chronic illness in other settings with caution. Second, clinical psychology doctoral students conducted the intervention groups, which raises a question about the feasibility of implementing the intervention outside of academic settings or in colleges or universities that do not have sufficient resources to train well-prepared group leaders. Third, it was not feasible to include objective measures of physical outcomes or of the transition from pediatric to adult medical care (e.g., adult clinic attendance), which awaits further research. Fourth, the control group received a relatively inactive intervention involving weekly emails with information about medical transition readiness corresponding to the topics addressed in the CSI, limiting comparison with other successful psychosocial interventions. Fifth, the analysis of medical transition behavior was conducted on cell sizes that included a small number of participants ( $n = 2$  to 13). As such, future research in larger samples is needed to replicate and confirm current findings about the impact of the CSI on medical transition behavior.

### **Clinical Implications**

In the current sample, over 40% of students did not have a primary care or specialty physician in the same city as their college. Greater distance from medical care might lead to some of the negative health outcomes commonly observed among young adults with chronic illness (e.g., increased use of emergency health services; Schwartz et al., 2011), particularly if the students' medical providers are located out of state. Notably, 46% of students in the current study did not use the university's health services, and less than half were registered with the Office for Students with Disabilities. Furthermore, the majority of participants in the current study did not use psychological services at the university, although they evidenced elevated rates of depression, anxiety, and psychiatric diagnoses as compared to healthy peers in other samples. It is important for student health, counseling and disability services to provide targeted outreach activities for undergraduate students with chronic illness in order to facilitate connections to local medical and mental health care providers they can turn to in times of need.

Findings suggest that undergraduates with chronic illness report relatively high rates of loneliness as compared to healthy peers. Nearly all participants in the current study qualitatively reported benefits of engaging with other young adults with chronic illness, which suggests that student counseling centers should offer group therapy services like the CSI that are specific to this population. Indeed, current findings support the feasibility and acceptability of conducting cognitive behavioral group therapy interventions for AYAs with chronic illness on college campuses. Furthermore, the impact of the CSI group was relatively uniform among illness-specific (e.g., perceived illness-related threat) and general (e.g., loneliness) mediators and outcomes. This suggests that particularly with extended intervention, the CSI holds promise for improving diverse indicators of psychosocial adjustment relevant to the successful transition to adulthood in AYAs with chronic illness.

The Chronic Illness Initiative (CII) at DePaul University represents a novel program founded in 2003 that was designed to support undergraduates with chronic illness (Royster & Marshall, 2008). This program, which has since been discontinued, offers a model for providing comprehensive psychosocial and educational services to undergraduates with chronic illness. Supportive services included a special faculty advisor who advocated for students' needs with faculty, the university financial aid office, and community organizations with services specific to individual's needs; support groups; and special academic and social programming, including a buddy program that linked advanced CII students with new students. The CII program also offered distance education options for students who were homebound for part or all of their university career. Albeit in an uncontrolled and nonrandomized study, preliminary findings indicated that CII students were significantly more likely to continue to their second academic year as compared to non-CII students with chronic illness (Royster & Marshall, 2008). Importantly, the CII was integrated into the administrative and budget structures of DePaul University, allowing for a sustained approach to supporting students with chronic illness. Ideally, the CSI group intervention would be offered as one of many college/university services to support all aspects of transitioning to adulthood for AYAs with chronic illness. The reality of limited funding of state colleges and universities makes it imperative for future studies of programs like the CII to provide components tests in order to improve efficacy and feasibility.

### **Directions for Future Research**

Future research should include comparison of the CSI with active controls (e.g., a CBT group for anxiety and depression) in order to determine whether the intervention offers benefits to AYAs with chronic illness beyond those available through similar interventions commonly offered by college counseling centers. Additionally, it will be important for future research to

include objective assessments of health and the transition from pediatric to adult medical care, in order to allow for comparison with self-report measures of illness-related distress and transition outcomes. Furthermore, future studies should examine whether individuals with a variety of professional backgrounds (e.g., graduate students outside the field of clinical psychology, social workers, nurses) can be trained in implementation of the intervention manual in order to increase feasibility in varied settings.

As evidenced by the intervention's positive impact on strengths fostered in PYD programs (i.e., competence, confidence, social connection), research is needed to determine whether adding the other core components of PYD programs (i.e., leadership opportunities and sustained adult-youth mentoring relationships) significantly heightens the impact of the intervention on psychosocial adjustment and adaptation to illness. Qualitative feedback from participants requesting an increase in the intensity and reach of the intervention suggests that it would be acceptable to: 1) increase the length of the intervention in order to allow for sustained mentoring relationships between group leaders and participants, as well as sustained peer mentoring relationships between participants; and 2) increase the intensity of the intervention by providing leadership opportunities outside of the intervention group sessions.

The Chronic Illness Peer Support (ChIPS) program in Australia is a comprehensive PYD program for AYAs with a variety of chronic illnesses that offers a model for future research aiming to incorporate both the current CBT-based life skills intervention and the other core components of PYD (Olsson, Boyce, Toumbourou, & Sawyer, 2005). ChIPS consists of an eight-week peer support group co-led by a health professional (e.g., nurse, social worker). Like the CSI group intervention, ChIPS support group sessions are held weekly for 90 minutes. After completion of the ChIPS support group, AYAs are eligible to participate in a one-week



leadership training program designed to prepare them to co-lead future support groups. Additionally, AYAs who have completed the support group are invited to participate in ChIP-PERS, an AYA-led ongoing social and recreational program. ChIP-PERS activities have included an annual camp, advocating for other AYAs with chronic illness, and publishing a quarterly newsletter (Olsson et al., 2005). Thus, ChIPS allows for ongoing opportunities for leadership and both peer mentoring (through ChIP-PERS) and adult-youth mentoring (via co-leading support groups). To date, ChIPS has served over 500 AYAs with chronic illness. Participants have qualitatively reported decreased social isolation, and female (but not male) participants have reported increased disease-related knowledge (Olsson et al., 2005). In future studies, CSI group alumni could similarly become eligible to co-lead future CSI groups through a training program. Additionally, CSI group alumni could be invited to participate in sustained leadership and mentoring activities through a program extension like ChIP-PERS. Such studies provide a natural next step in establishing a full components evaluation of a PYD program for AYAs with chronic illness.

## **Conclusions**

The current study is among the first to evaluate the life skills component of a positive youth development program for young adults with chronic illness in a randomized controlled trial. Furthermore, the CSI represents one of the first psychosocial interventions for this population to target medical transition readiness using evidence-based practices from cognitive behavioral therapy. Results demonstrate that the CSI positively impacted several factors indicative of participants' medical transition readiness as well as their likelihood of initiating the transition to adult medical care. Future research and clinical intervention development can build on the current findings by incorporating other core components of PYD, including provision of

leadership opportunities and sustained adult-youth mentoring relationships, and by evaluating the CSI in diverse populations and settings.

Table 7.  
*Coping Skills Intervention (CSI): Curriculum Overview*

Module	Session	PYD Topic	Activities and Skills
1. Thoughts, mood and chronic illness	1	Diagnosis: Illness and identity	Psychoeducation: link between thoughts and mood Expressive writing
	2	Living with illness	Cognitive restructuring: identifying negative and helpful thoughts
	3	Finding silver linings	Cognitive restructuring: strategies for replacing negative thoughts with helpful thoughts
2. Behaviors, mood and chronic illness	4	Health behaviors	Psychoeducation: link between behaviors (emphasis on health behaviors) and mood Relaxation training Behavioral activation
	5	Impact of illness on behaviors	Problem-solving and cognitive restructuring to overcome obstacles to healthy behaviors Behavioral activation
3. Relationships, mood and chronic illness	6	Relationships Talking to others about illness	Psychoeducation: link between relationships and mood Strengthening your social support network Communication skills
	7	Doctor-patient communication	Communication skills Problem-solving and cognitive restructuring to overcome barriers to using communication skills
4. Transition to adult medical care	8	Chronic illness and transitions	Psychoeducation: chronic illness and transitions Identify transition goals and needs Problem-solving and cognitive restructuring to overcome barriers to transition

Table 8.

*Descriptive Statistics for Study Measures and Between-Group (CSI vs. IM) Baseline Differences (Full Sample N = 54 – 63)*

Outcome	Possible Range	Range	CSI		IM		Full Sample		$\alpha$	<i>t</i>	<i>df</i>	<i>p</i>
			<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>				
TRAQ T1	1 to 5	2.75 to 5	4.16	.64	4.00	.58	4.07	.56	.87	-1.13	61	.27
TRAQ T3		2.7 to 4.95	4.27	.43	4.11	.60	4.19	.53	.89			
MOS GAS T1	0 to 100	20 to 100	63.94	23.13	61.89	22.56	62.95	22.69	.85	-.35	60	.73
MOS GAS T3		16 to 100	70.77	19.36	70.14	24.01	70.44	21.69	.92			
PCS T1	0 to 100	20.35 to 62.84	44.39	10.19	48.19	8.28	46.26	9.42	.76	1.60	59	.11
PCS T3		19.38 to 61.95	43.15	11.71	47.34	9.42	45.32	10.70	.81			
CES-D T1	0 to 60	6 to 45	24.43	7.50	20.06	7.17	22.28	7.61	.92	-2.36	61	.02*
CES-D T3		5 to 48	21.63	8.26	19.75	7.57	20.67	7.90	.93			
BSI-ANX T1	0 to 4	0 to 4	1.29	.91	.85	.88	1.07	.91	.86	-1.94	61	.06
BSI-ANX T3		0 to 4	1.21	1.22	.92	.82	1.06	1.03	.92			
BFSC T1	10 to 50	10 to 50	33.03	11.38	34.48	10.61	33.74	10.95	.92	.53	61	.60
BFSC T3			40.37	8.18	36.76	9.16	38.5	8.81	.91			
<b>Mediator</b>												
ULS T1	10 to 40	11 to 39	24.49	7.10	23.70	6.94	24.10	6.98	.91	-.44	61	.66
ULS T2		10 to 40	23.34	6.30	23.75	7.69	23.55	6.98	.92			
ULS T3		10 to 40	24.13	7.02	23.03	8.07	23.57	7.53	.94			
SEDMC T1	0 to 10	2.38 to 9.63	6.37	1.61	6.93	1.90	6.65	1.77	.95	1.26	58	.21
SEDMC T2		1.13 to 10	6.85	1.26	6.55	2.15	6.69	1.77	.96			
SEDMC T3		2.13 to 10	7.40	1.50	7.21	1.93	7.30	1.73	.97			
COPE T1	1 to 4	1.42 to 3.83	2.72	.53	2.72	.67	2.72	.60	.93	-.01	57	.99
COPE T2		1.54 to 3.88	3.00	.44	2.86	.69	2.93	.58	.94			
COPE T3		1.38 to 3.96	3.03	.39	2.84	.78	2.93	.62	.95			
BIPQ T1	0 to 80	5 to 71	47.20	12.02	37.88	14.96	42.61	14.23	.79	-2.72	57	.01*
BIPQ T2		10 to 63	44.71	8.35	39.62	14.95	42.12	12.33	.80			
BIPQ T3		4 to 68	41.26	9.63	37.42	15.05	39.27	12.77	.75			

Note. TRAQ = Transition Readiness Assessment Questionnaire; MOS GAS = Medical Outcomes Study General Adherence Scale; PCS = SF-12 Physical Component Summary Scale; CES-D = Center for Epidemiologic Studies Depression Scale; BSI-ANX = Brief Symptom Inventory –Anxiety subscale; BFSC = Benefit Finding Scale for Children; ULS = UCLA Loneliness Scale; SEDMC = Self-Efficacy for Disease Management Composite score; COPE = COPE and Emotional Approach Coping Scales - Approach-Oriented Coping Scale; BIPQ = Brief Illness Perceptions Questionnaire; *t*-tests were used to calculate group differences in conceptual mediator and outcome variables at baseline; \**p* < .05. \*\**p* < .01.

Table 9.

*Correlations between Outcomes at T1 and T3 with Mediators at T1 and T2 (N = 54 to 63)*

	ULS T1	ULS T2	SEDMC T1	SEDMC T2	COPE T1	COPE T2	BIPQ T1	BIPQ T2
TRAQ T1	-.14	-.12	.34 *	.17	.31 *	.37 *	-.22	-.08
TRAQ T3	-.07	-.15	.10	.20	.15	.34 *	-.02	-.07
MOS-GAS T1	-.18	-.02	.31 *	.18	-.02	-.01	-.29 *	-.16
MOS-GAS T3	-.17	-.14	.13	.31 *	.06	.11	-.21	-.37 *
PCS T1	-.16	-.16	.19	.25	-.02	-.04	-.52 **	-.43 **
PCS T3	-.17	-.20	.36 *	.41 **	.06	.00	-.45 **	-.46 **
BFSC T1	-.11	-.37 **	.43 **	.51 **	.65 **	.50 **	-.26 *	-.27 *
BFSC T3	.06	-.17	.19	.37 *	.51 **	.60 **	-.17	-.17
CES-D T1	.59 **	.39 **	-.54 **	-.34 *	-.07	.03	.44 **	.28 *
CES-D T3	.42 **	.39 **	-.47 **	-.34 *	.07	-.01	.34 *	.33 *
BSI-ANX T1	.51 **	.36 *	-.55 **	-.37 *	-.06	-.01	.48 **	.39 **
BSI-ANX T3	.38 **	.39 **	-.45 **	-.44 **	-.04	-.06	.35 *	.38 **

Note. TRAQ = Transition Readiness Assessment Questionnaire; MOS GAS = Medical Outcomes Study General Adherence Scale; SF-12 PCS = SF-12 Physical Component Summary Scale; CES-D = Center for Epidemiologic Studies Depression Scale; BSI-ANX = Brief Symptom Inventory –Anxiety subscale; BFSC = Benefit Finding Scale for Children; ULS = UCLA Loneliness Scale; SEDMC = Self-Efficacy for Disease Management Composite score; COPE = COPE and Emotional Approach Coping scales - Approach-Oriented Coping scale; BIPQ = Brief Illness Perceptions Questionnaire; \*p < .05. \*\*p < .01.

Table 10.  
*Correlations between Mediators at T1 (N = 63)*

	1	2	3	4
1 ULS T1	—			
2 SEDMC T1	-.51 **	—		
3 COPE T1	-.16	.50 **	—	
4 BIPQ T1	.42 **	-.63 **	-.31 *	—

Note. ULS = UCLA Loneliness Scale; SEDMC = Self-Efficacy for Disease Management Composite score; COPE = COPE and Emotional Approach Coping scales – Approach-Oriented Coping scale; BIPQ = Brief Illness Perceptions Questionnaire; \*p < .05. \*\*p < .01.

Table 11.  
*Correlations between Mediators at T2 (N = 56 – 57)*

	1	2	3	4
1 ULS T2	—			
2 SEDMC T2	-.57 **	—		
3 COPE T2	-.34 *	.61 **	—	
4 BIPQ T2	.52 **	-.75 **	-.45 **	—

Note. ULS = UCLA Loneliness Scale; SEDMC = Self-Efficacy for Disease Management Composite score; COPE = COPE and Emotional Approach Coping scales – Approach-Oriented Coping scale; BIPQ = Brief Illness Perceptions Questionnaire; \*p < .05. \*\*p < .01.

Table 12.  
*Correlations between Mediators at T3 (N = 55 – 56)*

	1	2	3	4
1 ULS T3	—			
2 SEDMC T3	-.56 **	—		
3 COPE T3	-.13	.38 **	—	
4 BIPQ T3	.52 **	-.65 **	-.32 *	—

Note. ULS = UCLA Loneliness Scale; SEDMC = Self-Efficacy for Disease Management Composite score; COPE = COPE and Emotional Approach Coping scales – Approach-Oriented Coping scale; BIPQ = Brief Illness Perceptions Questionnaire; \*p < .05. \*\*p < .01.



Table 13.

*Correlations between Outcomes at T1 (N = 61 – 63)*

	1	2	3	4	5	6
1 TRAQ T1	—					
2 MOS GAS T1	.22	—				
3 PCS T1	-.16	.07	—			
4 BFSC T1	.15	.05	-.13	—		
5 CES-D T1	-.15	-.22	-.26 *	-.18	—	
6 BSI-ANX T1	-.09	-.30 *	-.19	-.18	.65 **	—

Note. TRAQ = Transition Readiness Assessment Questionnaire; MOS GAS = Medical Outcomes Study General Adherence Scale; PCS = SF-12 Physical Component Summary Scale; CES-D = Center for Epidemiologic Studies Depression Scale; BSI-ANX = Brief Symptom Inventory –Anxiety subscale; BFSC = Benefit Finding Scale for Children; \*p < .05. \*\*p < .01.

Table 14.

*Correlations between Outcomes at T3 (N = 54 – 56)*

	1	2	3	4	5	6
1 TRAQ T3	—					
2 MOS GAS T3	.32 *	—				
3 PCS T3	-.25	.13	—			
4 BFSC T3	.20	.07	-.05	—		
5 CES-D T3	-.14	-.27 *	-.27 *	-.14	—	
6 BSI-ANX T3	-.27 *	-.29 *	-.17	-.17	.69 **	—

Note. TRAQ = Transition Readiness Assessment Questionnaire; MOS GAS = Medical Outcomes Study General Adherence Scale; PCS = SF-12 Physical Component Summary Scale; CES-D = Center for Epidemiologic Studies Depression Scale; BSI-ANX = Brief Symptom Inventory –Anxiety subscale; BFSC = Benefit Finding Scale for Children; \*p < .05. \*\*p < .01.

Table 15.

*Demographic Statistics (Full Sample N = 59 – 63)*

	CSI ( <i>n</i> = 32)		IM ( <i>n</i> = 31)		Full Sample		<i>t</i>	<i>df</i>	<i>p</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>			
<b>Age</b>	19.78	1.21	19.84	1.16	19.81	1.18	.19	62	.85
<b>Gender</b>	%	# Participants	%	# Participants	%	# Participants	$\chi^2$	<i>df</i>	<i>p</i>
Female	75.00	24	77.42	24	76.19	47	.02	62	.89
Male	25.00	8	22.58	7	23.81	15			
<b>Annual Family Income</b>	%	# Participants	%	# Participants	%	# Participants	$\chi^2$	<i>df</i>	<i>p</i>
Below \$50,000	28.12	9	29.63	8	26.90	17	.15	58	.93
\$50 – 99,999	34.40	11	29.63	8	30.16	19			
≥ \$100,000	37.50	12	40.74	11	36.51	23			
Not Reported	.00	0	12.90	4	6.35	4			
<b>Race/Ethnicity</b>	%	# Participants	%	# Participants	%	# Participants	$\chi^2$	<i>df</i>	<i>p</i>
White	50.00	16	41.94	13	46.03	29	3.89	62	.27
Latino/Hispanic	21.88	7	12.90	4	17.46	11			
Asian	21.88	7	22.58	7	22.22	14			
Other	6.25	2	22.58	7	14.29	9			
<b>Parent Education</b>	%	# Participants	%	# Participants	%	# Participants	$\chi^2$	<i>df</i>	<i>p</i>
< College Degree	28.12	9	22.58	7	25.40	16	.26	62	.61
≥ College Degree	71.88	23	77.42	24	74.60	47			

Note. CSI = Coping Skills Intervention group; IM = Informational Materials group; *t* and  $\chi^2$  tests were used to calculate differences in demographic variables by group assignment.

Table 16.

*Descriptive Statistics for Current College Students (Full Sample N = 61 – 63)*

<b>Year</b>	<b>CSI (n = 32)</b>		<b>IM (n = 31)</b>		<b>Full Sample</b>		$\chi^2$	<i>df</i>	<i>p</i>
	<b>%</b>	<b># Participants</b>	<b>%</b>	<b># Participants</b>	<b>%</b>	<b># Participants</b>			
Freshman	22.58	7	16.13	5	19.35	12	1.06	62	.79
Sophomore	32.26	10	25.81	8	29.03	18			
Junior	32.26	10	41.94	13	37.1	23			
Senior	12.9	4	16.13	5	14.52	9			
	<b>%</b>	<b># Participants</b>	<b>%</b>	<b># Participants</b>	<b>%</b>	<b># Participants</b>	$\chi^2$	<i>df</i>	<i>p</i>
<b>PCP in same city<sup>a</sup></b>	48.39	15	61.29	19	58.84	34	1.04	33	.31
<b>MD Specialist in same city<sup>a</sup></b>	48.39	15	66.67	20	57.38	35	2.08	34	.15
<b>Registered with Office for Students with Disabilities<sup>b</sup></b>	35.48	11	58.06	18	46.77	29	4.69	28	.10
<b>Uses Health Services<sup>b</sup></b>	56.25	18	51.61	16	53.97	34	.14	33	.71
<b>Uses Psychological Services<sup>b</sup></b>	34.38	11	19.35	6	26.98	17	1.8	16	.18
<b>Uses Support Group<sup>b</sup></b>	9.38	3	0	0	4.76	3			.24 <sup>e</sup>

Note. CSI = Coping Skills Intervention group; IM = Informational Materials group; <sup>a</sup>In the same city as the participant's college or university; <sup>b</sup>Participant uses these services at their college or university; <sup>c</sup>Fisher's Exact test was used to calculate the probability that this variable differed significantly by group;  $\chi^2$  tests were used to calculate differences in college student characteristics by group assignment.

Table 17

Number of Participants with Each Included Chronic Disease Diagnosis by Group (N = 63)

<b>Included Chronic Illness Diagnosis</b>	<b>CSI</b>	<b>Dx Age</b>	<b>IM</b>	<b>Dx Age</b>	<b>Total</b>
<b>Blood Disorders</b>	<b>0</b>		<b>1</b>		<b>1</b>
Idiopathic Thrombocytopenic Purpura	0		1	3	1
<b>Cancers</b>	<b>5</b>		<b>6</b>		<b>11</b>
Acute Lymphoblastic Leukemia	0		1	13	1
Brain Cancer	1	14	0		1
Hodgkin's Lymphoma	3	15, 20, 21	2	14, 20	5
Melanoma	1	13	1	17	2
Osteosarcoma	0		1	17	1
Unspecified	0		1	13	1
<b>Circulatory System Disorders</b>	<b>2</b>		<b>1</b>		<b>3</b>
Heart Disease	0		1	U	1
Hypertension	1	U	0		1
Postural Orthostatic Tachycardia Syndrome	1	16	0		1
<b>Congenital Disorders</b>	<b>2</b>		<b>2</b>		<b>4</b>
Bicuspid Aortic Valve	0		1	3	1
Bilateral Ear Atresia	0		1	0	1
Polycystic Kidney Disease	1	20	0		1
Polycystic Liver Disease	1	U	0		1
<b>Digestive Disorders</b>	<b>6</b>		<b>9</b>		<b>15</b>
Celiac Disease	2	15, 16	3	13, 18, 18	5
Crohn's Disease	1	16	3	18, 21, U	4
Gastroesophageal Reflux Disease	1	U	0		1
Ulcerative Colitis	2	15, 17	3	10, 15, 16	5
<b>Endocrine, Nutritional and Metabolic Disorders</b>	<b>5</b>		<b>6</b>		<b>11</b>
Type 1 Diabetes	2	11, 14	2	7, 9	4
Gilbert's Syndrome	1	11	0		1
Hypothyroidism	1	19	3	16, 18, U	4
Mitochondrial Disease	0		1	U	1
Polycystic Ovarian Syndrome	1	15	0		1
<b>Genitourinary Disorders</b>	<b>3</b>		<b>0</b>		<b>3</b>
Chronic Hydronephrosis	1	16	0		1
Endometriosis	2	14, 15	0		2

Table 17.

*Number of Participants with Each Included Chronic Disease Diagnosis by Group (N = 63; Continued)*

<b>Included Chronic Illness Diagnosis</b>	<b>CSI</b>	<b>Dx Age</b>	<b>IM</b>	<b>Dx Age</b>	<b>Total</b>
<b>Infectious and Parasitic Disorders</b>	<b>3</b>		<b>0</b>		<b>3</b>
Chronic Lyme Disease	2	16, 17	0		2
Hepatitis B	1	18	0		1
<b>Muskuloseletal and Connective Tissue Disorders</b>	<b>6</b>		<b>2</b>		<b>8</b>
Ankylosing Spondylitis	0		1	16	1
Systemic Lupus Erythematosus	3	12, 16, 17	0		3
Mixed Connective Tissue Disease	0		1	17	1
Cervical Facet Joint Syndrome	1	U	0		1
Rheumatoid Arthritis	2	16, 16	0		2
<b>Nervous System Disorders</b>	<b>2</b>		<b>3</b>		<b>5</b>
Chronic Migraines	1	18	1	U	2
Muscular Dystrophy	0		1	6	1
Status Migrainosus	0		1	U	1
Syringomyelia	1	0	0		1
<b>Optic Nerve and Visual Pathway Disorders</b>	<b>1</b>		<b>0</b>		<b>1</b>
Blind in one eye	1	U	0		1
<b>Respiratory Disorders</b>	<b>5</b>		<b>7</b>		<b>12</b>
Asthma	5	U	7	3, U	12
<b>Skin Disorders</b>	<b>1</b>		<b>2</b>		<b>3</b>
Chronic Dermatitis	1	17	0		1
Solar Urticaria	0		1	U	1
Cholinergic Urticaria	0		1	20	1

Note. Participants were not randomized to groups by chronic illness diagnosis due to the small number of participants with each specific diagnosis; CSI = Coping Skills Intervention group. IM = Informational Materials group. Dx age = age at diagnosis. U = unknown/not reported by participant.

Table 18.

*Number of Participants with Each Excluded Physical Comorbidity by Group (N = 9)*

<b>Other Participant-Reported Comorbidities</b>	<b>CSI</b>	<b>IM</b>	<b>Total</b>
<b>Blood Disorders</b>	<b>1</b>	<b>1</b>	<b>2</b>
Anemia	1	0	1
Neutropenia	0	1	1
<b>Digestive Disorders</b>	<b>4</b>	<b>0</b>	<b>4</b>
Gastritis	1	0	1
Irritable Bowel Syndrome	2	0	2
Leaky Gut Syndrome	1	0	1
<b>Immunological Disorders</b>	<b>0</b>	<b>1</b>	<b>1</b>
Antinuclear Antibodies	0	1	1
<b>Muskuloskeletal Disorders</b>	<b>4</b>	<b>0</b>	<b>4</b>
Scapulothoracic Syndrome	1	0	1
Shoulder Bursitis	1	0	1
Shoulder Tendonsis	1	0	1
Myofascial Pain Syndrome	1	0	1
<b>Nervous System Disorders</b>	<b>1</b>	<b>1</b>	<b>2</b>
Cyclic Vomiting Syndrome	0	1	1
Chronic Shoulder Pain	1	0	1
<b>Other</b>	<b>1</b>	<b>2</b>	<b>3</b>
Allergies (hypersensitivity reactions)	0	1	1
Chronic Fatigue Syndrome	0	1	1
Pre-Diabetes	1	0	1

Note. CSI = Coping Skills Intervention group; IM = Informational Materials group; to the greatest extent possible, disorders were grouped based on classifications specified in the 10th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10; World Health Organization, 1992).

Table 19.

*Additional Illness-Related Information by Group at Baseline (Full Sample N = 54 – 63)*

	CSI ( <i>n</i> = 32)			IM ( <i>n</i> = 31)			Full Sample			<i>t</i>	<i>df</i>	<i>p</i>
	<i>n</i>	<i>M</i>	<i>SD</i>	<i>N</i>	<i>M</i>	<i>SD</i>	<i>N</i>	<i>M</i>	<i>SD</i>			
<b>Age at Diagnosis</b>	32	15.16	3.89	28	12.86	5.93	60	14.08	5.04	-1.75	59	.09
<b># Known Peers with CI</b>	30	2.93	3.65	24	2.83	3.54	54	2.89	3.56	-0.1	53	.92
	CSI			IM			Full Sample			$\chi^2$	<i>df</i>	<i>p</i>
	Total <i>n</i>	%	# Participants	Total <i>n</i>	%	# Participants	Total <i>N</i>	%	# Participants			
<b>No Known Peers with CI</b>	30	23.33	7	24	41.67	10	54	31.48	17	2.08	53	.15
<b>Sees General Pediatrician</b>	32	31.25	10	31	29.03	9	63	30.16	19	0.04	62	.85
<b>Sees Pediatric Disease Specialist</b>	32	25	8	31	41.94	13	63	33.33	21	2.03	63	.15

Note. CSI = Coping Skills Intervention group; IM = Informational Materials group; *t* and  $\chi^2$  tests were used to calculate differences in demographic variables by group assignment.



Table 20.

*Number of Participants with Each Psychiatric Diagnosis by Group (N = 21)*

<b>Psychiatric Diagnosis</b>	<b>CSI</b>	<b>IM</b>	<b>Total</b>
<b>Anxiety Disorders</b>	<b>6</b>	<b>5</b>	<b>11</b>
Anxiety	3	4	7
Generalized Anxiety Disorder	3	1	4
<b>Bipolar Disorders</b>	<b>0</b>	<b>1</b>	<b>1</b>
Bipolar I Disorder	0	1	1
<b>Depressive Disorders</b>	<b>9</b>	<b>5</b>	<b>14</b>
Depression	7	5	12
Major Depressive Disorder	1	0	1
Premenstrual Dysphoric Disorder	1	0	1
<b>Eating Disorders</b>	<b>0</b>	<b>2</b>	<b>2</b>
Anorexia	0	1	1
Bulimia	0	1	1
<b>Neurodevelopmental Disorders</b>	<b>0</b>	<b>2</b>	<b>2</b>
Attention-Deficit/Hyperactivity Disorder	0	2	2
<b>Obsessive-Compulsive and Related Disorders</b>	<b>0</b>	<b>3</b>	<b>3</b>
Body Dysmorphic Disorder	0	1	1
Obsessive Compulsive Disorder	0	2	2
<b>Sleep-Wake Disorders</b>	<b>0</b>	<b>1</b>	<b>1</b>
Insomnia Disorder	0	1	1
<b>Trauma- and Stressor-Related Disorders</b>	<b>1</b>	<b>0</b>	<b>1</b>
Post-Traumatic Stress Disorder	1	0	1

Note. CSI = Coping Skills Intervention group; IM = Informational Materials group; disorders were grouped based on classifications specified in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5; American Psychiatric Association, 2013).

Table 21.  
*Main Effects of Group Assignment on Mediators and Outcomes (N = 63)*

Outcome	CSI $\beta$	SE	<i>P</i>	Interaction	SE	<i>p</i>	<i>R</i> <sup>2</sup>	$\chi^2$	df
TRAQ T3 M1	.11	.11	.31				.45	31.50	3
TRAQ T3 M2	-.05	.76	.95	.16	.79	.84	.45	31.50	4
MOS GAS T3 M1	<.01	.13	1.00				.22	13.41	3
MOS GAS T3 M2	-.05	.36	.89	.06	.39	.88	.22	13.43	4
PCS T3 M1	.02	.08	.81				.67	59.72	3
PCS T3 M2	.10	.41	.80	-.08	.40	.84	.67	59.76	4
CES-D T3 M1	-.08	.12	.51				.34	22.28	2
CES-D T3 M2	-.02	.37	.95	-.06	.42	.88	.34	22.30	3
BSI-ANX T3 M1	-.08	.10	.42				.54	42.97	3
BSI-ANX T3 M2	-.29	.14	.04*	.35	.18	.05*	.57	46.61	4
BFSC T3 M1	.22	.10	.03*				.49	39.22	3
BFSC T3 M2	.07	.31	.82	.16	.31	.61	.49	39.48	4
Mediator	CSI $\beta$	SE	<i>P</i>	Interaction	SE	<i>p</i>	<i>R</i> <sup>2</sup>	$\chi^2$	df
ULS T2 M1	-.09	.10	.38				.43	32.41	3
ULS T2 M2	.13	.37	.71	-.25	.38	.52	.44	32.83	4
ULS T3 M1	-.03	.12	.82				.33	22.54	3
ULS T3 M2	.77	.38	.04*	-.86	.39	.03*	.38	26.86	4
SEDMC T2 M1	.24	.08	<.01**				.62	53.09	3
SEDMC T2 M2	1.18	.31	<.01**	-.96	.31	<.01**	.67	61.49	4
SEDMC T3 M1	.25	.09	<.01**				.58	45.65	3
SEDMC T3 M2	1.12	.34	<.01**	-.90	.34	.01*	.61	51.94	4
Approach T2 M1	1.74	.09	.05*				.59	49.78	3
Approach T2 M2	.84	.39	.03*	-.69	.39	.08	.62	52.73	4
Approach T3 M1	.20	.09	.03*				.52	39.15	3
Approach T3 M2	1.19	.42	.01*	-1.03	.44	.02*	.56	44.29	4
BIPQ T2 M1	-.10	.08	.18				.72	71.72	3
BIPQ T2 M2	.72	.24	<.01**	-.92	.26	<.01**	.76	82.89	4
BIPQ T3 M1	-.14	.08	.09				.66	60.33	3
BIPQ T3 M2	.53	.28	.06	-.75	.30	.01*	.69	66.22	4

Note. All models have RMSEA < .01, SRMR < .08, CFI = 1.00, and  $\chi^2 p = \leq .01$ ; M1 = Model 1, which controls for T1 outcome and T1 depression; M2 = Model 2, which includes interaction between CSI and T1 outcome, as well as controls for T1 outcome and T1 depressive symptoms; TRAQ = Transition Readiness Assessment Questionnaire; MOS GAS = Medical Outcomes Study General Adherence Scale; PCS = SF-12 Physical Component Summary Scale; CES-D = Center for Epidemiologic Studies Depression Scale; BSI-ANX = Brief Symptom Inventory – Anxiety subscale; BFSC = Benefit Finding Scale for Children; ULS = UCLA Loneliness Scale; SEDMC = Self-Efficacy for Disease Management Composite score; Approach = COPE and Emotional Approach Coping Scales - Approach-Oriented Coping Scale; BIPQ = Brief Illness Perceptions Questionnaire; \**p* < .05. \*\**p* < .01.

Table 22.

*Mediators of the Association between CSI and Two-Month Outcomes (N = 63)*

<b>Outcome</b>	<b>Mediator</b>	<b>a</b>	<b>p</b>	<b>b</b>	<b>p</b>	<b>c</b>	<b>p</b>	<b>a x b</b>	<b>p</b>	<b>95% CI</b>	<b>c'</b>	<b>p</b>
MOS GAS T3	SEDM T2	3.42	<.01**	3.34	.01*	-2.36	.67	11.42	.04*	.74 to 22.10	9.06	.19
	BIPQ T2 <sup>d</sup>	17.42	.03*	-.59	<.01**	1.97	.72	-10.31	.07	-21.62 to .10	-8.34	.24
	BIPQ T2, at Low BIPQ T1	7.10	.03*	-.59	<.01**	1.97	.72	-4.19	.19	-10.49 to 2.10	-.87	.87
	BIPQ T2, at Mean BIPQ T1	-2.42	.03*	-.59	<.01**	1.97	.72	1.43	.40	-1.93 to 4.79	2.87	.59
	BIPQ T2, at High BIPQ T1	-11.97	.03*	-.59	<.01**	1.97	.72	7.06	.04*	.24 to 13.87	6.62	.25
PCS T3	SEDM T2	3.42	<.01**	1.38	.01*	-.89	.61	4.72	.04*	.16 to 9.28	3.83	.19
BSI-ANX T3	SEDM T2	3.42	<.01**	-.12	.04*	-.07	.72	-.40	.03*	-.75 to -.04	-.46	.09
BFSC T3	Approach T2	.28	.01*	4.73	.01*	3.10	.03*	1.31	.04*	.04 to 2.58	4.41	.01*
<b>Outcome</b>	<b>Mediator</b>	<b> <i>(a x b) / c</i> </b>		<b> <i>c' / c</i> </b>								
MOS GAS T3	SEDM T3	4.84		3.84								
	BIPQ T2	5.23		4.23								
	BIPQ T2, at Low BIPQ T1	2.13		.44								
	BIPQ T2, at Mean BIPQ T1	.73		1.46								
	BIPQ T2, at High BIPQ T1	3.58		3.36								
PCS T3	SEDM T2	5.30		4.30								
BSI-ANX T3	SEDM T2	5.71		6.57								
BFSC T3	Approach T2	.42		1.42								

Note. *a* = direct effect of CSI on mediator; *b* = direct effect of mediator on outcome; *c* = direct effect of CSI on outcome; *a x b* = indirect effect of CSI on outcome; *c'* = total effect of CSI on outcome; *a* through *c'* are observed coefficients; 95% CI = confidence intervals, calculated using bootstrapping analyses;  $| (a \times b) / c |$  = ratio of CSI indirect effect to CSI direct effect;  $| c' / c |$  = ratio of CSI total effect to CSI direct effect; <sup>d</sup>there was a significant indirect effect of the interaction between CSI and BIPQ T1 on MOS GAS ( $B = .26, p = .04$ ) and as such, results are presented for mediation models run separately at low (each participant's BIPQ total score -  $\bar{x}$  -  $SD$ ), mean (BIPQ total score -  $\bar{x}$ ), and high (BIPQ total score -  $\bar{x}$  +  $SD$ ) levels of perceived threat at baseline – please also note that when a modified version of the BIPQ that did not include items representing emotional distress was used, this finding was no longer significant; MOS GAS = Medical Outcomes Study General Adherence Scale; SEDMC = Self-Efficacy for Disease Management Composite score; BIPQ = Brief Illness Perceptions Questionnaire; SF-12 PCS = SF-12 Physical Component Summary Scale; BSI-ANX = Brief Symptom Inventory – Anxiety subscale, BFSC = Benefit Finding Scale for Children; Approach = approach-oriented coping, COPE and Emotional Approach Coping Scales. Models were run testing each of four conceptual mediators: 1) SEDMC, 2) BIPQ, 3) approach-oriented coping, and 4) loneliness, UCLA Loneliness Scale, at one-month as mediators of the association between group assignment and each of six conceptual outcomes at two months: 1) disease-related skills and knowledge (Transition Readiness Assessment Questionnaire), 2) MOS GAS, 3) SF-12 PCS, 4) depressive symptoms (Center for Epidemiologic Studies – Depression scale), 5) BSI-ANX, and 6) BFSC. All significant findings are presented here.

\* $p < .05$ ; \*\* $p < .01$

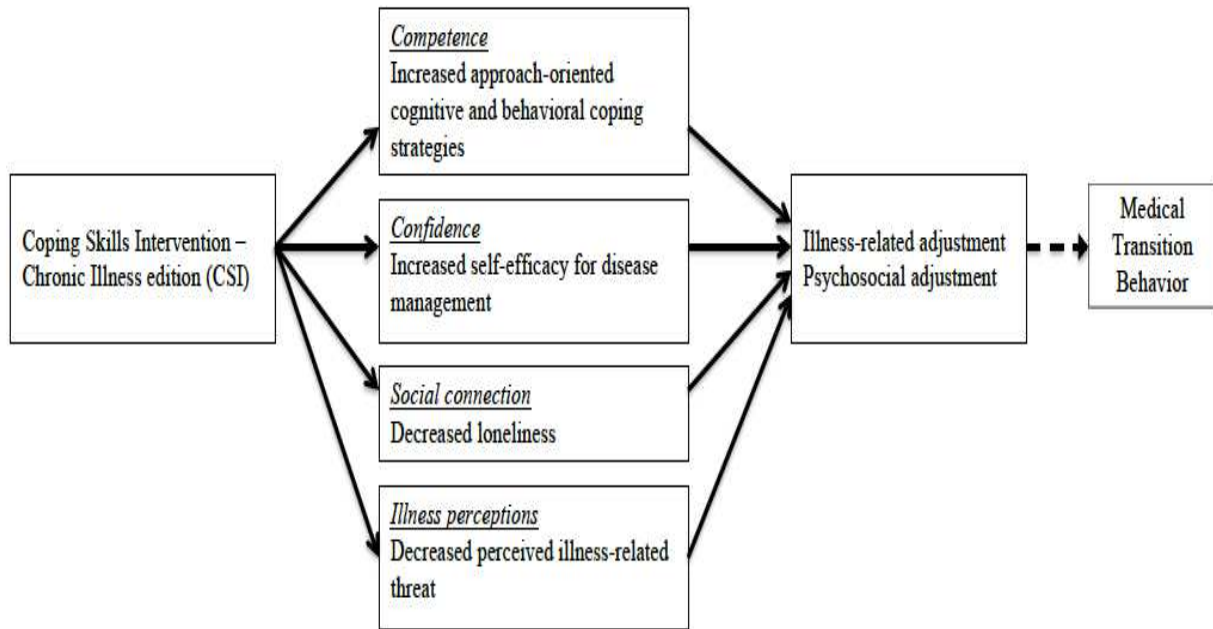


Figure 2. Conceptual model guiding the current study. Solid arrows represent links that have empirical support. Dashed arrows represent additional hypothesized links.

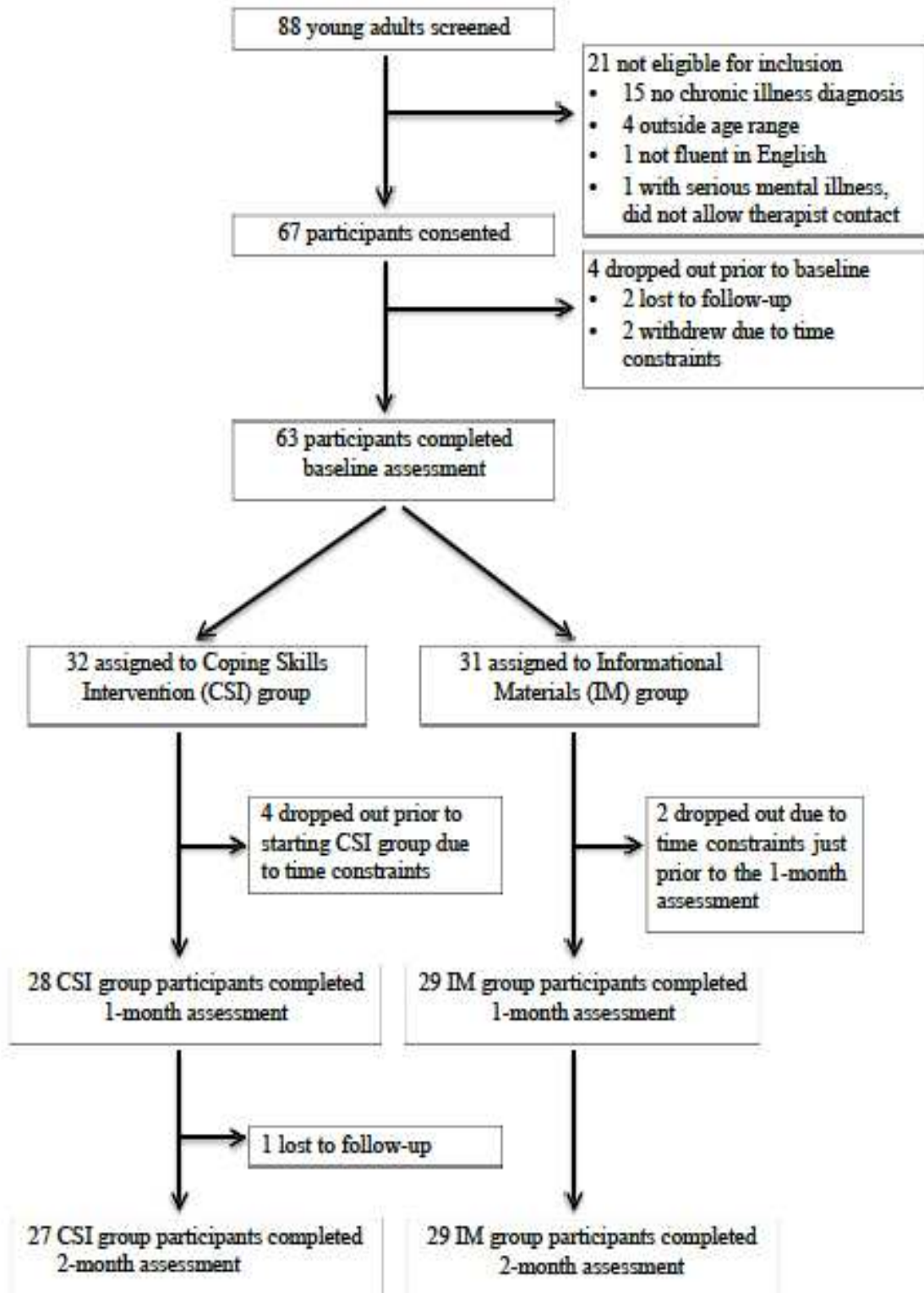


Figure 3. Flow of participants through the study.

## Disease-Related Skills and Knowledge

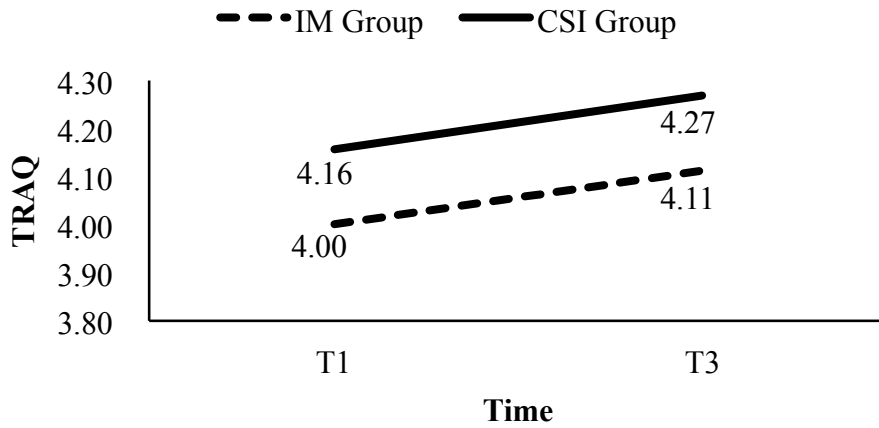


Figure 4. Mean scores on the Transition Readiness Assessment Questionnaire (TRAQ) by group over time. IM = Informational Materials group. CSI = Coping Skills Intervention group. T1 = baseline assessment. T3 = two-month assessment.

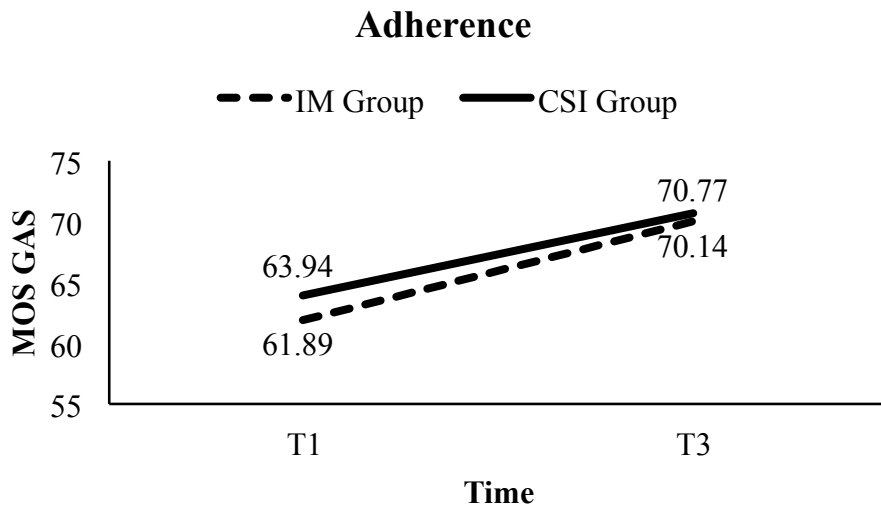


Figure 5. Mean scores on the Medical Outcomes Study General Adherence Scale (MOS GAS) by group over time. IM = Informational Materials group. CSI = Coping Skills Intervention group. T1 = baseline assessment. T3 = two-month assessment.

## Physical Health-Related Quality of Life

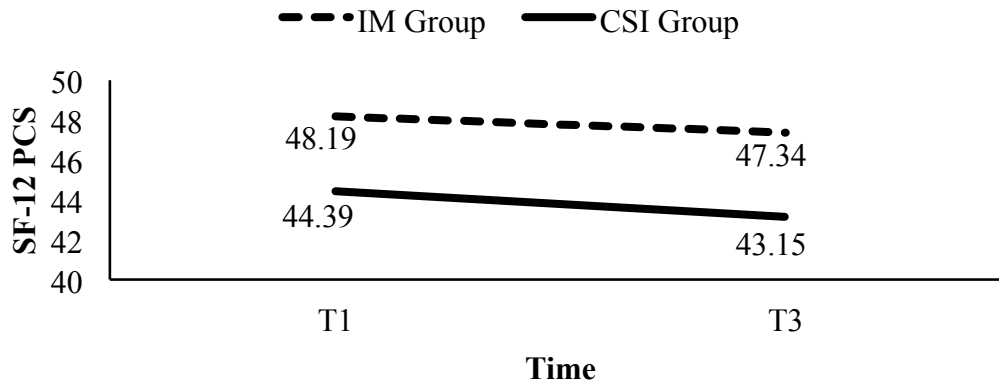


Figure 6. Mean scores on the SF-12 Physical Component Summary scale (SF-12 PCS) by group over time. IM = Informational Materials group. CSI = Coping Skills Intervention group. T1 = baseline assessment. T3 = two-month assessment.



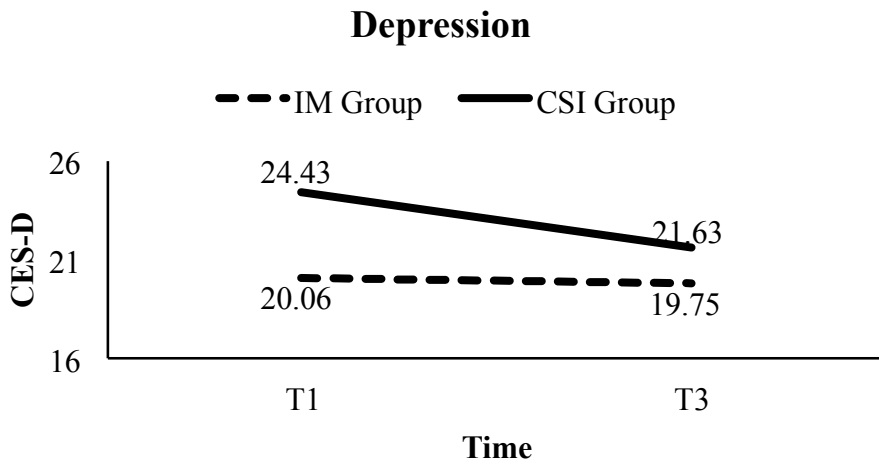


Figure 7. Mean scores on the Center for Epidemiologic Studies Depression scale (CES-D) by group over time. IM = Informational Materials group. CSI = Coping Skills Intervention group. T1 = baseline assessment. T3 = two-month assessment.

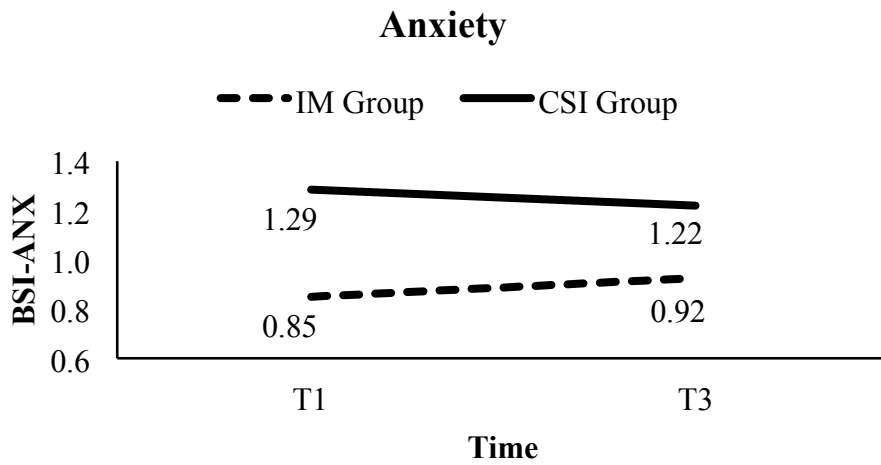


Figure 8. Mean scores on the Brief Symptom Inventory – Anxiety subscale (BSI-ANX) by group over time. IM = Informational Materials group. CSI = Coping Skills Intervention group. T1 = baseline assessment. T3 = two-month assessment.

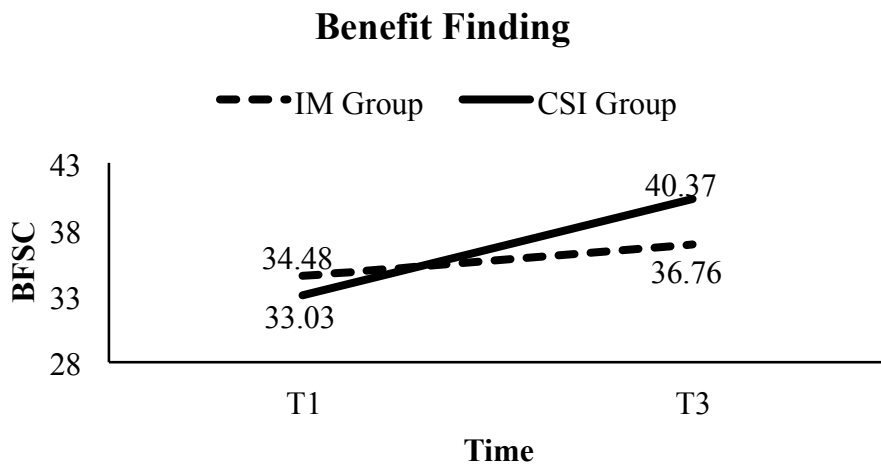


Figure 9. Mean scores on the Benefit Finding Scale for Children (BFSC) by group over time. IM = Informational Materials group. CSI = Coping Skills Intervention group. T1 = baseline assessment. T3 = two-month assessment.

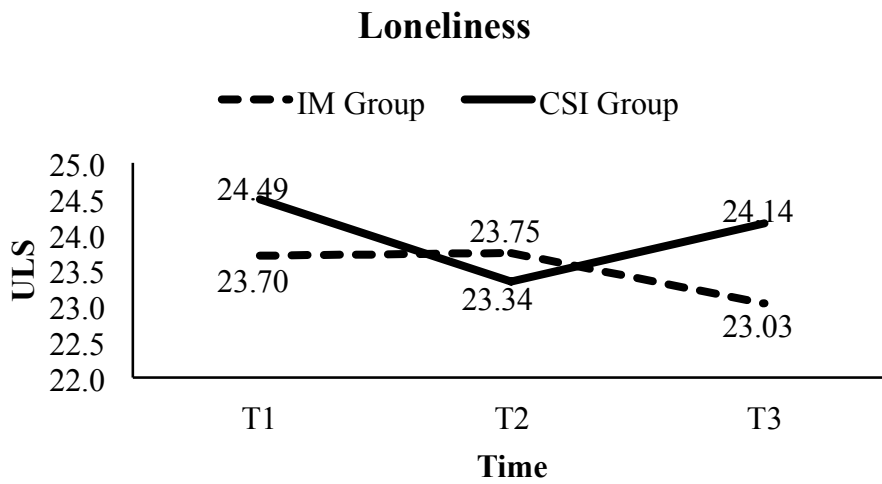


Figure 10. Mean scores on the UCLA Loneliness Scale (ULS) by group over time. IM = Informational Materials group. CSI = Coping Skills Intervention group. T1 = baseline assessment. T3 = two-month assessment.

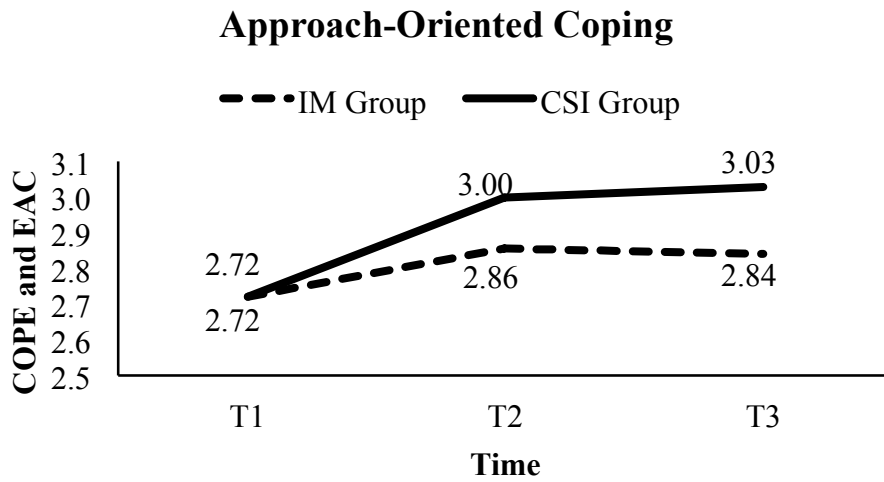


Figure 11. Mean scores on the Approach-Oriented Coping subscale of the COPE and Emotional Approach Coping scales (EAC) by group over time. IM = Informational Materials group. CSI = Coping Skills Intervention group. T1 = baseline assessment. T3 = two-month assessment.

### Perceived Illness-Related Threat

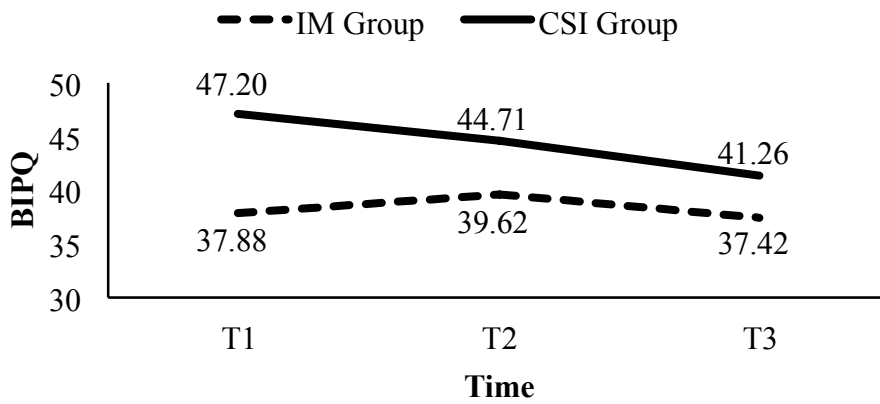


Figure 12. Mean scores on the Brief Illness Perceptions Questionnaire (BIPQ) by group over time. IM = Informational Materials group. CSI = Coping Skills Intervention group. T1 = baseline assessment. T3 = two-month assessment.

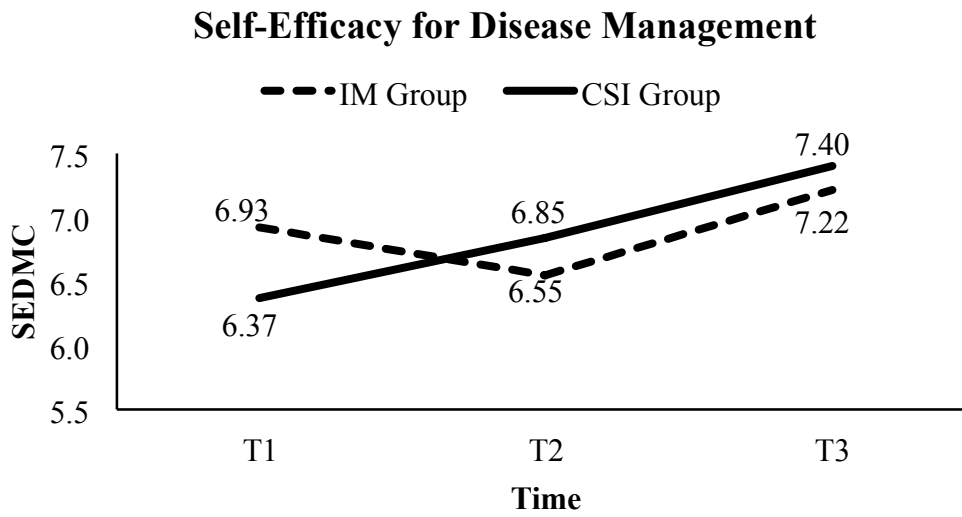


Figure 13. Mean scores on the Self-Efficacy for Disease Management Composite scale (SEDMC) by group over time. IM = Informational Materials group. CSI = Coping Skills Intervention group. T1 = baseline assessment. T3 = two-month assessment.

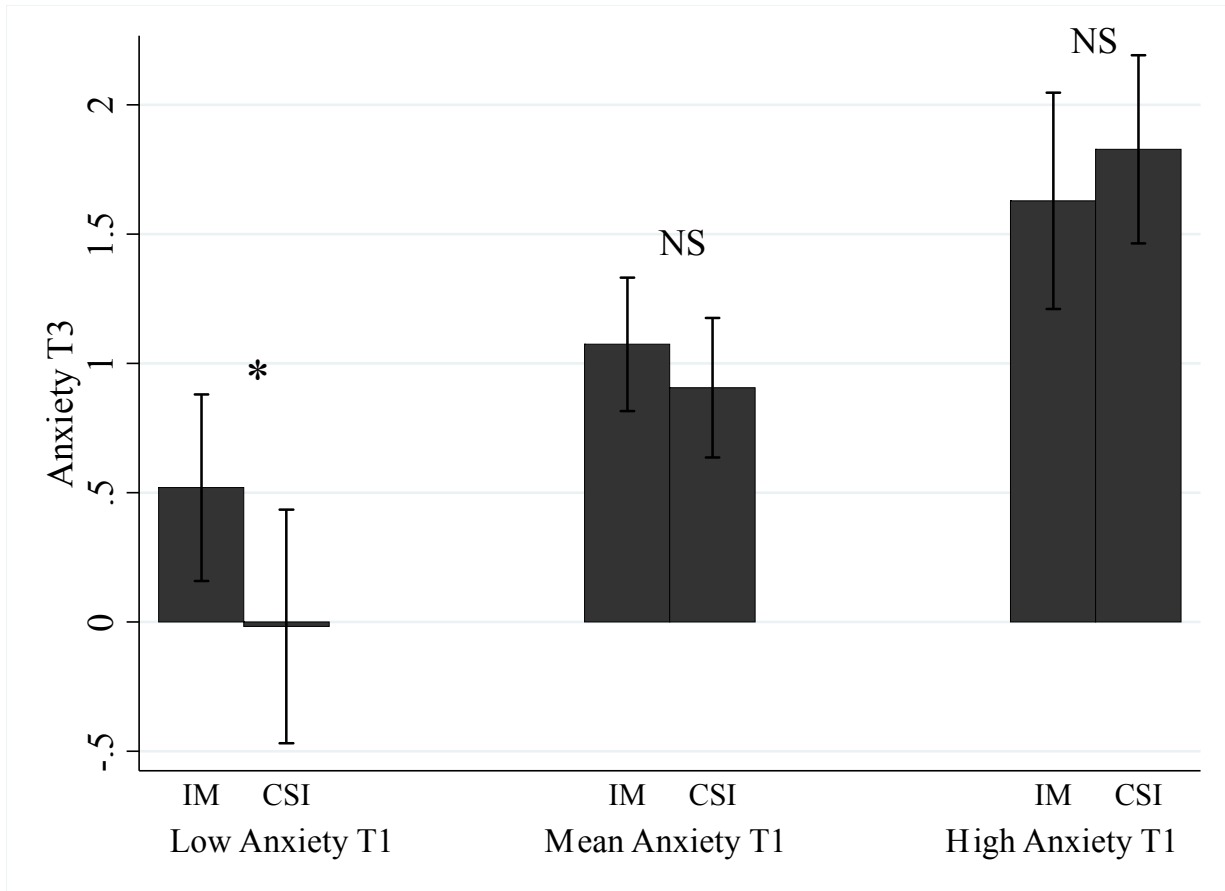


Figure 14. The association between group assignment and T3 anxiety (BSI-ANX) at different levels of T1 anxiety, controlling for T1 depression (CES-D). Error bars represent 95% confidence intervals. At low levels of T1 anxiety, CSI group members have significantly lower T3 anxiety as compared to IM group members ( $p = .05$ ). Group assignment is not associated with T3 anxiety at mean or high levels of T1 anxiety ( $p > .05$ ). NS = not significant.  $*p \leq .05$ .



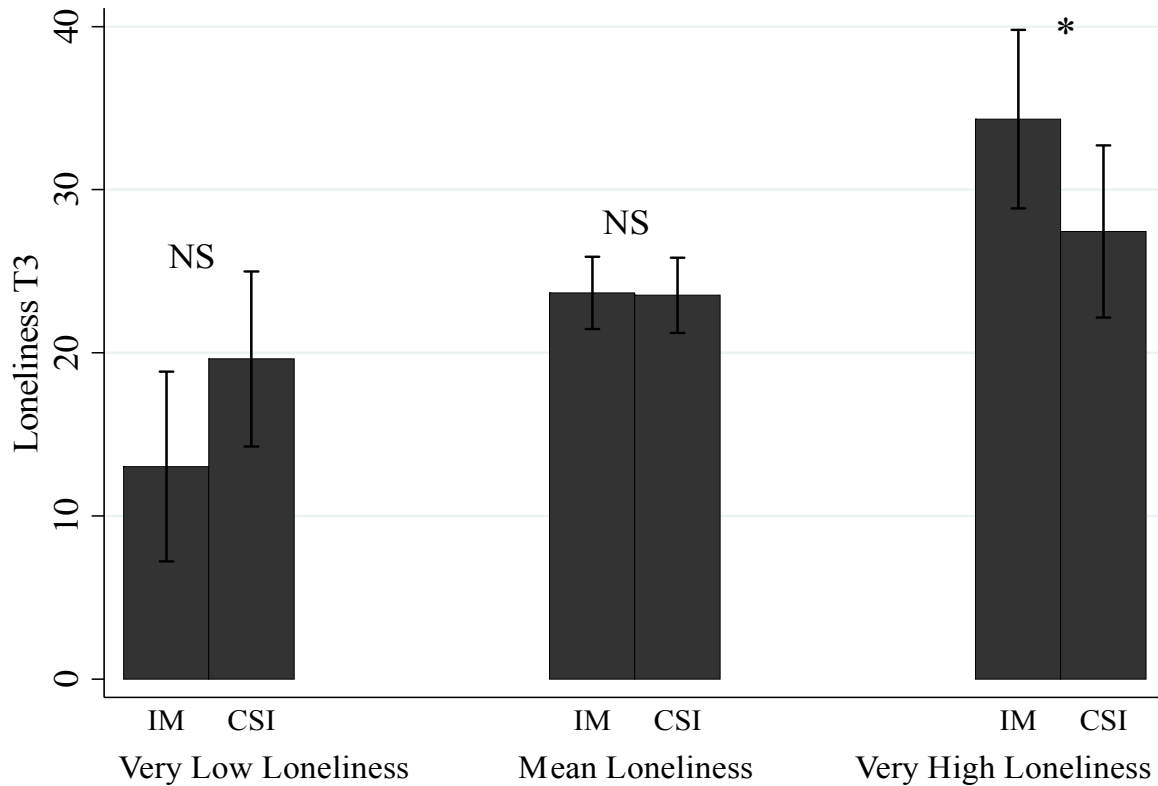


Figure 15. The association between group assignment and T3 loneliness (ULS) at different levels of T1 loneliness, controlling for T1 depression (CES-D). Error bars represent 95% confidence intervals. At very high levels of T1 loneliness ( $\bar{x} + 2SD$ ) CSI group members have significantly lower T3 loneliness as compared to IM group members ( $p = .05$ ). Group assignment is not associated with T3 anxiety at very low ( $\bar{x} - 2SD$ ) or mean levels of T1 anxiety ( $p > .05$ ). NS = not significant.  $*p \leq .05$

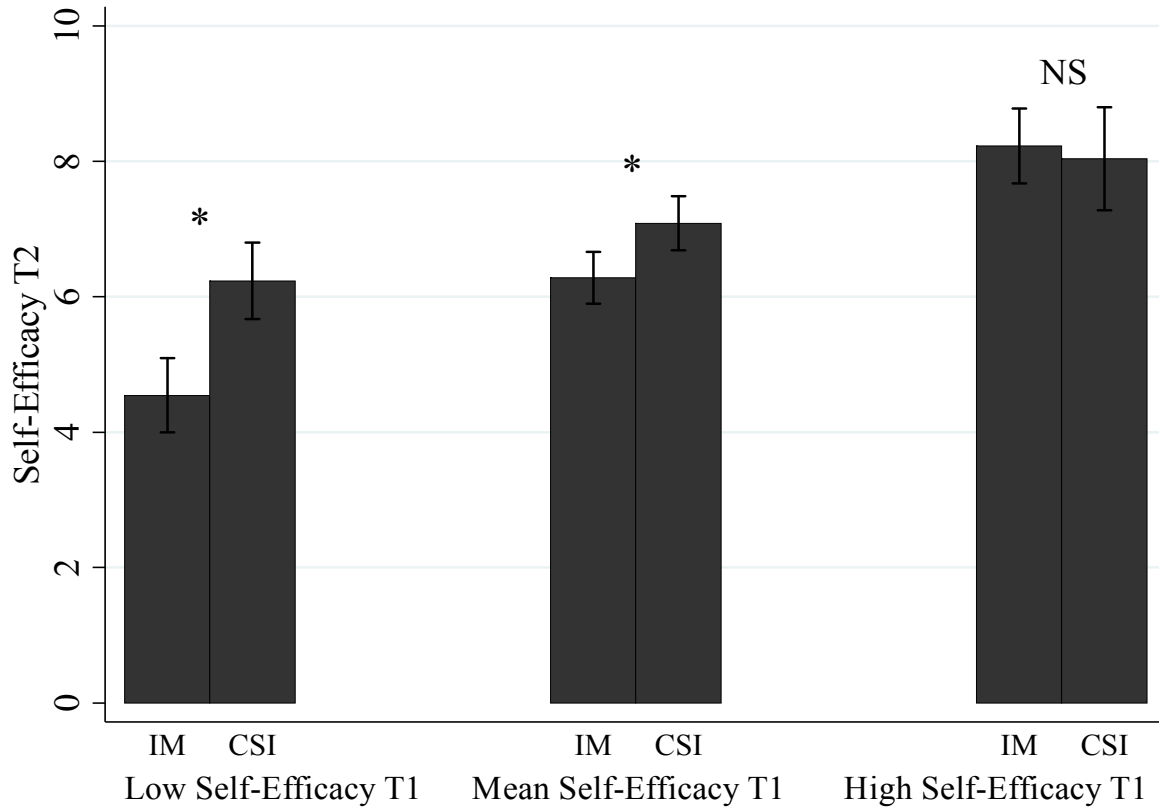


Figure 16. The association between group assignment and T2 self-efficacy (Self-Efficacy for Disease Management Composite score) at different levels of T1 self-efficacy, controlling for T1 depression (CES-D). Error bars represent 95% confidence intervals. At low and mean levels of T1 self-efficacy, CSI group members have significantly higher T2 self-efficacy as compared to IM group members ( $p < .05$ ). Group assignment is not associated with T2 self-efficacy at high levels of T1 self-efficacy ( $p > .05$ ). NS = not significant.  $*p \leq .05$

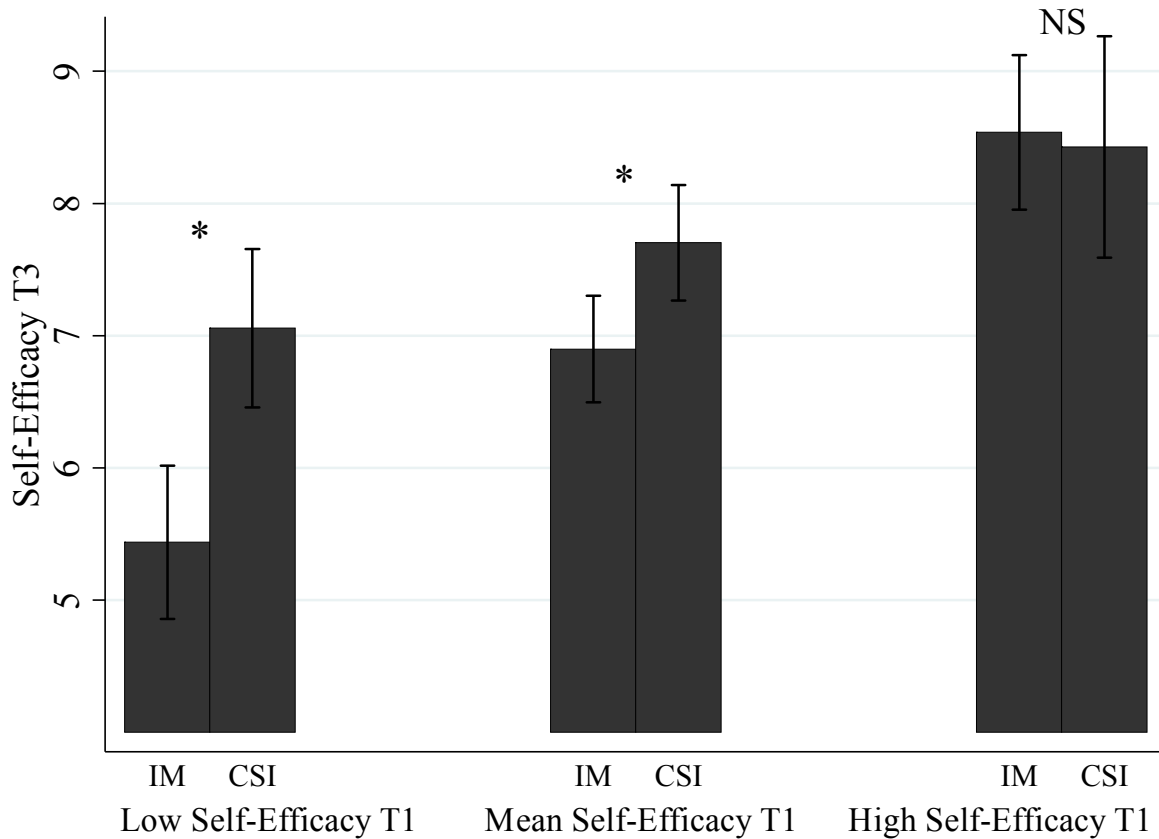


Figure 17. The association between group assignment and T3 self-efficacy (Self-Efficacy for Disease Management Composite score) at different levels of T1 self-efficacy, controlling for T1 depression (CES-D). Error bars represent 95% confidence intervals. At low and mean levels of T1 self-efficacy, CSI group members have significantly higher T3 self-efficacy as compared to IM group members ( $p < .05$ ). Group assignment is not associated with T3 self-efficacy at high levels of T1 self-efficacy ( $p > .05$ ). NS = not significant.  $*p \leq .05$

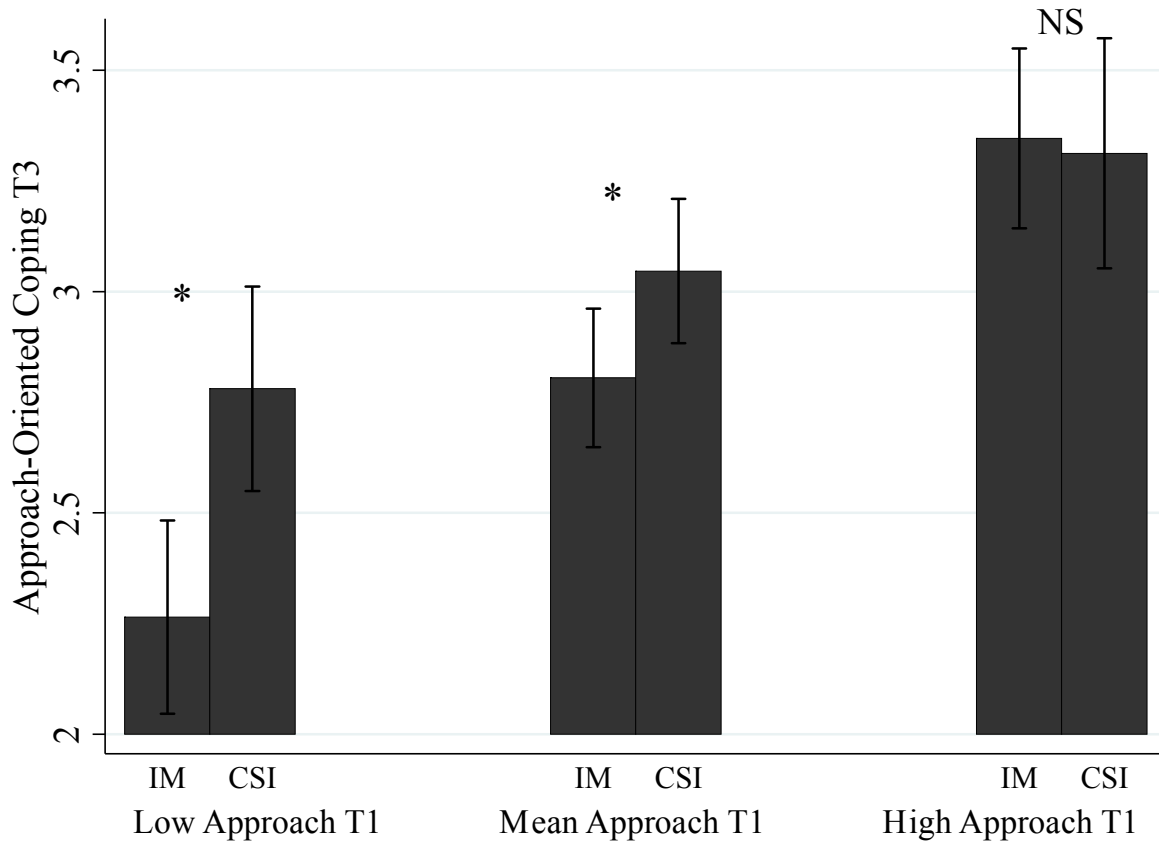


Figure 18. The association between group assignment and T3 approach-oriented coping (COPE and Emotional Approach Coping Scales) at different levels of T1 approach-oriented coping, controlling for T1 depression (CES-D). Error bars represent 95% confidence intervals. At low and mean levels of T1 approach-oriented coping, CSI group members have significantly higher T3 approach-oriented coping as compared to IM group members ( $p < .05$ ). Group assignment is not associated with T3 approach-oriented coping at high levels of T1 approach-oriented coping ( $p > .05$ ). NS = not significant.  $*p \leq .05$

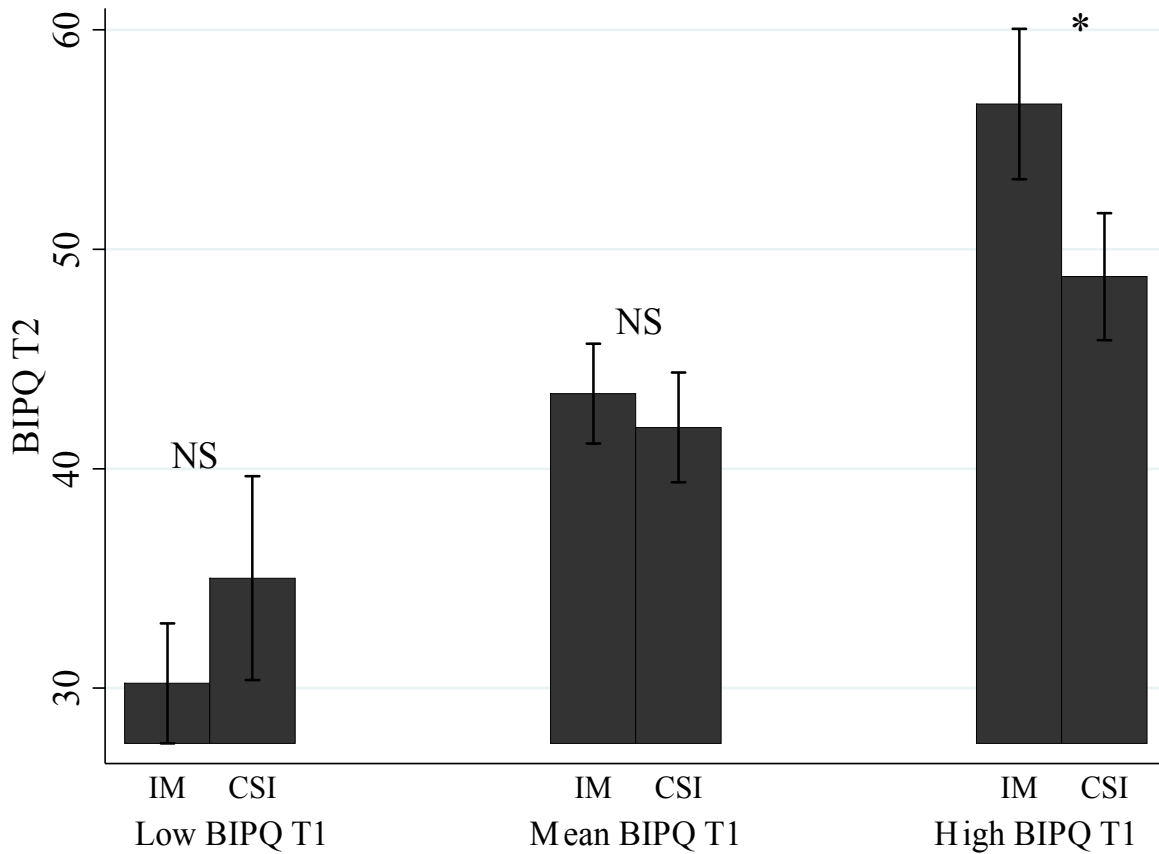


Figure 19. The association between group assignment and T2 perceived disease-related threat (BIPQ) at different levels of T1 disease-related threat, controlling for T1 depression (CES-D). Error bars represent 95% confidence intervals. At high levels of T1 disease-related threat, CSI group members have significantly lower T2 disease-related threat as compared to IM group members ( $p < .05$ ). Group assignment is not associated with T2 disease-related threat at low or mean levels of T1 disease-related threat ( $p > .05$ ). NS = not significant.  $*p \leq .05$

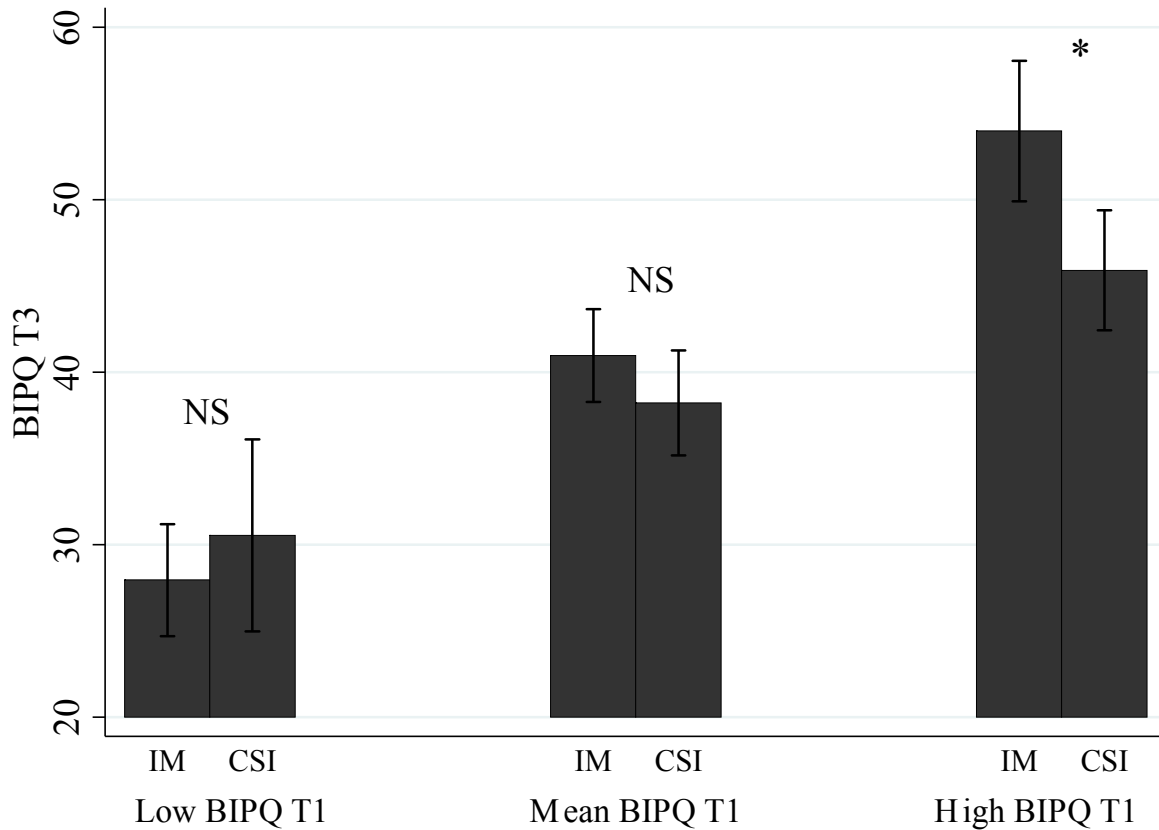


Figure 20. The association between group assignment and T3 perceived disease-related threat (BIPQ) at different levels of T1 disease-related threat, controlling for T1 depression (CES-D). Error bars represent 95% confidence intervals. At high levels of T1 disease-related threat, CSI group members have significantly lower T3 disease-related threat as compared to IM group members ( $p < .05$ ). Group assignment is not associated with T3 disease-related threat at low or mean levels of T1 disease-related threat ( $p > .05$ ). NS = not significant.  $*p \leq .05$

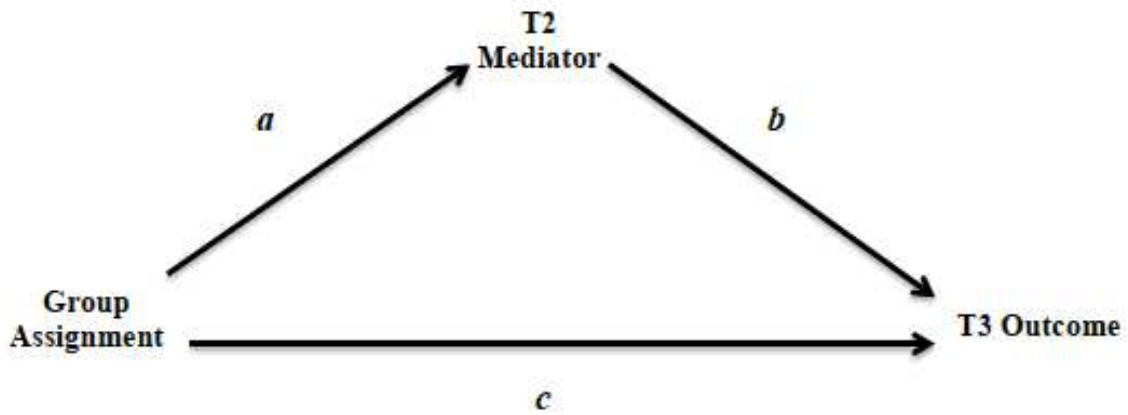


Figure 21. Relationship between group assignment, mediators and outcomes;  $a$  = direct effect of group assignment on mediator;  $b$  = direct effect of mediator on outcome;  $c$  = direct effect of group assignment on outcome;  $a \times b$  = indirect effect of group assignment on outcome.

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## Appendix A. Author-Constructed and Author-Adapted Measures

### *Demographic and illness-related variables*

Demographic and illness-related questions are adapted from Herts and colleagues (2014) and Maslow and colleagues (2013).

ID Number \_\_\_\_\_ Date \_\_\_\_\_

### *Demographic questions*

Age \_\_\_\_\_ Gender \_\_\_\_\_

What is your approximate yearly family income?

- |                                                 |                                               |                                               |
|-------------------------------------------------|-----------------------------------------------|-----------------------------------------------|
| <input type="checkbox"/> Less than \$20,000     | <input type="checkbox"/> \$20,000 to \$29,999 | <input type="checkbox"/> \$30,000 to \$39,999 |
| <input type="checkbox"/> \$40,000 to \$49,999   | <input type="checkbox"/> \$50,000 to \$59,999 | <input type="checkbox"/> \$60,000 to \$69,999 |
| <input type="checkbox"/> \$70,000 to \$79,999   | <input type="checkbox"/> \$80,000 to \$89,999 | <input type="checkbox"/> \$90,000 to \$99,999 |
| <input type="checkbox"/> \$100,000 to \$149,999 | <input type="checkbox"/> \$150,000 or more    |                                               |

What best describes your ethnic/racial background?

- |                                                        |                                                           |
|--------------------------------------------------------|-----------------------------------------------------------|
| <input type="checkbox"/> White/European American       | <input type="checkbox"/> Black/African-American           |
| <input type="checkbox"/> Latina/Hispanic               | <input type="checkbox"/> Asian (specify _____)            |
| <input type="checkbox"/> Indian subcontinent           | <input type="checkbox"/> Native Hawaiian/Pacific Islander |
| <input type="checkbox"/> Native American/Alaska Native | <input type="checkbox"/> Other (please specify _____)     |

What is your current living situation?  Alone  Roommates  With romantic partner  
 With parents/siblings  With spouse/children  
 Other

How far in school did your most highly educated parent go?

- Less than high school  High school graduate  Some college  College graduate  
 Graduate school  Professional degree (M.D., Ph.D., etc.)

Are you currently employed?  Yes, full time (40+ hours/week)

Yes, part time (less than 40 hours/week)

No

How many years of education have you completed? \_\_\_\_\_

Are you currently a student? \_\_\_\_\_

*Questions for current high school students*

If you are a high school student, what grade in school are you?

9<sup>th</sup>       10<sup>th</sup>       11<sup>th</sup>       12<sup>th</sup>

*Questions for current college or graduate students*

If you are a college student, what year in college are you?

First       Second       Third       Fourth

Other (please fill in year) \_\_\_\_\_

What college/university do you attend? \_\_\_\_\_

Do you have a primary care doctor in the same city as your school (e.g., Los Angeles)?

Yes       No

Do you see a physician specialist in the same city as your school?  Yes       No

Are you registered with the Office for Students with Disabilities (OSD) or equivalent office at your school?  Yes       No       N/A

If yes, what OSD services have you used? \_\_\_\_\_

\_\_\_\_\_

What other college or university resources have you used for health-related issues? Please briefly describe your reasons for using these services.

Health Services \_\_\_\_\_

Psychological services \_\_\_\_\_

Support group: \_\_\_\_\_

Other: \_\_\_\_\_



*Illness-related questions*

What do you consider to be your primary chronic physical illness (e.g., diabetes, epilepsy)?

\_\_\_\_\_

What was your age at diagnosis? \_\_\_\_\_

Do you have any other chronic illnesses?    \_\_\_ Yes    \_\_\_ No

If yes, how many? \_\_\_\_\_

If yes, please list: \_\_\_\_\_

Have you ever been diagnosed with a psychological disorder (e.g., depression)?    \_\_\_ Yes    \_\_\_ No

If yes what illness? \_\_\_\_\_

If yes, what was your age at diagnosis? \_\_\_\_\_

Do you have a documented learning disability?

If yes what kind of learning disability? \_\_\_\_\_

If yes, what was your age at diagnosis? \_\_\_\_\_

Have you ever been diagnosed with a physical disability?    \_\_\_ Yes    \_\_\_ No

If yes what kind of disability? \_\_\_\_\_

If yes, what was your age at diagnosis? \_\_\_\_\_

How many other young adults do you know with a chronic physical illness? \_\_\_\_\_

How many of your friends know about your chronic physical illness? \_\_\_\_\_

How many prescription medications are you currently taking? \_\_\_\_\_

Does anyone go with you to doctor's appointments? (Family, friend, significant other)

\_\_\_ Yes    \_\_\_ No

If yes, who? (check all that apply)

\_\_\_ Friend    \_\_\_ Parent    \_\_\_ Other Family Member    \_\_\_ Significant Other/Spouse

\_\_\_ Other (please specify) \_\_\_\_\_

*Questions assessing medical transition behavior*

Do you still see your pediatrician?  Yes  No

Do you have a primary care doctor (not a pediatrician)?  Yes  No

Do you still see your pediatric-focused medical specialist?  Yes  No

If yes, have you identified an adult-focused specialist to whom you will transfer?

Yes  No  There are no adult-focused specialists in my area

Are you currently seeing an adult-focused medical specialist?  Yes  No

*Intervention Attendance*

**Participant ID Number** \_\_\_\_\_ **Group ID Number** \_\_\_\_\_

**Instructions for group leaders:** Please check off the sessions attended by this participant.

\_\_\_\_\_ Session 1      \_\_\_\_\_ Session 2      \_\_\_\_\_ Session 3      \_\_\_\_\_ Session 4

\_\_\_\_\_ Session 5      \_\_\_\_\_ Session 6      \_\_\_\_\_ Session 7      \_\_\_\_\_ Session 8

Please note the reasons this participant gave for each absence:

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Group Leader Name: \_\_\_\_\_ Group ID: \_\_\_\_\_

**CSI Group Homework Tracker**

**Instructions for group leaders:** Please check homework at the beginning of each session and use this sheet to track which group members complete each assignment. After session 8, please total the number of assignments completed and return this sheet to Kate Herts.

Group Member Name	Writing Assignment 0	Week 1 HW	Writing Assignment 1	Week 2 HW	Writing Assignment 2	Week 3 HW	Week 4 HW	Week 5 HW	Week 6 HW

Group Member Name	Week 7 HW	Writing Assignment 7	Total ( / 11)

**CSI:**

**CHRONIC ILLNESS EDITION**  
 A Coping Skills Intervention for Young Adults with  
 Chronic Illness

*CSI Group Acceptability*

Thank you for completing the Coping Skills Intervention for Chronic Illness (CSI)! We would appreciate your feedback so that we can improve the group for future patients. To this end, please answer the questions below.

1. Please rate your overall experience with the CSI group:

1	2	3	4	5	6	7
Very Negative	Fairly Negative	A little Negative	Neutral	A little Positive	Fairly Positive	Very Positive

2. What did you like about the CSI group?

3. What did you find to be the most helpful about the CSI group?

4. What disappointed you about the CSI group?

5. What would you like to change about the CSI group?

6. Is there anything else you would like the group leaders to know?

*IM Group Acceptability*

Thank you for participating in the Informational Materials group! We would appreciate your feedback so that we can improve the materials for future patients. To this end, please answer the questions below.

1. Overall, how helpful did you find the information provided?

1	2	3	4	5
Not at all Helpful	Fairly Helpful	Somewhat Helpful	Mostly Helpful	Extremely Helpful

2. What did you find most helpful about the information?

3. What disappointed you about the information?

4. What would you like to change about the information?

5. Is there anything else you would like the researchers to know about the information?

*Fidelity to CSI-CI Manual*

Rater Initials \_\_\_\_\_ Group ID \_\_\_\_\_

*CSI Session 1* Session 1 Date \_\_\_\_\_

**Group leader...**

1. Had group members complete clinic paperwork upon arrival	Yes	No
2. Introduced self and noted will not share personal chronic illness status	Yes	No
3. Reviewed confidentiality considerations	Yes	No
4. Invited group members to introduce themselves	Yes	No
5. Reviewed participation agreement with participants	Yes	No
6. Led discussion of unique issues facing young adults with chronic illness	Yes	No
7. Discussed the challenge of transitioning from pediatric to adult medical care	Yes	No
8. Used Handout 1.1 to provide psychoeducation about CSI-CI, PYD and CBT	Yes	No
9. Discussed purpose of completing expressive writing assignments	Yes	No
10. Led discussion about diagnosis experiences	Yes	No
11. Led discussion of positive and negative aspects of illness experience	Yes	No
12. Used Handout 1.2 to provide psychoeducation about the links between thoughts, mood, and physical symptoms	Yes	No
13. Had group members complete and discuss Handout 1.2 Exercise A	Yes	No
14. Summarized key messages from session	Yes	No
15. Assigned Writing Assignment 1 and Thought Tracking homework	Yes	No
16. Invited feedback about the session	Yes	No
<b>Total</b>	_____	_____

*Fidelity to CSI-CI Manual*

Rater Initials \_\_\_\_\_ Group ID \_\_\_\_\_

CSI Session 2 Session 2 Date \_\_\_\_\_

**Group leader...**

1. Reviewed key messages from Session 1	Yes	No
2. Led discussion about living with chronic illness	Yes	No
3. Elicited pros and cons of accepting one's illness	Yes	No
4. Reviewed thought tracking homework with group members	Yes	No
5. Used Handout 2.1 to lead group members in a chaining activity to demonstrate the links between thoughts and mood	Yes	No
6. Used Handout 2.2 to provide psychoeducation about common cognitive distortions and checking negative thoughts for accuracy, completeness and balance	Yes	No
7. Elicited examples of cognitive distortions group members commonly engage in	Yes	No
8. Summarized key messages from session	Yes	No
9. Assigned Writing Assignment 2 and Catching Cognitive Distortions homework	Yes	No
10. Invited feedback about the session	Yes	No
<b>Total</b>	_____	_____



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Rater Initials \_\_\_\_\_ Group ID \_\_\_\_\_

*CSI Session 3* Session 3 Date \_\_\_\_\_

**Group leader...**

1. Reviewed key messages from Session 2	Yes	No
2. Led discussion about positive aspects of having a chronic illness	Yes	No
3. Reviewed cognitive distortions homework with group members	Yes	No
4. Used Handout 3.1 to provide psychoeducation about cognitive restructuring strategy Examining the Evidence	Yes	No
5. Used Handout 3.1 to provide psychoeducation about cognitive restructuring strategy Catch it, Check it, Change it	Yes	No
6. Used Handout 3.1 to provide psychoeducation about cognitive restructuring strategy Identifying Alternative Thoughts	Yes	No
7. Gave group members opportunities to practice each of the three cognitive restructuring strategies	Yes	No
8. Summarized key messages from session	Yes	No
9. Assigned Cognitive Restructuring homework	Yes	No
10. Invited feedback about the session	Yes	No
<b>Total</b>	_____	_____

*Fidelity to CSI-CI Manual*

Rater Initials \_\_\_\_\_ Group ID \_\_\_\_\_

CSI Session 4 Session 4 Date \_\_\_\_\_

**Group leader...**

1. Reviewed key messages from Session 3	Yes	No
2. Reviewed cognitive restructuring homework with group members	Yes	No
3. Led discussion about healthy behaviors	Yes	No
4. Elicited ideas about the impact of healthy behaviors on mood and physical health in the short and long terms	Yes	No
5. Used Handout 4.1 to provide psychoeducation about the links between behaviors, mood and physical symptoms	Yes	No
6. Led discussion about what constitutes a healthy activity and how that might vary based on physical symptoms	Yes	No
7. Used Handout 4.2 to lead group members in brainstorming ideas for healthy behaviors	Yes	No
8. Led group members in relaxation exercises: Deep Breathing and Progressive Muscle Relaxation	Yes	No
9. Distributed Handout 4.3 and asked group members to practice relaxation exercises at home over the next week	Yes	No
10. Summarized key messages from session	Yes	No
11. Assigned Healthy Activities Tracking Form homework	Yes	No
12. Invited feedback about the session	Yes	No
<b>Total</b>	_____	_____

*Fidelity to CSI-CI Manual*

Rater Initials \_\_\_\_\_ Group ID \_\_\_\_\_

*CSI Session 5* Session 5 Date \_\_\_\_\_

**Group leader...**

1. Reviewed key messages from Session 4	Yes	No
2. Reviewed healthy activities tracking homework with group members	Yes	No
3. Led discussion about obstacles to healthy behaviors	Yes	No
4. Used Handout 5.1 to provide psychoeducation about Problem Solving strategy for overcoming obstacles to healthy behaviors	Yes	No
5. Used Handout 5.1 to provide psychoeducation about Pacing Yourself strategy for overcoming obstacles to health behaviors	Yes	No
6. Elicited examples from group members about how they might use the Problem Solving and Pacing Yourself strategies	Yes	No
7. Used Handout 5.2 to guide group members to use cognitive restructuring strategies they have learned to overcome thought obstacles to healthy behaviors	Yes	No
8. Summarized key messages from session	Yes	No
9. Assigned Healthy Activities Tracking form homework	Yes	No
10. Invited feedback about the session	Yes	No
<b>Total</b>	_____	_____

*Fidelity to CSI-CI Manual*

Rater Initials \_\_\_\_\_ Group ID \_\_\_\_\_

*CSI Session 6* Session 6 Date \_\_\_\_\_

**Group leader...**

1. Reviewed key messages from Session 5	Yes	No
2. Reviewed healthy activities homework with group members	Yes	No
3. Led discussion about illness and relationships	Yes	No
4. Used Handout 6.1 to provide psychoeducation about the links between relationships, mood and physical symptoms	Yes	No
5. Using Handout 6.1, led group members to complete a chaining activity to demonstrate the link between relationships and mood	Yes	No
6. Used Handout 6.2 to provide psychoeducation about social support	Yes	No
7. Had group members map their social support networks using Handout 6.2	Yes	No
8. Led group members in brainstorming ideas for ways to build different kinds of social support	Yes	No
9. Summarized key messages from session	Yes	No
10. Assigned homework: 1. Complete a relationships and mood chaining activity and 2. Complete a healthy activity with other people and rate mood before and after	Yes	No
11. Invited feedback about the session	Yes	No
<b>Total</b>	_____	_____

*Fidelity to CSI-CI Manual*

Rater Initials \_\_\_\_\_ Group ID \_\_\_\_\_

CSI Session 7 Session 7 Date \_\_\_\_\_

**Group leader...**

1. Reviewed key messages from Session 6	Yes	No
2. Reviewed relationship skills practice homework with group members	Yes	No
3. Led discussion about doctor-patient relationships	Yes	No
4. Used Handout 7.1 to provide psychoeducation about communication styles and asked group members to identify their communication styles	Yes	No
5. Used Handout 7.2 to provide psychoeducation about assertiveness communication skills: making requests and expressing thoughts and feelings assertively	Yes	No
6. Engage group members in practicing each communication skills with a partner	Yes	No
7. Use Handout 7.3 to highlight how group members can use problem solving and cognitive restructuring to overcome obstacles to healthy relationships	Yes	No
8. Use Handout 7.3 to guide group members to complete EITHER a problem solving OR cognitive restructuring exercise to overcome obstacles to healthy relationships (may complete both if time permits)	Yes	No
9. Summarized key messages from session	Yes	No
10. Assigned Writing Assignment 7 and Assertiveness Skills Practice homework	Yes	No
11. Invited feedback about the session	Yes	No
<b>Total</b>	_____	_____

*Fidelity to CSI-CI Manual*

Rater Initials \_\_\_\_\_ Group ID \_\_\_\_\_

*CSI Session 8* Session 8 Date \_\_\_\_\_

**Group leader...**

- |                                                                                                                                                                                                       |     |    |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----|----|
| 1. Reviewed key messages from Session 7                                                                                                                                                               | Yes | No |
| 2. Reviewed assertiveness skills practice homework with group members                                                                                                                                 | Yes | No |
| 3. Led discussion about chronic illness and transitions                                                                                                                                               | Yes | No |
| 4. Emphasized the need for increased independence in managing one's own medical care during the transition to adult medical care                                                                      | Yes | No |
| 5. Used Handout 8.1 to provide psychoeducation about values and SMART goals                                                                                                                           | Yes | No |
| 6. Used Handout 8.1 to guide group members to write about their values in the domain of physical wellbeing and to identify a related SMART goal                                                       | Yes | No |
| 7. Use Handout 8.2 to highlight how group members can use problem solving and cognitive restructuring to overcome obstacles to successfully transitioning to adult medical care                       | Yes | No |
| 8. Use Handout 8.2 to guide group members to complete EITHER a problem solving OR cognitive restructuring exercise to overcome obstacles to successful transition (may complete both if time permits) | Yes | No |
| 9. Led group members in discussion of how they can use their experiences with illness and in the group to help others                                                                                 | Yes | No |
| 10. Led group members in reflecting on and providing feedback about their experiences in the group                                                                                                    | Yes | No |

**Total** \_\_\_\_\_

*Author-Constructed Introductory Questions to the Medical Outcomes Study General Adherence Scale (DiMatteo et al., 1993)*

Please briefly describe what your doctor has recommended that you do to manage your illness in the following categories:

- A. *Medication*: have you been prescribed medications, injections or other treatments? If so, please list and indicate how often you take each medication or engage in each treatment (e.g., 2x/day).
- B. *Health behaviors*: has your doctor recommended that engage in any behaviors to manage your illness, for example, checking insulin levels, drinking plenty of liquids, exercising or doing relaxation exercises to manage pain? Please describe.
- C. *Medical appointments*: how often do you have scheduled medical appointments (e.g., monthly)?

Considering your doctor's recommendations described above, how often was each of the following statements true for you during the past 4 weeks?

*Self-Efficacy for Managing Anxiety Scale*

This scale is adapted from the Chronic Disease Self-Efficacy Scales (Lorig et al., 1996).

We would like to know how confident you are in doing certain activities. For each of the following questions, please choose the number that corresponds to your confidence that you can do the tasks regularly at the present time.

1	2	3	4	5	6	7	8	9	10
Not at all confident									Totally confident

1. How confident are you that you can keep from feeling tense, keyed up, or so restless you can't sit still?
2. How confident are you that you can keep from feeling fearful or scared for no reason?
3. How confident are you that you can keep yourself from feeling nervous or shaky inside?
4. How confident are you that you can keep from having spells of terror or panic?
5. How confident are you that you can do something to make yourself feel better when you are fearful or scared?
6. How confident are you that you can do something to relax when you are feeling tense, keyed up or restless?
7. How confident are you that you can do something to calm down when you are nervous or feeling shaky inside?
8. How confident are you that you can do something to make yourself feel better when you have a spell of terror or panic?