



Applying the Self-determination Theory to Health-related Quality of Life for Adolescents with Congenital Heart Disease



Jenna L. Shackelford, PhD, RN, CPN^{*,1}, Susan J. Kelley, PhD, RN, FAAN, Regena Spratling, PhD, RN, APRN, CPNP

Byrdine F. Lewis College of Nursing and Health Professions, Georgia State University, Atlanta, GA, United States of America

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ABSTRACT

Purpose: The purpose of this study is to examine the relationship among the three innate needs of Self-Determination Theory (SDT), self-management of care and adherence to treatment, and the relationship to health-related quality of life (HRQOL) for adolescents with congenital heart disease (CHD).

Design and methods: A non-experimental, cross-sectional, correlational design was conducted in a sample of 92 participants with CHD, ages 13 to 18 years. For data analysis, Pearson's correlations were used to explore associations between variables, and the hypotheses were tested using multiple linear regression.

Results: Demographic and clinical data were collected: 15 ± 1.6 yrs; 59% male; 65% White; 43% mild CHD; 25% severe CHD. After controlling for covariates, regression analyses revealed relatedness ($\beta = 0.64$) and competence ($\beta = 0.79$) contributed significant variance to HRQOL, $R^2 = 0.56$, $p < .001$; however, autonomy and self-management of care and treatment adherence did not contribute significant variance to HRQOL.

Conclusions: This study found that relatedness and competence were significantly associated with HRQOL in adolescents with CHD; however, autonomy and self-management of care and adherence to treatment were not. These findings demonstrate the importance of further examining relatedness and competence in adolescents with CHD.

Practice implications: Nursing care should focus on the improvement of social support systems and interventions to increase self-efficacy for adolescents with CHD.

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Introduction

Congenital heart disease (CHD) is the most common congenital disorder and affects 8 out of every 1000 infants and 1% (or approximately 40,000) of infants born every year in the United States (U.S.) (American Heart Association [AHA], 2015). Life expectancy has increased in recent decades, with approximately 85 to 90% of children born with CHD surviving into adulthood (Goossens et al., 2011; Yeung, Kay, Roosevelt, Brandon, & Yetman, 2008). Despite improvements in life expectancy, many surgeries for moderate to complex CHD include palliative procedures (Yuan & Jing, 2009), and individuals who undergo such procedures face lifelong cardiac monitoring. Additionally, complications of moderate and complex CHD may be acute and life threatening and worsen over time, which may impair the health-related quality of life (HRQOL) of individuals with CHD.

Adolescents with CHD transitioning into adulthood have medical treatment requirements including preventative care (i.e., dental preventative care, endocarditis prophylaxis, and health maintenance screening and monitoring), medication adherence, and fluid balance maintenance. Care may also require further palliative surgeries, re-operative procedures, corrective surgeries, repairs of residual lesions, thoracic organ transplantation, or treatment of acquired heart disease (Singh & Kansara, 2013). Therefore, it is important for adolescents with CHD to be responsible for their care, recognize adverse symptoms, adhere to treatment and medication regimens, and attend follow-up appointments to successfully transition into adulthood.

The transition into adulthood for individuals with chronic illnesses such as CHD presents new challenges for adolescents, parents, and healthcare providers. Although guidelines recommend regular follow-up with specialists in adult care (Warnes et al., 2008), >60% of adults with CHD are either lost to follow-up or fail to seek specialty care (Goossens et al., 2011; Knauth-Meadows, Bosco, Tong, Fernandes, & Saidi, 2009; Yeung et al., 2008). Adherence to treatment and self-management of care is critical (DiMatteo, Giordani, Lepper, & Croghan, 2002), especially for adolescents with chronic conditions, because low adherence increases morbidity and contributes to poorer quality of life (QOL) (Lemanek, Kamps, & Chung, 2001). Impaired HRQOL has been

* Corresponding author at: School of Nursing, Byrdine F. Lewis College of Nursing and Health Professions, Georgia State University, Atlanta, GA, United States of America.

E-mail addresses: jennalynshackelford@gmail.com (J.L. Shackelford), skelley@gsu.edu (S.J. Kelley), rspratling@gsu.edu (R. Spratling).

¹ Present address: 2391 Heritage Park Circle NW, Kennesaw, GA 30019, United States of America.

found in adolescents with chronic conditions such as CHD, end-stage renal disease, asthma, obesity, and diabetes (Mellion et al., 2014; Varni, Limbers, & Burwinkle, 2007). Adolescence is a developmental period for establishing lifelong health-related behaviors (Schulenberg, Sameroff, & Cicchetti, 2004). Along with developmental changes in adolescence, adolescents with chronic illnesses face challenges related to their HRQOL. Therefore, self-management of care and adherence to treatment is necessary for a successful transition into adulthood and improved HRQOL for adolescents with CHD.

Theoretical background

The Self-Determination Theory (SDT) is a theory of human motivation which emphasizes the psychological aspects of health and personality as well as social development (Ryan & Deci, 2000). The SDT includes three innate psychological needs (relatedness, competence, and autonomy) that are essential for optimal functioning. There is empirical support for the relationship of autonomy, relatedness, and competence for individuals in healthcare settings and maintenance of health-related behaviors and behavioral change (Deci & Ryan, 2000; Deci, Vallerand, Pelletier, & Ryan, 1991). These specific needs and motivations are important for ongoing psychological growth, integrity, and well-being (Deci & Ryan, 2000). Also, there is evidence that adherence to treatment and self-management influence QOL and health status for adolescents with chronic illnesses (Zindani, Streetman, Streetman, & Nasr, 2006). Furthermore, SDT has been used to explain treatment adherence (Kennedy, Goggin, & Nollen, 2004; Williams et al., 2009).

Autonomy

Autonomy is being self-initiating and self-regulating of one's own actions (Deci et al., 1991) and is essential in the development of illness-related self-care behaviors in children and adolescents with chronic illness (Hanna, DiMeglio, & Fortenberry, 2005; Palmer et al., 2004). For autonomy to develop, the adolescent must be ready to assume more responsibility for health-related behaviors (Beacham & Deatrick, 2013). Researchers examined the Self-Determination Theory (SDT) to determine if greater autonomy support predicted more optimal motivational factors toward dietary self-care and if optimal motivational factors predicted better dietary self-care (Austin, Senecal, Guay, & Nouwen, 2011). Their findings indicated that adolescents with Type 1 diabetes who have better autonomous motivation for dietary self-care will have better outcomes with dietary self-care. The SDT was also tested to explain adherence to asthma medication regimens in adolescents with poorly controlled asthma (Bruzzese, Carcone, Lam, Ellis, & Naar-King, 2014). Autonomous motivation did not uniquely predict adherence above and beyond other SDT variables such as perceived confidence and parental support (Bruzzese et al., 2014). In summary, there is a need to clarify the role of autonomous motivation and autonomy support on self-management of care and adherence to treatment among adolescents with chronic illnesses, especially for adolescents with CHD, because of the complexity of care involved.

Relatedness

The development of securing and satisfying connections with others in one's social environment and the desire to love, be loved, and to care is relatedness (Deci et al., 1991; Deci & Ryan, 2000) and is closely connected to social support (Bekesi et al., 2011; Wysocki & Gavin, 2006). Social support is an important aspect of adjustment to living with a chronic illness (Bekesi et al., 2011; Wysocki & Gavin, 2006). For adolescents with chronic illnesses, social support has been related to adherence to medical regimens (Helgeson, Reynolds, Escobar, Siminerio, & Becker, 2007; Kahana, Frazier, & Drotar, 2008; Kyngas, 2004; La Greca, Bearman, & Moore, 2002). Familial social support plays a significant role in healthcare transition for adolescents with chronic illnesses

(Kahana et al., 2008). Peer support has also been associated with improved adherence to treatment for adolescents with diabetes (Helgeson et al., 2007). In addition, social support has been found to impact QOL for adolescents with CHD. Better social support was associated with better HRQOL (Teixeira et al., 2011; Wang, Hay, Clarke, & Menahem, 2014). It is necessary to understand the relationship between the concept of relatedness, namely, those relationships with parents, peers, and providers, and self-management of care and adherence to treatment for a successful transition into adulthood for adolescents with CHD.

Competence

Competence is an understanding of how to attain internal and external outcomes while being effective in performing actions (Deci et al., 1991). Competence is similar to Bandura's (1997) main construct of self-efficacy, and there is evidence that these concepts are similar (Hughes, Galbraith, & White, 2011). Iannotti et al. (2006) and Nouwen, Law, Hussain, McGovern, and Napier (2009) examined the relationship between self-efficacy for diabetes self-management and outcome expectations of diabetes self-management in adolescents with Type 1 diabetes. They found that higher self-efficacy for dietary care had a positive association with better diabetes self-management adherence and glycemic control (Iannotti et al., 2006) and better dietary self-care and less distress in adjustment to living with diabetes (Nouwen et al., 2009). King, Berg, Butner, Butler, and Wiebe (2014) examined parental involvement and adolescent adherence to a diabetes regimen and whether adolescent self-efficacy mediated the effect of parental involvement on adherence. They found more parental involvement has been associated with better adherence to diabetes management because it contributes to higher self-efficacy for self-management of diabetes care. Also, adolescents' self-efficacy mediated maternal acceptance, diabetes monitoring, and adolescent adherence (King et al., 2014). In addition, the relationship between self-efficacy and QOL has been studied in healthy adolescents and those with chronic illnesses. Roeser, Bruckner, Schwerdtle, Schlarb, and Kubler (2012) examined the relationship between general self-efficacy and HRQOL and found self-efficacy to cope with sleep problems was a strong predictor of HRQOL in healthy adolescents. Cramm, Strating, Roebroek, and Nieboer (2013) found general self-efficacy to be a strong predictor of an adolescent's emotional and physical QOL for adolescents with chronic illnesses. However, studies examining the relationship between self-efficacy and HRQOL in adolescents with CHD are missing.

Self-management of care and adherence to treatment

Self-management is defined as the ability to manage symptoms, treatment, physical and psychosocial outcomes, and lifestyle changes when living with a chronic condition (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002). Adherence to treatment is defined as the extent to which the behavior of taking medications, following diets, or executing lifestyle changes coincides with medical advice (Haynes, 1979). Annunziato et al. (2007) found that adolescents with liver transplants have significantly poorer medication adherence compared to child and adult liver transplant recipients. Ringewald et al. (2001) examined nonadherence following heart transplantation with older adolescents demonstrating lower rates of adherence to treatment. A study by Lawson et al. (2011) examined self-reported medication adherence and self-care skills among adolescents with chronic rheumatic disease. There were significant differences between younger and older adolescent groups when completing independent healthcare management tasks (e.g., filling prescriptions, scheduling appointments, arranging transportation, managing insurance, and recognizing adverse symptoms). However, there were no statistically significant differences between groups for medication management (e.g., when to take medications as directed and knowledge about medication names,

purposes, and side effects) and other health care skills (e.g., keeping a calendar of appointments and maintaining a personal medical file) (Lawson et al., 2011).

The relationship between self-management of care or adherence to treatment with HRQOL in adolescents with chronic illnesses has also been examined (Dobbels, Decorte, Roskams, & Van Damme-Lombaerts, 2010; Fredericks et al., 2008). Fredericks et al. (2008) conducted a cross-sectional study examining the relationship between adherence and HRQOL in adolescents with liver transplants. Findings indicated poor adherence behavior was significantly related to numerous domains of HRQOL, including worse physical, social, and school functioning, as well as worse total HRQOL (Fredericks et al., 2008). Dobbels et al. (2010) also examined the relationship among the variables of depression, QOL, treatment adherence, and presence of side effects to immunosuppressive regimens in adolescent liver recipients. Findings indicated no significant differences in comparisons of QOL and depression among patients, parents, and healthy controls or differences in treatment adherence between patients and parents (Dobbels et al., 2010). Further studies examining the relationship between self-management of care or adherence to treatment and HRQOL in adolescents with CHD are needed.

HRQOL

HRQOL is defined as the impact of an illness, medical therapy, or health service on the ability to participate and have satisfaction in the physical, psychological, and social experiences of life (Marino, 2012). When compared with healthy peers, adolescents with CHD had significantly lower HRQOL and lower physical and psychosocial functioning (Knowles et al., 2014) and significantly worse physical, psychosocial, social, and school functioning (Uzark et al., 2008). Spijkerboer et al. (2006) found adolescents with CHD had significantly lower levels of overall HRQOL when compared with healthy peers. In contrast to findings from multiple studies examining HRQOL and CHD, results indicated that adolescents and young adults with CHD had better HRQOL than their healthy peers for social and environmental dimensions of HRQOL (Teixeira et al., 2011). When examining HRQOL across disease severity for adolescents with CHD, researchers have found adolescents with complex CHD had worse physical and psychosocial functioning compared to less complex CHD (Eagleson, Justo, Ware, Johnson, & Boyle, 2013). Also, Mellion et al. (2014) found children and adolescents with complex CHD had significantly worse HRQOL compared with mild and moderate CHD (Luyckx, Missotten, Goossens, & Moons, 2012). In contrast, Spijkerboer et al. (2006) and Teixeira et al. (2011) found no significant differences in HRQOL across disease severity categories for adolescents with CHD. It is important to better understand the relationship between CHD severity and HRQOL because of the variations in findings across studies; therefore, further research focused on this relationship is needed.

While SDT has been applied to adolescents with various chronic diseases (Austin et al., 2011; Bruzzese et al., 2014), it has yet to be applied to either pediatric cardiology or its impact on HRQOL for adolescents with CHD. Therefore, this study fills a gap in the literature through its examination of the relationship among the SDT, self-management of care and adherence to treatment, and application to HRQOL for adolescents with CHD.

The purpose of this study is to examine the relationship among the three innate needs of the SDT (autonomy, relatedness, and competence), self-management of care and adherence to treatment, and its relationship to HRQOL for adolescents with CHD. In the current study, it was hypothesized that (1) higher autonomy, higher relatedness, and higher competence will contribute significant variance to better self-management of care and adherence to treatment; (2) higher autonomy, higher relatedness, and higher competence will contribute significant variance to better HRQOL; and (3) better self-management of care and adherence to treatment will contribute significant variance to better

HRQOL. The HRQOL and Transition of Adolescents with CHD to Self-Manage in Adulthood model was used for this study (Fig. 1). It is a model derived from the SDT model of health behavior adapted from Ryan, Patrick, Deci, and Williams (2008).

Methods

Design

This non-experimental, cross-sectional, correlational study examined the relationship among the three innate needs of SDT, self-management of care and adherence to treatment, and its relationship to HRQOL for adolescents with CHD.

Sample and setting

The calculated sample size was based on a minimum significance value set at an alpha of 0.05, anticipated effect size set at 0.15, and desired statistical power level of 0.80 for 5 predictor variables (Soper, 2015). Therefore, a convenience sample of 92 adolescents with CHD was recruited from 5 outpatient cardiology clinics associated with a large urban children's medical center which serves as the regional referral center for adolescents with CHD.

Self-reported participant characteristics included age, gender, ethnicity, school grade, developmental disabilities, number of parents and siblings in the household, number of medications, medical technology, number of months since the last surgical intervention, and CHD severity level. Participants self-reported their CHD severity by choosing their level of CHD severity (mild, moderate, or severe) on the demographic form. Level of CHD severity was measured using a CHD severity classification system (Hoffman & Kaplan, 2002). Medical records were also examined to confirm categorization of CHD severity. Inclusion criteria were that participants were 13 to 18 years of age, fluent in English, diagnosed with CHD, attended outpatient cardiology appointments, and had consistent school attendance over the past 2 months. Adolescents who had not been attending school regularly over the past 2 months and adolescents with significant chromosomal abnormalities and/or major developmental delays were excluded from the study. Sample characteristics are presented in Table 1.

Measures

Autonomy

Autonomy was measured by the Autonomy subscale of the Basic Psychological Needs Scale (Deci & Ryan, 2001). This self-report, 7-item, Likert subscale assesses the extent to which the psychological needs of autonomy are generally satisfied in an adolescent's life based on a 7-point response scale ranging from 1 (*not true at all*) to 7 (*definitely true*). Total scores were obtained by summing the responses with a potential total score of 7 to 49, with higher scores representing more autonomy. The Basic Psychological Needs Scale has been shown to be both a reliable and valid measure of Autonomy in adolescents (Kuzucu & Simsek, 2013; Simoes & Alarcao, 2013). For the current sample, Cronbach's alpha was 0.56.

Relatedness

Relatedness was measured using the Basic Psychological Needs Scale Relatedness subscale (Deci & Ryan, 2001). The Relatedness subscale of the Basic Psychological Needs Scale is a self-report, 8-item, Likert subscale that assesses relatedness on a 7-point response scale ranging from 1 (*not true at all*) to 7 (*definitely true*). Total scores were obtained by summing the responses with a potential total score of 56, with higher scores representing more relatedness. The Basic Psychological Needs Scale has been shown to be both a reliable and valid measure of Relatedness in adolescents (Kuzucu & Simsek, 2013; Simoes & Alarcao, 2013). For the current sample, Cronbach's alpha was 0.76.

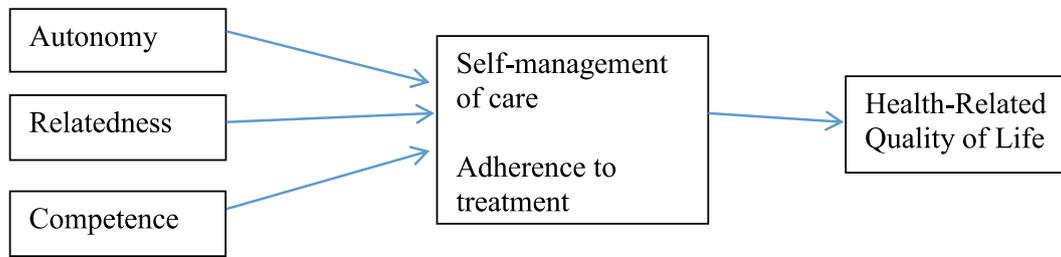


Fig. 1. HRQOL and transition of adolescents with CHD to self-manage in adulthood.

Relatedness was also measured using the Child and Adolescent Social Support Scale (Malecki, Demaray, Elliott, & Nolten, 1999). This self-report, 60-item, Likert type scale assesses perceived social support for adolescents consisting of 5 subscales including 12 items per subscale with 4 types of social support (emotional, informational, appraisal, and instrumental) that correspond to 5 potential sources of social support (parents, teachers, classmates, close friend, and school). This scale measures both frequency and importance of each item using a 6-point Likert scale ranging from 1 (*never*) to 6 (*always*) for frequency, and a 3-point Likert scale ranging from 1 (*not important*) to 3 (*very important*) for importance. Total scores were calculated by summing frequency ratings and importance scores for each subscale. Subscale scores were summed to obtain a total social support scale (Menon & Demaray, 2013), with

total possible scores ranging from 12 to 72. Higher scores represent more social support. The Child and Adolescent Social Support Scale has sound psychometrics for use with adolescents (Alderfer & Hodges, 2010; Malecki & Demaray, 2002). For the current sample, Cronbach's alpha was 0.97.

Competence

The Basic Psychological Needs Scale Competence subscale (Deci & Ryan, 2001) and the Generalized Self-Efficacy Scale (Schwarzer & Jerusalem, 1995) were used to measure competence. The Competence subscale of the Basic Psychological Needs Scale is a self-report, 6-item, Likert subscale that assesses competence on a 7-point response scale ranging from 1 (*not true at all*) to 7 (*definitely true*). Total scores were obtained by summing the responses with a potential total score of 42, with higher scores representing more competence. The Basic Psychological Needs Scale has been shown to be both a reliable and valid measure of Competence in adolescents (Kuzucu & Simsek, 2013; Simoes & Alarcao, 2013). For the current sample, Cronbach's alpha was 0.65.

The Generalized Self-Efficacy Scale is a self-report, 10-item, Likert scale which assesses general perceived self-efficacy of the strength of an individual's belief in their ability to respond to new or difficult situations using a 4-point rating scale from 1 (*not at all true*) to 4 (*exactly true*) for adolescents. Total scores were obtained by summing responses with a possible total score of 10 to 40 points or find a mean score of 1 to 4. The Generalized Self-Efficacy Scale has been found to be valid and reliable with adolescents (Lenganger, Kraft, & Roysamb, 2000; Luszczynska et al., 2010; Luszczynska, Gutierrez-Dona, & Schwarzer, 2005). For the current sample, Cronbach's alpha was 0.86.

Self-management of care and adherence to treatment

The UNC TRxANSITION Scale (Ferris et al., 2012) was used to measure self-management of care and adherence to treatment. This self-report, 32-item, Likert scale assesses disease and treatment knowledge, treatment adherence, and health self-management for adolescents with chronic illness. The scale consists of 10 domains (type of chronic health condition with 3 items, Rx: medications with 4 items, adherence with 3 items, nutrition with 3 items, self-management skills with 7 items, issues of reproduction with 4 items, trade/school with 1 item, insurance with 4 items, ongoing support with 1 item, and new health care providers with 2 items). The scale uses a 3-point rating scale from 0 (*no knowledge/self-management*) to 1 (*complete knowledge/self-management*). Total scores were obtained by summing all sub-domain scores and dividing the raw total score by the total number of eligible questions for a maximum score of 10. Higher scores indicate better disease and treatment knowledge, treatment adherence, and health self-management. The UNC TRxANSITION Scale has been found to be a valid and reliable instrument for adolescents (Cohen et al., 2015; Ferris et al., 2012). For the current sample, Cronbach's alpha was 0.91.

HRQOL

HRQOL was measured using the Pediatric Quality of Life (PedsQL) 4.0 Generic Core Scale (Varni, Burwinkle, Seid, & Skarr, 2003). This self-report, 23-item, Likert scale assesses 4 dimensions of HRQOL (physical functioning with 8 items, emotional functioning with 5 items, social

Table 1
Participant characteristics (N = 92).

Characteristics	M	(SD)	N	(%)
Age (years)	15.36	(1.66)	92	
Gender				
Male			54	(58.7%)
Female			38	(41.3%)
Ethnicity				
White, non-Hispanic			60	(65.2%)
Black or African American			14	(15.2%)
Hispanic			11	(12%)
More than one race			4	(4.3%)
Asian			2	(2.2%)
American Indian or Alaska native			1	(1.1%)
School grade (years)	9.65	(1.75)	92	
Minor developmental disabilities				
Yes			11	(12%)
No			81	(88%)
Type of minor developmental disability				
ADHD			1	
Autism spectrum disorder				
PDD			1	
Autism			1	
DiGeorge syndrome			2	
Other minor developmental disabilities			6	
Number of parents in the household	1.70	(0.49)	92	
Number of siblings in the household	1.75	(1.52)	92	
Number of medications taken per day	1.42	(1.76)	92	
Medical technology used				
Yes			2	(2.2%)
No			90	(97.8%)
Type of medical technology used				
Hearing aids			1	(1.1%)
Pacemaker			1	(1.1%)
Number of months since the last surgical intervention	86.13	(70.43)	53	
Number of months since the last hospitalization	64.07	(66.83)	54	
CHD severity (medical records)				
Mild			40	(43.5%)
Moderate			29	(31.5%)
Severe			23	(25%)
Self-reported CHD severity				
Mild			30	(32.6%)
Moderate			20	(21.8%)
Severe			5	(5.4%)
No response			37	(40.2%)

functioning with 5 items, and school functioning with 5 items) in adolescents with chronic health conditions based on a 5-point rating scale from 0 (*never*) to 4 (*almost always*). Total scores were obtained by summing all the items over the number of items answered on all the scales (range 0 to 100). Scores were transformed on a scale from 0 to 100, and items were reversed scored as follows: 0 = 100, 1 = 75, 2 = 50, 3 = 25, and 4 = 0. Higher scores indicate better HRQOL. The PedsQL 4.0 Generic Core Scale has been shown to be both a reliable and valid measure of HRQOL in healthy and chronically ill children and adolescents, including children with CHD (Bastiaansen, Koot, Bongers, Varni, & Verhulst, 2004; Limbers, Newman, & Varni, 2008; Uzark, Jones, Burwinkle, & Varni, 2003; Varni et al., 2003; Varni et al., 2007; Weissberg-Benchell et al., 2009;). For the current sample, Cronbach's alpha was 0.92.

Procedure

Recruitment of participants began once Institutional Review Board (IRB) approval was obtained from all clinical and university sites. The study participants were recruited using flyers posted and distributed by clinic staff to potential participants, and potential participants were asked by clinic staff about their interest in the study during clinic visits. If potential participants were interested, they were directed to contact the PI in person or by telephone or e-mail. The PI also made herself available in person during clinic visits. After potential participants were screened for eligibility, a face-to-face meeting was scheduled to explain the study and obtain verbal informed consent from parents or guardians or verbal informed assent from participants 17 years or younger, with the PI collecting the survey packet afterwards. If potential participants were unable to meet face-to-face, they were given the option to complete and return a mailed survey packet with a self-addressed, stamped return envelope. The survey packet included a demographic form and five self-report questionnaires. Each participant received or was mailed a \$10 gift card for participating in the study.

Data analysis

Scores of all variables were computed according to instrument instructions provided by the authors. All data were analyzed using SPSS Statistics, Version 24.0. Data were checked for accuracy, normal distribution, missing data, and outliers. Internal consistency reliability for each instrument was calculated for the sample. Demographic data and clinical characteristics (age, gender, ethnicity, school grade, developmental disabilities, number of parents and siblings in the household, number of medications, medication technology, number of months since the last surgical intervention, and CHD severity level), and major theoretical variables (relatedness, competence, autonomy, self-management of care and adherence to treatment, and HRQOL) were summarized by descriptive statistics. Preliminary analyses examined if any covariate (s) would be used in further analysis. Pearson's correlations were used to explore associations between variables with a minimum significance value set at an alpha of <0.05. A one-way analysis of variance (ANOVA) was performed to examine the relationship between CHD severity and HRQOL because CHD severity includes three groups: mild, moderate, and severe. For primary analyses, multiple regression examined the relationship between the SDT variables, self-management of care and adherence to treatment, and HRQOL, controlling for covariate(s) to examine the hypotheses in this study.

Results

Preliminary analyses

Patient demographic data and clinical characteristics were examined with respect to the study variables to determine if any covariate (s) would be used in further analysis. Pearson's correlations were used to explore associations between variables with a minimum significance

value set at an alpha of <0.05. Bivariate correlations were calculated and presented in Table 2 to describe the association among participant characteristics and major study variables. Pearson's correlation coefficients (*r*) were calculated for the normally distributed variables.

As shown in Table 2, age and grade were positively associated with competence (Generalized Self-Efficacy Scale scores) and self-management of care and adherence to treatment (UNC TRxANSITION Scale scores). Ethnicity and number of siblings in the household were positively associated with self-management of care and adherence to treatment. A positive association was found between developmental disabilities present, competence, and self-management of care and adherence to treatment.

The relationship among participant characteristics revealed a negative association between number of medications taken per day, number of months since recent surgical intervention, and number of months since recent hospitalization and HRQOL. However, a positive association was found between developmental disabilities present and HRQOL.

Bivariate correlations were used to examine the relationships among the major study variables and HRQOL, as reported in Table 3. Notably, there were significant associations found between autonomy (Autonomy subscale scores) and competence (Competence subscale scores and Generalized Self-Efficacy Scale scores) and relatedness (Relatedness subscale scores and Child and Adolescent Social Support Scale scores) and HRQOL. Based on bivariate correlations, higher autonomy, higher competence, and higher relatedness were associated with better HRQOL. In addition, a one-way analysis of variance (ANOVA) found that CHD severity was not significantly associated with HRQOL in the current study ($p > .05$).

Primary analyses

Multiple regression analyses were conducted to examine the relationship between the SDT variables, self-management of care and adherence to treatment, and HRQOL, controlling for covariates. Prior to regression analyses, variables were analyzed to check the assumptions for an ANOVA and linear regression. No violations were noted. Special adjustments (dummy variables) were made to nominal variables with more than two categories prior to regression analyses (Kellar & Kelvin, 2013). For regression analyses, the decision was made to dichotomize ethnicity into two groups—White, non-Hispanic and Other Race/

Table 2
Relationships among participant characteristics and major study variables.

	AS	CS	RS	CASTF	CASTI	GSES	UNCT	PedsQL
Age	.09	.07	-.06	.13	.07	.25*	.34**	.03
Grade	.09	.07	-.07	.13	.09	.28**	.44**	.04
Gender	-.05	-.15	-.08	-.10	-.08	.02	-.13	.02
Ethnicity	.12	.00	.03	.03	.00	-.097	.21*	.20
Dev dis	-.09	.12	.02	-.12	-.06	.35**	.29**	.24*
Parents	.06	-.05	.07	.13	.06	.15	.10	.15
Siblings	.00	-.04	.09	.09	.09	-.03	-.28*	.06
Medications	-.01	-.07	.03	.17	.03	-.20	-.01	-.45**
Surgery	.19	.11	-.06	.08	.04	.02	.14	-.23*
Hospital	.14	.07	-.10	.00	-.02	-.02	.14	-.27*
CHD severity ^a								

Note. (2-tailed). AS = Basic Psychological Needs Scale, Autonomy subscale; CS = Basic Psychological Needs Scale, Competence subscale; RS = Basic Psychological Needs Scale, Relatedness subscale; CASTF = Child and Adolescent Social Support Scale Total Frequency; CASTI = Child and Adolescent Social Support Scale Total Importance; GSES = Generalized Self-Efficacy Scale; UNCT = UNC TRxANSITION Scale; PedsQL = PedsQL 4.0 Generic Core Scale; Grade = Current Grade Level; Dev Dis = Developmental Disabilities Present; Parents = Number of Parents in the Household; Siblings = Number of Siblings in the Household; Medications = Number of Medications Taken Per Day; Surgery = Number of Months Since Recent Surgical Intervention; Hospital = Number of Months Since Recent Hospitalization.

* $p < .05$.

** $p < .01$.

^a One-Way ANOVA conducted for CHD severity.

Table 3
Relationships among major study variables.

	1	2	3	4	5	6	7
1. AS							
2. CS	.54**						
3. RS	.50**	.60**					
4. CASTF	.54**	.59**	.59**				
5. CASTI	.35*	.49**	.55**	.72**			
6. GSES	.35**	.55**	.33**	.46**	.36**		
7. UNCT	.25*	.22*	.08	.11	.09	.39**	
8. PedsQL	.29**	.44**	.40**	.22*	.08	.34**	.20

Note. (2-tailed). AS = Basic Psychological Needs Scale, Autonomy subscale; CS = Basic Psychological Needs Scale, Competence subscale; RS = Basic Psychological Needs Scale, Relatedness subscale; CASTF = Child and Adolescent Social Support Scale Total Frequency; CASTI = Child and Adolescent Social Support Scale Total Importance; GSES = Generalized Self-Efficacy Scale; UNCT = UNC TRxANSITION Scale; PedsQL = PedsQL 4.0 Generic Core Scale.

* $p < .05$.

** $p < .01$.

Ethnicity—because the current sample included a majority of White, non-Hispanic participants ($n = 59$).

Stepwise regression was conducted to determine what subset of the demographic data and clinical characteristics to include in further analysis for hypothesis one. All variables left in the model were significant at the 0.05 level. The four demographic variables and clinical characteristics that were related to self-management of care and adherence to treatment for the sample were the following: grade ($p < .001$); minor developmental disabilities present ($p = .0077$); White, non-Hispanic ethnicity ($p = .0276$); and number of siblings in the household ($p = .0412$). The demographic variables accounted for 35.4% variance in self-management of care and adherence to treatment ($R^2 = 0.3541$, $R^2_{adj} = 0.3222$).

Multiple linear regression was conducted to test the individual relationships between self-management of care and adherence to treatment and the variables, autonomy, relatedness, and competence. To control for other factors potentially confounding the relationship between autonomy, competence, relatedness, and self-management of care and adherence to treatment, the additional variables of grade level; minor developmental disabilities present; White, non-Hispanic ethnicity; and number of siblings in the household were added to the equation. Table 4 summarizes the multiple regression analysis for hypothesis one. Regression results indicated the model did not significantly add to the relationship with self-management of care and adherence to treatment ($R^2 = 0.444$, $R^2_{adj} = 0.375$, $F(6, 84) = 2.13$, $p = .0659$) and accounted for 44.4% of the variance. The β weights

Table 4
Results of multiple linear regression of contributors to self-management and adherence to treatment ($N = 90$).

Variable	b weights	Std. B weights	T	p-Value
Intercept	-5.0142		2.51	.143
AS	0.0697	0.0690	1.71	.922
CS	0.0080	0.0076	0.16	.8765
RS	-0.0040	-0.0047	-0.11	.9162
CASTF	-0.0079	-0.0654	-1.17	.2447
CASTI	0.0076	0.0314	0.61	.5441
GSES	1.0402	0.0830	1.96	.0540
Siblings	-0.2714	-0.0683	-2.13	.0364
White, non-Hispanic	0.8542	0.0695	2.18	.0322
Grade	0.4213	0.1241	3.72	.0004
Dev dis	1.1122	0.0618	1.75	.0837

Note. AS = Basic Psychological Needs Scale, Autonomy subscale; CS = Basic Psychological Needs Scale, Competence subscale; RS = Basic Psychological Needs Scale, Relatedness subscale; CASTF = Child and Adolescent Social Support Scale Total Frequency; CASTI = Child and Adolescent Social Support Scale Total Importance; GSES = Generalized Self-Efficacy Scale; Siblings = Number of Siblings in the Household; White, non-Hispanic = White, non-Hispanic Ethnicity; Grade = Current Grade Level; Dev Dis = Developmental Disabilities Present.

indicated that autonomy, relatedness, and competence did not significantly contribute to self-management of care and adherence to treatment when controlling for demographic variables. Although, the adjusted R^2 differed slightly from 0.322 to 0.3750 when controlling for demographic variables, this was not significant. Therefore, autonomy, relatedness, and competence did not contribute significant variance to better self-management of care and adherence to treatment.

For hypothesis two and three, stepwise regression was conducted to determine what subset of the demographic data and clinical characteristics to include in further analysis. All variables left in the model were significant at the $p < .1$ level. No other variables met the $p < .1$ significance level for entry into the model. The four demographic variables and clinical characteristics that were related to HRQOL for the sample were the following: minor developmental disabilities present ($p = .0611$); White, non-Hispanic Ethnicity ($p = .0185$); number of medications taken per day ($p = .0001$); and hospitalizations ($p = .0478$). The demographic variables accounted for 30.6% variance in HRQOL ($R^2 = 0.3057$, $R^2_{adj} = 0.2734$).

Multiple linear regression was conducted to test the relationships between the variables autonomy, relatedness, and competence, and HRQOL for hypothesis two. To control for other factors potentially confounding the relationship between autonomy, competence, relatedness, and HRQOL, the additional variables of minor developmental disabilities present; White, non-Hispanic ethnicity; number of medications taken per day; and hospitalizations were added to the equation. Table 5 summarizes the multiple regression analysis for hypothesis two. Regression results indicated the model did significantly add to the relationship with HRQOL ($R^2 = 0.5552$, $R^2_{adj} = 0.4996$, $F(6, 84) = 7.49$, $p < .0001$) and accounted for 55.5% of the variance. The β weights indicated that two variables, higher competence (Competence subscale scores: $\beta = 0.7896$, $t = 2.37$, $p = .0204$) and higher relatedness (Relatedness subscale scores: $\beta = 0.6403$, $t = 2.58$, $p = .0116$), significantly contributed to HRQOL when controlling for demographic variables. The β weights indicated that less importance of social support significantly contributed to HRQOL (Child and Adolescent Social Support Scale Importance scores: $\beta = -0.2217$, $t = -2.96$, $p = .0041$) when controlling for demographic variables. The adjusted R^2 increased from 0.2734 to 0.4996, which was significant. Therefore, competence and relatedness contributed significant variance to better HRQOL; however, autonomy did not.

For hypothesis three, multiple linear regression results indicated the model did not significantly add to the relationship with HRQOL ($R^2 = 0.3250$, $R^2_{adj} = 0.2853$, $F(1, 89) = 2.43$, $p = .1263$) and accounted for 32.5% of the variance. Table 6 summarizes the multiple regression analysis for hypothesis three. The β weights indicated that self-management of care and adherence to treatment did not significantly contribute to HRQOL when controlling for demographic variables. The

Table 5
Results of multiple linear regression of contributors to health-related quality of life ($N = 90$).

Variable	b weights	Std. B weights	T	p-Value
Intercept	25.6953		2.06	.0430
AS	0.0708	0.0260	0.26	.7959
CS	0.7896	0.2761	2.37	.0204
RS	0.6403	0.2820	2.58	.0116
CASTF	0.0557	0.1717	1.25	.2163
CASTI	-0.2217	-0.3386	-2.96	.0041
GSES	0.7291	0.0216	0.21	.8379
Dev dis	6.0455	0.1246	1.42	.1602
White, non-Hispanic	6.5571	0.1979	2.56	.0124
Medications	-3.4842	-0.3852	-4.55	<.0001
Hospital	-5.9204	-0.1838	-2.24	.0276

Note. AS = Basic Psychological Needs Scale, Autonomy subscale; CS = Basic Psychological Needs Scale, Competence subscale; RS = Basic Psychological Needs Scale, Relatedness subscale; CASTF = Child and Adolescent Social Support Scale Total Frequency; CASTI = Child and Adolescent Social Support Scale Total Importance; GSES = Generalized Self-Efficacy Scale; Dev Dis = Developmental Disabilities Present; White, non-Hispanic = White, non-Hispanic Ethnicity; Medications = Number of Medications Taken Per Day; Hospital = History of Recent Hospitalization.

Table 6
Results of multiple linear regression of contributors to health-related quality of life (N = 90).

Variable	b weights	Std. B weights	T	p-Value
Intercept	65.0063		7.01	.0001
UNCT	1.1418	0.1515	1.54	.1265
Dev dis	5.9419	0.1224	1.26	.2107
White, non-Hispanic	6.2247	0.1878	2.03	.0460
Medications	-3.3687	-0.3723	-4.03	.0001
Hospital	-7.0385	-0.2185	-2.29	.0246

Note. UNCT = UNC TRxANSITION Scale; Dev Dis = Developmental Disabilities Present; White, non-Hispanic = White, non-Hispanic Ethnicity; Medications = Number of Medications Taken Per Day; Hospital = History of Recent Hospitalization.

adjusted R^2 increased slightly from 0.2734 to 0.2853, but this was not significant. Therefore, self-management of care and adherence to treatment did not contribute significant variance to better HRQOL.

Discussion and conclusion

The current study examined the relationship among the Self-Determination Theory (SDT), self-management of care and adherence to treatment, and its relationship to HRQOL for adolescents with CHD. For hypothesis one, the results of regression analysis demonstrated that the model exploring the relationship between autonomy, relatedness, and competence explained additional variance in self-management of care and adherence to treatment when controlling for background variables. However, no SDT variables were found to significantly contribute to the model. Contrary to the hypothesis, the findings did not support hypothesis one because higher autonomy, higher relatedness, and higher competence did not significantly contribute to better self-management of care and adherence to treatment when controlling for background variables.

Although studies including adolescents with chronic illnesses provide insight, this was the first known study to examine the influence of autonomy on self-management of care and adherence to treatment for adolescents with CHD. Autonomy has been found to be an essential factor in the development of illness-related self-care behaviors in children and adolescents with chronic illnesses (Hanna et al., 2005; Palmer et al., 2004). Researchers have found that greater autonomous motivation was associated with better dietary self-care in adolescents with Type 1 diabetes (Austin et al., 2011). Also, higher autonomous motivation has been positively associated with higher asthma adherence for adolescents with poorly controlled asthma (Bruzzese et al., 2014). The findings from the current study differed from previous research examining the relationship between autonomy and self-management of care and adherence to treatment for adolescents with chronic illnesses. Results indicated a weak correlation, and regression results found no significant relationship between autonomy and self-management and adherence to treatment for adolescents with CHD.

The relationship between relatedness, or social support, and self-management of care and treatment adherence has been studied in adolescents with chronic illnesses. Better familial social support has been associated with better treatment adherence in adolescents with chronic illnesses, including those with renal, liver, heart, and lung transplants (Kahana et al., 2008). Also, better peer support has been associated with improved adherence in adolescents with diabetes (Helgeson et al., 2007; Wysocki & Gavin, 2006) and asthma (Terpstra, Chavez, & Ayala, 2012). Despite a significant correlation between relatedness and self-management of care and adherence to treatment in the current study, the results of the regression analysis suggested that relatedness did not contribute significant variance to self-management of care and adherence to treatment.

Studies have indicated more competence, or self-efficacy, has been associated with performing increased self-management of care and better treatment adherence. Research has found higher perceived self-efficacy scores have been associated with higher self-management

scores in adolescents and young adults with CHD and heart transplants (Uzark et al., 2015). Also, in a study of adults with CHD, higher self-care self-efficacy significantly contributed to better self-management (McCabe et al., 2015). In the current study, competence and self-management of care and adherence to treatment were moderately, significantly correlated using the Generalized Self-Efficacy Scale; however, there was no correlation using the Competence subscale. The correlation results in the current study and the findings in the literature demonstrate that better self-efficacy was associated with better self-management. However, when examining competence in a multivariate model, competence did not contribute significant variance to self-management of care and adherence to treatment.

The background variables accounted for a large amount of variance in self-management of care and adherence to treatment. When autonomy, relatedness, and competence were added to the equation, the regression model explained additional variance in self-management and adherence to treatment. However, the results indicated that autonomy, relatedness, and competence did not significantly add to the relationship with self-management of care and adherence to treatment.

For hypothesis two, the results of the regression analysis demonstrated that autonomy, relatedness, and competence explained a large amount of additional variance in HRQOL when controlling for background variables. Higher competence and higher relatedness significantly contributed to better HRQOL. Also, social support being of less importance to adolescents with CHD significantly contributed to better HRQOL. Relatedness and competence accounted for a large amount of additional variance in HRQOL. Therefore, the findings partially supported hypothesis two because higher relatedness and higher competence significantly contributed to better HRQOL when controlling for background variables.

Results indicated a significant relationship between relatedness and HRQOL for adolescents with CHD. As stated previously, higher relatedness, or social support, has been found to be associated with better QOL for adolescents with CHD (Teixeira et al., 2011; Wang et al., 2014). The findings in this study also suggested that social support being of less importance to adolescents with CHD significantly influenced better HRQOL. Based on similarities between current study findings and the previous literature including adolescents with CHD, interventions focused on improving social support networks and collaboration among parents, peers, and providers may significantly improve an adolescent's HRQOL.

Based on the significant findings between competence and HRQOL, higher competence significantly contributed to better HRQOL. This study extends previous research documenting the significant relationship between more competence and better HRQOL for adolescents with chronic illnesses including CHD (Cramm et al., 2013; Roeser et al., 2012; Uzark et al., 2015). As stated previously, more competence, or self-efficacy, has been found to be a strong predictor of HRQOL in adolescents with chronic illnesses (Cramm et al., 2013; Roeser et al., 2012). In addition, findings indicated a significant relationship between higher self-efficacy and higher QOL in adolescents and young adults with heart disease and heart transplants (Uzark et al., 2015). The findings of the current study are consistent with the literature and indicate a need to develop and test interventions to improve self-efficacy which may improve HRQOL for adolescents with CHD as they prepare for the transition into adulthood.

It is noteworthy that the background variables accounted for a large amount of variance in HRQOL in the study. In addition, the regression results indicated that relatedness and competence did significantly add to the relationship with HRQOL. Relatedness and competence accounted for additional variance in HRQOL, which was important.

Overall, the findings suggested the importance of improving relatedness and competence during adolescence to increase HRQOL before the transition into adulthood. Although results suggested autonomy influenced HRQOL, the correlation was weak. When examining autonomy in a regression model, autonomy did not significantly add to the

relationship with HRQOL. This was an important finding because it suggested that more relatedness and competence had greater impact on better HRQOL than autonomy. However, it is difficult to make conclusions about the relationship between autonomy and HRQOL because the Autonomy subscale had less than adequate reliability for the sample. Improving support networks among parents, peers, and healthcare providers while also providing better education and interventions to increase competence during adolescence may improve HRQOL for adolescents with CHD.

For hypothesis three, the results of the regression analysis demonstrated that self-management of care and adherence to treatment accounted for a small amount of additional variance of HRQOL when controlling for background variables. However, self-management of care and adherence to treatment did not significantly contribute to better HRQOL. Therefore, the findings did not support hypothesis three because better self-management of care and adherence to treatment did not significantly contribute to better HRQOL when controlling for background variables.

Findings indicated that there was not a significant relationship between self-management of care and adherence to treatment and HRQOL for adolescents with CHD. These findings differed from a study including adolescents with chronic illnesses where poor adherence behavior was significantly related to worse HRQOL (Fredericks et al., 2008). Dobbels et al. (2010) examined adolescent QOL and treatment adherence in adolescent liver transplant recipients. In contrast to the study by Fredericks et al. (2008), there was not a significant relationship between adolescent QOL and treatment adherence (Dobbels et al., 2010). The findings in the current study were consistent with previous research by Uzark et al. (2015) with adolescent and young adults with CHD and heart transplants that found higher PedsQL Psychosocial Functioning scores were not significantly associated with better self-management.

Although it was hypothesized that self-management of care and adherence to treatment would add significant variance to HRQOL based on previous literature with adolescents with chronic illnesses, the hypothesis was not supported for adolescents with CHD in the current study. Findings suggested self-management of care and adherence to treatment may not be essential for improving HRQOL when compared with other variables such as relatedness and competence.

Limitations of the study

Despite the contributions of this study, it is limited by the representativeness of the sample. Given geographic and recruitment limitations, the sample may not be representative of all adolescents with CHD. Recruitment was limited to several clinics in a large metropolitan area in the Southeastern U.S. Another limitation is the use of a non-randomized sample. While the participants had similar CHD severity levels and developmental disabilities compared to the population of adolescents with CHD in the U.S., the sample was relatively homogenous in regard to race. The racial diversity of the sample was not similar to that of adolescents with CHD in the U.S. In addition, the sample included 43.5% with mild CHD; therefore, overrepresentation of mild CHD may limit generalizability of the results. Another limitation included the small sample size and missing data. While the goal of 92 participants was achieved, several participants did not fully complete each survey. This may have been the result of conducting the study in an outpatient clinic where there are often time constraints, and some participants may have experienced respondent fatigue, as some of the instruments were lengthy. The Competence and Autonomy subscales of the Basic Psychological Needs Scale have empirical support for use with a large sample of adolescents; however, these subscales had less than adequate reliability for the present sample. This may have been the result of a smaller sample size with missing data for the two subscales. The Generalized Self-Efficacy Scale, which was also used to examine competence, demonstrated acceptable reliability. In regard to autonomy, there is

currently no widely-accepted instrument for measuring autonomy in adolescents with CHD, and the measure used in this study has not been used in other studies with this population. Therefore, it is difficult to make conclusions about the relationship between autonomy and other variables in this study because of low reliability for the Autonomy subscale. Future research should develop and test more reliable questionnaires to measure autonomy in this population. Finally, the cross-sectional, correlational study design was another limitation, as causality could not be established.

There are several possible explanations why some of the findings in our study differ from those found in prior research with adolescents with chronic illnesses. First, coping with CHD may have qualities that differ from other pediatric chronic illnesses. Second, almost half of the participants had mild CHD which could have impacted their HRQOL. Lastly, some of our findings could have differed due to measurement issues or the fact our sample was fairly homogenous.

Implications for nursing practice

Nursing care should focus on the improvement of social support systems and interventions to increase self-efficacy for adolescents with CHD. It is essential for healthcare providers, such as nurses, to provide resources and programs to prepare and support adolescents with CHD and their families for the transition into adulthood. Nurses can assess and help determine which type of social support, whether from peers, parents, or healthcare providers, is most important in meeting adolescents' specific needs. Also, nurses can encourage open communication between adolescents, parents, and providers.

Encouraging better competence, or self-efficacy, is essential to improving HRQOL for adolescents with CHD. Nurses can aid in enhancing self-care-related self-efficacy that includes being responsible for scheduling clinic appointments, communicating with providers, learning about medications and how to secure insurance coverage, as well as taking medications as prescribed. By assisting adolescents with CHD in establishing lifelong health-related behaviors, they may have a more successful transition into adulthood and better HRQOL.

In the current study, the self-reported CHD severity level differed from medical records, demonstrating missing knowledge concerning the level of severity of CHD among adolescents with CHD. It is also possible that some participants interpreted the item asking them to self-report their CHD severity as referring to how CHD has impacted their life as opposed to its medical classification. Nurses must educate adolescents about their CHD severity level so that they may better understand health complications, future medical and surgical management, and expectations of self-care associated with their CHD as they transition into adulthood. This understanding may promote better self-management of care and adherence to treatment and HRQOL.

Suggestions for future research

First, this study should be replicated using a larger, more representative sample of adolescents with CHD. Second, this was the first known study to examine the relationship among the SDT, self-management of care and adherence to treatment, and HRQOL for adolescents with CHD. Findings suggest the importance of relatedness and competence in improving HRQOL and an association between autonomy and HRQOL; however, future research is needed to expand on these findings with adolescents with CHD and other pediatric populations with chronic illness. Also, a better understanding of the influence of self-management of care and treatment adherence on HRQOL is essential for adolescents with CHD as they transition into adulthood. Lastly, intervention studies focused on improving social support and self-efficacy are needed for adolescents with chronic illness.

Conclusion

The findings in this study add to the body of knowledge about relationships among the SDT variables, self-management of care and adherence to treatment, and HRQOL for adolescents with CHD. This was the first known study to examine these relationships for adolescents with CHD. Not only are autonomy, relatedness, and competence positively correlated with HRQOL, but relatedness and competence contributed to better HRQOL for these adolescents. This study expanded upon evidence supporting the importance of improving social support networks and developing interventions to enhance self-efficacy that may ultimately lead to improved HRQOL adolescents living with CHD.

CRedit authorship contribution statement

Jenna L. Shackelford: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Software, Supervision, Validation, Visualization, Writing - original draft, Writing - review & editing. **Susan J. Kelley:** Conceptualization, Methodology, Supervision, Validation, Visualization, Writing - original draft, Writing - review & editing. **Regena Spratling:** Conceptualization, Methodology, Supervision, Validation, Visualization, Writing - original draft, Writing - review & editing.

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