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Risk-Taking Behaviors in Adolescents With Chronic Cardiac Conditions: A Scoping Review

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ABSTRACT

Problem: Advances in treatment and therapy for children with chronic cardiac conditions have extended their life expectancy. Risk-taking behavior among adolescents requires further exploration. Researchers conducted a scoping review to address a literature gap specific to risk-taking behavior among adolescents with chronic cardiac conditions.
Eligibility criteria: Sources were limited to (1) human subjects, (2) English language or translatable to English, (3) adolescents without age restrictions, (4) all research designs and (5) presence of a chronic cardiac condition.
Sample: Searches of six electronic databases (CINAHL Plus Full Text, PubMed, Web of Knowledge, Scopus, ProQuest and Grey Literature Report) were conducted to verify the empirical literature between 1975 and 2018. Seventeen sources were included in this review.
Results: Among the 17 sources, 12 sources examined risk-taking behavior by self-report among adolescents with chronic cardiac conditions. Tobacco, alcohol and/or other drug use and physical inactivity were the most prevalent risk-taking behaviors identified through this review.
Conclusions: Findings from this scoping review describe the types of risk-taking behaviors that adolescents with chronic cardiac conditions are engaging in, highlight similarities when compared to other types of chronic conditions, and serve as a foundation for future research among this population.
Implications: Discussion of risk-taking behaviors should be integrated into each healthcare encounter beginning in early adolescence and continuing through transition to adulthood and adult health care. Qualitative research studies may serve as an effective method by which to explore risk-taking behavior among adolescents with chronic cardiac conditions in greater detail.

Introduction

Chronic cardiac conditions may be congenital, acquired, or idiopathic. Each variation has a unique impact on a child's transition into adolescence. Congenital Heart Disease (CHD) and cardiomyopathies are the most common causes of cardiac failure among children. Other causes include arrhythmias, infections, or disease processes that cause high cardiac output (Masarone et al., 2017). Management of cardiomyopathies and other types of acquired or idiopathic cardiac conditions can be complex, based on variations in the severity of associated arrhythmia and heart failure (Yuan, 2018). Most children with cardiomyopathy or other types of mild to moderate cardiac dysfunction can be successfully managed with medical therapies (Masarone et al., 2017).

CHD, on the other hand, is best managed with planned, corrective or palliative surgical intervention (Masarone et al., 2017). The first successful repair of a congenital heart defect occurred in 1953, marking an evolution of treatment and therapies that have extended life expectancy, even for the most complex defects (Triedman & Newburger, 2016). Each year, approximately 10,000 children born with CHD require surgical intervention, and 85% to 90% will survive into adulthood (Triedman & Newburger, 2016). In 2000, the first survivors of the Norwood procedure for Hypoplastic Left Heart Syndrome (HLHS) reached adulthood, marking the first time in history that adult CHD patients outnumbered children with the same diagnosis (Lacina, 2009). Increased survival rates, along with advances in treatment modalities, allow for more adolescents to manage their chronic cardiac condition in the home setting. Return to school and social activities is encouraged as part of transition into adolescence, adding an additional layer of complexity in treatment and management (Berg, Snell, & Mahle, 2007; Birks, 2018; Birnbaum et al., 2015; Conway et al., 2016; D'Alessandro et al., 2012; Rossano et al., 2016; Stein et al., 2016; Triedman & Newburger, 2016).

Adolescence is marked by the onset of physiologically normal puberty and culminates when adult behavior and identity is recognized and accepted; its end is not clearly demarcated (Adolescent Health

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Committee, 2003). Adolescence is a volitional time, often impacted by social and cultural norms (Arnett, 2000). Risk-taking, an expected part of adolescent development, is essential for growth and maturation. Risky sexual behavior, substance abuse and violent acts are a health concern for all adolescents, including those with chronic cardiac conditions (Kaufman, 2006; Suris, Michaud, Akre, & Sawyer, 2008).

Adolescents may have decreased knowledge of their cardiac diagnosis, requirements for routine follow-up, activity recommendations or restrictions, and health risks, including ones that are sexual or reproductive in nature (Uzark et al., 2015). Routine cardiac care may focus on treatment compliance to preserve cardiovascular health, however, addressing risk-taking behavior as part of normal adolescent development is an essential component of modern management (Barsell, Everhart, Miadich, & Trujillo, 2018; Kaufman, 2006; Kunz et al., 2014; Pilapil & DeLaet, 2015; Reid, Irvine, McCrindle, Sananes, & Ritvo, 2004; Rianthavorn et al., 2004).

The availability of advanced therapies may encourage adolescents to downplay, forget, or ignore their condition because they feel healthy, and are able to receive treatment in an outpatient setting instead of the hospital, minimizing disruption to daily routines. Moreover, adolescents with cardiomyopathies may be asymptomatic or undiagnosed until they reach adolescence (Ellims, 2017). They may demonstrate a normal outward appearance, and identify and connect better with their peers, yet still feel anger or resentment towards their condition (Kaufman, 2006).

Scientists have conducted research specific to risk-taking behaviors among healthy adolescents and adolescents with chronic health conditions (Leelathipkul & Arunakul, 2018; Suris et al., 2008; Weitzman, Ziemnik, Quian, & Levy, 2015). Risk-taking behavior in the presence of a chronic cardiac condition may increase the likelihood of clinical complications from treatment non-compliance or adverse events (Barsell et al., 2018; Engelman et al., 2017; Kunz et al., 2014; Pilapil & DeLaet, 2015; Reid, Webb, McCrindle, Irvine, & Siu, 2008; Reid et al., 2004, Rianthavorn, Ettenger, Malekzadeh, Marik, & Struber, 2004;). Reid, Webb, et al. (2008) cite the need for additional research exploring risk-taking behavior among adolescents with chronic cardiac conditions.

Rationale

We conducted a scoping review, a comprehensive systematic methodology that considers various types of existing literature to examine existing evidence and map key concepts specific to risk-taking behavior in adolescents with chronic cardiac conditions (Peters et al., 2015). This literature review methodology was based on the framework by Arksey and O'Malley (2005), the recommendations from Levac, Colquhoun, and O'Brien (2010) and guidelines from the Joanna Briggs Institute (Peters et al., 2015), all of which informed the development of the PRISMA extension for scoping reviews (PRISMA ScR) (Tricco et al., 2018). The scoping review process involved the following steps: 1) establish scoping questions, 2) develop a search strategy that incorporated refereed material as well as grey literature, 3) execute searches of selected databases using key terms specific to risk-taking behavior among adolescents, 4) review all abstracts and grey literature returned through searches for relevance to scoping questions, 5) select sources that met inclusion criteria for thorough review, 6) chart data specific to risk-taking behaviors among adolescents with chronic cardiac conditions, and 7) collate, summarize and report the results, including implications for policy, practice and future research.

Objectives

The purpose of this scoping review was to address a literature gap specific to risk-taking behavior among adolescents with chronic cardiac conditions. The first objective was to describe the risk-taking behaviors among adolescents with chronic cardiac conditions. The second objective was to map concepts of risk-taking behavior among adolescents with chronic cardiac conditions and compare results with the six health-risk behaviors in the Youth Risk Behavior Survey (YRBS). The scoping questions were: 1) What are the risk-taking behaviors among adolescents with chronic cardiac conditions? and 2) How do the risk-taking behaviors of adolescents with chronic cardiac conditions compare to the YRBS health-risk behaviors?

Methods

Eligibility criteria

The search strategy was refined through iterative discussion among authors and in consultation with a local expert on risk-taking behavior among adolescents. The sources were limited to: 1) human subjects, 2) English language or translatable to English, 3) adolescents without age restrictions, 4) all research designs and 5) presence of a chronic condition. All peer reviewed, published literature meeting criteria was screened for eligibility. Abstracts were excluded from the scoping review if the primary population focused on: 1) adults, 2) mental health disorders, 3) pain as the primary chronic condition, 4) chronic conditions secondary to risk-taking behavior, and 5) healthy populations.

Information sources and search strategy

Searches of six electronic databases (CINAHL Plus Full Text, PubMed, Web of Science, Scopus, ProQuest and Grey Literature Report) were conducted to verify the empirical literature through 2018. We chose not to limit publication date due to the known gap in literature specific to risk taking behaviors among adolescents with chronic cardiac conditions. The earliest record found was published in 1979, and the most recent in 2018. Medical subject heading (MEsH) keywords used in each search were: adolescents, teenagers, young adults, teen, youth, heart failure, cardiac failure, chf, chronic heart failure, congestive heart failure, risk-taking behavior, and risky behavior. Attempts were made to contact authors whose work may have been updated after publication or dissemination. See Appendix A for full search strategy.

The initial search of databases resulted in 932 records. Two additional sources were added after review of relevant reference lists. Nine hundred and two sources remained after the removal of duplicates. One hundred and two sources were included in the first stage of screening of titles and abstracts. Forty-three sources progressed to full-text screening. Based on our eligibility criteria, 17 sources were included in this review (see Fig. 1).

Data charting process

Data from eligible sources were charted in a two-stage screening process using a standardized tool developed for this review. The charting document captured key elements from each source, documented risk-taking behaviors, measurement scales and main findings. Charting was an iterative process, and the document was expanded in the second stage of full-text screening to abstract the origin of each source, sample size, setting, presence of a chronic cardiac condition, measures, and findings for included sources. Full-text screening was completed independently by the first two authors, and conflicts were resolved through discussion and consensus. If unable to reach consensus, the third author was consulted to determine inclusion.

Data items

The authors defined “chronic cardiac condition” as having at least one of the following conditions for a period of three months or longer: 1) CHD; 2) inflammatory heart disease (cardiomyopathy, pericardial disease, and valvular disease); 3) heart failure; 4) arrhythmias and 5) rheumatic heart disease (Adams, Kirzinger, & Martinez, 2013; World Heart Federation, n.d.).

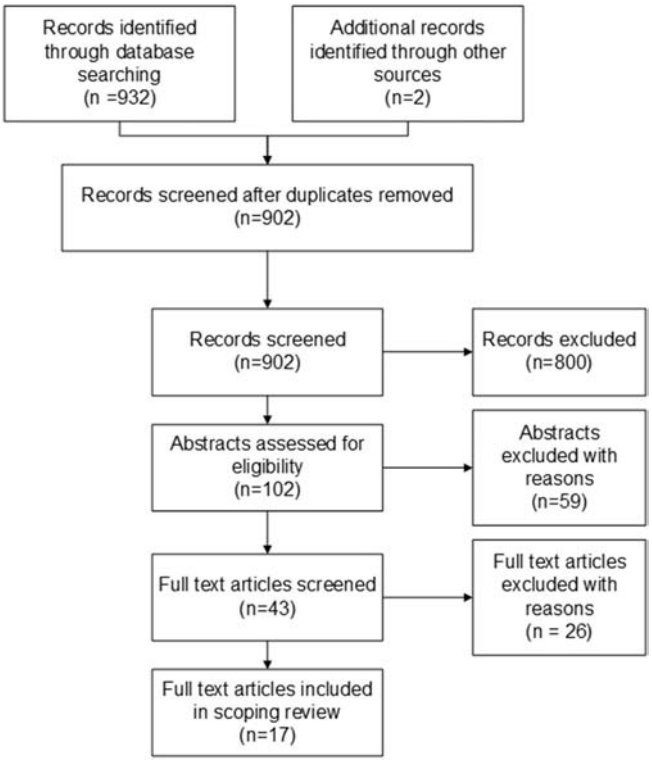

Fig. 1. Identification of sources in scoping review.

We categorized risk-taking behavior based on the 2017 YRBS priority health-risk behaviors: 1) unintentional injury/violence; 2) tobacco; 3) alcohol/other drugs; 4) sexual behaviors including unintended pregnancy, HIV and STI; 5) unhealthy diet; and 6) physical inactivity (Kann et al., 2018). The YRBS was developed by the Centers for Disease Control and Surveillance in the 1990s to monitor health behaviors that contribute to the leading causes of death, disability or social problems among youth in the US. The YRBS is a major source of nationally representative information about adolescent health risk and protective behaviors, and is comparable among subpopulations of youth (Kann et al., 2018).

Quality of evidence

The strength and quality of evidence was appraised using and the Johns Hopkins Nursing EBP Evidence Level and Quality Guide (Dang & Dearholt, 2017).

Synthesis of results

Results were synthesized based on study design and outcome, origin and year of publication, type of risk-taking behavior, participant age, and type of chronic cardiac condition. Table 1 provides an expanded summary of articles from the United States and Canada, sequenced in reverse chronological order, about risk-taking behavior among adolescents with chronic cardiac conditions. Appendix B includes a summary of articles from other countries. Additional synthesis of the risk-taking behaviors described among adolescents with chronic cardiac conditions by author and year is detailed in Table 2.

Results

Characteristics of included studies

Fourteen sources employed quantitative, descriptive, survey methodology (Barsell et al., 2018; Chen et al., 2007; Engelman et al., 2017; Goossens et al., 2013; Goossens et al., 2015; Gubelmann et al., 2018; Kendall et al., 2007; Kunz et al., 2014; Lesch et al., 2014; Luyckx et al., 2011; Massin et al., 2007;Reid et al., 2004; Reid, Siu, et al., 2008; Reid, Webb, et al., 2008). One source utilized descriptive mixed methods (Stilley et al., 2006). Two sources were non-research based descriptions of risk-taking behaviors among adolescents with chronic cardiac conditions (Dobbels et al., 2005; Pilapil & DeLaet, 2015). Seven sources were from the US ($n = 4$) (Barsell et al., 2018; Kunz et al., 2014; Pilapil & DeLaet, 2015; Stilley et al., 2006) and Canada ($n = 3$) (Reid et al., 2004; Reid, Siu, et al., 2008; Reid, Webb, et al., 2008). Eight sources were published between 2013 and 2018 (Barsell et al., 2018; Engelman et al., 2017; Goossens et al., 2013; Goossens et al., 2015; Gubelmann et al., 2018; Kunz et al., 2014; Lesch et al., 2014; Pilapil & DeLaet, 2015).

Characteristics of included samples

Thirteen sources examined risk-taking or health-risk behaviors among adolescents with CHD (Goossens et al., 2013; Goossens et al., 2015; Kendall et al., 2007; Lesch et al., 2014; Luyckx et al., 2011; Massin et al., 2007; Pilapil & DeLaet, 2015; Reid et al., 2004; Reid, Siu, et al., 2008; Reid, Webb, et al., 2008), Rheumatic Heart Disease (Engelman et al., 2017), and heart transplant recipients (Dobbels et al., 2005; Stilley et al., 2006). The exact type of chronic cardiac condition was unspecified in three sources (Barsell et al., 2018; Gubelmann et al., 2018; Kunz et al., 2014). One source compared health promoting behavior among adolescents with CHD and those without (Chen et al., 2007).

Participant age ranged between 7 (Kendall et al., 2007) and 37 years (Barsell et al., 2018). The most common range was between 14 and 19 years of age ($n = 5$) (Engelman et al., 2017; Goossens et al., 2013; Goossens et al., 2015; Kunz et al., 2014; Luyckx et al., 2011). Two sources did not specify an age range (Dobbels et al., 2005; Pilapil & DeLaet, 2015). Two sources recruited specific samples comprised of college students (Barsell et al., 2018), or mother-daughter dyads (Kunz et al., 2014).

Characteristics of risk-taking behaviors

Thirteen sources cited behaviors consistent with the six priority categories of risk-taking behavior in the YRBS (Chen et al., 2007; Goossens et al., 2013; Goossens et al., 2015; Gubelmann et al., 2018; Kendall et al., 2007; Kunz et al., 2014; Luyckx et al., 2011; Massin et al., 2007; Pilapil & DeLaet, 2015; Reid et al., 2004; Reid, Siu, et al., 2008; Reid, Webb, et al., 2008; Stilley et al., 2006). Four sources cited substance abuse as risk-taking behavior (Barsell et al., 2018; Gubelmann et al., 2018; Luyckx et al., 2011; Reid et al., 2004). Additional risk-taking behaviors were specific to poor oral hygiene (Chen et al., 2007; Goossens et al., 2015; Reid, Webb, et al., 2008); antisocial behavior (Goossens et al., 2013; Gubelmann et al., 2018; Luyckx et al., 2011); medication or treatment non-compliance (Dobbels et al., 2005; Engelman et al., 2017; Reid et al., 2004); missed appointments, tattoos and piercings (Stilley et al., 2006); and excessive internet use, and excessive gambling (Gubelmann et al., 2018).

Twelve sources examined self-reported risk-taking behavior (Chen et al., 2007; Engelman et al., 2017; Goossens et al., 2013; Goossens et al., 2015; Gubelmann et al., 2018; Kendall et al., 2007; Luyckx et al., 2011; Massin et al., 2007; Reid et al., 2004; Reid, Siu, et al., 2008; Reid, Webb, et al., 2008; Stilley et al., 2006). Tobacco and/or alcohol and other drug use was predominant among self-reported behaviors in seven sources (Goossens et al., 2013; Goossens et al., 2015; Gubelmann et al., 2018; Luyckx et al., 2011; Massin et al., 2007; Reid, Webb, et al., 2008; Stilley et al., 2006). Physical inactivity was prevalent among self-reported behaviors in four sources (Goossens et al., 2015; Kendall et al., 2007; Massin et al., 2007; Stilley et al., 2006), along with unhealthy diet in three sources (Gubelmann et al., 2018; Massin et al., 2007; Stilley et al., 2006). Sexual behaviors including unintended

Table 1
Expanded summary of risk-taking behavior among adolescents with chronic cardiac conditions in the United States (US) and Canada (ascending order).

Author (year)	Country	Purpose	Total N (n = cardiac)	Study design (Strength/quality ranking)[d]	Surveys and instruments	Risk-taking behaviors	Findings specific to risk-taking behavior
Barsell et al. (2018)	US	Examine impact of health literacy and health efficacy on college students with chronic conditions (heart condition)	$N = 147$ ($n = 6$)	Quantitative descriptive, predictive (3/B)	All Aspects of Health Literacy Scale, Chronic Disease Self-efficacy Scale, Health Behaviors Questionnaire	Substance use	Higher levels of self-efficacy and health literacy are significantly associated with general health behavior, wellness maintenance, and fewer substance abuse behaviors
Pilapil & DeLaet (2015)	US	Explore health risks among adolescents and young adults with special health care needs, including CHD[a]	n/a	Literature Review (5/B)	Not applicable	Tobacco, alcohol or other drugs, and sexual behaviors	Routine screening for alcohol, substance abuse, and drug use Females- increased risk for cardiovascular complications during pregnancy
Kunz et al. (2014)	US	Examine how peer/parent norms or personal beliefs about substance use influence use among female adolescents with chronic medical conditions (cardiac condition)	$N = 68$ (n = 19)	Quantitative descriptive, predictive (3/B)	Researcher developed survey incorporating items from other study instruments including but not limited to alcohol and tobacco use items from National Longitudinal Study of Adolescent Health Survey	Tobacco, alcohol or other drugs	44% ($n = 30$) report alcohol use 15% ($n = 10$) report tobacco use Significant correlation between acceptability of substance abuse personal beliefs and intention to engage in future alcohol use Personal beliefs, peer and parent norms, combined to account for significant variance in current alcohol and tobacco use
Reid, Siu, McCrindle, Irvine, and Webb (2008)	Canada	Examine sexual practices of adolescents and young adults with CHD focusing on risky sexual behaviors	($n = 321$)	Quantitative descriptive, correlational (3/A)	Items from the NCHRBS[b]	Sexual behaviors: not using birth control, using alcohol in conjunction with sex, and multiple partners	Sexual activity < peers: Adolescents 14% ($n = 19$) and young adults 48% (n = 19) 36% ($n = 70$) young adults and 72% ($n = 93$) adolescents who were sexually active engaged in >1 risky behavior Females concerns- fertility and pregnancy effects; more likely to have more than one partner; use alcohol and drugs with sex No gender differences in contraception
Reid, Webb, et al. (2008)	Canada	Examine frequency of substance use and oral hygiene among adolescents and young adults with moderate to complex CHD	($n = 328$)	Quantitative descriptive, correlational (3/A)	NCHRBS; Youth Risk Behavior Surveillance System; Dental health behaviors questions; SF-36[c]; Family Adaptability and Cohesion Evaluation Scales-III	Tobacco, alcohol or other drugs, and poor oral hygiene	Reported Substance use: young adult- -54% ($n = 107$) and adolescents- 28% ($n = 37$) Excellent oral hygiene: Only 15% ($n = 50$) No difference in smoking and marijuana compared with healthy controls Lifetime use of illicit drugs and alcohol: > among young adults with CHD than US college students
Stilley et al. (2006)	US	Examine the relationship between high risk behaviors, adherence and maturity among adolescent heart recipients	($n = 27$ phase 1; n = 9 phase 2)	Mixed Methods descriptive (3/A)	Researcher adapted questionnaire about adherence; Sentence Completion Test; Beck 2 Depression Inventory; Spielberger State-Trait Anxiety Inventory; State-Trait Anger Scale 2	Tobacco, alcohol or other drugs, unhealthy diet, physical inactivity, body piercing, tattoos, medication adherence, and treatment non-compliance	**Phase 1 (Quantitative)** Smoked: 11% ($n = 3$) Street Drugs: 11% (n = 3) Dietary challenges: 37% ($n = 10$) Exercised infrequently: 89% ($n = 24$) > 2 body piercings: 26% (n = 7) Tattoos: 33% (n = 9) Missed Medications: 63% ($n = 17$) Missed appointments: 67% ($n = 18$) **Phase 2 (Qualitative):** Six themes: trust, family support, social connections, outlook on life, life goals, and ability to change.
Reid et al. (2004)	Canada	Examine CHD prevalence and successful transfer to adult care	($n = 360$)	Quantitative predictive, cross-sectional, prevalence (3/A)	Standardized questionnaires (not named) SF-36	Substance abuse and treatment non-compliance	47% ($n = 170$) transferred success; Correlated with1) no substance use, 2) antibiotic prophylaxis, 3) independent at follow-up

[a] Congenital Heart Disease.
[b] National College Health Risk Behavior Survey.
[c] Short Form 36.
[d] Johns Hopkins Nursing Evidence Based Practice Strength and Quality Ranking (Strength: 3 = Non-experimental study, 5 = Non-research evidence; Quality: A = high, B = good).

Table 2
Synthesis of risk-taking behaviors, sample age and study design among adolescents with chronic cardiac conditions.

Risk taking behavior	Author (year)	Sample age (years)	Design
Unintentional Injury/Violence[a]	Gubelmann, Berchtold, Akre, Barrense-Dias, and Suris (2018)	15–24	Quantitative
Tobacco[a]	Goossens et al. (2015)	14–18	Quantitative
	Kunz et al. (2014)	14–19	Quantitative
	Luyckx, Goossens, Missotten, and Moons (2011)	14–18	Quantitative
	Reid, Webb, et al. (2008)	16–20	Quantitative
	Massin, Hovels-Gurich, and Seghaye (2007)	3–18	Quantitative
	Stilley et al. (2006)	15–31	Mixed Methods
	Pilapil and DeLaet (2015)	none specified	Literature Review
Alcohol/Other Drugs[a]	Goossens et al. (2015)	14–18	Quantitative
	Kunz et al. (2014)	14–19	Quantitative
	Goossens et al. (2013)	14–18	Quantitative
	Luyckx et al. (2011)	14–18	Quantitative
	Reid, Webb, et al. (2008)	16–20	Quantitative
	Stilley et al. (2006)	15–31	Mixed Methods
	Pilapil and DeLaet (2015)	none specified	Literature Review
Sexual Behaviors[a,b]	Reid, Siu, et al. (2008)	16–20	Quantitative
	Pilapil and DeLaet (2015)	none specified	Literature Review
Unhealthy Diet[a]	Gubelmann et al. (2018)	15–24	Quantitative
	Chen et al. (2007)	11–18	Quantitative
	Massin et al. (2007)	3–18	Quantitative
	Stilley et al. (2006)	15–31	Mixed Methods
Physical Inactivity[a]	Goossens et al. (2015)	14–18	Quantitative
	Chen et al. (2007)	11–18	Quantitative
	Kendall, Parsons, Sloper, and Lewin (2007)	7–17	Quantitative
	Massin et al. (2007)	3–18	Quantitative
	Stilley et al. (2006)	15–31	Quantitative
Categorical Behaviors[c]	Barsell et al. (2018)	18–37	Mixed Methods
	Gubelmann et al. (2018)	15–24	Quantitative
	Lesch, Specht, Lux, Frey, and Utens (2014)	10–30	Quantitative
	Goossens et al. (2013)	14–18	Quantitative
	Luyckx et al. (2011)	14–18	Quantitative
	Reid et al. (2004)	18–21	Quantitative
Other Behaviors[d]	Gubelmann et al. (2018)	15–24	Quantitative
	Engelman et al. (2017)	14–19	Quantitative
	Goossens et al. (2015)	14–18	Quantitative
	Goossens et al. (2013)	14–18	Quantitative
	Luyckx et al. (2011)	14–18	Quantitative
	Reid, Webb, et al. (2008)	16–20	Quantitative
	Chen et al. (2007)	11–18	Quantitative
	Massin et al. (2007)	3–18	Quantitative
	Reid et al. (2004)	18–21	Quantitative
	Stilley et al. (2006)	15–31	Mixed Methods
	Dobbels, Van Damme-Lombaert, Vanhaecke, and De Geest (2005)	none specified	Literature review

[a] Risky behavior categories of the Youth Risk Behavior Surveillance (YRBS).
[b] Sexual behaviors include the following: unintended pregnancy, HIV and STI, not using birth control, using alcohol in conjunction with sex, and multiple partners.
[c] Categorical behaviors include the following: substance abuse, risky or risk-taking behaviors.
[d] Other non-YBRS behaviors include the following: dental hygiene, medication and/or treatment non-compliance, excessive gambling, excessive internet use, anti-social behavior and/or social support; stress management; life appreciation; body piercing; tattoos.

pregnancy, HIV and STI were prevalent among self-reported behaviors in one source (Reid, Siu, et al., 2008), and violence/violent acts was reported in one source (Gubelmann et al., 2018).

Sources that did not examine self-reported risk-taking behavior instead: 1) considered how risk-taking behavior influences health literacy, self-efficacy, peer and parent norms and/or personal beliefs (Barsell et al., 2018; Kunz et al., 2014); 2) investigated the level of disease-specific knowledge in children, adolescents and young adults in the context of risk-taking behavior (Lesch et al., 2014); and 3) provided an overview or background specific to risk-taking behaviors among adolescents with chronic cardiac conditions (Dobbels et al., 2005; Pilapil & DeLaet, 2015).

Discussion

The purpose of this scoping review was to address a gap in the literature specific to risk-taking behavior among adolescents with chronic cardiac conditions. Through concept mapping, we validated that adolescents with chronic cardiac conditions engage in two categories of risk-taking: 1) behavior consistent with the six categories defined in the YRBS, and 2) other types of risk-taking behavior that are common among adolescents with chronic conditions. Limited publications exist specific to describing risk-taking behavior among adolescents with chronic cardiac conditions.

Quality of evidence

The quality of included sources was moderate, with 58% ($n = 10$) ranked A (high) and 42% ($n = 7$) ranked B (good) (Table 1; Appendix B). Sources were ranked A if authors had more than one publication included in this review, or whose findings built upon prior evidence. The overall strength of sources was moderate, with 88% ($n = 15$) ranked at Level 3 (non-experimental study) and 12% ($n = 2$) ranked at Level 5 (experiential and non-research evidence, such as a literature review). The quality of sources was deemed sufficient to satisfy the objectives of this scoping review.

Included studies

The body of literature in this scoping review includes descriptive research conducted with small to moderate convenience samples of adolescents with a broad range of chronic cardiac conditions. Over half of the studies deployed quantitative survey methodology, supporting the need for additional studies that are prospective and/or that use qualitative methodology to better understand the factors that contribute to risk-taking behavior among adolescents with chronic cardiac condition (Lesch et al., 2014; Reid, Webb, et al., 2008). The proportion of male and female adolescent subjects was generally equivalent except for one study, which focused on mother-daughter dyads (Kunz et al., 2014).

The definition of risk-taking behaviors varied within the reviewed articles. Researchers often used more than one instrument to measure self-reported risk-taking or health behaviors, confirming that there is no single tool that is considered a “gold standard” for assessing risk-taking behaviors among adolescents with chronic cardiac conditions. Questions from the YRBS were used to assess risk-taking or health risk behaviors among adolescents and young adults with CHD in one study (Reid, Webb, et al., 2008), and Goossens et al. (2013) described using the YRBS as a framework to develop questions for the HBS-CHD.

Three studies analyzed risk-taking behavior using the HBS-CHD (Goossens et al., 2013; Goossens et al., 2015; Luyckx et al., 2011), developed by Luyckx et al. (2011) to support the clinical assessment of health risk behaviors in people with CHD. The HBS-CHD is based on existing instruments assessing health risk behaviors in adolescents, including the Health Behavior Scale (HBS), YRBS, and Alcohol Use Disorders Identification Test (AUDIT), and includes items that could potentially indicate worsening outcomes in individuals with CHD (Goossens et al., 2013). The HBS-CHD has been deemed reliable and valid for use in assessing health risk behaviors among adolescents with CHD, and is used in research describing how disease-related knowledge and risk-taking behaviors evolve during the transition from adolescence into adulthood

(Goossens et al., 2013; Goossens et al., 2015). A version of the HBS-CHD is available for use in the United States (Goossens et al., 2013; P. Moons, personal communication, January 2, 2019).

Two studies surveyed health promoting behaviors (e.g. healthy diet, regular exercise) among adolescents with chronic cardiac conditions and their healthy peers (Chen et al., 2007; Gubelmann et al., 2018). For the purposes of this review, we considered low levels of health behaviors and externalizing behaviors as subsets of risk-taking behaviors, despite not identifying *health behaviors, health promotion,* or *externalizing factors* as key search terms. Health promoting behaviors among adolescents with chronic cardiac disease were similar when compared to their healthy peers (Chen et al., 2007; Gubelmann et al., 2018). The presence of a chronic cardiac condition did not prevent adolescents from engaging in poor health behaviors (Gubelmann et al., 2018) that could increase their risk of developing acquired cardiovascular disease during adulthood (Harris et al., 2018).

Included samples

The age range of subjects in the selected studies was seven to 31 years. Due to lack of reporting of mean/median age in several of the studies, we were unable to calculate a grand mean/median of this literature. The American Academy of Pediatrics considers a person *adolescent* if they are between the ages of 11 and 21, and differentiates between early (ages 11 to 14), middle (ages 15 to 17), and late (ages 18 to 21) adolescence (Hagan, Shaw, & Duncan, 2017). Yet, inconsistencies in the definition of adolescence exist, due to arbitrarily set chronological thresholds that are subject to wide variability (Adolescent Health Committee, 2003). Arnett (2000) has coined the term *emerging adulthood,* encompassing people between the ages of 18 and 25. Additional definitions include the period between the ages of 10 and 19 years old (Adolescent Health Committee, 2003). We refrained from limiting our search terms based on any specific age range due to the variety of operational definitions of adolescence. We included one study in this review that sampled college students between the ages of 18 and 37 (Barsell et al., 2018), and another study that sampled children and young people with CHD (Kendall et al., 2007), supporting the broad age range among adolescents in our body of literature.

Risk-taking behaviors

Findings from this scoping review continue to support the premise that risk-taking behaviors among adolescents with chronic cardiac conditions fit into the six categories of the YRBS. Tobacco, alcohol and/or other drug use and physical inactivity were the three most prevalent risk-taking behaviors identified, and were included in the development and validation of the HBS-CHD (Goossens et al., 2013; Goossens et al., 2015). Although adolescents with CHD report lower rates of smoking than their healthy peers, tobacco use (along with alcohol and other drug use) increases their risk of cardiovascular compromise (Harris et al., 2018; Pilapil & DeLaet, 2015) and mortality (Engelfriet et al., 2008). Reid, Webb, et al. (2008) found that adolescents with chronic cardiac conditions engaged in substance use at comparable or lower rates than their healthy peers, however, Massin and colleagues (2007) identified a high prevalence of tobacco use (including exposure to second-hand smoke) among their study population. Controlling or overprotective parenting styles may contribute to tobacco, alcohol, and/or other drug use (Luyckx et al., 2011; Reid, Webb, et al., 2008). Of greater concern is that, despite perceptions of increased risk associated with continued tobacco use, adolescents often continue to engage in the behavior into adulthood (Reid, Webb, et al., 2008).

Adolescents who demonstrate lower levels of maturity, self-efficacy and/or health literacy may be more prone to engage in risk-taking behaviors (Barsell et al., 2018; Stilley et al., 2006). Stilley et al. (2006) describe less mature adolescents as having a higher potential for non-adherence with post-transplant exercise regimens. When combined with unhealthy dietary practices, these findings are clinically significant. Massin et al. (2007) reported that parents of adolescents with chronic cardiac conditions and dietary deficiencies believed that their child engaged in less physical activity than their healthy peers. These behaviors may be attributed to real and perceived beliefs about limitations on physical activity and concerns for altered growth and nutrition that result in higher calorie, less nutrient-dense intake (Harris et al., 2018). Combined dietary non-adherence and low activity levels may increase the risk of additional modifiable cardiac risk factors, including atherosclerosis, among adolescents with chronic cardiac condition (Harris et al., 2018; Massin et al., 2007). Additionally, Kendall et al. (2007) found that 65% of their study population were unaware of their recommended level of physical activity and described instances where adolescents either engaged in not enough or potentially dangerous levels of physical activity, highlighting the importance of discussing health behaviors related to exercise as part of routine medical care (Chen et al., 2007).

Reid, Siu, et al. (2008) examined sexual and reproductive concerns among adolescents with CHD, and found that sexual activity increased with age, and engaging in more than one risky sexual behavior (e.g. multiple partners, questionable use of contraception, or drug and alcohol use before sex) was common. Further, they describe a relationship between poor family functioning and risky sexual behavior (Reid, Siu, et al., 2008). In another study, adolescent females with CHD were significantly more likely than males to ask for information about pregnancy and family planning (Lesch et al., 2014), which corroborates the need for providers to be more attentive to discussing sexual and reproductive health with adolescent patients (Reid, Siu, et al., 2008).

Additional risk categories that emerged as part of this review included poor oral hygiene (Chen et al., 2007; Goossens et al., 2015; Reid, Webb, et al., 2008), antisocial behavior (Goossens et al., 2013; Luyckx et al., 2011), medication or treatment non-compliance and missed appointments (Dobbels et al., 2005; Engelman et al., 2017; Reid et al., 2004), tattoos and piercings (Stilley et al., 2006), and excessive gambling and internet use (Gubelmann et al., 2018). Although these categories were outside of the six defined categories of the YRBS, they are not unique among adolescents with chronic cardiac conditions. Anti-social behavior has been reported among adolescents with various types of chronic conditions, including inflammatory bowel disease, childhood cancer and end-stage renal disease (Herzer, Denson, Baldassano, & Hommel, 2011; Stam, Hartman, Deurloo, Groothoff, & Grootenhuis, 2006), and may be further perpetuated among adolescents who engage in screen-based activities and/or gambling to compensate for condition-induced sedentary lifestyles. Husarova et al. (2016) reported an association between screen-based behavior (including internet use and video games) and long-term illness among adolescents, with over half of their study population exceeding recommended times for screen-based activity. Gambling, while not as prevalent when compared to healthy adolescents, exists among adolescents with childhood cancer, end-stage renal disease, Hirshprung's disease, anorectal malformations and esophageal fistula, and may delay psychosocial and social developmental milestones among adolescents with chronic conditions (Stam et al., 2006). Anti-social behavior, increased screen-based behavior, and gambling may serve as an outlet among adolescents with chronic conditions who struggle to maintain independence from family and caregivers and/or peer relationships.

Medication and treatment non-compliance are common among adolescents with diabetes, as well as non-cardiac solid organ recipients (Dobbels et al., 2005; Lerret & Stendahl, 2011; Rianthavorn et al., 2004; Wasserman, Anderson, & Schwartz, 2017). Piercing and tattoos pose a risk for healthy adolescents as well as those with chronic conditions, given risks of infection, trauma, and scarring (Hoover, Rademayer, & Farley, 2017). Poor oral hygiene can predispose people with a chronic cardiac conditions, as well as people with chronic kidney disease, to endocarditis (Chen et al., 2007; Habib Khan, Sarriff, Hayat Khan, Azreen Syazril, & Mallhi, 2015).

Evolving therapies and treatments have extended the life expectancy, even for the most complex cardiac conditions. Although adolescents with chronic conditions may have more contact with healthcare providers than their healthy peers, there does not seem to be an association with decreased risk-taking behaviors as a result (Suris & Parera, 2005). Instead, adolescents may exercise discretion in engaging in certain risk-taking behaviors (e.g. tobacco or marijuana use) based on condition-varying risks that could ameliorate symptoms in some cases, but exacerbate them in others (Britto et al., 1998; Weitzman et al., 2015). The presence of a chronic condition may not be a protective factor against adolescent risk-taking behavior, underscoring the importance of including anticipatory guidance and health promotion strategies during routine care (Suris & Parera, 2005).

Implications for research, policy and practice

Management that was once palliative in nature must broaden scope to incorporate strategies to support the biological and social transitions associated with normal adolescent development in the setting of a chronic cardiac condition. Additional research is needed to assess the impact of risk-taking behavior among adolescents with chronic cardiac conditions across the lifespan. Prospective studies that explore the relationship between non-adherence and clinical outcomes may remove negative implications associated with risk-taking and offer early intervention strategies aimed at health promotion. Longitudinal and qualitative studies may be helpful in exploring decisions to engage in behaviors, especially alcohol and drug use, and risky sexual behaviors. Health policies that support classroom-based education specific to safe sexual behaviors and drug and alcohol use may be helpful in decreasing risky behaviors among adolescents with chronic cardiac conditions. From a practical standpoint, discussions about risk-taking behaviors should begin in early adolescence, and take place at each healthcare encounter.

Mental health disorders among adolescents with CHD were purposely excluded from this scoping review in light of our broad approach to categorizing chronic cardiac conditions. Attention deficit/hyperactivity disorder (ADHD) has been associated with impulsive behavior that leads to increased risk-taking (Ortal et al., 2015; Pollak, Dekkers, Shoham, & Huizenga, 2019; Schoenfelder & Kollins, 2016). Children with CHD are at higher risk for neurodevelopmental impairments, including ADHD and autism spectrum disorders, which lead to impaired executive function (Calderon & Bellinger, 2015; Hansen et al., 2012; Tsao et al., 2017). Impulsivity and impaired executive function increase the likelihood that adolescents with ADHD will engage in risk-taking behavior (Ortal et al., 2015; Reynolds, Basso, Miller, Whiteside, & Combs, 2019). Future research specific to risk-taking behavior among adolescents with CHD and neurocognitive deficits is warranted.

Limitations

Although we conducted an extensive scoping review using the PRISMA ScR guidelines, several limitations require clarification. The search strategy was developed without the assistance of a research librarian. Limiting the review to English language may result in article selection bias. Study results from a specific culture or country cannot be generalized to others. Additional literature and resources may be available that were not found during the original searches of risk-taking behavior. Searching each type of risk-taking behavior in the context of chronic cardiac conditions and using a broader term of chronic conditions may yield additional results. Adult populations and mental health disorders were excluded from this scoping review. There is a lack of a universal definition for substance abuse and other risky behaviors, which creates difficulty in comparing studies. The results and future implications in this manuscript outweigh the identified limitations.

Conclusion

Research exploring the impact that evolving therapies and emerging technology have on adolescents with chronic cardiac conditions is limited, and the topic of risk-taking behaviors in this population must be approached thoughtfully. Differences in risk-taking behaviors among adolescents with chronic cardiac conditions appear to be minimal, especially when compared to other types of chronic conditions. Risk-taking behaviors in the presence of a chronic cardiac condition may increase the likelihood of subsequent clinical complications. These clinical complications, including modifiable risk factors for acquired cardiovascular disease, require further exploration (Harris et al., 2018; Lesch et al., 2014). Findings from this scoping review describe the types of risk-taking behaviors that adolescents with chronic cardiac conditions are engaging in, highlight similarities when compared to other types of chronic conditions, and serve as a foundation for future studies among this population.

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Declaration of Competing Interest

None.

References

Adams, P. F., Kirzinger, W. K., & Martinez, M. E. (2013). Summary health statistics for the U.S. population: National health interview survey, 2012. National Center for Health Statistics. *Vital and Health Statistics*, *10*(259), 1–95.

Adolescent Health Committee, & Canadian Paediatric Society (2003). Position statement: Age limits and adolescents. *Paediatrics & Child Health*, *8*(9), 577–578.

Arksey, H., & O'Malley, L. (2005). Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology*, *8*(1), 19–32.

Arnett, J. J. (2000). Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychologist*, *55*(5), 469–480.

Barsell, D. J., Everhart, R. S., Miadich, S. A., & Trujillo, M. A. (2018). Examining health behaviors, health literacy, and self-efficacy in college students with chronic conditions. *American Journal of Health Education*, *49*(5), 305–311. https://doi.org/10.1080/19325037.2018.1486758.

Berg, A. M., Snell, L., & Mahle, W. T. (2007). Home inotropic therapy in children. *The Journal of Heart and Lung Transplantation*, *26*(5), 453–457.

Birks, E. J. (2018). Intermediate- and long-term mechanical circulatory support. In D. Mancini, & S. A. Hunt (Eds.), *UpToDate*. Waltham, MA: UpToDate Inchttps://www.uptodate.com/contents/intermediate-and-long-term-mechanical-circulatory-support?search=mechanical%20circulatory%20support&source=search_result&selectedTitle=1~150&usage_type=default&display_rank=1 (accessed on February 5,2019).

Birnbaum, B. F., Simpson, K. E., Boschert, T. A., Zheng, J., Wallendorf, M. J., Schechtman, K., & Canter, C. E. (2015). Intravenous home inotropic use is safe in pediatric patients awaiting transplantation. *Circulation*, *8*(1), 64–70. https://doi.org/10.1161/CIRCHEARTFAILURE.114.001528.

Britto, M. T., Garrett, J. M., Dugliss, M. A., Daeschner, C. W., Jr., Johnson, C. A., Leigh, M. W., ... Konrad, T. R. (1998). Risky behavior in teens with cystic fibrosis or sickle cell disease: A multicenter study. *Pediatrics*, *101*(2), 250–256.

Calderon, J., & Bellinger, D. C. (2015). Executive function deficits in congenital heart disease: Why is intervention important? *Cardiology in the Young*, *25*(7), 1238–1246. https://doi.org/10.1017/s1047951115001134.

Chen, C. -W., Chen, Y. -C., Chen, M. -Y., Wang, J. -K., Su, W. -J., & Wang, H. -L. (2007). Health-promoting behavior of adolescents with congenital heart disease. *Journal of Adolescent Health*, *41*(6), 602–609.

Conway, J., VanderPluym, C., Jeewa, A., Sinnadurai, S., Schubert, A., & Lorts, A. (2016). Now how do we get them home? Outpatient care of pediatric patients on mechanical circulatory support. *Pediatric Transplantation*, *20*(2), 194–202. https://doi.org/10.1111/petr.12674.

D'Alessandro, D., Forest, S. J., Lamour, J., Hsu, D., Weinstein, S., & Goldstein, D. (2012). First reported use of the HeartWare HVAD in the US as bridge to transplant in an adolescent. *Pediatric Transplantation*, *16*(8), E356–E359. https://doi.org/10.1111/j.1399-3046.2012.01718.x.

Dang, D., & Dearholt, S. (2017). *Johns Hopkins nursing evidence-based practice: Model and guidelines* (3rd ed.). Indianapolis, IN: Sigma Theta Tau International.

Dobbels, F., Van Damme-Lombaert, R., Vanhaecke, J., & De Geest, S. (2005). Growing pains: Non-adherence with the immunosuppressive regimen in adolescent transplant recipients. *Pediatric Transplantation*, *9*(3), 381–390. https://doi.org/10.1111/j.1399-3046.2005.00356.x.

Ellims, A. (2017). Hypertrophic cardiomyopathy in the adolescent. *Australian Family Physician*, *46*, 553–557.

Engelfriet, P. M., Drenthen, W., Pieper, P. G., Tijssen, J. G. P., Yap, S. C., Boersma, E., & Mulder, B. J. M. (2008). Smoking and its effects on mortality in adults with congenital heart disease. *International Journal of Cardiology*, *127*(1), 93–97. https://doi.org/10.1016/j.ijcard.2007.05.008.

Engelman, D., Ah Kee, M., Mataika, R. L., Kado, J. H., Colquhoun, S. M., Tulloch, J., & Steer, A. C. (2017). Secondary prevention for screening detected rheumatic heart disease: Opportunities to improve adherence. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, *111*(4), 154–162. https://doi.org/10.1093/trstmh/trx035.

Goossens, E., Fieuws, S., Van Deyk, K., Luyckx, K., Gewillig, M., Budts, W., & Moons, P. (2015). Effectiveness of structured education on knowledge and health behaviors in patients with congenital heart disease. *The Journal of Pediatrics*, *166*(6), 1370–1376.

Goossens, E., Luyckx, K., Mommen, N., Gewillig, M., Budts, W., Zupancic, N., & Moons, P. (2013). Health risk behaviors in adolescents and emerging adults with congenital heart disease: Psychometric properties of the Health Behavior Scale-Congenital Heart Disease. *European Journal of Cardiovascular Nursing*, *12*(6), 544–557. https://doi.org/10.1177/1474515113475934.

Gubelmann, A., Berchtold, A., Akre, C., Barrense-Dias, Y., & Suris, J. C. (2018). 185 — Youths with chronic conditions show no direct association with risk behaviors. *Journal of Adolescent Health*, *62*, S95–S96. https://doi.org/10.1016/j.jadohealth.2017.11.193.

Habib Khan, Y., Sarriff, A., Hayat Khan, A., Azreen Syazril, A., & Mallhi, T. H. (2015). Infective endocarditis and chronic kidney disease: How to deal with complications. *The Malaysian Journal of Medical Sciences*, *22*(4), 73–75.

Hagan, J. F., Shaw, J. S., & Duncan, P. M. (2017). *Bright futures: Guidelines for health supervision of infants, children, and adolescents*. Elk Grove Village, IL: Bright Futures/American Academy of Pediatrics.

Hansen, E., Poole, T. A., Nguyen, V., Lerner, M., Wigal, T., Shannon, K., & Batra, A. S. (2012). Prevalence of ADHD symptoms in patients with congenital heart disease. *Pediatrics International*, *54*(6), 838–843. https://doi.org/10.1111/j.1442-200X.2012.03711.x.

Harris, K. C., Voss, C., Rankin, K., Aminzadah, B., Gardner, R., & Mackie, A. S. (2018). Modifiable cardiovascular risk factors in adolescents and adults with congenital heart disease. *Congenital Heart Disease*, *13*(4), 563–570. https://doi.org/10.1111/chd.12612.

Herzer, M., Denson, L. A., Baldassano, R. N., & Hommel, K. A. (2011). Patient and parent psychosocial factors associated with health-related quality of life in pediatric inflammatory bowel disease. *Journal of Pediatric Gastroenterology and Nutrition*, *52*(3), 295–299.

Hoover, C., Rademayer, C. -A., & Farley, C. L. (2017). Body piercing: Motivations and implications for health. *Journal of Midwifery & Women's Health*, *62*(5), 521–530.

Husarova, D., Geckova, A. M., Blinka, L., Sevcikova, A., van Dijk, J. P., & Reijneveld, S. A. (2016). Screen-based behaviour in school-aged children with long-term illness. *BMC Public Health*, *16*(1), 1–5. https://doi.org/10.1186/s12889-016-2804-8.

Kann, L., McManus, T., Harris, W. A., Shanklin, S. L., Flint, K. H., Queen, B., & Ethier, K. A. (2018). Youth risk behavior surveillance — United States, 2017. *MMWR Surveillance Summaries*, *67*(8), 1–114. https://doi.org/10.15585/mmwr.ss6708a1.

Kaufman, M. (2006). Role of adolescent development in the transition process. *Progress in Transplantation*, *16*(4), 286–290.

Kendall, L., Parsons, J. M., Sloper, P., & Lewin, R. J. (2007). A simple screening method for determining knowledge of the appropriate levels of activity and risk behaviour in young people with congenital cardiac conditions. *Cardiology in the Young*, *17*(2), 151–157. https://doi.org/10.1017/s1047951107000285.

Kunz, J. H., Greenley, R. N., Mussatto, K. A., Roth-Wojcicki, B., Miller, T., Freeman, M. E., & Lerand, S. (2014). Personal attitudes, perceived social norms, and health-risk behavior among female adolescents with chronic medical conditions. *Journal of Health Psychology*, *19*(7), 877–886. https://doi.org/10.1177/1359105313481077.

Lacina, S. J. (2009). What's new in outpatient cardiology? *Current Opinion in Pediatrics*, *21*(5), 605–610.

Leelathipkul, L., & Arunakul, J. (2018). Risk behaviors screening in adolescents with acute and chronic illness. *Journal of Adolescent Health*, *62*, S99. https://doi.org/10.1016/j.jadohealth.2017.11.200.

Lerret, S., & Stendahl, G. (2011). Working together as a team: Adolescent transplant recipients and nurse practitioners. *Progress in Transplantation*, *21*(4), 288–293. https://doi.org/10.7182/prtr.21.4.v1qu71831k931w47.

Lesch, W., Specht, K., Lux, A., Frey, M., & Utens, E. (2014). Disease-specific knowledge and information preferences of young patients with congenital heart disease. *Cardiology in the Young*, *24*(2), 321–330. https://doi.org/10.1017/S1047951113000413.

Levac, D., Colquhoun, H., & O'Brien, K. K. (2010). Scoping studies: Advancing the methodology. *Implementation Science*, *5*, 69–78.

Luyckx, K., Goossens, E., Missotten, L., & Moons, P. (2011). Adolescents with congenital heart disease: The importance of perceived parenting for psychosocial and health outcomes. *Journal of Developmental and Behavioral Pediatrics*, *32*(9), 651–659. https://doi.org/10.1097/DBP.0b013e3182331e99.

Masarone, D., Valente, F., Rubino, M., Vastarella, R., Gravino, R., Rea, A., ... Limongelli, G. (2017). Pediatric heart failure: A practical guide to diagnosis and management. *PEDN Pediatrics & Neonatology*, *58*(4), 303–312.

Massin, M. M., Hovels-Gurich, H., & Seghaye, M. C. (2007). Atherosclerosis lifestyle risk factors in children with congenital heart disease. *European Journal of Cardiovascular Prevention and Rehabilitation*, *14*(2), 349–351.

Ortal, S., van de Glind, G., Johan, F., Itai, B., Nir, Y., Iliyan, I., & van den Brink, W. (2015). The role of different aspects of impulsivity as independent risk factors for substance use disorders in patients with ADHD: A review. *Current Drug Abuse Reviews*, *8*(2), 119–133.

Peters, M. D. J., Godfrey, C., McInerney, P., Baldini Soares, C., Khalil, H., & Parker, D. (2015). Scoping reviews. In E. Aromataris, & Z. Munn (Eds.), *Joanna Briggs institute reviewer's manual* (pp. 1–24). South Australia: The Joanna Briggs Institute.

Pilapil, M., & DeLaet, D. (2015). Health risk behaviors in adolescents and young adults with special health care needs. *Current Opinion in Pediatrics*, *27*(1), 132–137. https://doi.org/10.1097/mop.0000000000000177.

Pollak, Y., Dekkers, T. J., Shoham, R., & Huizenga, H. M. (2019). Risk-taking behavior in attention deficit/hyperactivity disorder (ADHD): A review of potential underlying mechanisms and of interventions. *Current Psychiatry Reports*, *21*(5), 33. https://doi.org/10.1007/s11920-019-1019-y.

Reid, G. J., Irvine, M. J., McCrindle, B. W., Sananes, R., & Ritvo, P. G. (2004). Prevalence and correlates of successful transfer from pediatric to adult health care among a cohort of young adults with complex congenital heart defects. *Pediatrics (Evanston)*, *113*(3), e197–e205. https://doi.org/10.1542/peds.113.3.e197.

Reid, G. J., Siu, S. C., McCrindle, B. W., Irvine, M. J., & Webb, G. D. (2008). Sexual behavior and reproductive concerns among adolescents and young adults with congenital heart disease. *International Journal of Cardiology*, *125*(3), 332–338. https://doi.org/10.1016/j.ijcard.2007.02.040.

Reid, G. J., Webb, G. D., McCrindle, B. W., Irvine, M. J., & Siu, S. C. (2008). Health behaviors among adolescents and young adults with congenital heart disease. *CHD Congenital Heart Disease*, *3*(1), 16–25.

Reynolds, B. W., Basso, M. R., Miller, A. K., Whiteside, D. M., & Combs, D. (2019). Executive function, impulsivity, and risky behaviors in young adults. *Neuropsychology*, *33*(2), 212–221. https://doi.org/10.1037/neu0000510.

Rianthavorn, P., Ettenger, R. B., Malekzadeh, M., Marik, J. L., & Struber, M. (2004). Noncompliance with immunosuppressive medications in pediatric and adolescent patients receiving solid-organ transplants. *Transplantation*, *77*(5), 778–782.

Rossano, J. W., Lorts, A., VanderPluym, C. J., Jeewa, A., Guleserian, K. J., Bleiweis, M. S., Reinhartz, O., … Kirklin, J. K. (2016). Outcomes of pediatric patients supported with continuous-flow ventricular assist devices: A report from the Pediatric Interagency Registry for Mechanical Circulatory Support (PediMACS). The Journal of Heart and Lung S: The Official Publication of the International Society for Heart Transplantation, 35(5), 585–90.

Schoenfelder, E. N., & Kollins, S. H. (2016). Topical review: ADHD and health-risk behaviors: Toward prevention and health promotion. *Journal of Pediatric Psychology*, *41*(7), 735–740. https://doi.org/10.1093/jpepsy/jsv162.

Stam, H., Hartman, E. E., Deurloo, J. A., Groothoff, J., & Grootenhuis, M. A. (2006). Young adult patients with a history of pediatric disease: Impact on course of life and transition into adulthood. *The Journal of Adolescent Health*, *39*(1), 4–13. https://doi.org/10.1016/j.jadohealth.2005.03.011.

Stein, M. L., Yeh, J., Reinhartz, O., Rosenthal, D. N., Kaufman, B. D., Almond, C. S., & Maeda, K. (2016). HeartWare HVAD for biventricular support in children and adolescents: The Stanford experience. *ASAIO Journal*, *62*(5), e46–e51. https://doi.org/10.1097/MAT.0000000000000356.

Stilley, C. S., Lawrence, K., Bender, A., Olshansky, E., Webber, S. A., & Dew, M. A. (2006). Maturity and adherence in adolescent and young adult heart recipients. *Pediatric Transplantation*, *10*(3), 323–330.

Suris, J., Michaud, P., Akre, C., & Sawyer, S. M. (2008). Health risk behaviors in adolescents with chronic conditions. *Pediatrics*, *122*(5), e1113–e1118.

Suris, J., & Parera, N. (2005). Sex, drugs and chronic illness: Health behaviours among chronically ill youth. *European Journal of Public Health*, *15*(5), 484–488.

Tricco, A. C., Lillie, E., Zarin, W., O'Brien, K. K., Colquhoun, H., Levac, D., ... Straus, S. E. (2018). PRISMA extension for scoping reviews (PRISMA-ScR): Checklist and explanation. *Annals of Internal Medicine*, *169*(7), 467–473.

Triedman, J. K., & Newburger, J. W. (2016). Trends in congenital heart disease: The next decade. *Circulation*, *133*(25), 2716–2733. https://doi.org/10.1161/CIRCULATIONAHA.116.023544.

Tsao, P. C., Lee, Y. S., Jeng, M. J., Hsu, J. W., Huang, K. L., Tsai, S. J., & Kou, Y. R. (2017). Additive effect of congenital heart disease and early developmental disorders on attention-deficit/hyperactivity disorder and autism spectrum disorder: A nationwide population-based longitudinal study. *European Child & Adolescent Psychiatry*, *26*(11), 1351–1359. https://doi.org/10.1007/s00787-017-0989-8.

Uzark, K., Smith, C., Donohue, J., Yu, S., Afton, K., Norris, M., & Cotts, T. (2015). Assessment of transition readiness in adolescents and young adults with heart disease. The Journal of Pediatrics, 167, 1233–1238. doi.org/https://doi.org/10.1016/j.jpeds.2015.07.043.

Wasserman, R., Anderson, B. J., & Schwartz, D. D. (2017). Illness-specific risk-taking in adolescence: A missing piece of the nonadherence puzzle for youth with Type 1 Diabetes? *Diabetes Spectrum*, *30*(1), 3–10. https://doi.org/10.2337/ds15-0060.

Weitzman, E. R., Ziemnik, R. E., Quian, H., & Levy, S. (2015). Alcohol and marijuana use and treatment nonadherence among medically vulnerable youth. *Pediatrics*, *136*(3), 450–457. https://doi.org/10.1542/peds.2015-0722.

World Heart Federation (2019). Different heart diseases. https://www.world-heart-federation.org/resources/different-heart-diseases/.

Yuan, S. M. (2018). Cardiomyopathy in the pediatric patients. *Pediatrics and Neonatology*, *59*(2), 120–128.