Children living with type 1 diabetes and congenital heart disease in the West Bank, Palestine

Self-perceived health status, sense of coherence and the daily life experiences of these children and their parents

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Gothenburg 2019

Cover illustration by Ayed Arafa

To my father Shab'an and my mother Jamila

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ABSTRACT

Chronic diseases such as type 1 diabetes (T1D) and congenital heart disease (CHD) are lifelong conditions, need regular treatment, self-management, and health care follow-ups. Growing up with these conditions affects the children's and their parents' lives at various levels, because of the increased burden and responsibilities imposed on them. In addition, the particular socio-cultural conditions in the Palestinian West Bank can also be assumed to influence their daily life.

The overall aim was to explore the experiences of daily life in children and adolescents with T1D and CHD and their parents living in the West Bank, Palestine, and to describe self-perceived health status and sense of coherence (SOC) in these children compared with a healthy reference group.

In Study I and II, a qualitative descriptive design based on individual interviews was used to explore daily life experiences in children with T1D or CHD and their parents. In Study III and IV, a quantitative approach with a cross-sectional design was used to measure self-perceived health status and SOC in children with T1D or CHD and to compare them with a healthy reference group. PedsQL™ 4.0, Generic Core Scale was used to measure the self-perceived health status, whereas the SOC-13 scale was used for SOC.

 In Study I, children with T1D and their parents struggled to place themselves within the context of the disease and within their social context because of the impact of stigmatization and social constraints on their daily life. In Study II, children with CHD and their parents described how their daily life was influenced negatively by societal stereotyping, low access to specialized care due to the political situation, and the children's perceptions of their illness. Although these factors affected almost every aspect of their lives, they referred to a reliance on God facilitating their acceptance of their fate and lives.

In Study III, both children with T1D and a healthy reference group reported comparable self-perceived health status but low scores regarding SOC. In adolescents with T1D, a strong SOC was associated with better self-perceived health status and more optimal glycemic control. Boys with T1D reported higher self-perceived health status than girls. In Study IV, self-perceived health status was lower in children with CHD compared to a healthy reference group. SOC was low in both groups and no differences between the groups were found. Children with a mild CHD reported a better self-perceived health status, while children who had undergone heart surgery reported lower self-perceived health status. Furthermore, a stronger SOC was associated with higher self-perceived health status in adolescents with CHD.

To provide optimum care for children with T1D and CHD and their parents, health care providers need to understand the negative consequences associated with sociocultural conditions and beliefs about chronic illness. Monitoring self-perceived health status and taking the role of SOC into consideration in children with T1D and CHD may form the basis for future health care interventions for these children.

SAMMANFATTNING PÅ SVENSKA

Kroniska sjukdomar - såsom typ 1 diabetes (T1D) och medfödda hjärtfel (CHD) - är livslånga tillstånd, som kräver regelbunden behandling, egenvård och uppföljning inom hälso- och sjukvård. Att växa upp under dessa förhållanden påverkar barnens och deras föräldrars liv på olika nivåer, på grund av den ökade belastning och det ansvar som läggs på dem. Därtill kan de särskilda sociokulturella förhållandena på den Palestinska Västbanken antas påverka deras dagliga liv.

Det övergripande syftet med denna avhandling var att undersöka hur barn och ungdomar med T1D och CHD och deras föräldrar på Västbanken i Palestina erfar sitt dagliga liv, samt att beskriva självskattad hälsa och känsla av sammanhang (SOC) hos dessa barn och ungdomar jämfört med en frisk referensgrupp.

I Studie I och II användes en beskrivande kvalitativ ansats baserad på individuella intervjuer, för att utforska hur barn med T1D och CHD samt deras föräldrar erfar sitt dagliga liv. I Studie III och IV, användes en kvantitativ ansats, i form av en tvärsnittsstudie, för att mäta självskattad hälsa och SOC hos barn med T1D eller CHD jämfört med en frisk referensgrupp. Instrumentet PedsQL™ 4.0 Generic Core Scale användes för att mäta självskattad hälsa och SOC-13 skalan för att mäta känsla av sammanhang.

Studie I visade att barn med T1D och deras föräldrar dagligen kämpade med att förhålla sig både till sjukdomen och sitt sociala sammanhang på grund av stigmatisering och samhälleliga restriktioner. I Studie II beskrev barn med CHD och deras föräldrar hur deras dagliga liv påverkades negativt av samhällets stereotypiska syn, bristande tillgång till specialiserad vård på grund av den politiska situationen och barnens uppfattningar om sin sjukdom. Trots att detta påverkade nästan alla aspekter av deras liv hänvisade de till att förtröstan på Gud hjälpte dem att acceptera sitt öde och sina liv.

I Studie III rapporterade barnen med T1D och den friska referensgruppen jämförbara värden på självskattad hälsa men låga värden avseende känsla av sammanhang. Hos ungdomar med T1D var en stark känsla av sammanhang associerat med högre självskattad hälsa och bättre blodsockerkontroll. Pojkar med T1D rapporterade högre självskattad hälsa än flickor. I Studie IV var självskattad hälsa lägre hos barnen med CHD än hos den friska referensgruppen. känsla av sammanhang var lågt i båda grupperna och ingen skillnad kunde ses. Barn med mild CHD rapporterade högre självskattad hälsa,

medan barn som hade genomgått hjärtkirurgi rapporterade lägre självskattad hälsa. Vidare var en stark känsla av sammanhang associerat med högre självskattad hälsa hos ungdomar med CHD.

För att erbjuda optimal vård för barn med T1D och CHD och deras föräldrar behöver sjukvårdspersonal förstå de negativa konsekvenserna av sociokulturella förhållanden och de föreställningar om kronisk sjukdom som beskrivs och som får betydelse för att hantera sjukdomen i vardagen. Kontroll av självskattad hälsa och beaktande av betydelsen av känsla av sammanhang kan utgöra en grund för framtida interventioner inom hälso- och sjukvården för barn med T1D och CHD.

ملخص الدراسة

تحتاج الأمراض المزمنة السكري من النوع الأول وأمراض القلب الخلقية، وهي أمراض ترافق الانسان مدى الحياة، إلى علاج منتظم وإدارة ذاتية ومتابعة صحية. فالإصابة بهذه الأمراض تؤثر على حياة الأطفال وأولياء أمورهم على مختلف المستويات، بسبب الأعباء والمسؤوليات المتزايدة المفروضة عليهم. كما وتؤثر الظروف الاجتماعية والثقافية الخاصة في الضفة الغربية في فلسطين على حياتهم اليومية.

تهدف هذه الدراسة لتسليط الضوء على تجارب الحياة اليومية للأطفال والمراهقين المصابين بالنوع الأول من السكري وامراض القلب الخلقية، وأولياء أمورهم الذين يعيشون في الضفة الغربية في فلسطين، ووصف مدى اداركهم لتلك الحالة الصحيةً والشعور بالتماسك عند هؤلاء الأطفال مقارنةً مع مجموعة أخرى تتمتع بصحة جيدة.

استخدم نهج وصفي نوعي يستند على مقابلات فردية في الدراسة الأولى والثانية عن طريق تحليل المحتوى النوعي، من أجل استكشاف تجارب الحياة اليومية للأطفال الذين يعانون من النوع الأول من السكري وامراض القلب الخلقية وأولياء أمورهم. أما في الدراسة الثالثة والرابعة، فقد استخدام نهج كمي مع تصميم مقطعي لقياس مدى الإدراك للحالة الصحية ومدى الشعور بالتماسك عند الأطفال الذين يعانون من النوع الأول من السكري وأمراض القلب الخلقية ومقارنتها مع مجموعة أخرى تتمتع بصحة جيدة.

في الدراسة الأولى، وصف التحليل المعاناة اليومية للأطفال المصابين بالنوع الأول من السكري وأولياء أمورهم اثناء محاولتهم التأقلم مع المرض والتعامل مع المجتمع بسبب تأثير الوصمة والقيود الاجتماعية على حياتهم اليومية. أما في الدراسة الثانية، وصف الأطفال الذين يعانون من أمراض القلب الخلقية وأولياء أمورهم كيف تأثرت حياتهم اليومية سلبًا بالقوالب النمطية المجتمعية وضعف فرص الحصول على الرعاية الصحية المتخصصة بسبب الوضع السياسي، وتصورات الأطفال حول مرضهم. وعلى الرغم من أن هذه العوامل أثرت على كل جانب من جوانب حياتهم تقريبًا، إلا أنهم قالوا أنهم يعتمدون على الله لتسهيل تقبلهم لمصيرهم وحياتهم.

أما في الدراسة الثالثة، فقد كان الادراك الذاتي للحالة الصحية متماثلا لدى الأطفال الذين يعانون من النوع الأول من السكري والمجموعة التي تتمتع بصحة جيدة ولكن الشعور بالاتساق لم يكن كذلك، بل كان منخفضا. أما في حالة المراهقين الذين يعانون من النوع الأول من السكري، ارتبطت زيادة قوة الشعور بالتماسك مع ازدياد الادراك للحالة الصحية والسيطرة على نسبة السكر في الدم. وكان إدراك الصبيان الذين يعانون من النوع الأول من السكري للحالة الصحية أعلى منه عند الفتيات. أما في الدراسة الرابعة، فقد كان الادراك للحالة الصحية أقل لدى الأطفال المصابين بأمراض القلب الخلقية مقارنة بالمجموعة التي تتمتع بصحة جيدة. وكان الشعور بالتماسك منخفض لدى جميع المراهقين ولم توجد اية فروق بين المجموعتين في الدراسة الثالثة أو الدراسة الرابعة. كان الادراك للحالة الصحية عند الأطفال الذين يعانون من أمراض القلب الخلقية الخفيفة أفضل مقارنة بالأطفال الذين خضعوا لعملية جراحية في القلب، حيث كان الادراك أقل لديهم. كما تبين أن قوة الشعور بالتماسك تزداد بازدياد الادراك للحالة الصحية لدى الأطفال الذين يعانون من أمراض القلب الخلقية.

يحتاج مقدمو الرعاية الصحية إلى إدراك التأثير المحتمل للعوامل الاجتماعية والثقافية مثل الوصمة والقوالب النمطية للنوع الاجتماعي ونتائجها السلبية، وذلك من أجل توفير الرعاية المثلى للأطفال الذين يعانون من النوع الأول من السكري وامراض القلب الخلقية، حيث يستطيع مقدمو الرعاية الصحية دعم

هؤلاء الأطفال وأسرهم من خلال زيادة معرفتهم، عن طريق التدخلات التعليمية في البيئات المدرسية بشكل خاص والمجتمع بشكل عام فيما يتعلق بالأعراض والمسببات والآثار المترتبة على النوع الأول من السكري وامراض القلب الخلقية. أما التدخلات المستهدفة الأخرى المطلوبة فهي الاستراتيجيات التي تهدف إلى تعزيز قدرات الأطفال الذين يعانون من النوع الأول من السكري وامراض القلب الخلقية، فقد تزيد هذه التدخلات من الشعور بالتماسك وبالتالي تؤدي أيضًا إلى زيادة الادراك للحالة الصحية، وقد يكون لها أيضًا تأثير إيجابي على السيطرة على نسبة السكر في الدم وتقليل المضاعفات عند الأطفال المصابين بالنوع الأول من السكري. يجب على مقدمي الرعاية الصحية تقييم الأداء البدني والنفسي الاجتماعي بشكل منتظم لدى هؤلاء الأطفال من أجل تطوير وتنفيذ البرامج حسب الاحتياج.

LIST OF PAPERS

This thesis is based on the following studies, referred to in the text by their Roman numerals.

I. Elissa, K., Bratt, E.-L., Axelsson, A. B., Khatib, S., & Sparud-Lundin, C. (2017). Societal Norms and Conditions and Their Influence on Daily Life in Children with Type 1 Diabetes in the West Bank in Palestine. *Journal of Pediatric Nursing,* 33, 16-22. https:// doi: 10.1016/j.pedn.2016.12.005

II. Elissa, K., Sparud-Lundin, C., Axelsson, Å. B., Khatib, S., & Bratt, E.-L. (2018). Struggling and Overcoming Daily Life Barriers Among Children With Congenital Heart Disease and Their Parents in the West Bank, Palestine. *Journal of Family Nursing*, 24, 585-611.https://doi: org.ezproxy.ub.gu.se/1074840718809710.

III. Elissa, K., Bratt, E.-L., Axelsson, Å. B., Khatib, S., & Sparud-Lundin, C. Self-perceived health status and sense of coherence in children with type 1 diabetes in the West Bank, Palestine. Submitted

IV. Elissa, K., Sparud-Lundin, C., Axelsson, Å. B., Khatib, S., & Bratt, E.-L. Living with congenital heart disease under challenging conditions in the West Bank, Palestine: self-perceived health status and sense of coherence. In manuscript.

CONTENT

ABBREVIATIONS

CHD	Congenital heart disease
GCS	Generic Core Scales
HRQoL	Health-related Quality of Life
PedsQL	Pediatric Quality of Life Inventory
SOC	Sense of Coherence
T1D	Type 1 diabetes
WHO	World Health Organization

DEFINITIONS IN SHORT

Chronic disease   A lifelong condition that is incurable and needs regular treatment, care, and medical follow-up (Eiser, 1997).

Type 1 diabetes   A chronic condition resulting from destruction of B-cells of the pancreas, characterized by absolute insulin deficiency (Ozougwu, Obimba, Belonwu, & Unakalamba, 2013).

Congenital heart disease   A gross structural abnormality of the heart or intrathoracic great vessels that is actually or potentially of functional significance (Mitchell, Korones, & Berendes, 1971).

1 INTRODUCTION

My clinical background as a pediatric nurse working with children in hospitals and as an educator in pediatric and child health nursing led to an interest in the context of childhood chronic illnesses such as T1D and CHD. My interest developed when I noticed that nursing practice in Palestine follows the medical model of care and that the psychosocial needs of children with chronic illness and their families was addressed to a lesser extent. From my experience of working in hospitals, I noticed that T1D and CHD represented the most frequent admissions to pediatric departments because these conditions require continuous follow-up and treatment. Both of them are associated with a risk of serious physical complications that may affect the daily life of the affected children. Therefore, I was curious about the daily life experiences of children with chronic illness and those of their parents, as well as their health status and wellbeing. In addition, the majority of the existing research addressing these issues on these groups of children has been performed in high-income countries and the results from these studies may not be applicable in the specific context of Palestine. As the thesis examined two distinct chronic illnesses, its results may, to some extent, also represent the experiences of children with other chronic illnesses.

This thesis is conducted within health care sciences which is based on human sciences and aimed to help a person to maintain health and wellbeing (Hörberg, Ozolins, & Ekebergh, 2011). Health care science aims to deepen understanding of human being from a holistic perspective. Understanding experiences of living with a chronic illness such as T1D or CHD under specific social conditions and political situation is fundamental in health caring science.

1.1 THE PALESTINIAN CONTEXT

Understanding the Palestinian context in relation to sociocultural conditions, religion and the specific political situation is important to comprehend daily life experience, health status and psychosocial aspects properly. This study was conducted in the West Bank, Palestine. Palestine is an Arab state situated in the Middle East and was under Israeli control since1948. In 1994, the Palestinian Authority was established in accordance with the Oslo agreement. According to this agreement, the occupied Palestinian territory was divided into three zones. Zone A covers only 3% of the land but is under full control of the Palestinian Authority for both security and civilian affairs, and it includes urban areas of the West Bank. Zone B covers 27% of the land; here,

the Palestinian Authority is responsible for civilian affairs and shares security affairs with Israel. Zone C makes up 70% of the land and is exclusively governed by Israel. It is worth mentioning that the Palestinian Authority has no control of borders, movement of people and goods, or land and water rights. The total population of the West Bank is estimated to be around 3.01 million, and 38.9% are in the age range 0–14 years according to the Palestinian Central Bureau of Statistics (PCBS, 2017). The West Bank is estimated to have a land area of 5640 km^2 (Global Business and Investment Center, 2017). Its population density is considered high, with 532 inhabitants/km^2 (PCBS, 2017). The majority of the population, 73%, lives in urban areas, 17% in rural areas, and 9% in refugee camps (PCBS, 2012).

The social structure of the Arab society is shaped by social values, norms, and religion. Therefore, it is seen to influence the structures, as well as the practices of the society. In Arab-Muslim societies, including Palestine, family is considered to be the basic social unit where beliefs, values, and traditions are taught to children; it is also recognized to be the main social security system for the individual. The structure of the Palestinian family is patriarchal and traditional (Haj-Yahia, 2005; Joseph, 2010). Accordingly, the man is head of the household and is solely responsible for providing economic support for his family. The women are expected to get married, take care of children, and maintain the home; it is considered important that they do not bring shame on the family honor (Aroian, Katz, & Kulwicki, 2006).

 The Palestinian community can be described as a fairly homogeneous mixture of Muslims (94%), Christians (6%), and a small Jewish minority (Giacaman et al., 2009). The religious beliefs of Muslims have a powerful influence on their wellbeing and attitude to striving to be in good health, and Islamic teachings influence their approach to seeking health care and their acceptance of and coping with their chronic illness complications (Odeh Yosef, 2008; Ypinazar & Margolis, 2006). Several studies have emphasized the vital role of religious beliefs in patients with different chronic illnesses, such as heart disease and cancer, in different Arab and Muslim countries (Al-Azri, Al-Awisi, Al-Rasbi, & Al-Moundhri, 2014; Najafi Ghezeljeh & Emami, 2014; Rahnama, Khoshknab, Seyed, Ahmadi, & Arbabisarjou, 2015).

Political and unstable conditions in the West Bank, such as closures, checkpoints, and the separation wall, continue to split families (Batniji et al., 2009; Keelan, 2016; Spellings, 2014), restrict movement, and limit the individual's access to land, education, jobs, and health care facilities. In addition, these political stressors lead to poverty and unemployment, and they tend to create barriers that prevent families from achieving wellbeing (Batniji

et al., 2009; Giacaman et al., 2009; Spellings, 2014). Furthermore, the unstable political and economic conditions deteriorate the patient's health, and compromise the organization of the Palestinian health care system and the quality of health services provided in Palestine (Giacaman et al., 2009). The Palestinian Ministry of Health transfers patients to Israel, Jordan, Egypt, and East Jerusalem when critical medical interventions or services are unavailable in the Ministry of Health hospitals in the West Bank (Keelan, 2016). To enter Jerusalem or Israel, Palestinian patients and their families have to apply for special permits from the Israeli authorities, and the process of obtaining a permit is often complicated and difficult (WHO, 2016).

2 BACKGROUND

The background presents childhood chronic health conditions, T1D, CHD, their prevalence, their impact on daily life for the child and family, and summarizes previous studies relating to health, SOC and ecological system theory.

2.1 CHILDHOOD CHRONIC HEALTH CONDITIONS

Today, due to improvements in medical care, children with congenital or childhood onset conditions generally survive into adulthood (American Academy of Pediatrics, 2011). This has led to an increasing population of young persons with long-term illnesses requiring lifelong medical follow-up (Perrin, Bloom, & Gortmaker, 2007).

A chronic disease is a lifelong, incurable condition that needs regular treatment, care, and medical follow-up (Eiser, 1997). Furthermore, a chronic disease might affect various aspects of daily life, such as physical, cognitive, emotional, and social functions (Mahon, O'Brien, & O'Conor, 2014; Taylor, Gibson, & Franck, 2008). Children's and their families' daily lives are significantly affected by a chronic disease, because it introduces new expectations and limitations that need to be addressed on a daily basis (Marshall, Carter, Rose, & Brotherton, 2009). The interest in health care for young persons with chronic diseases has shifted from medical outcomes such as survival to a greater emphasis on wellbeing, daily life experiences, health status and psychosocial outcomes as an essential construct for capturing health outcomes in children and adolescents (Bratt, Luyckx, Goossens, Budts, & Moons, 2015; Emmanouilidou, Galli-Tsinopoulou, Karavatos, & Nousia-Arvanitakis, 2008; Klatchoian et al., 2008; Knowles et al., 2016).

Living with a chronic condition during childhood and adolescence can result in depression, negative feelings, poor school performance, low self-esteem, and low self-concept (Ferro & Boyle, 2013; Woodgate, 2008). It has been found that chronic illness not only influences the daily life of the child with chronic illness but also influences the entire family. Having a child with a chronic disease can place stress on the parents' daily life, causing depression and anxiety, especially if the chronic condition is highly demanding (Boman et al., 2004; Hansen, Weissbrod, Schwartz, & Taylor, 2012; Jantien Vrijmoet-Wiersma, Ottenkamp, van Roozendaal, Grootenhuis, & Koopman, 2009). Caring for a child with a chronic illness can impose emotional, psychosocial,

physical, and financial burdens on parents (Erickson, 2013; Patterson, Holm, & Gurney, 2004; Williams et al., 2009).

2.2   TYPE 1 DIABETES

T1D is a chronic condition resulting from the destruction of B cells in the pancreas, characterized by absolute insulin deficiency (Ozougwu et al., 2013). The main cause of T1D is unknown, but it is an autoimmune disorder in which genes and environmental factors are believed to be involved in its initiation (Ozougwu et al., 2013; Yoon & Jun, 2005). Due to a deficiency of insulin, the glucose concentration in blood rises and can result in ketoacidosis and death if the condition is left untreated (Brandy Tabor, 2008).

T1D is one of the most frequent and serious chronic childhood diseases (Betts & Swift, 2003; Skrivarhaug, 2013; Soltesz, Patterson, & Dahlquist, 2009; Tolbert, 2009). T1D incidence has increased globally (Diamond Project Group, 2006; Harjutsalo, Sund, Knip, & Groop, 2013; Lin et al., 2014). Worldwide, one in every 400–600 children and adolescents is affected by T1D (Evert et al., 2008; Nabors & Bartz, 2013). Approximately, 86 000 children around the world develop T1D each year (International Diabetes Federation, 2015). In 2014, in the West Bank in Palestine, 144 persons between the age of 5 and 25 years were diagnosed with T1D (Palestinian Health Information Center, 2015).

Living with T1D necessitates that children and their families adhere to a rigorous regimen for managing the disease and keeping blood glucose levels within an acceptable range in order to prevent short-term and long-term complications. Managing T1D imposes daily care activities including blood glucose monitoring, physical exercise, regulating dietary intake and frequent insulin injections (Evert et al., 2008; Nabors & Bartz, 2013; Schmidt, 2007). Adhering to these responsibilities and activities is a challenge for children and adolescents (Davis et al., 2001; Lehmkuhl et al., 2009; Petitti et al., 2009).

Since T1D is complex and demanding, (Davis et al., 2001; M. Marshall et al., 2009; Silverstein & Patrick, 2007) parental support is essential for promoting adherence to diabetes self-care (Miller & Dimatteo, 2013; Nabors, Ritchey, Wassenhove, & Bartz, 2011). Thus, caring for a child with T1D can be emotionally and physically exhausting for parents (Johnson, 2013; Pateraki et al., 2015) and can result in stress and depression, particularly in mothers (Malerbi, Negrato, Gomes, & Brazilian Type 1 Diabetes Study Group, 2012; Nabors et al., 2011; Whittemore, Jaser, Chao, Jang, & Grey, 2012). In addition, qualitative studies have shown that children and adolescents with T1D

experience stigma and feeling different from their peers (Hapunda, Abubakar, van de Vijver, & Pouwer, 2015; Haugvik, Beran, Klassen, Hussain, & Haaland, 2017). This can have a negative outcome, such as impaired psychosocial wellbeing and worsened physical health due to avoiding self-care activities (Abdoli, Doosti Irani, Parvizi, Seyed Fatemi, & Amini, 2013; Fritz et al., 2016).

2.3 CONGENITAL HEART DISEASE

CHD is considered the most common birth defect and is universally classified as mild, moderate, or complex. CHD affects 9.1 in every 1000 live births (van der Linde et al., 2011; Zaqout, Aslem, Oweida, & De Wolf, 2014). Advances in early diagnosis, medical and surgical management, and postoperative care have increased survival rates and today approximately 90% of these children reach adulthood in some countries (Moons, Bovijn, Budts, Belmans, & Gewillig, 2010). This has resulted in an increasing group of children with CHD now requiring long-term and lifelong follow-up (Mackie, Rempel, Rankin, Nicholas, & Magill-Evans, 2012; Warnes et al., 2001).

CHD is defined as "a gross structural abnormality of the heart or intrathoracic great vessels that is actually or potentially of functional significance" (Mitchell et al., 1971, p.324). In 80% of the patients the cause is unknown, although some believe it occurs as a result of multifactorial inheritance as an interaction between genetic and environmental factors (Blue, Kirk, Sholler, Harvey, & Winlaw, 2012).

Children with CHD experience several stressors and challenges regarding physical, psychosocial, educational, and behavioral issues (Karsdorp, Everaerd, Kindt, & Mulder, 2007; Olsen, Sørensen, Hjortdal, Christensen, & Pedersen, 2011). Patients with a complex CHD have more difficulties with speech, attention, and hyperactivity (Sable et al., 2011; Shillingford et al., 2008). In a recent systematic review by Chong et al. (2018), the authors found that children and adolescents with CHD experienced a sense of frustration, abnormality, and fear of discrimination as a result of changes in their physical appearance, difficulties with academic achievement, and lifestyle constrains. The results also revealed some gender differences, as older boys were deprived from taking part in physical activities while girls were more occupied with concerns about fertility and their body image. From the parent's perspective, caring for a child with CHD can be described as a stressful experience with an impact on family life at various levels due to the increased burden and responsibilities imposed on these families (Almesned, Al-Akhfash, & Mesned, 2013; Wei, Roscigno, Hanson, & Swanson, 2015; Wray et al., 2018; Wray &

Maynard, 2006). In a previous systematic review Wei et al. (2015) concluded that 75% of the children with CHD reported greater stress, depression, emotional ups and downs, and anxiety than the general population. Furthermore, family life was impacted, such as relationships, finances, and quality of life. However, in 25% of the articles, parents of children with CHD did not report higher levels of stress than parents of children without CHD.

2.4   HEALTH

Living with a chronic condition has been shown to significantly impact the daily life of the affected children and to alter their self-perceived health status and health-related quality of life (HRQoL) (Adeyemo, Ojewunmi, Diaku-Akinwumi, Ayinde, & Akanmu, 2015; Varni, Limbers, & Burwinkle, 2007).

Despite several theories and models attempted to explain health, the concept of health is still a subject of debate and there is a lack of consensus on its definition (Eklund, Karlsson, Crondahl, Sunnemark, & Andersson, 2013). For example, the World Health Organization (WHO) views health as a subjective, comprehensive, and multidimensional concept (World Health Organization, 1986). The WHO definition highlights both social and personal resources for individuals in their daily life as much as physical capacities. It also acknowledges that health is more than absence of disease. From another point of view, Antonovsky (1979) developed the salutogenic model, which viewed health as a continuum, on an axis between ease (health) and disease (illness), as well as a resource-oriented concept of stress management, which focuses on resources that maintain and improve the movement toward health (Antonovsky, 1979). The central idea in the salutogenic model is sense of coherence (SOC), which concentrates on an individual's resources and abilities to maintain health and wellbeing. SOC can predict health and is associated with perceived health (Eriksson & Lindström, 2006, 2007).

To understand health, the cultural context and heterogeneity of individuals have to be taken into consideration (Bircher, 2005). For each person, health has its own meanings (Huber et al., 2011) so measuring self-perceived health status (PedsQL) and SOC can describe health and wellbeing from the individual perspective. In this thesis, the definition of health is developed from the WHO definition and existing literature (Eklund Karlsson et al., 2013; Svalastog, Donev, Kristoffersen, & Gajović, 2017; Tengland, 2007) and includes overall health status, such as mental, physical, spiritual, and social wellbeing, and the individual's ability to deal with mental and physical challenges during the course of life.

To avoid using confusing terms, it is worth mentioning that self-perceived health status, QoL and HRQoL are different but related concepts, which is the subject of debate, and there is no agreement on the definitions (Moons, Budts, & De Geest, 2006). Therefore, these concepts cannot be used interchangeably. HRQoL focuses on the effect of health status on a patient's QoL. Furthermore, Moons et al. (2006) argued that the concept of HRQoL is used frequently by researchers when they are actually referring to the perceived health of the patients. In addition, some HRQoL instruments are measuring self-perceived health status or self-reported health rather than HRQoL (Karimi & Brazier, 2016). In this thesis, the instrument PedsQL™ 4.0 Generic Core Scales (GCS) was used to assess self-perceived health status, as suggested by Karimi and Brazier (2016) and Moons et al. (2006).

Adhering to the complex and demanding regimen of maintaining an adequate metabolic control and avoiding short and long term complications in children with T1D is challenging and not easily achieved or maintained by children and adolescents, and this might influence self-perceived health status and QoL (Kalyva, Abdul-Rasoul, Kehl, Barkai, & Lukács, 2016). A systematic literature review by Nieuwesteeg et al. (2012) conducted from the year 2000 to 2012, including 17 studies on QoL in children and adolescents with T1D, concluded that although children with T1D had to follow a complex, demanding regimen, their QoL was not impaired compared to healthy peers. However, this systematic review also showed that disease-specific QoL problems, including a negative impact of diabetes on daily functioning, diabetes-related worries, and less satisfaction with life, were certainly present. On the other hand, in Kuwait, Abdul-Rasoul, AlOtaibi, Abdulla, Rahme, and AlShawaf (2013) reported lower total generic QoL in children with T1D than healthy controls. Furthermore, various factors have been proposed to be important predictors for lower QoL such as female gender, longer diabetes duration, age, poor glycemic control, and economic class (Hassan, Musa, Hai, Fathy, & Ibrahim, 2017; Kalyva, Malakonaki, Eiser, & Mamoulakis, 2011; Lukács & Barkai, 2013).

Studies on QoL in children and adolescents with CHD have reported conflicting results, which could be due to weaknesses in methodological rigor (Bratt & Moons, 2015). A systematic review of studies published between 2000 and 2012 (Bertoletti, Marx, Junior, Pedro, & Pellanda, 2014) reported conflicting results. For example, Mellion et al. (2014) found that total physical health and psychosocial health summary scores were lower in children with CHD than in a healthy control group. In addition, a study conducted in Saudi Arabia among children with CHD concluded that this disease had an impact on all dimensions of QoL (Azhar, AlShammasi, & Higgi, 2016).

On the other hand, a study by Bratt et al. (2015) concluded that young people with CHD reported fairly good self-perceived health status, measured with PedsQL™ 4.0 GCS, and asserted that symptom management, physical appearance, communication, and cognitive domains need specific attention. In addition, children with complex CHD usually reported lower scores of QoL than those with mild and moderate types of CHD (Sertçelik, Alkan, Sapmaz, Coşkun, & Eser, 2018).

2.5   SENSE OF COHERENS

Antonovsky's salutogenic model concentrates on an individual's resources and abilities to maintain health and wellbeing, rather than concentrating on the pathogenic perspective (Antonovsky, 1979). It can clarify how individuals, regardless of distressing circumstances and hardships, remain well. SOC is a key concept of the salutogenic model and consists of three dimensions: (1) *comprehensibility*, which refers to how a person perceives the stimuli that one encounters as consistent, structured and clear, (2) *manageability*, which is the extent to which one perceives that the available resources are sufficient to meet life's demands, and (3) *meaningfulness*, which refers to the extent to which one feels that life makes sense emotionally (Antonovsky, 1979). The individual's SOC is shaped by positive and negative experiences as well as internal and external resources (Antonovsky, 1987).

SOC has been found to be closely connected with health. Individuals with a strong SOC, have lower manifestations of the disease and lower distress, which means that those individuals develop effective coping strategies, adopt healthy behavior and find successful ways to label stressful events and challenges in their daily life (Eriksson & Lindström, 2006; Pillay et al., 2015). As a result, they maintain their health.

In addition, studies have shown strong SOC to be associated with high perceived health and QoL (Apers, Luyckx, et al., 2013; Eriksson & Lindström, 2005). SOC also was found to act as a predictor of health and health resources that promote and influence QoL (Eriksson & Lindström, 2007). For example, SOC in adolescents with CHD was found to be a predictor of physical, emotional, social, and school functioning domains of self-perceived health (Apers, Luyckx, et al., 2013). In patients with type 1 and type 2 diabetes, SOC scores were correlated with better glycemic control (Ahola, Saraheimo, Forsblom, Hietala, & Groop, 2010; Cohen & Kanter, 2004).

Chronic illness among children is associated with various degrees of stress that may significantly impact their health. For example, some studies found that

SOC scores were lower in patients with chronic diseases and linked this to negative life events and/or health deterioration (Bergman, Malm, Berterö, & Karlsson, 2011; Gauffin, Landtblom, & Räty, 2010; Merakou et al., 2013). In contrast, recent studies on SOC among patients with CHD found stronger SOC among these patients than healthy groups, and it was claimed that stronger SOC in these patients was a result of them learning to cope with their illness and to discuss their concerns with their parents and health care providers (Apers, Moons, et al., 2013; Moons & Norekvål, 2006).

SOC moderates the health impact of social stressors (Eriksson & Lindström, 2007) and may be a key factor that mediates the effect of social conditions and the Israeli occupation on the wellbeing and adjustment of children with T1D and CHD in the West Bank, Palestine. SOC can be assumed to have a vital role in coping with chronic illness, and by measuring the level of SOC it might be possible to determine how children with T1D and CHD find their daily life comprehensible, manageable, and meaningful in the specific context of the West Bank.

2.6   THEORETICAL STANDPOINT

THE ECOLOGICAL SYSTEM THEORY

The ecological system theory developed by Bronfenbrenner (1977,1979) is used as an overall theoretical standpoint of this thesis. The theory can be used to understand human development, taking the entire ecological system into consideration, and it clarifies the relationships within and between subsystems. It also depicts the interactions of systems in various settings, and it incorporates aspects of the environment that highlight the multifaceted nature of a person's life course, such as the individual's environment, social groups, learning, and development. The micro-, meso-, exo- and macrosystem are the main levels of influence in this theory. These systems are constantly interacting and influencing each other. The theory acknowledges both the internal and external barriers as well as the protective factors that could influence the child and family (Figure 1).
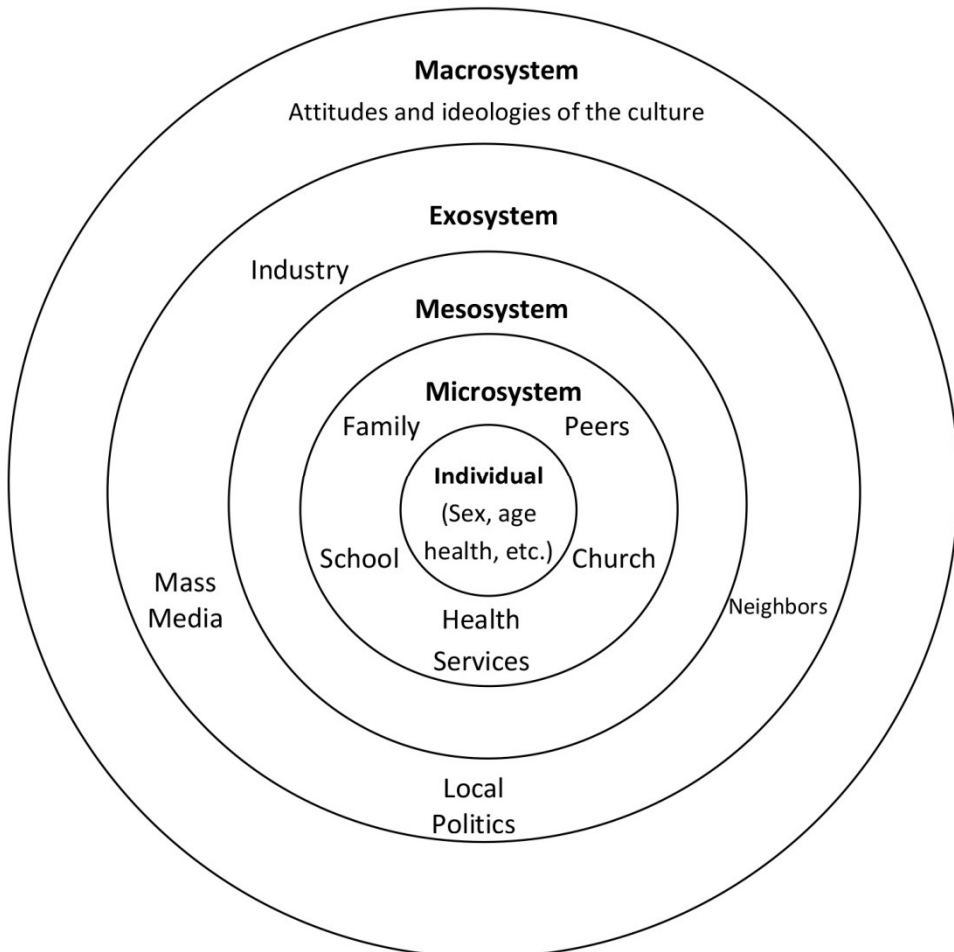
Figure 1. Bronfenbrenner's ecological model, adapted from Adolescents Living with HIV:
Emerging Issues in Public Health in South Africa, by Woollett (2016)

Adopting the ecological system theory in this thesis will improve the comprehension of the fundamental meaning of the child's daily life experiences. The ecological point of view incorporates a comprehensive perspective of persons and environments, so neither can be comprehended outside the context of its association with the other (Bronfenbrenner, 1979; Bronfenbrenner, 2005). Therefore, developing knowledge about individual's health in relation to living conditions, environment, traditions, culture and relationships is highly emphasized in health care science (Hörberg et al., 2011).

The microsystem of the child with chronic illness consists of the relationship a child has with his immediate environment. This includes experiences with

family, friends, teachers, and life in school. These experiences include activities, social roles, and interpersonal relationships, which are essential for the individual's health and wellbeing. The ability of the family to function depends on the characteristics of each member, such as the type of chronic illness and the parental relationship.

The mesosystem consists of the relationship between two microsystems, such as the interaction between the child's family and peers and school. These interactions could have positive and negative influences on the individual. For example, a difficult experience at home for a child with his family members could be eased by a supportive peer relationship. In addition, the daily life experiences in the child's and family's micro- and mesosystem can affect health beliefs, attitudes, and health-related behavior (Gray, 2015; Woollett, 2016).

The exosystem represents the settings that influence the individual's immediate environment and microsystem, although the individual does not have an active role. These settings or contexts include the parent's workplace, the child's school, peer group, family social network, neighborhood community, and the availability and quality of health services for individuals (Bronfenbrenner, 1979).

The macrosystem includes the societal and cultural context in which the microsystem, mesosystem and exosystem are embedded. It is shaped by cultural and religious beliefs, values, and norms (Bronfenbrenner, 1977, 1997). It also includes economic, political and polices factors that may impact the care and services available for individuals with chronic illness (Pask et al., 2018). Therefore, this theory is highly applicable as a theoretical standpoint for this thesis, which explores families' lives under the very specific social conditions of the Palestinian West Bank. These conditions can be assumed to influence the families' prerequisites and experiences of living with a child with a chronic illness such as T1D or CHD. The dynamic, constant, and bidirectional interaction of micro-, meso-, exo-, and macrosystems could influence the child's SOC. A person's health and wellbeing is related to their connectedness to their environment. In this thesis, the systems within the ecological model that might be associated with the daily life experiences of children with T1D and CHD and their parents, as well as the children's self-perceived heath status and SOC, will be considered.

3 RATIONAL

Recently there has been a substantial increase in research addressing psychosocial aspects and impact of chronic disease on the daily life of children with chronic illness as T1D and CHD. Such aspects are fundamental for health care sciences. The majority of these studies have been conducted in Western countries and their results may not be applicable in the specific context of Palestine. However, it is important to emphasize that the sociocultural and political context, family dynamics, religion, and health care systems vary across countries and societies, and it is likely that these factors have an impact on wellbeing and psychosocial issues. Living with a chronic illness such as T1D or CHD in occupied territories like the West Bank is likely associated with challenging social conditions that can influence self-management and societal and family support in daily life.

In the context of childhood chronic illness in the West Bank, there is a lack of studies in children with T1D and CHD and their families. A better understanding of the daily life experiences of children and their families, management of the child's chronic illness, wellbeing, and health status is essential to capture chronic illness outcomes in these children. With increased knowledge, health care providers will be better able to recognize the complexity of living and coping with T1D or CHD in the West Bank and better equipped to provide appropriate interventions, strategies, and support to children with chronic illness.

4 AIM

The overall aim of this thesis was to explore the experiences of daily life in children and adolescents with T1D and CHD and their parents living in the West Bank, Palestine, and to describe self-perceived health status and SOC in these children compared with a healthy reference group.

4.1 SPECIFIC AIMS

Study I   The aim of this study was to explore the experience of daily life in children with T1D and their parents in the Palestinian West Bank.

Study II   The aim of this study was to explore the experience of daily life in children with CHD and their parents in the Palestinian West Bank.

Study III   The aim of this study was (i) to measure self-perceived health status and SOC in children with T1D living in the Palestinian West Bank, (ii) to compare with a healthy reference group, and (iii) to examine self-perceived health status and SOC correlate with medical and sociodemographic characteristics.

Study IV   The aim of this study was (i) to measure self-perceived health status and SOC in children with CHD living in West Bank, Palestine, (ii) to compare this group with a healthy reference group and (iii) to examine potential correlates between self-perceived health status/SOC and medical and sociodemographic characteristics.

5 METHODS

5.1 DESIGN

A multi-method approach using both qualitative and quantitative methods was used to explore and understand the daily life of children with chronic illnesses such as T1D and CHD. This approach has the advantage of providing a more complete picture of the studied phenomena and thereby enriching and enhancing the evidence base (Polit & Beck, 2012). The analysis for each study was performed separately. An overview of the four studies is presented in Table 1.

In Study I and II, a qualitative descriptive approach was used to explore daily life experiences in children with T1D and CHD and their parents. This method can enable children with chronic illnesses and their parents to share their narratives regarding how they experience their daily life in their own words, allowing them to describe and explain their feelings, needs, and challenges. A qualitative descriptive study is the method of choice when detailed descriptions of phenomena are desired (Sandelowski, 2000a).

Qualitative descriptive studies have their roots in naturalistic inquiry (Lambert & Lambert, 2012; Sandelowski, 2000b) and are conducted within the constructivist paradigm, which is often called the naturalistic paradigm (Guba & Lincoln, 1989; LeCompte, Tesch, & Goetz, 1993; Polit & Beck, 2012). Based on naturalistic inquiry, reality is multiple and subjective, and the research is conducted in the real-life setting and within the context in which the study is planned, because it is impossible to understand realities in isolation of their context (Lincoln & Guba, 1985; Patton, 2002).

In Study III and IV, a quantitative approach with a cross sectional design was used to measure self-perceived health status and SOC in children with T1D or CHD and to compare them with a healthy reference group in the Palestinian West Bank. The quantitative approach provided frequency data and enabled comparisons between groups and between measurable variables. This approach allows researchers to explain a phenomenon by applying statistical procedures to numerical data in order to generalize findings (Leedy, 1993; Yilmaz, 2013); it is conducted within the positivist paradigm, which asserts that reality is fixed and can be objectively studied (Polit & Beck, 2012).

Understanding individual's perspective, experience, reaction and coping strategies in relation to health and illness is fundamental in health care sciences. The focus of health care science is the development of knowledge of the patient from a holistic approach (Hörberg et al., 2011). Consequently, optimal care can be developed.

Table 1. Overview of the studies in the thesis

	Study I	**Study II**	**Study III**	**Study IV**
Design	Qualitative Descriptive	Qualitative Descriptive	Quantitative Cross-sectional	Quantitative Cross-sectional
Data Collection	Individual interviews	Individual interviews	Questionnaires, PedsQL™ 4.0 SOC-13	Questionnaires, PedsQL™ 4.0 SOC-13
Participants	Children (n=10) Parents (n=10)	Children (n=9) Parents (n=9)	Children with T1D (n=100) Reference group of healthy children (n= 300)	Children with CHD (n=100) Reference group of healthy children (n= 300)
Data Analysis	Qualitative content analysis	Qualitative content analysis	Descriptive and comparative statistics	Descriptive and comparative statistics

PedsQL = Pediatric quality of life inventory; SOC = sense of coherence

5.2 SETTING, PARTICIPANTS AND RECRUITMENT PROCESS

5.2.1 STUDY I AND II

A purposeful sampling procedure was used to select participants, which aimed to reflect the diversity of the population (Polit & Beck, 2012). To achieve a good sampling variance, the participants were selected from different cities, villages, and camps, as well as from different age groups and both sexes. Purposeful sampling is a way of choosing information-rich cases for in-depth study (Patton, 2002). In Study I, ten children (n=10) with T1D and their parents

(n=10) were recruited to take part. In Study II, nine children (n=9) with CHD and their parents (n=9) were enrolled. As part of the recruitment process, letters with study information and consent forms were sent to the Palestine Diabetes Institute, the Diabetes Friends' society and a Charitable hospital in East Jerusalem, which cover cities, villages and camps in the south, north, and middle region of the West Bank, asking for their agreement to recruit participants. Upon receiving their agreement, all potential participants were identified with the assistance of the nurses and the secretary in the diabetes clinic and department of pediatric cardiac surgery and CHD at the hospital and the secretary of the diabetes association. Children and parents who met the eligibility criteria and were willing to describe their everyday lives were provided with the study information letter and consent form. In Study I, children with T1D aged 8–18 years with a diagnosis of T1D at least six months prior to the study were eligible for inclusion in the study sample. In Study II, the inclusion criteria were children with CHD aged 8–18 years. In both studies, parents were also asked to participate. Initially, families were contacted by staff at recruitment facilities and those who agreed to participate in the study were approached by the researcher by telephone. During the initial telephone contact, the researcher explained the nature of the study and arranged the interview location according to the participant's preference. Parents signed the consent form and children gave their assent verbally before the interviews.

5.2.2   STUDY III AND IV

Letters including study information were sent to two hospitals, three cardiac clinics, two diabetes clinics, two diabetes societies, and six primary and high schools in the West Bank, asking for their agreement to recruit children with CHD or T1D, or healthy children for the reference group, to take part in the study. All of these approached hospitals, clinics, and schools agreed to recruit participants. Participants were recruited by nurses who were working in the diabetes or cardiac clinics where the children attended regularly for follow-ups. In addition, diabetes societies, cardiac clinics, and hospitals had full name and address records for these children. Staff from the diabetes clinics, cardiac clinics, and hospitals contacted participants by telephone and informed them about the nature of the study. Families who agreed to be enrolled in the study agreed to be contacted by the researcher to arrange for a meeting with the parents to include their children in the studies. Parents of participants signed a consent form and their children gave assent before taking part in the study.

In Study III, a convenience sample of 100 children with T1D was selected from two diabetes clinics and two diabetes societies with a referral area covering cities, villages, and camps in the south, north, and middle of the West Bank.

They were eligible if they were aged 8–18 years and had a diagnosis of T1D with duration greater than six months prior to the study. Exclusion criteria were other chronic diseases. In Study IV, a convenience sample of 100 children with CHD was chosen from two hospitals and three cardiac clinics with a referral area covering cities, villages, and camps in the south, north, and middle of the West Bank. Patients were eligible if they were 8–18 years of age and had a diagnosis of CHD. Exclusion criteria were other chronic diseases and /or intellectual impairments.

For the reference group, school administrators were approached by the researcher and, when approval for the study had been granted, heads of the schools informed parents about the nature of the study and the parents who agreed to their child's participation signed a consent form.

A reference group consisting of 300 healthy children aged 8–18 years was selected from six primary and high schools from north, south, and middle of the West Bank. Children with any chronic disease and/or intellectual impairments were excluded.

5.3   DATA COLLECTION

5.3.1   STUDY I AND II

Data was collected via face-to-face interviews with ten children with T1D and their parents in Study I and nine children with CHD and their parents in Study II. The interviews were conducted by the researcher in the participants' preferred location. In Study I, 12 interviews were conducted in the participants' homes according to their request, while the remaining eight interviews were performed in a private room in the diabetes clinic or diabetes society. In Study II, the interviews were carried out in the participants' homes. As the child's and parent's point of view are not always congruent, the interviews with children and their parents were conducted individually. This method gave them the possibility to speak openly about their daily life experiences without feeling hindered by each other's presence. Feeling free to describe personal feelings, thoughts, and meanings about their daily life is vital to the interviews (Marshall, Carter, Rose, & Brotherton, 2009). In Study I and II, the interview guide was constructed by the research team and the interviews were conducted in Arabic, as the participants and the researcher share this language in common. In addition, all interviews were audio-recorded with the permission of the participants. The following main questions were posed to participants in Study I: "Can you tell me about your life today compared to before you got your diabetes?", "Can you tell me how you manage your diabetes during an ordinary

day at home and school?", and "Can you describe any challenges you face in helping your child manage diabetes?" Follow up questions were used to elicit more detailed information, such as, "What do you mean?", "How do you feel about that?", and "Can you give me an example?" In Study I, the interviews were conducted between January and August 2014 and lasted between 35 and 70 minutes. In Study II, the following main questions were posed to the children: "Can you describe your CHD and how do you think it affects your daily life?", "What is a typical day like for you right now?", and "On a typical day, what sorts of things do you do that might set you apart from your friends?"

For the parents, the following main questions were posed: "Can you describe your child's CHD and how you think it affects your child's daily life?", "Can you tell me about how you think your life and your family's life are affected by the fact that your child has a CHD?", "How has the diagnosis influenced your child (emotionally, physically, and socially)?" The interviews were performed between March and December 2015; they lasted between 30 and 60 minutes.

5.3.2 STUDY III AND IV

Children with T1D or CHD filled out self-reported questionnaires independently in a room in the outpatient clinic while waiting for their consultation under the supervision of researcher or nurses. For families who agreed to participate in the study but preferred to be visited at home, the researcher arranged to visit the family so that the child could take part in the study. These children filled out the self-reported questionnaires at home, under the supervision of the researcher. In Study III, all the families who were approached agreed to allow their child to participate. In Study IV, all agreed except for two families who declined due to lack of time.

For the reference group, children and adolescents completed the self-reported questionnaires in the classroom under the supervision of the researcher or a research colleague. All agreed and no one declined.

Sociodemographic data were gathered via a sociodemographic questionnaire that included questions about age, sex, and place of residence. In Study III, medical information including duration of diabetes, mode of insulin administration, and the most recent HbA1c level were collected from patients' medical records. As proposed by the International Society for Pediatric and Adolescent Diabetes (ISPAD), glycemic control was divided into three categories of the Diabetes Control and Complications Trial and International Federation of Clinical Chemistry HbA1c values; optimal <7.5%/58 mmol/mol,

suboptimal 7.5-9.0%/58-75 mmol/mol and high risk >9%/75 mmol/mol (Rewers et al., 2009). In Study IV, clinical characteristics of the participants with CHD included information such as primary CHD diagnosis, prior heart surgery, and complexity of heart defect, and were retrieved from medical records and discharge summary reports.

Self-perceived health status was measured with the Arabic version of PedsQL™ 4.0, Generic Core Scales (GCS). This instrument is considered reliable and valid for use in both healthy and chronically ill pediatric populations (Arabiat, Elliott, Draper, & Al Jabery, 2011). PedsQL™ 4.0 GCS has been validated in a variety of conditions, such as asthma, cancer, heart disease, rheumatology, and diabetes (Varni, Limbers, & Burwinkle, 2007). PedsQL™ 4.0 GCS was used to measure self-perceived health status in children aged 8–18 years (diabetes group n=100, CHD group n=100, reference group n=300). PedsQL™ 4.0 GCS is composed of 23 items on a five-point Likert scale ranging from 0 to 4, where 0 is never a problem and 4 is almost always a problem. The PedsQL™ 4.0 scales are designed to provide a summary score in two dimensions; the Physical Health Summary Score and the Psychosocial Health Summary Score, which is composed of Emotional, Social, and School Functioning subscales (Varni, Seid, & Rode, 1999). Items are reverse-scored and linearly transformed to a 0–100 scale (0=100, 1=75, 2=50, 3=25, 4=0), so that higher scores indicate better self-perceived health status. The total score of a scale is the sum of all the items divided by the number of items answered on all the scales.

Sense of coherence was assessed by the Arabic version of the SOC-13 questionnaire. The SOC scale is considered a reliable, valid, and cross-culturally applicable instrument (Eriksson & Lindström, 2005). It consists of 13 items divided into three subscales. The subscales are: 1) ***Comprehensibility***, which refers to the extent to which a person sees internal and external stimuli as consistent, structured, clear, and predictable (five items); 2) ***Manageability****,* which is the extent to which one perceives that one's resources are sufficient to meet life's demands (four items); 3) ***Meaningfulness****,* measuring to what extent a person views life's demands and challenges as worthy of commitment and dedication (four items). Each item is scored on a seven-point Likert scale and the total score ranges from 13 to 91. A high score indicates that the person has a strong SOC. Cut-off points for categorizing low, moderate, and high scores are ≤60, 61–75, and ≥76, respectively (Mendel, Bergenius, & Langius, 2001). The SOC scale was used to measure SOC among children aged 13–18 years (diabetes group n=49, CHD group n=52, reference group n=150). Children under 13 years old were excluded because of the nature of the

questionnaire, as the ability of young children to comprehend the constructs and scales is limited.

5.4   DATA ANALYSIS

5.4.1   STUDY I AND II

Qualitative content analysis (QCA) was performed to analyze data following the steps described by Graneheim and Lundman (2004). QCA is considered the appropriate approach for analyzing qualitative descriptive studies (Sandelowski, 2000b) because it deals with the manifest content of a text as well as interpretation of the latent content. Interpretation of manifest and latent content can range from low interpretation to high abstraction of the data. Furthermore, QCA is considered a useful method to preserve research rigor and trustworthiness in interpretation and synthesis of the findings (Graneheim & Lundman, 2004). All interviews were transcribed verbatim and translated from Arabic to English by the researcher. In Study I, the transcriptions were imported to NVIVO 10 software to facilitate data management, coding, and retrieval, and the coded datasets were subjected to further in-depth analysis. According to the steps outlined by Graneheim and Lundman (2004), the transcripts were read a number of times in order to gain a holistic sense of the participants' experience. Text about daily life experience of children with T1D and CHD and their parents was extracted and divided into meaning units of words, sentences, or paragraphs. These meaning units were then condensed into shorter statements, abstracted, and labeled with a descriptive code without losing the core meaning. Finally, through reflective and collaborative discussions among the researchers about the accuracy of interpretations throughout the abstraction process, the codes were grouped into subthemes and themes. Example from the analytical process is presented in Table 2.

Table 2. Examples from the analytical process (Study II)

Meaning unit	Condensed	Code	Subtheme	Theme
It's God's will so I have to accept it as what is from God is good, thank God for everything. What God wants it should be. And I am satisfied with the wisdom of God.	Feeling thankful, satisfied with God's will and relying on God	Thankful and relying on God	The impact of religion and fatality as a facilitator in managing the disease	Socio-cultural burden and finding comfort
He was negatively affected by how friends deal with him as they prevented him from playing because they thought he is weak and sick. His nervousness might be due to feelings of inadequacy as he couldn't participate in the activities that he likes such as play	Friends prevented him from playing as they thought he is too weak and sick to play	Labeling and devaluing	Stereotyping and feeling of being devalued	Socio-cultural burden and finding comfort

5.4.2   STUDY III AND IV

Statistical analyses were performed with SPSS for Windows, version 24. Frequencies, percentages, mean scores, and standard deviations were used to describe participant characteristics. Unpaired two-group analysis for nominal data such as sex, place of residency was analyzed using chi-square tests. Clinical characteristics, such as diabetes duration, mode of insulin administration, and HbA1C level in Study III and primary CHD diagnosis, prior heart surgery, and complexity of heart defect in Study IV, were performed using chi-square tests.

The Mann–Whitney U test was employed to compare age, self-perceived health status, and SOC. Spearman's rank correlation coefficient test was used to assess the interrelationships between self-perceived health status, SOC, age, sex, place of residency, and clinical characteristics. For all analyses, $p \leq 0.05$ was considered statistically significant.

6 ETHICAL CONSIDERATIONS

Study approval was obtained from the Research Committee at Al-Quds University and the Palestine Diabetes Institute, Palestine. Ethical guidelines and principles were considered through all stages of the research process as addressed by Declaration of Helsinki (World Medical Association, 2013). The principles apply to all human subjects, adults and children. The United Nations Convention on the Rights of the child (UNCRC) emphasizes the importance of participatory involvement of children and adolescents in all matters affecting their lives, including research (Bell, 2008). Including children and adolescents in research, to hear their voices, their experiences, and their perspectives on life, is very important (Wyness, 2013) and essential to improving their health care (Santelli et al., 2003). However, children and adolescents are considered a vulnerable group as research subjects and sometimes it is hard to obtain their permission and to preserve their rights. Therefore, it is essential for the researcher to follow ethical guidelines addressed by UNCRC in order to protect children's rights before, during, and after the research (Bell, 2008). The researchers also have to understand the developing capabilities, unique needs, and perspectives of children and adolescents (Crane & Broome, 2017) and to assess the risks and benefits (Santelli et al., 2003). The potential risk in Study I and II is that the participants may feel uncomfortable, distressed, or embarrassed while disclosing their experiences or thoughts. For this reason, the interviewer established an atmosphere of trust in order to make participants feel safe and comfortable when disclosing their experiences. The participants were provided with oral and written information about the nature of the study, including an assurance that participation is voluntary and participants can withdraw at any time. Furthermore, participants were reminded of their right to skip any question and to withdraw from study at any time. None of the participants withdrew from the studies. Participants were informed that they would not receive any direct benefits from their participation in the study. In addition, participants were assured that all information would be treated in the strictest confidence. Identifying details were removed from the documents and replaced by an identification number. Prior to enrolment in each study, the parents signed a consent form and the children gave their assent.

7 RESULTS

7.1 STUDY I AND II

In Study I, 10 children with T1D, six mothers, and four fathers were included. Half of the children were girls. The median age was 13.5 years (range 8.0–16.0) for children with T1D, 35.5 years (range 28.0–49.0) for mothers, and 37.5 years (range 32.0–42.0) for fathers. Twelve of the participants lived in urban areas, four in rural areas and four in camps. All of the mothers were housewives, while two fathers were employees and two were manual workers. All of the children were living with their parents.

In Study II, nine children with CHD, five mothers, and four fathers were included. The median age was 15 years (range 8-17) for children with CHD, 40 years (range 28-50) for mothers, and 55 years (range 31-59) for fathers. The participants were selected from different areas, eight from urban areas, six from rural areas, and four from camps. All of the mothers were housewives, three of the fathers were manual workers, and one was an employee. Two of the children had simple CHD, four as moderate and three as complex CHD. Overview of the Overall theme, themes and subthemes in Study I and II is presented in Table 3.

The analysis described the daily life struggle of these children and their parents, as they strived to place themselves and their disease within their social context. Daily life was impacted negatively by social stereotyping, children's perception of their chronic illness, and political conflict (Study II). Children's and parents' perceptions about chronic illness were shaped by societal and traditional gender norms, which affected how they accommodated the disease into their life. They experienced stigmatization and felt that chronic illness contributed to others perceiving them in a negative and judgmental way. This difficult experience left them with deep frustration and influenced their ability to interact with peers, resulting in social isolation (Study I and II).

Children and parents preferred to keep the chronic illness secret in order to protect the family's reputation and to avoid negative consequences of stigma in relation to marriage, social standing, and career paths. The children and their parents were worried that girls with T1D and girls and boys with CHD would be unable to marry because they believed T1D and CHD to be hereditary genetic diseases, which would affect the girls' ability to assume the traditional role as potential wives and mothers (Study I and II). In addition, daily life

Table 3. Overall themes, themes and subthemes in Study I and II

Study I : Children with T1D	
Facing the social reality of diabetes	
Stigmatization	*Social constraints*
Feeling different Concealing signs of the disease Keeping illness as a secret	Restricting social events Gender implications Excluded from school activities Imposing Economic Burden

Study II : Children with CHD			
Facing and managing challenges			
Socio cultural burden and finding comfort	*Physical and external limitations*	*Self-perception and concerns about not standing out*	*Limitations in access to health care due to the political situation*
Stereotyping and feelings of being devalued	Physical symptoms limiting daily life	Body image concerns	Barriers in access to health care
The impact of religion and fatality as a facilitator in managing the disease	Restrictions imposed by the societal environment	Worries about marriage opportunities	Social isolation when hospitalized
	Financial difficulties		

T1D = type 1 diabetes; CHD = congenital heart disease

struggles were evident for girls with diabetes due to cultural restrictions influencing their ability to do physical training outside home; as a consequence, the girls found it difficult to control their diabetes (Study I).

Both children with T1D and CHD felt different than their peers and classmates. They were worried about standing out in their social life and not being like everyone else, which intensified their emotional pain, suffering, and dissatisfaction with their life (Study I and II). To avoid being different and the negative consequences associated with stigma, children with T1D were

preoccupied with hiding their disease management tasks. The threat of diabetes complications did not motivate the children to follow their treatment regimen because they thought that their social image was more essential than their health (Study I). Children with CHD were preoccupied with how to hide their surgical scars by wearing turtlenecks as a way to avoid being the center of attention. Girls felt ashamed of their appearance and less attractive, which affected their self-esteem and self-confidence (Study II).

Children with T1D and CHD were sometimes excluded from school activities because school staff feared complications associated with physical activity. Some children with CHD were excluded from school activities as they were hindered by their symptoms such as breathlessness, chest pain, fainting, fast heart rate, and exhaustion during physical activities. The exclusion from, or restricted participation in physical and recreational activities hurt them emotionally and socially (Study I and II).

The high cost of managing chronic illness was an issue for all parents, even though they had medical insurance. The unavailability of some medications in governmental and UN Relief and Works Agency clinics forced these parents to buy medications and medical products themselves. Caring for a child with a chronic illness placed a large economic burden on the family and had a great impact on various aspects of their daily life. To afford expensive daily treatment, some parents deducted from the family's daily budget and some borrowed money from relatives and friends (Study I and II).

Children with CHD who were in need of more advanced treatment, such as open heart surgery or cardiac catheterization, were referred to East Jerusalem or Israeli hospitals, because hospitals in the West Bank are not sufficiently equipped to treat these children. Because of mobility restrictions and closures imposed by the Israeli authorities in the West Bank, children with CHD and their parents faced barriers and difficulties regarding access to more specialized healthcare facilities. They also felt socially isolated during their hospitalization in Israel or East Jerusalem. To enter East Jerusalem and Israel, children and parents need to be granted permission, and on some occasions the permit for both parents was denied; on other occasions, just the father's permit was denied, with no reason given by the Israeli authorities. Denying permits to parents of children with CHD intensified suffering for these families and made them less able to support each other. In addition, some mothers experienced social isolation as they were alone with their sick child at an Israeli hospital when none of their family members could get a permit to visit them and to support them during that difficult time (Study II).

To overcome daily life struggles and challenges such as pressure from the community, and to cope with the disease itself, children with CHD and their parents adopted a sense of fatality as a facilitator in managing the disease. They believed that everything in the universe is controlled by God's will and everything that is related to health or illness is a result of divine fate, so they had to accept what God had chosen for them (Study II).

7.2   STUDY III

7.2.1   SOCIODEMOGRAPHIC AND MEDICAL CHARACTERISTICS

A total of 100 children with T1D and 300 children from a healthy reference group were included. The mean age was 12.5 years (SD 2.7) for the study group and 12.7 years (SD 2.6) for the reference group. Sex was equally distributed in both groups. The mean diabetes duration was 5.6 years (SD 3.0). Insulin was administered through multiple daily injections in 88.8 % of the children; the others used insulin pumps. The mean HbA1c level was 8.8 % or 73.0 mmol/mol (SD 1.6), and 17.0% of patients had an average HbA1c level in the 'optimal control' range, 41.4% in the 'suboptimal control' range, and 41.4% in the 'high risk of metabolic complications' range.

7.2.2   SELF-PERCEIVED HEALTH STATUS

The mean PedsQL score was 80.0 (SD 15.3) in the study group and 80.4 (SD 12.6) in the reference group, showing no significant difference in self-perceived health status. However, boys in the study group had significantly higher PedsQL scores than girls (mean 84.0 vs 75.21, p=0.004) on the generic scale. In contrast, no significant gender differences were found in the reference group.

7.2.3   SENSE OF COHERENCE

Of the 100 children with T1D, 49 adolescents aged 13–18 years completed the SOC scale, along with 150 adolescents in the reference group. SOC value was low for both groups. The mean SOC score was 58.0 (SD 16.1) for adolescents with T1D and 55.1 (SD 12.1) for adolescents in the reference group. This was in the low SOC range (below 61) for both groups. No statistically significant differences in SOC score between the study group and the reference group were found.

7.2.4 CORRELATIONS

Among children with T1D, a positive correlation was found between SOC score and PedsQL score, (r_s 0.59, p<0.001), showing that stronger SOC was associated with higher self-perceived health status. A negative correlation was found between PedsQL score and HbA1c level (r_s -0.30, p=0.003), indicating that higher self-perceived health status was associated with better glycemic control. A similar negative correlation was found between SOC score and HbA1c level (r_s -0.36, p=0.012), indicating that stronger SOC was associated with better glycemic control.

7.3 STUDY IV

7.3.1 SOCIODEMOGRAPHIC AND MEDICAL CHARACTERISTICS

A total of 100 children with CHD and 300 children from a healthy reference group were included. Almost 43.0 % of the study group and 49.0 % of the reference group were girls. The mean age was 12.4 years (SD 3.1) for the study group and 12.7 years (SD 2.6) for the reference group. More than 43.0 % of the study group was classified as having mild CHD, 35.0 % as having moderate CHD, and 20.0 % as having complex CHD. Seventy-four percent had a history of cardiac surgical procedures.

7.3.2 SELF-PERCEIVED HEALTH STATUS

The mean PedsQL score was 69.3 (SD 18.9) in the study group and 80.4 (SD 12.6) in the reference group, showing significant difference in self-perceived health status (p <0.001). This significant difference in self-perceived health status was evident in all domains (physical, emotional, social, and school functioning).

7.3.3 SENSE OF COHERENCE

Of the 100 children with CHD, 52 adolescents aged 13–18 years completed the SOC scale, along with 150 adolescents in the reference group. The mean SOC score was 59.6 (SD 19.2) for adolescents with CHD and 55.1 (SD 12.1) for adolescents in the reference group. This was in the low SOC range (below 61) for both groups. No statistically significant differences in SOC score between the study group and the reference group were found.

7.3.4 CORRELATIONS

Among the 100 children with CHD, PedsQL score was negatively correlated with complexity of CHD (r_s -0.27, p=0.006), showing that children with more complex heart disease scored lower on self-perceived health status. In addition, a positive correlation was found between PedsQL score and prior heart surgery (r_s 0.35, p<0.001), indicating that children who did not undergone previous heart surgery scored higher on self-perceived health status. A positive correlation was also found between PedsQL score and SOC score (r_s 0.58, p<0.001), showing that stronger SOC was correlated with higher self-perceived health status. No correlation was found between SOC scores and medical characteristics in adolescents with CHD.

7.4 SUMMARY

The results of Study I and II revealed that children with T1D and CHD and their parents were highly impacted by stigma, societal stereotyping, their perception of their chronic illness, and political conflict. These factors prevented these children, girls in particular, from adopting healthy self-care behaviors to manage their chronic illness; their opportunities to interact with peers were also affected, resulting in social isolation. The children and their parents were also worried about lack of marriage opportunities. Although this affected every aspect of their lives, they explained that their reliance on God facilitated their acceptance of their fate and lives. The results of Study III and IV showed comparable self-perceived health status in children with T1D and the reference group, whereas the children with CHD had lower self-perceived health status. Children with complex heart disease and those who had undergone heart surgery scored lower on self-perceived health status. However, boys with T1D reported higher self-perceived health status than girls. SOC was low in all the adolescents and no differences between the groups were found in either Study III or Study IV. Higher scores of SOC and self-perceived health status were both correlated with better glycemic control in children with T1D. Furthermore, a stronger SOC was associated with higher self-perceived health status in children with T1D and CHD.

7.4.1 COMPARISON OF PEDSQL AND SOC BETWEEN CHILDREN WITH T1D AND CHD

Children with CHD scored significantly lower on PedsQL than children with T1D. This significant difference in self-perceived health status was evident in all domains (physical, emotional, social, and school functioning). Children with CHD had more difficulties in all domains of PedsQL. SOC was low in

both groups and no differences between the groups were found. The comparison between children with T1D and CHD is presented in Table 4.

Table 4. PedsQL and SOC: Comparison between children with T1D and CHD.

	Children with T1D n=100	Children with CHD n=100	p-value*
PedsQL	Mean ($\pm$ SD)	Mean ($\pm$ SD	
Emotional	71.3 (20.6)	64.5 (23.1)	0.029
Social	85.1 (18.2)	76.1 (21.23)	0.001
School	79.0 (17.9)	71.3 (24.2)	0.012
Psychosocial	78.5 (15.6)	70.2 (18.8)	0.001
Physical	82.7 (17.3)	67.6 (23.5)	<0.001
Total score	80.0 (15.3)	69.3 (18.9)	<0.001
SOC	n= 49	n=52	
Meaningfulness (4–28)	18.9 (6)	19.4 (6.2)	0.619
Manageability (4–28)	18.4 (6.3)	17.9 (7.0)	0.830
Comprehensibility (5–35)	20.8 (7.5)	22.2 (8.3)	0.381
Total score SOC	58.0 (16.1)	59.6 (19.2)	0.630

T1D = type 1 diabetes; CHD = congenital heart disease
PedsQL = Pediatric quality of life inventory; SOC = sense of coherence
SD = standard deviation
Psychosocial: the sum of the items in the *Emotional*, *Social*, and *School functioning* scales divided by the number of items answered.
* Statistical comparisons were conducted with the Mann-Whitney U test

8 DISCUSSION

This thesis provides insights into what children with T1D and CHD and their parents, experience in their daily lives in the West Bank, Palestine. It also deepens our knowledge and understanding of the psychosocial aspects by describing the self-perceived health status and SOC in these children. The sociocultural context in which children with chronic illness and their parents live has a great impact on their daily life. The prevailing values and beliefs of the society about chronic illness determine how members of the community treat the families of those with chronic illnesses. The results have highlighted how children and parents have attempted to cope with the barriers and challenges they come to encounter on a daily basis. The findings addressed how immediate environmental, political, and sociocultural factors interact and affect people's resources and management of their vulnerable situation; an awareness of these factors is essential for health care providers and policy makers. In addition, the lack of knowledge about T1D and CHD illnesses in the Palestinian society has led to negative responses and consequences, not only for the individual, but for the family as a whole.

8.1 FINDINGS FROM THE VIEWPOINT OF THE ECOLOGICAL MODEL

The findings will be discussed in relation to the ecological system theory, as it addresses the contextual factors associated with chronic diseases, such as T1D and CHD, as well as the impact it has had on the lives of children living with those illnesses (Figure2). It also addresses the lives of their parents, and the self-perceived heath status and SOC of these children.

At the macro level, the results indicated that feeling stigmatized was the main factor affecting the children and their family members' experiences. The society and others perceived them in a negative and judgmental way (Study I and II). This finding is in line with previous research, indicating that the effect of the stigma of the disease could be as significant as suffering from the disease symptoms themselves (Weiss, Ramakrishna, & Somma, 2006). Daily life includes struggles with sociocultural conditions, as well as values and beliefs about chronic disease, and may impact the children's and parents' ability to cope and result in social isolation and marginalization. Societal stereotyping and stigma toward children with chronic illness may also affect other systems such as the children's and parents' beliefs about chronic illnesses (the *microsystem*). In Palestine, children with T1D and CHD and their families

report that they struggle with negative social reactions. Therefore, when one family member experiences stigma, the whole family is assumed to be affected.
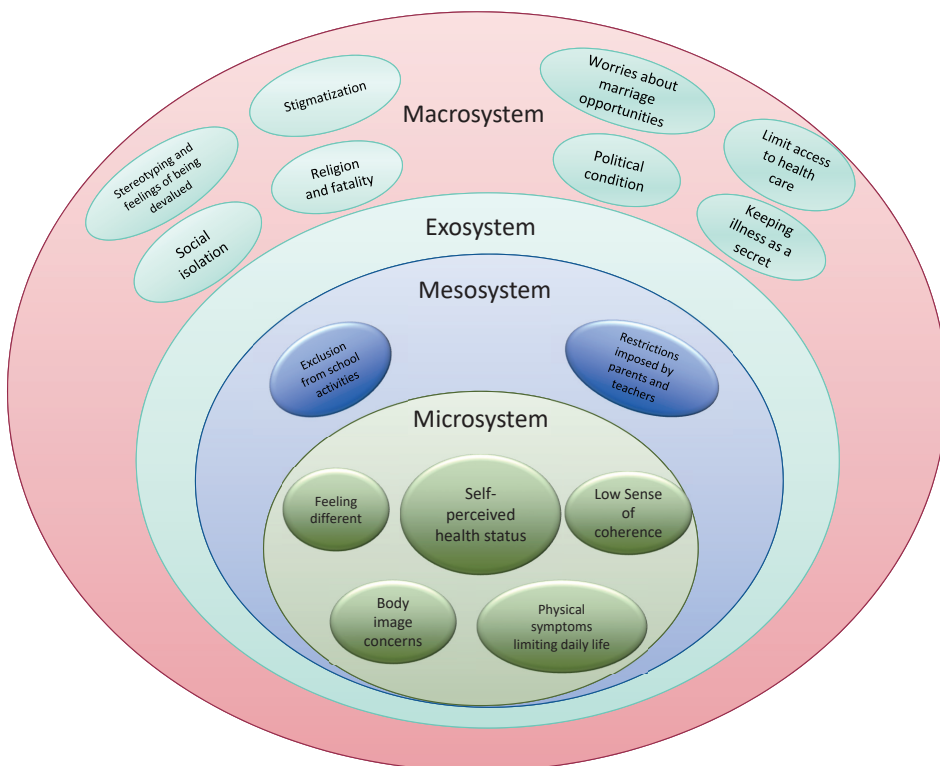

Figure 2. Model presenting the findings of results from the viewpoint of the ecological model

In the Arab-Muslim culture, chronic diseases continue to be viewed as a matter of shame, with the individual situation reflecting on the entire family (Al Khateeb, Al Hadidi, & Al Khatib, 2014; Hammad, Kysia, Rabah, Hassoun, & Connelly, 1999). Therefore, the families of children with chronic illness interviewed in Study I and II preferred to hide the child's illness in order to be socially accepted and to avoid stigma. Similarly, Moola, Fusco, and Kirsh (2011) reported that most Canadian adolescent with CHD preferred to keep their illness secret to avoid negative social experiences, such as exclusion and being perceived as fragile, weak, and different. Families in Study I and II also feared that people would view the chronic condition as a sign of a hereditary defect. Hence, all family members could be affected by the child's chronic

illness, including consequences for their social standing and marriageability. In addition, stigma can have negative outcomes on young persons with chronic illness; for example, children with T1D may attempt to hide their condition by avoiding diabetes self-care activities (Schabert, Browne, Mosely, & Speight, 2013), which result in an adverse effect on their psychosocial wellbeing and physical health (Brazeau et al., 2018). Children's avoidance of their diabetes regimen could be due to their belief that their peers would then perceive them as normal, leading them to fit in with a particular group.

This thesis also emphasized the daily life struggles of girls with T1D and CHD, their vulnerability to sociocultural values, and prevailing attitudes towards children with chronic illness, in addition to their parents' goal to get them married in the future (Study I and II). Arab societies, including Palestine, continue to be traditional and patriarchal with regard to gender (Haj-Yahia, 2005; Joseph, 2010). Therefore, girls and women with T1D and CHD can be seen as a potential burden in a future marriage, because they might not be able to maintain the female role that is expected by Arab society. Given that marriage is considered one of the main duties for the woman in Arabic Muslim families (Aroian et al., 2006), unmarried women are seen as failing to adopt their traditional role as wives, mothers, and caregivers (Haj-Yahia, 2005). Therefore, Arab women with chronic illness are considered not healthy enough to assume their traditional roles. This phenomenon was reported in young women with diabetes and thalassemia in Iran, India and Jordan, who had difficulties finding a marriage partner due to sociocultural norms (Abdoli, Abazari, & Mardanian, 2013; Abdoli, Doosti Irani, Hardy, & Funnell, 2018; Al-Awamreh, 2014). Women with diabetes in Iran and India are thought to be unsuitable candidates for marriage because of the assumed risk of infertility, high-risk pregnancies, passing diabetes on to their children, or bearing children with a congenital abnormality (Abdoli et al., 2018; Abdoli, Doosti Irani, et al., 2013). Such societal misunderstanding could have negative consequences that greatly impact the female adolescent, as well as her parents in the short and long term. Better health outcomes have clearly been achieved in recent decades for pregnant women with diabetes and congenital heart disease and their children, due to advances in diabetes and cardiac care (Kapoor, Sankaran, Hyer, & Shehata, 2007; Niwa, 2018; Uebing, Gatzoulis, von Kaisenberg, Kramer & Strauss, 2008). These improved outcomes need to be communicated to combat the negative consequences, working on macro, meso and individual system levels. In addition, different strategies can be adopted by policymakers and health care providers to combat stigma, by providing an appropriate educational program that focuses on symptoms, etiology, and implications of T1D and CHD.

In contrast, individuals with T1D in Western countries do not face the same problems in finding a spouse (Børte & Ottersen, 2012). This may reflect the higher degree of public knowledge about T1D, which in turn would reduce the cultural stigma about the disease (Børte & Ottersen, 2012). Furthermore, patients with CHD in Western countries are faced with different difficulties in their daily life, such as whether to disclose their illness, as they struggle with the process of normalization and the feeling of being different or being accepted as normal (Berghammer, Dellborg, & Ekman, 2006; Claessens et al., 2005). Nonetheless, stigmatization is still experienced in some Western countries by children with other chronic illnesses, such as epilepsy, cystic fibrosis, and HIV (Bogart et al., 2008; Kerr, Nixon, & Angalakuditi, 2011; Pakhale et al., 2014).

Study III demonstrated a correlation, but weak, between sex and self-perceived health status in children with T1D, favoring boys. This is in line with previous studies conducted in Jordan and Saudi Arabia among adolescents with T1D (Al-Akour, Khader, & Shatnawi, 2010; Al-Hayek et al., 2014), in which girls had lower HRQoL than boys. This was suggested to be related to the culture, as males have easier access to medical treatment than females. As shown in Study I, social and cultural factors in Palestine make it extremely difficult for young women with T1D to be physically active and these obstacles prevent them from meeting their needed lifestyle changes.

An additional macrosystem factor in the Palestinian West Bank is the unstable political situation. Studies have shown that this ongoing political instability has led to economic difficulties and has restricted access to specialized health care for families with a child living with chronic illness (Batniji et al., 2009; Giacaman et al., 2009; Spellings, 2014). Study II further showed that their limited access to advanced health care further threatened the child's and the family´s health and wellbeing, because they were isolated from their families. Parents who have social support are able to better cope with their child's illness and have improved psychosocial outcomes (Fletcher, 2011; Rini et al., 2008). A report by WHO (2014) showed how patients have to take long diversions around the separation wall, walk through Israeli checkpoints, and endure long delays at the checkpoint barriers. The report pointed out that this can be tiring for critically ill and disabled patients, which places an additional burden on these families.

On the other hand, the ecological system theory also addresses protective factors that can help children with chronic illness, and their parents, to overcome their daily life struggles. Such a factor is religious belief, which was found in Study II to facilitate and empower families to fulfill God's divine

destiny for their lives. Therefore, the perception that the CHD was their spiritual fate was prevalent. This finding is in line with previous studies conducted on participants with different chronic illnesses, such as heart disease and cancer, in different Arab and Islamic countries (Al-Azri et al., 2014; Najafi Ghezeljeh & Emami, 2014; Rahnama et al., 2015). Religious faith as a source of support is not only limited to Islam; it also features in the lives of people with chronic illness from other religious backgrounds, such as Christianity, Hinduism, and Judaism (Reynolds, Mrug, & Guion, 2013; Selway & Ashman, 1998; Sira, Desai, Sullivan, & Hannon, 2014). Moreover, religious beliefs have been found to play a vital role in the mental and physical health of patients with chronic illness, as their faith helps them to accept their illness and learn to cope with it (Babamohamadi, Negarandeh, & Dehghan-Nayeri, 2011; Hosseini, Sharif, Ahmadi, & Zare, 2010; Nabolsi & Carson, 2011). On the other hand, having a chronic illness may lead to aggravated guilt feelings, religious struggle, and the perception of illness as a sin or punishment by God. As a result, religiosity could also inhibit a child from finding the ability to cope with their chronic illness and have a negative impact on their well-being and quality of life (Drutchas & Anandarajah, 2014; Reynolds, Mrug, Hensler, Guion, & Madan-Swain, 2014).

On the micro level, Study II showed that daily life struggles with physical symptoms affected the children's ability to take part in physical and social activities, because it could limit their daily life activities and lead to a feeling that they have failed to achieve what other children can do. An additional microsystem factor for children with chronic illness is body image; in Study II, children with CHD described negative perceptions of their physical appearance and diminished self-worth and self-confidence. This could affect children's interaction with their peers and could result in social isolation.

Regarding self-perceived heath status in children with T1D (Study III) the findings showed no significant difference in self-perceived health status on the PedsQL GCS between children with T1D and the reference group. This finding is congruent with a systematic review by Nieuwesteeg et al. (2012) that concluded that QoL scores were similar among children with T1D and healthy peers. The authors in this review attributed this finding to the current advances in diabetes treatment regimen that led to diminish of depression among children with diabetes by time. However, this systematic review found that disease-specific psychosocial aspects, such as the negative impact of diabetes on daily functioning, worries, and lower satisfaction with life, were certainly present in patients with T1D (Nieuwesteeg et al., 2012). Another explanation for the similar level of self-perceived health in this thesis could be that children with T1D may have adapted to live with a chronic disease as argued by

Caferoğlu, İnanç, Hatipoğlu, and Kurtoğlu (2016). It is noticeable that PedsQL 4.0 GCS did not capture disease-specific aspects which might affect the health and wellbeing of children with T1D (Study III) but the instrument allows for comparison with a healthy reference group. On the other hand, in Kuwait, Abdul-Rasoul et al. (2013) used PedsQL 4.0 GCS and reported lower scores in children with T1D. The authors explained the findings to the influence of T1D on children and to the lack of autonomy and preoccupation with chronic complications.

At the meso level, Study I and II illustrated how children with chronic illnesses and their parents are embedded in multiple microsystems. These microsystems interact with each other and are affected by the external mesosystem, for example, being excluded from school activities by teachers. This can pose a barrier to children with T1D struggling to adhere to recommended lifestyle behaviors, and can thereby affect their diabetes management. Children with diabetes should be encouraged to be physically active and to take part in all regular school activities (Lawrence, Cummings, Pacaud, Lynk, & Metzger, 2015). Furthermore, exclusion from school activities could also affect these children emotionally and socially. Therefore, supportive interaction between children and their teachers is vital to advance the children's normal behavioral and social development; exclusion from school activities should be minimal and only in accordance with the student's care plan (Lawrence et al., 2015).

Study IV showed that self-perceived health status of children with CHD was low. A significant difference was found between children with CHD compared to the reference group in physical and psychosocial summary scores. This finding is supported by Mellion et al. (2014) and Uzark et al. (2008), who found that PedsQL GCS were significantly lower among children with CHD and cardiovascular diseases in comparison with a healthy group. Lower physical functioning score or summary score may be due to restrictions placed on children by parents, teachers, and health care providers (Study II and IV). Uzark et al. (2008) explained that lower physical functioning in children with CHD could be due to parents' overprotective behavior and underestimation of their children's physical capabilities and a consequence of seeing them as vulnerable. Unnecessary restrictions could limit children's interaction with peers and result in social isolation and lower PedsQL scores. The severity of CHD also plays a role in lower physical functioning due to impairment of the circulatory system (Mellion et al., 2014; Müller, Christov, Schreiber, Hess, & Hager, 2009). It is worth mentioning that many children with CHD can safely participate in physical activities, which means that children's physical capabilities should be evaluated individually and on a regular basis as appropriate (Mellion et al., 2014). To promote positive psychosocial

development in children, it is important that they participate in physical and recreational events with peers to gain friendships (Müller et al., 2009). Uzark et al. (2008) and Hövels-Gürich et al. (2006) argued that lower school functioning in children with CHD could reflect the complexity of the heart disease and neurodevelopmental impairments in the areas of attention, academic achievement, and intelligence.

Contrary to our findings, Atmadja, Tobing, Evalina, Sofyani, and Ali (2017) reported that Indonesian children with CHD and a history of corrected heart surgery aged 13-18 years had similar social, emotional, and school functioning compared to a healthy reference group. In addition, a study by Bratt et al. (2015) found that young people with CHD reported fairly good self-perceived health status and claimed that domains such as symptom management, physical appearance, communication, and cognitive functioning need more attention. In addition, children with complex CHD have shown lower QoL scores than those with mild and moderate types of CHD (Sertçelik et al., 2018).

There is inconsistency in the results from QoL studies in children with CHD, as some found lower QoL compared to healthy reference groups, while other studies reported the reverse (Bertoletti et al., 2014). This inconsistency can be explained by weaknesses in methodological rigor (Bratt & Moons, 2015).

In Study III, better self-perceived health status was correlated, but weakly, with better glycemic control. This finding is in line with previous studies conducted by Kalyva et al. (2011) and Samardzic, Tahirovic, Popovic, and Popovic-Samardzic (2016). Optimal glycemic control is considered the cornerstone in diabetes care to minimize late complications of diabetes mellitus (Diabetes Control and Complications Trial (DCCT), 1986; Diabetes Control and Complications Trial Research Group, 1993; Nathan & Group, 2014). In Study IV, a positive correlation, between self-perceived health status and complexity of heart disease was found, however the correlation was weak. A study conducted in Egypt, found that severity of illness and type of heart defect were associated with poorer HRQoL (Arafa, Zaher, El-Dowaty, & Moneeb, 2008). In addition, studies of children with CHD have demonstrated that those with simple CHD report higher QoL compared with those with complex CHD (Noori, Teimouri, & Boryri, 2017; Ternestedt et al., 2001). On the other hand, no association between severity of CHD and QoL was found by Krol et al. (2003).

The present thesis showed that the total SOC scores among children with T1D and CHD and the reference groups were low, with no significant differences between study and reference group (Study III and IV). Although the effect of

political violence, sociocultural conditions, and socioeconomic status on SOC were not measured in this thesis, it is possible that these factors could decrease SOC in adolescents in the West Bank, Palestine. A study conducted among a general population in the eastern Democratic Republic of Congo concluded that cumulative exposure to political violence is inversely correlated with SOC (Pham, Vinck, Kinkodi, & Weinstein, 2010). It was proposed that living in areas of political violence with unstable and disorganized living conditions, low socio-economic standards, weak generalized resistance resources, and a different perception of the SOC construct, could give lower SOC scores (Abu-Kaf, Braun-Lewensohn, & Kalagy, 2017; Braun-Lewensohn & Sagy, 2011a, 2011b; Braun-Lewensohn & Sagy, 2010). Furthermore, previous studies have found that SOC scores diminished in patients with chronic diseases and attributed this to negative life events and/or health deterioration (Bergman et al., 2011; Gauffin et al., 2010; Merakou et al., 2013). A person with a stronger SOC is considered more likely able to adopt a healthy lifestyle and habits and a good level of adherence to medical instructions (Ahola et al., 2010; Antonovsky, 1979; Lindmark, Stegmayr, Nilsson, Lindahl, & Johansson, 2005). Furthermore, Study III found that higher SOC scores were correlated, with better glycemic control, and this result is supported by other studies conducted in patients with T1D and T2D (Ahola et al., 2010; Cohen & Kanter, 2004). Knowing that glycemic control is vital in diabetes care, adolescents with T1D and low SOC may perceive their life and situation as incomprehensible, unmanageable, and not meaningful; as a result, they may be unable to identify and use the resources that would improve their health status.

Moreover, the present thesis found that participants with a strong SOC perceived their health status as better (Study III and IV). This finding has been confirmed by other research showing that high SOC was related to high QoL (Eriksson & Lindström, 2005). Apers, Luyckx, et al. (2013) found SOC to be a predictor of physical, emotional, social, and school functioning domains of generic perceived health in children with CHD.

9 METHODOLOGICAL CONSIDERATIONS

The ecological system theory by Bronfenbrenner (1977,1979) was adopted in this thesis to give a deeper understanding of the meaning of daily life experiences of children with chronic illness, their parents, and to examine the impact of chronic illnesses on self-perceived health status and SOC in West Bank, Palestine. This framework clarified how the different results are related to each other, and facilitated the synthesis and interpretation of the findings.

A qualitative descriptive approach was used to explore daily life experiences of children with T1D and CHD, and their parents. In qualitative studies, trustworthiness is achieved by ensuring credibility, dependability, transferability and confirmability (Lincoln & Guba, 1985). To enhance *credibility* in Study I and II, many factors were taken into consideration, such as choosing a purposeful sampling method in the selection of participants. This assured that all participants had experience of the phenomenon of interest. Addressing preconceptions is vital in ensuring that the findings and interpretations reflect the perspectives of the participants rather than the researchers' preconceived ideas. To minimize researcher preconceptions, regular meeting were held with all the members of the research group during the analysis process to negotiate the emerging findings in Study I and II. *Dependability* was ensured by developing an interview guide to be used with all the participants. The researcher started the interview in Study I and II with the same broad question in order to identify important topics for the children and their parents. Furthermore, when more clarification was needed, similar probe questions were used in all interviews. To enable the children and their parents to talk freely, they were interviewed individually. *Transferability* of the findings to the context of children with T1D and CHD and their parents living in similar sociocultural and political contexts and conditions, such as in other Arab Muslim societies and communities around the world is possible. To ensure transferability in this thesis, a clear description of sociocultural and political context and religion in the West Bank, Palestine was considered in this thesis as suggested by Graneheim & Lundman (2004) and Smith (2004). Transferability can also be attained by presenting findings with appropriate quotations (Graneheim & Lundman, 2004). *Confirmability* was attained as the researcher gave a detailed description of the process of data collection, analysis and interpretation of data.

The sample size in Study I and II was relatively small, but in accordance with qualitative research, whereas data saturation was considered to be reached. The concept of saturation is considered a marker for achieving adequate sample

size in qualitative studies (Moser & Korstjens, 2017). In the qualitative studies in this thesis, data saturation of the codes was achieved when the coding and categorizing of the emerging themes reached a state of redundancy, and no new or relevant information or data emerging regarding the themes. In addition, the members of the research team found that the extracted data was rich enough to address the aim of the qualitative studies in this thesis.

Small sample size and the use of the convenience sampling in Study III and IV is an issue that has to be considered, especially for SOC, where only half of the participants (the adolescents) could be included due to the questionnaire´s intended population (>13 yrs). It is recommended that future studies take this into consideration and thus recruit a larger sample of children with CHD and T1D, and a reference group that is matched according to sociodemographic characteristics. The ability to detect group differences and the relationships between SOC and PedsQL may be enhanced with a larger sample.

Working with researchers of different languages was a challenge since interviews were conducted in Arabic and analysis was done in English. To overcome this challenge, the members of the research team discussed the translated ideas and the analysis was checked with the original Arabic text to gain understanding and agreement between members of the research team.

In Study III and IV, a cross-sectional design was employed, which limited the determination of causality. The participants were recruited from different diabetes and cardiac clinics, societies, and hospitals that cover different geographical districts of the West Bank. This gave a representative sample with regard to type of residence, age and gender since a randomly selected population was not possible.

The use of self-reported questionnaires in Study III and IV is a potential limitation because self-report rating scales rely on the participants' individual judgments at the time of data collection. Furthermore, children may have difficulties reflecting on their own health, leading them to over- or under-report their health status (Moksnes, Espnes, & Lillefjell, 2012). In order to reduce the risk of responses being based on social desirability, confidentiality was assured at the time of data collection.

The generic PedsQL scale (Arabic version) was used to assess the self-perceived health status of children and adolescents with T1D and CHD in Study III and IV because Arabic versions of the diabetes-specific and cardiac-specific PedsQL modules are not currently available. This reduces the

comparability of the findings with studies that had access to localized versions of the diabetes-specific and cardiac-specific modules.

Socioeconomic variables, particularly the income and education of the parents, are very important because these factors influence self-perceived health and SOC. However, since we interviewed children, we could not rely on their opinion as they might have limited knowledge about their parents' education or they might evaluate their economic status falsely. This reporting bias could affect the validity of the information about the parents' education and the families' economic status.

The qualitative studies in this thesis highlight how children with T1D and their parents were stigmatized by chronic illness. The studies presented in this thesis were independent of each other rather than sequential, and the quantitative studies aimed, from the beginning, to measure only self-perceived health status and SOC. Therefore, the stigma that emerged in Study I and II was not followed up in Study III and IV, which is a limitation.

10 CONCLUSIONS AND IMPLICATIONS

- Lack of knowledge and misconceptions about chronic conditions such as T1D and CHD in the Palestinian society might lead to negative outcomes regarding physical health, psychosocial wellbeing and self-care activities in children with T1D and CHD.

- The low SOC in adolescents with T1D, CHD and in the reference group could be due to the unstable political situation, sociocultural conditions and lower socioeconomic status in the West Bank, Palestine. Health care providers need to find strategies that can help children to identify internal resources, abilities and coping capabilities in order to improve self-perceived health status and wellbeing. The unstable political situation in the West Bank also have implications to access of care due to restricted access to specialized health care and thereby, further impact the child's and the families' health and well-being.

- Health care providers need to recognize the possible impact of sociocultural factors such as stigma, gender stereotyping and their negative consequences. By increasing knowledge through educational interventions addressing school settings particularly but also society in general, regarding symptoms, etiology and implications of T1D and CHD, health care can support these children and their families. Other targeted interventions needed are strategies aiming to strengthening the capabilities and abilities of children with T1D and CHD. Such interventions might have potential to increase SOC and therefore also lead to an increased self-perceived health status. Furthermore, it is possible that it also have positive impact on glycemic control and decrease complications in children with T1D. It is crucial to identify children who are at risk in order to develop targeted preventive interventions to enhance self-perceived health in these children.

- Lower self-perceived health status in children with CHD highlighted the need for health care providers to assess and evaluate physical and psychosocial functioning on a regular basis in these children in order to develop and implement programs as appropriate.

11 FUTURE RESEARCH

- The findings of Study I and II highlighted the sociocultural burden on daily life of children with T1D and CHD and their parents. To understand stigma, its complexity, and its impact and burden on children with chronic illness and their families, future research addressing stigma is needed. Further research is also needed to understand the experience and perspectives of healthy siblings, the extended family, teachers, and health care providers concerning T1D and CHD in children.
- The findings of Study III and IV indicate the need for longitudinal studies to examine causal relationships and to identify the potential influences on SOC and self-perceived health status. This long-term perspective can provide valuable input when developing services for children with T1D and CHD. The findings also reinforce the need for further research to examine the effect of political and sociocultural conditions on SOC, both in children with chronic illness and in healthy children in the Palestinian West Bank. In addition, preferably future studies should use the diabetes-specific and cardiac-specific scale to capture diabetes and cardiac-specific aspects to capture negative impact of T1D and CHD on daily functioning. Therefore it is imperative to translate these specific scales into Arabic.
- Finally, future research should evaluate the effectiveness of the services and resources currently available for children with T1D and CHD and their families in the Palestinian West Bank.

ACKNOWLEDGEMENTS

This thesis was supervised at the Institute of Health and Care Sciences, Sahlgrenska Academy at the University of Gothenburg. I am deeply grateful to this institute for giving me the opportunity to be a doctoral student.

Throughout my thesis process, many people have given me so much support and energy without which I would not be able to complete this thesis. I would like to sincerely express my gratitude to you all.

First, I give thanks to God for giving me the abilities and strength to complete this thesis.

I would like to thank all the participants in the studies, especially the children with T1D and CHD and their parents; without you this study would not have been possible.

My main supervisor **Åsa Axelsson**: thank you so much for helping me to become a doctoral student, an opportunity that has changed my life. Thank you for your constant support and encouragement. I am very grateful for your meaningful insights, ideas, and guidance for my research throughout. Thank you for your critical comments that led the way. I am also very grateful for your help with the practicalities of getting the thesis printed in Sweden. . Your expertise, encouragement, and help ensured that this thesis became a reality.

My co-supervisor **Carina Sparud Lundin:** for your patience, thoughtfulness, brilliance in supervision, and constructive criticism of my writing. I feel very lucky to have had your supervision, continued encouragement, and friendship. Your unfailing encouragement through the most challenging moments was invaluable. I am so thankful for your kind words and empathy that lifted me up when I was down. Your expertise and knowledge about T1D and about qualitative and quantitative research enriched me as a student and researcher.

My co-supervisor **Ewa-Lena Bratt:** for your time, energy, and patience. Thank you for believing in me. I was impressed by your academic arguments, advice, and valuable suggestions that helped me to develop my understanding throughout this research and to find my own path as a student and a researcher. Thank you for your guidance in helping me to understand statistics. I have benefited so much from your expertise in conference presentations and grant funding. Thank you for opening up both your mind and heart to me.

REFERENCES

Abdoli, S., Abazari, P., & Mardanian, L. (2013). Exploring diabetes type 1-related stigma. *Iranian journal of nursing and midwifery research, 18*(1), 65.

Abdoli, S., Doosti Irani, M., Hardy, L. R., & Funnell, M. (2018). A discussion paper on stigmatizing features of diabetes. *Nursing open, 5*(2), 113-119.

Abdoli, S., Doosti Irani, M., Parvizi, S., Seyed Fatemi, N., & Amini, M. (2013). Living in the shadow and light: Iranian youths' responses to diabetes-related stigma. *European Online Journal of Natural and Social Sciences: Proceedings, 2*(2), 439-448.

Abdul-Rasoul, M., AlOtaibi, F., Abdulla, A., Rahme, Z., & AlShawaf, F. (2013). Quality of life of children and adolescents with type 1 diabetes in Kuwait. *Medical Principles and Practice, 22*(4), 379-384.

Abu-Kaf, S., Braun-Lewensohn, O., & Kalagy, T. (2017). Youth in the midst of escalated political violence: sense of coherence and hope among Jewish and Bedouin Arab adolescents. *Child and adolescent psychiatry and mental health, 11*(1), 42.

Adeyemo, T. A., Ojewunmi, O. O., Diaku-Akinwumi, I. N., Ayinde, O. C., & Akanmu, A. S. (2015). Health related quality of life and perception of stigmatisation in adolescents living with sickle cell disease in Nigeria: A cross sectional study: HRQoL of Nigerian Adolescents. *Pediatric Blood & Cancer, 62*(7), 1245-1251.

Ahola, A. J., Saraheimo, M., Forsblom, C., Hietala, K., & Groop, P.-H. (2010). The cross-sectional associations between sense of coherence and diabetic microvascular complications, glycaemic control, and patients' conceptions of type 1 diabetes. *Health and Quality of Life Outcomes, 8*, 142-142.

Al-Akour, N., Khader, Y. S., & Shatnawi, N. J. (2010). Quality of life and associated factors among Jordanian adolescents with type 1 diabetes mellitus. *Journal of Diabetes and Its Complications, 24*(1), 43-47.

Al-Awamreh, K. M. (2014). *Experiences and coping strategies of Jordanian parents of children with Beta Thalassaemia Major* (Doctoral dissertation).University of Hull. Retrieved from https://hydra.hull.ac.uk/assets/hull:11263a/content

Al-Azri, M. H., Al-Awisi, H., Al-Rasbi, S., & Al-Moundhri, M. (2014). Coping with a diagnosis of breast cancer among Omani women. *Journal of health psychology, 19*(7), 836-846.

Al-Hayek, A. A., Robert, A. A., Abbas, H. M., Itani, M. B., Al-Saeed, A. H., Juhani, A. E., . . . Al-Sabaan, F. S. (2014). Assessment of health-related quality of life among adolescents with type 1 diabetes mellitus in Saudi Arabia. *Saudi medical journal, 35*(7), 712.

Al Khateeb, J. M., Al Hadidi, M. S., & Al Khatib, A. J. (2014). Arab Americans with disabilities and their families: A culturally appropriate approach for counselors. *Journal of Multicultural Counseling and Development, 42*(4), 232-247.

Almesned, S., Al-Akhfash, A., & Mesned, A. (2013). Social impact on families of children with complex congenital heart disease. *Annals of Saudi medicine, 33*(2), 140-143.

American Academy of Pediatrics, A. A. o. F. P., American College of Physicians. (2011). Supporting the health care transition from adolescence to adulthood in the medical home.(Report). *Pediatrics, 128*(1), 182.

Antonovsky, A. (1979). Health, stress, and coping. *(1. ed.). San Francisco: Jossey-Bass.*

Antonovsky, A. (1987). *Unraveling the mystery of health: How people manage stress and stay well*: Jossey-bass.

Apers, S., Luyckx, K., Rassart, J., Goossens, E., Budts, W., & Moons, P. (2013). Sense of coherence is a predictor of perceived health in adolescents with congenital heart disease: A cross-lagged prospective study. *International Journal of Nursing Studies, 50*(6), 776-785.

Apers, S., Moons, P., Goossens, E., Luyckx, K., Gewillig, M., Bogaerts, K., & Budts, W. (2013). Sense of coherence and perceived physical health explain the better quality of life in adolescents with congenital heart disease. *European Journal of Cardiovascular Nursing, 12*(5), 475-483.

Arabiat, Elliott, B., Draper, P., & Al Jabery, M. (2011). Cross-cultural validation of the pediatric quality of life inventory™ 4.0 (PedsQL™) generic core scale into arabic language. *Scandinavian journal of caring sciences, 25*(4), 828-833.

Arafa, M. A., Zaher, S. R., El-Dowaty, A. A., & Moneeb, D. E. (2008). Quality of life among parents of children with heart disease. *Health and Quality of Life Outcomes, 6*(1), 91.

Aroian, K. J., Katz, A., & Kulwicki, A. (2006). Recruiting and retaining Arab Muslim mothers and children for research. *Journal of Nursing Scholarship, 38*(3), 255-261.

Atmadja, S., Tobing, T. C., Evalina, R., Sofyani, S., & Ali, M. (2017). Quality of life in children with congenital heart disease after cardiac surgery. *Paediatrica Indonesiana, 57*(6), 285-290.

Azhar, A. S., AlShammasi, Z. H., & Higgi, R. E. (2016). The impact of congenital heart diseases on the quality of life of patients and their families in Saudi Arabia: biological, psychological, and social dimensions. *Saudi medical journal, 37*(4), 392.

Babamohamadi, H., Negarandeh, R., & Dehghan-Nayeri, N. (2011). Coping strategies used by people with spinal cord injury: a qualitative study. *Spinal cord, 49*(7), 832.

Batniji, R., Rabaia, Y., Nguyen–Gillham, V., Giacaman, R., Sarraj, E., Punamaki, R. L., . . . Boyce, W. (2009). Health as human security in the occupied Palestinian territory. *The Lancet, 373*(9669), 1133-1143.

Bell, N. (2008). Ethics in child research: rights, reason and responsibilities. *Children's Geographies, 6*(1), 7-20.

Berghammer, M., Dellborg, M., & Ekman, I. (2006). Young adults experiences of living with congenital heart disease. *International Journal of Cardiology, 110*(3), 340-347.

Bergman, E., Malm, D. A. J., Berterö, C., & Karlsson, J.-E. (2011). Does one's sense of coherence change after an acute myocardial infarction?: A two-year longitudinal study in Sweden. *Nursing and Health Sciences, 13*(2), 156-163.

Bertoletti, J., Marx, G. C., Junior, H., Pedro, S., & Pellanda, L. C. (2014). Quality of Life and Congenital Heart Disease in Childhood and Adolescenc. *Arquivos brasileiros de cardiologia, 102*(2), 192-198.

Betts, P. R., & Swift, P. G. F. (2003). Doctor, who will be looking after my child's diabetes? *Archives of disease in childhood, 88*(1), 6-7.

Bircher, J. (2005). Towards a dynamic definition of health and disease. *Medicine, Health Care and Philosophy, 8*(3), 335-341.

Blue, G. M., Kirk, E. P., Sholler, G. F., Harvey, R. P., & Winlaw, D. S. (2012). Congenital heart disease: current knowledge about causes and inheritance. *Medical Journal of Australia, 197*(3), 155-159.

Bogart, L., Cowgill, B., Kennedy, D., Ryan, G., Murphy, D., Elijah, J., & Schuster, M. (2008). HIV-Related Stigma among People with HIV and their Families: A Qualitative Analysis. *AIDS and Behavior, 12*(2), 244-254.

Boman, K. K., Viksten, J., Kogner, P., Samuelsson, U., Barn- och ungdomskliniken i, L., Linköpings, u., . . . Östergötlands Läns, L. (2004). Serious illness in childhood: the different threats of cancer and diabetes from a parent perspective. *The Journal of pediatrics, 145*(3), 373-379.

Børte, S., & Ottersen, V. S. (2012). *Stigmatization of children with chronic diseases, exemplified by type 1 diabetes mellitus.: Differences between India and Norway.* University of Oslo. Retrieved from https://www.duo.uio.no/bitstream/handle/10852/29163/Prosjekt-S-Borte.pdf?sequence=4

Brandy Tabor, C. (2008). Understanding and Treating Diabetic Ketoacidosis. *Internal Medicine, 29*(4), 227-233.

Bratt, E.-L., Luyckx, K., Goossens, E., Budts, W., & Moons, P. (2015). Patient-reported health in young people with congenital heart disease transitioning to adulthood. *Journal of Adolescent Health, 57*(6), 658-665.

Bratt, E.-L., & Moons, P. (2015). Forty years of quality-of-life research in congenital heart disease: Temporal trends in conceptual and methodological rigor. *International Journal of Cardiology, 195*, 1-6.

Braun-Lewensohn, O., & Sagy, S. (2011a). Coping Resources as Explanatory Factors of Stress Reactions During Missile Attacks: Comparing Jewish and Arab Adolescents in Israel. *Community Mental Health Journal, 47*(3), 300-310.

Braun-Lewensohn, O., & Sagy, S. (2011b). Salutogenesis and culture: Personal and community sense of coherence among adolescents belonging to three different cultural groups. *International Review of Psychiatry, 23*(6), 533-541.

Braun-Lewensohn, O., & Sagy, S. (2010). Sense of coherence, hope and values among adolescents under missile attacks: A longitudinal study. *International Journal of Children's Spirituality, 15*(3), 247-260.

Brazeau, A.-S., Nakhla, M., Wright, M., Henderson, M., Panagiotopoulos, C., Pacaud, D., . . . Dasgupta, K. (2018). Stigma and its association with glycemic control and hypoglycemia in adolescents and young adults with

type 1 diabetes: Cross-sectional study. *Journal of medical Internet research, 20,* e151.

Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American psychologist, 32*(7), 513-531.

Bronfenbrenner, U. (1979). *The Ecology of Human Development: Experiments by Nature and Design:* Cambridge, Mass: Cambridge, MA: Harvard University Press.

Bronfenbrenner, U. (2005). *Making human beings human: Bioecological perspectives on human development:* Thousand Oaks, CA: Sage.

Caferoğlu, Z., İnanç, N., Hatipoğlu, N., & Kurtoğlu, S. (2016). Health-Related Quality of Life and Metabolic Control in Children and Adolescents with Type 1 Diabetes Mellitus. *Journal of clinical research in pediatric endocrinology, 8*(1), 67.

Chong, L. S., Fitzgerald, D. A., Craig, J. C., Manera, K. E., Hanson, C. S., Celermajer, D., . . . Tong, A. (2018). Children's experiences of congenital heart disease: a systematic review of qualitative studies. *European journal of pediatrics*, 177(3), 319-336.

Claessens, P., Moons, P., de Casterlé, B. D., Cannaerts, N., Budts, W., & Gewillig, M. (2005). What does it mean to live with a congenital heart disease? A qualitative study on the lived experiences of adult patients. *European Journal of Cardiovascular Nursing, 4*(1), 3-10.

Cohen, M., & Kanter, Y. (2004). Relation Between Sense of Coherence and Glycemic Control in Type 1 and Type 2 Diabetes. *Behavioral Medicine, 29*(4), 175-185.

Crane, S., & Broome, M. E. (2017). Understanding ethical issues of research participation from the perspective of participating children and adolescents: A systematic review. *Worldviews on Evidence-Based Nursing, 14*(3), 200-209.

Davis, C. L., Delamater, A. M., Shaw, K. H., La Greca, A. M., Eidson, M. S., Perez-Rodriguez, J. E., & Nemery, R. (2001). Brief report: Parenting styles, regimen adherence, and glycemic control in 4- to 10-year-old children with diabetes. *Journal of Pediatric Psychology, 26*(2), 123-129.

Diabetes Control and Complications Trial (DCCT). (1986). The Diabetes Control and Complications Trial (DCCT): design and methodologic considerations for the feasibility phase. *Diabetes, 35*(5), 530-545.

Diabetes Control and Complications Trial Research Group. (1993). The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus. *New England journal of medicine, 329*(14), 977-986.

Diamond Project Group. (2006). Incidence and trends of childhood Type 1 diabetes worldwide 1990-1999. *Diabetic medicine, 23*(8), 857-866.

Drutchas, A., & Anandarajah, G. (2014). Spirituality and coping with chronic disease in pediatrics. *Rhode Island Medical Journal, 97*(3), 26.

Eiser, C. (1997). Effects of chronic illness on children and their families. *Advances in Psychiatric Treatment, 3*(4), 204-210.

Eklund Karlsson, L., Crondahl, K., Sunnemark, F., & Andersson, Å. (2013). The meaning of health, well-being, and quality of life perceived by roma people in west Sweden. *Societies, 3*(2), 243-260.

Emmanouilidou, E., Galli-Tsinopoulou, A., Karavatos, A., & Nousia-Arvanitakis, S. (2008). Quality of life of children and adolescents with diabetes of Northern Greek origin. *Hippokratia, 12*(3), 168.

Erickson, K. L. (2013). Raising Children with Type 1 Diabetes and Celiac Disease: Parental Experiences.

Eriksson, M., & Lindström, B. (2005). Validity of Antonovsky's Sense of Coherence Scale: A Systematic Review. *Journal of Epidemiology and Community Health (1979-), 59*(6), 460-466.

Eriksson, M., & Lindström, B. (2006). Antonovsky's sense of coherence scale and the relation with health: a systematic review. *Journal of Epidemiology and Community Health (1979-), 60*(5), 376-381.

Eriksson, M., & Lindström, B. (2007). Antonovsky's sense of coherence scale and its relation with quality of life: a systematic review. *Journal of epidemiology and community health, 61*(11), 938-944.

Evert, A. B., Hanson, J. H., Hood, K., Jameson, P., Kadihiro, J. K., Lawlor, M. T., . . . Roemer, J. (2008). Management of children with diabetes in the school setting. *Diabetes Education, 34*(3), 439-443.

Ferro, M. A., & Boyle, M. H. (2013). Self-concept among youth with a chronic illness: a meta-analytic review. *Health psychology, 32*(8), 839-848.

Fletcher, P. C. (2011). My Child has Cancer: Finding the Silver Lining in Every Mother's Nightmare. *Issues in Comprehensive Pediatric Nursing, 34*(1), 40-55.

Fritz, H., DiZazzo-Miller, R., Bertran, E. A., Pociask, F. D., Tarakji, S., Arnetz, J., . . . Jaber, L. A. (2016). Diabetes self-management among Arab Americans: patient and provider perspectives. *BMC international health and human rights, 16*(1), 22.

Gauffin, H., Landtblom, A.-M., & Räty, L. (2010). Self-esteem and sense of coherence in young people with uncomplicated epilepsy: A 5-year follow-up. *Epilepsy and Behavior, 17*(4), 520-524.

Giacaman, R., Khatib, R., Shabaneh, L., Ramlawi, A., Sabri, B., Sabatinelli, G., . . . Laurance, T. (2009). Health status and health services in the occupied Palestinian territory. *The Lancet, 373*(9666), 837-849.

Global Business and Investment Center. (2017). *Palestine (West Bank and Gaza) education system and policy handbook: Volume 1. Strategic information and developments*. International Business Publications: Washington, DC.USA.

Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse education today, 24*(2), 105-112.

Gray, P. (2015). *Sense of Coherence in Adolescents and Their Families in a Swedish Speaking Community in Finland* (Unpublished doctoral thesis). Northumbria University. Retrieved from http://nrl.northumbria.ac.uk/27994/1/Pamela%20Gray%20FINAL%20THESIS%208.6.2016.pdf

Guba, E. G., & Lincoln, Y. S. (1989). *Fourth generation evaluation*. Newbury Park, Calif: Sage.

Haj-Yahia, M. M. (2005). On the characteristics of patriarchal societies, gender inequality, and wife abuse: The case of Palestinian society. *Adalah's Newsletter, 20*1-6: retrieved from http://www.adalah.org/uploads/oldfiles/newsletter/eng/nov05/fet.pdf

Hammad, A., Kysia, R., Rabah, R., Hassoun, R., & Connelly, M. (1999). *Guide to Arab culture: Health care delivery to the Arab American community*. Dearborn, MI: Arab Community Center for Economic and Social Services. Retrieved from https://www.accesscommunity.org/sites/default/files/documents/health_and_research_cente_21.pdf

Hansen, J. A., Weissbrod, C., Schwartz, D. D., & Taylor, W. P. (2012). Paternal involvement in pediatric Type 1 diabetes: fathers' and mothers' psychological functioning and disease management. *Families, Systems, & Health, 30*(1), 47.

Hapunda, G., Abubakar, A., van de Vijver, F., & Pouwer, F. (2015). Living with type 1 diabetes is challenging for Zambian adolescents: qualitative data on stress, coping with stress and quality of care and life. *BMC endocrine disorders, 15*(1), 20.

Harjutsalo, V., Sund, R., Knip, M., & Groop, P.-H. (2013). Incidence of Type 1 Diabetes in Finland. *Journal of the American Medical Association, 310*(4), 427-428.

Hassan, M., Musa, N., Hai, R. A., Fathy, A., & Ibrahim, A. (2017). Assessment of health-related quality of life in Egyptian adolescents with type 1 diabetes: DEMPU survey.(Report). *Journal of Pediatric Endocrinology and Metabolism, 30*(3), 277.

Haugvik, S., Beran, D., Klassen, P., Hussain, A., & Haaland, A. (2017). "My heart burns"–A qualitative study of perceptions and experiences of type 1 diabetes among children and youths in Tajikistan. *Chronic illness, 13*(2), 128-139.

Hörberg, U., Ozolins, L.-l., & Ekebergh, M. (2011). Intertwining caring science, caring practice and caring education from a lifeworld perspective—Two contextual examples. *International Journal of Qualitative studies on Health and Well-being, 6*(4), 10363.

Hosseini, N., Sharif, F., Ahmadi, F., & Zare, M. (2010). Striving for balance: coping with epilepsy in Iranian patients. *Epilepsy & Behavior, 18*(4), 466-471.

Hövels-Gürich, H. H., Konrad, K., Skorzenski, D., Nacken, C., Minkenberg, R., Messmer, B. J., & Seghaye, M.-C. (2006). Long-term neurodevelopmental outcome and exercise capacity after corrective surgery for tetralogy of Fallot or ventricular septal defect in infancy. *The Annals of thoracic surgery, 81*(3), 958-966.

Huber, M., Knottnerus, J. A., Green, L., van der Horst, H., Jadad, A. R., Kromhout, D., . . . van der Meer, J. W. (2011). How should we define health? *British Medical Journal, 343*, d4163.

International Diabetes Federation. (2015). IDF Diabetes Atlas. 7th ed. Retrieved from http://www.diabetesatlas.org/

Jantien Vrijmoet-Wiersma, C. M., Ottenkamp, J., van Roozendaal, M., Grootenhuis, M. A., & Koopman, H. M. (2009). A multicentric study of disease-related stress, and perceived vulnerability, in parents of children with congenital cardiac disease. *Cardiology in the Young, 19*(6), 608-614.

Johnson, L. N. (2013). *Parent Distress in Life with a Child with Type 1 Diabetes.* (Unpublished doctoral thesis).University of South Florida. Retrieved from http://scholarcommons.usf.edu/etd/4698

Joseph, S. (2010). Gender and citizenship in the Arab world. *Al-Raida Journal*, (129-130), 8-18..

Kalyva, E., Abdul-Rasoul, M., Kehl, D., Barkai, L., & Lukács, A. (2016). A cross-cultural study on perceived health-related quality of life in children and adolescents with type 1 diabetes mellitus. *Journal of diabetes and its complications, 30*(3), 482-487.

Kalyva, E., Malakonaki, E., Eiser, C., & Mamoulakis, D. (2011). Health-related quality of life (HRQoL) of children with type 1 diabetes mellitus (T1DM): self and parental perceptions. *Pediatric diabetes, 12*(1), 34-40.

Kapoor, N., Sankaran, S., Hyer, S., & Shehata, H. (2007). Diabetes in pregnancy: a review of current evidence. *Current Opinion in Obstetrics and Gynecology, 19*(6), 586-590.

Karimi, M., & Brazier, J. (2016). Health, health-related quality of life, and quality of life: what is the difference? *Pharmacoeconomics, 34*(7), 645-649.

Karsdorp, P. A., Everaerd, W., Kindt, M., & Mulder, B. J. (2007). Psychological and cognitive functioning in children and adolescents with congenital heart disease: a meta-analysis. *Journal of Pediatric Psychology, 32*(5), 527-541.

Keelan, E. (2016). Medical Care in Palestine: Working in a Conflict Zone. *The Ulster medical journal, 85*(1), 3.

Kerr, C., Nixon, A., & Angalakuditi, M. (2011). The impact of epilepsy on children and adult patients' lives: Development of a conceptual model from qualitative literature. *Seizure, 20*(10), 764-774.

Klatchoian, D. A., Len, C. A., Terreri, M. T. R., Silva, M., Itamoto, C., Ciconelli, R. M., . . . Hilário, M. O. E. (2008). Quality of life of children and adolescents from São Paulo: reliability and validity of the Brazilian version of the Pediatric Quality of Life InventoryTM version 4.0 Generic Core Scales. *Jornal de pediatria, 84*(4), 308-315.

Knowles, R. L., Tadic, V., Hogan, A., Bull, C., Rahi, J. S., & Dezateux, C. (2016). Self-Reported Health Experiences of Children Living with Congenital Heart Defects: Including Patient-Reported Outcomes in a National Cohort Study. *PloS one, 11*(8), e0159326.

Krol, Y., Grootenhuis, M. A., DestrÉe-Vonk, A., Lubbers, L. J., Koopman, H. M., & Last, B. F. (2003). Health related quality of life in children with congenital heart disease. *Psychology and Health, 18*(2), 251-260.

Lambert, V., & Lambert, C. (2012). Qualitative descriptive research: an acceptable design. *Pacific Rim International Journal of Nursing Research, 16*(4), 255-256.

Lawrence, S., Cummings, E., Pacaud, D., Lynk, A., & Metzger, D. (2015). Managing type 1 diabetes in school: Recommendations for policy and practice. *Paediatrics & Child Health, 20*(1), 1-6.

LeCompte, M. D., Tesch, R., & Goetz, J. P. (1993). *Ethnography and qualitative design in educational research*: Academic Press.

Leedy, P. D. (1993). *Practical research: planning and design.*: New Jersey: Prentice-Hall.

Lehmkuhl, H. D., Merlo, L. J., Devine, K., Gaines, J., Storch, E. A., Silverstein, J. H., & Geffken, G. R. (2009). Perceptions of type 1 diabetes among affected youth and their peers. *Journal of clinical psychology in medical settings, 16*(3), 209-215.

Lin, W.-H., Wang, M.-C., Wang, W.-M., Yang, D.-C., Lam, C.-F., Roan, J.-N., & Li, C.-Y. (2014). Incidence of and Mortality from Type I Diabetes in Taiwan From 1999 through 2010: A Nationwide Cohort Study: e86172. *PLoS One, 9*(1).

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Newbury. *CA: Sage.*

Lundahl, BW, Kunz, C., Brownell, C., Tollefson, D., & Burke, BL *(2010). A meta-analysis of motivational interviewing: Twenty-five years of empirical studies. Research on Social Work Practice, 20*(2), 137159.

Lindmark, U., Stegmayr, B., Nilsson, B., Lindahl, B., & Johansson, I. (2005). Food selection associated with sense of coherence in adults. *Nutrition Journal, 28*(4), 9.

Lukács, A., & Barkai, L. (2013). *Physical fitness and health-related quality of life in children and adolescents with type 1 diabetes mellitus* (Doctoral dissertation).Universityof Debrecon . Retrieved from: https://dea.lib.unideb.hu/dea/bitstream/handle/2437/170113/Lukacs_Andrea _ertekezes-t.pdf?seque

Mackie, A. S., Rempel, G. R., Rankin, K. N., Nicholas, D., & Magill-Evans, J. (2012). Risk factors for loss to follow-up among children and young adults with congenital heart disease. *Cardiology in the Young, 22*(3), 1-9.

Mahon, G., O'Brien, B., & O'Conor, L. (2014). The experience of chronic illness among a group of Irish patients: a qualitative study. *Journal of Research in Nursing, 19*(4), 330-342.

Malerbi, F. E. K., Negrato, C. A., Gomes, M. B., & Brazilian Type 1 Diabetes Study Group. (2012). Assessment of psychosocial variables by parents of youth with type 1 diabetes mellitus. *Diabetology and Metabolic Syndrome, 4*(1), 48.

Marshall, M., Carter, B., Rose, K., & Brotherton, A. (2009). Living with type 1 diabetes: perceptions of children and their parents. *Journal of clinical nursing, 18*(12), 1703-1710.

Mellion, K., Uzark, K., Cassedy, A., Drotar, D., Wernovsky, G., Newburger, J. W., . . . Limbers, C. (2014). Health-related quality of life outcomes in children and adolescents with congenital heart disease. *The Journal of pediatrics, 164*(4), 781-788. e781.

Mendel, B., Bergenius, J., & Langius, A. (2001). The sense of coherence: A tool for evaluating patients with peripheral vestibular disorders. *Clinical Otolaryngology & Allied Sciences, 26*(1), 19-24.

Merakou, K., Koutsouri, A., Antoniadou, E., Barbouni, A., Bertsias, A., Karageorgos, G., & Lionis, C. (2013). Sense of coherence in people with

and without type 2 diabetes mellitus: an observational study from Greece. *Mental health in family medicine, 10*(1), 3.

Miller, T. A., & Dimatteo, M. R. (2013). Importance of family/social support and impact on adherence to diabetic therapy. *Diabetes Metab Syndr Obes, 6*, 421-426.

Mitchell, S. C., Korones, S. B., & Berendes, H. W. (1971). Congenital heart disease in 56,109 births. Incidence and natural history. *Circulation, 43*(3), 323-332.

Moksnes, U. K., Espnes, G. A., & Lillefjell, M. (2012). Sense of coherence and emotional health in adolescents. *Journal of Adolescence, 35*(2), 433-441.

Moola, F., Fusco, C., & Kirsh, J. A. (2011). What I wish you knew': Social barriers toward physical activity in youth with congenital heart disease (CHD). *Adapted physical activity quarterly, 28*(1), 56-77.

Moons, P., Bovijn, L., Budts, W., Belmans, A., & Gewillig, M. (2010). Temporal trends in survival to adulthood among patients born with congenital heart disease from 1970 to 1992 in Belgium. *Circulation, 122*(22), 2264-2272.

Moons, P., Budts, W., & De Geest, S. (2006). Critique on the conceptualisation of quality of life: a review and evaluation of different conceptual approaches. *International journal of nursing studies, 43*(7), 891-901.

Moons, P., & Norekvål, T. M. (2006). Is Sense of Coherence a Pathway for Improving the Quality of Life of Patients Who Grow Up with Chronic Diseases? A Hypothesis. *European Journal of Cardiovascular Nursing, 5*(1), 16-20.

Moser, A., & Korstjens, I. (2017). Series: Practical guidance to qualitative research: part 3: sampling, data collection and analysis, *European Journal of General Practice, 24*(1), 9-18.

Müller, J., Christov, F., Schreiber, C., Hess, J., & Hager, A. (2009). Exercise capacity, quality of life, and daily activity in the long-term follow-up of patients with univentricular heart and total cavopulmonary connection. *European heart journal, 30*(23), 2915-2920.

Nabolsi, M. M., & Carson, A. M. (2011). Spirituality, illness and personal responsibility: the experience of Jordanian Muslim men with coronary artery disease. *Scandinavian journal of caring sciences, 25*(4), 716-724.

Nabors, L., & Bartz, J. (2013). Type I Diabetes in Children: Facilitating Adherence to Medical Regimens. In Title of the book and Editors *Type 1 Diabetes*: Intech.

Nabors, L., Ritchey, P. N., Wassenhove, B. V., & Bartz, J. (2011). Type I Diabetes in Children and Adolescents,. In C.-P. Liu (Ed.), *Type 1 Diabetes - Complications, Pathogenesis, and Alternative,Treatments,* (pp. 85-94): INTECH Open Access Publisher. Retrieved from http://www.intechopen.com/books/type-1-diabetes-complications-pathogenesis-and-alternative-treatments/type-i-diabetes-in-children-and-adolescents

Najafi Ghezeljeh, T., & Emami, A. (2014). Strategies for recreating normal life: I ranian coronary heart disease patients' perspectives on coping strategies. *Journal of clinical nursing, 23*(15-16), 2151-2161.

Nathan, D. M., & Group, D. E. R. (2014). The diabetes control and complications trial/epidemiology of diabetes interventions and complications study at 30 years: overview. *Diabetes care, 37*(1), 9-16.

Nieuwesteeg, A., Pouwer, F., van der Kamp, R., van Bakel, H., Aanstoot, H.-J., & Hartman, E. (2012). Quality of life of children with type 1 diabetes: a systematic review. *Current diabetes reviews, 8*(6), 434-443.

Niwa, K. (2018). Adult Congenital Heart Disease with Pregnancy. *Korean circulation journal, 48*(4), 251-276.

Noori, N., Teimouri, A., & Boryri, T. (2017). Quality of Life in Children and Adolescents with Congenital Heart Diseases in Zahedan, Iran. *International Journal of Pediatrics, 5*(1), 4193-4208.

Odeh Yosef, A. R. (2008). Health beliefs, practice, and priorities for health care of Arab Muslims in the United States: Implications for nursing care. *Journal of Transcultural Nursing, 19*(3), 284-291.

Olsen, M., Sørensen, H. T., Hjortdal, V. E., Christensen, T. D., & Pedersen, L. (2011). Congenital heart defects and developmental and other psychiatric disorders: a Danish nationwide cohort study. *Circulation, 124*(16), 1706.

Ozougwu, J., Obimba, K., Belonwu, C., & Unakalamba, C. (2013). The pathogenesis and pathophysiology of type 1 and type 2 diabetes mellitus. *Journal of Physiology and Pathophysiology, 4*(4), 46-57.

Pakhale, S., Armstrong, M., Holly, C., Edjoc, R., Gaudet, E., Aaron, S., . . . Balfour, L. (2014). Assessment of stigma in patients with cystic fibrosis. *BMC pulmonary medicine, 14*(1), 76.

Palestinian Central Bureau of Statistics. (2012). On the eve of the international population day 11/07/2012. Retrieved from: http://www.pcbs.gov.ps/Portals/_pcbs/PressRelease/int_Pop_2012e.pdf

Palestinian Central Bureau of Statistics. (2017). The international population day 11/07/ 2017. Retrieved from: http://www.pcbs.gov.ps/post.aspx?lang=en&ItemID=1975

Palestinian Health Information Center. (2015). Health Status in Palestine 2014, Nablus, Palestine: . *Ministry of Health*

Pask, S., Pinto, C., Bristowe, K., van Vliet, L., Nicholson, C., Evans, C. J., . . . Murtagh, F. E. (2018). A framework for complexity in palliative care: A qualitative study with patients, family carers and professionals. *Palliative Medicine, 32*(6), 1078-1090.

Pateraki, N. S., Mantzourani, E., Darvyri, P. P., Alexopoulos, E. C., Varvogli, L., Mamoulakis, D., . . . Chrousos, G. P. (2015). Stress Management in Parents of Children with Diabetes Type 1: A Randomized Controlled Trial. *Psychology, 06*(08), 1040-1050.

Patterson, J. M., Holm, K. E., & Gurney, J. G. (2004). The impact of childhood cancer on the family: a qualitative analysis of strains, resources, and coping behaviors. *Psycho-Oncology, 13*(6), 390-407.

Patton, M. (2002). *Qualitative research and evaluation methods*. Sage Publications.

Perrin, J. M., Bloom, S. R., & Gortmaker, S. L. (2007). The Increase of Childhood Chronic Conditions in the United States. *Journal of the American Medical Association , 297*(24), 2755-2759.

Petitti, D. B., Klingensmith, G. J., Bell, R. A., Andrews, J. S., Dabelea, D., Imperatore, G., . . . Waitzfelder, B. (2009). Glycemic control in youth with diabetes: the Search for diabetes in Youth Study. *The Journal of pediatrics, 155*(5), 668-672. e663.

Pham, P. N., Vinck, P., Kinkodi, D. K., & Weinstein, H. M. (2010). Sense of coherence and its association with exposure to traumatic events, posttraumatic stress disorder, and depression in eastern Democratic Republic of Congo. *Journal of Traumatic Stress, 23*(3), 313-321.

Pillay, B., Lee, S. J., Katona, L., De Bono, S., Burney, S., & Avery, S. (2015). A prospective study of the relationship between sense of coherence, depression, anxiety, and quality of life of haematopoietic stem cell transplant patients over time. *Psycho‐Oncology, 24*(2), 220-227.

Polit, D. F., & Beck, C. T. (2012). *Nursing research: generating and assessing evidence for nursing practice*. Philadelphia: Wolters Kluwer Health/Lippincott Williams & Wilkins.

Rahnama, M., Khoshknab, M. F., Seyed, B. M. S., Ahmadi, F., & Arbabisarjou, A. (2015). Religion as an alleviating factor in Iranian cancer patients: a qualitative study. *Asian Pacific journal of cancer prevention, 16*(18), 8519.

Rewers, M., Pihoker, C., Donaghue, K., Hanas, R., Swift, P., & Klingensmith, G. J. (2009). Assessment and monitoring of glycemic control in children and adolescents with diabetes. *Pediatric Diabetes, 10*(s12), 71-81.

Reynolds, N., Mrug, S., & Guion, K. (2013). Spiritual coping and psychosocial adjustment of adolescents with chronic illness: The role of cognitive attributions, age, and disease group. *Journal of Adolescent Health, 52*(5), 559-565.

Reynolds, N., Mrug, S., Hensler, M., Guion, K., & Madan-Swain, A. (2014). Spiritual coping and adjustment in adolescents with chronic illness: A 2-year prospective study. *Journal of Pediatric Psychology, 39*(5), 542-551.

Rini, C., Manne, S., Duhamel, K., Austin, J., Ostroff, J., Boulad, F., . . . Redd, W. H. (2008). Social Support From Family and Friends as a Buffer of Low Spousal Support Among Mothers of Critically Ill Children: A Multilevel Modeling Approach. *Health Psychology, 27*(5), 593-603.

Sable, C., Foster, E., Uzark, K., Bjornsen, K., Canobbio, M. M., Connolly, H. M., . . . Meadows, A. K. (2011). Best practices in managing transition to adulthood for adolescents with congenital heart disease: the transition process and medical and psychosocial issues: a scientific statement from the American Heart Association. *Circulation, 123*(13), 1454-1485.

Samardzic, M., Tahirovic, H., Popovic, N., & Popovic-Samardzic, M. (2016). Health-related quality of life in children and adolescents with type 1 diabetes mellitus from Montenegro: relationship to metabolic control. *Journal of Pediatric Endocrinology and Metabolism, 29*(6), 663-668.

Sandelowski, M. (2000a). Focus on research methods-whatever happened to qualitative description? *Research in nursing and health, 23*(4), 334-340.

Sandelowski, M. (2000b). Whatever happened to qualitative description? *Research in Nursing & Health, 23*(4), 334-340.

Santelli, J. S., Smith Rogers, A., Rosenfeld, W. D., Durant, R. H., Dubler, N., Morreale, M., . . . Schissel, A. (2003). Guidelines for Adolescent Health

Research: A position paper of the Society for Adolescent Medicine. *Journal of Adolescent Health, 33*(5), 396-409.

Schabert, J., Browne, J., Mosely, K., & Speight, J. (2013). Social stigma in diabetes: A framework to understand a growing problem for an increasing epidemic. The Patient: Patient-Centered Outcomes Research, 6 (1), 1-10.

Schmidt, C. (2007). Self-care in children with type 1 diabetes: A Survey of Mothers. *MCN, The American Journal of Maternal/Child Nursing, 32*(4), 223-229.

Selway, D., & Ashman, A. F. (1998). Disability, religion and health: A literature review in search of the spiritual dimensions of disability. *Disability & Society, 13*(3), 429-439.

Sertçelik, T., Alkan, F., Sapmaz, Ş. Y., Coşkun, Ş., & Eser, E. (2018). Life quality of children with congenital heart diseases. *Turkish Archives of Pediatrics/Türk Pediatri Arşivi, 53*(2), 78.

Shillingford, A. J., Glanzman, M. M., Ittenbach, R. F., Clancy, R. R., Gaynor, J. W., & Wernovsky, G. (2008). Inattention, hyperactivity, and school performance in a population of school-age children with complex congenital heart disease. *Pediatrics, 121*(4), e759-e767.

Silverstein, J., & Patrick, S. (2007). Guidelines for insulin management of diabetes in school. *School nurse news, 24*(2), 9-12.

Sira, N., Desai, P. P., Sullivan, K. J., & Hannon, D. W. (2014). Coping strategies in mothers of children with heart defects: A closer look into spirituality and internet utilization. *Journal of Social Service Research, 40*(5), 606-622.

Skrivarhaug, T. (2013). Mortality in childhood-onset type 1 diabetes: Nationwide population based data from Norway. *Norsk epidemiologi, 23*(1), 89-93.

Smith, M. (2004). Killing the angel in a room of one's own. Being as unconscious as possible when writing up qualitative research. *Journal of social work practice, 18*(2), 255-265.

Soltesz, G., Patterson, C., & Dahlquist, G. (2009). Diabetes in the young: a global perspective. *Global trends in childhood type, 1*, 364-370.

Spellings, C. R. (2014). *The Role of Family in Wellbeing and Quality of Life among Palestinian Adults* (Doctoral Dissertation). The University of Tennessee. Retrieved from https://trace.tennessee.edu/cgi/viewcontent.cgi?article=3951&context=utk_graddiss

Svalastog, A. L., Donev, D., Kristoffersen, N. J., & Gajović, S. (2017). Concepts and definitions of health and health-related values in the knowledge landscapes of the digital society. *Croatian medical journal, 58*(6), 431.

Taylor, R. M., Gibson, F., & Franck, L. S. (2008). A concept analysis of health-related quality of life in young people with chronic illness. *Journal of Clinical Nursing, 17*(14), 1823-1833.

Tengland, P.-A. (2007). A two-dimensional theory of health. *Theoretical Medicine and Bioethics, 28*(4), 257.

Ternestedt, B.-M., Wall, K., Oddsson, H., Riesenfeld, T., Groth, I., & Schollin, J. (2001). Quality of life 20 and 30 years after surgery in patients operated on for tetralogy of Fallot and for atrial septal defect. *Pediatric Cardiology, 22*(2), 128-132.

Tolbert, R. (2009). Managing Type 1 Diabetes at School: An Integrative Review. *The Journal of School Nursing, 25*(1), 55-61.

Uebing, A., Gatzoulis, M. A., Von Kaisenberg, C., Kramer, H.-H., & Strauss, A. (2008). Congenital heart disease in pregnancy. *Deutsches Arzteblatt international, 105*(19), 347.

Uzark, K., Jones, K., Slusher, J., Limbers, C. A., Burwinkle, T. M., & Varni, J. W. (2008). Quality of life in children with heart disease as perceived by children and parents. *Pediatrics, 121*(5), e1060-e1067.

van der Linde, D., Konings, E. E. M., Slager, M. A., Witsenburg, M., Helbing, W. A., Takkenberg, J. J. M., & Roos-Hesselink, J. W. (2011). Birth prevalence of congenital heart disease worldwide: a systematic review and meta-analysis. *Journal of the American College of Cardiology, 58*(21), 2241.

Varni, J. W., Limbers, C. A., & Burwinkle, T. M. (2007). Impaired health-related quality of life in children and adolescents with chronic conditions: a comparative analysis of 10 disease clusters and 33 disease categories/severities utilizing the PedsQL 4.0 Generic Core Scales. *Health Qual Life Outcomes, 5*(1), 43-43.

Varni, J. W., Seid, M., & Rode, C. A. (1999). The PedsQL™: measurement model for the pediatric quality of life inventory. *Medical care, 37*(2), 126-139.

Warnes, C. A., Liberthson, R., Danielson, G. K., Dore, A., Harris, L., Hoffman, J. I. E., . . . Webb, G. D. (2001). Task Force 1: the changing profile of congenital heart disease in adult life. *Journal of the American College of Cardiology, 37*(5), 1170-1175.

Wei, H., Roscigno, C. I., Hanson, C. C., & Swanson, K. M. (2015). Families of children with congenital heart disease: A literature review. *Heart & Lung: The Journal of Acute and Critical Care, 44*(6), 494-511.

Weiss, M. G., Ramakrishna, J., & Somma, D. (2006). Health-related stigma: Rethinking concepts and interventions 1. *Psychology, health & medicine, 11*(3), 277-287.

Whittemore, R., Jaser, S., Chao, A., Jang, M., & Grey, M. (2012). Psychological experience of parents of children with type 1 diabetes: a systematic mixed-studies review. *Diabetes Education, 38*(4), 562-579.

Williams, P. D., Ridder, E. L., Setter, R. K., Liebergen, A., Curry, H., Piamjariyakul, U., & Williams, A. R. (2009). Pediatric Chronic Illness (Cancer, Cystic Fibrosis) Effects On Well Siblings: Parents' Voices. *Issues in Comprehensive Pediatric Nursing, 32*(2), 94-113.

Woodgate, R. L. (2008). Feeling States: A New Approach to Understanding How Children and Adolescents With Cancer Experience Symptoms. *Cancer Nursing, 31*(3), 229-238.

Woollett, N. (2016). Adolescents Living with HIV: Emerging Issues in Public Health in South Africa. In *Children and Young People Living with HIV/AIDS* (pp. 65-88). Springer, Cham.

World Health Organization. (1986). The Ottawa Charter for Health Promotion: First International Conference on Health Promotion, Ottawa, 21 November 1986. Geneva: WHO; 1986.

World Health Organization. (2014). Right to health: Crossing barriers to access health in the occupied Palestinian territory, 2013. Retrieved from:

http://www.emro.who.int/images/stories/palestine/documents/WHO_
RTH_crossing_barriers_to_access_health.pdf?ua=1

World Health Organization. (2016). Right to health: Crossing barriers to access health in the occupied Palestinian territory, 2014-2015. Retrieved from: http://www.emro.who.int/images/stories/palestine/documents/WHO_-_Access_Report_2014-15_-Final.pdf?ua=1

World Medical Association. (2013). World Medical Association Declaration of Helsinki: Ethical principles for medical research involving human subjects. *Journal of the American Medical Association, 310*, 2191-2194.

Wray, J., Brown, K., Tregay, J., Crowe, S., Knowles, R., Bull, K., & Gibson, F. (2018). Parents' experiences of caring for their child at the time of discharge after cardiac surgery and during the postdischarge period: Qualitative study using an online forum. *Journal of medical Internet research,* 20(5): e155.

Wray, J., & Maynard, L. (2006). The needs of families of children with heart disease. *Journal of Developmental & Behavioral Pediatrics, 27*(1), 11-17.

Wyness, M. (2013). Children's participation and intergenerational dialogue: Bringing adults back into the analysis. *Childhood, 20*(4), 429-442.

Yilmaz, K. (2013). Comparison of quantitative and qualitative research traditions: Epistemological, theoretical, and methodological differences. *European Journal of Education, 48*(2), 311-325.

Yoon, J.-W., & Jun, H.-S. (2005). Autoimmune destruction of pancreatic β cells. *American journal of therapeutics, 12*(6), 580-591.

Ypinazar, V. A., & Margolis, S. A. (2006). Delivering Culturally Sensitive Care: The Perceptions of Older Arabian Gulf Arabs Concerning Religion, Health, and Disease. *Qualitative Health Research, 16*(6), 773-787.

Zaqout, M., Aslem, E. S., Oweida, F. S., & De Wolf, D. (2014). Prevalence of congenital heart disease among Palestinian children born in the Gaza Strip. *Cardiology in the Young, 24*(5), 905-909.