Being physically active as an adult with congenital heart disease

Annika Bay
“It might take a year,
   it might take a day,
   but what’s meant
   to be will always
   find its way”

To Per, Linnèa & Jesper with love
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ABSTRACT

Background: Due to advances in medical and surgical care adults with congenital heart disease (CHD) is a growing and aging population, that now outnumber the children with CHD. In general, adults with CHD have reduced aerobic exercise capacity and nearly half of the patients do not reach current recommendations on physical activity. It is known that a low level of physical activity is associated with an increased risk for acquired cardiovascular disease. Studies has shown that adults with CHD are at the same, or even higher risk as the general population, for developing acquired cardiovascular disease.

Aim: The overall aim was to explore physical activity in adults with CHD with respect to associated factors, exercise self-efficacy and their own experiences.

Methods: This thesis is based on four papers. Paper I included 471 adults with CHD from three tertiary care centres in Sweden. The participants completed questionnaires measuring patient reported outcomes (e.g. SF-12) including physical activity level. Paper II was based on data from 79 adults with CHD from two tertiary care centers in Sweden and 42 matched controls. All participants completed questionnaires on exercise self-efficacy and quality of life, wore an activity monitor during four consecutive days and performed muscle endurance tests. Paper I and II were of cross-sectional design and analyses were done using logistic regression. In paper III and IV data were collected through structured interviews for 14 participants. They were asked about their experiences of being physically active (paper III), what they considered as physical activities, and their experiences of enablers and barriers to physical activity (paper IV). Qualitative content analysis was used in papers III and IV.

Results: Physical activity level (paper I) and exercise self-efficacy (paper II) were strongly associated with age where those over 40 years had a lower level of physical activity and lower exercise self-efficacy. Further, in paper I, it appeared that patient reported outcomes from SF-12 were strongly associated with physical activity level. In paper II, exercise self-efficacy was associated with performance in a muscle endurance tests. Paper III revealed an overall theme – It’s like balancing on a slackline that illustrates how adults with CHD described themselves in relation to physical activity. This overall theme consisted of four themes: (1) Being an adventurer – enjoying the challenges of physical activity; (2) Being a realist – adapting to physical ability; (3) Being a non-doer – lacking prerequisites for physical activity and (4) Being an outsider – feeling excluded.
depending on physical ability. In paper IV, the analysis revealed a description of what adults with CHD consider to be physical activity and considered as enablers and barriers for physical activity. Four categories appeared; physical aspects, psychological aspects, psychosocial aspects and environmental aspects. In the psychosocial aspect, social support and encouragement in childhood to be physically active and no restrictions from e.g. parents, teachers and health care increased physical activity in adulthood.

Conclusions: Age, social support and accepting physical limitations seem to have an important impact regarding physical activity level and exercise self-efficacy. In contrast, the complexity of CHD and other medical factors appear to be of less importance for adults with CHD in relation to physical activity. In order to support adults with CHD to increase their physical activity and reach their full potential, it is important to explore and consider the various aspects that may affect physical activity in this population.

Keyword: Adult congenital heart disease, congenital heart disease, heart defect, physical activity, exercise self-efficacy, muscle function, quality of life, nursing, interviews, content analysis, prevention
<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ACHD</td>
<td>Adults with congenital heart disease</td>
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<tr>
<td>APPROACH-IS</td>
<td>Assessment of Patterns of Patient-Reported Outcomes in Adults with Congenital heart disease – International Study</td>
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<td>CHD</td>
<td>Congenital Heart Disease</td>
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<td>ESE</td>
<td>Exercise Self-Efficacy</td>
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<td>EQ-5D</td>
<td>EuroQol-5 dimension questionnaire</td>
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<td>GUCH</td>
<td>Grown-up Congenital Heart disease</td>
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<td>HADS</td>
<td>Hospital Anxiety and Depression Scale</td>
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<td>HBS-CHD</td>
<td>Health Behaviour Scale-Congenital Heart Disease</td>
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<td>ICN</td>
<td>International council of nurses</td>
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<td>ISACHD</td>
<td>International Society for Adult Congenital Heart Disease</td>
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<td>LAS</td>
<td>Linear Analogue Scale</td>
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<td>MCS</td>
<td>Mental Component Summary</td>
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<td>MET</td>
<td>Metabolic equivalent</td>
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<tr>
<td>NYHA</td>
<td>New York Heart Association functional class</td>
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<td>PAL</td>
<td>Physical activity level</td>
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<td>PCS</td>
<td>Physical Component Summary</td>
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<td>QoL</td>
<td>Quality of Life</td>
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<td>RN</td>
<td>Registered Nurse</td>
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<td>SF-12</td>
<td>Short form health survey</td>
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<td>SOC</td>
<td>Sense of Coherence</td>
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<td>SWEDCON</td>
<td>The SWEdish registry of Congenital heart disease</td>
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<td>SWLS</td>
<td>Satisfaction With Life Scale</td>
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<td>WHO</td>
<td>World Health Organisation</td>
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Tack vare medicinska framgångar har antalet vuxna med medfödda hjärtfel ökat och överstiger numera antalet barn med motsvarande diagnos. De flesta lever ett liv utan större begränsningar och klarar av att göra det de vill och utsätter sig för. Majoriteten har dock någon grad av nedsatt fysisk kapacitet och cirka hälften uppnår inte gällande rekommendationer för fysisk aktivitet. Låg fysisk aktivitet är en riskfaktor för förvärvad hjärtsjukdom och studier har visat att vuxna med medfödda hjärtfel har samma och kanske även större risk att insjukna än den övriga befolkningen.

I avhandlingens delarbeten har faktorer som kan påverka nivån av fysisk aktivitet bland vuxna med medfödda hjärtfel analyserats. Vidare har faktorer som kan påverka tilltron till sin egen förmåga att vara fysiskt aktiv studerats. I avhandlingen ingår också intervjustudier där vuxna med medfödda hjärtfel beskrev sina erfarenheter av fysisk aktivitet, vilka aktiviteter de relaterade till som fysisk aktivitet och slutligen möjligheter och hinder för att vara fysiskt aktiva.


Fysiska aspekter; möjliggörande faktorer var att de hade den fysiska styrkan till att vara fysiskt aktiv, medicinska åtgärder hade förbättrat deras fysik, dagsformen både möjliggjorde och förhindrade fysisk aktivitet, och som hinder framkom symtom av hjärt sjukdomen i sig och andra sjukdomstillstånd.

Psykiska aspekter; möjliggörande faktorer var att de hade en positiv inställning till fysisk aktivitet, motivation till att vara fysiskt aktiv och motsatsen blev således ett hinder, brist på motivation, vilken inställning de hade till sin egen prestation var både en möjlighet men också ett hinder om de hade för stora krav på sig själva. Rädsla för att fysisk aktivitet kunde förvärra deras hjärtfel beskrevs av deltagarna som ett hinder.

Psykosociala aspekter; uppmuntran och stöd från föräldrar, lärare och vänner hade stor betydelse, och om det saknades blev det ett hinder till att vara fysiskt aktiv, även i vuxen ålder. Information till berörda parter möjliggjorde fysisk aktivitet medan brist på kunskap och förståelse blev ett hinder. Att ha en sämre fysisk kapacitet jämfört med andra blev ett hinder, då deltagarna beskrev att de inte ville visa för andra att de blev andfådda eller cyanotiska.

Omgivande aspekter; struktur och planering möjliggjorde fysisk aktivitet och bristande struktur framstod som ett hinder. Tekniska hjälpmedel såsom mobilapplikationer och pulsklockor ökade den fysiska aktiviteten medan brist på faciliteter såsom omklädningsrum och duschar på arbetsplatsen upplevdes som ett hinder för exempelvis kunna promenera till arbetet. Klimatet beskrevs som ett hinder där både kyla och värme försvårade den fysiska aktiviteten.

Ålder, socialt stöd och en acceptans av de fysiska begränsningarna var av stor betydelse för nivån av fysisk aktivitet och exercise self-efficacy. Däremot verkar komplexiteten av det medfödda hjärtfelet eller andra medicinska faktorer vara mindre viktigt för vuxna med medfött hjärtfel i relation till fysisk aktivitet. För att kunna stöta vuxna med medfödda hjärtfel att öka sin fysiska aktivitet och nå sin fulla potential är det betydelsefullt att beakta olika aspekter som kan påverka fysisk aktivitetsnivån i denna grupp.
I have been a registered nurse (RN) within cardiology for more than 25 years and have met patients with heart disease throughout my entire career. When I worked as a nurse in the outpatient clinic for adults with CHD, I was often surprised at how many of the persons with a complex diagnosis of CHD claimed that they had no barriers of managing life. Many of them were as active as they wanted to be and did not hesitate to perform physical activity. In contrast, there were persons with a mild heart disease, who did not manage physical activity because of their heart disease.

The observation that the heart defect did not actually matter for many of the patients raised my curiosity and I wanted to achieve more knowledge about reasons for this attitude. My doctoral studies have given me the opportunity to perform research in this field, and hopefully the results of this thesis can lead to a deeper knowledge and understanding of how adults with CHD experience physical activity. This knowledge can be used to design support for increased physical activity in this population.
ORGINAL PAPERS

This thesis is based on the following papers, referred to in the text by their Roman numerals I-IV:


Papers I-III are reprinted with permission from the respective publisher.
INTRODUCTION

Due to advances in paediatric cardiac care, the majority of children born with congenital heart disease (CHD) reach adulthood, and therefore adults with CHD is a growing and aging population (1, 2). Although many adults with CHD live their lives as normal as possible are not restricted by their limitations (3) and are generally satisfied with their lives (4), there are however new challenges for this population (5, 6). The improved survival may lead to long-term complications and an increased need for re-interventions when patients grow older (7). Adults with CHD are exposed to the same, or even higher, risk of developing acquired cardiovascular disease as the general population (8-13). A recent study indicated an increased risk already at a younger age (11). It is also known that a low level of physical activity is associated with increased risk for acquired cardiovascular disease (14-17).

In patients with CHD it was shown that exercise training is safe (18, 19) and it increases the aerobic capacity (20, 21). Further, a higher physical activity level is associated with a better quality of life (22). Despite these, and along with the knowledge that many adults with CHD are as active as their peers, many do not reach the level of physical activity recommended for health promotion (23). This makes prevention of acquired cardiovascular disease and promotion of physical activity even more important for adults with CHD.
BACKGROUND

Congenital heart disease (CHD)

Nearly 1 out of 100 children are born with CHD, this constitutes almost a third of the children that are born with major malformation, which makes CHD the most common innate anomaly (1, 24). Thanks to the development of surgical methods and specialized care, the number of children that survive into adulthood has increased (2, 25) and currently up to 95% reach adulthood (26).

The definition of CHD is a gross structural abnormality of the heart or great vessels (27). The diagnosis of CHD is often classified into three groups based on the complexity of the heart lesion, (simple complexity, moderate severity and great complexity) (28), however, another common classification on complexity is simple versus complex (29). The incidence of CHD varies around the world and there seems to be some geographical variations, but little is known about the true incidence (30). The most used terminology for adults with CHD are GUCH (Grown-up Congenital Heart disease) and ACHD (Adult Congenital Heart Disease).

In general, the aetiology of CHD is unknown. In some cases (8-10%) there are however, syndromes with chromosomal abnormalities associated with CHD, such as trisomy 13, trisomy 18, Down syndrome, Turner syndrome and DiGeorge syndrome. There are also single gene defects such as Alagille syndrome, Holt-Oram syndrome and Noonan syndrome. Concerning the dominating non-syndromal CHD, the aetiology is less clear. Some environmental factors e.g. maternal diabetes mellitus (31-33), maternal obesity, alcohol use and rubella infection are known as associated explanations (6, 34).

Studies has shown that the number of adults (>18 years age) with CHD has increased and now outnumbers the paediatric population with CHD. Thus, adults now constitute the majority of the population with complex CHD (25). In Europe, the number of adults with CHD is estimated to be almost 2.3 million in comparison to 1.9 million children with CHD (35). In Sweden, the number of adults with CHD is estimated at 40000, and the population is relative young with a median age of 39 years for women and 36 years for men. A minor gender difference exists (men 51.5% and women 48.5%) (36, 37).
Most of these patients are surgically treated, but they are not cured and as a consequence of the improved survival, long-term complications, such as arrhythmias, heart failure, endocarditis etc., increase as the patients grow older (6). The population of adults with CHD has increased over the last decades as a result of the decreased early mortality. Research shows that the median survival for patients with a mild lesion does not differ from the general population. However, for persons with moderate or severe disease, the median survival are 75 and 53 years respectively (38). Common causes of death are chronic heart failure and sudden death, there are also non-cardiovascular causes such as malignancy and pneumonia. In the all-cause mortality predictors were presented as; age, sex, the complexity of the CHD, endocarditis, arrhythmias, myocardial infarction and pulmonary hypertension (39). Further, the overall risk for death was still described as higher in children and young adults with CHD than in matched controls. Even if the mortality rate has decreased between 1970 and 1993, patients with CHD born in the early 1990s still had a higher risk for death (40). Furthermore, with the growing population of adults with CHD, it is important to improve the quality of care and to deliver care in an individual and to those with the greatest needs (6, 7).

Living with congenital heart disease

In the nursing literature, living with chronic illness has been an important perspective to explore. When it comes to previous research on adults with CHD, the focus has been on early survival, surgical outcomes, survival rate, and cardiac function. CHD was earlier seen as a life-threatening condition, but due to the dramatic development within the area of paediatric cardiology including diagnostics, surgical interventions, and both medical and nursing care, CHD is now often considered as a chronic condition. Nowadays, research also focuses on experiences, as well as long-term outcomes such as health, quality of life (QoL) and sense of coherence (SOC). The World Health Organisation (WHO) has defined health (1946) as follows; “health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity” (41). This definition is a widely known and may point to an ideal state of health that is not realistic. In 1986, WHO revised and defined health as a resource for everyday life and not just the objective of living (42). Further, health is described as a positive concept that emphasizes social and personal resources, as well as physical capacity (42). Moons et al. (2006) described that self-perceived health, measured using a linear analogue scale (LAS), seems to be good in adults with CHD, and does not differ from healthy controls (43). In a Swedish population of adults with CHD, Berghammer et al. (2013) show that, on a group level adults with CHD,
appear to have good health as estimated with EuroQol-5 dimension questionnaire (EQ-5D) (44). It was also stated that the health status was negatively influenced by symptoms, such as pain/discomfort and anxiety/depression (44).

A large multicentre study (4) reported, that on a group level overall QoL, assessed using LAS (0 to 100) and the Satisfaction with Life Scale (SWLS) (5 to 35), was generally good, with a median of 80 on the LAS and 27 on SWLS. Older age, being unemployed, or being disabled was linked to poor QoL. Other important aspects were never having been married and a poor New York Heart Association functional class (NYHA). In addition, when using the LAS to measure QoL, it was found that adolescents with CHD had better QoL than adolescents from a general population (median QoL 82 vs 80) (45). This latter study also measured SOC, which refer to a persons generalized world view and it consists of three dimensions; comprehensibility, manageability and meaningfulness. The study reported that adolescents with CHD seemed to have higher SOC than adolescents from the general population. This higher SOC, together with a higher perceived physical health, might explain higher QoL in the adolescents with CHD (45). In contrast to the reports on high QoL in adults with CHD it was shown that this population may have an increased risk of mood and anxiety disorders (46). Furthermore, in a recent study, it was confirmed that mood and anxiety disorders are more common in adults with CHD compared to the general population (47).

Within the field of nursing research, some research has focused on experiences using qualitative methods. As described above many of the adults living with a complex CHD are the first generation to undergo new surgical methods, and there are therefore a number of new questions about experiences in this population. Berghammer et al (2006) described that some persons have ambivalent feelings of being healthy or not, while others described themselves as being just like everyone else and are to be judged as healthy (3, 48). Living with CHD and having health challenges, such as medical needs, shaped their lives as children and remained throughout adulthood (49). It also affected how they relate to others (e.g. parents, siblings, and friends) and the choices they made in life (49). However, it was not just negative to grow up with CHD, instead they felt that the CHD strengthened their personalities, clarified their values and increased their sense of empathy (49). A previous study showed that a majority of adolescents and young adults with CHD realize that their disease was irreversible (50). They preferred to take control over their disease instead of being controlled by the disease. Therefore, they developed coping strategies that identified their limitations and protected themselves in order to
maintain physical health (50). This is not unique for the CHD population. A previous review described adult patient’s experience of living with chronic illness as a complex, dynamic, cyclical and multidimensional process (51). The process illustrates living with chronic illness in five areas; acceptance, coping, self-management, integration and adjustment (51). In addition, a review on the experience of living with a variety of chronic illnesses during adolescence, described similar results and pointed out that the burden of chronic illness does not necessarily need to be disease specific (52).

Organisation of care

Although some of the adults with CHD have been surgically corrected, they are not cured (53). They are in need of lifelong expert care to optimize medical and psychosocial issues (35). Today, adults with CHD, particularly those with moderate and severe complexity of their heart lesion, are often cared for in a specialized health care organisation. This means that the group of adults will have lifelong needs of care and in order to meet these different needs there are recommendations regarding the organization of care (7). The guidelines stratify patient care into three levels; patients who need care at a specialized centre, patients with shared care between specialized centres and with general adult cardiac service and patients who can be managed in “non-specialist” clinics (7). There are a number of challenges to be taken care of during the lifespan, such as therapeutic considerations, i.e. medical treatment, and non-cardiac issues. For example, there may be problems with acceptances for health insurance (in some countries) and life insurance, problems participating in sports or exercise, and medical issues related to pregnancy (7).

Adults with CHD need varied clinical expertise in order to have their needs met. In some countries, for example, the United Kingdom, there are nurse-led clinics for adults with CHD (54). Here the nurses offer information and advices based on their specialist knowledge and expertise. They also provide time for discussing emotional support, well-being, self-management and symptoms (54). Other areas to be covered in nurse-led clinics could include physical examination, telephone support, patient education, coordination of care and follow-ups (55). However, there are nurse-led clinics in other chronic diseases as well, that focus on all aspects of living with a chronic disease, for example, providing education about the disease and paying attention to the patient’s function in everyday life (56). Examples of such areas are oncology care (56) heart failure (57) and rheumatology (58). In Sweden there are specialized centres for adults with CHD, with a multi professional approach that, consist of physicians, nurses, physiotherapists and at some centres also psychologists, but as yet there are no nurse-led clinics.
Promotion of health and prevention of acquired cardiovascular disease

According to the International council of nurses (ICN) the definition of nursing is “promotion of health, prevention of illness, and the care of ill, disable and dying people” (59). It is important that nurses, with an overall perspective, motivates and supports persons towards a healthier lifestyle. The National board of health and welfare in Sweden, has published guidelines regarding healthier lifestyles (60). The guidelines include recommendations on how to prevent diseases by changing unhealthy habits, such as smoking, over consuming alcohol, insufficient physical activity and unhealthy dietary habits.

The risk factors for acquired cardiovascular disease, are associated with lifestyle and are therefore possible to change, e.g. smoking habits, dietary habits, physical inactivity and psychosocial factors (61). In the prevention of cardiovascular disease the aim is to reduce the risk of developing acquired cardiovascular disease, on a general population level or on the individual level. On the population level, this includes advocating a healthy lifestyle behaviour, such as regular exercise, dieting recommendations and smoking cessation (62). On the individual level, this can include prescription of medical treatment for example for hypertension and high cholesterol in those who have moderate and high-risk for developing cardiovascular disease (61, 63). Secondary prevention aims to target those with present cardiovascular disease, with medical treatment and lifestyles changes to reduce the risk of recurrent cardiovascular events, for example myocardial infarction (61).

In adults with CHD, the risk of type 2 diabetes mellitus, hypertension, and hyperlipidaemia are the same as in the general population (8-11, 13). Earlier research has, however, shown that this group of patients had an increased cardiovascular risk already at a lower age (11, 64). The fact that many adults with CHD, have had heart surgery in childhood and in addition are in potential need of re-interventions later on, primary prevention for acquired cardiovascular disease may be of importance. Furthermore, insufficient physical activity level is globally the fourth leading risk factor for mortality (65).

Physical activity

Physical activity is defined as all body movement that results in increased energy consumption. The physical activity can be done in everyday activities at home, at school
or at work. Physical exercise is defined as planned, structured and repetitive physical activity that aims to maintain or improve fitness or strength (66).

WHO’s recommendation (65) for physical activity focuses on primary prevention for non-communicable diseases and general health of the population worldwide. WHO’s recommendation states that adults aged 18-64 years should practise moderate-intensity aerobic physical activity at least 150 minutes per week or vigorous-intensity aerobic physical activity 75 minutes per week. The physical activity should include muscle-strengthening activities twice a week that involve the major muscle groups (65). Studies have shown that approximately half of the adults with CHD do not reach the current recommendations on physical activity. Corresponding findings have been reported in children (23, 67), although, they are equally active as their peers (23). Physical activity in adults with CHD is safe and beneficial (18). With a few exceptions, the majority of adults with CHD are recommended to exercise. The prescriptions of intensity level and type of activity should be individually prescribed and preceded by a physician’s detailed physical examination (18, 68). Age and NYHA functional class were previously suggested as related to physical activity level (23).

Earlier research has focused on children and adolescents’ experience of being physically active, and how they use strategies to participate and adapt the level of challenge (69, 70). Chiang et al. (2011) described that if the adolescents understood how their physical limitation impacted on exercise, and focused on strength and allowed for their limitations, they could participate in physical activity (69). Similar findings were described by Bjorbækmo & Englesrud (2008) where children with CHD accepted their limitations and adjusted the activity so they could participate like anyone else (70). It has been reported that patients and physicians estimate the physical ability differently, and self-reported data were shown to be of great relevance in evaluating a person’s view on physical activity (71). McKillop et al (2017) investigated perceptions and behaviours in physical activity among young adults with CHD and, showed that family members have a great influence on how physical activity is viewed when being an adult (72). However, knowledge is sparse about the experience of physical activity among adults with exclusively complex CHD, i.e. those with known reduced physical capacity, and those in a larger age span.
**Physical capacity**

It is well known that physical activity contributes to a healthy lifestyle and decrease the risk of acquired cardiovascular diseases (14, 15). Previous studies have focused on physiological limitations and have shown that on a group level adults with CHD have reduced aerobic exercise capacity and impaired muscle endurance (73-76). However, the degree of impairment varies within diagnosis groups. Further, the complexity of lesion, e.g. patients with univentricular or systemic right ventricle is associated with impaired exercise capacity (77). Also the reduction of exercise capacity over time in adults with CHD seems to be the natural history (78). For this group aging is associated with variables such as peak oxygen uptake (73), and when measured in a general population peak expiratory flow and grip strength (79) declines over time. Also, in adults with CHD reduced physical ability is associated with increased mortality (80).

**Exercise self-efficacy**

The concept self-efficacy was developed by Bandura in the -1970s, as a social cognitive theory and is defined as “belief in one’s capabilities to organize and execute the courses of action required for producing given attainment” (81, 82). Exercise self-efficacy, *i.e.* the confidence of being physically active, has been measured in different chronic diseases using various exercise self-efficacy scale (83-86). Exercise self-efficacy has been reported in a limited number of CHD studies, mostly on children and adolescents, thus indicating that exercise self-efficacy is of importance for participating in physical activities (87). The ability to be physically active among patients with CHD may be related to certain factors such as parents’ attitudes, cardiologists’ recommendations, exercise self-efficacy and competing interests (72, 87-89). Exercise self-efficacy can influence how adults with CHD view physical activity, however, only a few studies have addressed exercise self-efficacy on this specific adult population (90) and the knowledge of factors associated with exercise self-efficacy is sparse.
RATIONALE

The population of adults with CHD is relatively new, constantly increasing and nowadays exceeds the paediatric population (1). The increased survival might lead to long term complications and a need of re-interventions as patients grow older therefore regular follow ups are of great importance (6). Many adults with CHD are known to be insufficiently active to reach the current recommendations for physical activity to promote health. Most have a reduced exercise capacity and a low physical activity level (23). Furthermore it is well known that low physical activity is an important general risk factor for acquired heart disease and mortality (61). In order to support adults with CHD to adopt a healthier lifestyle and to identify patients at risk for physical inactivity, knowledge of factors associated with unfavourable physical activity level is needed. Exercise self-efficacy may influence how adults with CHD perform physical activity. Previous research has mostly focused on children and adolescents (85, 87, 91), whereas only a few studies have addressed exercise self-efficacy in this specific adult population. Reports on perspectives of physical activity in adults with CHD are sparse. To be able to support and encourage adults with CHD to increase their physical activity, knowledge about their own experiences and behaviours related to physical activity needs to be further explored.
AIM

The overall aim was to explore physical activity in adults with congenital heart disease with respect to associated factors, exercise self-efficacy and their own experiences.

The specific aims in the thesis were:

➢ To investigate factors associated with physical activity level among adults with congenital heart disease (paper I).
➢ To identify factors related to low exercise self-efficacy in adults with congenital heart disease, and potential strategies for being physically active (paper II).
➢ To illuminate how adults with congenital heart disease describe themselves in relation to physical activity (paper III).
➢ To describe what adults with congenital heart diseases consider as physical activity, and what they considered as enablers and barriers for physical activity (paper IV).
METHODS

The thesis contains both quantitative and qualitative methods in order to increase knowledge and understanding so as to give a comprehensive picture of physical activity in adults living with CHD. The first two studies had quantitative designs and based on the findings in these studies, an interview guide was formulated for the two last qualitative studies. By using a mix of methods in research it may contribute to capture, explain and understand the phenomena and help fill the gap of knowledge (92). An overview of study designs and study population is presented in table 1.

Table 1. Overview of study designs and study populations in papers I-IV.

<table>
<thead>
<tr>
<th>Study design</th>
<th>Paper I</th>
<th>Paper II</th>
<th>Paper III</th>
<th>Paper IV</th>
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<td>Participants</td>
<td>n</td>
<td>471</td>
<td>70</td>
<td>14</td>
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<tr>
<td>Sex F</td>
<td>n (%)</td>
<td>230 (49)</td>
<td>33 (42)</td>
<td>7 (50)</td>
</tr>
<tr>
<td>Age</td>
<td>Mean±SD</td>
<td>38.0±14.1</td>
<td>36.7±14.6</td>
<td>32.4±14.3</td>
</tr>
<tr>
<td>Complexity of CHD</td>
<td>n</td>
<td>172</td>
<td>38</td>
<td>-</td>
</tr>
<tr>
<td>Single</td>
<td></td>
<td>212</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Moderate</td>
<td></td>
<td>87</td>
<td>41</td>
<td>14</td>
</tr>
<tr>
<td>Complex</td>
<td></td>
<td>-</td>
<td>42</td>
<td>-</td>
</tr>
</tbody>
</table>

n, number; SD, standard deviation; F, female; CHD, congenital heart disease; 1Prospectively collected data according to a pre-specified protocol, a data from APPROACH-IS & SWEDCON, b Data from SWEDCON, *Paper IV, c Paper I & II, contain patients within same diagnosis, but classified according to different systems.

Assessment of Patterns of Patient-Reported Outcomes in Adults with Congenital Heart disease – International Study (APPROACH-IS)

Paper I was a part of a larger international multicentre study APPROACH-IS that is aimed to investigate patient-reported outcomes in adults with CHD (93). The whole international study population included patients from 15 countries from 5 continents and was performed from April 2013 to March 2015, in partnership with the International Society for Adult Congenital Heart Disease (ISACHD). The questionnaire used in APPROACH-IS consisted of different validated and reliability-tested instruments.
measuring patient reported outcomes, it has been extensively used in previous studies (93) (table 3).

**The SWEdish registry of Congenital heart disease (SWEDCON)**

In papers I and II, data from adult patients were extracted from SWEDCON (37). SWEDCON was created in the early 1990s. In 2009, it included a paediatric and surgical section, and in 2014, a foetal register was added to the registry. Data are registered at every visit by each of the seven centres specialized in adults with CHD as well in some county hospitals. The SWEDCON register is longitudinal and follows patients with CHD over time, from when they are born until death. The register includes for example, data on age, sex, diagnosis, interventions, medication (cardiovascular drugs), NYHA-class, symptoms, smoking habits and EQ-5D (36).

**Participants**

Inclusions criteria for papers I-IV are presented in Table 2. In paper I, 471 adults (≥ 18 years) with CHD participated in the study. The participants were identified and selected from SWEDCON. There were 912 eligible patients who met the inclusion criteria for APPROACH-IS (93), and questionnaires were sent to the patients home address. Forty three patients could not be reached or actively declined to participate. Of the remaining 869 patients, 471 (54.2%) returned their filled-in questionnaire. All patients had their regular follow-up at one of the three included large specialized centre for adult patients with CHD, *i.e.* Gothenburg, Stockholm and Umeå. The cardiac lesions were classified as simple, moderate or severe complexity (27, 93).

In paper II, 79 adults (≥ 18 years) with CHD were recruited from specialized centre for adults with CHD in Umeå and Lund in Sweden and the study was performed from May 2011 – to December 2012. There were 113 patients who met the inclusion criteria (table 2) and were asked to participate. Of these, 23 declined, 5 did not appear, and 6 did not complete the exercise self-efficacy scale. Participants were recruited into four different diagnosis groups to achieve a balanced diversity of diagnoses and complexities. The groups were then divided into two groups, simple and complex according to previous classification used by others (29) also this harmonizes with expected exercise capacity (73). In paper II there were also controls that consisted of 42 age and gender-matched persons, who lived in the Umeå area that had been randomly recruited via the Swedish national population register. Initially, 129 controls were asked for participation and, 86
declined and 1 did not appear. For each gender, the patients were ranked according to age. For every consecutive pair of patients with the same gender a control person with the mean age of this pair of patients was recruited.

The studies in papers III and IV were performed from May 2016, to January 2017. Twenty-four patients with complex CHD (27), at the specialized centre in northern Sweden were selected from the clinic waiting list. Patients were contacted and asked for participation in an interview in connection to a regular follow up visit. Variation regarding gender, age and socio-demographic variables was pursued. Fourteen of the 24 patients agreed to participate.

Table 2. Inclusions criteria for papers I-IV

<table>
<thead>
<tr>
<th>Paper I</th>
<th>Diagnosis of CHD, defined as a structural abnormality of the heart or intra-thoracic great vessels that was present at birth and was actually or potentially functionally significant. Age (≥ 18). Diagnosis established before adolescence (i.e. before 10 years of age). Attended continued follow-up at a CHD centre or included in a national/regional register. Physical, cognitive, and language capacities to allow completion of the self-report questionnaires.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paper II</td>
<td>Periodic out-patient medical visits for CHD, and a clinically stable condition over the past three months.</td>
</tr>
<tr>
<td>Paper III &amp; Paper IV</td>
<td>Diagnosis of complex CHD. Age (≥18). Periodic out-patient medical visit for CHD, and a clinically stable condition over the past three months. Ability to speak and understand Swedish.</td>
</tr>
</tbody>
</table>

Data collection

In paper I, the APPROACH-IS survey package was sent by surface mail to the eligible patients and in the Swedish branch of APPROACH-IS data were collected from May 2014 to March 2015.

In paper II, according to the study protocol, the muscle endurance tests were performed first, followed by the application of the activity monitor and finally the patients completed the questionnaires. All tests were performed during a clinic visit.

Individual semi-structured interviews (94) were performed from May 2016-January 2017. The interviews were carried out at the out-patient clinic by AB (thesis author), using an interview guide (95) formulated on the basis of the findings and further questions from papers I and II.
Methods of measurements

Table 3. Overview of methods and instruments

<table>
<thead>
<tr>
<th>Questionnaires</th>
<th>Paper I</th>
<th>Paper II</th>
</tr>
</thead>
<tbody>
<tr>
<td>HBS-CHD</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>HADS</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>LAS/SWLS</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>SF-12</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>SOC</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>ESES</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>EQ-5D</td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Muscle endurance</th>
<th>Paper I</th>
<th>Paper II</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shoulder flexion</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Heel lift</td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Physical activity</th>
<th>Paper I</th>
<th>Paper II</th>
</tr>
</thead>
<tbody>
<tr>
<td>Actiheart</td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

HSB-CHD, health behaviour scale–congenital heart disease; HADS, Hospital anxiety and depression scale; LAS/SWLS, linear analogue scale/satisfaction with life scale; SF-12, 12-item short form health survey; SOC, sense of coherence; ESES, exercise self-efficacy scale; EQ-5D, EuroQol-5 Dimension questionnaire; Actiheart, (CamNTech Ltd, Cambridge, UK)

Health Behaviour Scale – Congenital Heart Disease (HBS-CHD) (paper I)

To assess physical activity level (PAL) and health behaviour, the Health Behaviour Scale (HBS-CHD) (96) was used. The HBS-CHD contained items regarding alcohol use, tobacco use, dental care and physical activity. The physical exercise score was calculated based on the usual time (in hours) spent per week, in various activities such as extremely physically demanding sports (e.g. basketball and long distance running) and moderately demanding sports (e.g. jogging and volley-ball). The scale ranges from 0–∞, with higher scores indicating higher levels of physical activity.

Hospital Anxiety and Depression Scale (HADS) (paper I)

Anxiety and depression were measured by using the specially developed scale for medical populations and included two seven-item subscales (HADS-Anxiety & HADS-Depression). The score ranged from 0–21, with higher scores reflecting greater psychological distress (97).

Linear Analogue Scale (LAS)/Satisfaction with Life scale (SWLS) (paper I)

The overall quality of life (QoL), was measured using the Linear Analogue Scale and the Satisfaction with Life Scale. The LAS is a vertically oriented scale graded from 0 (worst imaginable QoL) to 100 (best imaginable QoL). The SWLS includes five statements and
assesses the patient’s judgment of life satisfaction (93); it ranges from 1 (strongly disagree) to 7 (strongly agree) with a total sum from 5 (extremely dissatisfied) to 35 (extremely satisfied).

Orientation to life Questionnaire 13 item (SOC-13) (paper I)
For the measurement of sense of coherence (SOC), the short version of Antonovsky’s 13 item Orientation to life Questionnaire (SOC-13) was used (98). This consists of a seven point-point semantic differential scale ranging from 1 (very seldom) to 7 (very often) to evaluate the three components of SOC; comprehensibility (five items), manageability (four items) and meaningfulness (four items). The total score ranged from 13 to 91 where the higher score indicated a stronger SOC.

Short Form Health Survey (SF-12) (paper I)
The 12-item Short Form Health Survey (SF-12) measure perceived health was used, this consists of eight domains where the patient scores from 0 to 100 (99). A higher score reflects better perceived health. The SF-12 produces a Mental Component Summary (MCS) and Physical Component Summary (PCS) (99).

The Exercise Self-Efficacy Scale (paper II)
The Swedish version of the exercise self-efficacy scale was used to evaluate exercise self-efficacy. The Exercise Self-Efficacy (ESE) scale is an instrument used to evaluate the confidence of being physically active. The scale consists of 10 items; each item is scored on a four point Likert scale ranging from 1-4, (1=not at all true, 2=rarely true, 3=moderately true, 4=always true). The best possible ESE scale score is 40 points. The ESE scale is a validated instrument with high internal consistency and scale integrity (86).

The EuroQoL-5 Dimension Questionnaire (paper II)
The Swedish version of the EQ-5D self-reported questionnaire was used to measure health related quality of life. The EQ-5D was developed by the EuroQoL group and is a validated and non-disease specific instrument that evaluates health related quality of life (100). The questionnaire evaluates health status in five dimensions – mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each dimension consists of three levels – no problem, some or moderate problems and extreme problems. The information from EQ-5D questionnaire can be converted into an index (EQ-5D index) by using a formula weighting all levels in each dimension using an index tariff based on preferences.
in a British general population. The EQ-5D\textsuperscript{index} value for best possible health status is 1, and the worst possible health status or death is 0 (-0.53) (100).

**Muscle endurance tests (paper II)**
Muscle endurance was measured with unilateral isotonic shoulder flexion and heel lift. The shoulder test was performed with the participant lifting a weight (two kg for women and three kg for men) in the hand of the dominant side. Participants were asked to elevate the arm from 0° to 90° of flexion as many times as possible at a frequency of 20 repetitions per minute as guided by a metronome. Heel lift was performed with the participant standing on one leg on a 10° tilted wedge while touching the wall with the fingertips for balance. The contralateral foot was held slightly above the floor. The participants were asked to perform as many heel-lifts as possible at a frequency of 30 repetitions per minute guided by a metronome (75, 101). Muscle endurance tests were designed for patients with heart failure (101). Nowadays this test is used in the clinical routine of adults with CHD.

**Monitoring of physical activity (paper II)**
Physical activity was objectively measured by using the validated and reliable Actiheart monitor, (CamNTech Ltd, Cambridge, UK) (102) a combined heart rate monitor and accelerometer for ambulatory use was used. The monitor was worn day and night during four consecutive days that had followed the clinic visit. The extent to which participants reached the current WHO recommendations (65) on physical activity for promoting health was analysed. For details see Sandberg et al. 2016 (23).

**Interviews (papers III & IV)**
The interviewer started with the open question “Can you tell me what physical activity means to you?” This introduction question was followed by “Can you tell me about your experience of physical activity?” In order to further develop the participant’s reasoning about emotions and thoughts about physical activity, follow-up questions were asked (94). The interviews lasted between 20 and 45 minutes (median=32) and were digitally recorded and transcribed verbatim by the thesis author.
Data analysis

Statistics
All statistical calculations in papers I and II were performed using SPSS 20-23 (IBM, Armonk, NY, USA). In both studies the distribution of data was visually assessed for normality. Differences in means were tested with Student’s t-test and ratios tested with chi²-test. In both studies multivariable models were constructed including variables evaluated at the univariate level and variables of potential interest i.e. sex. In paper I the multivariate model was based on univariate variables with \( p < 0.05 \) and in paper II with \( p \leq 0.15 \). Multivariable testing was performed in a manual backward manner (table 4 and table 5). During the multivariate assessment, the output was evaluated for each step in order to detect signs of potential interactions. The null hypothesis was rejected for \( p \)-values < 0.05.

In paper I; PAL was calculated by summarising the time spent at an activity \( \geq 3 \text{MET} \) (Metabolic equivalent). Based on the current WHO recommendations on physical activity for promoting health in adults aged 18-64 (2.5 h/week spent \( \geq 3 \text{METs} \)) (65), the population was grouped into two categories – high PAL (\( \geq 3 \text{ METs} \geq 2.5 \text{ h/week} \)) and low PAL (\( \geq 3 \text{ METs} < 2.5 \text{ h/week} \)).

In paper II, exercise self-efficacy in patients was categorised into low (exercise self-efficacy \( \leq 29 \) points) (n=34), based on the lowest quartile within controls and high (exercise self-efficacy \( > 29 \) points) (n=45) based on the upper three quartiles. The EQ-5D index was dichotomized into EQ-5D index=1 vs. EQ-5D index < 1.

Qualitative content analysis
For papers III and IV, the analysis was performed in several steps, using qualitative content analysis according to Graneheim et al. (103, 104). The text was read several times, with the purpose of getting a sense of the whole. By using a computer-based qualitative tool, Open code software package (105) the text corresponding to the aim was identified and then divided into meanings units and condensed into codes that described the content. Depending on the research question and the aim of the paper the content was interpreted and abstracted. Qualitative content analysis focuses on interpretation of texts and can results in both categories and themes. Categories relates mainly to descriptive
content levels and express the manifest content of the text *i.e.* “the what” (106). Theme relates to the underlying meaning through the data, and expresses the latent content of the text *i.e.* “what is it about” In paper III, the results are reported in themes. Meaning units were coded, and codes based on similarities and dissimilarities were sorted into sub-themes and themes and further abstracted to an overall theme. In paper IV the results are presented in categories. Meaning units were coded and codes were compared and sorted into enablers and barriers, and further sorted into subcategories. The subcategories were then abstracted into four categories (103, 104). To enhance credibility in papers III and IV, all steps in the analysis were perused and discussed by the authors. In paper III subthemes and themes were formulated which responded to how participants described themselves in relation to physical activity. In paper IV subcategories and categories were formulated to show enablers and barriers to physical activity. Throughout the process the codes and categories were compared to the original text to ensure stringent and trustworthy analysis.

**Ethical considerations**

All four studies conformed to the principles in the Declaration of Helsinki (107). Prior to participation in the studies all patients and controls, gave their informed consent. The participants were informed that they could withdraw at any time without explanation. All information; for example, questionnaires and transcript interviews, were handled confidentially decoded and kept in a locked space and only the research group had access to the codes and the corresponding names. There is always a risk that participation in studies may cause discomfort among participants, *e.g.* that unpleasant memories arise when talking about experiences or when filling in questionnaires. With this in mind, the participants’ reactions were observed during the interviews and if necessary the interview could be paused. However, this was never the case, instead, the participants were eager to tell about their experiences and they wanted the knowledge about CHD to increase publicly.

All studies were approved by Ethics Review Boards, paper I (APPROACH-IS) was first approved in Belgium by the institutional Review board of the University Hospitals Leuven/KU Leuven Belgium (the international coordinating centre). The Swedish part was approved by the regional Ethics Review Board in Gothenburg (the national coordinating centre) (nos: 713-13, T100-14 and T207-14). Papers II, III and IV were approved by the Regional Ethical Review Board in Umeå registration number; 2011-51-31 M, 2011 (II) and 2016-78-32M, 2016 (III & IV).
RESULTS

Physical activity level (paper I)

In paper I the aim was to investigate factors associated with physical activity level for adults with CHD. Participants reporting high PAL, (≥ 3 METs ≥2.5h/week) and thus reaching the WHO recommended level on physical activity, were younger, had less prescribed medications, and had fewer symptoms and less comorbidity. Participants with high PAL rated higher on QoL (LAS and SWLS), SF-12’s mental health component summary (MCS) and on SF-12’s physical health component summary (PCS). Variables with a possible influence on high PAL were first tested in a univariate model. Significant variables were; age (p = ≤ 0.001), cardiovascular medication (p = 0.009), symptoms (p = 0.02), comorbidity (p = 0.02), LAS (p = ≤ 0.001), SWLS (p = 0.005) PCS (p = ≤ 0.001) and MCS (p = ≤ 0.001). Notably, in our study, the degree of complexity of the heart lesion was not associated with PAL. When tested in multivariate logistic regression age and PCS/MCS/QoL (separately tested) were independently associated with high PAL. The results for the univariate and multivariate model are shown in table 4. In table 4, there are only data on PCS but MCS and QoL, assessed using LAS and SWLS, yielded similar results.

Exercise self-efficacy (paper II)

Paper II, aimed to identify factors related to low exercise self-efficacy in adults with CHD, and potential strategies for being physically active. Patients with low exercise self-efficacy (n=34) were older (p=0.001), had more complex lesions (p=0.05), had more often NYHA class III (p=0.01), performed less shoulder flexions (p=0.001) and performed fewer heel lifts (p=0.05) compared with patients with high exercise self-efficacy. In the group with high exercise self-efficacy, exercise self-efficacy did not differ from controls. Variables possibly explaining exercise self-efficacy were tested in univariate logistic regression where higher age, lower number of shoulder flexion and higher NYHA class were associated with lower exercise self-efficacy and when tested in multivariate logistic regression age and shoulder flexion remained associated with low exercise self-efficacy (Table 5).
Table 4. Univariate and multiple regression analyses for variables associated with high PAL (≥3MET ≥2.5 hour/week).

<table>
<thead>
<tr>
<th>Variable tested</th>
<th>Univariate regression, p-values</th>
<th>Multiple regression step 1, p-values</th>
<th>Multiple regression step 2, p-values</th>
<th>Multiple regression step 3, p-values</th>
<th>Multiple regression step 4, p-values</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age years</td>
<td>p= ≤0.001</td>
<td>p= 0.001</td>
<td>p= 0.001</td>
<td>p= 0.001</td>
<td>p= 0.001</td>
</tr>
<tr>
<td>Medication yes</td>
<td>p= 0.009</td>
<td>p= 0.77</td>
<td>p= 0.79</td>
<td>Out</td>
<td>Out</td>
</tr>
<tr>
<td>Symptom yes</td>
<td>p= 0.02</td>
<td>p= 0.38</td>
<td>p= 0.37</td>
<td>p= 0.35</td>
<td>Out</td>
</tr>
<tr>
<td>Comorbidity yes</td>
<td>p= 0.02</td>
<td>p= 0.82</td>
<td>Out</td>
<td>Out</td>
<td>Out</td>
</tr>
<tr>
<td>PCS*</td>
<td>p= ≤ 0.001</td>
<td>p= ≤ 0.001</td>
<td>p= ≤ 0.001</td>
<td>p= ≤ 0.001</td>
<td>p= ≤ 0.001</td>
</tr>
</tbody>
</table>

PCS, physical component summary; Bold indicate p < 0.05.
Table 5. Univariate and multiple regression analyses for variables associated with low exercise self-efficacy ≤ 29

<table>
<thead>
<tr>
<th>Variable tested</th>
<th>Univariate regression, p-values</th>
<th>Multiple regression step 1, p-values</th>
<th>Multiple regression step 2, p-values</th>
<th>Multiple regression step 3, p-values</th>
<th>Multiple regression step 4, p-values</th>
<th>Multiple regression step 5, p-values</th>
<th>Multiple Regression step 6, p-values</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age years</td>
<td>p=0.002</td>
<td>p=0.02</td>
<td>p=0.02</td>
<td>p=0.03</td>
<td>p=0.02</td>
<td>p=0.01</td>
<td>p=0.006</td>
</tr>
<tr>
<td>Smoking yes*</td>
<td>p=0.15</td>
<td>p=0.07</td>
<td>p=0.06</td>
<td>p=0.1</td>
<td>p=0.1</td>
<td>p=0.1</td>
<td>Out</td>
</tr>
<tr>
<td>Shoulder flexion (reps)</td>
<td>p=0.007</td>
<td>p=0.07</td>
<td>p=0.06</td>
<td>p=0.04</td>
<td>p=0.04</td>
<td>p=0.01</td>
<td>p=0.02</td>
</tr>
<tr>
<td>Heel lift (reps)</td>
<td>p=0.05</td>
<td>p=0.45</td>
<td>p=0.5</td>
<td>Out</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Complex lesion</td>
<td>p=0.05</td>
<td>p=0.69</td>
<td>Out</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NYHA III</td>
<td>p=0.02</td>
<td>p=0.37</td>
<td>p=0.4</td>
<td>p=0.3</td>
<td>p=0.2</td>
<td>Out</td>
<td></td>
</tr>
<tr>
<td>EQ-5D index &lt; 1*</td>
<td>p=0.06</td>
<td>p=0.29</td>
<td>p=0.3</td>
<td>p=0.4</td>
<td>Out</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

reps, repetitions; NYHA, New York Heart Association functional class; EQ-5D, EuroQol-5 Dimension questionnaire. Bold indicates p ≤ 0.05. *Including in the multivariable model.
Relation to physical activity described by adults with CHD (paper III)

Paper III aimed to illuminate how adults with CHD described themselves in relation to physical activity. The overall theme, *It’s like balancing on a slackline*, consisted of four themes (Table 6).

![Figure 1. Themes](https://example.com/figure1)

Table 6. Subthemes and Themes

<table>
<thead>
<tr>
<th>Subthemes</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Liking physical challenges</td>
<td>Being an adventurer - enjoying the challenges of physical activity</td>
</tr>
<tr>
<td>Having physical strength to be physically active</td>
<td>Being a realist - adapting to physical ability</td>
</tr>
<tr>
<td>Accepting physical limitations</td>
<td>Being a non-doer - lacking prerequisites for physical activity</td>
</tr>
<tr>
<td>Adjusting physical activity to ability</td>
<td></td>
</tr>
<tr>
<td>Maintaining health</td>
<td></td>
</tr>
<tr>
<td>Lacking interest in physical activity</td>
<td></td>
</tr>
<tr>
<td>Lacking motivation to perform physical activities</td>
<td></td>
</tr>
<tr>
<td>Lacking physical strength to perform physical activity</td>
<td></td>
</tr>
<tr>
<td>Wishing to be physically active like others</td>
<td>Being an outsider - feeling excluded depending on physical ability</td>
</tr>
<tr>
<td>Lacking understanding from others</td>
<td></td>
</tr>
<tr>
<td>Being discriminated by others</td>
<td></td>
</tr>
</tbody>
</table>
Being an adventurer - enjoying the challenges of physical activity; the adventurer gladly entered the line and had the physical strength to manage it. This symbolized risking something without being sure of the outcome but still enjoy the challenges.

Being a realist - adapting to physical ability; the realist adapted the level of challenge to manage. This symbolized adjusting the activity by tensing or shortening the slackline to adapt the physical limitations. They expressed an uncertainty if they could be physically active in the future, depending on the uncertainty of how long health would persist and the knowledge that health might deteriorate. They told about the importance of being physically active to maintain health.

Being a non-doer - lacking prerequisites for physical activity; the non-doer lacked the interest or physical capacity. The theme symbolized having no interest or motivation to participate in the activity with an understanding that it would not be fun, and because of this they did not try or have any experience of performing the activity. Some did not have enough strength to perform the activity, others lacked experience which made it even harder to try due to fear of not being able to manage.

Being an outsider - feeling excluded depending on physical ability; the outsider experienced exclusion while not managing to enter the line. The theme symbolized that the activity became too difficult to perform, even if they wanted to they were not able to do it. They described a sense of exclusion when they were not able to be physically active as others, and thus not be as able to participate in activities. The lack of understanding from others led to feelings of discomfort in the situation.
Activities, enablers and barriers to physical activity when living with CHD (paper IV)

In paper IV the aim was to describe what adults with CHD considered as physical activity, and what they considered as enablers and barriers for physical activity. The participants described a large number of different activities. For some physical activity was seen as exercise that, consisted of both muscle exercise training and aerobic exercise training. For others, physical activity was every day activities such as outdoor activities and other activities such as playing with children (Figure 2).

Figure 2. Activities for being physically active.
The analysis revealed four categories; physical aspects, psychological aspects, psychosocial aspects and environmental aspects (Figure 3).

Figure 3. Categories and sub-categories of aspects affecting being physically active.

Physical aspects

*Aerobic fitness* was described as an enabler to be physically active. The exercise training had given results and they had increased their physical ability and did not need the same time for recovery. *Medical treatment* was an enabler that had improved their physical abilities, such as replacement of the heart valve or a pacemaker. However, a described barrier to physical activity was *the heart defect*, conversely for some symptoms, such as palpitations, breathlessness or feeling of low blood pressure. The participant described that they simply lacked the physical ability to be physically active. Another barrier was *comorbidity*, such as migraine or joint related pain that affected the ability to be physical active. The current *energy level* was an aspect that could be interpreted as both an enabler and a barrier. The adults with CHD described that if they had a good day at school or at work, had enough sleep and nutrition, they could feel strong and full of energy to perform physical activity. In contrast the opposite became a barrier.
Psychological aspects

Positive emotions in relation to physical activity was an enabler, physical activity was described as a distraction and made it them think of something else for a while. Fear of movements was described as a barrier, some thought it could be harmful to their heart to perform exercise and, they were afraid that the pulse would increase and that they became breathless. If the adults with CHD had a positive attitude towards physical activity, i.e. thought it was fun to exercise and challenge, they were also more motivated to perform more. On the other side, this was also expressed as a barrier, i.e. if they had no interest or lacked motivation, they were not willing to make the effort. One sub-category described as both an enabler and a barrier, was attitude towards oneself that described an inner strength owing to that the self-confidence had increased during adulthood. It was easier to adapt the right level of effort and they did not compare themselves with others to the same extent in older age. As a barrier, attitude towards oneself described too high demand on oneself with regard to physical activity.

Psychosocial aspects

Some of the adults with CHD described that the fact that they had impaired capacity compared to others was a barrier, they did not want others to see that they became breathless or cyanotic. Encouragement from others was described as an enabler, adults with CHD who had been encouraged by their parents or teachers during childhood had a more positive attitude towards physical activity. They had never even thought about whether it was possible or not. In the opposite perspective being restricted by others became a barrier, the participants never had the opportunity to learn to be physically active. This led to them not being physically active as adults, even when they might have had the ability. Furthermore, an enabler described was specific information to parents and teachers that was given from the health care. This would include information about the child’s heart defect and about the importance of being physically active and more individualized advices on appropriate activities. On the contrast, lack of knowledge and understanding became a barrier, in causing unnecessary limitation of physical activity.

Environmental aspects

A described enabler was technical devices, such as mobile applications or heart rate monitors, it was encouraging to see improvements in their performance. Limited by physical environment was described as a barrier; challenging terrain with hills and rocks, lack of facilities, such as dressing room and showers, and the climate, i.e. if it was cold, it took so
much effort from the body to stay warm, so there was no energy left to be physically active. *Structure* was a key word expressed both as an enabler and as a barrier when it came to physical activity in this population. Participants had to schedule their training and have a structure on how to set up the exercise. Difficulty to find functional *structure* was described as a barrier, if they worked full time, there was not much time left to be physically active and they did not have time to recover.
DISCUSSION

The overall aim in this thesis was to explore physical activity among adults with CHD with respect to associated factors, exercise self-efficacy and their own experiences.

The main findings exploring physical activity among adults with CHD, was that they appeared to have a diverse relationship to physical activity. Our studies show that regarding the physical activity level (paper I) and exercise self-efficacy (paper II), age had a major impact; adults with CHD over 40 years of age had both a low physical activity level and low exercise self-efficacy. We also show (paper I) that a higher perceived health status may increase the physical activity level, and the use of patient reported outcomes is a way to provide useful information. Furthermore, muscle endurance capacity was of importance for exercise self-efficacy (paper II). The complexity of the heart lesion and other medical factors seem to be of less importance for being physically active or not. Instead, there was an acceptance and an adaption of physical activity level that matched participants’ physical abilities (paper III). Furthermore, physical activity was described to created positive emotions and thus an incentive to pursue the activity. Encouragement to be physically active in childhood and avoidance of activity restrictions from parents, teachers and health providers seemed to be important for physical activity in adulthood. However, factors leading to decreased physical activity level were; having an invisible disability - with the difficulties to explain non-participation in activities (psychosocial aspects), not having interest or motivation to perform physical activity (psychological aspects) and palpitations, breathlessness and the current energy level (physical factors)(paper IV).

Surprisingly the interviews showed that many adults with complex CHD described themselves being physically active (papers III & IV). They described that they performed strenuous physical activities, e.g. muscle exercise training and aerobic fitness exercise training. The participants also expressed that they enjoyed challenging themselves and that they had the strength to be physically active. This is in line with previous research, which shows that adults with CHD do not want the heart disease to stop them from being physically active (3, 108). They focus on enablers instead of barriers, and have a view of themselves as strong and healthy. These findings are consistent with paper II, when measuring exercise self-efficacy in 79 adults with CHD, where a majority state that they have high exercise self-efficacy. However, it has been reported that in comparison with their healthy peers, adults with CHD, had lower exercise self-efficacy (75).
Our findings concerning physical activity level and exercise self-efficacy showed that factors related to low physical activity level and low exercise self-efficacy were age (>40 years) and low muscle endurance capacity (paper II), the latter represented by low performance in performing repeated shoulder flexions. In general, aging is associated with a decrease in physical activity level (109) and it is known that age affect many biological variables, not the least morbidity and mortality (110). Physical variables such as peak oxygen uptake (73), peak expiratory flow and grip strength (79), that are measures of physical performance, all decrease with aging. However, a possible contributing factor to the relation between age and low physical activity level might be that older adults with CHD were given advice on restrictions regarding physical activity, during their childhood (88, 111). This is not surprising since these adults are the first generation to reach adulthood, and when they were growing up, there were no guidelines for promoting appropriate physical activity. The qualitative papers (III & IV) confirmed that adults with CHD, who were restricted or not encouraged in childhood, continued to be physically inactive as an adult. Our findings also show that support and encouragement from parents, teachers and health providers are of major importance to increase participation in physical activity. Similar results have been reported by others, albeit on young adults with CHD, thus indicating that this may also be a problem in a somewhat younger population (72). For students, school nurses could play an important role in facilitating the communication between the health care team and school, and in educating school personnel and other students about the CHD (112).

In our studies, adults with CHD described that becoming an adult led to changed habits of physical activity, mainly due to lack of time (paper IV). Physical activity competed with family life, full time work or other things that were prioritized. A study on middle-aged women, described that women’s participation in physical activity was affected by the expectations they perceived from others (113). Others have described that lack of participation in exercise programs were due both to limited time (89) and being tired after a long work day (72). It may be speculated that adults with CHD become more tired after physical and mental work and perhaps they need more time for recovery. We also found that the possibility to plan and structure the physical activity was helpful for performance, this was something also stressed in a review by Williams & French (2011) (114). Those authors also described that providing instructions, e.g. information on where to go for exercise training was associated with the physical activity level (114). Nevertheless, to avoid that adults with CHD refrains from physical activity it is necessary to individualize exercise prescription (68) in order to encourage them to hopefully enjoy a physically active lifestyle.
In the qualitative papers III and IV we found that adults with complex CHD adjusted their physical activity level to their actual ability. According to previous research (115-117), and as shown in this thesis, adults with CHD described an acceptance of the disability. Adults with CHD are born with the disability and thus they do not know any other life situation. By using their knowledge and experience of their own heart defect, opportunities were created to manage activities both regarding physical activities and in everyday life. In order to prevent being exhausted, they sometimes restricted their own physical activity. Previous research, on adolescents with CHD classed as simple complexity, described that the persons developed strategies to maintain a balance in their exertion of physical activity. For example, they try to rest during the exercise and avoid exercise involving running, for example full-court basketball (69). In addition, others described that the social context had an impact on physical activity. If the participants felt that they were comfortable in the situation, they could participate on their own level; it was “not a big deal”. They were striving for normality and wanted to be seen as everyone else. In contrast to this, a psychosocial aspect was the feeling of having an invisible disease. Children (70) and young adults (48) described the conflict between always explaining about their disease but also the wish that others were aware of their limitations. In thesis we show that this is also valid for adults with a broader age span and thus throughout life in persons with CHD.

Adults with CHD who describe themselves as a “non-doer” (paper III) were interpreted to have low exercise self-efficacy, i.e. lacking confidence in their ability to be physically active. They described that they never had been active or were not interested in being physically active. Further, it appeared that they avoided trying sports, due to fear of not being able to continue because of their physical limitations. Instead of adjusting the activity to their abilities, their focus was on the physical and psychological barriers. For example, a physical aspect could be that they felt palpitations, experience of low blood pressure or breathlessness (paper IV). It might be interpreted that the lack of experience of performing physical activities led to a poor knowledge of the normal physiological responses to exercise. It could mean that over time, they developed a fear of movement, and also thought that physical exertion could be harmful to the heart. Furthermore, a lack of experience from being physically active in childhood created barriers to perform physical activity in adulthood. This has been shown in adolescents and young adults with different complexities of CHD (72, 118). In this thesis we show that it is also valid in a wide age span of adults. This not only highlight the importance of information regarding physical activity in school but also that these issues must be considered in the persons social and professional life at all ages.
Factors such as medication, symptoms and comorbidity, were identified in the univariate model as associated with the physical activity level. However, these variables did not prove important in the multivariate analysis (paper I). This is of interest since these variables were described in our qualitative studies to be barriers for physical activity (paper IV). One explanation might be that medication, symptoms and comorbidity on an individual level are important while in the context of other variables, the importance decreases. Furthermore, it is well known that on a group level the complexity of the heart lesion is associated with lower aerobic capacity (73). In contrast, in our studies, and also shown by others (119, 120) the severity of the cardiac lesion per se did not appear to be of importance for the physical activity level. Our interpretation is that this reflects the variation of physical capacity (73) within a specific diagnosis group.

Although adults with CHD have been palliated or corrected surgically, they are not cured and therefore in need of life-long medical follow-up care. Many may also need further interventions later in life. Some of the participants described a fear of losing health due to their underlying CHD, and they were aware of the importance of preventing their physical condition from deteriorating. Prevention of acquired cardiovascular disease is intuitively necessary, although not yet implemented in treatment guidelines regarding adult patients with CHD. The knowledge from this thesis may help healthcare professionals to support adults with CHD to adopt a healthy lifestyle, regarding physical activity. One clinical implication could be to develop an intervention program with multidisciplinary health care providers to decrease the risk for acquired cardiovascular disease and to retain health.

**Framework for transition into clinical practice**

The results will be compared against components in the Health Beliefs Model (figure 4), in order to confirm the model as relevant for adults with CHD. The model can then be an inspiring framework for an intervention.

**The Health Beliefs Model**

The Health Beliefs Model was constructed in the early 1950’s in an attempt to investigate the knowledge and changes in attitude necessary for people to be able to change their health behaviour, through for example information campaigns. Later on, the model was applied on patients’ response towards symptoms and compliance with prescribed medical treatment (121).
The Health Belief Model’s construction described by Champion & Skinner, 2008 (122);

- **Perceived Susceptibility** - describes the subjective perception of the risk of getting a disease or condition.
- **Perceived Severity** – describes the feelings concerning the severity of the perceived threat.
- **Perceived Benefits** – describes that even if a person perceives a threat to a serious condition/illness, their behaviour is affected to change the health problem if the person perceive the benefits of the various actions.
- **Perceived Barriers** – describes the potential negative aspects of changing behaviour, which the person weighs the expected benefits against.
- **Cues to action** – describes the triggers that possibly can start a behavioural change.
- **Self-Efficacy** – describes the individual’s confidence in their own ability to implement changes.
- **Other Variables** – examples are age, gender, ethnicity, personality, socioeconomics and knowledge.

The likelihood that a person will change their health behaviour depends largely on two factors; if the person experiences a threat to their health or if the perceived cost-effectiveness is high. The perceived threat depends on how high they estimate their risk of illness and how serious the illness is. The perceived cost-efficiency is based on the extent to which it is believed that the change in health behaviour may counteract the risk for disease. In addition, the benefits for changing health behaviour must exceed the barriers to performing the change in health behaviour (123, 124). Self-efficacy *i.e.*, an entity that describes the individual’s confidence in their own ability to implement tasks, was added to the model in the 1980’s (125). The Health Belief Model has been used in interventions in different diseases. For example; in a study including patients with chronic obstructive pulmonary disease, the aim was to enhance the patients’ health belief and self-efficacy in the treatment. The result showed that the participants scored better on both the health belief scale and self-efficacy scale after the intervention (126). The Health Belief Model was also used in another recent study on preventing skin cancer among Iranian farmers through education in protective behaviours (127). Likewise, there were positive results, where the participants increased their preventive behaviours against skin cancer (127). Carpenter (2010) (124) made a meta-analysis of the effectiveness of the Health Belief Model. The summary was that the severity, benefits and barriers of the model’s variables seem to predict behaviour better in prevention of a negative health condition, than what compliance to a treatment program for an existing
condition/illness does (124). To the best of our knowledge, no nurse-led intervention programs regarding health behaviours in adult with CHD have been evaluated or implemented.

The findings of this thesis are discussed below in relation to the components in the Health Belief Model as described above. The Roman numerals represent papers in the thesis.

**Demographic variables & psychological characteristics** - In papers I & II, the demographic variable “age” was associated with both physical activity level and exercise self-efficacy. Other variables, such as personality and knowledge that were studied and interpreted in the qualitative studies, likely affect the adult with CHD’s perception and therefore influence health-related behaviour.

**Susceptibility/Seriousness** – In paper III we show that adults with CHD are aware that they are not cured and some described that there is a risk of not being able to maintain health.

**Perceived threat** - In paper III, the participants describe a fear of losing health due to the heart disease. This means that the fear of losing health includes both medical consequences and potential effects on work, family life and social relations.

The perceived barriers vs. perceived benefits - Paper III & IV, show how adults with CHD describe themselves as physically active (paper III) and clarifies what kind of barriers and
enabling factors they experience for being physically active (paper IV). Although most of the adults with CHD expressed that they know that increased physical activity is good for their health (paper III), the perceptions of benefits must exceed the barriers to perform the activity (123).

Cues to action- All papers in the thesis included this aspect. Different triggers might start the activity. In paper IV it was described that information and education from healthcare professionals, to the patients, parents, peers and teachers were of importance for being physically active. The increased knowledge may lead to increased encouragement for children to be physically active, which later in life enables physical activity as an adult. As described in paper III, some expressed that they always were aware of the disease. Their understanding of their condition and the importance of maintaining health may trigger an increased level of physical activity. In addition, individual counselling on appropriate physical activities and continued follow-ups by a multidisciplinary team may also be a factor that affects the level of physical activity.

Self-efficacy- Papers II, III and IV shows that the ability to be physically active is affected by the participants’ self-efficacy to perform exercise. As shown in paper II, exercise self-efficacy was affected by medical factors, such as complexity and NYHA class in the univariate model, but in the final multivariate model only by muscle endurance capacity and age. Furthermore, being a “non-doer” (paper III) with little interest or capacity for being physical active, is probably associated with low self-efficacy. This is at least partly due to limited experience of physical activity. In paper IV, further psychosocial factors, exemplified by overprotection and lack of understanding, were described and are likely to influence self-efficacy. My interpretation of data from this thesis is that self-efficacy may trigger cues to action. However, this interpretation is entirely my own and is not a part of the original model of Health Belief Model.

Likelihood of engaging in health-promoting behaviour- Even if the research projects included in this thesis were not initially created to fit the Health Belief Model, the components seem to correspond to our findings in the different papers. Therefore, the model is suggested to be relevant for the population of adults with CHD. Based on the knowledge from our studies and inspiration from the different components in the Health Belief Model, there may be an opportunity to create intervention programs that enhance a health-promoting behaviour.
Draft of an intervention program for promotion of increased healthy behaviours in adults with CHD:

The aim of the study will be to investigate if the participants increase their healthy behaviours. The suggested study design is a randomised controlled trial, with one intervention group and one control group. The investigators and participants will not be blinded for the intervention.

The participants in the intervention group will have an ordinary follow-up by their physician and in addition, receive a 30 minute nurse-led visit at the clinic that entails talking about health behaviours. The controls will have an ordinary follow-up by their physician. Follow-ups in the interventions group will occur at 1 month, 3 months by telephone or mail, and finally at 6 months with a clinical follow-up and appropriate questionnaires.

The controls will only receive the questionnaires by surface mail with prepaid return envelopes and then will have their scheduled follow-up with the physician.

1. Demographic variables and psychological characteristics will be collected from the patient, medical records and SWEDCON register.
2. Before the visit, or in connection with the visit, the participants will fill in the questionnaires.
3. Based on susceptibility and seriousness examine how the participants perceive the threat of decreasing health. What do they know about their heart disease, condition, long-terms complications etc?
4. Question will be posed about their individual enablers and barriers in order to enhance healthy behaviour.
5. Investigate their self-efficacy in managing healthy behaviours through conversations and also by using appropriated questionnaires.
6. Ask about what kind of triggers that may help them to come to cue to action. Individual advice concerning the health-related behaviour they want to change.
7. Have scheduled follow-ups, by telephone or mail, and finally a visit at the clinic after 6 months.
Methodological discussion

Using a mix of methods, quantitative and qualitative, made it possible to answer the research questions and to view the findings from different perspectives. This leads to more comprehensive knowledge about the phenomenon studied (92, 128, 129), i.e. physical activity when living with CHD. The advantage of using interviews, in addition to quantitative methods, provided a deeper and more detailed story about the experience of being physically active in this population.

For the cross-sectional design in papers I and II, data from SWEDCON were used and provided a unique prospect to identify patients eligible for participating in our research. APPROACH-IS is a multicentre study, with collaboration of 15 countries from 5 continents. In total 4028 adults with CHD participated. For the Swedish part in APPROACH-IS (paper I) 912 patients were eligible and 471 participated (130). The low response rate is a potential problem, however, the response rate in paper I where more than 54 % completed questionnaires is comparable with similar studies (131-133).

As a part of the Swedish branch of APPROACH-IS, nonresponse analysis was possible in post hoc evaluation using data from SWEDCON (130). Since all patients in the Swedish branch of APPROACH-IS were selected from the quality register of SWEDCON, it was possible to identify those who did not participate. Thus, participants could be compared with non-participants regarding several variables. The conclusion was that participants and non-participants were relatively comparable groups and participants from the Swedish branch of APPROACH-IS could be seen as representative for the SWEDCON population (130).

Nonresponse analysis in paper II, was made in a post hoc analysis (23). The aim was to compare the participating patients, with those who declined participation or did not appear at clinical visit. In this analysis, no differences in age, sex or complexity of the lesion appeared (23). The sample size in paper II may appear relatively small but considering the unique population of adults with CHD and the use of questionnaires, muscle endurance tests and physical activity monitoring, our sample size is comparable to other studies in similar populations.

In paper I and in part of paper II, self-reported outcomes were used. There is always a risk of individual over- and underestimation of variables (134). Peripheral muscle function is an important contributing factor to the aerobic capacity. In paper II we used a muscle endurance test consisting of shoulder flexions and heel lift that was originally validated on patients with heart failure (101). Furthermore, these tests are not reliant on advanced equipment and were
performed in the clinic during participants’ visits. The tests have also been used in adults with CHD, by others (74) and are currently common routine during visit at the out-patient clinic. To objective measure physical activity, a wearable heart rate monitor was used, (Actiheart, CamNTech Ltd, Cambridge, UK) (102). To assess physical activity by sole use the heart rate might be misleading due to influences by other factors e.g. temperature, emotional state and caffeine consumption. However, research shows that heart rate increases linearly with the intensity of the activity (135). The advantage with our method is that it combines heart rate with data from the accelerometer. Thus, both increase in heart rate and in movement are required to record physical activity.

In papers III and IV, 24 patients were asked for participation and 14 accepted. The interviews were performed at the clinic, using a semi-structured interview guide with open-ended questions and at time clarifying questions (95). As a RN with experience of adults with CHD my pre-understanding and my experience of the context might have influenced the interviews and also the interpretation of the text (95). My pre-understanding may also have been helpful during the interview, to open up participants’ narratives concerning physical activity and to provide relevant follow-up questions. I strived to have a familiar and curious approach during the interviews, and to let the participants’ develop their answers. The participants were interviewed on one occasion, but the interview guide had two directions for research questions; 1. Relations to physical activity and 2. Enablers and barriers to being physically active. Qualitative content analysis was used in both papers with the intention to describe and to achieve trustworthiness. To achieve trustworthiness some concepts must be discussed i.e. credibility, dependability and transferability (103, 104). To achieve credibility and transferability, the recruitment of the participants was designed to maximise the variability of demographic characteristics (104, 136). The sample size or number of interviews is not possible to suggest, instead it is important that the data are rich and correspond to the aims (137). In both papers quotations from the narratives were used to strengthen the credibility (138). To ensure that dependability was reached, several researchers, from various professions and with varying knowledge about the specific study group, were involved in the analysis process, in discussing codes, categories, subthemes and themes (103). Furthermore, a text cannot be reduced to only one meaning (139)and the interpretation of the data in this thesis illustrates the most probable interpretation of the experiences of being physically active as an adult and living with CHD. It is up to the reader to decide whether or not the findings are transferable to other contexts (103, 104).
CONCLUSION AND CLINICAL IMPLICATIONS

Adults with CHD seem to have a diverse relationship to physical activity, and this involves various aspects throughout the lifespan. Age, social support and accepting physical limitations appear to have important impacts on physical activity level and exercise self-efficacy. In contrast, the complexity of CHD and other medical factors appear to be of less importance for adults with CHD in relation to physical activity. In order to support adults with CHD to increase their physical activity and reach their full potential, it is important to explore and consider the various aspects that may affect physical activity in this population. By comparing results in this thesis with components in the Health Belief Model, the model was considered as relevant for the study population. The Health Belief Model is thereby suggested to be useful as a framework for future prevention program for adults with CHD.

With a multidisciplinary approach, and by including adults with CHD in the team, individualized support for increasing the physical activity level, and in the long-term hopefully decrease the risk for developing acquired cardiovascular diseases may be reached.

Another possible clinical implication may be to increase the knowledge of this patient group in nursing education and in specialist education, e.g. cardiology nurses, paediatric nurses and district nurses.
FURTHER RESEARCH

The work with this thesis has given inspiration for further investigations. (1) First of all the suggested implementation of an intervention based on the Health Belief Model is planned. (2) Furthermore aging is an important variable in relation to physical activity level. Since the population of adults with CHD is becoming older, with a current median age of 39 years, there is a challenge to tackle their needs in the future. The effect of aging in this population requires careful attention and follow-up studies. (3) In this thesis, the interviews were only with adults with complex CHD, further research should also include adults with simple and moderate CHD, to gain more knowledge about how they experience physical activity.
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APPENDIX

The interview guide.

Intervjuguide

- Vad är fysisk aktivitet för dig?
- Kan du berätta om vad du gör när du är fysisk aktiv?
- Kan du berätta om hur du upplever det att vara fysiskt aktiv?
- Kan du berätta om en situation när du har tyckt att det varit positivt att vara fysisk aktiv:
  - Jag undrar också på vilket sätt du upplevde att det var positivt?
  - Vad tänkte du då?
  - Vad kände du då?
- Berätta om en situation när du upplevde det besvärligt att vara fysiskt aktiv:
  - På vilket sätt upplevde du att det var besvärligt/negativt?
  - Vad tänkte du då?
  - Vad kände du då?
  - Vad gjorde du då när du ändå fortsatte fast du upplevde att det var besvärligt?
  - Övervann?
  - Vad är det som gjorde att du gav upp?
  - Hur kände du då när du kände att du inte orkade?
  - Hur tänkte du?
- Vill du vara fysiskt aktiv? Varför/varför inte?
- Vad är det som gör att du är fysisk aktiv?
  - Plikt
  - Lust ”gruppträck”
- Vad ser du för vinst av att vara fysiskt aktiv?
- Hur var det när du var barn? Var du fysiskt aktiv?
- Kunde/fick du vara fysiskt aktiv?
- Ser du något hinder med att vara fysiskt aktiv?
- Kan du berätta om vad som möjliggör/motiverar dig?
- Behöver du någon hjälp/ något stöd i att förändra din fysiska aktivitet? I så fall vilken/vilket?
- Använder du några tekniska hjälpmedel, såsom mobil applikationer eller dylikt?