

“I choose not to worry anymore”:
how children with a congenital heart disease
and their parents experience participation
in physical activity

Master thesis

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"ONDERGETEKENDE

Geertruida Nympha Marjam van der Feen

bevestigt hierbij dat de onderhavige verhandeling mag worden geraadpleegd en vrij mag worden gefotokopieerd. Bij het citeren moet steeds de titel en de auteur van de verhandeling worden vermeld."

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ABSTRACT

Background and aim

Research has highlighted the benefits of regular physical activity for children with a congenital heart disease. These health benefits are within reach for nearly all of these children. However, various studies have reported low physical activity levels among this group. Research has identified no differences in physical activity based on the severity of the heart disease, which suggests that other factors may be influential. Little is known about how these children perceive physical activity, and their perceptions could differ from those of their healthy peers. Therefore, the objective of this study is 1) to explore facilitators and barriers to participation in physical activity as experienced by children with a congenital heart disease and their parents, and 2) to identify these factors in order to propose future research and inform clinical practice to enhance participation in physical activity in this unique population.

Methods

This study employs an exploratory qualitative design that involves an inductive thematic analysis.

Results

Eighteen semi-structured interviews were conducted with children with a congenital heart disease and their parents. Three boys, four girls, three fathers and eight mothers were interviewed. The children were aged between 8 and 18 years, with a variety of complex congenital heart diseases and recruited from a children's hospital in the Netherlands. Four explicit themes were derived: 'normal child', 'child as patient', 'child imposes his own physical activity restrictions' and 'non-specific'. In addition, two interpretative themes were developed: 'normalisation' and 'take child into consideration'.

Conclusion, clinical relevance and future research

The present study contributes to our knowledge of facilitators and barriers to participation in physical activity as experienced by children with a congenital heart disease and their parents. The findings highlight needs for recommendations that are written in accessible language as well as early referral of these children to paediatric physiotherapy. Future research could be conducted to determine the effectiveness of early referral to paediatric physiotherapy on participation in physical activity. Future studies could focus on the relationship between comorbidity and physical activity, the relationship between sleep and physical activity and the relationship between distress tolerance and physical activity.

Keywords: congenital heart disease, exercise, child, adolescent, parents

INTRODUCTION

Congenital heart disease (CHD) is a common birth defect. Approximately 9 in 1,000 children are born with CHD each year.¹ Congenital heart disease can range from mild lesions that spontaneously resolve to severe and complex defects that eventually require expert cardiologic care and surgical correction. Signs and symptoms depend on the specific type of problem. Nowadays, improvements in paediatric cardiology, corrective cardiac surgery and medical management allow most children with CHD to reach adulthood.²

Research has highlighted the benefits of regular physical activity for children with CHD.³⁻⁹ Physical activity is defined as 'any bodily movement produced by skeletal muscles that results in energy expenditure'.¹⁰ In current study, physical activity consists of activities of daily life, such as active transport or active play, and participation in leisure or competitive sports. Physical activity can improve cardiopulmonary fitness, muscle strength, exercise tolerance and quality of life.¹¹⁻¹³ Regular physical activity at a recommended level can be performed at all ages by nearly all patients with CHD.^{8, 14-19} The health benefits of a physically active lifestyle are within reach for nearly all children with CHD, including those with surgically corrected CHD. Many of these children have no medical restrictions to physical activity.

However, various studies have reported low physical activity levels among this group.²⁰⁻²³ The reduced physical activity levels among children with CHD are often independent of exercise capacity, which indicates that physical inactivity is likely due to inactive behaviour.^{21, 22} Research has identified no differences in physical activity based on CHD severity, which suggests that other factors may be influential.^{20, 24} There are also no differences between children with and without a disability in terms of fulfilling the recommended daily amount of physical activity.^{20, 23, 25, 26} Children with CHD and their healthy peers are equally inactive, and both groups often fail to meet physical activity guidelines for public health. Little is known about how children with CHD perceive physical activity. The facilitators and barriers that they experience could differ from those of their healthy peers. Research has highlighted parental overprotection, psychosocial factors, the child's self-efficacy, recommendations from cardiologists and unnecessary restrictions to physical activities as factors that may influence the degree of participation in physical activity by children with CHD.^{13, 27-31} Qualitative research can increase insight into these possible factors.³² However, to date, little qualitative research has investigated this topic and few studies have directly accessed the views of children.³³⁻³⁵ Moreover, given that parents play an important role in the lives of their children, it is imperative to consider their perspectives as well.

Previous studies have examined several facilitators and barriers to participation in physical activity as experienced by children with chronic childhood conditions such as cystic fibrosis, spina bifida and cerebral palsy.³⁶⁻³⁹ However, it is unknown if these facilitators and barriers are the same among children with CHD, as no study has yet identified these factors in this population. The complex needs of this unique population demand research on this topic to

inform clinical practice and, in turn, improve participation in physical activity.^{32, 40, 41} Therefore, the objective of this study is 1) to explore facilitators and barriers to participation in physical activity as experienced by children with CHD and their parents, and 2) to identify these factors in order to propose future research and inform clinical practice to enhance participation in physical activity in this unique population.

MATERIALS AND METHODS

Design and data collection

This study employs an exploratory qualitative design that involves an inductive thematic analysis.^{42, 43} Thematic analysis is a method for identifying and analysing themes within data. In an inductive approach, the themes strongly link to the data themselves; it is a process of coding the data without trying to fit them into a preexisting framework or theory. The data for this study stems from interviews with children with CHD and their parents. The data were collected through an iterative process of sampling, interviewing and analysis based on constant comparison until saturation was achieved. Saturation occurs once the addition of more participants to a study does not result in new perspectives, novel themes or differences in the results of the analysis.⁴⁴

A single semi-structured interview with open-ended questions was performed with each participant. The first author conducted all interviews. She is an experienced and trained interviewer who works as a physiotherapist but was not involved in the patient care of the participants. Open-ended questions were posed to allow participants to express their experiences in their own words. The first author also designed the semi-structured interview schedule based on the literature (Appendix 1).^{33-35, 39} Questions were phrased in general terms and were not strictly followed, and further questions emerged from the dialogue between the interviewer and interviewee.⁴⁵ The interviews were held in the hospital or in the participant's home. Five children requested that their parents accompanied them during the interview. Eight parents were interviewed without the presence of their children. All interviews were audio recorded, and field notes with contextual details were compiled. Interviews were conducted in Dutch, which is the native language of both the interviewer and the interviewees. The data collection took place between February and April of 2018.

Participants

In order to gather rich, relevant and diverse data and explore all possible factors, this study employed purposive, maximum variation sampling.⁴⁶ Male and female children between the ages of 8 and 18 years who have any of a variety of CHD and underwent corrective cardiac surgery within the first six years of their life were recruited. Also the parents of such children were recruited.⁴⁷ Children, parents or both could participate in this study. The participants were sampled from a children's hospital in the Netherlands. To request participation, the first author called eligible participants. An informational letter and request for informed consent

were sent via e-mail. If they agreed to participate, subjects filled out a statement of informed consent. The Medical Research Ethics Committee (MREC) of the Utrecht Medical Center has declared in their letter of 08 November 2017 (reference number WAG/mb/17/033764) that the Medical Research Involving Human Subjects Act (WMO) does not apply to this study and that therefore an official approval of this study by the MREC UMC Utrecht is not required under the WMO. The study was conducted according to the principles of the Declaration of Helsinki (WMA, version 64, 2013).

Data analysis

The data analysis followed the six phases of thematic analysis by Braun and Clarke (Table 1).⁴² This iterative process involved reading and re-reading the data and coding fragments to yield potential themes and a thematic map. This process was repeated until the themes reached a point of saturation. Finally, key themes with corresponding representative quotations were identified on an explicit level to describe the data and reveal patterns as well as on an interpretative level to identify the underlying ideas, assumptions and conceptualisations in an attempt to theorise the significance of the patterns and their broader meanings and implications.⁴² The themes were classified under two dimensions: facilitators and barriers to participation in physical activity. A theme was classified as a facilitator if participants believed that it encouraged their participation and as a barrier if participants expressed that it hindered or prevented their participation. NVivo Pro software was used for the analysis of the data.⁴⁸

Trustworthiness

To enhance trustworthiness and rigour, participant recruitment was designed to maximise the variability in age and gender and the variation in CHD. Sampling included both children and parents. Furthermore, a peer review process was integrated throughout the analysis process to enhance the reliability of the data. The peer review group consisted of 12 last year master's degree students in clinical health sciences and a supervisor. Representative quotations from the transcribed interviews were selected to strengthen the credibility, and software was utilised to enhance transparency. The 'Consolidated criteria for reporting qualitative studies' (COREQ) were followed to produce the report.⁴⁹

Table 1.
Phases of thematic analysis

Phase	Description of the process
1. Familiarising with the data	Transcribing the data, reading and re-reading the data, noting initial ideas ¹
2. Generating initial codes	Coding interesting features across the entire data set, collating data relevant to each code ¹
3. Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme ^{1,2,3}
4. Reviewing themes	Checking if themes work in relation to coded extracts and the entire data set, generating a thematic map ^{1,2}
5. Defining and naming themes	Ongoing analysis to refine the specifics of each theme, generating clear definitions and names for each theme ^{1,2,3}
6. Producing the report	The final opportunity for analysis by producing a scholarly report of the analysis ¹

Note. Adapted from "Using thematic analysis in psychology," by Braun and Clark, 2006. ¹First author ²Peer review group ³Sample checked by second reviewer

RESULTS

Baseline characteristics

A total of 13 parents were asked to participate in this study, and 11 accepted the invitation. Of the two who declined, one was not interested, and the other one was ill during the appointment. Seven children of these parents were requested to take part, and all seven accepted. The total sample of 18 participants was sufficient to attain saturation in the data and adequately reflect experiences regarding participation in physical activity among this specific population. Table 2 provides the participant characteristics. The interviews ranged from 6 to 37 minutes, with an average duration of 20 minutes.

Table 2.
Characteristics of the children and parents

	Children (n=7)	Parents (n=11)
Age (year)	Mean 14 (range 11-17)	Mean 45 (range 36-52)
Age of their children (year)		Mean 12 (range 8-17)
Sex (M/F)	3/4	3/8
Diagnoses		
TOF	1	
TGA	2	
ccTGA	2	
CoA	1	
F	5	

M = Male, TOF = Tetralogy of Fallot, TGA = Transposition of the great arteries, cc = congenitally corrected, CoA = Coarctation of the aorta, F = Fontan procedure

Themes

Four themes were identified on an explicit level: 'normal child', 'child as patient', 'child imposes his or her own physical activity restrictions' and 'non-specific'. Two themes were identified on an interpretative level: 'normalisation' and 'take child into consideration'. The themes are presented with representative quotations to illustrate them (in the text and Appendix 2; P = parent and C = child). Figure 1 shows the visual representation of interrelationship between themes.

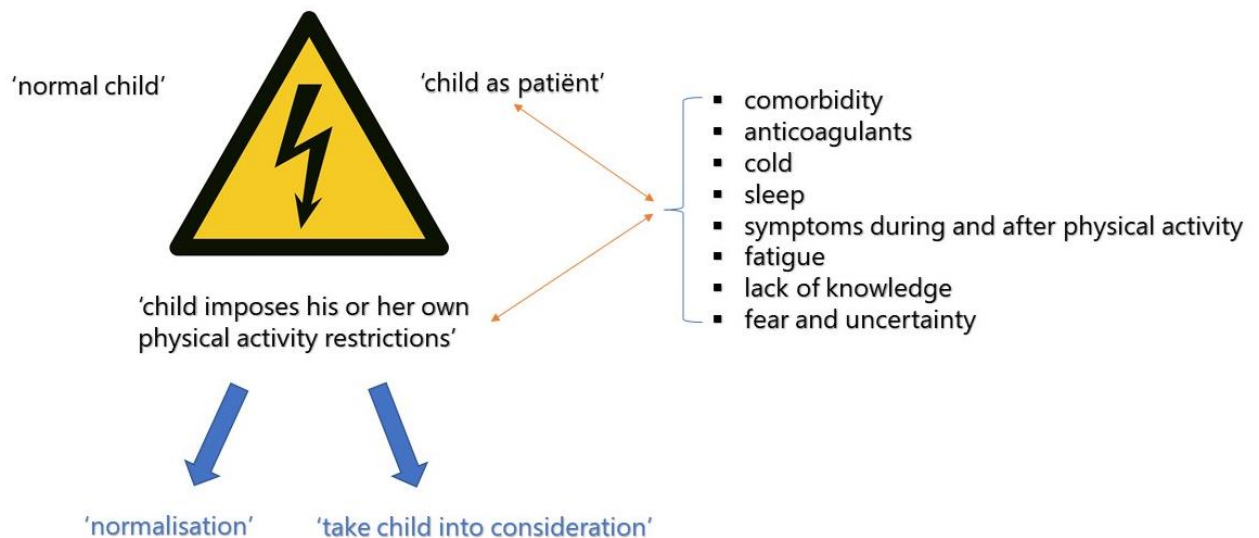


Figure 1. Visual representation of interrelationship between themes

'Normal child'

Almost all parents focused on thinking of their children as normal.

P1: 'My daughter is no different than my other children'.

The child thinks of himself as normal or wants to be normal. Family, friends and other people also view the child as normal.

P7: 'People see a normal child'.

Parents and children are fine with the way the child participates in physical activity. Even though everyone aims to view the child as 'normal', there is tension between the norm and the problems due to CHD that the child experiences.

P10: 'I just want a normal child, but I have a child with a disability'.

'Child as patient'

Both children and parents described the children as patients with several health problems and limitations due to CHD. The following subthemes were apparent.

Comorbidity

Non-cardiac comorbidity can be barrier to participation in physical activity. The participants in this study mentioned brain damage as well as psychological and psychiatric problems.

Contact limitations when on anticoagulants

Many children with CHD must take anticoagulants and may consequently need to limit certain physical activities in order to reduce the chance of injury. Contact limitations when on anticoagulants are a strong barrier.

Cold

Parents and children mentioned problems with staying warm in cold water or cold temperatures. Cold weather and cold water can be barriers to outdoor activities and swimming because of the difficulty of the child to stay warm.

Sleep

Sleep was highlighted as an important factor to function properly and participate in physical activity.

Symptoms during and after physical activity

Various symptoms hindered the children during and after physical activities. These disease factors are significant barriers. The parents and children mentioned fatigue, palpitations, blue or purple lips and fingers, turning white and gray, breathlessness and pain during physical activity. They also reported sore legs and exhaustion after physical activity.

C2: 'I got a lot of stitches and stuffy feeling that I really...kind of...I always describe it as if some kind of knives went into my chest and...yes, and that really got squeezed into it. I got very stuffy. I was very tired and I could not breathe properly. Then I stopped with playing football. That is just the limit. Really. I didn't want that pain every game and every training session'.

Fatigue

Every participant cited fatigue as a clear barrier to participation in physical activity. It was also mentioned in the previous subtheme. However, fatigue can be a complicated symptom. For example, it is often unclear whether the fatigue derives from the heart defect or from psychological problems, poor sleep or excessive deconditioning due to inactivity. It could also be laziness rather than fatigue or simply an aspect of adolescent behaviour.

P9: 'It is a bit complicated. At the age they become teenagers, they become a bit lazy. And gaming is easier than exercising...'

Lack of knowledge

Children and parents noted a lack of understanding of both the cardiac condition and the consequences of participating in physical activities. This knowledge gap is a clear barrier.

C18: 'I want to, but I do not know how to become more physically fit'.

Insufficient knowledge among sports coaches and teachers at school can also present a barrier, as the child is limited in whether he or she can participate or continue to engage in the activity. Parents and children reported a scarcity of information regarding participation in physical activity.

Fear and uncertainty

Fear and uncertainty comprise another major theme. Parents mentioned a fear of cardiac calamities or death in the past – especially during the period of the operation – but admitted that they also experience it in the present.

P10: 'Well, fingers crossed...We just enjoy the time we have with her. Maybe she will be 60 years old, we do not know that. But she also feels our fear, the fear of death. She does feel that'.

Fear was also a significant theme among the children, who referenced fear of having a heart attack, overexertion during physical activities, and death. Uncertainty about restricting physical activity was also a prominent theme. For example, both children and parents were uncertain of how much exercise is safe and how much is dangerous.

P9: 'How much can he handle? I don't know. I think it's pretty scary'.

Occasionally, parents, trainers and teachers are protective and restrict the child. Overprotection seems more common in trainers and teachers than in parents.

'Child imposes his or her own physical activity restrictions'

Both parents and children do see a need for physical activity restrictions but believe that these restrictions should be determined by the children themselves. They should be internally imposed ones.

C8: 'I just go as far as I can. I do everything. And if it doesn't work, that's just the way it is...'

The parents noted that the children were capable of determining when to stop engaging in physical activity. When asked to describe how they decided this, the children mentioned a strange feeling or heavy breathing, fatigue and a fast heartbeat. However, parents prompted the question of whether children are capable of knowing when to stop.

P9: 'If he feels his breathing, he stops. We think that he can do more. But we do not know if he can do more'.

In this regard, the children reported that they would use the condition as an excuse or explain that they must respect their own limitations in accordance with their doctors' instructions.

Another child shared that the doctor had told her that it was safe to exercise while experiencing palpitations, but she would still stop because 'her body felt like she had to stop'. It is an immense responsibility for these children to cope with the uncertain and ambiguous limitations of their bodies.

'Non-specific'

This study also identified facilitators and barriers non-specific for children with CHD. For instance, the role of parents seems to be crucial and can be encouraging or more passive in nature. Parents can be role models. Physical activities together with family or friends can be facilitators, as can the child's internal drive to move and be physical active. A perceived or real lack of time and financial resources can be a barrier. In addition, screen time was mentioned as an important barrier. Physical activities as habits and social events can be facilitating, and respondents mentioned active transport, such as biking, in many interviews.

'Normalisation'

On an interpretative level, the theme of 'normalization' emerged. Almost all parents emphasised that they think of their children as normal. This perspective is beneficial since it is intensely draining to constantly worry about life-threatening cardiac problems. The parents and children have to live with fear and uncertainty, and one coping method is to view their children or themselves, respectively, as normal. The parents explained that they had to adopt this survival strategy in order to have normal lives. One mother articulated her struggle to view and treat her child as a normal child:

P9: 'It was a very conscious choice – in the first place, for him, but it is also survival for yourself'.

Parents appeared to employ a strategy of normalisation as second nature. They tried to reconcile the discrepancy between their 'normal' children and their children as patients, and some were not aware of the inherent contradiction.

P16: 'My child has no physical limitations. But she is a heart child, of course, so she must be careful with physical activity that is simply not possible with her heart'.

P4: 'I see her as normal. But I keep an eye on her, of course. The fear remains'.

Despite recognising the limitations to participation in physical activities, parents and children were accepting the amount of physical activity and normalised the situation. Consequently, children and parents can struggle to determine if they or their children require help, advice or guidance.

'Take child into consideration'

Although the children were considered normal and were permitted to establish their own boundaries in physical activities, the interviews suggested that the whole environment takes the children into account. Such consideration can be a barrier to participation in physical activity.

P9: 'We often think he can do more physically, but his environment treats him as a patient, much more than we do'.

Parents take the child into account to protect him or her from discomfort and frustration.

P13: 'I don't want her to join organised sport because then she continuously runs against her physical limit. Do you have to confront them with it every week?'

The parents also noted that teachers and coaches would be cautious with the children. This behaviour could be due to fear or a lack of knowledge.

P9: 'I said to his trainer once, you know, if you take him out so often, I do not think he likes to play football anymore'.

This way of addressing the child and his physical challenges prevented the child from learning to cope with his limitations and building distress tolerance.

DISCUSSION

The present study explores and analyses facilitators and barriers to participation in physical activity as experienced by children with CHD and their parents. Besides non-specific factors, they experience facilitators and barriers that are unique to this population. The study identifies challenges regarding comorbidity, anticoagulants, cold weather and water, sleep, symptoms during and after physical activity, fatigue, a lack of knowledge of the cardiac condition and the consequences of participating in physical activities, and coping with fear and uncertainty. Two themes are developed on an interpretative level to identify the underlying ideas, assumptions and conceptualisations, namely normalisation and taking the child into consideration.

Regular physical activity for children with CHD is vital to improving their health. The results of this study lead to several opportunities to propose future research and inform clinical practice to enhance participation in regular physical activity. The relationship between comorbidity and physical activity could be a topic for future research.⁵⁰ The importance of sleep and the relationship between sleep and physical activity needs further investigation.⁵¹ The various symptoms that hindered the children during and after physical activity are often inevitable. However, it is important that the children learn to cope with these symptoms and learn to manage fear and uncertainty. The interview data reveal that the children were expected to impose their own physical activity restrictions. However, they do not know how to do this or on what basis, so they are overly cautious or cite their CHD as an excuse. The findings suggest that parents and children use normalisation as a coping style. However, due to this coping style it can be difficult to determine if they or their children need help, advice or guidance on physical activity. Furthermore, because of the approach of taking the child

into consideration, the children do not learn to cope with the uncertain and ambiguous limitations of their body and cannot build distress tolerance.

In concordance with the present study, two recent studies have identified fear of cardiac calamities or death as a major barrier to physical activity.^{52, 53} Need for written physical-activity-related resources that employ specific yet easy-to-understand language was also identified.⁵² Despite the numerous existing recommendations regarding physical activity and training in paediatric patients with CHD, the present study emphasises this need.^{4, 6, 7, 14-17, 40, 54-56} Apparently, rules and practice recommendations exist, but children and their parents are not aware of these guidelines or they are not easy to understand. Research has mentioned parental overprotection as a major barrier to participation in physical activity.²⁹⁻³¹ However, the findings of the current study do not support this. Our findings suggest that other people such as teachers and coaches are more cautious with the children and thereby overprotective.

To implement the research findings in clinical practice, it is important to have recommendations for children, parents, teachers and coaches that are written in accessible language. Apparently, the existence of recommendations in scientific journals or the advice from paediatric cardiologists to be more physically active is not enough to improve participation in physical activity. Early referral by paediatric cardiologists to paediatric physiotherapy is needed. Paediatric physiotherapists are optimally positioned to instruct these children to cope with the uncertain and ambiguous limitations of their bodies. They can teach the children during physical activity what it is like to exert physical effort, and what is possible and allowed. The children will have more knowledge and will build distress tolerance. Further research could be conducted to determine the effectiveness of early referral to paediatric physiotherapy on participation in physical activity. In view of the outcome of the present study, future research on the relationship between physical activity and distress tolerance of children with CHD and their parents would be interesting. Poor distress tolerance may increase the likelihood of avoidance, which may include avoidance of physical activity.

The results must be interpreted in view of certain limitations of the study. Since cultural context varies by country, the experiences of children and parents who participated in this study may differ from those of families who live in other countries. In addition, the study included participants from only one hospital, which may give a skewed result. However, the participant recruitment was designed to maximise the variability in age and gender and the variation in CHD, and it sampled both children and parents.

Conclusion

The present study contributes to our knowledge of facilitators and barriers to participation in physical activity as experienced by children with CHD and their parents. These findings highlight needs for recommendations that are written in accessible language as well as early

referral of these children to paediatric physiotherapy. Future research could be conducted to determine the effectiveness of early referral to paediatric physiotherapy on participation in physical activity. Future studies could also focus on the relationship between comorbidity and physical activity, the relationship between sleep and physical activity and the relationship between distress tolerance and physical activity.

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APPENDIX 1 Semi-structured interview schedule

Interview with child

Current behaviour regarding physical activity

- Can you tell me how active you are?
- What kind of physical activities do you perform (for example, playing outside, playing in the schoolyard, gym, cycling, swimming, leisure or competitive sports)?
- Can you describe your experiences with physical activities and sports?
- Do you enjoy physical activity? Why or why not?

Facilitators

- Would you like to be more physical active?
- Which facilitators do you experience regarding physical activity?
- Can you describe an example from your own experience?
- Which solutions are available to become more physically active?

Barriers

- Can you describe what makes you less physically active?
- Which barriers to physical activity do you experience?
- Can you describe an example from your own experience?

Interview with parent

Current behaviour regarding physical activity

- Can you tell me something about the physical activities of your child?
- What kind of physical activities does he or she perform (for example, playing outside, playing in the schoolyard, gym, cycling, swimming, leisure or competitive sports)?
- Could you describe your experiences regarding the physical activities of your child?
- Do you think your child likes physical activity?
- Do you think it is important for your child to be physical active?
- Do exercise and sports play a role in your family?

Facilitators

- Would you like your child to be more physically active?
- What facilitates your child to be more physically active?
- What could help your child to be more physically active?
- Can you describe an example from your own experience?
- What could you do yourself to make your child more physically active?

Barriers

- Can you describe what makes your child less physically active?
- Which barriers to physical activity do you or your child experience?
- Can you describe an example from your own experience?

APPENDIX 2 Representative quotations per theme

'Normal child'

Parents think of their child as normal.

P11: 'I did not want to give her a special treatment'.

P13: 'Just like a normal child. Just as normal as possible'.

P16: 'She is not limited in anything. She just functions as a normal child'.

The child thinks of him or herself as normal or desires to be normal.

C3: 'I hardly think about it'.

C2: 'It is just naturally. I am normal. You really do not see anything on the outside – only if I am wearing a bikini'.

P11: 'She wants to be normal. She wants to do everything'.

Others view the child as normal.

P4: 'She is a normal child. Other people look at her as normal'.

There is tension between being normal and being a patient.

P11: 'She is normal, but she is also limited by her heart defect. She really can't do everything, even if she wants to'.

'Child as patient'

Comorbidity

P10: 'We are almost certain that she has small brain damage that affects her movement and physical activity'.

P17: 'In the last few years, she has been not physically active, but it is not related to her heart defect. She has autism or a depressive disorder'.

Contact limitations when on anticoagulants

P4: 'She really likes judo, karate and kickboxing, just like her friends, but she can't do it'.

Cold

C18: 'It is very difficult for me to stay warm. My body and fingers are cold very quickly'.

P6: 'His body just has a lot more work to do to keep on temperature. He is cold so quickly. He comes out of the water, and then he is completely blue. Then he wants to go home'.

Sleep

P11: 'She slept a lot from an early age. She still has to take a nap in the afternoon'.

Symptoms during and after physical activity

C12: 'I feel that I get tired. And then usually my heart beats a bit faster, and then sometimes also very irregularly'.

P14: 'Well, he is easily out of breath'.

C15: 'He turns completely white and gray, then blue lips...'

C18: 'I get palpitations when I cycle or climb the stairs to the first floor'.

C1: 'It is especially those sore legs what she suffers from. Not fatigue or other things'.

P10: 'When we go to the pool, we can't do anything else for the rest of the weekend. Then she has reached her tax. She is exhausted. Afterwards, you see the consequences'.

Fatigue

P16: 'Well, she is also a bit lazy. If something is difficult to do, exercising or something else...That is always difficult. Is it laziness, or is it...Yes, what it is? It is a big question for us'.

C18: 'I am very tired. I can't do it. And then my sports teacher says that I just do not feel like it. But I'm just tired. I am dizzy and shaky, you know. It's annoying, because they think you're just lazy'.

P4: 'She is often tired. Or lazy...I don't know'.

C2: 'My classmates say that I am lazy. I try to join, but I just can't'.

P17: 'The fatigue stops her from doing anything. Then she says: I am too tired. Now her condition has become so bad that everything is already too exhausting for her'.

Lack of knowledge

Among parents

P9: 'I asked the doctor: what can he do? Just try, he said. But you want to hear: he can walk 10 minutes today. And 15 minutes tomorrow'.

Among children

C2: *'Well, I thought, oh, especially with the shuttle run test: can I do that?'*

Among sport coaches and teachers at school

C2: *'There was no knowledge among the coaches. It is a very small chance that things go wrong. But they do not know that. They get panicked. They say, "stop exercising".'*

C8: *'Then the football trainer sent me off the field. Then he asks: Are you okay? But I can go on, you know. I just want to continue playing'.*

P9: *'The physical guidance, let's be honest, doesn't get any attention'.*

Fear and uncertainty

Fear of death among parents

P10: *'You did not give your nine-day-old child to the surgeon and looked at him and said, "please, do the best you can"...The cardiologist said, "you know, the children who die, they have a cardiac arrest or the circulation stops". Yes, that is true. That is possible'.*

P7: *'We have a monitor in his room. We always keep an eye on him in case of emergency'.*

P16: *'If it went wrong, and you go home without your daughter, yes...if...'*

P7: *'I think I have already passed that point. I'm not afraid. I am more afraid of how. How. Because I want, if something happens, I want to be with him. I want him to be not afraid'.*

Fear among children

C18: *'Well, I'm afraid I'll have a heart attack'.*

P10: *'She asked, "am I going to die?" Of course, I am not going to tell her that there is a chance she will die'.*

P9: *'I think he thinks it is a bit scary too. It is a bit exciting. I can understand that. I think there must be someone next to him who says, no, you can still go on, you know, come on, go on and on. Look, that would help'.*

Uncertainty

C8: *'I do not know if I can continue. That is difficult, also for a trainer. I do not know if I can take a step further to become a bit fitter. I do not know'.*

P9: *'I think he can just join the class on the bicycle tour, but I'm not sure'.*

Restriction by parents and teachers

C3: *'I was restricted to move by my mother'.*

C2: *'The teachers are very careful with me. But it is not as bad as it looks like'.*

'Child imposes his or her own physical activity restrictions'

Child knows when to stop

P1: *'She can try anything she wants. She feels if it is ok. She clearly indicates where her limits are'.*

P14: *'He can feel where his limits are'.*

P16: *'We always say, "do what you can do. You will notice if you can't do it"'.*

Feeling of reaching physical limitation

C15: *'Then I feel I'm a bit weak, a little bit frail. A weird feeling'.*

C3: *'At that point, my breathing became heavier and I could no longer go on'.*

C12: *'Then I feel that I get tired. And then my heart starts to beat faster, and sometimes also very irregularly. But if I rest for a little while, it is ok again'.*

Doubt over child's capability to set boundaries

P9: *'It is a very good excuse, and nobody knows whether it is justified or not. We don't know. It is difficult...If he feels his breathing, he stops. Maybe it would be better to continue. You know, we think that he can do more, but we do not know whether he can do more'.*

C3: *'It is also a good excuse to sit on the side with gym'.*

P9: *'I asked my son, "why don't you run faster?" He said, "the doctor always said that I must respect my own limits. What is my limit then?" And then I thought, that is a very good question! I don't know!'*

'Non-specific'

Role of the parents

C15: *'Then my mother says, "get off that phone and go outside!"'*

P4: *'But I can't force her. If she doesn't want to exercise...'*

P1: 'Sports are important in our family. It is a part of life'.

Together with family or friends

P13: 'We go out a lot together, walking or cycling'.

P7: 'He did exercise together with his friend'.

Internal drive

P7: 'She has a very strong drive to move. She loves to move'.

C18: 'I like moving. And in the long run you will also become happier'.

Screen time

C8: 'If I can choose between sitting in my pajamas on the couch with my mobile phone or playing outside...Then I will choose the first'.

Habit and social event

C2: 'It was always obvious with friends. I just went'.

Active transport

C15: 'I have to cycle 18 kilometres to school every day. That's okay'.

'Normalisation'

P9: 'Actually, parents are the worst to ask how the child is doing. You learn not to pay attention. Of course, you pay attention in the beginning. But if you do that, you just do not have a life'.

P10: 'I am not afraid that she will drop dead, because if I should...I've had it in the beginning, but if you live like this, then you have no life. I choose not to worry anymore'.

'Take child into consideration'

C5: 'It is taken into account. I can stop with gym earlier because my teacher knows it too. Sometimes he says, "are you ok?" They take it into account – the children too'.

P4: 'They take her into account at school. They know how she is'.

C8: 'And they take me into account. We had to run two laps, and then the trainer said, "a whole round is not good for you, just stop"'.

SAMENVATTING

Doelstelling

Fysiek actief zijn is heel belangrijk voor kinderen met een aangeboren hartafwijking. Vaak hebben ze geen restricties voor sport of bewegen. Maar veel van deze kinderen bewegen wel te weinig. Nu blijkt uit onderzoek dat de hoeveelheid beweging niet gerelateerd is aan de ernst van de aandoening. Er moeten dus andere factoren een rol spelen in waarom deze kinderen zo weinig bewegen. Er is nog weinig bekend over hoe deze kinderen het ervaren om fysiek actief te zijn en of hun ervaring anders is dan die van gezonde leeftijdsgenoten. Daarom is het doel van deze studie het exploreren en analyseren van bevorderende en belemmerende factoren voor fysieke activiteit bij kinderen met een aangeboren hartafwijking. Deze bevindingen kunnen gebruikt worden om vervolgonderzoek richting te geven en de behandeling en begeleiding van deze kinderen te verbeteren.

Methode

Dit is een kwalitatieve studie waarbij gebruikt is gemaakt van een inductieve thematische analyse.

Resultaten

Er zijn in totaal 18 semi-gestructureerde interviews afgenomen bij kinderen met een aangeboren hartafwijking en hun ouders. Er zijn 3 jongens en 4 meisjes geïnterviewd en 3 vaders en 8 moeders. De kinderen waren tussen de 8 en 18 jaar oud, hebben allemaal een complexe aangeboren hartafwijking en zijn patiënt bij hetzelfde kinderziekenhuis in Nederland. In de analyse kwamen 4 beschrijvende thema's naar voren: "normaal kind", "kind als patiënt", "kind geeft zelf grens aan" en "niet-specifiek". Twee interpretatieve thema's kwamen naar voren: "kloppend maken" en "rekening houden met het kind".

Conclusie, klinische relevantie en aanbevelingen voor vervolgonderzoek

Deze studie heeft verschillende bevorderende en belemmerende factoren voor fysieke activiteit bij kinderen met een aangeboren hartafwijking aan het licht gebracht. Het belang van duidelijke, begrijpelijke en toegankelijke richtlijnen voor omgaan met fysieke activiteit is naar voren gekomen, alsook het belang van een snelle verwijzing van de kindercardioloog naar de kinderfysiotherapeut. Vervolgonderzoek naar het effect van een snelle verwijzing naar kinderfysiotherapie op de hoeveelheid fysieke activiteit wordt aangeraden. Ook onderzoek naar de relatie tussen comorbiditeit en fysieke activiteit, de relatie tussen slaap en fysieke activiteit en de relatie tussen frustratietolerantie en fysieke activiteit wordt aangeraden.

Trefwoorden: aangeboren hartafwijking, fysieke activiteit, kind, ouders