

ADHD follow-up care

the children's perspective

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Abstract

Background

Attention-Deficit/Hyperactivity Disorder (ADHD) is a common disorder with an estimated worldwide prevalence of approximately 5% in children and adolescents. After the diagnosis is made, the children must be periodically evaluated and monitored during the 'ADHD follow-up care'. Currently, little is known about the quality of care for ADHD in the Netherlands. However, there are indications that the ADHD follow-up care has shortcomings in primary care. To gain more insight in the current quality of the follow-up care, the Health Council of the Netherlands recommends to investigate this. Therefore, it is important to examine the children's perspective regarding the ADHD follow-up care, besides investigating the perspective of the professionals, parents and politics. By doing so, the knowledge about the current quality of follow-up care will be supplemented.

Objective

The aim of this research was to gain insight in the quality of the follow-up care for children with ADHD from the perspective of children with ADHD. Knowledge of the perceptions and experiences of children with ADHD of the current quality of follow-up care could identify potential areas of improvement regarding the follow-up care.

Methods

A qualitative exploratory research method was used, using individual semi-structured interviews. The research was carried out in region Twente in the Netherlands. The nine interviewed children were aged from 9 till 11 years and have ADHD as primary disorder. The interviews were analyzed using open-coding thematic analysis. The identified themes and subthemes were used to reflect the experiences, needs, and preferences of the interviewed children.

Results

A total of seven themes were identified reflecting the experiences, needs, and preferences of the children regarding the follow-up care, including: transfer of responsibility, dependency of children on their environment, involvement of the children, equality of interaction, degree of openness of the children, a person of trust, and accessibility of the follow-up care. Children experienced that the follow-up care is provided at regular intervals by secondary care. However, the follow-up is not provided at regular intervals when the responsibility is transferred to the general practitioners. The experience regarding the follow-up care differs per child because their parents and teachers cope differently with ADHD. It is unclear how the school cooperates with the care providers. Regarding the needs, children indicated to have certain needs, but there is no communication about those needs by the parents, teachers, and care providers. The children indicated that they have a need to be treated equally. There is a difference in knowledge about the importance of the follow-up care and the character of the child, which results in a difference in the needs for follow-up care. Regarding the preferences, children prefer to be treated by a secondary care provider over a general practitioner. During the performance of the follow-up care, children prefer to be helped by one and the same person, with knowledge about ADHD, who they know, and is familiar to them. The children have different preferences regarding the frequency of the follow-up care, ranging from once a year to twice a week. Lastly, children have different preferences for the location of the follow-up care.

Conclusion

Through this research, it became evident how the follow-up care is provided, giving insight in the current quality of the follow-up care. Many needs and preferences were identified, which can be used in the optimization of the follow-up care in the Netherlands.

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1 Introduction

1.1 Background

Attention-Deficit/Hyperactivity Disorder (ADHD) belongs to the externalizing mental disorders.¹ The disorder is characterized by a combination of behavioural traits including inattentiveness and hyperactivity-impulsivity, whereby the disruptive effect of the behaviour on the environment is central.^{1,2} The behavioural traits usually occur in childhood, but it can also predominate at later age before being recognized.² ADHD is only diagnosed in children from 6 years and older, because from that age the diagnosis is reliable.¹ The diagnostic classification system DSM-IV-TR distinguishes three subtypes of ADHD, including the predominantly inattentive type, the predominantly hyperactive-impulsive type, and the combined type, which is the most common type where both subtypes occur together.¹ Due to the impulsive behaviour and slower rates of processing information, children and adolescents diagnosed with ADHD experience problems related to education and social functions.^{3,4} ADHD has overlap with other neurodevelopmental problems, including autistic spectrum disorders.⁵ In addition, ADHD often presents comorbidity with other psychiatric and behavioural disorders such as oppositional defiant disorders, major depressive disorders, and anxiety disorders.^{4,5} This will give additional challenges on those children with ADHD with regard to their school performances and social functions.⁴

Worldwide, ADHD is common with an estimated prevalence of approximately 5%.⁶ Over the past few years, international studies have shown a strong increase in the number of diagnoses of children with ADHD.¹ It is almost certain that this applies in the Netherlands as well.¹ At the moment, it is unknown how many children and adolescents have ADHD in the Netherlands.⁷ This is because there are no valid studies available since the studies use different sources and diagnostic classification systems, including DSM-5 and ICD-10.⁷ However, according to Fischer et al., it is assumed that 3-5% of the children below the age of 16 and 1-3% of the adolescents have ADHD, and it occurs more often in boys compared to girls.¹ The prescription of ADHD medication is increasing, both internationally and in the Netherlands.^{1,7} Moreover, there is a growth in the use of care for ADHD related complaints.⁷ This shows that the request for help from patients with ADHD is increasing.⁷

Several risk factors can contribute to the occurrence of ADHD. It is known that ADHD has a genetic component, like having a biological relative with ADHD which is related to the occurrence of ADHD.^{1,5,8} Besides the heritable factors, there are several environmental factors that are correlated with ADHD.⁵ Whether a child with genetic predisposition develops ADHD depends on influences from the environment.⁹ Prenatal exposure to nicotine and alcohol, low birth weight, or the living situation and radical events, such as domestic violence or divorced parents, make a child more prone to develop problems related to ADHD.^{5,9} However, the exact etiology of ADHD is unknown and is based on initial hypotheses.^{1,3-5} It is believed that a chemical imbalance of neurotransmitters, including dopamine and norepinephrine, in the prefrontal cortex lead to deficits in cognitive processing, attention, motor planning, speed of processing responses and other behavioural issues observed in ADHD.^{4,5}

The Dutch national multidisciplinary guideline for the assessment and treatment of ADHD in children of the Trimbos Institute consists of recommendations and procedural instructions to support daily practice for professionals who are involved in children with ADHD.¹ The diagnosis of ADHD is based on behavioural characteristics observed in multiple environments.² The diagnostics requires both medical and psychosocial expertise, whereby both the family and school should be involved.¹ The treatment of ADHD consists of pharmacotherapy and behavioural/psychosocial treatment.¹ Medical treatment

usually means the intake of a stimulants, like methylphenidate which is an amphetamine-like substance covered by the Opium Act.^{1,2} The treatment focusses on the provision of information, prevention or reduction of the symptoms, limiting the consequences, and improving or restoring the social functioning.¹ The diagnosis of ADHD is made and the treatment is started by professionals in specialized services, including child psychiatrists, psychologists, and paediatricians. These specialized services are according to the Dutch healthcare system the secondary care.¹ Besides secondary care, the diagnose can be made by a general practitioner (GP) included in primary care.² According to the guideline issued by the Dutch College of General Practitioners (NHG), the diagnoses can be made by a GP when they have sufficient knowledge and expertise in ADHD and have the availability of effective treatment options in the general practice.²

After the diagnoses is made, the children must be periodically evaluated and checked, which is defined as the 'ADHD follow-up care'.¹⁰ The ADHD follow-up care consists of treatment monitoring and evaluation, including medical and behavioural/psychosocial treatment.¹ During the follow-up care, the effect of the medical and non-medical treatment and possible side effects of the pharmacotherapy will be evaluated.² Attention is paid to physical complaints, including i.e. aggressive behaviour, anxiety, and tics.² According to the Dutch national multidisciplinary guideline and the NHG directive, GPs have to focus on the monitoring of the medical treatment of ADHD and the providing of follow-up prescriptions during the ADHD follow-up care, which have to be performed every six months.^{1,2} This allows adjustment of the medication during the ADHD follow-up care and support continuation of patients in treatment.¹¹ The follow-up care is crucial for optimizing efficacy, minimizing adverse events, and evaluating the continuing need for medication.¹²

1.2 Problem definition

There are indications that the ADHD follow-up care has shortcomings in primary care.^{13,14} The ADHD follow-up care appears to be poor for children who are treated with medication by their GPs.¹⁵ Although GPs are responsible for about 50% of prescriptions for ADHD, either by initiating therapy (6–20%) or by writing out repeat prescriptions (61%), it appears that GPs have problems with fulfilling their central role in the follow-up care.^{1,16} According to Faber et al., 19% of the investigated children did not receive any follow-up care from their GPs.¹⁵ In addition, the ADHD follow-up care is often forgotten by the GPs.^{15,16} This indicates that the GPs do not fully comply with the directives. This may be due to lack of time, cooperation, knowledge, instructions and experience.¹⁷⁻²⁰ As a result, specialized mental healthcare services in secondary care often continue to provide follow-up care instead of the GPs.⁷ This results in long waiting lists in mental healthcare and expensive services.⁷ This may contribute to existing problems in the primary care, like inadequate treatment, medicalization and a shortage of systematic ADHD follow-up care.^{7,15} However, according to the Health Council of the Netherlands, the insight into the actual provided care for children and adults with ADHD is insufficient.²¹ Little is known about the quality of care for ADHD in the Netherlands.^{7,21} Therefore, the Health Council of the Netherlands recommends to investigate the quality of the follow-up care.⁷

Since 2015, Dutch municipalities are responsible for the youth care services including mental care, instead of the Dutch National Government because of deficiencies in the previous system.²² The decentralization of care was aimed at providing more effective integrated care that is tailored to the needs, preferences and circumstances of children and families as fast and nearby as possible with attention for (cost)effectiveness of the provided care.^{10,23} To be able provide care closer to the children with ADHD, there must be accessible ADHD follow-up care which is provided close to the child, e.g. at their school or general practice.¹⁰ The follow-up care should also be tailored to the medical, psychological and social circumstances of the child and their family.¹⁰ According to the clinical

guidelines, the follow-up care should be provided close to the children already.^{1,2,24} However, as described before, secondary care frequently provides the ADHD follow-up care instead of primary care.⁷ Therefore, it can be stated that this is not in line with one of the decentralisation objectives of providing the follow-up care closer to the child. This is because primary care can be given close to the child in comparison with secondary care, because it is more accessible, requires less travel time, and appointments can be made on short notice.²⁵

To gain insight in the quality of healthcare provided, professionals and organisations have to monitor and evaluate whether their care meets the needs of the patients.²⁶ Several stakeholders are involved in the optimization of the quality of the ADHD follow-up care, including health care professionals, teachers, parents, and children with ADHD. The Health Council of the Netherlands recommends to study the quality of the follow-up care.⁷ For this reason, it is important to examine the perspective of the children, besides investigating the perspective of the professionals, regarding the ADHD follow-up care. The last years, foreign studies have been studying the experiences and impact of ADHD as well as experiences of the diagnoses and treatment in children with ADHD, but they do not take the follow-up care into account.^{27,28} Moreover, a German team of the 'Database of Individual Patients' Experiences' (DIPEX international) studied the experiences of primary care and the primary/secondary care interface of children with complex physical and mental health condition, including ADHD, with the use of interviews.²⁹⁻³¹ However, this study is not published publicly but is yet used as reference in several reports.²⁹⁻³¹ Unfortunately, it is unclear if the statements made about the experiences in these reports are focused on children with ADHD or other disorders, whereby no conclusions could be made regarding experiences of the follow-up care. In the Netherlands, recent projects 'AHAD' in Katwijk, 'Tornado' in Nijmegen, and 'Eureka' in Enschede were focussed on achieving an integrated care program in starting and monitoring ADHD treatment for children with ADHD with a central role for the primary care.^{7,14,17,32} The Eureka project tried to include the children's perspective regarding the quality of care, but they had too little response to make conclusions.¹⁴ The Tornado project stated they investigated the children's experiences and satisfaction of the Tornado program compared with care as usual.¹⁷ However, they did not describe the experiences and only made conclusions that the clinical outcomes, including the satisfaction, were well and similar to those achieved with care as usual.³³ No conclusions were made about the experiences of the children regarding their follow-up care.¹⁷ Meanwhile, the experiences of parents regarding the ADHD follow-up care have been examined in previous research.³⁴ Nevertheless, the experiences of children with ADHD regarding the ADHD follow-up care are unknown.

To be able to customize care to the needs of the patients, the perspective of the children has to be included in the evaluation of quality of care.²⁶ Since there is no evidence about the experiences of children regarding the ADHD follow-up care, research is needed. The input of children with ADHD about their experiences regarding the ADHD follow-up care is important to ensure that the follow-up care meets the needs of these children.²⁹ According to Barbosa et al., care that is tailored to the needs and preferences of the children and parents may result in higher satisfaction and better treatment adherence.³⁵ With the children's perspective regarding the ADHD follow-up care, there is potential to create integrated follow-up care tailored to the needs and preferences of the children with ADHD. Eventually, this may lead to an improvement in the quality of ADHD follow-up care.^{7,10}

1.3 The aim of this research

The aim of this research is to gain insight in the quality of the follow-up care for children with ADHD. To achieve this aim, it is necessary to analyse the perspective of the children as well regarding the current ADHD follow-up care. By means of this new insight from children with ADHD, knowledge of

the perceptions and experiences of children with ADHD of the current quality of follow-up care will be obtained. With this insight, potential areas of improvement of the quality of follow-up care will be identified. This insight can be used to create integrated ADHD follow-up care that is tailored to the circumstances and meets the needs and preferences of these children with ADHD. Furthermore, this information can be used by professionals to improve the quality of follow-up care for children with ADHD. In addition, this information can be used to improve the clinical guidelines of the ADHD follow-up care.

2 The research question(s)

This study will give answer to the following research question:

“How should the ADHD follow-up care be provided according to school-aged children (9-11 years) with uncomplicated ADHD in the region of Twente?”

The research question is addressed in three sub-questions:

- 1) *What are the experiences of school-aged children (9-11 years) with uncomplicated ADHD regarding the follow-up care by healthcare professionals and school professionals in the region of Twente?*
- 2) *What are the needs that school-aged children (9-11 years) with uncomplicated ADHD have regarding the ADHD follow-up care by healthcare professionals and school professionals in the region of Twente?*
- 3) *What are the preferences that school-aged children (9-11 years) with uncomplicated ADHD have regarding the ADHD follow-up care by healthcare professionals and school professionals in the region of Twente?*

The research question and sub-questions are interesting for every child with ADHD, meaning each age category as well as children with comorbidities. Nevertheless, due to delineation, there is an age limit of 9 to 11 years old and only children with uncomplicated ADHD are included. ‘Uncomplicated ADHD’ is defined as children with ADHD as primary disorder hence no comorbidities. The term ‘school-aged children’ is defined as children that are in primary schools or special education. The term ‘healthcare professionals’ is defined as the healthcare professionals active in primary care and secondary care for children with ADHD. ‘School professionals’ is defined as teachers and internal tutors.

This research derives from a question of the Academic Collaborative Centre Youth in Twente. This question derived from issues of the municipalities of Twente regarding the distribution of care purchase for ADHD. Therefore, children living in the municipalities of Twente are recruited for this research. In addition, the results of this research may be used by municipalities of Twente in the distribution of care purchase for ADHD.

2.1 Research outline

The introduction provided information about the different subtypes of ADHD, the prevalence, the etiology, the treatment, and the organisation of the ADHD follow-up care. In addition, the problem and the aim of this research is described as in chapter 1. Chapter 3 contains theoretical information about the terms ‘quality of care’ and ‘patient experiences’ and a framework to measure the quality of care children is introduced. Chapter 4 outlines the chosen research methodology. Chapter 5 presents the results of this research. In chapter 6, the conclusion is given and the results are discussed. At last, chapter 7 presents the bibliography and chapter 8 the abbreviations.

3 Theoretical framework

As described in the introduction, little is known about the quality of care for ADHD in the Netherlands.^{7,21} To be able to acquire insight into the quality of care provided, it is necessary to measure the quality of care.²⁶ To gain insight in the quality of healthcare provided, professionals and organisations have to monitor and evaluate whether they provide for the needs of the patients.²⁶ Through feedback measurements, like surveys and in-depth interviews, the experiences of patients with their care can be measured.³⁶ This can be used as initiative for improvement of the quality of care.³⁶ Experiences of patients with regard to their received care can be seen as a fundamental component of the quality of care.³⁷ The perspective of patients can provide a deeper insight into the experience of facing illness and their interaction with health services.²⁶ There is need to capture the 'patient experience' of care received, because the experiences of the patients can provide feedback to improve the quality of care.^{38,39} According to Wolf et al., the definition of The Beryl Institute reflects the concept of patient experience as a whole.⁴⁰ The patient experience by The Beryl Institute is defined as *"The sum of all interactions, shaped by an organization's culture, that influence patient perceptions across the continuum of care."*⁴¹ According to Coulter et al., feedback from the experiences of patients can be useful because: it gives understanding in current problems in care delivery; it monitors the impact of changes; it gives information about the care pathways; it reflects the performance of the professionals; it informs about the quality of services; and it enables public accountability.³⁶ Therefore, it is important to take experiences of patients into account when evaluating quality of care, likewise the experiences of children.

To be able to assess the quality of care, understanding the term of quality of care is necessary. A widely used definition of quality of care derives from the Institute of Medicine (IOM), which states that *"Quality of care is the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge."*⁴² Quality of care can also be described in a simpler manner as whether individuals can access the health structures and processes of care which they need and whether the care received is effective.⁴³ The World Health Organisation (WHO) defines the quality of care as *"The extent to which health care services provided to individuals and patient population improve desired health outcomes."*⁴⁴ In order to achieve this, the WHO describes six dimensions of quality. These dimensions require that health care must be effective, efficient, accessible, equitable, safe, and patient-centred.⁴⁵ As can be seen, the term quality of care is multi-dimensional and can be interpreted in various ways, dependent on who is being asked.^{46,47} According to Donabedian, quality of care can be defined as *"The maximization of the benefits over risks of both technical and interpersonal aspects of patient care."*⁴⁸ Donabedian defined quality much broader than simply the ability to enhance health.³⁹ The Donabedian model describes three components of quality, including; technical quality, which describes the ability to improve health outcomes; process quality, which describes the management of the interpersonal process; and structure quality, which is related to the quality of facilities.⁴⁷ Within the interpersonal process, the client satisfaction is important because it gives information on the success of the provider at meeting the values and expectations of the patients.³⁹ This model can be used for examining health services and evaluating quality of health care.⁴⁷

To measure the quality of care several models can be used, like the Donabedian model. However, models used to measure the quality of care for adults cannot be directly translated to children.^{26,49} This is because there is a difference in health determinants, disease patterns, preventive and therapeutic health services, and data services for children comparing with adults.⁴⁹ In addition, there is a limited

number of quality of care measures specifically focused on health care for children.²⁶ Therefore, the Models of Child Health Appraised (MOCHA) project established the MOCHA conceptual framework to assess the quality of care for children.²⁹ The MOCHA conceptual framework represents determinants of child health and the proximal determinants of primary care quality for the evaluation of quality of health care for children.²⁹ The MOCHA conceptual framework is visualized in figure 1. The MOCHA conceptual framework is based on three existing theoretical frameworks, including Bronfenbrenner’s ecological model of determinants of health, a modified Kringos model of determinants of quality of primary care (based on the Donabedian model), and a life course epidemiological framework of childhood health and disease.²⁹ The Bronfenbrenner’s model describes the influence of environmental factors on the health development of children, including influence of the micro-, meso-, exo-, and macrosystem.⁵⁰ The Donabedian model describes the determinants of the quality of health care services.²⁶ As described before, the health care system of this model is defined by means of its structure, process, and outcome.^{26,47} With the combination of these three models, the MOCHA conceptual framework describes the determinants of child health, which is dependent on the age and phase of a child, and it describes the determinants of primary care quality.

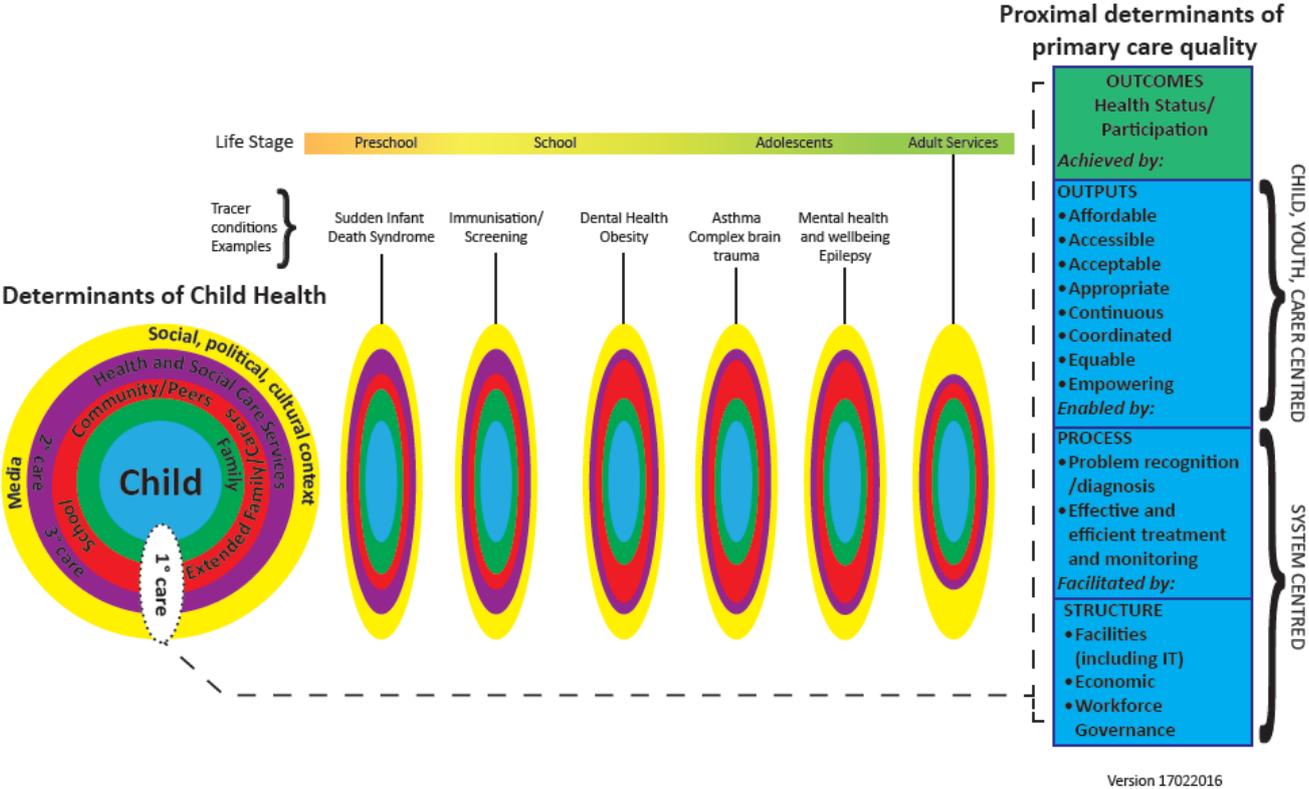


Figure 1: the MOCHA Conceptual Framework²⁹

To measure the quality of care from the perspective of the children, the eight relevant outputs of health systems from a child, youth and carer centred perspective are considered. These are included in the child centered proximal determinant of primary care quality. The determinants of primary care quality are affordability, accessibility, acceptability, appropriateness, continuity, coordination, equitability, and empowerment.²⁹

Kringos et al., describes the determinant affordability of care as “the financial barriers that patients experience to receive primary care services, such as co-payments and cost-sharing

*arrangements*⁵¹. A child is depending on his/her parents regarding the financial barriers a child can experience. Financial barriers can include the level of health insurance or the possibility of the parents to pay for medication and travel expenses out-of-pocket, which influences the care a child can receive.

The determinant accessibility of care is defined as *“the availability of good health services within reasonable reach of those who need them and of opening hours, appointment systems and other aspects of service organization and delivery that allow people to obtain the services when they need them”*⁵². The accessibility is divided in the availability of primary care, the geographic accessibility, and the accommodation of accessibility. Accessible care for children can include the location and the travel distance of the care needed, e.g. that there is a reasonable distance for an appointment with a youth psychiatrist.

The determinant acceptability of care is defined by Evans et al. as *“people’s willingness to seek services, based on their judgement of effectiveness of the service and whether or not they are treated with dignity and respect”*⁵². The acceptability of a service experienced can be low when the care perceived by the children is ineffective. Besides, the acceptability is low when social and cultural factors discourage the children and their parent from seeking services of care.

The determinant appropriateness of care is divided in two types of appropriateness, namely appropriateness of a service and appropriateness of the setting in which care is provided.⁵³ Appropriateness of service is defined as *“a service that is expected to do more good than harm for a patient with a given indication or set of indications”* and appropriateness of setting is determined by *“whether the patient's clinical characteristics, and the services required for his or her care, match the setting in which the care is provided”*⁵³. Within this determinant, it can be measured whether the care the children receive is the appropriate care that they need to receive. For example, the appropriate care for children with ADHD that take medication is that they see a GP every six months to check the effect and side-effects of the medication.¹

The determinant continuity of care is defined from the patient perspective as *“the patient's experience of a 'continuous caring relationship' with an identified health care professional”* and from the provider perspective as *“the delivery of a 'seamless service' through integration, coordination and the sharing of information between different providers”*⁵⁴. The continuity of care included the presence of a respectful and long-term relationship between the child and the care provider.

The determinant coordination of care is defined by Kringos et al. as *“the ability of primary care providers to coordinate use of other levels of health care”*⁵¹. This is reflected by the presence of a gatekeeping system, the structure of the primary care practice, skill-mix of primary care providers and integration between primary and secondary care and between primary care and public health services.⁵¹ The coordination of care can include the coordination between primary and secondary providers in the care for children.

The determinant equitability of care is divided in the equity in access and the equity in health. Equity in Health is defined by Kringos et al., as *“the absence of systematic and potentially remediable differences in health status across population groups”* and equity in access is defined as *“the extent to which access to primary care services is provided on the basis of health needs, without systematic differences on the basis of individual or social characteristics”*⁵¹. Every child with the same needs should receive the same care, despite of, e.g. the social-economic status of the parents.

Finally, the determinant empowerment of care is defined as *“a social process of recognizing, promoting and enhancing people’s abilities to meet their own personal needs, solve their own problems and mobilize the necessary resources to feel in control of their own lives”*⁵⁵. It is divided in the knowledge, skills, and involvement that the child and the parents have and receive. The empowerment of care can include the knowledge and skills a child has learned to be able to cope with their condition well. The empowerment of a child may be low when they are not being involved in decisions about one’s health.

The seven determinants are described more extensively in table 3, appendix A. With the help of the determinants of primary care quality, it can be measured whether the current care meets the quality standards. Besides the determinants of primary care quality, the MOCHA conceptual framework consists of the determinants of child health, which includes the child itself, the family, the school, community/peers, primary and secondary care, health and social care services, media, and social, political and cultural context.²⁹ The determinants of child health will lead to a certain quality of the healthcare system, which in turn can be mapped by the determinants of primary care quality. With these determinants, the experiences of children with the current quality of care can be measured. Ultimately, it can be explored if the current care meets the quality standards represented by the determinants of primary care quality according to the children.

4 Methods

In this chapter, the research methodology is described. The research design and procedure are given and information about the study participants is presented. Besides, the proceeding of the data collection method is presented. At last, the data analysis method is described.

4.1 Research design

A qualitative exploratory research method was used in this study to answer the research question and sub-questions. The aim of this study was to seek answers to questions about 'how', 'why', or 'what', which indicated that a qualitative research method is appropriate.⁵⁶ In addition, a qualitative approach was chosen because the topic of this study is new, never addressed, and existing theories do not apply with the group of people under study.⁵⁷ This makes this study an exploratory research.⁵⁸ Furthermore, the aim of this study was to obtain the thoughts and experiences of people, which makes a qualitative approach more suitable to gain more in-depth information about the subject of this study.⁵⁸

4.2 Research procedure

The data was collected through individual interviews with children with ADHD. This method was chosen to be able to respond to the personal experiences of each interviewed child. In addition, this approach was suitable because the interviewer was able to gain more in-depth understanding of the topics.^{38,59} In this research, children had to talk about personal experiences which indicates that individual interviews are suitable to deal with these sensitive topics.^{59,60} With individual interviews, the likelihood of useful responses was increased due to the fact the interviewer can explain or clarify questions.⁵⁹ In addition, it allowed the interviewer to be flexible during the interview to every particular child and their particular circumstances, which may be useful in children with ADHD.⁵⁹

A proper and trusting relationship between the interviewer and the interviewed children is important to collect more data and gain more insight in the experiences of the children.⁶¹ To be able to create a good relationship, the interviews were conducted face-to-face instead of by telephone or online. Every child is different, likewise during the interviews. Besides, there may be possible problems due to the specific health problem of this research, such as impulsive reactions and focus problems. Therefore, it was important that the interviewer was free to change the order of the questions as well as the formulation of the questions. The interviewing of hyperactive children needed a flexible interview method. Furthermore, it is important that all topics are addressed during the interview. As a result, the interviews were semi-structured in this study.

4.3 Study participants

4.3.1 Inclusion and exclusion criteria

Children were included when they met the following inclusion criteria: school-aged children in the year of 9 to 11, children diagnosed with ADHD as primary disorder hence no comorbidities, children living in the municipalities of Twente, and children who speak Dutch. Children were excluded from this study when they: are younger than 9 years or older than 11 years, have comorbidities, live outside the municipalities of Twente, or do not speak Dutch. Both children who take medication as well as children who do not take medication for their ADHD were included in this research as they received different follow-up care.

4.3.2 Recruitment of the respondents

The research was executed in the municipalities of Twente. Children were recruited for the study through five ways. The first way was through the mental healthcare institute Karakter, which is operational in Twente. Karakter is a centre for child and youth psychiatry which diagnoses and treats children with, among others, ADHD. Karakter was asked to contact eligible children and their parents to invite them to participate through the Personal Information Form (PIF) made for the parents and their child (appendix B and C, in Dutch). The second way was through the 'Oudervereniging Balans Twente'. This is an association which exchanges knowledge and experiences between parents, professionals, education, and science of children with developmental problems, including ADHD. From here, a message was placed on their Facebook page and on their website to contact parents of eligible children. The third way was through a target group meeting of parents of children with ADHD and professionals from the educational field organised by Balans Twente. The researcher had the opportunity to introduce the research during that meeting and contact parents of eligible children. Through this target group meeting, contact was made with Attendiz, which was the fourth way of recruitment. Attendiz is the school board of special education of Twente. Attendiz was asked to contact eligible children and their parents to invite them to participate through the PIFs. Last, the network of the researcher was used and emails had been sent to contact persons of multiple schools in the region of Twente to contact eligible children and their parents.

4.3.3 Sample size

The aim of the researcher was to have substantive saturation. However, a maximum of 6-8 interviewed children was set for the feasibility of this study given the time period in which the study had to take place.

4.4 Proceeding of the interviews

4.4.1 Execution of the interviews

The interviews were preferably conducted at the home of the children, because their home can be considered as a place of comfort for the children which may decrease anxiety.⁶¹ Besides, the interviews were preferably performed without the attendance of the parents. The interviews took place at the time and day preferred by parents and child.

Before each interview, the PIFs had been sent to the parents and child. At the beginning of the interview, the proceeding of the interview was explained to the parents and child. Besides, any uncertainties from the PIFs were clarified. The parents were asked to confirm that the child indeed met the inclusion criteria. Because the children were below the age of 12, written informed consent (appendix D, in Dutch) was obtained by the parents.⁶² The child was asked for his assent for the interview. Confidentiality was assured to the parents and child and was maintained using identification numbers for each child participant. After the written informed consent of the parents and the assent of the child was obtained, the interview started. The interviews were recorded using an audio recorder on a mobile phone. At the end of the interview, the child was thanked for its participation with a toy.

4.4.2 Interview protocol

To create a trusting relationship with the child, on advance of the interview, questions have been asked about, e.g. the hobbies of the child. A topic guide was used during the execution of the interviews, which can be found in appendix E (in Dutch). The topics have been derived using the MOCHA conceptual framework. The questions asked during the interview were open. The interview consisted of three parts. In every part of the interview, the interviewer responded to the answers of

the interviewed children with supplementary questions to explore the reasons behind the answers. Furthermore, additional questions were derived from previously given answers.

The first part of the interview

The first part of the interview consisted of the experiences of the child regarding to the follow-up care considering the whole environment of the child. At first, the questions were focused on the child itself and the family. The interview started with the following question: *'How was it for you when you heard you have ADHD?'*. Thereafter, questions were focused on friends and other activities, like sports. A question asked was: *'How do your friends interact with you?'* Then, questions were focused on the school of the child. A question asked in this part was: *'What about your ADHD stands out to your teacher?'*. At last, the questions were focused on the health care services. A question asked was: *'What happened since you know you have ADHD?'*

The second part of the interview

In the second part of the interview, the focus was on the needs of the child regarding to the follow-up care. The questions were focused on what the child needs in his/her environment within the follow-up care. Questions were derived from the answers of the first part of the interview. A question asked to begin this part was: *'What do you need to ensure that you can cope with your ADHD well?'*

The third part of the interview

The third part of the interview was focussed on the preferences of the child regarding to the follow-up care. The questions were focused on preferences regarding the person who will give the follow-up care. A question asked to begin this part was: *'What would you like to do better yourself?'*. In addition, questions were focused on preferences regarding the location of the follow-up care and the person who will give the follow-up care. Questions asked to in this part were: *'With whom do you prefer to talk? Why that person?'*

4.4.3 Interview techniques

The interviewer was empathic and responsive during the interviews to gain the information needed.⁶³ Furthermore, the interviewer asked the questions without judgements and provided positive feedback during the interviews. To be able to obtain sincere answers from the children, a solution-orientated interview technique was used. Within this technique, scales were used as a method to clarify and understand the answers of the children. The answers were discussed with pictograms (smileys) which represent a scale of 1 (sad smiley) till 10 (happy smiley), which can be found in appendix F. Repeating the answers and summarizing the answers were used to find out if the perception of the interviewer was in consensus with the perception of the child.⁶⁴ Besides, the interviewer allowed silence to give the child space to be able to think about his answer. The interviewer used pictograms of the main aspects of the interview, including the family, friends and activities, school, and healthcare providers (appendix G). Through the pictograms, structure was created during the interviews.

4.4.4 Risks and burdens of the interview

The expectation of the risks and burdens of the interview on the child were minimal. However, the children could be overstimulated by the interviews. Besides, it was possible that questions asked about the ADHD follow-up care could recall unpleasant memories of the child. This was prevented by careful listening to the children and observation of the reactions of the children during the interviews, both verbal and non-verbal. In addition, the situation of every individual child was considered. On beforehand, the parents were asked to indicate what the child will express when he feels uncomfortable, so the interviewer had an indication when to bring the parents in or to stop the

interview. Besides, the parents and children were able to stop the interview at all times with or without reason, but this did not occur during the interviews.

4.5 Ethical approval

Permission to carry out this research was granted by the ethical committee of Karakter under file number 139-18. The ethical committee of the Faculty of Science and Technology of the University of Twente has adopted the assessment of the ethical committee of Karakter.

4.6 Data analysis

4.6.1 Data management

The recorded interviews were transcribed verbatim using Microsoft Word and the recorder application of the Samsung S8. To ensure confidentiality, all participant identifiers, such as names and specific locations, were removed or replaced by a letter. After each interview, the interview was transcribed and analysed before the next interview was executed. Hereby, the interviewer was able to study the information that was obtained. It was used as feedback for the interviewer, so better in-depth questions could be asked in the next interviews.

The following demographic characteristics of the interviewed children were noted from each interview in the transcript document: age, gender, date of diagnoses, and family composition. In addition, the location of the interview, whether the child is in primary school or special education, whether the child uses medication, and the presence of the parents during the interview were noted. These characteristics may affect the results of the interviews and were thereby considered.

Field notes and interview transcripts of nine interviews were conducted. The field notes implied the characteristics of the interviewed children. The data was stored at the laptop of the researcher and a back-up was made on the Google Drive account of the researcher. The data was kept secure and confidential as the researcher was the only one able to access the computer and Google Drive account. The interviewer/researcher, the primary and secondary supervisors, and the project manager Innovation of Karakter Academy had access to the anonymized data. The data is archived on the database of the University of Twente. The audio recordings were deleted permanently. On request to the primary supervisor, making the data available will be considered.

4.6.2 Analysing the data

Inductive thematic analysis was used to subject themes in experiences, needs, and preferences of the children regarding the ADHD follow-up care. To analyse the data, 'Atlas.ti' was used within this study. Open coding was used to optimize the acquisition of new insights.⁵⁶ The six stage plan for thematic analysis by Braun and Clarke was used in this study, which existed of: familiarizing with the data; generating initial codes; searching for themes; reviewing themes; defining and naming themes; producing the report.⁶⁵

During the second stage of generating initial codes, the first two interviews were coded by two assessors, including the first coder (researcher) and the second coder (colleague researcher). The first and second coder coded the data independently. First, the first coder selected text fragments from the transcripts and coded these transcripts. The second coder coded the same text fragments independently from the first coder, using the coding scheme provided by the first coder. To measure the interrater reliability, the Cohen's kappa was calculated of the first two interviews.⁶⁶ Differences in classification in coding were discussed between the two assessors until consensus was reached. Cohen's kappa of the first and second interview was 0.849 and 0.873, indicating almost perfect

agreement.⁶⁶ Due to the high interrater reliability of the coding in the first two interviews, the researcher coded the remaining interviews alone.

After generating initial codes, the themes were defined. Codes that did not fit into the main themes were put together as 'miscellaneous'. The main themes were used to reflect the experiences, needs, and preferences of the interviewed children. The answer to the research question, on how the follow-up care should be provided according to school-aged children with ADHD, followed from the answers to the sub-questions. In chapter 6 'discussion', it was assessed to what extent the identified themes correspond with the seven determinants of quality of care of the MOCHA conceptual framework.

5 Results

In this chapter, the results are presented. First, the characteristics of the interviewed children are outlined. Thereafter, the results of the thematic analysis are presented, supported by quotations of the interviews.

5.1 Characteristics of the interview participants

A total of nine interviews were conducted. The characteristics of the interviewed children are presented in table 1. In total, eight boys and one girl were interviewed with an average age of 10 years. Through the message on the webpage of the 'Oudervereniging Balans Twente, one child was recruited. The other nine children were recruited through the network of the researcher by emailing contact persons of multiple schools. The duration of the interviews was between 28 and 39 minutes with an average of 33 minutes.

Table 1: *Characteristics of the interviewed children*

	Age	Gender	Date of diagnoses	Family composition	Location of interview	Type of school	Presence of parents during interview	Medication
Child X	10	Male	This year	Youngest child, one older sister	At the home of the child	Primary school	Mother was present	No
Child Y	10	Male	At the age of six	Oldest child, 2 younger sisters (one also with ADHD)	At the school of the child	Primary school	Mother was present	Yes
Child Z	11	Male	At the age of eight	Parents divorced, mixed family. (Mother also has ADHD)	At the home of the child	Special education	Parents were not present	No
Child A	11	Male	At the age of nine	1 younger brother, 1 brother (also with ADHD) and 1 sister	At the school of the child	Primary school	Parents were not present	Yes
Child B	9	Female	At the age of six	Youngest child, 1 older sister (also with ADHD)	At the school of the child	Primary school	Parents were not present	Yes
Child C	9	Male	At the age of six	Oldest child, 1 younger sister	At the home of the child	Special education	Parents were present	Yes
Child D	11	Male	At the age of six	Parents divorced, youngest child, 1	At the school of the child	Special education	Parents were not present	Yes

				older brother				
Child E	9	Male	At the age of six	Youngest child, 1 older brother (also with ADHD)	At the home of the child	Special education	Parents were present	Yes
Child F	11	Male	At the age of six	Has 1 older and 1 younger brother. Mother has also ADHD.	At the home of the child	Special education	Mother was present	Yes

5.2 Results of the thematic content analysis

A total of 702 text fragments and 194 codes were found in the data of the performed interviews. Using the six stage plan for thematic analysis by Braun and Clarke, 7 main themes and 22 subthemes were identified by grouping the codes.⁶⁵ The following main themes were defined: dependency of children on their environment, accessibility of the follow-up care, involvement of the children, equality of interaction, degree of openness of the children, transfer of responsibility and a person of trust. Each subtheme represents a finding regarding the experiences, needs, or preferences. The main themes and sub-themes are explained more extensively in table 2.

Table 2: *The identified main themes and subthemes*

Main theme	Subtheme
Transfer of responsibility	<ul style="list-style-type: none"> • The follow-up care is provided at regular intervals when secondary care providers have the responsibility (experiences) • The follow-up care is not provided at regular intervals when the responsibility is transferred to the GPs (experiences) • Differences in the completeness of the provided follow-up care of secondary and primary care (experiences)
Dependency of the children on their environment	<ul style="list-style-type: none"> • The experience of children with the follow-up care depends on the parents (experiences) • The experience of children with the follow-up care differs per school (experiences) • The medication is handled differently per parent and school (experiences)
Involvement of the children	<ul style="list-style-type: none"> • The cooperation between care providers and school is unclear (experiences) • Parents act as intermediaries between the care providers and school (experiences) • There is a lack of communication between the child and the parents, school, and care providers regarding their needs (needs) • Children prefer a change in the interaction at home or school (preferences)

	<ul style="list-style-type: none"> • There is a difference in knowledge between children regarding the importance and therefore the need for follow-up care (needs)
Equality of interaction	<ul style="list-style-type: none"> • Difference in experience regarding equality of interaction (experiences) • Children want to be treated equally at school as the other children without ADHD (needs)
Degree of openness of the children	<ul style="list-style-type: none"> • Some children have a need to talk about their ADHD because they consider it as useful (needs) • Some children consider it as not nice or annoying to share their experiences with ADHD and have therefore lower need to talk about their ADHD (needs)
Accessibility of the follow-up care	<ul style="list-style-type: none"> • The timing of the follow-up care depends on the wellbeing of the child (experiences) • Children prefer the location of the follow-up care close to home or do not have a preference (preferences) • Children prefer the person of the follow-up care over the distance to the follow-up care (preferences) • The preference of the frequency of the follow-up care differs per child (preferences)
A person of trust	<ul style="list-style-type: none"> • The follow-up care is often executed by the same person (experiences) • Children prefer the follow-up care from one and the same person (preferences) • Children prefer the follow-up care from a secondary care provider over the GP (preferences)

In the next paragraphs, themes regarding the experiences, needs, and preferences of the follow-up care are clarified and supported by quotations of the interviews. The transcript number and participant identifier are presented after each quotation. The original Dutch quotations and the transcript line numbers can be found in appendix H.

5.2.1 Transfer of responsibility

The theme transfer of responsibility is about the responsibility of the follow-up care that is transferred from secondary care to the GP. When a child is stable or no longer receives therapy from secondary care providers, the follow-up care is performed by the GP instead of secondary care providers.

The follow-up care is provided at regular intervals when secondary care providers have the responsibility

This sub-theme outlines that the follow-up care is done at regular intervals when the secondary care providers, like Mediant or Karakter, have the responsibility. Children indicated that they have follow-up care from secondary care providers once every two months.

The follow-up care is not provided at regular intervals when the responsibility is transferred to the GPs

GPs get the responsibility for the follow-up care when the child is stable or no longer has therapies in secondary care. Children indicated that they did not receive any follow-up care or only once a year when the GP is responsible. One child who does not take medication pointed out that he did not ever received any follow-up care from a GP. The children did not receive the follow-up care at regular intervals when the GP has the responsibility.

Differences in the completeness of the provided follow-up care of secondary and primary care

The complete follow-up care exists of measuring the vital signs, examine the treatment adherence, and talking about the wellbeing of the child. Regarding secondary care, children pointed out that during the follow-up care, secondary care providers measured the vital signs and talked about the child's wellbeing. They talked about events that happened at school or at home. All children, except for two children who do not (yet) received follow-up care, have experienced follow-up care and could describe the procedure of the follow-up care.

'Then they, you have to stand on a scale then you are weighed, then they look how big you are, and you have here such blood pressure pump and then they will pump it, and then they put their fingers on your arm to see what your heartbeat is.' (transcript 7: D)

However, for the two children who received follow-up care from a GP, it is unclear if the GP, besides measuring the vital signs, talked with the child about how it is going. It is unclear if the GPs execute the follow-up care completely.

5.2.2 Dependency of the children on their environment

This theme implies that children are dependent on how the environment copes with their ADHD and therefore, how they experience the follow-up care.

The experience of children with the follow-up care differs per school

Children are dependent on the schoolteachers and their coping-mechanism with ADHD, which affects how the children experience the follow-up care. The interviews showed that teachers cope with the hyperactivity or concentration problems of the child with the use of different tools, e.g. a headphone or wobble cushion, which influences their behaviour positively. In contrast, sometimes, a teacher does not use tools and children feel that their teacher is angry with them because of the hyperactive behaviour.

'L: when is she mad at you?

D: if she thinks I do not listen well, or sometimes, she says that I am very busy' (transcript 7: D)

Children pointed out that they do not always have a conversation with the teachers regarding the behaviour at school, at home, or whether they need something to cope with their ADHD in class. One child indicated that the teacher personally asked how it is going. Often, children indicated that the teacher only asked in general in class how everyone is doing at the beginning of the day and not one-to-one to the child itself. The interviews showed that the children do not have contact with the internal tutors at school regarding the ADHD. The children indicated that they are not familiar with an internal tutor or they commented that they only have to go to an internal tutor when they have had a conflict with other children.

The experience of children with the follow-up care depends on the parents

The children are dependent on their parents and their coping-mechanism with ADHD, which affects how the children experience the follow-up care. The interviews showed that parents use different methods to cope with the hyperactivity of the child. Some parents allow their child to play outside to lose his energy and other parents have help from social district teams. Children indicated that they depend on their parents regarding the possibilities of buying tools for the child, e.g. a wobble cushion, to decrease hyperactive behaviour. Frequently, children indicated that another family member has ADHD as well, which can cause complex family situations and influences the behaviour of the child.

'(name brother) is very busy, daddy is very busy, I am very busy, and that is very annoying for mama and yes, everyone' (transcript 8: E)

The medication is handled differently per parent and school

Children depend on their parents and school regarding the dealing with and the providing of the medication. Of the nine interviewed children, seven take stimulants which has a positive effect on their behaviour. One child who does not take medication indicated that his parents are against the use of medication, and therefore he does not take medication and still experiences concentration problems. This shows the dependency of the children regarding the choice of treatment of their parents. In addition, some children indicated that they only take medication at school and not at home or in the weekend. Some children pointed out that they are responsible for their own medication or sometimes the parents hand over the medication to the children. Regarding school, one child described that the teacher and classmates were helping him remember to take his medication. In addition, in one case, the teacher saves reserve medication in class. In contrast, one child pointed out that the teacher sometimes forgot to help him remember to take his medication. Consequently, the child suffered from stomach discomforts.

'Yes, because most of the time, always if I have to take my medication at school, at the second break, then the teacher always says it and then I am, I get used to the fact that the teacher says it every time. And then one day, the teacher forgets it again, and then I forget to take my medication, and then I already eat and have to take my medication, and then sometimes, I get stomach acid.' (transcript 9: F)

5.2.3 Involvement of the children in the follow-up care

The involvement of children in the follow-up care implies the communication and cooperation between the child and the parents, school, and care providers.

The cooperation between care providers and school is unclear

Parents, school, and care providers have to cooperate and communicate with each other during the ADHD trajectory of the child. However, children indicated that it is often unclear for them if and how the school and care providers cooperate and coordinate care. The children pointed out that they have not seen a person from a primary or secondary care provider at school or do not know if a care provider ever cooperates with school.

Parents act as intermediaries between the care providers and school

Children indicated that their parents act as intermediaries to communicate between care providers and school about the ADHD trajectory. Children described that parents have to communicate changes or recommendations from the care providers to the school teacher, but children do not know exactly what is being passed on.

'Karakter is going to say it to my parents, my mother is going to say it to the teacher that he should pay attention to this and such things.' (transcript 4: A)

There is a lack of communication between the child and the parents, school, and care providers regarding their needs

The needs of the children should be communicated with the parents, care providers and school. During the interviews, it became apparent that children often have a need for support regarding their ADHD, but there is not asked or listened to that need. Children indicated they want more help or guidance at school, some children pointed out a need for a place of rest at home to be able to unwind, and some children have a need to make use of a tool at school, e.g. a headphone.

'Yes, a headphone, if there is a lot on the corridors, outside, the classrooms and corridors are, the walls are not very thick, so you can hear everything' (transcript 9: F)

Children prefer a change in the interaction at home or school

The interviews showed that children preferred a change at school or at home. Regarding home, children preferred a change regarding improvement of its own behaviour or the need for a place of rest. Regarding school, the children indicated they prefer a change at school regarding to do better at math or the need for a tool to be able to increase their concentration. Children pointed out they have a need at school to use a headphone, change of place in the classroom, a drawing sheet, or a wobble cushion.

There is a difference in knowledge between children regarding the importance and therefore the need of follow-up care

The interviews showed a difference in knowledge of children about the importance of the follow-up care which results in different needs in follow-up care. Seven of the nine children indicated they need these follow-ups, apart from the fact that measuring the blood pressure is seen as unpleasant by one child. Some children understand and can explain very well why they need the follow-up care.

'I would like it to see if I still have ADHD or if it is still going well' (transcript 4: A)

'They have to find out how many milligrams I can have, because I then weight that high or something. Not that I get too much, that is not good for you' (transcript 7: D)

However, two of the nine interviewed children did not know why the follow-up care is important and indicated that they do not need follow-up care.

'I don't know; I don't think so really. Because then they only say if it is getting better or not, or that it is getting worse' (transcript 1: X)

5.2.4 Equality of interaction

Equality of interaction implies that children with ADHD are equally treated as other children without ADHD at school, home, sport club, and by their friends.

Difference in experience regarding equality of interaction

In the interaction between the child and their family, sports club and friends, children indicated that they are treated equally. Regarding school, some children indicated that the teacher treats them equally as other children in class. In contrast, some children pointed out that the teacher does not treat them equally as other children in class. One child described that he believes the teacher pays more attention to him because the teacher knows he has ADHD.

'But I think the teacher pays more attention to me, I think, because I have ADHD, and she thinks I am very busy, but that is not always the case. Sometimes, other children in class are busier than me, and to me, the teacher warns me very quickly, while I am not even that busy' (transcript 7: D)

Children want to be treated equally at school as the other children without ADHD

Most children indicated that they want to be treated normally. The interviews showed that the children want the teacher to treat them the same as the other children in class without ADHD. As the quotation below describes, children indicated that they do not want that the teacher pays too much attention to them. The children with ADHD pointed out that they do not want to feel special or different, they do not want to stand out in class.

'That I am very busy all the time, but she also has to pay attention to other children who are busier than me. That she is not specifically looking at me, only at how I am doing then. Because I have ADHD and she knows it, and the other children do not have ADHD, so she pays more attention to me' (transcript 7: D)

5.2.5 Degree of openness of the children

The degree of openness implies the extent to which the children talk about their ADHD.

Some children have a need to talk about their ADHD because they consider it as useful

The interviews showed that some children have a need to talk about their ADHD. Some children described that they have a need to tell their story to the healthcare providers or school teacher about their well-being. They pointed out to have a need for follow-up care and to talk about their problems.

*L: But you would like it if the teacher is coming to you to ask personally how it is going?
B: That is useful
L: Yes? Why do you think it is useful?
B: Because sometimes it is not really fun, but actually, sometimes, it is also not nice in class' (transcript 5: B)*

These children have told the class, friends, and sport that they have ADHD. They indicated to have some support to other children with ADHD.

'I like that, then he knows how I handle it and how I act at school and stuff' (transcript 4: A)

Some children consider it as not nice or annoying to share their experiences with ADHD and have therefore lower need to talk about their ADHD

Some children indicated to have less need to talk about their ADHD and problems with healthcare providers and school teachers. They described that they do not want the teacher to ask how it is going. When a teacher asks in general to the class how it is going, it can be hard for a child to say what is really on its mind.

*'B: That it is just not really nice
L: What do you mean?
C: It is just not nice because then you also have to tell it to the whole class, sometimes that also is not nice' (transcript 5: B)*

Some children pointed out that they do not have a need to talk with healthcare providers because they do not need someone to interfere with them. The interviews showed that in some families there is not talked openly about ADHD. Therefore, some children described that they are not used to talk about ADHD and its additional problems. They indicated that they did not feel comfortable to tell their sport club about ADHD.

'Yes, but I think it is just really annoying when they interfere every time, because they think it is not going well or something' (transcript 7: D)

'Well I don't know, if you just having a conversation and you suddenly say 'hey I have ADHD'. If someone asks about it I would say yes, but I do not say it like that from my own' (transcript 3: Z)

5.2.6 Accessibility of the follow-up care

The accessibility of the follow-up care implies the location and the travel distance to the follow-up care, the frequency of follow-up care, and the timing of the follow-up care.

The timing of the follow-up care depends on the wellbeing of the child

The follow-up care takes place at a certain timing. Children indicated that they receive (more) follow-up care when their behaviour deteriorated, which implies, e.g. a decrease in the concentration at school, increase in hyperactive behaviour, and sleeping problems.

L: But you don't have to go to Mediant anymore?

F: No, because it is going pretty well' (transcript 9: F)

'It depends on how it is going. If it is going less well, then, for example, I have to go back again to have another conversation about that' (transcript 7: D)

The quotations describe that the children have less appointments with the care providers when the behaviour improves and the children have an increase in appointments when the behaviour deteriorates. In addition, children indicated that they receive less attention at school when the behaviour improves as well. For example, children described that the teacher does not have a conversation about their ADHD anymore, because the performance of the child at school has improved.

Children prefer the location of the follow-up care close to home or do not have a preference

The interviews showed different preferences regarding the location of the follow-up care. Most children did not indicate the distance of the follow-up care as unpleasant. Still, some children commented they prefer the follow-up care close to home, so they can go there by themselves. In contrast, some children did not have a preference regarding the location of the follow-up care.

'Because I just, I don't mind where it is' (transcript 7: D)

Children prefer the person of the follow-up care over the distance to the follow-up care

The GP is often settled closer to the home of the children than secondary care providers. Nevertheless, one child considers it more important by who the follow-up care is provided than the travel distance to the location of the institution.

L: So, you prefer that? If it was closer?

C: yes

L: Because the general practitioner is a bit closer from here

C: I do not know

L: A general practitioner in (name of the city)

C: Then I think, it is closer

L: Yes, would you then prefer to go to the general practitioner?

C: No

L: No? and why not?

C: Because I like to talk to (name youth psychiatrist) much more' (transcript 6: C)

The preference of the frequency of the follow-up care differs per child

The preferences regarding the frequency of the follow-up care differs per interviewed child. The follow-up care is preferred by the interviewed children from once a year to twice a week, related to the experiences of the children with the follow-up care. Children who had more or positive experiences with the follow-up care, preferred a higher frequency of follow-up care comparing with children with

a less or negative experiences with the follow-up care. The children commented they prefer a conversation with a teacher about how it is going from once to twice a week. In contrast, some children indicated they do not have a preference regarding the frequency of follow-up care given. The interviews showed that some children only want to have a conversation about their wellbeing when they think it is needed or only when someone explicitly asks the child.

5.2.7 A person of trust

This theme implies that children trust the person who provides the follow-up care.

The follow-up care is often executed by the same person

The follow-up care is executed by a person from primary or secondary care, like a GP or a youth psychiatrist. The interviews showed that in one child, the follow-up care was not performed by the same person, which she described as 'not convenient'. All other children indicated that they received follow-up care by the same person.

Children prefer the follow-up care from one and the same person

The interviews showed that the children who have a need for follow-up care, prefer to be helped by the same person during all follow-ups. The children indicated that they prefer the same person with whom they can share their story and who measures the vital signs. The children commented they prefer the same person for the follow-up care, because then the person is familiar with the children. In addition, some children suggested that they know what to expect during the follow-up care when they are treated by the same person. One child pointed out that he preferred one person who he can talk to instead of different persons. The children pointed out that they prefer to talk to a secondary care provider, their parents, teacher or friends. Overall, the children indicated they prefer to know the person who is performing the follow-up care.

'She knows where I still suffer from, and she also knows how to help me instead of when I have someone else who does everything over again' (transcript 6: C)

'No, not from school and neither from the general practitioner. No, actually only someone who knows me well.' (transcript 3: Z)

Children prefer the follow-up care from a secondary care provider over the GP

Some children indicated the GP as not preferable regarding the providing of follow-up care. This is because the GP has not enough knowledge about the ADHD according to the children. Regarding the performance of the follow-up care, four of the nine interviewed children explicitly preferred a person from a secondary care provider, like Mediant or Karakter. Children prefer to talk to someone from a secondary care provider, because they know the children from the beginning, have the knowledge, and they listen better. Two children commented they prefer a secondary care provider regarding the follow-up care, because the conversation remains between the child and the secondary care provider.

'The general practitioner does not know it; at Karakter they just have... If I have pain in my leg or something, then they send me, I do not know exactly anymore where they send me, somewhere to look how well I am, but they do not know that I have ADHD.' (transcript 4: A)

'By the same person who, who helped me the first time, who knows who I am, what I am and how bad it is' (transcript 4: A)

6 Conclusion and discussion

This research assessed the perspective of the children regarding the current ADHD follow-up care. Through interviews with nine children, it was identified how the ADHD follow-up care is currently experienced by these children and what these children's needs and preferences are. This gave important information on how the follow-up care should be provided according to these children with ADHD.

6.1 Conclusion

Regarding the experiences, it can be concluded that the follow-up care is done at regular intervals when secondary care providers have the responsibility. However, when the responsibility is transferred from secondary care to GPs, it is remarkable that the follow-up care is not done or provided only once a year and also, it is unclear if the GPs perform the follow-up care completely. Most children experienced that the follow-up care is being executed by the same person. Some children only receive follow-up care when their behaviour and/or performance at home and school has deteriorated. The cooperation between school and care providers is often unclear for the children. The children indicate that their parents act as intermediaries between school and care providers. Another striking finding is that the teachers and parents cope differently with the child and their ADHD and medication, which influences the behaviour of the child and therefore the experiences with the follow-up care.

Regarding the needs, it can be concluded that some children have needs at home or school, e.g. a place of rest or the use of a tool, but it is remarkable that there is no communication about these needs between the child and the parents, teachers, or care providers. Another finding is that the children have a need to be treated equal to other children at school. Most children have a need for follow-up care. However, it differs per child to what extent they have a need to talk about their ADHD. In addition, children with knowledge about the follow-up care have higher need in follow-up care comparing with children with less knowledge about the follow-up .

Regarding the preferences for the follow-up care, it can be concluded that the children prefer to be treated by one and the same person who is familiar with them. The children prefer a secondary care provider over a GP regarding the performing of the follow-up care, because they know the children from the beginning, have knowledge about ADHD, listen well, and provide confidentiality of the conversation. Children have different preferences regarding the location of the follow-up care. Some children prefer the follow-up care provided close to home, some do not have a preference, and some consider the person who gives the follow-up care as more important than the location of the follow-up care. Another notable finding is that the preferences regarding the frequency of the follow-up care strongly differs per child, related to the experiences of the children with the follow-up care. The preferences are ranging from once a year to twice a week.

Answering the research question about how the follow-up care should be provided, it can be concluded that the follow-up care should be provided by one and the same person, who the children know and knows them, has knowledge about ADHD, treats the children equally, and communicates with the children about their needs. The distance to the follow-up care should be small or has no preference. The follow-up care should be provided from once a year to twice a week.

6.2 Comparisons with the literature

The finding that children do not receive any or only receive follow-up care once a year, falls below the standards described in the Dutch national multidisciplinary guideline.¹ This finding of poor follow-up care is consistent with a Dutch study from Faber et al.¹⁵ In addition, similar findings were found in a study performed in the United States.¹¹ The finding that there are no regular intervals of follow-up care when the responsibility of the follow-up care is transferred from secondary care to GPs, can be confirmed by the research from Faber et al. as well.¹⁵ They stated that the follow-up care under supervision of the GPs suggests an urgent need for improvement.^{11,15}

The Dutch national multidisciplinary guideline state that the follow-up care should be provided by a physician with knowledge and experience with ADHD to be able to examine the medical treatment.¹ This is in line with the statements made by the interviewed children about the knowledge of secondary care providers. However, the interviewed children do not believe a GP has enough knowledge about ADHD. The lack of knowledge in GPs regarding ADHD can be confirmed by several studies, who state that GPs consider themselves not sufficiently competent to take over the monitoring of the medical treatment of children from specialists from secondary care.¹⁷⁻²⁰ However, by improving the knowledge of GPs regarding ADHD, GPs felt confident to start and monitor ADHD medication in children with uncomplicated ADHD.^{13,17}

The NHG directive and Dutch national multidisciplinary guideline describe that GPs have to focus on the measurement of the vital signs, assessment of the medication adherence, and the providing of follow-up prescriptions during the follow-up care.^{1,2} In addition, according to Health Council of the Netherlands, the general practice should have a more central role in the ADHD trajectory.⁷ This is not in line with the preferences described by the interviewed children, they indicated the GP as not preferable regarding the providing of the follow-up care. This is because the interviewed children do not believe the GP knows them well enough. This is in contrast with an article of mental health care physician and GP van Manen et al.¹⁶ According to their opinion, the GPs should be more involved in the ADHD trajectory because a GP is familiar with the children.¹⁶ However, when GPs are more involved in the ADHD trajectory, children may see the GP as familiar and are more willing to obtain follow-up care from them.

Regarding the conclusion of the dependency of children, it is found that children depend on their environment regarding their experiences with care. This is in line with research from Mangione-Smith et al.⁶⁷ In addition, the children indicated that their parents and teachers cope differently with the ADHD, which can be confirmed by several studies.⁶⁸⁻⁷⁰ The interviews showed that children depend on their parents regarding medication use. This is consistent with a research from Charach et al., which state that parents are the key decision makers regarding their child's care.⁷¹ The finding that parents cope differently with medication complies with several studies focused on simulant use in children with ADHD.⁷¹⁻⁷³ These studies showed that there exists multiple factors which influences parents decisions about the use of stimulants.⁷¹⁻⁷³ However, none of these studies are initiated from experiences of children, but from experiences of teachers and parents.

The interviews showed that there is a lack in the involvement of children during their ADHD trajectory. Through the lack of involvement, children experienced a lack of communication about their needs and a lack of knowledge about ADHD. This finding is consistent with several studies which state that there is a lack in conversational contribution of children, lack in involvement in the decision-making process, and they state that children are not content with the lack of communication.⁷⁴⁻⁷⁶ There are no studies done regarding the children's involvement explicitly in ADHD and there is a little data collected about the children's experiences of involvement.⁷⁴ However, there is evidence which state that certain groups are less likely to be involved in the care process, like children with disabilities.⁷⁴ There should

be an improvement in the communication with the children about their wellbeing and needs regarding the ADHD, by including reports from parents and teachers regarding educational and behavioural progress, provided monthly, to be able to have an optimal management of the follow-up care.⁷⁷

The MOCHA conceptual framework is used to compare the identified themes and the determinants of primary care quality.²⁹ Some determinants of the framework seem to correspond with the identified themes which emerged during the interviews, including 'dependency of the children on their environment', 'accessibility of the follow-up care', 'degree of openness of the children', 'transfer of responsibility', 'a person of trust', and 'involvement of the children'. However, the identified theme 'equality in interaction' is not mentioned as determinant in the framework. The framework mentioned the importance of equality in access and health, but not in interaction at e.g. school by the teachers. In addition, the MOCHA determinant 'coordination of care' seems not to correspond with any of the identified themes. This determinant did not emerge during the interviews and might be not important for children. Regarding the definitions of some determinants of the framework, it is noticed that there is more focus on a parents' perspective instead of the perspective of the children. Like in the determinant 'empowering', which defines the subdomain 'skills' as "*Enhances the skills in taking care of my child and my child's health.*"⁷⁸, the focus is on the skills of the parents instead of the children. In addition, the framework did not embed the school and secondary care. The framework does embed the integration of primary- and secondary care, but the focus of this framework is on the primary care.²⁹ However, regarding the follow-up care for children with ADHD, also professionals at school, professionals at secondary care, and social district teams are involved.²⁴ The interaction at home was often mentioned by the children during the interviews and is not mentioned in the framework as well. These persons and providers are not mentioned in the framework but may influence the quality of care. To be able to gather complete knowledge of the quality of the ADHD follow-up care, the framework should be more focussed on the children's perspective and the interaction between all providers who are involved or can affect the follow-up care.

6.3 Strengths and limitations

The results gave various insights in the quality of the follow-up care from the perspective of children. A strength of the thematic analysis is that through the open approach of coding and defining of themes, the researcher was able to generate unanticipated findings and insights in the experiences, needs, and preferences of the children. Another strength of this research is the fact that the first two interviews were coded by two persons and a high Cohen's kappa was calculated. This indicated a high interrater reliability of the coded interviews.⁶⁶

A limitation of this research is that saturation of the data has not been reached after nine interviews. Therefore, it is not guaranteed that this research obtained all aspects. Another limitation is that only children attending schools in Enschede were recruited for this research. This will influence the outcome regarding the representativeness of the results for children with ADHD in the region of Twente. In addition, more boys than girls were interviewed, which indicate that this study may have little generalizability. However, overall, more boys than girls are diagnosed with ADHD¹, which makes the interviewed group of children more representative. Another limitation is the risk of selection bias due to the process of recruitment. The contact persons who searched and contacted eligible children might have had a reason to choose one child over another child for this interview. Moreover, it could be that only parents with a stable family situation allow their child to participate in this research. This might lead to the fact that the results cannot be generalised.

The researcher had no experience with qualitative research and conducting of interviews with children. Therefore, the quality of the first interviews may differ from the last interviews as the interviewer was able to practice her interview skills. This may have affected the internal validity of the results of this study. To compensate this, the researcher has practiced her interviewing skills beforehand. In addition, the six stage plan for thematic analysis by Braun & Clarke is used as a method for the data analysis, which is an accessible method for researchers with little or no experience with qualitative research.⁶⁵

6.4 Implications

The results of this research can be of value for professionals to improve the quality of the follow-up care and to improve the clinical guidelines of the ADHD follow-up care. The results of this research can be of value for the municipalities of Twente in the distribution of care purchase for ADHD.

Through the exploratory nature of this research, it is necessary to have further research to gain more insight in the quality of the ADHD follow-up care. Therefore, it is recommended to:

- Expand the research to other regions or provinces in the Netherlands, because the experiences regarding the follow-up care could be different per region.
- Do further research with children about the preferences regarding the frequency of the follow-up care by doing more interviews, because the interviews showed a strong difference in preferences in this.
- Do further research on the possibilities of the involvement of the school during the follow-up care, e.g. the possibilities for a more prominent role for teachers and internal tutors, because some children described they have a need to talk about their ADHD with their teacher.
- Do further research whether the GP, besides measuring the vital signs, asks the children about their wellbeing and treatment adherence, because the children indicated that it is unclear whether the GPs perform the complete follow-up care.
- Investigate the experiences, needs and preferences of the follow-up care focused on children who do not take medication, because this research obtained little information about the follow-up care at children who do not take medication.
- Do further research with different professionals, i.e. GPs, physicians working in youth health care, and child psychiatrists, to investigate which person suits the preferences of the children regarding the providing of the follow-up care.
- Develop a framework that measures the quality of care of children with ADHD that takes all providers into account, because the MOCHA conceptual framework is focussed on children as well as caregivers and is mainly focused on primary care.

This research gave insight in how the follow-up care should be provided conform children with ADHD, which can be applied in practice. Therefore, it is recommended to:

- Increase the communication between the children and their teachers, parents, and care providers about the children's needs, because there is no frequent communication about those needs.
- Have regular conversations by the teachers, parents, and care providers with the children about their wellbeing, also when the child's behaviour and performance at school is improved. The child should be monitored frequently.
- Increase the involvement of the children in the care process at school or during the follow-up care. To achieve this, it is recommended that the parents, teachers, and care providers

communicate more with the children about the importance of the follow-up care, so they are more involved in, and have more knowledge about their ADHD.

- Improve the provision of the follow-up care by GPs by adhering to the guidelines.
- Treat the children equal in class by the teacher, despite the fact whether children have ADHD or not.
- Create agreements between the teachers, parents and children regarding the providing of medication at school.
- Create a guideline regarding the role and responsibilities of teachers in the dealing with medication in class, because it seems that the children get too much responsibility in this.
- Improve the providing of information to the parents about the use of medication, to increase the medication adherence among children.

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8 Abbreviations

ADHD	Attention-Deficit/Hyperactivity Disorder
DIPEX	The Database of Individual Patients' Experiences
GPs	General practitioners
NHG	Dutch College of General Practitioners
IOM	Institute of Medicine
MOCHA	Models of Child Health Appraised
PIF	Personal Information Form
WHO	World Health Organisation

Appendix A: determinants of primary care quality

Table 3: Description of the determinants of primary care quality

Factor	Subdomain	Definition
Affordable	Affordability of PC	Financial barriers to receive primary care services, such as co-payments and cost-sharing arrangements ⁵¹ .
Accessible	Availability of PC	The volume and type of primary care services relative to population needs ⁵¹ .
	Geographic accessibility of PC	Remoteness of services in terms of travel distance for patients ⁵¹ .
	Accommodation of accessibility	The manner in which resources are organized to accommodate access (e.g. appointment system, after-hours care arrangements, home visits) ⁵¹ .
Acceptable	Acceptability of PC	People's willingness to seek services, based on their judgement of effectiveness of the service and whether or not they are treated with dignity and respect ⁵² .
Appropriate	Appropriateness of service	A service that is expected to do more good than harm for a patient with a given indication or set of indications ⁵³ .
	Appropriateness of setting	Whether the patient's clinical characteristics, and the services required for his or her care, match the setting in which the care is provided ⁵³ .
Continuous	Longitudinal continuity of care	Having a long-term relationship between primary care providers and their patients in their practice beyond specific episodes of illness or disease ⁵¹ .
	Informational continuity of care	An organized collection of each patient's medical information readily available to any health care provider caring for the patient ⁵¹ .
	Relational continuity of care	The quality of the longitudinal relationship between primary care providers and patients, in terms of accommodation of patient's needs and preferences, such as communication and respect for patients ⁵¹ .
Coordinated	Gatekeeping system	The level of direct access for patients to health care providers without a referral from a primary care provider ⁵¹ .
	Primary care practice and team structure	The extent to which practices are shared, team size and tenure ⁵¹ .
	Skill-mix of primary care providers	Diversification and substitution of primary care providers ⁵¹ .
	Integration of primary care-secondary care	Care integration can be achieved through specialist outreach models and clinical protocols facilitating shared care ⁵¹ .
	Integration of primary care and public health	The extent to which primary care providers collaborate with practitioners from the public health sector to provide services that influence health ⁵¹ .
Equable	Equality in access	The extent to which access to primary care services is provided on the basis of health needs, without systematic differences on the basis of individual or social characteristics ⁵¹ .

	Equity in Health	The absence of systematic and potentially remediable differences in health status across population groups ⁵¹ .
Empowering	Knowledge	Providing the required medical knowledge to manage their own health ⁷⁸ .
	Skills	Enhances the skills in taking care of my child and my child's health ⁷⁸ .
	Involvement	Being involved in decisions about ones health ⁷⁸ .

Personeninformatie voor deelname aan kwalitatief onderzoek

De follow-up zorg van kinderen met ADHD: wat vinden kinderen zelf?

Inleiding

Geachte heer/mevrouw,

U ontvangt deze brief omdat uw kind ADHD heeft. Ik wil u vragen of uw kind mee mag doen met een verkennend onderzoek. Ik zou graag met uw kind willen praten over zijn/haar ervaringen met de begeleiding van zijn/haar ADHD. Meedoen is vrijwillig. Omdat uw kind jonger is dan 12 jaar, is er schriftelijke toestemming van u nodig om mee te doen. Voordat u beslist of uw kind meedoet aan dit onderzoek, krijgt u uitleg over wat het onderzoek inhoudt. Lees de informatie rustig door. U kunt mij om uitleg vragen bij eventuele onduidelijkheden.

Algemene informatie

Ik stel mij graag eerst voor. Mijn naam is Laura van Schie en ik ben momenteel bezig met mijn afstudeeropdracht van de master Health Sciences (gezondheidswetenschappen) aan de Universiteit van Twente (UT). Hiervoor doe ik in opdracht van de GGD Twente onderzoek gericht op de zorg bij kinderen van 9 tot 11 jaar met ADHD. Het gaat dan vooral om de zorg die geleverd wordt nadat de diagnose ADHD is gesteld en er is gestart met een behandeling. We noemen dat: follow-up zorg. De follow-up zorg bestaat uit het volgen en evalueren van uw kind. Dit is belangrijk om de behandeling zo goed mogelijk af te stemmen op uw kind en de bijwerkingen tot een minimum te beperken.

Doel van het onderzoek

Het doel is om inzicht te verkrijgen in hoe de ADHD follow-up zorg zou moeten worden gegeven volgens kinderen tussen de 9 en 11 jaar met ADHD. Ik wil graag meer weten over de ervaringen die uw kind heeft met de follow-up zorg. Daarnaast wil ik erachter komen wat de behoeften en voorkeuren zijn van uw kind met betrekking tot de follow-up zorg. Dit inzicht kan mogelijk gebruikt worden om de follow-up zorg te verbeteren.

Achtergrond van het onderzoek

Momenteel zijn er aanwijzingen dat de ADHD follow-up zorg niet goed verloopt. Hierdoor moeten kinderen en ouders voor deze zorg vaak langdurig naar gespecialiseerde geestelijke gezondheidszorg diensten. Dit heeft lange wachtlijsten en dure zorg tot gevolg. De follow-up zorg wordt bij voorkeur dicht bij huis gegeven, passend bij de persoonlijke omstandigheden van het kind en zijn/haar familie. In een eerder onderzoek werden vragen hierover aan ouders gesteld. Wij willen nu graag ook aan kinderen vragen wat hun ervaringen en behoeften zijn. Mogelijk kan de follow-up zorg met deze kennis beter worden afgestemd op wat zij nodig hebben.

Wat houdt meedoen in?

Om achter de ervaringen en behoeften van kinderen met ADHD te komen met betrekking tot de follow-up zorg, wil ik een interview met uw kind houden. De interviews duren naar verwachting tussen de 30 en 45 minuten. Het interview vindt plaats bij u thuis of op een andere plek, afhankelijk van uw wens of de wens van uw kind. Het tijdstip voor het interview wordt overlegd met u. Het interview zal op elk moment gestopt worden wanneer uw kind of uzelf dit aangeeft. Hiervoor hoeft u geen reden te geven. De interviews worden opgenomen met een audiorecorder. Na verwerking van de resultaten zal de opname worden vernietigd.

Waarom uw kind?

U wordt gevraagd om uw kind deel te laten nemen aan het onderzoek omdat:

- Uw kind tussen de 9 en 11 jaar is;
- Gediagnosticeerd is met ADHD zonder comorbiditeit (geen andere stoornissen);
- Hiervoor behandeling krijgt, dit kan medicamenteus of niet medicamenteus;
- Nederlands spreekt

Wat wordt er van u verwacht?

Het interview is bij voorkeur alleen met uw kind; als uw kind angstig is zonder het bijzijn van u of uw partner, kunt u in de ruimte aanwezig blijven.

Mogelijke risico's van het onderzoek

Er zijn geen risico's verbonden aan dit onderzoek.

Mogelijke voor- en nadelen

Een voordeel van deelname aan het onderzoek is dat de onderzoeksresultaten zullen helpen bij het afstemmen van de follow-up zorg op de behoeften en voorkeuren van kinderen met ADHD. Dit zal uiteindelijk de kwaliteit van de follow-up zorg kunnen verbeteren. Nadelen van deelname voor u en uw kind is dat het tijd kost om het interview te houden. Het interview heeft geen gevolgen voor de behandeling van uw kind.

Als u niet wilt dat u kind meedoet of wilt stoppen met het onderzoek

U beslist zelf of uw kind meedoet aan het onderzoek. Deelname is vrijwillig. Tevens wordt er bij uw kind om toestemming gevraagd voor deelname.

Het interview zal gestopt worden wanneer uw kind of uzelf dit aangeeft, met of zonder reden.

Einde van het onderzoek

Deelname aan het onderzoek stopt als:

- Het interview is afgenomen bij uw kind
- U of uw kind zelf kiest om te stoppen
- GGD Twente of Universiteit Twente besluit het onderzoek te stoppen

Het onderzoek is klaar als er 6-8 kinderen geïnterviewd zijn. Na het verwerken van de resultaten zal ik u informeren over de belangrijkste uitkomsten van het onderzoek.

Hoe garanderen we de vertrouwelijkheid van de informatie?

Elke deelnemer krijgt een identificatienummer dat op de gegevens komt te staan. Tijdens het uitwerken van de interviews, zullen persoonsgegevens (zoals namen en specifieke locaties) verwijderd worden of vervangen worden door een identificatienummer.

Alle gegevens van uw kind blijven vertrouwelijk en worden geanonimiseerd opgeslagen. Alleen ik als onderzoeker weet welk identificatienummer uw kind heeft. Daarnaast kunnen alleen bevoegde personen, zoals mijn supervisors van de UT, toegang krijgen tot de verzamelde geanonimiseerde gegevens om te controleren of het onderzoek goed en betrouwbaar uitgevoerd is.

Heeft u vragen?

Bij vragen kunt u contact opnemen met mij, Laura van Schie, via e-mailadres l.m.vanschie@student.utwente.nl.

Ondertekenen toestemmingsformulier

Als u toestemt dat uw kind meedoet aan het onderzoek, zal voorafgaand de interviews gevraagd worden de toestemmingsverklaring te ondertekenen. Het is nodig dat beide ouders/wettelijke verzorgers de toestemmingsverklaring voor ouders/voogden ondertekenen. Omdat uw kind jonger is dan 12 jaar, hoeft uw kind dit niet te ondertekenen. De toestemmingsverklaring wordt ook door mij ondertekend. Nadat de toestemmingsverklaring is ondertekend zal het interview beginnen.

Bedankt voor uw tijd en aandacht om deze informatiebrief te lezen.

Met vriendelijke groet,
Laura van Schie

Begeleiders UT:
Dr. M.M. Boere-Boonekamp
Dr. J.A. van Til

Begeleider GGD Twente:
Drs. M.T. Cerneus

Begeleider Karakter:
S. van Rosmalen - Kaijadoe

Personeninformatie voor deelname aan kwalitatief onderzoek

De follow-up zorg van kinderen met ADHD: wat vinden kinderen zelf?

Hoi!

Ik wil je graag uitnodigen om mee te doen met mijn onderzoek! Je mag zelf weten of je mee wilt doen. Maar voordat je besluit mee te doen, wil ik je graag wat uitleggen over het onderzoek. Dit staat hieronder beschreven. Dit mag je rustig doorlezen en erover praten met je ouders. Je mag mij om hulp vragen als je iets niet snapt.

Even voorstellen

Ik stel mij graag eerst even voor. Ik ben Laura en ben momenteel bezig met een opdracht voor mijn studie. Ik doe namelijk onderzoek over kinderen met ADHD, dit gaat dus ook over jou!

Waar kan jij mij bij helpen?

Jij kan mij erg helpen bij het onderzoek! Ik wil namelijk graag meer weten over de zorg die jij hebt gekregen sinds je weet dat je ADHD hebt. Hierbij wil ik graag weten hoe jij vindt dat dit nu gaat en hoe jij graag wilt hoe deze zorg eruitziet. We hopen hiermee de zorg te kunnen verbeteren.

Wat gaat er gebeuren?

Om erachter te komen wat jij graag wilt, zou ik het erg leuk vinden om met jou te praten! Dit gebeurt bij jou thuis of op een andere plek, als jij of je ouders dat willen. De interviews zullen ongeveer een half uur duren. Als je tijdens het gesprek wil stoppen, dan kun je dit gewoon aangeven en stoppen we meteen. Je mag zelf weten of je mee wilt doen. Alleen ik ben aanwezig bij het gesprek. Het gesprek zal worden opgenomen en na mijn onderzoek gooi ik de opname weg.

Waarom vraag ik jou?

Jij bent de perfecte persoon om mee te praten omdat jij tussen de 9 en 11 bent en ADHD hebt.

Heb je nog vragen?

Als je iets niet snapt kun je dit vragen aan je ouders of aan mij.

Groetjes,
Laura van Schie

Appendix D: written informed consent (in Dutch)

Toestemmingsverklaring

Voor deelname aan het kwalitatieve onderzoek:
ADHD follow-up zorg: het kinderperspectief

VOOR DE OUDERS/VOOGD:

Ik ben naar tevredenheid over het onderzoek geïnformeerd. Ik heb de schriftelijk informatie goed gelezen. Ik weet dat de gegevens en resultaten van het onderzoek alleen anoniem en vertrouwelijk aan derden bekend gemaakt zullen worden. Ik ben in de gelegenheid gesteld om vragen over het onderzoek te stellen. Mijn vragen zijn naar tevredenheid beantwoord.

Ik begrijp dat tijdens het onderzoek audio wordt opgenomen en dat dit materiaal, of bewerking hiervan, uitsluitend voor analyse en/of wetenschappelijke presentaties zal worden gebruikt.

Ik heb goed over de deelname aan het onderzoek kunnen nadenken. Ik stem geheel vrijwillig in met de deelname aan dit onderzoek. Ik heb het recht mijn toestemming op ieder moment weer in te trekken zonder dat ik daarvoor een reden behoeft op te geven.

Ik stem toe met deelname van aan het onderzoek.

Achternaam en voorletters :

.....

Relatie tot de deelnemer:

.....

Datum:

.....

Handtekening:

.....

Achternaam en voorletters:

.....

Relatie tot de deelnemer:

.....

Datum:

.....

Handtekening:

.....

VOOR DE UITVOERENDE ONDERZOEKER:

Ondergetekende verklaart dat de hierboven genoemde personen zowel schriftelijk als mondeling over het bovenvermelde onderzoek geïnformeerd zijn. Hij/zij verklaart tevens dat een voortijdige beëindiging van de deelname door bovengenoemde persoon, voor haar/hem, verder geen gevolgen heeft.

Naam:

Functie:

Datum:.....

Handtekening:.....

Topic guide

De follow-up zorg van kinderen met ADHD: wat vinden kinderen zelf?

Naam deelnemer: (..... jaar)

Naam interviewer: Laura van Schie

Datum:

Locatie:

Introductie:

→ **PIFs doornemen:** tijd nemen voor de kennismaking (ouders en kind)

- Voorstellen
- Doel van het gesprek:
Ik wil graag meer weten over de zorg en begeleiding en controle die jij hebt gekregen sinds je weet dat je ADHD hebt (follow-up zorg). Hierbij wil ik graag weten hoe jij vindt dat dit nu gaat en hoe jij graag wilt hoe deze zorg eruitziet. We hopen hiermee de zorg te kunnen verbeteren.
- Duur van het gesprek
- Wat gebeurt er met de uitkomsten
*Gesprek wordt opgenomen en anoniem verwerkt
→ laat het kind zelf een naam kiezen die wordt gebruikt bij het anonimiseren (zelf bedachte naam of evt. naam van huisdier)*
- Mogen te allen tijde stoppen met het interview
- Controle of deelnemer voldoet aan de inclusiecriteria
- Vragen van ouders en kind?

→ **Written informed consent tekenen** (ouders en onderzoeker)

→ **Audio aanzetten**

Drie hoofd topics:

1. **Ervaringen: Positieve- en negatieve ervaringen met betrekking tot de follow-up zorg.**
2. **Behoeften: Behoeften van de kinderen met betrekking tot de follow-up zorg.**
3. **Voorkeuren: Voorkeuren van kinderen met betrekking tot de follow-up zorg.**

Topic guide en mogelijke vragen*:

1. Ervaringen

- Het kind zelf / familie
 - Hoe was het om te horen dat je ADHD hebt? Je weet dat je ADHD hebt, wat merk je daarvan? Wat zijn de voor- en nadelen? Hoe ga je hiermee om?
 - Hoe gaat het thuis? Heb je broertjes of zusjes? Hoe gaan zij en je ouders met jou om? Hoe vind je dit?
 - Hebben jouw ouders begeleiding gehad om met jouw ADHD te leren omgaan? Wat merk je hiervan?
- Vrienden / activiteiten
 - Weten je vrienden dat je ADHD hebt? Hoe gaan zij met jou om?
 - Ken je andere kinderen met ADHD? Hoe vind je dit?
 - Zit je op een sport/club? Hoe gaan ze hier met jou om? Hoe vind je dit?

* Hulpmiddel bij doorvragen: Welke smiley (verdrietig tot blij) vind het je het nu? Wat zou er anders moeten om bij de blij smiley te komen?

- School
 - o Weten ze op school dat je ADHD hebt? Wat merkt jouw juf/meester aan jou dat jij ADHD hebt? Hoe gaan ze hier mee om?
 - o Houden de meester/juffrouw rekening met jou in de klas op school? Vragen en luisteren ze naar jouw verhaal over hoe het gaat?
- Gezondheidszorg: zorgverleners
 - o Wie heeft ADHD vastgesteld? Wanneer was dit? Wat is er allemaal gebeurd nadat je weet dat je ADHD hebt (behandeling)?
 - o Word je wel eens gecontroleerd door bv. een huisarts/jeugdarts/etc. op hoe het met je gaat?
 - Zo ja, door wie dan? En wat doet degene dan precies tijdens zo'n controle moment? Word je altijd door hem/haar gecontroleerd of is het ook wel eens verschillend? Voel je je prettig bij hem/haar? Hoe vaak moet je er heen? Is het ver reizen? Hoe vind je het om op controle te gaan?
 - Zo nee, zou je dat fijn vinden dat er af en toe wordt gekeken hoe het met je gaat?
 - o Heb jij het gevoel dat er wordt samengewerkt tussen school, jou, je ouders, en je behandelaar (huisarts, jeugdarts/verpleegkundige, Karakter)? Hoe gaat dat?

2. Behoeften:

- Omdat je ADHD hebt, moet er af en toe gekeken worden hoe het met je gaat. Heb jij iets nodig wat ervoor zorgt dat je goed met je ADHD om kan gaan? (Zoals bijv. goede begeleiding vanuit school, steun van je ouders/vrienden)
 - o Zo ja, Wat voor begeleiding/controle heb jij nodig? (thuis / activiteiten buitenhuis (sport/clubs) / school / gezondheidszorg) Waarom heb jij dit dan nodig?
 - o Zo nee, waarom heb jij geen begeleiding/controle nodig?

3. Voorkeuren

- Voorkeuren in presenteren/gedrag van het kind
 - o Zijn er dingen waarvan jij vindt dat beter kunnen? (bijv. op school of contact met je vrienden etc.)
 - Zo ja, wat kan er dan beter? Waarom moet dit beter? Hoe zou jij dit kunnen bereiken? Wat heb je hiervoor nodig?
 - Zo nee, waarom niet?
 - o Wat zou je zelf beter willen kunnen? Waarom wil je dit? Hoe zou jij dit kunnen bereiken? Wat heb je hiervoor nodig?
- Voorkeuren in follow-up zorg
 - o Op welke plekken (thuis / activiteiten (sport/clubs) / school / gezondheidszorg) moet er als eerste iets veranderen? Welke situatie wil je verbeterd hebben? Waarom?
 - o Met wie kan je het beste praten? Wie luistert het beste naar jou? Waarom vind je dat? Hoe vaak wil je met diegene praten? Waar wil je dit (dichtbij huis of niet)?

Afsluiting

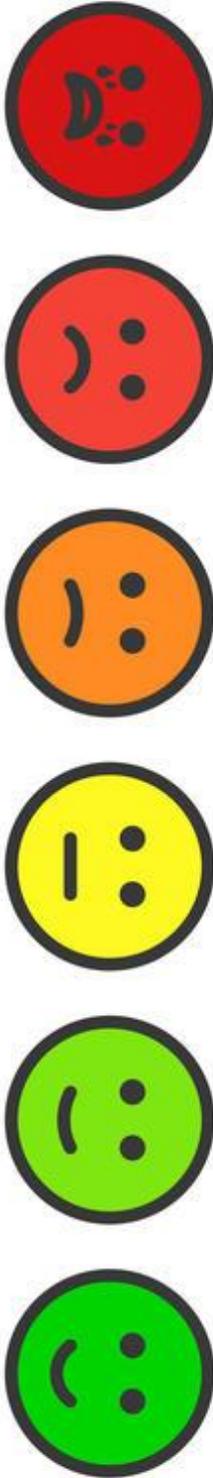
- Zijn er nog dingen we niet hebben besproken in dit gesprek?
- Heb je nog vragen aan mij?

→ Audio uitzetten

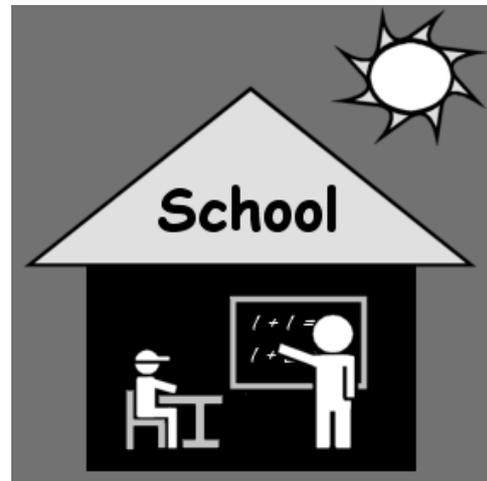
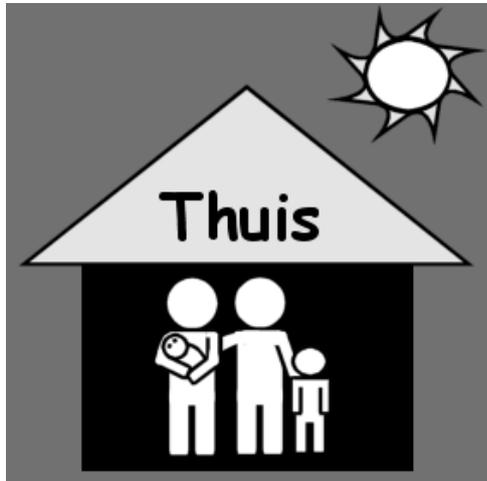
→ Kind en ouders hartelijk bedanken voor de tijd en het gesprek

- Vragen aan ouders of zij behoefte hebben aan exemplaar van uiteindelijke verslag
- Bij vragen na het interview aangeven dat ouders mij te allen tijde kunnen mailen

Appendix F: interview techniques – smileys



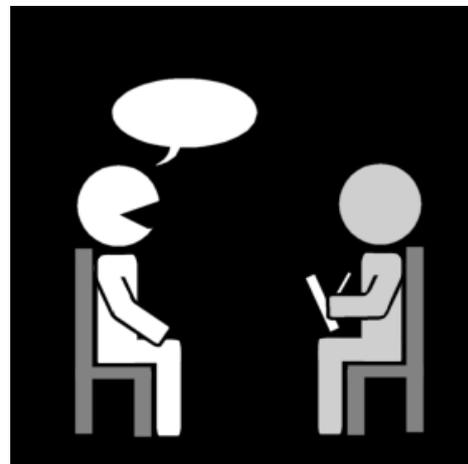
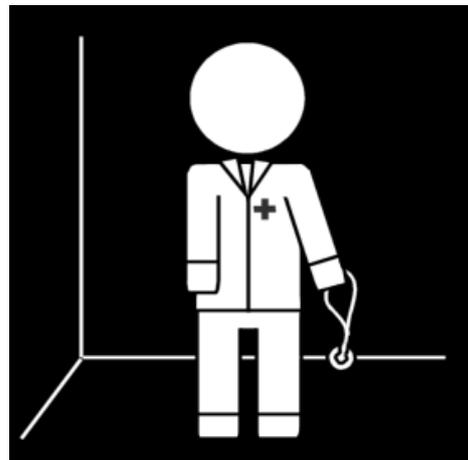
Appendix G: interview techniques – pictograms



Vrienden en activiteiten



Zorgverleners



Appendix H: translated quotations

Table 4: *the translated quotations from Dutch to English*

English translation	Dutch translation
then they, you have to stand on a scale then you are weighed, then they look how big you are, and you have here such a blood pressure pump and then they will pump it, and then they put their fingers on your arm to see what your heartbeat is. (transcript line number: 17540:17769)	dan gaan ze, dan moet je op een wegschaal dan word je geweegt dan kijken zo hoe groot je bent, en je moet zo'n hier zo bloeddruk pomp hebben en dan gaan ze pompen, en dan doen ze vingers op je arm om te kijken wat je hartslag had (transcript line number: 17540:17769)
L: But you don't have to go to Mediant anymore? F: no, because it is going pretty well (transcript line number: 12076:12168)	L: maar daar hoeft je nu niet meer heen naar Mediant? F: nee want het gaat best wel goed met me (transcript line number: 12076:12168)
'it depends on how it is going. If it is going less well, then, for example, I have to go back again to have another conversation about that' (transcript line number: 25499:25753)	het ligt er nou net aan hoe het gaat. Als het minder goed gaat, dan moet ik er bijv. weer een andere keer weer naar toe om daar weer een gesprek over te hebben (transcript line number: 25499:25753)
Karakter is going to say it to my parents, my mother is going to say it to the teacher that he should pay attention to this and such things (transcript line number: 24700:24842)	Karakter gaat zeggen tegen mijn ouders, mijn moeder zegt het weer tegen de leraar dan kan A een moet een beetje hier opletten enzo zulk dingen (transcript line number: 24700:24842)
L: when is she mad at you? D: if she thinks I do not listen well or sometimes she says that I am very busy (transcript line number: 13324:13614)	L: wanneer is ze boos op jou dan? D: als ze vindt dat ik niet goed luister soms of dat ze zegt dat ik heel druk ben (transcript line number: 13324:13614)
(name brother) is very busy, daddy is very busy, I am very busy, and that is very annoying for mama and yes everyone (transcript line number: 3392:3619)	(naam broer) doet heel druk, papa doet heel druk, ik doe heel druk, en dat is heel irritant voor mama en ja iedereen (transcript line number: 3392:3619)
Yes, because most of the time, always if a have to take my medication at school, at the second break yes, then the teacher always says it and yes than I am, I get used to that the teacher is says every time. And then one day the teacher forgets it again and then I forget to take my medication and then an already eat and have to take my medication, and then I sometimes get stomach acid. (transcript line number: 16327:16709)	ja omdat meestal als ik altijd als ik mijn pil altijd moet nemen op school, bij de 2 ^e pauze ja, ehm, dan zegt juffrouw dat altijd en ja en dan ben ik, raak ik gewend dat juffrouw dat elke keer zegt. En dan vergeet juffrouw het de ene dag weer en dan ben ik mijn pil vergeten en dan heb ik al gegeten en dan moet ik mijn pil nemen, en dan krijg ik zo soms wel maagzuur (transcript line number: 16327:16709)
Yes, a headphone, if there is a lot on the corridors, outside, the classrooms and corridors are, yes, the walls are not very thick, so you can hear everything (transcript line number: 11015:11206)	ja, een koptelefoon, als het veel op de gangen, buiten, ja zeg maar de klassen en de gangen zijn, ja de muren zijn niet heel dik dus je hoort alles (transcript line number: 11015:11206)
I would like it to see if I still have ADHD or if it is still going well (transcript line number: 31209:31289)	ik zou het wel willen ze kijken of ik nog ADHD heb of dat het nog goed gaat (transcript line number: 31209:31289)
they have to find out how many milligrams I can have because I then weight that high or something. Not that I get too much, that is not good for you (transcript line number: 18003:18255)	ze moeten ook kijken hoeveel mg ik mag omdat ik dan zoveel weeg ofzo (transcript line number: 18003:18255)
I don't know, I don't think so really. Because then they only say I it is getting better or not, or that it is getting worse	dat weet ik niet, ik denk het eigenlijk niet. want dan zeggen ze alleen maar of het beter gaat of niet, of dat het slechter gaat

(transcript line number: 8903:9226) That I am very busy all the time, but she also has to look at other children who are busier than me. That she is not specifically looking at me, only at how I am doing then. Because I have ADHD and she know it, and the other children have not so she pays more attention to me (transcript line number: 15305:15638)	(transcript line number: 8903:9226) zegmaar dat ik de hele tijd druk ben, maar ook naar andere kinderen te kijken die drukker dan mij zijn dat ze niet specifiek naar mij gaat kijken alleen maar hoe ik dan doe. omdat ik ADHD heb en ze weet dat, en de andere kinderen niet dus ze let echt meer op mij en dan ja (transcript line number: 15305:15638)
L: But you would like it if the teacher is coming to you to ask personally how it is going? B: that is useful L: Yes? Why do you think it is useful? B: because sometimes is not really fun, but actually, sometimes, it is also not so nice in class (transcript line number: 12006:12506)	L: maar je zou je het wel fijn als ze is naar jou gewoon persoonlijk komt om te vragen hoe het gaat? dat is wel handig L: ja? Waarom is dat handig? B: omdat het soms niet echt leuk is, maar eigenlijk ehm soms gaat het ook niet echt fijn in de klas. (transcript line number: 12006:12506)
I like that, then he knows how I handle it and stuff and how I act at school and stuff (transcript line number: 9169:9320)	dat vind ik wel fijn, dan weet hij ook hoe ik er om mee ga enzo hoe ik op school doe enzo (transcript line number: 9169:9320)
B: That it is just not really nice L: what do you mean? C: It is just not nice because then you also have to tell it to the whole class, sometimes that also isn't nice' (transcript line number: 11246:11551)	dat het gewoon niet echt leuk is L: hoe bedoel je? B: het is gewoon niet leuk want dan moet ik het ook tegen de hele klas zeggen, dat is ook soms niet leuk (transcript line number: 11246:11551)
Yes, but I think it is just really annoying when they look every time because they think it is not going well or something (transcript line number: 22983:23099)	ja maar ik vind het gewoon heel vervelend als ze elke keer gaan kijken omdat ze denken dat het niet goed gaat ofzo. (transcript line number: 22983:23099)
Well I don't know if you just having a conversation and you suddenly say 'hey I have ADHD'. If some asks about it, I would say yes. But I do not say it like that from myself (transcript line number: 8192:8362)	nou weet niet als je gewoon een gesprek voert en dan zeg je in 1 keer hey ik heb ADHD. Als iemand er na vraagt dan zou ik wel ja zeggen. Maar ik zeg het niet zo uit mezelf (transcript line number: 8192:8362)
By the same person who, who helped me the first time, who knows who I am, what I am and how bad it is (transcript line number: 23071:23193)	door dezelfde persoon die mij, die bij de eerste keer die mij heeft geholpen, die weet wie ik ben wat ik ben en hoe erg. (transcript line number: 23071:23193)
She knows where I still suffer from, and she also knows how to help me instead of when I have someone else who does everything over again (transcript line number: 13997:14172)	zij weet dan ook waar ik allemaal nog last van heb, en zij weet dan ook waarmee ze mij moet helpen in plaats van als ik iemand anders heb die alles nog is een keer over doet (transcript line number: 13997:14172)
The general practitioner does not know it, at Karakter they just have... If I have pain in my leg or something, then they send me, I do not know exactly anymore where they send me, somewhere to look how well I am, but they do not know that I have ADHD. (transcript line number: 23251:23510)	ehm huisarts weet het zelf niet, bij karakter hebben ze gewoon.. als ik pijn heb in mijn been of eh dan sturen ze mij naar weet niet meer waren ze me heen sturen, ergens om te kijken hoe het met mij gaat, maar zij weten zelf niet of ik ADHD hebt (transcript line number: 23251:23510)
No, not from school and neither from the general practitioner. No actually only someone who knows me well. (transcript line number: 18270:18361)	Z: nee niet van school en ook niet van huisarts. nee eigenlijk alleen iemand die mij goed kent (transcript line number: 18270:18361)
Because I just, I don't mind where it is (transcript line number: 27242:27293)	omdat ik gewoon, ik vind het niet erg waar het is (transcript line number: 27242:27293)
L: So, you prefer that? If it was closer? C: yes L: Because the general practitioner is a bit closer from here	L: dus dat zou je het fijner vinden als het dichterbij was? C: ja L: want de huisarts is wel weer wat dichterbij van hier

<p>C: I do not know L: A general practitioner in (name of the city) C: Then I think, it is closer L: Yes, would you then prefer to go to the general practitioner? C: No L: No and why not? C: Because I like to talk to (name youth psychiatrist) much more (transcript line number: 20546:20725)</p>	<p>C: dat weet ik niet L: een huisarts in (plaatsnaam) denk ik C: dan is dat wel dichterbij denk ik L: ja, en zou je het dan fijner vinden om dan naar de huisarts te gaan? C: ehm, nee L: nee en waarom niet? C: omdat ik het veel fijner vind als ik met (naam jeugdpsychiater) kan praten (transcript line number: 20546:20725)</p>
<p>But I think the teacher pays more attention to me, I think, because I have ADHD, and she thinks I am very busy, but that is not always the case, other children in class are sometimes busier than me, and to me, the teacher warns me very quickly, while I am not even that busy (transcript line number: 9437:9724)</p>	<p>maar ik vind de juffrouw let zeg maar meer op vind ik, omdat ik ADHD hebt, en denkt ze dat ik heel druk ben, maar dat is ook niet altijd zo, andere kinderen bij mij in de klas zijn soms drukker dan mij, en naar mij, juffrouw waarschuwt mij heel snel, terwijl ik niet eens zo heel druk ben (transcript line number: 9437:9724)</p>