



MASTER THESIS

ADHD AFTERCARE, THE CLIENTS' PERSPECTIVE

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Abstract

Background

ADHD is a frequent disorder, characterized by a persisting pattern of inattention/hyperactivity-impulsivity that interferes with functioning and development. When left untreated, it can pose a burden on children, their families and their community. Adequate treatment and monitoring of ADHD is essential for the wellbeing of patients.

As of 2015, a change in the Dutch law means that the responsibility for the ADHD care for children has been shifted from the central government to municipalities. As a result, municipalities are looking into new ways to provide effective and efficient ADHD care. When formulating how to provide healthcare, the patients must be involved and the patient experiences can help to improve healthcare. However, no research of the patients experience with the current provision of ADHD aftercare could be found.

Objective

The objective of this research is to investigate what the needs and preferences of the parents of young patients are concerning ADHD aftercare, and what strengths and weaknesses the parents of young patients experience in the current organization of ADHD aftercare.

Method

A qualitative approach was used, using semi-structured interviews. The research was carried out in the Dutch municipality of Enschede. The parents of children aged from 6 up until 11 with ADHD were considered for inclusion. The interviews were analysed using open-coding thematic analysis. Main themes and subthemes identified were used to reflect the needs and preferences of the interviewed parents. The World Health Organizations' responsiveness framework was used to describe the experienced strengths and weaknesses.

Results

Four themes reflecting the needs and preferences of the parents were identified: Communication: Parents have a need for the provision of information and feedback. Patient-centred approach: Parents are looking for a patient-centred approach, with individual attention for their child. Division of tasks: Parents regard the division of tasks as an important topic; they want an elaborate part in the aftercare for themselves as parents and mention the importance of the role the school can have. Request for help for the parents: There is a request for help for the parents themselves, as they seek support and guidance from the healthcare providers for themselves.

Regarding the experienced strengths and weaknesses, it was found that in the current organization limited involvement of the parents is seen as a weakness, as is a limited amount of feedback towards the parents is a weakness. Strengths of the current organization are prompt attention given to concerns, and an good environment of trust and confidentiality.

Conclusion

This research found parents' needs and preferences concerning ADHD aftercare, which can be used to take the clients' perspective into account when considering how ADHD aftercare should be provided. Furthermore, knowledge about the found strengths and weaknesses experienced in the current organization of ADHD aftercare can help improve the organization of ADHD aftercare.

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1.Introduction

1.1 Background:

Attention deficit hyperactivity disorder, widely known as ADHD, is a frequent disorder with a worldwide prevalence of 5.29% (Polanczyk *et al.*, 2007). In the clinically commonly used diagnostic manual for psychiatric diseases, the DSM V, ADHD is classified as a neurobiological development disorder characterized by a persisting pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development (American Psychiatric Association, 2013).

ADHD is often diagnosed in childhood, with symptoms continuing into adolescence and adulthood (American Psychiatric Association, 2013). When left untreated it can pose a burden on children, their families and their community, for example because of a negative impact on relationships and academic achievements (Hamed *et al.*, 2015). The treatment of ADHD can involve both nonpharmacological and pharmacological strategies. In the Netherlands the treatment plan for children with ADHD, as described by the Dutch National Healthcare Institute (Zorginstituut Nederland, 2017), starts with nonpharmacological measures, such as education, parenting advice, and if desired parenting support. If clear indications for persistent limited functioning remain, behavioural therapy can also be offered. If the combination of the former does not give the desired improvement, supporting medication, such as stimulants which enhance neurotransmission of dopamine and norepinephrine, can be prescribed (Biederman & Faraone, 2005).

Although treatment usually cannot improve bad outcomes such as poor academic performance and antisocial behaviour to a normal level, it has been shown that individuals who do not receive treatment have worse long-term outcomes compared to children who are treated (Shaw *et al.*, 2012). Adequate treatment and monitoring of ADHD is essential.

1.2 Statement of the problem:

As of 2015, a change in the Dutch law means that the responsibility for the mental care for youth is shifted from the central government to the municipalities ("Jeugdwet," 2015). The goal of this decentralization of care is the provision of care closer to citizens, and better organization of tailor-made care (kenniscentrum movisie, 2015). Furthermore, the decentralisation of care is associated with cutback measures in expenditure (Health Council of the Netherlands, 2014). Municipalities are now considering new ways of organizing effective and efficient care for children, in line with the goals of the decentralization.

The ADHD care consist of the diagnosis, treatment and aftercare after the diagnosis. As prescribed in the Dutch guidelines for ADHD treatment, diagnosis of ADHD in children is done in the second line of care (Trimbos, 2007). This decision to keep the diagnosis in the specialist second line of care is supported by the majority of general practitioners, key players in the first line of care (Hassink-Franke *et al.*, 2016). After initial diagnosis however, the aftercare for psychosocial problems, such as uncomplicated ADHD, frequently continues to be provided in the second line of care (Health Council of the Netherlands, 2014). An often heard question in the context of delivering appropriate care is whether this cannot be dealt with in the better accessible first line of care (Health Council of the Netherlands, 2014).

With respect to the 2015 decentralization goals, organizing ADHD aftercare in the first line of care could contribute to moving care closer to the patient. Recent projects (AHAD, Tornado, Eureka) have already aimed at improving the care for children with ADHD with a central role for primary care (Health Council of the Netherlands, 2014; Zorggroep Katwijk, 2012). Furthermore the emergence of the so called "POH-GGZ" (nurse practitioner specialised in mental care in the GPs office) is called an important

development in more efficiently triaging patient in primary care and making sure appropriate care is delivered (Health Council of the Netherlands, 2014).

The development of new ways to organize ADHD aftercare is not an aim in itself, the quality of care must be served and the patients must benefit. When formulating how to establish a new care organization patients have to be involved and their preferences should be taken into account (Health Council of the Netherlands, 2000). However, no research of the patients experience with the current provision of ADHD aftercare could be found.

1.3 Aim of this study:

The aim of this study is to supplement the knowledge on ADHD aftercare by adding the clients' perspective of the organization of ADHD aftercare. This research aims to investigate what the needs and preferences of the parents of young patients are concerning ADHD aftercare, and what strengths and weaknesses the parents of young patients experience in the current organization of ADHD aftercare.

2. Research question

This research aims to add the clients' perspective of the organization of ADHD aftercare for young children. Because of practical concerns regarding research with young children, it was decided to use the parents of the children for this research. Furthermore, the study will be performed in the municipality of Enschede. This studies' research questions are:

2.1 Research questions

- 1) What are the needs and preferences concerning ADHD aftercare of the parents of school-aged children with ADHD within the municipality of Enschede?
- 2) What strengths and weaknesses experienced by parents of school-aged children with ADHD can be identified in the current organization of ADHD aftercare for children with ADHD within the municipality of Enschede?

2.2 Research outline

The introduction of this paper provided an introduction about ADHD, and the organization of ADHD aftercare. The next chapter contains the background information on previous patient experience research. Chapter 4 will outline the chosen research methodology. In chapter 5 the results will be presented and in chapter 6 the found results will be discussed and a conclusion will be presented.

3. Patient experiences

The current research investigates the experiences with ADHD aftercare. By researching the experience that parents of young children with ADHD have with ADHD aftercare, we want to find out if the care is in line with the parents' needs and preferences and which strengths and weaknesses the parents experience within the current organization of ADHD aftercare. In this chapter, we elaborate further on the concept "patient experiences", a concept which is increasingly being used in literature. This chapter starts with background information about the development of research into the experiences of patients with received care. Secondly, we elaborate further on the definition of patient experiences. We will introduce the WHO framework of responsiveness to describe the experienced strengths and weaknesses, and elaborate on suitable methods to collect data about the patients' experiences.

3.1 Background

Traditionally decisions concerning what healthcare is best for a patient were often made solely by the health professionals, with the reasoning that patients often lack the technical knowledge necessary for making a fully informed decision (Valentine & Ortiz, 2003). Over the past decades, there has been a change in this decision making, as patients preferences are increasingly being included in the process (Lavela, 2014). What has changed over the years, is how the concept of health is defined. With the creation of the World Health Organization in 1948, health was defined as "*A state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.*" (Valentine & Silva, 2003). This definition shows a traditional definition of health, "the absence of disease or infirmity", and redefines health where it is recognized that a health system must address both the medical needs of individuals as well as other factors affecting patient well-being (Valentine & Silva, 2003).

Several decades after this definition of health by the WHO, patient satisfaction as a separate factor affecting the patient well-being has first been investigated by Donabedian in his pioneering work on the quality of medical care (Donabedian, 1988). Donabedian names patient satisfaction an indispensable measure of quality of care, mostly for two important reasons: it gives information on the provider's success of meeting the patients' expectations, which is important for the management of interpersonal patient-doctor relation. Secondly, patient satisfaction is important because it is linked to health outcomes. A patient who is not satisfied may fail to follow recommendations (Donabedian, 1988).

Since Donabedian, the interest in measuring patient satisfaction has grown (Valentine & Silva, 2003). With the growth in knowledge however, a distinction in different patient-reported outcome measures has also emerged (Valentine & Silva, 2003). It has increasingly been recognized that there is a need to capture what is called the patient experience as something distinct from the satisfaction with the care received alone (Valentine & Silva, 2003). Usage of the term patient experience and attempts to measure it have increased rapidly (Valentine & Silva, 2003). Currently patient experience is considered an important indicator for the performance of healthcare (Murray, *et al.*, 2003; Valentine & Silva, 2003), and therefore patient experiences are increasingly being recognized a pillar of quality in healthcare.

3.2 Conceptualization of patient experiences

In the literature, many different measures of patient experiences are being used (de Silva, 2013; Lavela, 2014). This follows from ambiguity surrounding the definition, as there is no standardized definition for the concept (Wolf, 2014). Different definitions lead to different measures being used, and so the first step in considering how patient experiences should be characterized is finding a definition for the concept (de Silva, 2013; Lavela, 2014; Wolf, 2014).

In the most recent review of the literature on definitions for patient experience, Wolf *et al.* examined what definitions have been used and what elements, constructs and themes are key in those definitions (Wolf, 2014). Wolf *et al.* identified 18 sources that provide a definition for patient experience. According to Wolf *et al.*, the most complete definition of patient experiences is the one provided by the Beryl institute: *“The sum of all interactions, shaped by an organization's culture, that influence patient perceptions across the continuum of care.”* (The Beryl Institute, 2017). In this research, this definition by The Beryl institute will be used to define the concept of patient experience.

3.3 Responsiveness to characterize healthcare interactions

The next step is to consider how we can use this definition to characterize the parents experience with the ADHD aftercare. For the purpose of characterizing patients interactions with a healthcare system, the World Health Organization has created the concept of responsiveness, around which it bases its view of patient experience (Wolf, 2014). This concept was introduced by the WHO to achieve uniform measurement of patient experiences as a performance indicator (Scheerhagen *et al.*, 2015). It is one of three intrinsic health system performance goals, together with Fair financing and financial risk protection and Health (Darby *et al.*, 2000).

Patient experience as responsiveness is found in eight domains: Dignity, Autonomy, Confidentiality, Communication, Prompt attention, Social support, Quality of basic amenities, and Choice of care provider (Valentine & Bonsel, 2007), as shown in Table 1.

Table 1: Description of the World Health Organization Responsiveness domains	
Domain	Description
Dignity	Dignity refers to treating someone with respect and concern, in a manner that respects his/her privacy (Darby <i>et al.</i> , 2000).
Autonomy	Autonomy is the concept of being self-determined, instead of being determined from outside. It entails the need to provide enough information to patients for informed consent, the need to involve individuals (and their families where appropriate) in the decision-making process if they wish so and the right of patients of sound mind to refuse treatment (Valentine & Silva, 2003).
Confidentiality	Confidentiality refers to creating an environment of privacy, maintaining the confidentiality of information provided by the patients and keeping information in patient medical records confidential (Darby <i>et al.</i> , 2000).
Communication	Communication refers to providers listening carefully to the concerns of patients, and explaining the illness and treatment options clearly to patients and providing time for patients to ask questions (Valentine & Silva, 2003).
Prompt attention	Prompt attention is defined as care provided as soon as necessary (Valentine & Silva, 2003). Patients should be able to get care fast in emergencies, waiting times for appointments, consultation and treatment should be short, waiting lists for consultation and treatment should be short and healthcare facilities should be geographically accessible (Darby <i>et al.</i> , 2000).
Social support	Social support refers to support for the patients by their social surrounding to be cared for and loved, valued and esteemed. It includes for example visits and support by relatives and friends and space for religious practices (Darby <i>et al.</i> , 2000; Scheerhagen <i>et al.</i> , 2016).

<i>Quality of basic amenities</i>	Quality of basic amenities refers to the extent to which the healthcare environment is welcoming and pleasant for the patients (Valentine & Silva, 2003).
<i>Choice of care provider</i>	Choice is the power or opportunity to select, which requires more than one option (Scheerhagen <i>et al.</i> , 2016).

The WHO responsiveness model has been used in order to investigate healthcare systems, such as outpatient mental healthcare (Forouzan *et al.*, 2016), or primary care (Murante *et al.*, 2017). However, it has been shown that this model can also be applied to a smaller healthcare subsystem, such as ADHD care, as was done by Scheerhagen *et al.* when they applied it to maternity care (Scheerhagen *et al.*, 2015). They used the responsiveness model as the conceptual basis for the development of their own client experience research for measuring the client experience with maternity care.

As the WHO responsiveness model was built on the idea to capture peoples actual experience with healthcare, it seems to meet the search for a useable concept to measure patient experiences (Valentine & Silva, 2003). The next question to consider, is what method we should use to measure the patient experience within the eight domains of responsiveness. This question will be dealt with in the next paragraph.

3.4 Methods to measure patient experiences

There are different methods mentioned in literature to collect patient experience data. Here we will provide an overview of the available methods and the pros and cons of these methods. The methods can be divided in *quantitative methods*, *qualitative methods* and *mixed methods*, the latter being a combination of quantitative and qualitative methods (Lavela, 2014).

Quantitative methods

According to the UK's Health Foundation most recent evidence scan on methods for measuring patient experience, surveys are the most used method to measure patient experience, and they dominated the quantitative research methods which means there are many existing validated survey tools (de Silva, 2013). This is a potential advantage, because this means there are a lot of surveys to use or adapt for research. Other advantages are that surveys allow for standardization, they can be administered anonymous, they are quick to implement and relatively inexpensive, they can be easy to analyse, they can reach a large number of people and they can be administered in a variety of ways (e.g. online, handing out hard copies, by post etc.).(de Silva, 2013) All those advantages make surveys an often-favoured tool. There are however also disadvantages to surveys. Surveys give the difficulty that they do not offer much response choice and respondents cannot respond in their own words (Lavela, 2014; Schneider & Palmer, 2002). Whereas when respondents can express themselves in their own terms they feel more able to evaluate critically several aspects of care (Huby, 1997). This means that surveys might not be able to delve in-depth. It is also difficult to cover sensitive issues with surveys, and there might be a non-response and exclusion of those who do not have good literacy (de Silva, 2013).

Qualitative methods

Distinct from the mentioned quantitative survey research methods, are some qualitative research methods. Traditional qualitative methods include interviews and focus groups (Braun & Clarke, 2006). Qualitative methods for patient experience research offer the opportunity to obtain a more in-depth understanding, as researchers can move beyond the limitations of structured questions and use open-ended questions (Lavela, 2014). With the open-ended questions the respondents are encouraged to

describe their experience in their own words, which as mentioned makes them more able to evaluate critically several aspects of care (Huby, 1997).

Both interviews and focus groups offer the advantage of going more in-depth, by giving the patient the opportunity to express him or herself. Other advantages these methods share are that they can explore unexpected responses immediately and they can be used to probe the reasons for people's opinion (de Silva, 2013). Common downsides of both methods is the fact that the results depend on the skill of the interviewer, they can be time-consuming, it requires effort to make sense of detailed qualitative data and they cannot be performed anonymously so there might be social desirability bias (de Silva, 2013). There are also differences between focus group interviews and one-on-one interviews. With focus group interviews, feedback from others might spark ideas however the downside to this might be that participants can be affected by consensus bias. Furthermore, it takes even more time to set up a focus group interview. (de Silva, 2013).

When comparing the mentioned commonly used methods for patients' experience research, some of the named advantages and disadvantages are especially relevant for the current research. Firstly, it is relevant for the current research to be able to conduct an in-depth investigation for which the interview and focus group interview might be better suited. Furthermore, surveys are not ideal for covering sensitive issues, and we consider the inquiry of parents about their children's healthcare to be a sensitive issue. Third, when comparing interviews and focus group interviews the added time and effort needed to set up focus group interviews is seen as a disadvantage.

Taking together all of the above, it is concluded that interviews are the best method for this research. Further and more precise information about the research method will be provided in the next chapter.

4. Method

In this chapter, the research methodology is described, elaborating on what steps were taken and what research was carried out to answer the research questions. The chapter is divided in two parts: first a section describing the data collection method and secondly a section describing the data analysis method.

4.1 Data collection

4.1.1 Methodological approach

To answer the research questions, data on the ADHD aftercare experience by parents of young patients was collected. The method used to collect the data was a qualitative approach, using semi-structured interviews. The reason for choosing this approach is that interviews are suitable to gain a more in-depth understanding of the issue (Lavela, 2014), interviews are suitable for possibly sensitive topics such as the conversation with parents about the care their children receive (de Silva, 2013; Barriball & While, 1994), and interviews can explore unexpected responses immediately and they can be used to probe the reasons for people's opinion (de Silva, 2013).

4.1.2 Study population

The research was carried out in the Dutch municipality of Enschede. The parents of children aged from 6 up until 11 with ADHD were considered for inclusion. Parents of children younger than 6 were excluded because ADHD cannot be classified reliably in those young children (Trimbos, 2007). Children older than 11 were excluded because in the Netherlands starting from the age of 12 children will go from elementary school to secondary school. Furthermore, only parents of children who receive aftercare for ADHD as primary disorder were included.

Exclusion of parents was done if they did not speak Dutch. Apart from that all parents of children from 6 up until 11 with the diagnosis ADHD and living in the municipality of Twente were candidates for inclusion.

4.1.3 Recruitment of respondents

Recruitment of respondents was done by contacting healthcare providers in the municipality of Enschede. Because of doctor-patient confidentiality, the healthcare providers were asked to contact the parents of eligible patients and send them a previously drafted invitation to participate in this research project. Different healthcare providers involved in ADHD aftercare were contacted: The municipal health service, the general practitioners' organization for the region and a mental healthcare institute.

We were unsuccessful in trying to recruit respondents through the municipal health service and the general practitioners' organization within the time available. Through the mental healthcare institute 20 parents were contacted by the institute, from which 11 agreed to share their contact information. After contacting these 11 parents of patients, 8 agreed to participate.

4.1.4 Proceedings of the interviews

The interviews took place at a location convenient to the respondent, 7 interviews were held in the respondents' home and one interview was conducted at the University of Twente. The length of the interviews was between 38 and 55 minutes with an average of 43 minutes. Before each interview the proceeding of the interview was explained to the respondents. The respondents were assured confidentiality and written informed consent was obtained from all respondents (Appendix A, in Dutch). After written consent was obtained, the interview started and every interview was recorded using a handheld dictaphone. In one case, the handheld dictaphone only recorded the first part of the

interview. Unfortunately, this was discovered after the interview. This interview was excluded from further analysis because a large part of the interview was missing.

4.1.5 Interview protocol

To guide the conversation in the interview, a semi-structured interview guide was developed (appendix B, in Dutch). The first part of the interview consisted of questions to confirm that the respondent did indeed meet the inclusion criteria, which was the case for all respondents. Following, three questions were asked to get a picture of the specific situation for the child of the interviewed parents. The first question was how the child was doing at the time of the interview. This question was meant to open a conversation about the child, without immediately starting with questions about ADHD. The second question was if the parents could elaborate on how the ADHD was diagnosed. This question was meant to steer the conversation towards the ADHD, and to get an idea of what contact with healthcare the child has had for his ADHD. The third question was if the parents can describe how the ADHD aftercare has been so far. This question about aftercare was open-ended and meant to get an understanding of the aftercare the child has received. With this question, the parents started talking about their experiences of the aftercare their child has received.

In the second part of the interview the conversation went more in-depth in the experiences with the ADHD aftercare. The respondents were encouraged with two open-ended questions to tell about their positive and negative experiences during the care path. Depending on the answers the respondents gave, follow-up questions were asked. A set of more in-depth follow-up questions on expected topics were prepared, however respondents were not prompted to discuss topics they did not come up with themselves.

The third part of the interview was aimed at identifying any remaining needs and preferences not previously mentioned during the interview. The respondents were asked what they thought the ideal aftercare should look like. After this question was answered, the respondents were asked what would have to change to the current situation to achieve their ideal care pathway. Lastly the respondents were asked what elements of the ADHD aftercare organization discussed during the interview they find most important.

4.1.6 Ethical approval

Permission to carry out this research was granted by the ethical committee of the Faculty of Behavioural, Management and Social Sciences of the University of Twente under file number BCE17265.

4.2 Data analysis

4.2.1 Analysing the data

The recorded audio was transcribed verbatim using *Transcribe* by Wreally Studios and Microsoft Word. In the resulting text files, all information which could lead to the respondents was deleted, such as names.

The resulting text file was analysed using an open-coding thematic analysis where different themes that are in the data were determined. To this end, the six stage (data familiarization, initial code generation, search for themes, review of themes, theme definition and labelling, report writing) plan for thematic analysis by Braun and Clarke was used (Braun & Clarke, 2006).

The goal of the first stage, the data familiarization stage, is to become familiar with the depth and breadth of the content. The first step in becoming familiar with the data was taken when the data was transcribed, but additionally in this stage the text was read and re-read in an active way, searching for

meanings and patterns. During this phase, some first notes were made to collect ideas for coding that are useful in the following phases.

The second stage involved the generation of initial codes from the data. With these codes, features in the data that appear interesting for analyses were marked. With the coding, extracts from the data have been organized into meaningful groups. Individual extracts of data could be coded more than one time or as many times as relevant. At the end of this stage all data has been coded and collated, resulting in a list of different codes identified across the data set.

In the third stage, searching for themes, all identified codes were sorted into potential themes. Different codes were combined to form overarching themes. Thought was given to the relationship between themes and between different levels of themes such to identify possible main themes or subthemes. Codes which were left and did not belong anywhere else were at this stage put together as “miscellaneous”.

In the fourth stage, reviewing themes, the formed candidate themes were re-considered and refined by re-reading the data within the candidate themes. Some themes were left out because there was not enough data to support them, other themes were subdivided and yet other themes were put together into overarching themes.

The fifth stage, defining and naming themes, the themes were further refined. We identified what the essence of each theme is about. In this phase, we made sure that the themes capture the right aspects of the data and the collated data within each theme is coherent and consistent. At the end of this stage the final worked-out themes have been made.

The sixth stage, producing the report, a report was made to show the value of each identified theme. Using data extracts the scope and content of each theme is shown. Using the identified themes, arguments in relation to the research questions were made. The found themes can be found in the next chapter.

4.2.2 Procedure of answering the research questions

To answer the research questions,

- 1) What are the needs and preferences concerning ADHD aftercare of the parents of school-aged children with ADHD?
- 2) What strengths and weaknesses experienced by parents of school-aged children with ADHD can be identified in the current organization of ADHD aftercare for children with ADHD within the municipality of Enschede?

the following approach was used:

The answer to the first question followed from the performed thematic analyses. The main themes and subthemes identified were used to reflect the needs and preferences of the interviewed parents in section 5.3. To answer the second question, the WHO responsiveness framework was used to describe the experiences. The way in which this was done is by connecting the identified segments with the eight domains of responsiveness as described in section 3.3. The result, as presented in the next chapter in section 5.4, is a description of the strengths and weaknesses experienced by the parents in ADHD aftercare as described using the WHO responsiveness framework.

5. Results

In this chapter, the results of the research are presented. First, the characteristics of the participants are presented. Following, the result of the thematic analysis is presented. Then the answers to research question 1 and 2 are, supported by data segments from the interviews. All data segments are translated to English, the original Dutch fragments can be found in Appendix C.

5.1 Characteristics of participants

A total number of seven interviews were included. From these interviews, 3 interviews were conducted with both parents and 4 interviews were conducted with a single parent.

The children of the parents were between 7 and 11 years old, with the average age being 9. Four of the children were boys, the other three children were girls.

5.2 Result of the thematic analysis

After the thematic analysis a total of 171 coded segments found in the data were grouped into main themes using the six stage plan for thematic analysis by Braun and Clarke (Braun & Clarke, 2006). The following four main themes were identified: communication, division of tasks, patient-centred approach, request for help for the parents (Table 2).

Table 2: Identified themes	
Theme	Description
Communication	The theme communication consists of data segments referring to the communication during the care process. References to communication are interwoven through all interviews, and it seems an important theme in all aspects of ADHD care.
Division of tasks	This theme entails the question who should have what role in the ADHD aftercare process. The organization of tasks is a frequent theme within the data and seems to be an important factor of ADHD aftercare. The roles which were frequently discussed within this theme were the parents, the healthcare provider and the school. Furthermore, the coordination between the different roles is part of this theme.
Patient-centred approach	During the interviews, multiple references were made to a patient-centred approach; an approach where the patient is central and there is attention for the individual during the care.
Request for help for the parents	During the interviews, it became clear that the parents themselves have a request for help from healthcare for which they would like to see more attention.

5.3 Needs and preferences concerning ADHD aftercare

The first question is: What are the needs and preferences concerning ADHD aftercare of the parents of school-aged children with ADHD? In this section the four identified themes, reflecting the needs and preferences of the parents, are presented.

5.3.1 Communication

Provision of information on ADHD

A prevalent topic was the communication between the healthcare providers and the parents, regarding the ADHD their child is diagnosed with. The diagnosis ADHD raises questions by the parents, they want to know what the diagnosis means for their child and what steps they should take.

[our child] has received the diagnosis ADHD and we had to figure everything out ourselves. How should we continue? And what is going to happen? How should we handle everything? - (Transcript line number 1809-1811)

While the quotation describes the initial stage after ADHD diagnosis, and not necessarily the ADHD-aftercare, it is a clear sign of the need parents have for the provision of enough information on ADHD by their child's healthcare providers. The parents want to receive information aimed at them, as parents, because the diagnosis has consequences for the way the parents have to raise their children.

You know, the whole thing is unfamiliar to us. We were told that our child has ADHD, and then one starts to think, alright, but what exactly does that mean? - (Transcript line number 2928-2929)

Feedback

During the aftercare stage, the topic of communication was frequently touched upon by comments on feedback from the healthcare providers. Parents want the healthcare providers of their child to provide them with information or feedback from the conversations and sessions their child has with them. As parents themselves are most of the time not present during conversations the healthcare providers have with their child, parents expect the healthcare providers to keep them up-to-date on what has been talked about and has been done.

You know, [healthcare providers] should provide some more feedback [...] they should show what they are doing, because the children themselves are generally jaded after an hour or forty-five minutes. They themselves won't tell you what they've done. Then it would be nice if they would keep a journal of what has been done for us to read.. now I usually hear about it only after three or four days. - (Transcript line number 2418-2422)

I don't really mind that we had to ask for a parent conference ourselves. You know we can. But personally, if I was the [healthcare provider] I would further incorporate it in the aftercare/treatment. For example, every fourth time, three meetings with the child and then one with the parents. Even if it's only a very short meeting. - (Transcript line number 773 - 776)

Parents have a need for feedback from the healthcare providers. Parents would prefer the healthcare to be organized in such a way that a system of feedback and communication to the parents is incorporated. Information and the provision of feedback should preferably be available to the parents without the need for parents to ask for it.

5.3.2 Patient-centred approach

The theme patient-centred approach is about organizing the care around the individual patient. During the interviews, the need for care aimed at the individual patient, where healthcare providers have attention for the individual situation of each child became visible.

Individual attention

It became clear that parents have a need for an organization where there is attention for the individual traits of their children.

You know, [the situation] isn't the same for everyone. We're both working parents, not fulltime, but there is difference between psycho education for a very traditional household, e.g. the man works and the woman takes care of the household, and psycho education for us. You need a different sort of support or a different kind of psycho education, maybe a different content so to speak. (Transcript line number 805 - 809)

Given the individualist character of ADHD care for children, parents reckon that there might not be one way of organizing care which is ideal for multiple children.

And then you also need to know who the child is. I don't think there is one specific approach, except that you will have to pay attention to the child at that moment. I don't think.. there is not really one way of doing this. There might be certain features which are unique to children with ADHD, but I don't think you can put everything under the same umbrella. (Transcript line number 1464 - 1468)

Whatever care organization is present, it is important that one should not ignore the distinctions between children but take them into account. Parents are looking for an approach where there is attention for the individual.

Continuity of care

Also part of a patient-centred approach is the importance the interviewed parents place on having a good bond with the healthcare provider. Parents emphasized that it is nice if their child is seen by one and the same healthcare provider, and the care is continuous without interruptions made by switching from one provider to another.

And it is very nice that he has been seen by the same person all this time. Someone needs to learn your strengths and learning points and because he stays with the same person this person knows his strengths and learning points. (Transcript line number 1388- 1390)

In the end, it is often about the face behind the story. It's about whether the faces are familiar. And because it concerns long-term processes I think the general practitioner would be a logical choice because he stays around longer than the municipal health service. (Transcript line number 940 - 942)

When considering the organization of ADHD aftercare, it is thus important to take into account that parents prefer that there are not many switches in persons involved in the care and that there is time to build a relationship of trust between the healthcare provider and the child.

5.3.3 Division of tasks

This theme entails the division of tasks between the most important parties involved in the ADHD-aftercare organization. Statements as to whom should have what task within the organization have been made throughout the interviews. Especially prevalent are statements regarding the role the parents themselves should have in the ADHD aftercare. Furthermore, the coordination between the involved actors is an important topic.

Parents

During the interviews parents stated that the role of their role is very important within ADHD aftercare. The parents are the ones who see their children most and who know their children best.

We think that in the end it's mostly about what we as parents have to do. You know they are seeing him as well, but I think 80-90 percent of it is done by us. We will have to do it. - (Transcript line number 793 - 794)

You [the child] will receive help, and your father and mother will also receive help and support to understand you as best as possible. (Transcript line number 3227 - 3228)

Parents have a need to be involved in the care, and emphasize the importance of the role they have. They want the healthcare providers to be aware of this and think the care can be improved by involving the parents more in the care.

School

Besides their own role, the interviewed parents also value the role the school of their children can play. The school is also a place where the children spend much of their time. Furthermore, the school is a place where many of the children have to deal the most with the negative sides of having ADHD, and struggle the most. Getting the right help to deal with school is thus important for many of the children, and so the school should be involved.

The most important person in the school is the child's teacher, and parents reckon that the way in which the teacher interacts with the child is very important.

We also notice that the teacher starts to understand some things. They have of course also received our son's diagnosis and only now we notice that they start to act. They facilitate re-examination, allow him to take music and a fidget spinner to the class room. They know that they will have to plan everything with him [...] And they started planning and organizing and you could really see him grow. (Transcript line number 888- 897)

All parents want the school to have a role in the ADHD aftercare, because they see that the role they play is also important. Parents feel that the teacher of the children can also be helped by bringing him/her in contact with the healthcare providers, so the teacher can better understand what process the child is going through. In turn, improving the situation at school will improve the care for their child.

Coordination between school and home

In line with the importance of involving the parents and the school, there were also statements made about the importance of the coordination between the two.

I think it is very useful to work together with each other, also with the school and your healthcare organization, because the child will then know that everything is the same. And he or she doesn't have any margin or ambiguity to.. you know.. do things different on school than at home. (Transcript line number 3200 -3203)

Parents prefer an ADHD aftercare organization where the school has a defined role and there is a clear collaboration between the school, the healthcare and the family. All three should be more or less on one line, communicating the same message to the child. There should be explicit attention in ADHD aftercare for the role the school, the healthcare provider and the parents play individually, and the way in which the three should work together.

5.3.4 Request for help for the parents

During the interviews, it became apparent that a number of the parents' main healthcare demand was to get support for themselves. The parents had difficulties raising their children and dealing with their children, and so they were seeking for coaching and help for themselves.

You know, the request for help is actually for me. I want to know how to deal with this, how I should handle this situation. (Transcript line number 2246 - 2247)

We never had the intention to use the diagnosis to get ADHD medication or anything.. Actually.. you see I know that there is no such thing as a manual for

children, but some better guidelines tips and advises.. that was actually our wish and the reason for seeking a diagnosis. (Transcript line number 134-137)

This request is somewhat in line with the above-mentioned role parents want to have within ADHD aftercare. If parents were to get training and support, they would be better able to help their children.

That was a real switch-over for us. It took us, and especially me, a lot of effort because at once we had to be very strict and “tough” for our child. I should give any space. So at first I had quite a lot of difficulty doing so. But if I look back now, a year later, and look at the results than I know it has not been for nothing. (Transcript line number 3172-3176)

Thought should thus be given to the support the parents of the children receive. With some parents, it is clear that they are in need for help themselves, stating that the request for help from healthcare can be ascribed to themselves. The notion of involvement of the parents within the care for their children is found in the other identified themes as well, and shows the need the parents have for recognition of their role.

In summary

This research identified four main themes, communication, division of tasks, patient-centred approach and request for help for the parents, which contain the important needs and preferences the interviewed parents have in relation to the organization of ADHD aftercare. The main findings are:

- There is a need for sufficient provision of information on ADHD, and the provision of feedback from the healthcare providers.
- Parents advocate the importance of individual attention and continuity of care, without interruptions by switching healthcare provider.
- Besides the child and the healthcare provider the parents and the school are also seen as important players in the organization of ADHD aftercare. There is a need for elaborate involvement of the parents, and the parents prefer the school to be actively involved.
- There is a request for help by the parents, as some of them also seek support and guidance from healthcare providers for themselves.

5.4 Experienced strengths and weaknesses in the current organization

The second question is: What strengths and weaknesses experienced by parents of school-aged children with ADHD can be identified in the current organization of ADHD aftercare for children with ADHD within the municipality of Enschede? Below the results of analysing the text segments for experienced strengths and weaknesses is presented, organized within the domains of the responsiveness as introduced by the WHO (N. B. Valentine & Silva, 2003).

5.4.1 Autonomy

As described the concept of autonomy concerns the self-determination of patients, in this case the children, but also when appropriate the involvement of their families.

Throughout the interviews, the parents argue that the young age of the children makes it necessary to involve the parents. The parents should then thus also be well-informed about the care process, to be able to support making decisions.

As I told, it's mostly the feedback and some insights for the parents.. and involving the parents [which is lacking]. (Transcript line number 376-3789)

It can be seen as a weakness of the current organization that parents are not as much involved and informed as they want to be. Parents generally ask healthcare providers if they can be more involved, and they would like to see the involvement of the parents as an appropriate support for their young children.

5.4.2 Confidentiality

Confidentiality is, as defined, about being trusted with confidential information. A strength found within the current organization of ADHD aftercare is the bond of trust build with the healthcare providers. The parents mentioned that it is good that there was in most cases just one healthcare provider involved in the contact with their children, so a bond of mutual trust could be made.

Until now there is only one person [involved in the aftercare], well sometimes an intern as well but that doesn't matter. And indeed, that is positive, that we don't have to switch healthcare provider all the time because nowadays you see that everywhere. (Transcript line number 2968-2971)

And it is very nice that he has been seen by the same person all this time. Someone needs to learn your strengths and learning points and because he stays with the same person this person knows his strengths and learning points. (Transcript line number 1388- 1390)

The healthcare providers created an environment of privacy and trust, which is seen as important for supporting these young children.

5.4.3 Communication

The theme communication was also discovered using the thematic analysis. We discovered the parents' need for the provision of enough information on ADHD from their child's healthcare providers.

The lack of available information and communication about ADHD from the healthcare providers towards the parents is seen as a weakness in the current organization.

You don't have a clue where to start searching [for information]. (Transcript line number 2255 - 2256)

I would have wanted to get some more information, just a short description of what is ADHD, what should one take into account. (Transcript line number 803-804)

By improving the provision of information, the organization could possibly improve. This becomes apparent through the interviews as some parents are specifically positive about a report with more information about the diagnosis which they received from their healthcare provider.

This [the report] gives a lot of information about.. you know.. his problems. (Transcript line number 766-367)

Providing this report seems typical for one healthcare provider, and not an example of the general organization. However, including methods like these does apparently satisfy the parents and might improve the organization.

Another aspect of communication which was discovered is the provision of feedback from the healthcare providers to the parents. The small amount in which feedback is currently provided to the parents is a weakness of the current organization. Parents have a need for the provision of feedback, but they feel that currently the provision of feedback is not sufficiently integrated as a part of the organization.

I don't really mind that we had to ask for a parent conference ourselves. You know we can. But personally, if I was the [healthcare provider] I would further incorporate it in the aftercare/treatment. For example, every fourth time, three meetings with the child and then one with the parents. Even if it's only a very short meeting. -
(Transcript line number 773 - 776)

It was pointed out that when asked the healthcare providers will certainly facilitate more feedback for the parents, but the organization could improve if it were more integrated.

5.4.4 Prompt attention

Parents reported that, although they would want to see that parent involvement became more integrated in the organization, when asked the healthcare providers were quick to acknowledge the concerns of the parents and to accommodate.

This can be seen as a strength of the current organization, as soon as healthcare providers are aware of the request for help, they will accommodate to provide care.

In summary

The experienced strengths and weaknesses are related to four domains of responsiveness; autonomy, confidentiality, communication and prompt attention. The main findings are:

- The somewhat limited involvement of the parents can be described as a weakness of the current organization. Considering the young age of the children, it is appropriate to fully inform the parents.
- A strength is that there is a good environment of trust and confidentiality, which adds to the care process as described by the parents.
- There is a limited amount of feedback towards the parents, which is seen as a weakness in communication. Parents reckon that the organization can improve with better feedback mechanisms.
- A strength of the current organization is that prompt attention was given to concerns raised by the parents.

6. Conclusion and discussion

The aim of this study was to supplement the knowledge on ADHD aftercare by adding the clients' perspective of the organization of ADHD aftercare. The focus was on the development of knowledge about the needs and preferences of the parents of school-aged ADHD patients concerning ADHD aftercare, and by investigating what strengths and weaknesses parents of school-aged children with ADHD experience in the current organization of ADHD aftercare.

6.1 Conclusion

In conclusion, the current research examined ADHD aftercare from the perspective of the parents of young children receiving it. Parents' needs and preferences concerning ADHD aftercare were found, and they give client information which can be taken into account when considering how ADHD aftercare should be provided. Four main themes concerning the organization of ADHD aftercare important to the parents were identified. Related to the first theme, communication, the need for sufficient provision of information on ADHD and for feedback from the healthcare providers towards the parents was discovered. In relation to the second theme, a patient-centred approach, the needs for individual attention and continuity of care were discovered. The organized care should be patient-centred, and continuously provided without interruptions by switching between healthcare providers. The third theme identified, the division of tasks, entails the roles of the parents, the school and the healthcare provider. In relation to these roles, there is the need for more elaborate involvement of the parents. Further the involvement of the school and the coordination between the parents, school and healthcare provider are important aspects of the organization of ADHD aftercare. A request for help for the parents was found as the fourth theme. Parents struggle with unfamiliarity with the diagnosis, and experience difficulties raising their child for which they would want help from the healthcare providers.

Furthermore, strengths and weaknesses of the current provision of ADHD aftercare as experienced by the parents were found. These findings are related to four of the eight domains of the WHO responsiveness model (Darby *et al.*, 2000); autonomy, confidentiality, communication and prompt attention. In relation to autonomy, the somewhat limited involvement of the parents in the aftercare process can be described as a weakness of the current organization. The parents are not fully informed about the care process, and given the young age of the children it could be considered appropriate to fully inform them. In relation to confidentiality, the bond of trust between healthcare providers and the children can be seen as a strength of the current organization. There is an environment of trust and confidentiality, which adds to the care process as described by the parents. The domain communication is also a theme found using the thematic analysis, and with respect to this domain the minimal amount of feedback from the healthcare providers towards the parents of the children can be seen as a weakness in the current organization. Parents have a need for the provision of feedback, and they reckon that the organization can improve with better feedback mechanisms for the parents. The last domain present in the data was prompt attention, as the interviewed parents pointed out that, upon request, prompt attention was given to concerns raised by the parents which can be seen as a strength of the current organization. These strengths and weaknesses show the clients' perspective of the current organization, information which can help to improve what currently exists.

6.2 Past literature

The finding that there is a need for the provision of information and feedback to the parents, is consistent with previous research in the field of children receiving mental healthcare (Cunningham *et al.*, 2008; Haine-Schlagel & Walsh, 2015; Siklos & Kerns, 2006). In a detailed study into the information preferences of parents of children with mental health problems, it was found that 84% of the parents

want to receive more information from their child's mental healthcare provider about the problems their children are facing (Cunningham *et al.*, 2008). From this 84%, about half (51%) of the parents are specifically seeking for materials which provide step-by-step solutions to them for the behavioural and/or emotional problems their children are facing. The other 49% of the parents are seeking for information helping them to understand, rather than solve, their child's problems. Given that there are different information preferences, Cunningham *et al.* recommend that communication strategies should be consistent with the preferences of the parents (Cunningham *et al.*, 2008). No quantitative distinction between different communication strategies is present in the results of the current study, but this research found that parents are seeking for an active role in the treatment of their children, which includes receiving solutions from the healthcare provider to help them solve their children's problems.

The discovery that parents want an active role in the care for their children is in line with previous research (Coates, 2016; Haine-Schlagel & Walsh, 2015). Parents want to be recognized for their expertise and see themselves as a valuable resource in their child's life (Coates, 2016; Johansson, Andershed, & Anderzen-Carlsson, 2014). Parent involvement is an important factor to consider in improving the quality of mental healthcare for children, as for example the involvement of family members increases the likelihood of compliance with treatment and increases stability of the family's living situation (Hoagwood, 2005; Mackean *et al.*, 2012).

With regard to the other findings about the division of tasks, it is clear that there are a number of different actors involved in ADHD aftercare. ADHD care in general is a multidisciplinary process, and organizing the division of tasks has been extendedly described in the important Multidisciplinary ADHD Guideline for Children and Youth developed for the organization of ADHD care in the Netherlands (Trimbos, 2007). This guideline also specifies what parties should be involved and how tasks should be divided. The advises of the multidisciplinary guideline are in line with the needs for division of tasks we discovered: the guideline advises an important role for the parents and parent involvement, involvement and coordination with school and a sufficient exchange of information between the parties involved (Trimbos, 2007). Interestingly, although these advises are in line with the discovered needs, the strengths and weaknesses analyses found that parents still experience that they are not enough involved and that the involvement of the schools does not seem to be integrated in the organization.

The current research found a request for help for the parents. This request can also be found in comparable literature on parents experience with mental care (Coates, 2016; Siklos & Kerns, 2006). In an evaluation of inpatient moderate Youth Mental Health services in New South Wales, Australia, parents also mention they needed support and guidance for themselves (Coates, 2016). Furthermore, the parents of children with autism also frequently turn to healthcare providers for support for themselves (Siklos & Kerns, 2006). A reason why parents have a request for help for themselves, might be because parenting a child with ADHD often leads to high levels of frustration and stress for the parents (Baker, 1994).

With regard to the strengths and weaknesses analyses, the fact that four of the eight domains of responsiveness, dignity, social support, quality of basic amenities and choice of care provider, were not in the data likely follows from two reasons. First, it might partially be because the focus in our research was on a healthcare subsystem. Not all domains of responsiveness might be as important when focussing on one healthcare subsystem such as ADHD care, e.g. Scheerhagen *et al.* found that the domains of dignity and communication were selected as the most important ones in their research on maternity care (Scheerhagen *et al.*, 2015). Given the research methodology, without the incorporation of responsiveness framework in the interview protocol, the fact that that the four

domains autonomy, confidentiality, communication and prompt attention are present might mean that these four are the important domains in ADHD aftercare.

A second explanation for the fact that not all domains of responsiveness were found might be the method of data-analysis used. The data was first coded and divided in themes using the open-coding thematic analysis (Braun & Clarke, 2006). Because comparison with the domains of responsiveness was done after this stage, some domains which were initially in the data might have been disregarded in the coding and theme definition stage.

6.3 Strengths and limitations of current research

The results of this research should be interpreted with the awareness of some limitations in the methodology used. A limitation of the current research is the risk of selection bias due to the process of recruitment of respondents. A call for respondents was made using various channels. All found participants responded to the call from one mental healthcare facility and no participants responded to calls from other institutions such as the general practitioner. The healthcare facility can only provide insured care with a referral from the GP, so all were referred by their GP. However, the GPs might have a reason to refer one particular kind of patient to this institute, which could cause a bias. It is not known if the respondents are a particular group within the researched population, the mental healthcare facility is not specialised in a particular kind of ADHD patients. The healthcare facility may however offer a particular kind of care, which may be different from care provided by other health providers. It is not known if the care provided by this one mental healthcare provider differs from others, which means that it is not known if the strengths and weaknesses found are representative for ADHD aftercare in the municipality of Enschede.

With regard to the research methodology, a strength of the methodology is the openness of the approach. The open-ended questions in the interview encouraged the participants to describe their experiences in their own words. Beforehand unanticipated answers and insights have been discovered. While the open ended and fairly general questions also asked for a greater amount of time and effort from the respondents, possibly discouraging them to participate, the relatively long length of the interviews also gave participants all the time to talk about their experiences. At the end of every interview all respondents stated that everything they wanted to discuss was addressed. A possible limitation of the open ended and fairly general questions is the risk that the answers of the respondents can vary in degree of details. Respondents may have different interpretations of the same questions. When necessary this was overcome by follow-up questions and explanations by the researcher.

A strength of the analyses method used, the thematic analyses with open coding and theme formation, is that it offered the possibility to discover beforehand unexpected findings and insights in the parents' experiences. At the same time, a limitations of the thematic analyses without the full use of an existing theoretical framework to anchor the analytic claims is that the interpretative power of the findings is limited (Braun & Clarke, 2006). To compensate this, the findings are sufficiently backed with quotes extracted from the data to support the interpretations of the data made by the researcher.

6.5 Recommendations

To investigate the responsiveness within a healthcare subsystem, the WHO has developed specific questionnaires. In the current research, the domains of responsiveness are not integrated in the interview, but used during the analyses. For future research, to make a leap towards measuring the responsiveness of this health subsystem, materials provided by the WHO to measure responsiveness could be integrated in the methodology.

In the current research, the parents of children with ADHD were interviewed. In order to further work towards more patient-centred care, the young children themselves should also be interviewed. In the current research, it was found that although parents act in the interest of their children, many statements made were regarding the care the parents themselves are seeking for. Although this is considered an interesting finding, it can be questioned whether the interest of the children and the parents always align and therefore interviews with the young children themselves should be performed.

In the current research, the need for the provision of information was found. In their research, Cunningham *et al* found different subtypes of communication preferences in parents of children receiving mental healthcare, and recommended that for realizing potential benefits of information transfer the transfer strategy should be consistent with the parents communication preferences (Cunningham *et al.*, 2008). Further and more detailed research into the found need for communication preferences should be performed, in order to further specific define what information parents need and to identify and define different information needs with the parents of children receiving ADHD aftercare.

In order to investigate the current population, it can be recommended to make use of the network of healthcare professionals for recruitment. Doctor-patient confidentiality makes it difficult to find respondents without the active involvement of healthcare professionals.

The conversations with the participants resulted in practically usable recommendations, to improve the organization of ADHD aftercare. First, the mentioned recommendation to integrate a feedback mechanism in the ADHD aftercare. Specifically, it is recommendable to consider a digital feedback mechanism such as a phone application, or an online module, to streamline and improve communication between healthcare providers and parents. Secondly, the healthcare organization could be more responsive to the questions which arise because of the diagnosis ADHD by preparing information for the parents. In the cases where such information was provided, the parents viewed it as very positive however when this information was not provided parents were left with questions. In many cases a diagnosis will raise questions, and by being aware of this fact and preparing for it the experience for the parents might improve. Thirdly, this research found the request for help the parents have. It is recommended to integrate counselling and care for the parents in the ADHD aftercare programs.

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Appendix A – Informed Consent Form

Toestemmingsverklaringformulier (informed consent)

Titel onderzoek: Patiënt voorkeuren voor ADHD-nazorg in Enschede

Onderzoeker: H. van der Wel

In te vullen door de deelnemer

Ik verklaar op een voor mij duidelijke wijze te zijn ingelicht over de aard, methode, doel en de risico's en belasting van het onderzoek. Ik weet dat de gegevens en resultaten van het onderzoek alleen anoniem en vertrouwelijk aan derden bekend gemaakt zullen worden. Mijn vragen zijn naar tevredenheid beantwoord, ik heb geen verdere vragen.

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 stem geheel vrijwillig in met deelname aan dit onderzoek. Ik behoud me daarbij het recht voor om op elk moment zonder opgaaf van redenen mijn deelname aan dit onderzoek te beëindigen.

Naam deelnemer:

Datum:

Handtekening deelnemers:.....

In te vullen door de uitvoerende onderzoeker

Ik heb een mondelinge en schriftelijke toelichting gegeven op het onderzoek. Ik zal resterende vragen over het onderzoek naar vermogen beantwoorden. De deelnemers zal van een eventuele voortijdige beëindiging van deelname aan dit onderzoek geen nadelige gevolgen ondervinden.

Naam onderzoeker: *H. van der Wel*

Datum:

Handtekening deelnemers:.....

Appendix B – Interview protocol

Interview protocol – Introductie

- ➔ Datum:.....
- ➔ Tijdstip:.....
- ➔ Locatie:.....

[Lees voor] Mijn naam is - ik studeer Gezondheidswetenschappen en Technische Geneeskunde aan de Universiteit van Twente. Voor mijn afstudeeropdracht doe ik onderzoek naar de ervaringen en behoeftes van kinderen tussen de 6-11 jaar met ADHD tijdens het nazorg traject. Dit traject gaat in nadat de diagnose is gesteld en een behandeling is voorgesteld. Zo dadelijk wil ik u graag interviewen over de ervaringen van uw kind en u aangaande de ADHD-nazorg die uw kind heeft ontvangen.

Enige tijd geleden bent u uitgenodigd om aan dit onderzoek deel te nemen, waarop u heeft aangegeven dit te willen. U heeft hierbij al enige informatie over mijn onderzoek ontvangen, ik zou nu graag wat meer uitleggen over het interview dat ik wil afnemen.

Het interview duurt naar verwachting 45 minuten. Ik heb voor dit interview vaststaande vragen voorbereid die ik u wil stellen, waarna ik u graag wilt uitnodigen verder op de thema's in te gaan die u belangrijk vindt. Om te zorgen dat het interview precies wordt uitgevoerd lees ik een aantal delen letterlijk voor van papier.

Voor een goede analyse van uw antwoorden wil ik graag een audio opname van dit gesprek maken, doormiddel van een audiorecorder. De audio die wordt opgenomen of bewerkingen daarvan worden uitsluitend voor analyse of wetenschappelijke presentaties gebruikt.

Ik vraag u tijdens ook naar herinneringen aan het traject wat u en uw kind hebben doorlopen. Dit kunnen vervelende herinneringen betreffen, indien u ergens niet over wilt vertellen dan kunt u dit aangeven. Daaropvolgend heeft u ten alle tijden het recht om zonder opgaaf van redenen uw deelname aan dit onderzoek te stoppen.

Ik hoop u voldoende informatie te hebben geven, heeft u nog verdere vragen?

➔ Heeft u verdere vragen?

.....
.....

[Lees voor] Als u geen verdere vragen heeft, dan zou ik u willen vragen een toestemmingsverklaring formulier in te vullen. Met dit formulier geeft u aan dat u volledig bent ingelicht de aard, methode, doel en de risico's en belasting van het onderzoek. Verder teken ik ervoor dat ik uw gegevens en resultaten alleen anoniem en vertrouwelijk aan derden bekend maak.

➔ Informed consent formulier ondertekenen

[Lees voor] Dan zou ik nu graag het interview willen starten en de audio opname apparatuur aan willen zetten.

➔ ZET AUDIO RECORDER AAN

Deel 1: Algemeen – Situatieschets

Dan wil ik eerst even wat gegevens noteren

[Lees voor] Oké, dan beginnen we nu het interview. Zou u allereerst wat meer kunnen vertellen over uw zoon/dochter met ADHD?

Om te beginnen, een aantal formelere vragen

1. Wat is de naam van uw kind?

2. Wat is de geboortedatum van uw kind?

3. Woont uw kind in de gemeente Enschede?

4. Zit uw kind nog op de basisschool?

Situatieschets

[Lees voor] Ik zou nu graag wat verder ingaan op het verloop van de situatie voor [naam uw kind]

- 1. Hoe gaat het op dit moment met [naam]?**
 - a. Welke school zit uw kind
 - b. Gaat het goed op school
 - c. Gaat het goed thuis?
- 2. Kunt u mij vertellen hoe de ADHD-diagnose is gegaan?**
 - a. Wanneer werd de diagnose ADHD gesteld
 - b. Door wie werd de diagnose ADHD gesteld
 - c. Wie waren er betrokken bij de diagnose en het starten van de behandeling?
 - d. Hoe lang heeft het geduurd tussen uw eerste gesprek en de diagnose ADHD?
 - e. Voor welke behandeling is er gekozen?
 - f. Wanneer dacht u dat uw zoon ADHD had?
- 3. Kunt u omschrijven hoe het nazorg traject tot nu toe is verlopen?**
 - a. Loopt dit traject nog steeds?

Deel 3: Ervaringen bij het doorlopen traject

[Lees voor] Wij hebben het net gehad over wat er is gebeurd nadat de diagnose ADHD was gesteld. Ik wil het nu graag hebben over hoe jullie alles wat er is gebeurd hebben ervaren. Ik wil het graag hebben over uw ervaringen en de ervaringen van uw zoon/dochter. Uw zoon/dochter is er nu niet bij, maar u mag ook voor hem/haar praten.

- 1. Als u kijkt naar het traject wat we bij de vorige vraag hebben besproken, zijn er dan onderdelen die u als positief heeft ervaren?**
- 2. Zijn er onderdelen van het traject die u als negatief heeft ervaren?**
- 3. Ik heb alle onderwerpen die ik had voorbereid voorgelegd, zijn er na deze vragen bij u nog andere positieve of negatieve ervaringen opgekomen waar we het nog niet over hebben gehad?**
- 4.**

Deel 4: Ideale beeld

[Lees voor] Nu we hebben doorgesproken hoe de zorg er in werkelijkheid heeft uitgezien, en hoe u dat heeft ervaren, ben ik benieuwd te horen hoe de zorg ideaal geregeld zou moeten zijn. Als ervaringsdeskundige op dat gebied wil ik u daar graag over vragen:

- 1. Hoe zou volgens u de ideale begeleiding na de diagnose ADHD eruitzien?**
 - a. Wat zou er aan de bestaande zorg moeten veranderen om dat voor elkaar te krijgen?
- 2. Als er nou tussen alle dingen waar we het over gehad hebben één ding is wat goed geregeld zou moeten zijn, wat is dat dan?**

3. Afsluiting

[Lees voor] Hiermee ben ik aan het einde gekomen van mijn vragen. Heeft u nog vragen aan mij?

[Lees voor] Hartelijk dank voor uw deelname aan dit onderzoek! Ik schakel nu de audio opname uit.

➔ **Schakel audio opname uit**

➔ **Tijdstip uitschakelen:.....**

[Lees voor] Als ik klaar ben met afnemen van alle interviews zal ik de resultaten verzamelen en analyseren. Hierna verwerk ik dit tot een verslag. Zal ik u ook een exemplaar van dit verslag toe sturen? Kan dit via het bij mij bekende mailadres of ontvangt u liever een exemplaar via de post?

Ja/Nee

Adres:.....

Mailadres:.....

[Lees voor] Mocht u nog verdere vragen hebben na dit interview dan kunt u contact met mij opnemen via de mail.

Themalijst interview

Thema 1: Betrokkenheid behandelaars

- Welke behandelaars zijn er betrokken bij de zorg voor uw kind?
 - Wat is de rol van de verschillende behandelaars
 - Ziet u één duidelijke hoofdbehandelaar (of regiebehandelaar?)
- Hoeveel verschillende behandelaars zijn er betrokken (geweest)
 - Hoe heeft u het wisselen tussen behandelaars ervaren?
- Bij welke behandelaar heeft u de meest prettige ervaring?
 - Zijn er behandelaars die u als minder positief heeft ervaren?
 - Welk verschil tussen behandelaars zorgt voor de verschillende waardering?

Thema 2: Frequentie van zorg

- Hoe vaak heeft uw kind contact met zijn/haar behandelaar?
 - Zou u het prettig vinden als er meer of minder contact was?

- Denkt u dat een verandering in de hoeveelheid contact een effect heeft op de behandeling?

Thema 3: Bereikbaarheid van de zorg

- Hoe bereikbaar is uw behandelaar voor u, bijvoorbeeld als u vragen heeft?
- Vind u het belangrijk om uw behandelaar snel te kunnen bereiken?

Thema 4: Samenwerking met school

- Is de school van [naam kind] op de hoogte van de diagnose?
- Is de school betrokken in het zorg proces?
- Denkt u dat betrokkenheid van de school belangrijk/nodig is?
 - Zou de school betrokken moeten zijn?
 - Hoe zou de school betrokken kunnen/moeten zijn?

Thema 5: Duidelijkheid/overzichtelijkheid van het zorg traject

- Is de zorg tot nu toe zo verlopen als u van tevoren had gehoord en/of verwacht?
 - Is er een verschil tussen uw verwachting en de werkelijkheid
 - Zijn de verschillende keuzes die gemaakt zijn duidelijk voor u geweest?
- Wat vindt u van de informatievoorziening rondom het nazorg traject?

Thema 6: Ondersteuning van de ouders

- Heeft de diagnose ADHD iets verandert voor u bij bijvoorbeeld de opvoeding?
- Is u ondersteuning en informatie aangeboden over hoe u het beste kan handelen als ouder?
 - Op welke manier krijgt u ondersteuning
 - Heeft u behoefte aan (meer) ondersteuning?

Appendix C – Translated quotes

English translation	Dutch
[our child] has received the diagnosis ADHD and we had to figure everything out ourselves. How should we continue? And what is going to happen? How should we handle everything? - (Transcript line number 1809-1811)	[ons kind] krijgt de diagnose ADHD en je moet er zelf maar achteraan vangen. Hoe ga je er verder mee om wat kan er gebeuren. Hoe doe je het allemaal. - (Transcript line number 1809-1811)
You know, the whole thing is unfamiliar to us. We were told that our child has ADHD, and then one starts to think, alright, but what exactly does that mean? - (Transcript line number 2928-2929)	Weetje, het is allemaal zo onbekend he. Ze zeggen jouw kind heeft ADHD en dan denk ja ja mijn kind heeft ADHD wat houdt het in - (Transcript line number 2928-2929)
You know, [healthcare providers] should provide some more feedback [...] they should show what they are doing, because the children themselves are generally jaded after an hour or forty-five minutes. They themselves won't tell you what they've done. Then it would be nice if they would keep a journal of what has been for us to read.. now I usually hear about it only after three or four days. - (Transcript line number 2418-2422)	ja weetje, [healthcare provider] zou wat meer moeten terugkoppelen [...] laten zien wat zij doen, want de kinderen zijn over het algemeen naar een uur of drie kwartier zo uitgeput. Dat ze zelf niet meer aangeven wat er gebeurd is. En dan zou het toch handig zijn als er ook weer een schriftje wordt meegegeven wat er is gedaan en meestal hoor ik het pas twee drie dagen later. (Transcript line number 2418-2422)
I don't really mind that we had to ask for a parent conference ourselves. You know we can. But personally, if I was the [healthcare provider] I would further incorporate it in the aftercare/treatment. For example every fourth time, three meetings with the child and then one with the parents. Even if it's only a very short meeting. - (Transcript line number 773 - 776)	dat we zelf om een oudergesprek moesten vragen dat vind ik prima om te doen hoor. Want dat kunnen we ook wel. Maar ik zou dat in de nazorg/behandeling als ik [healthcare provider] was zou ik dat wat meer er tussendoor vlechten. Dus bijvoorbeeld drie keer het kind, 1x de ouders. Ook als is het maar even kort. -(Transcript line number 773 – 776)
You know, [the situation] isn't the same for everyone. We're both working parents, not fulltime, but there is difference between psycho education for a very traditional household, e.g. the man works and the woman takes care of the household, and psycho education for us. You need a different sort of support or a different kind of psycho education, maybe a different content so to speak. (Transcript line number 805 - 809)	Weetje want [de situatie] is natuurlijk ook niet voor iedereen hetzelfde. Wij werken allebei, niet fulltime, maar er is een verschil dat je de psychoeducatie voor een heel traditioneel man werkt en vrouw doet huishouden doet dan heb je een andere vorm van begeleiding of een andere vorm van psychoeducatie, misschien een andere inhoud dan bij ons bij wijze van spreken. (Transcript line number 805 - 809)
And then you also need to know who the child is. I don't think there is one specific approach, except that you will have to pay attention to the child at that moment. I don't think.. there is not really one way of doing this. There might be certain features which are unique to children with ADHD, but I don't think you can put everything under the same umbrella. (Transcript line number 1464 - 1468)	Dan moet je nog dat kind leren kennen. Ik denk niet dat daar 1 specifiek ding voor is behalve dat je met ieder kind gewoon rekening moet houden op dat moment. Ik denk niet dat daar... er is geen algemeen papiertje voor. Er zijn wel bepaalde kenmerken die bij die kinderen horen maar, ik denk niet dat je dat over 1 kam kan scheren zeg maar. (Transcript line number 1464 - 1468)
And it is very nice that he has been seen by the same person all this time. Someone needs to learn your strengths and learning points and	En is het wel heel fijn dat hij steeds bij hetzelfde persoon heeft gezeten. Want iemand moet jouw kwaliteiten en leerpunten ook leren kennen en

because he stays with the same person this person knows his strengths and learning points. (Transcript line number 1388- 1390)	als hij bij dezelfde persoon blijft dan weet diegene dat. (Transcript line number 1388- 1390)
<i>In the end it is often about the face behind the story.</i> It's about whether the faces are familiar. And because it concerns long-term processes I think the general practitioner would be a logical choice because he stays around longer than the municipal health service. (Transcript line number 940 - 942)	Maar goed het gaat natuurlijk ook vaak over gezichten. Het gaat over zijn dat bekende gezichten die dat doen. Weetje en het zijn natuurlijk langjarige trajecten dan is wat mij betreft een huisarts denk ik een logischer gezicht wat lang blijft dan een GGD. (Transcript line number 940 - 942)
We think that in the end it's mostly about what we as parents have to do. You know they are seeing him as well, but I think 80-90 percent of it is done by us. We will have to do it. (Transcript line number 793 - 794)	Want uiteindelijk denken wij van het grootste deel gaat over wat wij moeten doen. Dat wat ze met hem doen weetje daar denk ik ja 80-90 procent doen wij. Wij moeten het doen. (Transcript line number 793 - 794)
You [the child] will receive help, and your father and mother will also receive help and support to understand you as best as possible. (Transcript line number 3227 - 3228)	Jij wordt geholpen maar ook papa en mama worden geholpen en krijgen begeleiding om jou zo goed mogelijk te kunnen begrijpen. (Transcript line number 3227 - 3228)
We also notice that the teacher starts to understand some things. They have of course also received our son's diagnosis and only now we notice that they start to take action. They facilitate re-examination, allow him to take music and a fidget spinner to the classroom. They know that they will have to plan everything with him [...] And they started planning and organizing and you could really see him grow. (Transcript line number 888- 897)	Ook bij de leerkrachten zien wij nu gewoon een aantal kwartjes vallen die hebben natuurlijk ook die diagnose van onze zoon gekregen en pas nu zien wij dat ze inderdaad af en toe een tekort op de cito toets en een dag later nog een keer toestaan, dat hij muziek meeneemt, dat hij fidget spinners heeft. Dat ze met hem moeten plannen [...] En dan gingen ze plannen en organiseren en dan zag je hem echt, echt groeien. (Transcript line number 888- 897)
I think it is very useful to work together with each other, also with the school and your healthcare organization, because the child will then know that everything is the same. And he or she doesn't have any margin or ambiguity to.. you know.. do things differently on school than at home. (Transcript line number 3200 -3203)	Ik denk wel dat als jij met elkaar samenwerkt ook met de school en de instantie waar jij bij loopt denk ik dat het wel heel zinvol is omdat het kind dan wel weet van het is allemaal hetzelfde. En ik heb daarin geen ruimte en onduidelijkheid van hem... op school doen ze dit en thuis doen ze dat. (Transcript line number 3200 -3203)
You know, the request for help is actually for me. I want to know how to deal with this, how I should handle this situation. (Transcript line number 2246 - 2247)	Weetje, de hulpvraag zou eerder aan mijn kant toegeschreven moeten worden. Van hoe ga ik hier mee om. Hoe moet ik handelen in dit geval. (Transcript line number 2246 - 2247)
We never had the intention to use the diagnosis to get ADHD medication or anything.. Actually.. you see I know that there is no such thing as a manual for children, but some better guidelines tips and advises.. that was actually our wish and the reason for seeking a diagnosis. (Transcript line number 134-137)	We hebben in principe nooit de intentie gehad van goh we willen graag een indicatie zodat we eventueel medicatie kunnen ofzo, waar het met name.. kijk ik weet dat er van kinderen geen handboek bestaat, maar wat betere richtlijnen en tips en adviezen en dat was eigenlijk de wens waarom we een indicatie wouden. (Transcript line number 134-137)
That was a real switch-over for us. It took us, and especially me, a lot of effort because at once we had to be very strict and "tough" for our child. I should give any space. So at first I had quite a lot	Dat was voor ons echt een hele omschakeling. Het heeft ook best wel veel met name met mij veel moeite gekost omdat je in een keer heel streng en tussen aanhalingstekens hard moet

of difficulty doing so. But if I look back now, a year later, and look at the results than I know it has not been for nothing. (Transcript line number 3172-3176)	zijn voor je kind. Geen ruimte kunt geven. Dus ik heb daar eigenlijk in eerste instantie best wel moeite mee gehad maar als ik nou een jaar later kijk en het resultaat zie is het niet voor niks geweest. (Transcript line number 3172-3176)
As I told, it's mostly the feedback and some insights for the parents.. and involving the parents [which is lacking]. (Transcript line number 376-3789)	Met name wat ik zeg van follow-up en dat vind ik allemaal een stukje inzichtelijk maken voor de ouders zelf en het erbij betrekken van de ouders dat vind ik het negatieve kant. (Transcript line number 376-3789)
Until now there is only one person [involved in the aftercare], well sometimes an intern as well but that doesn't matter. And indeed that is positive, that we don't have to switch healthcare provider all the time because nowadays you see that everywhere. (Transcript line number 2968-2971)	Ik heb tot nu toe echt alleen met één persoon, ja af en toe loopt er dan een stagiaire mee maar dat is ook niet erg. Maar dat is dus ook wel heel positief inderdaad dat je niet continu wisselt, want dat heb je tegenwoordig echt overal. (Transcript line number 2968-2971)
You don't have a clue where to start searching [for information]. (Transcript line number 2255 - 2256)	Je weet bij god niet meer waar je moet gaan vissen en waar je moet gaan zoeken. (Transcript line number 2255 - 2256)
I would have wanted to get some more information, just a short description of what is ADHD, what should one take into account. (Transcript line number 803-804)	had ik het wel graag gewild even gewoon hele korte schets van wat is ADHD waar moet je aan denken. (Transcript line number 803-804)
This [the report] gives a lot of information about.. you know.. his problems. (Transcript line number 766-367)	Dat [het rapport] geeft veel duidelijkheid van goh waarom heeft hij zijn.. euh ja zijn dingetjes. (Transcript line number 766-367)