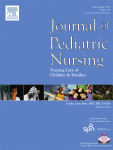
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ADHD and Everyday Life: Healthcare as a Significant Lifeline

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Highlights

* •

ADHD pervades all aspects of the family's everyday life.

* •

Health professionals are important allies in overcoming disruptive phases.

* •

Parents should be involved as experts.

* •

Mental and physical aspects should be integrated in healthcare.

* •

Health professionals should provide care using a family-centred approach.

Abstract

Aim

The aim of this qualitative study was to explore parental experiences of how [healthcare practices](https://www.sciencedirect.com/topics/nursing-and-health-professions/health-care-practice) and healthcare professionals in hospital clinics in Denmark influence [everyday life](https://www.sciencedirect.com/topics/medicine-and-dentistry/activities-of-daily-living) of parents with a child with ADHD.

Design and Methods

The methodology was focused ethnography. Participant observation and interviews were used as the primary data collection methods. Fifteen families of children with ADHD were included from somatic and psychiatric hospital clinics.

Results

Three main themes emerged from the experiences of the families: When the house of cards collapses in everyday life, Treading water before and after receiving the ADHD diagnosis, and Healthcare as a significant lifeline.

Conclusions

Accessibility to healthcare, trusting relationships and healthcare professionals recognizing how ADHD pervades all aspects of everyday life appear to be important factors in providing a lifeline for parents to help them regain confidence and control in disruptive phases. The parents depend on help from healthcare professionals and family-centred care to manage the complex challenges in everyday life.

* [Previous article in issue](https://www.sciencedirect.com/science/article/pii/S0882596316304468)
* [Next article in issue](https://www.sciencedirect.com/science/article/pii/S0882596316302846)

Keywords

Attention deficit hyperactivity disorder

ADHD

Parents

Healthcare services

Healthcare professionals

Practice Implications

Healthcare professionals regardless of specialty need to consider how to involve the parents as experts on their child and their family in a family-centred approach involving regular clinics visits as well. Care, assessment and [treatment](https://www.sciencedirect.com/topics/medicine-and-dentistry/therapeutic-procedure) should reflect the uniqueness of each family and there is a need for a holistic approach to integrate mental and physical aspects of healthcare. Consultancy and interventions should be provided for healthcare professionals who feel inadequately prepared to engage with families of children with ADHD.

Background

The prevalence of attention deficit hyperactivity disorder (ADHD) is increasing and ADHD is one of the most frequent [mental disorders](https://www.sciencedirect.com/topics/medicine-and-dentistry/mental-disorder) among children and adolescents ([Polanczyk et al., 2007](https://www.sciencedirect.com/science/article/pii/S0882596316301221" \l "bb0180), [Thomas et al., 2015](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0210), [Willcutt, 2012](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0235)). The estimated worldwide prevalence in children and adolescents is 5–7% ([Polanczyk et al., 2007](https://www.sciencedirect.com/science/article/pii/S0882596316301221" \l "bb0180), [Thomas et al., 2015](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0210), [Willcutt, 2012](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0235)), and the core symptoms are inattentiveness, hyperactivity and [impulsivity](https://www.sciencedirect.com/topics/medicine-and-dentistry/impulsiveness) ([Cormier, 2008](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0045)). Research suggest that symptoms of ADHD or early development deviations may be present in early childhood of children later diagnosed with ADHD, however the diagnosis is usually not applied until school age ([Arnett et al., 2013](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0005), [Lemcke et al., 2016](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0130)). ADHD is associated with impairment in social, emotional, academic and behavioural functioning as well as familial relationships ([Caci et al., 2013](https://www.sciencedirect.com/science/article/pii/S0882596316301221" \l "bb0040), [Johnston and Mash, 2001](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0090), [McIntyre and Hennessy, 2012](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0145), [Moen et al., 2011](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0155)). Previous reviews highlight disturbances in family functioning as ADHD seems to affect [everyday life](https://www.sciencedirect.com/topics/medicine-and-dentistry/activities-of-daily-living) of the whole family ([Johnston and Mash, 2001](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0090), [Laugesen and Gronkjaer, 2015](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0120)). Parents struggle to maintain a manageable family life and find it difficult to raise and support the child, though different strategies are used to cope ([McIntyre and Hennessy, 2012](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0145), [Moen et al., 2011](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0155)). Parents utilize many resources to optimize the functioning of their child, and they are burdened by feelings of guilt, self-blame as the responsibility for the child is sometimes overwhelming ([Johnston and Mash, 2001](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0090), [McIntyre and Hennessy, 2012](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0145), [Moen et al., 2015](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0160)). In addition, the relationships with their partner and the child's siblings may be affected, and the parents are more likely to be stressed than parents of children without ADHD ([Johnston & Mash, 2001](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0090)). At the same time, parents play an important role in improving the child's functioning and changing behavioural symptoms of the child ([Cormier, 2008](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0045), [Deault, 2010](https://www.sciencedirect.com/science/article/pii/S0882596316301221" \l "bb0065)).

Children with ADHD often have comorbidities and co-existing [healthcare needs](https://www.sciencedirect.com/topics/nursing-and-health-professions/health-care-need) suggesting that they need multiple approaches from a range of professionals in a diversity of settings including [healthcare practices](https://www.sciencedirect.com/topics/nursing-and-health-professions/health-care-practice) ([Jensen and Steinhausen, 2015](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0085), [Moen et al., 2011](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0155), [Silva et al., 2014](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0205)). Literature on healthcare service use suggests that children with ADHD are more likely to be admitted to hospitals, and that children subsequently diagnosed with ADHD use more hospital services than children without ADHD in early childhood ([Leibson et al., 2001](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0125), [Schieve et al., 2012](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0200), [Silva et al., 2014](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0205)). ADHD children tend to have more medical conditions such as allergies, asthma, incontinence, and epilepsy ([Holmberg et al., 2015](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0080), [Lin et al., 2016](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0135), [Tsai et al., 2014](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0215), [von Gontard and Equit, 2015](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0070))than children without ADHD, and they are frequent users of healthcare services in both [paediatric](https://www.sciencedirect.com/topics/medicine-and-dentistry/pediatrics) and [mental health clinics](https://www.sciencedirect.com/topics/nursing-and-health-professions/mental-health-center) ([Reid-Searl et al., 2009](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0185), [Schieve et al., 2012](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0200)). However, caring for children with mental disorders in general paediatric settings appears s to provide challenges for nurses and healthcare providers as they feel inadequately prepared and incompetent ([Buckley, 2010](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0030), [Reid-Searl et al., 2009](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0185)). Parents have been identified as key partners in healthcare, and previous research shows that their perceptions should be integrated in decisions and [treatment](https://www.sciencedirect.com/topics/medicine-and-dentistry/therapeutic-procedure) plans ([Cormier, 2008](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0045), [Davis et al., 2012](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0060), [McGoron et al., 2014](https://www.sciencedirect.com/science/article/pii/S0882596316301221" \l "bb0140)). Healthcare experiences of parents of children with special needs demonstrate barriers to healthcare in that care and treatment tend to be fragmented and that healthcare professionals tend not to consider the unique needs of the families ([Bultas, 2012](https://www.sciencedirect.com/science/article/pii/S0882596316301221" \l "bb0035), [Miller et al., 2009](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0150)). Studies suggest that care coordination and family-centred care are important factors in supporting the families of children with special healthcare needs ([Kuo et al., 2011](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0110), [Miller et al., 2009](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0150), [Nolan et al., 2007](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0175)). However, parents of children with ADHD seem to fight for professional support and their needs may not always be met ([Laugesen & Gronkjaer, 2015](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0120)). Furthermore, research regarding parental perspectives on care in diverse healthcare settings is limited. Knowing that everyday life is significantly impacted by living with a child with ADHD and that healthcare experiences are under-represented in research, this study aimed to examine parental experiences of how healthcare influences everyday life with a child with ADHD.

Aim

The aim of this study was to explore parental experiences of how [healthcare practices](https://www.sciencedirect.com/topics/nursing-and-health-professions/health-care-practice) and healthcare professionals in hospital clinics in Denmark influence [everyday life](https://www.sciencedirect.com/topics/medicine-and-dentistry/activities-of-daily-living) of the parent with a child with ADHD. The research questions were how parents of children with ADHD; 1) experience collaboration with healthcare services and healthcare professionals, 2) feel supported by healthcare professionals in everyday life and 3) perceive barriers and enablers in healthcare.

Methodology

Focused ethnography (FE) was chosen as an appropriate methodology underlining the importance of contextual and cultural factors in hospitals to understand parental experiences of healthcare services and collaboration with healthcare professionals ([Higginbottom et al., 2013](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0075), [Roper and Shapira, 2000](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0190), [Venzon Cruz and Higginbottom, 2013](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0220)). FE is a niche within ethnography allowing the research question to focus on specifically parental experiences in somatic/paediatric and psychiatric contexts ([Higginbottom et al., 2013](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0075), [Roper and Shapira, 2000](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0190), [Venzon Cruz and Higginbottom, 2013](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0220)). FE is used to gain a better understanding of the experiences of specific aspects of people's ways of life, and participant observations, interviews and document analysis are substantial to explore the complexities in the culture ([Higginbottom et al., 2013](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0075), [Roper and Shapira, 2000](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0190), [Venzon Cruz and Higginbottom, 2013](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0220)).

Study Setting

The data were collected at a public general university hospital and a psychiatric hospital in Denmark. The settings for the study involved two general paediatric [outpatient clinics](https://www.sciencedirect.com/topics/nursing-and-health-professions/outpatient-department) and two child and adolescent [mental health clinics](https://www.sciencedirect.com/topics/nursing-and-health-professions/mental-health-center). The general paediatric outpatient clinics are located at the general University Hospital and the two mental health clinics are located at the psychiatric hospital. The four clinics were chosen because children with ADHD regularly had appointments in the clinics. The two general paediatric clinics were: an outpatient clinic for overweight children and a neuro [paediatric clinic](https://www.sciencedirect.com/topics/nursing-and-health-professions/pediatric-hospital). The two child- and adolescents mental health clinics were: an ADHD clinic and a day unit for children with [mental health disorders](https://www.sciencedirect.com/topics/medicine-and-dentistry/mental-disorder). The time that the children or families spend in the clinics ranged from 45 min to 8 h. The families met a variety of health professionals such as nurses, doctors, [dietitians](https://www.sciencedirect.com/topics/nursing-and-health-professions/dietitian), psychologists, occupational therapists, physiotherapists, and child development health professionals.

Participants

A combination of purposeful, convenient and maximum variation sampling procedures were used to recruit participants. Purposeful sampling was applied with the aim of selecting participants who would provide unique and rich information of value to the study ([Creswell, 2013](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0050)). As such participants with experiences of having a child with ADHD who received hospital-based care and treatment were selected. Convenient sampling strategies were utilized because participants were included if they had an appointment in one of the clinics in the period of data collection ([Creswell, 2013](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0050)). Maximum variation sampling was used to target the range of hospital settings that the families attend, thus participant experiences representing both the general and the psychiatric hospital were included.

Included were parents of children diagnosed with ADHD (F90: [Hyperkinetic disorders](https://www.sciencedirect.com/topics/medicine-and-dentistry/hyperkinetic-disorder) and F98.8: Attention deficit disorder without hyperactivity) according to the ICD-10 Classification of Mental and Behavioural Disorders ([WHO, 1992](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0225)) aged 5–12 years. For this study, parents were defined as biological parents, step parents or people with parental responsibilities for the child. Both single parents, parents living together or divorced parents were invited to participate in the study. Families of children not yet diagnosed with ADHD were excluded. The inclusion of families was assisted by professionals working in the clinics. The families were approached by the professional who provided the families initial information about the study. If a family showed interest in participating, the researcher contacted the family by phone or met with them face to face prior to the healthcare meeting to provide more information about the study. In addition, the researcher regularly attended the clinics to screen [medical records](https://www.sciencedirect.com/topics/medicine-and-dentistry/medical-record) and lists of patients to identify relevant participants. The final sample included 15 families of children with ADHD ([Table 1](https://www.sciencedirect.com/science/article/pii/S0882596316301221#t0005)). Two children were diagnosed with ADD and 13 with ADHD, nine had co-existing physical or developmental diseases.

Table 1. Participant characteristics.

| **Family** | **Participants (formal interview)** | **Participants (observation)** | **Clinic, included from** | **Child characteristics (gender, age)** |
| --- | --- | --- | --- | --- |
| **A** | Biological mother | Biological mother | Mental health | Boy, 7 years old |
| Biological father (2 observations with both parents) |
| **B** | Biological mother | Biological mother | Mental health | Girl, 7 years old |
| **C** | Biological father | Biological father | Mental health | Boy, 12 years old |
| Partner | Biological mother |
| Father's partner |
| **D** | Biological mother | Biological mother | Mental health | Girl, 12 years old |
| Partner | Partner |
| **E** | Biological mother | Biological mother | Mental health | Boy, 9 years old |
| **F** | Biological mother | Biological mother | Mental health | Boy, 12 years old |
| **G** | Foster mother | Foster mother | Mental health | Boy, 11 years old |
| Foster father | Foster father |
| **H** | Biological Mother | Biological mother | Paediatric | Boy, 12 years old |
| Biological father | Older sister (2 observations) |
| **I** | Biological Mother | Biological mother | Paediatric | Boy, 9 years old |
| Biological father | Biological father |
| **J** | Biological mother | Biological mother | Mental health | Girl, 7 years old |
| **K** | Biological mother | No field observations (nurse from the ADHD clinic telephoned the mother) | Mental health | Boy, 10 years old |
| **L** | Grandmother | Grandmother | Paediatric | Girl, 9 years old |
| Partner | Partner |
| **M** | Biological mother | Biological mother | Paediatric | Girl, 10 years old |
| Biological father |
| **N** | Biological mother | Biological mother | Paediatric | Boy, 11 years old |
| **O** | Biological mother | Biological mother | Paediatric | Boy, 11 years old |
| **Age range** | 29–59 | 29–59 |  | 7–12 |
| **Duration of sessions, (range)** | 40–80 min | 45–90 min |  |  |

Data-Collection

Participant observations and interviews were the primary sources of data collection. [Medical records](https://www.sciencedirect.com/topics/medicine-and-dentistry/medical-record) provided demographic information such as child age, year of diagnosis, co-morbidities, parental age, and parents' employment status. In agreement with FE, participant observations were short term and the fields were visited in certain intervals whenever a family visited one of the hospital clinics ([Knoblauch, 2005](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0105), [Roper and Shapira, 2000](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0190)). Data were collected consecutively between February and November 2015 starting in the mental health settings following the paediatric settings. Data collection ended when the research team through discussions evaluated there was adequate amount of data to represent a variety of parental experiences in mental health and paediatric settings.

Participant Observation

Sixteen short but intensive participant observations were undertaken ([Table 1](https://www.sciencedirect.com/science/article/pii/S0882596316301221#t0005)). Predominately the “observer-as-participant role” was used as the researcher's participation in activities was reduced ([Roper & Shapira, 2000](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0190)). The researcher wrote notes and observed activities and interactions in the meetings but was in the majority of the meetings invited by the families or health professionals to join a conversation or activity. This promoted the interaction between the researcher, health professionals and families. Prior to participant observations, the researcher spent time in the various settings to gain insight into the context and to introduce health professionals to the study. This allowed the health professionals to ask questions about the project and get familiar with the researcher.

Interviews

Informal and formal interviews were conducted following the participant observations. Informal interviews were conversations with participants that were not pre-arranged ([Higginbottom et al., 2013](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0075), [Roper and Shapira, 2000](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0190)). The informal interviews took place before and after healthcare meetings and the researcher asked questions about the activities and interactions. Formal interviews were organized with the participants ([Higginbottom et al., 2013](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0075), [Roper and Shapira, 2000](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0190)). They took place 1–14 days after the observations. Three interviews were conducted in the participant's private home, and 12 interviews took place in a meeting room in the hospital, the venue was selected by the participants. The interviews used a semi-structured interview guide with open-ended questions covering the researcher's observations, the families' everyday life and experiences with healthcare. Each family decided who would participate in the interviews, and ten individual and five dyadic interviews were conducted ([Table 1](https://www.sciencedirect.com/science/article/pii/S0882596316301221#t0005)).

Data Analysis

The analysis of data was iterative and it occurred at different stages in the process, e.g. while collecting data, in between interviews, participant observations. Ethnographic analysis is concerned with seeking patterns and relationships across the dataset ([Roper & Shapira, 2000](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0190)). This process was assisted by thematic analysis to strengthen the systematic approach ([Braun and Clarke, 2006](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0025), [Crowe et al., 2015](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0055)). The analysis involved a non-linear process with five phases ([Braun and Clarke, 2006](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0025), [Crowe et al., 2015](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0055)). In phase one, the interviews were taped and transcribed by the primary author and the participant observations were transcribed from notes written by the primary author during the healthcare meetings. The primary author also read and re-read the interviews and the observations several times. A few drafts were discussed with all co-authors. The primary author listened to the interviews several times and memos on reflections and insights of the data were written. In phase two, the primary author generated initial codes. Codes were descriptive labels assigned to segments of the text, and data were organized into meaningful groups. The codes were discussed with all authors. In phase three, the search for relationships between the groups and codes began and overarching themes emerged. The primary author and one of the co-authors conceptualized the ideas and patterns by envisaging potential relationships between groups of data and the underlying contextual values and beliefs. The groups of data were then clustered systematically into three candidate main themes, each accompanied by three subthemes and codes representing healthcare influencing everyday life. Finally, in phase four and five the candidate themes and sub themes were reviewed, defined and named to identify the essence of what each theme was about ([Braun and Clarke, 2006](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0025), [Crowe et al., 2015](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0055)). This process was discussed and agreed upon with all authors of the manuscript. Nvivo 10 (Nvivo qualitative data analysis software; QSR International Pty Ltd. Version 10, 2014) was used as a data management tool to assist the analytical process ([Bazeley, 2007](https://www.sciencedirect.com/science/article/pii/S0882596316301221" \l "bb0010)). [Table 2](https://www.sciencedirect.com/science/article/pii/S0882596316301221#t0010) provides an example of the relationship between codes, subthemes and main theme in main theme one.

Table 2. When the house of cards collapses. Relationship between main theme, sub-themes and codes.

| **Main theme** | **Sub-themes** | **Codes** |
| --- | --- | --- |
| **When the house of cards collapses in everyday life** | ADHD influencing everyday life | Help in everyday life |
| Living as normally as possible |
| Being on duty around the clock |
| Concerns for the future |
| Striving to maintain control |
| Experiences of established networks |
| Diverse reactions of the child |
| Difficulties with medication |
| Physical challenges |
| Other behavioural problems |
| Physical challenges |
| Family challenges | Financial challenges |
| Mental health challenges in the family |
| Influence on parental relationship |
| Family unity |
| Siblings |
| Significant others |
| Parental emotions and re-evaluation | Feeling “wrong” |
| Sole responsibility |
| Feeling confident |
| Insecurity |
| Despair and frustrations |
| Re-evaluation |

Ethical Considerations

The study was approved and registered at the Danish Data Protection Agency (2008-58-0028). The researcher provided the participants written and verbal information with anonymity and confidentiality being ensured. Participation was voluntary and the participants could withdraw at any time. The participants all signed an [informed consent](https://www.sciencedirect.com/topics/medicine-and-dentistry/informed-consent) form. It was of great importance for the researcher that the parents felt comfortable with her presence during the observations and during the interviews. The families willingly participated in the study and shared their thoughts and knowledge.

Findings

The three main themes: When the house of cards collapses in everyday life, Treading water before and after receiving the ADHD diagnosis and Healthcare as a significant lifeline are closely intertwined. The themes are presented in no particular order, and they need to be considered as a whole to address the aim of the study.

When the House of Cards Collapses in Everyday Life

This theme concerns the vulnerability of the families. The house of cards collapsing reflects how the stability of everyday life easily falls apart when having a child with ADHD The theme reflects the influence of ADHD on everyday life, family challenges and parental emotions. At some stages of life disturbances will affect the child, “*Their class teacher was on sick leave again the rest of the year and it overturned his world…he was led down again.*” (A).These changes impact the whole family as the child may need more attention or reacts differently at home. Parents strive to maintain control of their lives by using strategies such as predicting challenging situations. However, the parents occasionally lose control of their child's behaviour, “*It is so hard to watch him go crazy not knowing how to handle it…you can't get to him…it is hard on me too.*” (E). The constant concerns for their child's functioning and behaviour, whether it is acting out or being withdrawn is exhausting for the whole family. They are not always able to prevent the house of cards from collapsing, “*we were in tatters…my partner was going crazy, he was about to move out of the house and couldn't stand being there…*” (B). This causes feelings of frustration, hopelessness and [despair](https://www.sciencedirect.com/topics/medicine-and-dentistry/hopelessness) as the parental strategies to protect the family unit fail, and they described, “*being stuck in an unhealthy pattern.*” (B).·In addition, some families face challenges such as financial strains and other physical or mental [health problems](https://www.sciencedirect.com/topics/medicine-and-dentistry/disease). However, if one of the parents is diagnosed with ADHD, this is sometimes viewed as an advantage as they described recognizing the child's feelings and behaviour “*…I actually think I know how she is feeling because I can relate to it and recognize it from myself and sometimes we talk about that she is not alone with the diagnosis*” (M). In contrast, parents with ADHD encounter challenges concerning the child's need for structure in everyday life and in the child-parent relationship, e.g. one child had no contact with his father because of the father's severe ADHD.

When the house of cards collapses, the parents depend on help and support to overcome the disruptive phase. Each family uses different approaches in seeking assistance. Some parents turn to healthcare professionals, e.g. a nurse from their regular ADHD clinic, yet others seek support from significant others such as a school teacher, a social worker or a relative. Nevertheless, occasionally parental beliefs of the ideal support are complicated by different worldviews as parental perspectives and the restrictions of the supporting systems may conflict. This was for instance observed at a day unit network meeting considering future school opportunities regarding a girl newly diagnosed with ADHD. The participants included seven people from the local authorities, the day unit, the child's school, and the mother (J).

“*The child's current school teacher tells how J has been worried for years and that another school offer should be considered, she looks at the mother who cries silently and nods. The teacher puts a hand on J's arm, and J says, “Until now, school has not been a good experience for my daughter, and I am so worried about relapse in her symptoms, if she is to return to a non-special school.” She looks at the psychologist from the day unit, who nods and says that he agrees referring to the severity of the girl's symptoms. Yet, the atmosphere in the room seems silent and tense as the representative from the child development team (PPR) from the local authorities says that options in the present school need to be considered as they won't promise a special school offer*” (J).

Parents seem caught in the middle of their own beliefs and the premises underlying the supporting systems as there were disjoints of the parents expectations and the support that was provided. The parents feel that their concerns are not always heard and that they rely on people with no insight into their situations to make essential decisions for their family. Overall, the picture of everyday life is that it is fragile and unpredictable and can easily be disrupted, which creates the necessity of help from more systems, professionals or others.

Treading Water Before and After Receiving the ADHD Diagnosis

This theme embraces parental experiences before and after their child is diagnosed with ADHD, and it covers the meaning of getting the diagnosis, drifting alone in healthcare and other systems and wasting time. Frequently, the parents sense that something is wrong long before the child is diagnosed with ADHD, and they refer negatively to the time passed before their concerns are validated. One (O) stated:

“*…well…I always felt that he was just like his big brother, different…and he has always had a hard time with many things…and then something would happen in the different schools he went to…he was to see a psychologist or special teacher but some things kept coming up and they just kind of forgot about it…and he was just unmanageable (they said) and then when we finally got to the mental health clinic, he did have ADHD*.” (O)

Being dismissed caused parental frustrations and insecurity, and parents described “*feeling wrong*,” as their impressions is that the professionals consulted for assistance view their parenting skills as incompetent. Parents struggle to have their concerns recognized by professionals, which adds to frustrations and feelings of drifting alone to deal with the challenges of everyday life.

Commonly, parents experienced that once referred for assessment for ADHD, the system is effective and the diagnosis provided quickly. The parents expressed relief about the diagnosis because healthcare professionals validate their concerns and recognize the symptoms of the child, “*And well…even though we tried to change things ourselves in the process it was still very helpful to be confirmed that what we have seen and what we do is good.*” (A). Confirming that the child has ADHD helps the parents regain confidence in their parenting skills, and they feel reassured not to “*feel wrong*”. Generally, the parents trust that the diagnosis provides new opportunities in receiving support for their child. Nevertheless, ADHD appears to be “*a bomb*” because parents encounter a different struggle for appropriate support for their child in which they feel like they tread water. The struggle involves a diversity of parental strategies and demands resources as well as increased parental commitment and advocacy skills. Families of children with primary [physical disorders](https://www.sciencedirect.com/topics/medicine-and-dentistry/disease) subsequently diagnosed with ADHD perceive that ADHD pervades all aspects of life whereas physical challenges are perceived as focused to certain areas. However, support is not always provided sufficiently, “…*well I feel I lack information and support or education about ADHD as his physical challenges were the primary (the primary diagnosis).*” (N).

In adapting to life with a child with ADHD, accessibility to healthcare is significant for parents to feel supported and not treading water. One parent (B): “*They have always been there (for us) and I never called them and felt that they didn't have the time to talk to me…you actually don't feel that you are a hindrance.*” In contrast, parents feel that they are wasting time if healthcare professionals are difficult to access, because “*…almost every day off would be spend at the hospital*.” (K). Accessibility to the child's regular ADHD clinic, the clinic that the family usually attended, appears to support parents in everyday life. An example is that the parents described having “*back up*” when the child behaves different from normal at home or if they have questions about medication. Furthermore, health professionals from the regular clinics become allies in the struggle for appropriate support, as they can have influence on the decisions of supporting systems which the parents feel unauthorized to do.

In summary, the theme reflects parental experiences of treading water, not only before the child is diagnosed with ADHD but also following the diagnosis. The healthcare system and healthcare professionals may influence everyday life positively by being accessible and supportive after the diagnosis.

Healthcare as a Significant Lifeline

This theme manifests the significance of healthcare in everyday life reflecting the impact of professionals' support, conflicting or shared perspectives and interactions between the child, parents and professionals. Parents' relationships with professionals who become allies in healthcare are built on trust, faith in knowledge and respect. This was specifically evident in relationships with professionals from the regular clinics, who appear to be important because they know the families' stories: “*well…it is about feeling safe I think…instead of meeting a new person every time but also because when it is the same person, they know more about K* (F)…” Although some of the meetings were focused on adjusting the child's ADHD medication, the professionals would still address non-medical aspects of everyday life. The regular meetings with known professionals recognizing the impact of ADHD in everyday life provide stability in an unstable situation:

“*It gives us stability about him and his development, that they know what he was like at the last meeting, I don't have to explain it, they know what he is like now…they remember him well, and we are treated as a family and not a number.*” (I)

In addition, being treated with respect and as a family improves the trusting relationship and the parents feel supported and acknowledged. The trusting relationship is also built on the personality and values of the professional. One parent expressed that, “*Well I think she is very competent and she recognizes our worries…and I also really like her as a person (laughing)*” (F). Additionally, the faith depends on the professional's interactions with or recognition of the child, e.g. as observed in a day unit when a child development caregiver talked to the mother of a boy with ADHD about his condition. The caregiver started the conversation by saying, “*first of all he is a very polite and charming boy, liked by children as well as adults in the unit.*” (A). The mother smiled and they chatted and laughed about the child's behaviour before addressing the child's challenges and the treatment plan. Following the meeting, the mother explained how good it felt, when someone spoke positively about her child. The child's behaviour was acknowledged and the child was not reduced to a diagnosis, which results in experiences of being supported and recognized. In addition, parents view professionals as role models in regards to how they engage with the child, and how they set limits for the child. However, presence of the child may also result in parents holding back information, “*and there were things we wanted to tell…and it was hard with him present*” (C). The parents do not wish the child to know about their worries, which may inhibit parents giving information to the health professionals.

Parents literally talked about professionals who “*get the child*” meaning that those who understand how to handle the child and how to engage with the child are important in the trusting relationship. Health professionals “*Getting the child*” is linked to them recognizing the uniqueness of the whole family and including the child as a person and not a diagnosis. This includes sharing the parental understanding of ADHD pervading all aspects of everyday life. However, conflicting perspectives, expectations and lack of understanding can be barriers to a trusting relationship between parents and professionals. This was particularly apparent when the families attended appointments regarding healthcare issues other than ADHD. One mother said:

“*well…the ones (professionals) we met…maybe they don't know about ADHD because they have their own (specialty), but I think they lack understanding …they keep asking him about everything, even though he is restless and turn his back on them…they just keep going on without including me.*” (H)

Parents met professionals who ignored or overlooked the signals from the child and carried on with their task. According to parents, some professionals avoid the fact that the ADHD of the child compromises other healthcare issues. This means that they focus on just one element in healthcare without considering ADHD in communication, assessment and treatment. This results in a fragmented and non-holistic delivery of care. Furthermore, parents experience is that they are not included as experts on their own family, which causes an atmosphere of distrust as observed with H who attempted to engage in the conversation to help out her child: *the mother resigns and stares into vacancy padding some papers at the table the rest of the meeting* (H). When parents are not involved and their perspectives not considered, they feel disappointed and left with the sole responsibility of managing both the ADHD and other healthcare issues. This adds to the experiences of drifting alone in healthcare. In summary, healthcare is a significant lifeline when the professional-parental relationship is based on trust, faith in professional knowledge, respect and a holistic delivery of care considering the uniqueness of each family's challenges and resources. However, the lifeline may be affected by lack of acknowledgment of how ADHD pervades every aspect of everyday life.

Discussion

The study sought to explore parental experiences of how healthcare influences everyday life when living with a child with ADHD. The findings suggest that the families' everyday life is fragile and can easily be disrupted creating the necessity for help and support from others including healthcare professionals. The families encounter difficulties before and after the child is diagnosed with ADHD, and at times they experience treading water and drifting alone trying to handle the everyday challenges with their child. In addition, they feel abandoned by professionals who do not recognize their worries. However, accessibility to healthcare, trusting relationships and healthcare professionals recognizing how ADHD pervades all aspects of everyday life are important factors in providing a lifeline for parents to help them regain confidence and control in disruptive phases.

The parents fight for what they believe would be the appropriate support for their child and family, and they adapt strategies and engage with allied healthcare professionals from whom they feel supported in their attempt to influence decisions in a variety of systems. Despite the [frailty](https://www.sciencedirect.com/topics/medicine-and-dentistry/frailty) of everyday life and the emotional burdens on the parents, the findings of giving care to a child with ADHD also reflect resilient parental abilities as the parents put up a fight for their child. Resilient abilities seem to be important in parenting a child with ADHD and it is consistent with findings of [health care](https://www.sciencedirect.com/topics/medicine-and-dentistry/health-care) experiences of parents of children with [autism spectrum disorder](https://www.sciencedirect.com/topics/medicine-and-dentistry/pervasive-developmental-disorder) (ASD) ([Bekhet, Johnson, & Zauszniewski, 2012](https://www.sciencedirect.com/science/article/pii/S0882596316301221" \l "bb0015)). Parents who possess indicators of resilience are better able to handle the adversity associated with parenting a child with ASD ([Bekhet et al., 2012](https://www.sciencedirect.com/science/article/pii/S0882596316301221" \l "bb0015)). A review by Black and Lobo on the concept of family resilience reflects that all families encounter challenges at some stages of life, and it considers the families' abilities to adapt or rebound in crisis ([Black & Lobo, 2008](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0020)). Families of children with ADHD need resilience to regain control of their lives in disruptive phases, and factors within the family such as positive [outlook](https://www.sciencedirect.com/topics/nursing-and-health-professions/angiographic-catheter) and family communication are found to enable the ability to bounce back and return to the previous way of functioning ([Black & Lobo, 2008](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0020)). However, resilience in families of [children with developmental disabilities](https://www.sciencedirect.com/topics/medicine-and-dentistry/children-with-developmental-disabilities) also seems to be affected by external resources in terms of positive experiences with services and support being beneficial in strengthening their resilience ([Muir & Strnadová, 2014](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0170)). On this basis, accessibility to healthcare services and allied healthcare professionals supporting the families in both medical and non-medical issues may be a way of enhancing the families' resilience.

For parents to feel supported a trusting relationship built on faith in professional knowledge and respect as well as the personality and values of the healthcare professional were found to be essential in the present study. The relationship between the patient and caregiver has been widely examined in [nursing care](https://www.sciencedirect.com/topics/nursing-and-health-professions/nursing-care) as shown in a newly published umbrella review ([Wiechula et al., 2016](https://www.sciencedirect.com/science/article/pii/S0882596316301221" \l "bb0230)). Values displayed by the nurse, knowledge and skills, communication and trust and confidence in the care were found to be important elements in the relationship between patients and professionals. Furthermore, a trusting relationship is of great importance in meeting the individual and fundamental needs of the patient and family ([Kitson et al., 2013](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0095), [Kitson et al., 2014](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0100)). Thereby the relationship is fundamental in supporting and recognizing the families, when they seek assistance in healthcare. This study has identified that professionals who engage with the child, set limits and respect the child as a person may be important role models in helping the parents cope with situations at home. However, barriers to the trusting relationship arise when parents are not included as experts on their own family. Research suggests that parents prefer their perspectives to be included in decision making ([Davis et al., 2012](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0060)). Furthermore, another barrier is healthcare professionals focusing on the task rather than the person ([Kitson et al., 2013](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0095), [Kitson et al., 2014](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0100)). Compared to the findings of this study, barriers perceived by the parents include healthcare professionals and services focusing solely on their specialty without assessing the child's and the family's challenges in care and treatment.

Healthcare is just one element of the external resources and systems which the families depend on for support ([Russell et al., 2011](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0195), [Wright et al., 2015](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0240)). Yet, the findings encapsulate healthcare as an important element in influencing everyday life positively. Nevertheless, parents also experience non-holistic care in that the impact of ADHD is not always recognized in the context of co-existing [healthcare needs](https://www.sciencedirect.com/topics/nursing-and-health-professions/health-care-need). Consistent with findings of this study, parents of children diagnosed with ASD report that some healthcare professionals ‘*just don't get it*’ meaning that there is a lack of understanding of how the autism spectrum disorder affects everyday life, how the parents should be included in healthcare, and how they are emotionally burdened ([Bultas, 2012](https://www.sciencedirect.com/science/article/pii/S0882596316301221" \l "bb0035)). This may link to paediatric professionals' in somatic settings feelings of inadequacy and lack of confidence and knowledge in providing care for families with mentally ill children ([Buckley, 2010](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0030)). A premise for healthcare is that the services work in siloes within specialties, which suggests the need for co-ordinated care across services to integrate ADHD, co-existing disorders and other needs, although this may be difficult to accomplish given the diversity of systems involved ([Russell et al., 2011](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0195)). Family-centred care principles such as respect, partnership, direct medical care and decision making reflecting the child within the context of his/her family, home, school appear to be important in providing holistic and integrated care ([Kuo et al., 2012](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0115)). Healthcare professionals seem to be important for the families' experience of integrated care as they help [*translating*](https://www.sciencedirect.com/topics/medicine-and-dentistry/translating-language)*the language* between services and authorities. Yet, findings of this study also reveal that holistic healthcare in every specialty is just as important to families' experiences of consistency. This requires professionals in every specialty taking responsibility for their contribution to integration of care and acknowledge the impact of ADHD on everyday life ([Russell et al., 2011](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0195)).

Strengths and Limitations

This study focused exclusively on healthcare experiences from the parent's perspective. Both dyadic and individual interviews were conducted as the families chose who would participate in the interviews. This may be either an advantage or a disadvantage in that individual interviews may reveal information that would have been withheld if more people were present whereas the interaction among participants may encourage ideas and knowledge that would not have been remembered ([Morgan, Ataie, Carder, & Hoffman, 2013](https://www.sciencedirect.com/science/article/pii/S0882596316301221#bb0165)). The participant observations were short, and the perspectives of the involved health professionals and the children with ADHD were not included. This may prevent a complete understanding of the underlying cultural factors and the influence of the organizational systems on the care and treatment being provided. In addition, the broad sample selection in both paediatric and mental health clinics provided nuanced and various perspectives in four specific [outpatient clinics](https://www.sciencedirect.com/topics/nursing-and-health-professions/outpatient-department), hence these experiences may not reflect other outpatient or inpatient clinics.

Implications for Clinical Practice

Healthcare professionals regardless of specialty need to consider how to involve the parents as experts on their child and their family in a family-centred approach involving regular clinics as well. This includes professionals taking on responsibility for their particular role in the [care pathway](https://www.sciencedirect.com/topics/medicine-and-dentistry/care-pathway) recognizing how ADHD pervades every aspect of everyday life. Care, assessment and treatment should reflect the uniqueness of each family and there is a need for a holistic approach to integrate mental and physical aspects in healthcare. Consultancy and interventions should be provided for healthcare professionals who feel inadequately prepared to engage with families of children with ADHD.

Implications for Research

Parental perspectives are the focus in this study and therefore perspectives of healthcare professionals in mental health clinics and paediatric clinics should be included in future research. A mixed methods approach mapping the families' healthcare pathways before and after the ADHD diagnosis including parental and professional perceptions in the diversity of settings may enhance a comprehensive understanding of barriers and enablers in healthcare. This will be useful in designing interventions aimed at supporting healthcare professionals in providing a family-centred care that recognizes the families' needs. Further, the present study focused on parental experiences in a variety of hospital-based healthcare practice settings, it may be relevant in future studies to explore how the care that is provided differs across paediatric and mental health settings.

Conclusion

This study revealed healthcare as a significant lifeline in everyday life, although healthcare is just one element in a diversity of systems supporting families of children with ADHD. The findings point to the importance of healthcare services and professionals being accessible and treating the families with respect. This includes involving the parents in planning care ensuring that it is customized to recognize the impact of ADHD on everyday life. The parents depend on help from healthcare professionals and family-centred care principles to manage the complexities of challenges in everyday life and to feel supported when interacting with other services and system. Allies in healthcare and trusting relationships are found to be enablers of providing this support for the families.

Anonymous Author Disclosure

On behalf of all authors regarding the manuscript, “The ADHD bomb” – healthcare as a significant lifeline, I declare no financial interest or potential conflicts of interest.

Britt Laugesen.

Disclosure Statement

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Health-care professionals may help the family provide child life care at home. Laugesen et al [22] also emphasizes that health-care professionals should assist parents to understand how the disease pervades all aspects of everyday life for the parents to help them regain their self-confidence and manage the complex challenges. Swallow et al [23] promoted parents and professionals to collaborate to develop a novel Online Parent Information and Support application to support home-based clinical care-giving for other long-term conditions.

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In general, the adolescents preferred their parents to talk with HCPs while they just listened. This may be problematic, as parents sometimes withhold information when the child with ADHD is present (Laugesen et al., 2017), and parents may have a different perspective on the adolescents' life with ADHD (Charach et al., 2014). Without the adolescent's active involvement, there is a risk that important information may not be shared with HCPs.

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Overall, the findings show that parents are burdened and guilt, blame, stigmatization, exhaustion, and reconciliation are part of their everyday life (Laugesen et al., 2016; Laugesen & Groenkjaer, 2015). The data analysis resulted in three interconnected themes: 1) When the house of cards collapses in everyday life, which covers how ADHD influences everyday life, the family challenges, and parental emotions and re-evaluation, 2) Treading water before and after the ADHD diagnosis, which illustrates the meaning of getting the diagnosis, how the parents before the child is diagnosed experience drifting alone in healthcare and supporting systems and wasting time, and 3) Healthcare as a significant lifeline, which covers the impact that the support of health professionals and the systems has on the families, how parents experience conflicting or shared perspective with healthcare professionals, and the essential relationships and interactions between child, parents, and professionals (Laugesen et al., 2017). A total of 521,193 children born in Denmark from 1995 to 2002 were prospectively followed from birth until 12 years of age.

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