Children with ADHD

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Laugesen, Britt

DOI (link to publication from Publisher):
10.5278/vbn.phd.med.00093

Publication date:
2017

Document Version
Publisher's PDF, also known as Version of record

Citation for published version (APA):
Laugesen, B. (2017). *Children with ADHD: A mixed methods study on parental experiences, everyday life, and health care use*. Aalborg Universitetsforlag. https://doi.org/10.5278/vbn.phd.med.00093

CHILDREN WITH ADHD

A MIXED METHODS STUDY ON PARENTAL EXPERIENCES, EVERYDAY LIFE, AND HEALTH CARE USE

BY
BRITT LAUGESEN

DISSERTATION SUBMITTED 2017

AALBORG UNIVERSITY
DENMARK

CHILDREN WITH ADHD:
A MIXED METHODS STUDY ON PARENTAL EXPERIENCES, EVERYDAY LIFE, AND HEALTH CARE USE

by

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Dissertation submitted: January 2017

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PhD Series: Faculty of Medicine, Aalborg University

ISSN (online): 2246-1302
ISBN (online): 978-87-7112-866-6

Published by:
Aalborg University Press
Skjernvej 4A, 2nd floor
DK – 9220 Aalborg Ø
Phone: +45 99407140
aauf@forlag.aau.dk
forlag.aau.dk

Printed in Denmark by Rosendahls, 2017

ENGLISH SUMMARY

Background

Attention deficit hyperactivity disorder (ADHD) in children and adolescents is a common mental disorder, with core symptoms that impair several domains of functioning. These domains include social relationships, education and family life. Parents play an essential role in supporting the child, yet they find caring for the child with ADHD challenging and everyday life is disrupted. The child's everyday life includes visits to various health care settings, as children with ADHD require multi-faceted support, including support from hospital-based healthcare services and healthcare professionals. There is a paucity of literature on parental experiences and characteristics of hospital-based healthcare use.

Aim

The overall aim of this thesis was to integrate qualitative and quantitative data to provide new insights into the parental experiences, the complexities of everyday life, and hospital-based health care use, among children with ADHD. Three studies were undertaken, and the aims of Studies 1,2, and 3 were:

- To identify and synthesize the best available evidence on parental experiences of living with a child with ADHD, including their experiences of ADHD health care and other services (Study 1).
- To explore parental experiences of how health care professionals in hospitals in Denmark influence the everyday lives of families with a child with ADHD (Study 2).
- To compare the mean number of medical and psychiatric hospital-based services in children with and without ADHD, and to assess the independent effect of ADHD on hospital-based service use. The aim was also to identify child, parental, and socioeconomic-related risk factors associated with medical and psychiatric service use in children with ADHD (Study 3).

Methods

The research design was a multistage mixed methods study with a core convergent design. Three studies were included in the mixed methods study. Study 1 was a systematic review of qualitative evidence, which aggregated findings from 21 research papers; Study 2 was a focused ethnographic study and included participant observations and interviews with 15 parents of children with ADHD in medical and psychiatric hospitals. Study 3 was a historical cohort study using nationwide registers to follow a cohort of children in the first 12 years of life, and examine medical and psychiatric health care use. Findings from Studies 1, 2, and 3 were integrated through narrative weaving and joint displays.

Results

The findings show that having a child with ADHD affects the whole family. Parents are burdened with the responsibility of the child. Parental experiences of living with a child with ADHD are complex, and include experiences of guilt, hope, blame, stigmatization, and exhaustion. The everyday lives of families of children with ADHD are vulnerable, as ADHD pervades all aspects of everyday life. The parents depend on support from medical and psychiatric hospital-based health care services to manage everyday life. Furthermore, children with ADHD use significantly more medical and psychiatric services in hospitals than children without ADHD during the first 12 years of life. ADHD independently affects service use, even when controlling for a comprehensive set of explanatory variables. The integrated findings show that: 1) parental stressors affect everyday life and hospital-based service use; 2) the parents have concerns for their child from early childhood, and fight to have their concerns validated; and 3) health care professionals are important for parents to navigate the persistent challenges of everyday life.

Conclusion

This thesis shows that ADHD affects the everyday life of the families as well as healthcare use in hospitals. Children with ADHD use more medical and psychiatric services during the first 12 years of life than children without ADHD. The findings encapsulate a vulnerable everyday life, and point to the importance of families being met with acceptance and respect in hospital-based health care services from early childhood. It is important for health care professionals, regardless of specialty, to engage with the individual families and to contribute to consistency of the health care experience.

DANSK RESUME

Baggrund

ADHD er en hyppigt forekommende psykiatrisk lidelse blandt børn og unge, hvis kernesymptomer påvirker flere domæner i barnets liv som sociale relationer, uddannelse og familieliv. Forældre spiller en væsentlig rolle med hensyn til at støtte barnet og forbedre barnets evne til at fungere. Forældre finder det vanskeligt at have et barn med ADHD, og de oplever mange udfordringer i hverdagslivet. Hverdagslivet inkluderer oplevelser med sundhedsvæsnet, idet børn med ADHD og forældre typisk har behov for hjælp og støtte, der indebærer multiple facetter. I den eksisterende litteratur er der begrænset opmærksomhed på forældres oplevelse med den pleje og behandling, der ydes i hospitals regi og på karakteristik af hospitalskontakter blandt børn med ADHD.

Formål

Det overordnede formål med denne afhandling var at integrere kvalitative og kvantitative data med henblik på at opnå større indsigt i forældres oplevelser, kompleksiteter i hverdagslivet og i hospitalskontakter blandt børn med ADHD. Formålet blev undersøgt gennem udførelse af tre studier med følgende formål:

- At identificere og syntetisere den bedste tilgængelige evidens vedrørende forældres oplevelse af at leve med et barn ADHD samt deres oplevelser med kontakter til sundhedsvæsenet (Studie 1).
- At udforske forældres oplevelser med hospitalsbaserede sundhedskontakter og sundhedsprofessionelle, samt disse kontakters betydning for hverdagslivet (Studie 2).
- At sammenligne det gennemsnitlige antal somatiske og psykiatriske hospitalskontakter blandt børn med ADHD og børn uden ADHD og at vurdere, hvordan ADHD påvirker brug af hospitalskontakter. Desuden at identificere risikofaktorer, der er associeret med brug af somatiske og psykiatriske hospitalskontakter (Studie 3).

Metode

Designet var et mixed metode studie, der inkluderede tre studier: Studie 1 var et systematisk review baseret på kvalitative forskningsartikler. Studie 2 var et fokuseret etnografisk studie med deltagerobservationer og interviews med 15 forældre til børn med ADHD i psykiatriske og somatiske hospitalsafdelinger. Studie 3 var et historisk kohortestudie, hvor nationale sundhedsregistre blev anvendt til at følge en

børnekohortes hospitalskontakter i deres første 12 leveår. Fund fra studie 1,2, og 3 blev integreret gennem ”narrative weaving” og ”joint displays”.

Resultater

Fundene viser, at et barn med ADHD påvirker hele familien, og forældre føler sig tynget af ansvaret for barnet. Forældres oplevelser med at leve med et barn med ADHD er komplekse, og oplevelserne indebærer skyld, håb, bebrejdelse, stigmatisering og udmattelse. Hverdagslivet med et barn med ADHD er sårbart, idet ADHD påvirker alle aspekter af hverdagslivet. Forældre har behov for støtte fra somatisk og psykiatrisk hospitalsvæsen med henblik på at kunne håndtere hverdagen. Desuden er børn med ADHD i deres første 12 leveår i hyppigere kontakt med både somatisk og psykiatrisk hospitalsvæsen end børn uden ADHD. At have ADHD øger antal hospitalskontakter, selv når der justeres for et omfattende sæt forklarende variable. Tre integrerede fund viste, at: 1) stressfaktorer i familien påvirker hverdagslivet og brug af hospitalsydelser; 2) forældre er bekymrede for deres barn allerede tidligt i barndommen, og de kæmper for at få disse bekymringer bekræftet; 3) sundhedsprofessionelle er vigtige ressourcer for forældre til børn med ADHD for at kunne navigere og håndtere de vedvarende udfordringer i hverdagslivet.

Konklusion

Denne afhandling viser, at ADHD påvirker familiernes hverdagsliv og antal af hospitalskontakter. Børn med ADHD er oftere i kontakt med somatisk og psykiatrisk hospitalsvæsen i de første 12 leveår end børn uden ADHD. Fundene peger på et sårbart hverdagsliv, hvor det at blive mødt med forståelse, accept og respekt i hospitalskontakter fra tidlig barndom har stor betydning for familierne. Det er væsentligt, at sundhedsprofessionelle, uanset speciale, engagerer sig i den individuelle familie og bidrager til forældres oplevelse af sammenhæng i sundhedskontakter på tværs af specialer.

ACKNOWLEDGEMENTS

This thesis is based on three studies carried out during employment in the Clinic for Woman and Child Diseases and Urology, Aalborg University Hospital, in collaboration with the Psychiatric Research Unit, Aalborg Psychiatric Hospital, and the Clinical Nursing Research Unit at Aalborg University Hospital. It has been three enlightening, challenging, and fantastic years. This work would not have been possible without the involvement of numerous people, whom I wish to acknowledge:

First, I wish to thank the parents of children with ADHD who voluntarily and without hesitation agreed to participate in Study 2. You all contributed significantly to this research, and you have my deepest respect. In addition, I would like to acknowledge the leaders and the health care professionals at the participating departments for assisting the inclusion of participants, and for showing great interest in this study.

Second, I wish to thank my five incredible supervisors, who generously shared their knowledge throughout this PhD. To my PhD supervisor, Marlene Briciet Lauritsen, I thank you for opening the door to this field of research and for continuous encouragement, for your sincere interest in qualitative and nursing research, and for your trust in me as an upcoming researcher. To my co-supervisor, Erik Elgaard Sørensen, I thank you for initiating and navigating the way into becoming a PhD student, for your never-ending support, and for believing that I could accomplish this. To Mette Grønkjær, my “wingman” for several years, I thank you for your amazing professional, as well as personal, skills, for your always open door and faith in me, for encouragement and constructive feedback. To my co-supervisor, Rikke Jørgensen, I thank you for inspiring and enthusiastic discussions on Mixed Methods, for your reassurance, for always being an inspiration with respect to constructive feedback, and for your continuously good humor. To my co-supervisor, Philippa Rasmussen, I thank you for generously welcoming my family and me to Australia, for interesting and constructive discussions at the wonderful coffee shops in Adelaide, for setting time aside to inspiring meetings during my stay in Adelaide, and for always being supportive.

I wish to thank Alison Kitson for kindly welcoming me, and letting me be a part of the inspiring environment at Adelaide Nursing School, University of Adelaide, Australia, for 3 months.

I wish to thank the staff at Adelaide Nursing School, University of Adelaide, Australia, for making me feel very welcome, and for inspiring discussions and meetings during my stay.

I wish to thank the staff at the Clinical Nursing Research Unit at Aalborg University Hospital for providing a nice and engaging atmosphere, and for good discussions during coffee breaks and lunch.

I wish to thank Christina Mohr Jensen and Søren Kjærdgaard Boldsen for assistance, and for kindly sharing their knowledge with respect to Study 3.

I wish to thank my fellow PhD students at the Clinical Nursing Research Unit at Aalborg University Hospital for always inspiring and clarifying discussions, and for willingly sharing their knowledge. A special and warm thanks to my fellow PhD students at the "PhD office" for celebrating successes, for encouragement during challenging phases, for our laughs, for being supportive colleagues, and for making me feel that I was never alone during these 3 years.

I wish to thank my parents, my parents-in-law, and my friends for showing interest in my work, for practical as well as emotional support, for "just being there," and for helping me balance my work life with social life.

I wish to thank my amazing husband and girls, Ulrich, Nikoline, and Marie, for helping me accomplish this PhD study. I cannot express enough gratitude for your endless support, for patiently listening when I was excited as well as when I was concerned, for continually providing backup, for coming all the way to Australia with me without hesitation, and for always believing in me. You are the best.

Britt Laugesen, December 2016

LIST OF PAPERS

Peer-reviewed protocol

Laugesen B, Groenkjaer M, Parenting experiences of living with a child with attention deficit hyperactivity disorder: a systematic review of qualitative evidence protocol. *JBI Database of Systematic Reviews & Implementation Reports* 2014;12(12):41–53.

Paper I

Laugesen B, Groenkjaer M, Parenting experiences of living with a child with attention deficit hyperactivity disorder: a systematic review of qualitative evidence. *JBI Database Syst Rev Implement Rep* 2015;13:169–234.

Paper II

Laugesen B, Lauritsen, Lauritsen MB, Jørgensen R, Sørensen EE, Rasmussen P, Grønkjær M. Living with a child with attention deficit hyperactivity disorder: a systematic review. *Int J Evid Based Healthc* 2016;14(4):150–165.

Paper III

Laugesen B, Lauritsen MB, Jørgensen R, Sørensen EE, Grønkjær M, Rasmussen P. The ADHD bomb – health care as a significant lifeline. Submitted July 2016 to *Journal of Pediatric Nursing*.

Paper IV

Laugesen B, Jørgensen R, Jensen CM, Kjærsgaard SB, Sørensen EE, Grønkjær M, Rasmussen P, Lauritsen MB**.** ADHD in childhood: Health care use in a Danish birth cohort during the first 12 years of life. Submitted January 2017 to *PEDIATRICS*.

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Abbreviations

ADHD:	Attention deficit hyperactivity disorder
ADD:	Attention deficit disorder
CI:	Confidence interval
DPNR:	Danish National Patient Register
DPCRR:	Danish Psychiatric Central Research Register
GP:	General practitioner
ICD-10:	International Classification of Diseases, 10th revision criteria
IRR:	Incidence rate ratio
JBI:	Joanna Briggs Institute

CHAPTER 1. INTRODUCTION

Having been a registered nurse in pediatric and medical settings for several years before entering research, I experienced periods of discomfort and insecurity when caring for mentally-ill patients in pediatric medical wards and clinics. The thesis of my Masters of Science in Nursing in 2013 was a meta-synthesis on pediatric nurses' experiences of caring for children with mental illness (1). The meta-synthesis confirmed that the majority of pediatric nurses also felt uncomfortable and insecure (1). The Master's thesis concluded that caring for patients with mental disorders in general pediatric hospitals are characterized by contradicting experiences as nurses recognize the patients' needs, yet at the same time, they keep a distance towards the patients and families. Furthermore, the meta-synthesis showed that caring for children with mental illness in medical settings is complex and multi-faceted and the care depends on contextual circumstances as well as nurses' insecurity and vulnerability (1). This knowledge triggered my curiosity of how the parents of the children on the other hand experience health care and collaboration with health care professionals. The parents rely on help and support from professionals who potentially find caring for them difficult and complex.

Children with mental disorders is a heterogeneous population for investigation, and their experiences of health care may differ depending on the type of disorder. For this PhD study, the families of children with ADHD, specifically the children and their parents, were the chosen population due to the increasing awareness of this diagnosis in recent years (2,3). The ADHD diagnosis continues to cause discussions and debates in society, and knowledge and attitudes vary among children, parents, teachers and health care professionals (4,5). Thus, parents of children with ADHD are likely to encounter challenges in their everyday lives and in health care systems. This PhD thesis sought to investigate the complexities of everyday life and health care by using both qualitative and quantitative methods.

Conducting this research led to invaluable meetings with vulnerable, yet powerful and resilient parents of children with ADHD who fought for their children and their families. In addition, the investigation encompassed insights into the families' everyday lives and enhanced knowledge on health care experiences and trends in health care use. The study provided a deeper and more nuanced understanding of how health care, health care experiences, and everyday life are interconnected for families with a child with ADHD. This will be further elaborated in the thesis.

CHAPTER 2. BACKGROUND

2.1. PREVALENCE AND SYMPTOMS OF ADHD

Attention deficit hyperactivity disorder (ADHD) is a neurodevelopmental disorder and one of the most common mental disorders in children and adolescents (2,3). The incidence of ADHD has increased in recent years. However, estimates of the diagnosis vary considerably worldwide within and between countries and may to some extent be explained by differences in the diagnostic criteria used (2,3). Recent meta-analyses present pooled estimates of 5.3% and 7.2% (2,3). In general, prevalence estimates are higher in males than in females (2). The meta-analysis by Rae et al. showed a higher prevalence of ADHD in studies from the Middle East compared with North America and lower estimates in European studies compared with those from North America (3). The contemporary assumption is that ADHD is caused by genetic and environmental factors (6,7). Associations between socioeconomic disadvantages and ADHD have also been found along with several other characteristics, such as low birthweight, suggesting that ADHD is a heterogeneous and complex disorder and that multiple factors lead to increased risk of ADHD (6,8-11).

According to national guidelines, the ADHD diagnosis in Denmark has increased from approximately 1,000 children and adolescents in 2001 to 8,000 children and adolescents in 2011 (12). These numbers may be underestimated as they are based on hospital-registered diagnoses not counting the children and adolescents who receive their diagnoses at a child and adolescent psychiatric practitioners or in the private sector (12). Incidence rates from a national register study show that the diagnosis of ADHD has increased since 1998 (13). These national trends are likely related to increased knowledge, awareness, and recognition rather than an increase in individuals developing ADHD (13). Register-based studies have found increased prescription rates of stimulant medication for children and adolescents with ADHD and significant regional differences in treating and diagnosing ADHD (14-16).

ADHD is characterized by inappropriate activity level, low frustration tolerance, impulsivity, poor organization of behavior, distractibility, and inability to sustain attention and concentration (17). These characteristics constitute inattentiveness, hyperactivity, and impulsivity as the core symptoms of ADHD (17). Studies suggest that the symptoms of ADHD or developmental deviations may be present in early childhood, although the diagnosis is usually not applied until school age (18,19). ADHD is associated with impairment in social, emotional, academic and behavioral functioning as well as in familial relationships (10,20-22). ADHD is considered to persist into adulthood (23,24). Additionally, ADHD is associated with higher risks of poor outcome in adulthood, such as a deprived work life, substance abuse, and criminality across the lifespan, which sustains the severity of the disorder (25,26).

2.2. HEALTH-RELATED IMPAIRMENTS IN CHILDREN WITH ADHD

ADHD is associated with a variety of health-related impairments and studies show increased use of health care services and extended medical costs (27-29). Larsson and colleagues found that children with ADHD consistently use more health, mental health, and education services than children with other mental health or neurodevelopmental disorders (30). Furthermore, children with ADHD from families with lower socioeconomic status have shown to pertain more comorbidity and impaired functioning than children with ADHD from families with higher income (30).

The majority of studies have focused on associations of ADHD and other psychiatric disorders and evidenced that ADHD is associated with oppositional defiant disorder, conduct disorder, depression and anxiety disorder and autism spectrum disorder among others (17,30-32). However, an increasing awareness of physical problems and medical co-morbidity in children with ADHD is reflected in the literature, and the children may be more likely to experience physical problems and co-morbidities (33). Studies show associations between ADHD and increased medical hospitalizations, for instance, caused by respiratory disorders and infections as well as increased risk of injuries (34-37). Furthermore, children with allergies, asthma, enuresis and severe headaches are more likely to be diagnosed with ADHD (34-36). Studies on patterns of health care use in medical and psychiatric hospital settings appear to be limited, although it may be important for health care services, health care professionals and organizers of health care to consider such characteristics to meet the children and families' needs of assessment, treatment, and support (30).

Supplementary to increased health-related impairments and co-morbidity, health-related quality of life is decreased in children with ADHD (38). Children with ADHD report lower subjective well-being overall than children without ADHD. This research area is not extensively investigated in the literature, but is it suggested that the subjective well-being might be impacted by comorbid conditions (38).

2.3. ADHD AND FAMILY LIFE

ADHD may affect all aspects of a child’s life (11,32,39). Studies show that the lives of parents and siblings are also affected as they are challenged by the difficulties that entail living with the child with ADHD (11,32,39). The impairment of everyday life comprises practical and psychological aspects of daily life, school life and social life (11,39). Various disturbances of family life have been observed, for instance, the parents report increased contact with the child’s school due to educational problems (10,11,40). Additionally, living with a child with ADHD, causes problematic parent-child relationship and increased levels of parenting stress and psychopathology (11,32,41). These difficulties have been evidenced to be exacerbated in children with comorbid problems (11,32,41). The families’ social life is inhibited, as the parents worry how the child with ADHD will behave on social visits, holidays, and other events. (39). Further, the parents have stigma-related experiences caused by negative views from the community or family and friends, which add to social isolation (42).

The parents worry about conflicts between the child with ADHD and siblings, and that they spend little time with siblings because of the attention provided to the ADHD child (43,44). In addition, the child with ADHD and their siblings report being less happy with their family and less happy with life overall compared with families without ADHD (38). A study on adults with ADHD reporting on childhood experiences supports the complexities in family life showing impaired relationship with peers, siblings and parents compared to children without ADHD (45). Moen et al. found that parents of children with ADHD have poorer family function than parents of children without ADHD (46). In addition, the family climate is affected by shifting moods and conflicts and the parents struggle to create a stable and structured family life to avoid conflicts within the family and manage daily life (43). Family stress and strain may be either pre-existing in the family or a result of managing a child with ADHD (47). Other studies on parenting experiences describe that parents find it difficult to raise and support the child and that parents struggle to overcome the burdens of everyday life and learn how to handle the child (22,48,49). The parenting challenges may increase when the child with ADHD enter teenage years as greater parent-child conflicts and higher levels of anger intensity compared to parents of typical adolescents have been described (11,32).

Parents are integral to supporting children with ADHD, and the children rely on their parents for symptom recognition and health care seeking even before the diagnosis is provided (47). Parents have to pull many strings to optimize the functioning of their child, yet they are burdened by feelings of guilt, and self-blame as the responsibility for the child is sometimes overwhelming (43,49). In addition, the parents may be strained by other family characteristics, such as parental mental health problems or socioeconomic difficulties which add to the family challenges (17,50). Thus, due to the described challenges, parents of children with ADHD may be in a vulnerable position.

The majority of studies imply that raising a child with ADHD affects family lives negatively, yet studies report that parents may benefit from early identification and help and support from professionals (5,51). The everyday lives of families are further challenged as the parents fight for appropriate support, and it appears that they may be strained by coordinating care and treatment as diverse settings and professionals tend not always to collaborate (51-53).

2.4. SERVICES AND PROFESSIONALS SUPPORTING FAMILIES OF CHILDREN WITH ADHD

Children with ADHD have complex care needs, which reinforce a multimodal approach and they are often treated with medication and a variety of psychosocial and psychoeducational interventions to improve their functioning (54). As a consequence of health-related impairment and impairment in social, emotional, academic and behavioral functioning, the parents of children with ADHD require help from a variety of systems, including hospital-based health care services, general practitioners, educational systems, social systems, and other resources to improve the children´s functioning (55,56).

Previous studies have identified that general practitioners (GPs) and public health nurses are among the first health care professionals that parents of children with ADHD encounter when seeking help (57,58). However, complications are observed in these encounters as the GPs and other health professionals lack knowledge on ADHD (57,59). As identified in a systematic review, all health care professionals and teachers as well as parents require education if parental concerns are to be identified and managed correctly (57,59). This is important to ensure appropriate access to specialist service (57,59).

In Denmark, some of the children and adolescents with less severe mental health problems receive help from child and adolescent psychiatric practitioners, social services, and school psychologists. Others require hospital care and treatment that are provided in a variety of medical and psychiatric hospital settings, such as inpatient care, outpatient services, or day care programs. Treatment, care, and support are provided and planned in multidisciplinary teams consisting of psychiatrists, pediatricians, psychologists and sometimes in collaboration with school psychologists and teachers. (60,61). However, previous studies found that the families of children with ADHD may have unmet care needs with regards to support for the whole family and care coordination (53,62). A Norwegian study found that children and adolescents with mental disorders use multiple health services (63). The study estimates that when a child has a serious mental health problem, six to 10 professionals are involved across health care services (63). Moreover, treatment and care across the health care system are provided in silos, and parents become the primary care coordinators (53,64).

Although parents play a fundamental role in positive outcomes for the child, studies of parental perspectives on health care services are sparse (43,57). Additionally, the parents' success in the parenting role requires support from the social network, educational and other services (43,57). Previous studies suggest that parental perceptions should be integrated into decision and treatment plans (17,65,66). Furthermore, studies suggest that care coordination and family-centered care are essential in supporting families of children with special health care needs (53,67,68). However, challenges exist, as parents report having unmet care needs (62).

2.5. SUMMARY AND RATIONALE FOR THIS RESEARCH

ADHD is a common mental disorder in children and adolescents, with core symptoms that impair several domains of functioning, including social relationships, education, and family life. Living with a child with ADHD influences the everyday lives of siblings and parents. The child's everyday life includes visits to health care settings, since children with ADHD require multi-faceted support from hospital-based health care services among others. Parents play an essential role in supporting the child and in improving the functioning of the child. Early identification and support may be beneficial to reduce negative outcomes of children with ADHD. However, parental experiences of not receiving appropriate support from health care services and professionals exist. The parents of children with ADHD search for support, and there is a paucity of literature on parental experiences of health care services. In addition, knowledge on how hospital-based health care may influence the everyday life of the families is limited. Further, children with ADHD have an increased risk of co-existing mental and physical problems, and they are frequent users of health care services, yet national studies on characteristics of hospital-based health care use do not exist. The rationale for conducting this study was, therefore, to provide new insights into the parental experiences, the complexities of everyday life, and hospital-based health care use among children with ADHD.

CHAPTER 3. RESEARCH AIM

In this section, the overall aim of the thesis, and the aims and research questions of Studies 1, 2, and 3 are presented. This is followed by a short section in which the terms *ADHD, parents and health care* are operationalized for the purpose of this PhD.

Overall aim of thesis

The overall aim of this PhD thesis was to integrate qualitative and quantitative data to provide new insights into the parental experiences, the complexities of everyday life, and hospital-based health care use among children with ADHD.

Study 1 (review protocol, Papers I and II)

The aim of Study 1 was to identify and synthesize the best available evidence on parental experiences of living with a child with ADHD, including their experiences of ADHD health care and other services.

Research questions:

- How does living with a child with ADHD affect family life?
- What are the parental challenges of having a child with ADHD?
- How do parents experience collaboration with health care settings and other services?

Study 2 (Paper III)

The aim of Study 2 was to explore parental experiences of how health care and health care professionals in hospitals in Denmark influence the everyday lives of families with a child with ADHD.

Research questions:

How do parents of children with ADHD:

- Experience collaboration with health care services and health care professionals?
- Feel supported in everyday life?
- Perceive barriers and enablers in health care?

Study 3 (Paper IV)

The aim was to study hospital-based health care use in a Danish birth cohort during the first 12 years of life. The aim was threefold:

- To compare the mean number of medical and psychiatric hospital-based services in children with and without ADHD
- To assess the independent effect of ADHD on hospital-based service use,
- To identify child, parental, and socio-economic-related risk factors associated with medical and psychiatric service use in children with ADHD.

Definitions

ADHD, *parents* and *health care* are three continuous terms of this PhD thesis. To clarify how these are conceptualized in this research, a short operationalization of each term is presented below.

ADHD

Children with ADHD include both children with ADHD and children with ADD in this thesis. ADHD is short for attention, deficit, hyperactivity disorder. ADD is short for attention, deficit, disorder. It is important to notice that the definitions of ADHD vary across Studies 1, 2, and 3. In Study 1, all studies reporting parental experiences of ADHD regardless of diagnostic criteria were included. For Studies 2 and 3, the International Classification of Diseases, 10th revision criteria (ICD-10) was used to identify children with ICD-10 codes F90.0, F90.1, F98.8 (69).

Parents

Parents were defined as the social family, and were thus the adults with whom the child lived. This included biological parents, parents with parental responsibilities of the child, such as grandparents and foster parents, and partners of biological parents. Single parents, as well as parents living together, were included. Despite the focus on the parents in this PhD thesis, this investigation also encapsulated findings related to the family of the child with ADHD

Health care and health care professionals

Health care included patient assessment, treatment and care in various medical (non-psychiatric) and psychiatric hospitals. As such, the participants in Studies 2 and 3 were selected from these settings. In Study 1, health care was not restricted to hospital-based health care. Health care professionals refer to the health care providers that the children and parents met in the hospitals, such as nurses, doctors, psychologists, physiotherapist, and other practitioners. Because of the focus on parental experiences of everyday life and health care in Studies 1 and 2, experiences with other health care practitioners, such as GPs and private specialists, are also present in this thesis.

CHAPTER 4. RESEARCH DESIGN

In this section, mixed methods is presented as the overall research methodology for this thesis. This is followed by a presentation of the research design and three levels of integration across Studies 1, 2, and 3. Integration occurs at the study design level, at the methods level, and at the interpretation and reporting level (70).

4.1. MIXED METHODS

The rationale for choosing mixed methods was that the overall aim was complex and could not be examined by qualitative or quantitative approaches alone (71,72). The overall aim comprises the mixed methods question of this thesis, and the integration of qualitative and quantitative findings was based on meta-syntheses (Study 1), explorations (Study 2), and descriptions (Study 3). These approaches were important to study parental experiences, everyday life, and health care use among children with ADHD. Mixed methods draws on the strengths of both quantitative and qualitative approaches and provides an innovative approach with several advantages, including using multiple data sources for studying the area of interest (71,72). Not being limited to either the traditional quantitative or qualitative designs of exploring or explaining, enables an extended investigation of research questions that cannot be answered by one approach alone (71,72). The mixed methods approach applied in this thesis was based on the definition by John Creswell:

> “[Mixed methods is] an approach to research in the social, behavioral, and health sciences in which the investigator gathers both quantitative (closed-ended) and qualitative (open-ended) data, integrates the two, and then draws interpretations based on the combined strengths of both sets of data to understand research problems” (72 p. 2).

The mixed methods approach by John Creswell was initially introduced in 1994, and it has evolved ever since (73,74). The approach offers descriptions of a variety of mixed methods designs supplemented by principles and practical guidelines of how to achieve integration in mixed methods studies (70,71,73). The integration of quantitative and qualitative data can be used to enhance knowledge gained from the different stages in a study (70,71,73).

The philosophical assumption of this mixed methods study is pragmatism (73,75,76). Creswell argues that the underlying philosophical assumption of mixed methods is that the nature of the research question drives to the choice of methods (71). The pragmatic paradigm places the research aim as central and applies diverse approaches to examine the aim (71). Pragmatism has gained acceptance in mixed methods because this approach accepts that some knowledge is constructed and some knowledge is based on the reality of the world in which people live (71,75-77). Accordingly, in pragmatism, the existence of both the natural and physical world, as well as the social and psychological world, is recognized. Furthermore, pragmatism has been suggested to improve communication between different paradigms (75,77,78). Pragmatic researchers focus on the "what" and "how" instead of being committed to one single philosophy or reality (71). Thus, pragmatism claims that the dichotomy between post-positivism and constructivism should be abandoned (73,78). Research conducted within this tradition acknowledges that different theories and perspectives can be useful concurrently. Therefore, diverse research methods, such as field observations, interviews, and data collected from registers, assisted in addressing the aim of this investigation.

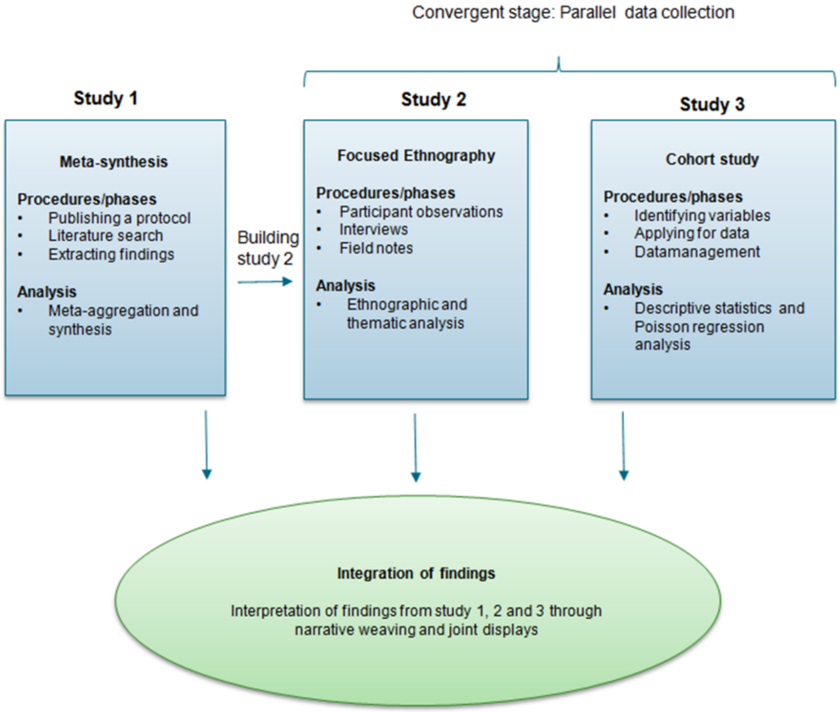
In the literature, discussions revolve around the philosophical assumptions of mixed methods research. These discussions identify that qualitative approaches are traditionally associated with constructive or interpretive epistemologies whereas quantitative studies are traditionally associated with positivistic or post-positivistic epistemologies (71,77). As such, the underlying philosophical assumptions of mixed methods studies are questioned, including the possibility to combine qualitative and quantitative methods despite their diversity. In response, pragmatism, transformative emancipation, dialectic pluralism, critical realism and pragmatism among others have been suggested as meaningful philosophical perspectives (71,75,77-79). However, according to Creswell and others who convey the importance of focusing attention on the research problem and relevant methods instead of philosophical incompatibilities, pragmatism is an important and relevant assumption for mixed methods research (71,75).

Mixed methods requires that the researcher learns about multiple methods and approaches and understand how to integrate them correctly (71,72,75). Therefore, it was important to recognize the traditions, the worldviews and the rigorousness of each method used. Thus, Studies 1, 2, and 3 were conducted and published in stages to accredit the singular methodology. According to Creswell and colleagues, combination and integration of quantitative and qualitative data is the hallmark of mixed methods research (70,71,80). Integration is an intentional process by which the researcher brings qualitative and quantitative approaches together (70,71,80). (70,72,81). The premise of mixed methods is that the integration of data leads to more than the sum of its parts (81). For this thesis, integration was needed to provide the full potential of the mixed methods approach and gain new insights regarding the aim of the study. The research design and the levels of integration are further elaborated in the following sections.

4.2. RESEARCH DESIGN

The design of this PhD thesis was a multistage mixed methods study with a core convergent design as presented in Figure 1 (70-72). The design consisted of three individual studies and included three stages of data collection. Study 1 was a meta-synthesis, Study 2 was a focused ethnography, and Study 3 was a cohort study. Initially, Study 1 provided a fundamental understanding of parental experiences of everyday life and health care for their child with ADHD. This was followed by a core convergent design with parallel data collection consisting of Studies 2 and 3.

Figure 1. A multistage mixed methods study with a core convergent design



4.3. INTEGRATION AT THE DESIGN LEVEL

Integration at the design level was accomplished by using a multistage design (70-72). In mixed methods, integration at the design level can be accomplished by using basic designs or advanced designs (70-72). The basic designs include an exploratory sequential approach, an explanatory sequential approach and a convergent approach (70-72). The data collection of convergent designs happens concurrently whereas in sequential approaches, the data collection and analysis of data inform the next phase of data collection (70-72). Advanced designs include multiple designs, which are defined as multiple phases of data collection, including various combinations of exploratory/explanatory sequential approaches or convergent approaches (70-72). Multiple phases of data collection involve three or more phases of data collection (70-72). This is consistent with the three studies of this PhD thesis, therefore, a multistage design was chosen (70-72).

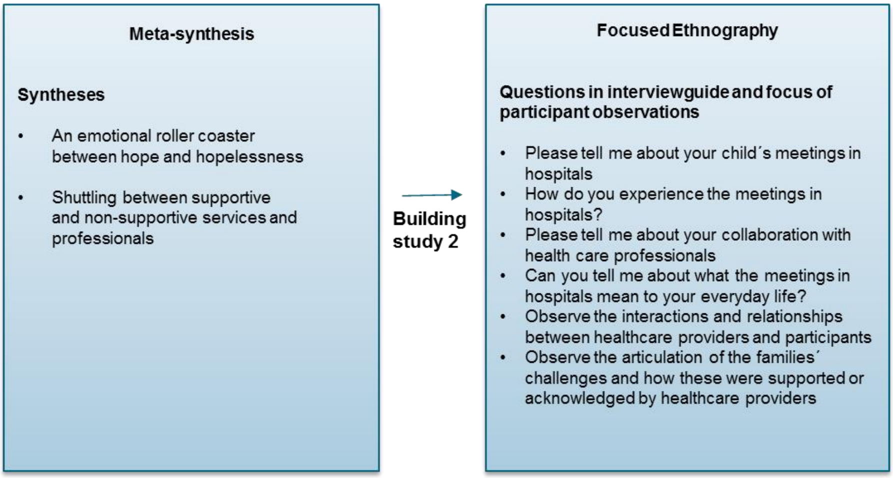
Data collection in the convergent stage of this PhD study took place almost concurrently as the ethnographic data were collected in phases during 2015. Simultaneously, the process of identification and application for data in national registers began. The data from the registers were not received until April 2016 and therefore, the data analysis of Study 2 was accomplished before the analysis of Study 3 began. This provided the opportunity of adjusting a few elements in Study 3. Based on preliminary findings from Study 2, we decided to include health care use before the ADHD diagnosis was applied. In addition, we defined parents as the parents with whom the child lived in Study 3 because parents with parental responsibilities appeared in Study 2 to include biological parents as well as stepparents and grandparents. The adjustments were in line with the perspectives of Creswell arguing that an iterative process can proceed, although data collection occurs in parallel (72).

4.4. INTEGRATION AT THE METHODS LEVEL

The integration at the methods level adhered to building and merging in this thesis. In mixed methods, integration at the methods level occurs through linking the methods of data collection and analysis (70-72). Study 1 was linked to Study 2 through building. Usually, building occurs in studies adhering to sequential approaches within mixed methods studies (70-72). The Creswell’s approach requires that sequential approaches include both a qualitative and a quantitative component (70-72). Studies 1 and 2 were both qualitative in this PhD study, which excludes a traditional sequential approach. However, as presented in the following section, we choose to refer to building, because of the close link between Studies 1 and 2.

Building at the methods level occurred because findings of Study 1 informed the aim and data collection approach of Study 2. The aim of Study 2 was developed based on a study showing a paucity of the literature regarding parental experiences of health care for their child. In addition, the syntheses of Study 1 inspired the interview and observation guides of Study 2 as exemplified in Figure 2. Studies 2 and 3 examined experiences and descriptions of hospital–based health care convergent.

Figure 2. An example of building Study 2 from Study 1



Meta-synthesis

Syntheses

- An emotional roller coaster between hope and hopelessness
- Shuttling between supportive and non-supportive services and professionals

Building study 2

Focused Ethnography

Questions in interviewguide and focus of participant observations

- Please tell me about your child´s meetings in hospitals
- How do you experience the meetings in hospitals?
- Please tell me about your collaboration with health care professionals
- Can you tell me about what the meetings in hospitals mean to your everyday life?
- Observe the interactions and relationships between healthcare providers and participants
- Observe the articulation of the families´ challenges and how these were supported or acknowledged by healthcare providers

4.5. INTEGRATION AT THE INTERPRETATION AND REPORTING LEVEL

Integration at the interpretation and reporting level of Studies 1, 2, and 3 occurred through the staged approach as the results of Studies 1, 2, and 3 were reported in separate papers (70). In this thesis, the findings of Studies 1, 2, and 3 were brought together for analysis to expand insights of the experiences and complexities of everyday life and hospital-based health care (70-72). The narrative approach was used to integrate the findings and includes integration of the findings from the three studies through a unifying analysis and interpretation (70). In addition, joint displays were applied (Section 6.4.1.). Joint displays facilitate the integration of data by bringing the data together through visual displays and assist in drawing out new insights beyond the information gained from the separate qualitative and quantitative findings (81). The coherence (fit) of integration as described by Fetters et al. was assessed through possible confirmation, expansion, and discordance of the findings (70).

CHAPTER 5. METHODS

In the following section, methods of Studies 1,2 and 3 are presented. This includes information on methods, participants, material, data collection, and data analysis based on the completed papers. This is followed by the overall ethical considerations for Studies 1, 2, and 3. Supplementary information concerning methodology, data collection, and the researcher's role is provided for Study 2.

5.1. STUDY 1

Methods

Study 1 was a qualitative systematic literature review using the approach offered by Joanna Briggs Institute (JBI) (82). The meta-synthesis followed the JBI guidelines of planning, undertaking and writing up a systematic review. The meta-synthesis adhered to a systematic process of retrieving relevant studies, critical appraisal of the studies and the process of extracting qualitative findings from the included studies (83,84). Relevant qualitative studies to include were identified through a systematic search strategy. The literature searches were performed in PubMed, Embase, PsycINFO and CINAHL and the search in each database was customized using both controlled thesaurus terms and natural language terms for synonyms. The searches included various combinations of the following keywords; Attention deficit hyperactivity disorder, ADHD, children, adolescents, parents, mother, father, family, psychosocial factors, life impairment, life experiences, attitude to life, life change events, parents' psychosocial factors, experience, attitude, perception, perspective, daily life, family life. An example of the search strategy in CINAHL can be found in Appendix A (also published in paper I).

Studies included

A total of 21 qualitative research articles concerning parents' experiences of living with a child with ADHD and/or parents' experiences of ADHD health care services were included. Collaboration with health care professionals in and outside of the hospital were also included. Ten studies used grounded theory (49,85-93), three studies used phenomenology (22,44,94), two studies used a feminist/narrative approach (95,96) and one study used ethnography (97). Five studies did not identify any specific methodology, but stated that they used a qualitative methodology as an approach (21,48,98-100). A presentation of the studies is provided in Table 1 (a summary of tables published in paper I and II). The parents were defined as biological parents or persons who had parental responsibilities for the child.

Table 1. Studies included in the meta-synthesis

Study	Methodology	Methods	Phenomena of interest
Carol Ho S et al., 2011	Qualitative exploratory study	Interviews	The perceptions of parents with a child with ADHD
Davis CC et al., 2012	A qualitative approach	Interviews	Family-centered care in families' stories about treatment decision making for their child with ADHD
Firmin MW, Phillips AA, 2009	Grounded theory	Interviews	The daily experiences of families with children with ADHD.
Garro LC, Yarris KE, 2009	Ethnography	Interviews Video data	The experiences of a family with a boy with ADHD
Hallberg U et al., 2008	Grounded theory	Interviews	The main concern of being parents of teenage daughters with ADHD
Harborne A et al., 2004	Grounded theory	Interviews	How parents and children understand the causes of ADHD
Hermansen MS, Miller PJ, 2008	Phenomenology	Interviews	The everyday life and the struggles of an ADHD child as perceived by their mothers
Kendall J, 1998	Grounded theory	Interviews Observations	The everyday experiences of families with ADHD children
Kildea S, Wright J, Davies J, 2011	Qualitative methodology	Interviews	Stakeholders' conceptualizations and solutions concerning ADHD in CAMHS
Koro-Ljungberg M, Bussing R, 2009	Grounded theory	Focus group interviews	How parents of adolescents with ADHD manage courtesy stigma in their lives
Lin M, Huang X, Hung B, 2008	Phenomenology	Interviews	The experiences of primary caregivers who are bringing up school-aged children with ADHD
Malacrida C, 2001	Feminist research	Interviews	What is it like to be a mother of children with ADHD confronting multiple "helping" professionals
McIntyre R, Hennessy E, 2012	Qualitative exploratory study	Interviews	To explore the experiences of parents of children with ADHD in Ireland
Moen OL et al. 2011	Phenomenology	Interviews	The everyday experience of being a parent to a child with ADHD
Perry CE et al., 2005	Grounded theory	Interviews Field notes Narratives	How Latino parents managed their child´s ADHD within the sociocultural context of their everyday lives
Peters K, Jackson D, 2008	Narrative-based feminist approach	Interviews	The perceptions and experiences of mothers parenting a child with ADHD
Segal R, 1998	Qualitative approach	Interviews	The daily experiences of families with children who have ADHD
Segal ES, 2001	Grounded theory	Interviews	The experience of mothers of children with ADHD with the goal of understanding their needs
Singh I, 2004	Grounded theory	Interviews	Mothers' perspectives of blame in relation to ADHD diagnoses and Ritalin use
Taylor M, Houghton S et al., 2008	Grounded theory	Interviews	How mothers of children with ADHD get their children ready for school
Wallace N, 2005	Grounded theory	Interviews	The perceptions and experiences of mothers of boys with ADHD

Data extraction and analysis

The data of the meta-synthesis were the findings of the primary authors. Thereby, the data in the meta-synthesis were verbatim themes and concepts representing findings of the included studies (82). The extracted findings were illustrations, such as direct quotations of participant's voices, fieldwork observations, or other supporting data (82). The credibility of each finding was assessed using three levels of credibility as defined by JBI (82). In total, 129 findings were extracted from the included studies. To comply with JBI, a meta-aggregative approach to synthesizing the findings was obtained to aggregate the findings into a combined whole that was more than the sum of the individual findings (101). The JBI software supported this approach, and the 129 findings were aggregated into 15 categories based on similarity of meaning. This was followed by a further aggregation, which resulted in 6 synthesized findings.

5.2. STUDY 2

Methodology

The methodology of Study 2 was focused ethnography. Focused ethnography is a niche within traditional ethnography that tend to be problem-focused and context specific and the knowledge learned is expected to be useful for health care professionals (102-105). In its tradition, ethnography is a research design that studies culture and focuses on the perspectives of those who live in the culture (106-108). Ethnographers study situations as they occur in their natural setting to gain in-depth perspectives and work together with the informants to produce a cultural description, long term field-observations being substantial to understand the complexities of the culture being explored (104,107). The focus of study 2 was pre-selected and specified to parental experiences of how health care influences everyday life with a child with ADHD and therefore focused ethnography was more appropriate. Focused ethnography is considered suitable for health care research allowing the research questions to be problem-focused and context-specific (102-105). Focused ethnography is used to gain a better understanding of the experiences of specific aspects of people´s ways of life and being (102-105). In addition, the field observations in this study were short-term, and the fields were visited at certain intervals. This is also in agreement with focused ethnography justifying that the field observations are short-range and not necessarily continual (102-105).

Participants

Fifteen parents of children with ADHD were included in the study. The children were between five and 12 years of age and diagnosed with ADHD (F90) according to ICD-10 (69). Two children were diagnosed with ADD and 13 children were diagnosed with ADHD; nine had co-existing physical or developmental diseases such as cerebral palsy, enuresis, overweight, and autism spectrum disorder. Both single parents, parents living together or divorced parents were invited to participate in the study. This resulted in participant observations and interviews with 13 biological mothers, 4 biological fathers, 1 foster mother, 1 foster father, 1 grandmother and 3 partners living together with the biological father/mother of the child with ADHD. The parents were between 29 and 59 years of age.

Data collection

Participant observations and interviews were the primary sources of data collection. The participant observations were short-term and undertaken in two general paediatric outpatient clinics and two child and adolescent mental health clinics in public hospitals in Denmark. Participant observations with 14 of the 15 families were undertaken, as one family canceled their appointment in the psychiatric outpatient clinic. The family was still interviewed afterwards in their home. Within two families, it was possible for the researcher to participate in two health care meetings during the time of data-collection. Thus 16 participant observations were undertaken. The activities and interactions in the meetings were observed. Medical records provided demographic information about the child and family.

Informal and formal interviews were conducted. Informal interviews were conversations with participants that were not pre-arranged (103,104). The informal interviews took place before and after health care meetings. Formal interviews were organized with the participants (103,104). The families decided who would participate in the formal interviews and this yielded ten individual and five dyadic interviews. In this study, dyadic interviews refer to interviews with two persons in that either both parents or a partner to one of the parents participated (109).

The formal interviews were semi-structured with open-ended questions (110) (Appendix B). Each interview was individual and varied as the interviews began with the researcher asking questions about the activities and experiences from the researcher’s observations in the health care meetings. Additionally, the interviews covered the families’ everyday life and experiences with health care. The interview guide was adjusted several times during the period of data collection; for example, after covering the observations, the researcher initially attempted to address more health care issues. However, most participants were more concerned with telling about everyday life perspectives. Thus, questions of everyday life were prioritized which initiated further conversation on the parents’ experiences of health care and collaboration with health care professionals.

The researcher’s role during data-collection

During participant observations, the most predominant role was the “observer-as-participant role” as the researcher’s participation in activities was reduced at the families’ hospital meetings (103). The observations in focused ethnography are usually short, thus this role is typically used in focused ethnography (102,103). However, efforts were made to establish a relationship with the participants. Prior to the participant observations, the researcher called the participant by phone to provide additional information and make arrangements. On the day of the health care meeting, the researcher came early and in most cases met the participants before the meeting started. Thereby, a brief relationship was already established and the researcher experienced that the families under investigation willingly shared their experiences and were eager to ensure that the researcher understood and encapsulated their experiences.

The researcher observed the activities and the interactions among health care professionals and the families by being physically present at the table with the participants. This provided an opportunity for the researcher to perceive events and understand meanings of the issues that were addressed in the health care meetings (102,103). The health care professionals led the conversations and provided examinations, care, and treatment for the children and the families. Occasionally, the researcher joined the conversation and took part in few activities in the meeting. This promoted the interaction and relationship between the researcher, health professional, and the family and contributed to the observations and conversations being less formal.

Data analysis

The data analysis was iterative and occurred at different stages in the process, including during data collection, in between interviews, and during participant observations. The ethnographic analysis inspired by Roper & Shaphira and Hammersly & Atkinson (103,108) was assisted by thematic analysis involving a non-linear process with five phases (111,112). Phase one included transcribing, reading and re-reading interviews and participant observations. In phase two, initial codes were generated. In phase three, relationships between groups were identified and overarching themes emerged. These overarching themes were clustered into three candidate main themes. In phase four and five, the themes were reviewed, defined and named to identify the essence of what each theme was about (111,112). NVIVO was used as a data management tool to assist the analytical process (113). Tables showing the relationship between theme, sub-themes and codes are presented in the findings section (6.2) of this thesis.

5.3. STUDY 3

Research design

Study 3 was a historical cohort study identified by using Danish nationwide registers (114). In Denmark like other Scandinavian countries, unique possibilities for studying large, nationwide historical cohorts in health care exist because of the nationwide registers (115). The Danish Civil Registration System provides linkage between the national registers through the personal identification number assigned to all Danish residents (116).

Study population

The total cohort included all children born in Denmark in 1995-2002 with full follow-up time for twelve years. Within the cohort, children with a first-time registered ADHD diagnosis were identified in the Danish Psychiatric Central Research Register (DPCRR) or the Danish National Patient Register (DNPR) (117,118). ICD-10 codes F90.0, F90.1, and F98.8 were used to identify children with ADHD (69).

Data sources

DPCRR and DNPR contain electronic and encrypted information about hospital admissions and outpatient visits of all persons entering public hospitals in Denmark. In the DPCRR, information on psychiatric admissions has been collected since 1969 (117). The DNPR was established in 1977, and the register covers medical (since 1977) as well as psychiatric admissions (since 1995) in hospitals (117,118). Since 1995, information on outpatient services was added to both registers (117,118).

Outcome measures and explanatory variables

Visits and admissions to medical and psychiatric hospital services were the outcome variables in this study. Health care service use was the number of outpatient visits and inpatient admissions to Danish hospitals registered in DNPR and DPCRR during the 12 years of follow-up. Thus, if patients had multiple records per day per outpatient clinic, these additional records did not count in the calculation of the total number of visits.

Explanatory variables included variables related to child-, parent-, and socio-economic characteristics. The Danish Medical Birth Register provided information on birth-related characteristics: birthweight, week of gestation at the time of birth, birth order, multiple births, the age of both biological parents at the time of child’s birth, and maternal smoking during pregnancy. In addition, parents’ psychiatric disorder and socioeconomic variables including cohabitation status and parental income obtained from social registers in Statistics Denmark were included.

Data analysis

Descriptive statistics were used to present the distribution of child characteristics and explanatory variables in children with and without ADHD. Additionally, the mean number of hospitals visit and admissions in medical and psychiatric hospitals per year during the 12 years of follow-up was calculated.

To assess the effect of ADHD on medical and psychiatric service use, Poisson regression analysis were used. Poisson regression analysis is appropriate when the outcome variable is an independent count (119). However, since hospital visits are assumed to predict additional hospital visits, the assumption of independence was not completely fulfilled in this study. The data revealed numerous outliers, and thus the data failed to conform to a Poisson distribution (119). To account for this by not making any distributional assumptions, we applied bootstrap with 1000 repetitions to all the regression analyses (120).

In the multivariate model, the population was the total cohort of children, and ADHD was included as a variable to assess its effect on service use. In the adjusted multivariate model, all explanatory variables were included to assess the effect of ADHD on service use when controlling for all other variables. Explanatory variables for the models were selected a priori. To detect potential risk factors associated with service use, only the cohort of children with ADHD was included. In the multivariate analyses, we assessed the association of all explanatory variables on medical and psychiatric service use in children with ADHD.

5.4. ETHICAL CONSIDERATIONS

Prior to conducting this PhD, the overall study plan, including Studies 1, 2, and 3 were approved and registered at the Danish Data Protection Agency (2008-58-0028).

Considering Study 2, all the participants were provided written and verbal information with anonymity and confidentiality being ensured (Appendix C). Participation was voluntary, and the participants could withdraw at any time. The participants all signed an informed consent form (Appendix D). The ethical guidelines for nursing research in Scandinavia were fulfilled (121). Head nurses and leading doctors at the departments granted the researcher access to conduct participant observations. The staff was informed about the study on scheduled meetings. Nurses and other health care professionals employed in the departments assisted in identifying participants for the study. Typically, the professionals would contact the families and facilitate the contact between the researcher and the parents. The researcher would get in contact with the parents to inform them thoroughly about the study and arrange participant observations and interviews. The families of children with ADHD may be in a vulnerable situation, and it was of great importance for the researcher that the families felt comfortable with her presence during the observations. In addition, the parents were the ones to decide when and where it would be appropriate to meet for the interviews. With respect to Study 3, all personal information from the Danish registers were anonymized before receiving data. The anonymized data were stored in a central database in Statistics Denmark and were only accessible using individual personalized codes.

CHAPTER 6. FINDINGS

In this section, summarized findings from Studies 1, 2, and 3 are presented based on the completed papers for each study. Furthermore, the integrated mixed methods findings are presented through narrative weaving and joint displays.

6.1. STUDY 1

The meta-aggregation resulted in six synthesized findings: 1) An emotional roller coaster between hope and hopelessness, 2) *Mothers as advocates in a battlefield within the system and family*, 3) *Parental experiences in a crossfire of blame, self-blame and stigmatization*, 4) *Shuttling between supportive and non-supportive services and professionals*, 5) *Routines, structures and strategies within everyday life, and* 6) *Despite multiple challenges, it is not all bad*. Table 2 provides an example of the relationships between the meta-synthesis, categories and study findings regarding meta-synthesis 1. Tables showing all meta-syntheses can be found in Papers I and II (122,123).

Meta-synthesis 1: An emotional roller coaster between hope and hopelessness
This synthesis showed how parents of children with ADHD tended to balance between hope and hopelessness. They felt helpless and overwhelmed by the burdens of their responsibility for the child with ADHD. The burdensome responsibility seemed to increase when the child grew older as parents experienced an escalation in problems when the children became teenagers. However, the parents seemed to accept their child´s diagnosis over time and revised their expectations for the child. They regained hope for the future.

Parents described being exhausted and on duty around the clock, because caring for a child with ADHD was demanding. The demanding nature of the child left limited time to spend with siblings and partners. This brought forth feelings of guilt, in addition, the parents tended to disagree on how to handle the child. This contributed to tense relationships in the family. Further to feelings of guilt was that parents frequently were frustrated and felt incompetent, as they found it difficult to help their child manage school, family life, and social life.

Table 2: Meta-synthesis 1: An emotional roller coaster between hope and hopelessness

Synthesized findings	Categories	Study findings
An emotional roller coaster between hope and hopelessness	Disruption of family life	Assigning blame Child blame Family conflicts Impact on family Maternal experiences unique to dealing with hyperactive early-rising children Outlasting disruption Parents´ relationships with siblings: From provocation to insufficient support Siblings Stresses The child takes over Trying to solve family conflicts Feelings of anger and hostility
	Emotional burdens	Being on duty around the clock Bundle of negative feelings Caregiving burden Connection and maternal instinct Emotional burdens Emotional distress parental suffering Emotional impact Great difficulties encountered in child care Grief Living at the edge of one´s capability Parents struggling and getting nowhere The caring responsibilities as overwhelming Transferring responsibility

Meta-synthesis 2: Mothers as advocates in a battlefield within the system and family

This synthesis relates to mothers describing that having a child with ADHD necessitated advocacy skills. Advocacy skills included protecting and supporting the child in many aspects of life, for instance in school. The mothers were highly involved in their child´s lives as they fought to accomplish appropriate support for the child. The mothers took on the responsibility of teaching professionals how to handle the child and they engaged in policy work to ensure better conditions for the child. Fulfilling advocacy tasks also comprised coordinating between diverse health care professionals and they struggled for support in various systems. Advocating for various systems was time-consuming, and some gave up working full time. Furthermore, the mothers also seemed to be on a battlefield in the family. They described lacking support and understanding from their husbands and the extended family, although they accepted having the overall responsibility for the child.

Meta-synthesis 3: Parental experiences in a crossfire of blame, self-blame, and stigmatization

This synthesis illustrates how blame was twofold. The parents experienced being blamed for their child´s behavior, yet they also blamed themselves for their child´s difficulties and questioned their parenting abilities. Likewise, some parents experienced that other members of the family or the community doubted their parenting skills and they felt judged and stigmatized by them. It seemed that having a child with ADHD may interrupt the families’ social life as they sometimes isolated themselves to avoid stigma from others. The child receiving the diagnosis of ADHD occasionally replaced guilt with relief, as the diagnosis assisted in explaining the challenges of the child. However, for some parents, this was a short-term relief because of the stigma related to the diagnosis.

Meta-synthesis 4: Shuttling between supportive and non- supportive services and professionals

This synthesis shows that the parents needed support from a variety of professionals and systems, including educational, social welfare, and health care systems to optimize the functioning of their child, and to enable the best support for their child. Although some parents felt supported by individual teachers or doctors, they in general needed to fight for support and they encountered challenges in meetings with professionals and supporting services. Parents questioned if the professionals had enough knowledge of ADHD as they were not prepared to provide care that dealt with the child and family’s challenges. Parents viewed professionals to be supportive if they provided family-centered care considering the range of problems associated with ADHD, their family situation and the individual needs of the involved family members. With respect to health care professionals, parents requested that they emphasized and understood how living with a child with ADHD affected each member of the family and how disruptive family life could be.

Meta-synthesis 5: Routines, structures, and strategies within everyday family life

This synthesis shows how the parents turned to routines, structures and strategies to organize their everyday lives and be prepared to overcome stressful situations. Stressful periods of the day were for instance mornings before getting the child to school, afternoons with homework and bedtime. The parents attempted to structure and plan everything ahead, such as waking up early to be prepared to guide the children step-by-step during the mornings, and preparing dinner before the turbulent afternoons. The parents used different motivational strategies, including negotiation and praise as an alternative of scolding to overcome the challenges and make the child complete tasks in time. However, cultural contrasts appeared in the included studies as it was common to punish the child by smacking or yelling in some countries. It seemed that learning about their child´s diagnosis led to a better understanding.

Meta-synthesis 6: Despite multiple challenges, it is not all bad

This synthesis covers that the parents repeatedly had ups and downs. During long periods of life, they were trying to survive the disruptive phases, yet they strived towards normality and did things, that families without children with ADHD would do. They infrequently succeeded which contributed to frustrations and anger. The parents described always being in a state of adjusting to new situations facing diverse challenges. Regardless of the challenges and the times of hopelessness, learning about the diagnosis facilitated that parents accepted the child´s diagnosis and revised their expectations for the child and their family life. This brought along optimism about the future, and they were capable of enjoying the good periods. To contend and adapt to new situations appeared to be essential elements in restoring and feeling content in life

6.2. STUDY 2

The analysis of data resulted in three main themes which are closely interconnected: 1) *When the house of cards collapses in everyday life*, 2) *Treading water before and after "the ADHD bomb"* and 3) *Health care as a significant lifeline*. In this section, summaries of the findings are presented and supplemented with tables for each theme showing the connection between theme, sub-themes, and codes (the tables were not included in Paper III).

When the house of cards collapses in everyday life

This theme illustrates how everyday life with a child with ADHD was fragile and how the house of cards could easily collapse. The vulnerabilities of the families and their everyday lives necessitated help from health care professionals, teachers, social workers or relatives. Changes in the child´s everyday life affected the child and impacted the whole family as the child reacted to variations and needed more attention when adjusting to new situations. Additionally, the parents described how the constant focus on and concerns for the child with ADHD caused frustrations and that the parents in periods were exhausted. The parents experienced how they were not always capable of preventing the house of cards from collapsing and that the relationship with their partner was impacted. In addition, further familial challenges were related to financial strains and other physical or mental health problems in the family, such as one child having no contact with his or her father due to the father´s severe ADHD.

Yet, sometimes it was perceived as a gain if one of the parents had a well-treated ADHD diagnosis as they recognized the child's difficulties and needs.

The parents relied on help and support when the house of cards collapsed. Nevertheless, the parents sometimes felt that their worries and concerns were not recognized. In addition, the parents' beliefs of appropriate support for their child and family were often incongruent with what was accessible and offered by professionals and supporting systems.

Table 3: When the house of cards collapses in everyday life

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 behavioral 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

Treading water before and after “The ADHD Bomb”

This theme covers parental experiences of treading water before and after their child is diagnosed with ADHD and how health care professionals may influence their everyday life positively by being accessible and supportive. The parents often sensed that their child acted differently from other children long before the child was diagnosed with ADHD. The parents referred to this period with frustrations because of the struggle to have their concerns validated. Before the diagnosis was applied, the parents perceived, that professionals did not acknowledge their concerns and that their parenting skills were questioned. This generated the feeling of drifting alone to deal with the challenges of everyday life. Once referred to psychiatric examination for ADHD, the parents experinced that the health care system was effective and the diagnosis applied relatively quickly.

Although the parents expressed relief about the diagnosis, it was also “a bomb” as they encountered new struggles for appropriate support for their child. Once again, they felt as if they were treading water. In this period, accessibility to health care was essential. A close relation to health care was important for the parents to adjust to life with a child with ADHD and to feel supported and have back up. Health care professionals from the child´s regular psychiatric or medical clinic became allies; for example, the parents relied on health care professionals, as they sometimes succeeded in influencing decisions made by supporting systems. Families of children with primary physical disorders subsequently diagnosed with ADHD tended to perceive that ADHD pervaded all aspects of life, whereas physical challenges were perceived to be focused on certain areas. This made the ADHD diagnosis more impairing with respect to daily functioning. However, support was not always provided sufficiently, as the parents described that they lacked support regarding ADHD, in particular, if the focus was entirely on the physical issues in health care meetings.

Table 4: Treading water before and after “The ADHD Bomb.”

Theme	Sub-themes	Codes
Treading water before and after “The ADHD Bomb”	The meaning of getting the diagnosis	Parents diverse attitudes to the diagnosis Requesting mental health investigation Validations of concerns Being referred to investigation Normalizing Being dismissed Child’s reaction to the diagnosis Viewing the diagnosis as a label
	Drifting alone in health care and supporting systems	Parental strategies to overcome being let down Confidence in the system Collaboration with educational systems Burdening health care or other systems No diagnosis no support Requesting more support Being an advocate Speaking the same language
	Wasting time	Accessibility Coordinating work and time Challenges of divorced parents A waste of time

Health care as a significant lifeline

This theme illustrates the importance of health care in everyday life. Health care could be a significant lifeline if the professional-parental relationship was based on trust, faith in professional knowledge, respect and a holistic delivery of care. In addition, the uniqueness of each family’s challenges and resources should be emphasized. The values and personality of the health care professionals contributed to a trusting relationship, and to the families feeling safe and acknowledged. The parents spoke positively of professionals, who acknowledged and engaged with the child as opposed to professionals reducing the child to its diagnosis.

The parents considered health care to be a lifeline when things were difficult at home, especially if they had a close relationship with the professionals. Furthermore, it was important for the parents that professionals addressed everyday life challenges, although the health care meeting was, for instance, an appointment about medication. However, the lifeline could be trimmed by the lack of acknowledgment of how ADHD pervaded every aspect of everyday life, and if the parents were not as involved as specialists in their own child and family. This brought forth feelings of frustration and disappointment. In addition, conflicting perspectives, lack of understanding and overlooking the signals from the child were possible barriers of a trusting relationship.

Table 5: Health care as a significant lifeline.

Theme	Sub-themes	Codes
Health care as a significant lifeline	Impact of health professionals' and the systems' support	Being understood and acknowledged Professional knowledge and competencies Knowing the health care professional- Doubting professionals Recognition of vulnerability Experiences with specialists Interventions besides medication Difficulties with medication Coordinate care Consistency of venue Lights ahead
	Conflicting or shared perspectives	Family-centered perspective Recognition of being the expert on your family Not being supported and understood Being a person and not the diagnosis Do they know about the ADHD diagnosis? Professionals' recognition of the child ADHD compromising other health care issues The unique family perspective
	Essential relationships and interactions between child, parents and professionals	Influence on the child Involving the parents Parental collaboration with professionals Child's reaction to health care appointments The father's role and perspective Professional observations Preparing for a meeting in the clinic Conversation with a child present

6.3. STUDY 3

Characteristics of the study population

A total of 521,193 children born in Denmark from 1995–2002 were followed prospectively from birth until 12 years of age. Within this cohort, 11,360 children were identified first time with a registered clinical diagnosis of ADHD in hospitals in Denmark. The sex distribution was 79% males versus 21% females, and the mean age at first time registered diagnosis was 8.5 years (Table 1 can be found in Paper IV). Baseline characteristics in children with ADHD differed from the birth cohort. They were more likely to have lower birth weight and be born preterm. They had more medical and psychiatric hospital visits than children without ADHD.

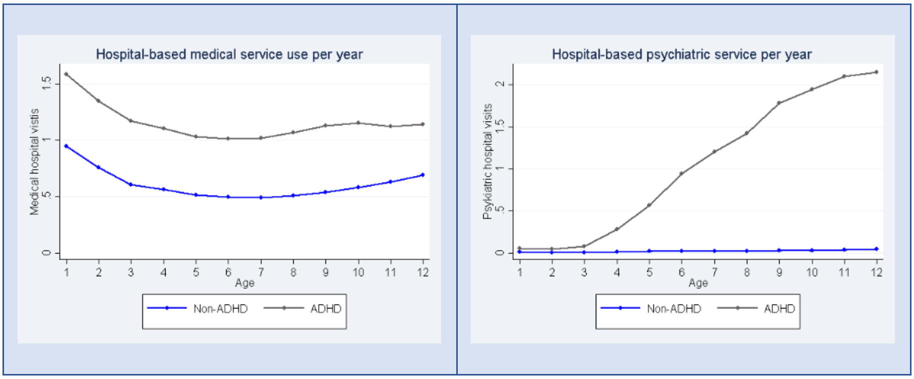
Parents of children with ADHD differed from the cohort in that maternal and paternal age tended to be lower, mothers were more likely to smoke during pregnancy, and 44.6% of parents of children with ADHD versus 26% of parents of children without ADHD were registered with a psychiatric diagnosis. In addition, the parents of children with ADHD were less likely to live together or be married and more likely to be divorced or single. Parents of children with ADHD had lower income and lower levels of education compared to children without ADHD. With respect to regional differences, more children with ADHD lived in the Capital, in region Zealand and in the Middle region of Jutland compared to Region North and Region South.

The effect of ADHD on hospital-based service use

Figure 3 shows that regardless of age during the 12 years of follow-up, children with ADHD consistently had more medical health care service use on average than did children without ADHD. Psychiatric service use was significantly higher in children with ADHD than in children without ADHD.

The results of the multivariate Poisson regression analysis showed that ADHD was associated with increased medical as well as psychiatric service use. The crude estimate of ADHD was IRR 1.80 (95% CI 1.76–1.84) for medical visits and 52.46 (95% 50.38–54.63) for psychiatric visits. Adjusting these analyses for all potential explanatory variables showed the same trends; ADHD increased medical service use with IRR 1.55 (95% CI 1.52–1.59). In addition, the adjusted analyses showed that children with ADHD attended psychiatric services almost 41 times (IRR 40.46. 95% CI (38.53–42.48)) more often than the background population.

Figure 3: Medical and psychiatric service use in children with ADHD and children without ADHD (the figure is included in paper IV)



Risk factors associated with medical and psychiatric health care use in children with ADHD

Table 6 presents an extract of table 2 in paper IV and shows adjusted analysis of the associations of explanatory variables with medical and psychiatric service use in children with ADHD.

Low birthweight and prematurity were associated with higher rates of medical health care contacts. This tendency was not seen for psychiatric service use. Children with ADHD of parents diagnosed with a psychiatric diagnosis at hospitals showed higher rates of medical and psychiatric service use than those of parents without a psychiatric diagnosis. Being divorced or single was associated with increased psychiatric service use compared to living together. For medial service use, being divorced was associated with decreased service use compared to living together.

Low or non-education in parents were associated with increased medical service use in children with ADHD compared to any higher level of education. Children of parents with a postgraduate degree had the lowest rate of medical service use. The lowest rate of both medical and psychiatric service use was revealed in children with parents with short-cycle higher educations. High parental income was associated with increased medical service use. With respect to psychiatric service use, low income was associated with decreased service use.

Table 6: Risk ratios of medical and psychiatric service use in children with ADHD

	Medical service use		**Psychiatric service use**	
Explanatory Variables	IRR adjusted	CI 95%	IRR adjusted	CI 95%
Birthweight				
< 1000g (extremely low)	1.92	(1.55-2.36)	0.85	(0.62-1.17)
< 1500g (very low)	1.64	(1.39-1.94)	0.91	(0.68-1.23)
< 2500g (low)	1.28	(1.15-1.42)	1.03	(0.90-1.17)
> 2500g (normal)	1.00		1.00	
> 4500g (high)	1.04	(0.93-1.17)	1.05	(0.94-1.18)
Gestation				
<28 weeks (extremely preterm)	1.81	(1.37-2.38)	0.70	(0.49-1.01)
< 32 weeks (very preterm)	1.55	(1.33-1.81)	1.28	(0.98-1.66)
<37 weeks (preterm)	1.19	(1.10-1.29)	1.02	(0.93-1.12)
>37 weeks (term)	1.00		1.00	
Parents' registered with a psychiatric disorder				
No	1.00		1.00	
Yes	1.12	(1.07-1.17)	1.09	(1.03-1.14)
Parents' cohabitation status				
Living together/married	1.00		1.00	
Divorced	0.92	(0.87-0.97)	1.11	(1.04-1.18)
Single since birth of child	0.97	(0.90-1.05)	1.11	(1.02-1.22)
Parents' level of education				
None	1.17	(1.06-1.29)	1.10	(0.98-1.23)
Basic school	1.11	(1.03-1.18)	0.92	(0.85-1.00)
Secondary school	0.93	(0.8-1.06)	0.97	(0.81-1.17)
Vocational education	1.00		1.00	
Short-cycle higher Education	0.89	(0.81-0.97)	0.89	(0.81-0.98)
Bachelor's degree	0.93	(0.87-0.99)	1.02	(0.95-1.10)
Postgraduate degree	0.84	(0.76-0.93)	1.00	(0.90-1-11)
Income				
≤ 300.000	1.00	(0.95-1.06)	0.91	(0.85-0.97)
>300.000	1.00		1.00	
>425.000	1.10	(1.02-1.17)	1.06	(0.98-1.14)

6.4. INTEGRATED MIXED METHODS FINDINGS

The overall aim of this PhD thesis was to integrate qualitative and quantitative data to provide new insights into the parental experiences, the complexities of everyday life, and hospital-based health care use among children with ADHD. In response to the aim, the integration of findings from Studies 1, 2, and 3 led to three mixed methods findings: 1) *Family stressors influencing everyday life and health care use,* 2*) Long-term prospects of having concerns validated*, and 3) *The importance of health care in navigating the persistent challenges of everyday life.*

The mixed methods findings were constructed based on an iterative, analytical, interpretive and selective process. The analytical process aimed to gain new insights and not to validate the qualitative findings with the quantitative findings or reverse. The fit of integration as described by Fetters and colleagues assisted the analytic and interpretive process (70). Thus, findings relevant for integration were selected through possible confirmation, expansion and discordance of the findings (70). In the following sections, the mixed methods findings are presented in narrative weaving followed by joint displays in which meta-syntheses and main themes are presented in italics and the categories and sub-themes with dots.

6.4.1. MIXED METHODS FINDING 1

Family stressors influencing everyday life and health care use

This integrated finding covers a variety of parental and family characteristics and strains that contribute to the challenges of living with a child with ADHD. Study 1 showed that the interrelationship of the parents was affected, as they tended to disagree on how to handle the child with ADHD. In addition, mothers experienced lack of support from their husbands and the extended family and conflicts between the parents were revealed. This contributed to the difficult everyday life with a child with ADHD and caused frustrations and despair. Exploring the parental experiences in Study 2 complemented that the parental relationship was burdened and suggests that it is partly explained by the strains and exhaustions from the constant concerns for the child with ADHD. Study 3 confirmed the existence of difficulties in parental relationships, as 42.6% of the parents versus 28.8% of parents without children with ADHD were divorced during follow-up. Further analysis showed that being divorced was associated with increased psychiatric service use (IRR 1.11). Thus, it is possible that once referred to psychiatric services, some single or divorced parents need more support for their child than parents who live together.

The parental characteristics shown in Study 3 suggest additional family challenges, such as low income, and that 44% of the parents had a registered psychiatric disorder. Study 1 adds that some parents gave up working or worked part time due to the advocacy role of the mothers, which may affect parental income. Furthermore, increased rates of medical and psychiatric service use were shown in children who had a parent with a registered psychiatric disorder (IRR 1.12, IRR 1.09, respectively). Yet children of parents with low income were less likely to use psychiatric health care services than those with higher income. Thus, family stressors appear to affect service use differently. This may be caused by different needs or characteristic of the individual family; for example, parents with psychiatric disorders might need increased support to manage a child with ADHD. Findings from Studies 1 and 2 complemented that mental health problems were present in the families; for example, some parents were diagnosed with ADHD and encountered difficulties concerning the child’s need for structure in everyday life and in the child-parent relationship. However, contrasting findings were also revealed in Study 2 as being a parent diagnosed with ADHD was shown to increase the parents’ understanding of the child’s behavior and needs. Despite the family stressors, they adjusted to their situations and it seemed that the parents comprised resources to be emphasized when planning treatment and care for the children and their parents.

Table 7: Joint display of mixed methods finding 1

<table>
<tr><th colspan="3"><i>Family stressors influencing everyday life and health care use</i></th></tr>
<tr><td>Study 1</td><td colspan="2"><i>An emotional roller coaster between hope and hopelessness</i>
• Disruption of family life
<i>Mothers as advocates in a battlefield within the system and family</i>
• Becoming professional parents
• Mothers as advocates
• Mothers having the overall responsibility
<i>Despite multiple challenges, it is not all bad</i>
• Contending and adapting
• It is not all bad</td></tr>
<tr><td>Study 2</td><td colspan="2"><i>When the house of cards collapses in everyday life</i>
• ADHD influencing everyday life
• Family challenges</td></tr>
<tr><td>Study 3</td><td><i>Parental characteristics (%)</i>
<table>
<tr><td>Parental psychiatric disorder</td><td>44.6%</td></tr>
<tr><td>Divorced during follow-up</td><td>42.6%</td></tr>
<tr><td>Income/year
≤ 300.000
>300.000
>425.000</td><td>
39%
39%
20.1%</td></tr>
</table></td><td><i>Predictors of health care use (IRR adjusted)</i>
<table>
<tr><td colspan="2">Psychiatric disorder</td></tr>
<tr><td>Medical service use</td><td>1.12</td></tr>
<tr><td>Psychiatric service use</td><td>1.09</td></tr>
<tr><td colspan="2">Divorced</td></tr>
<tr><td>Medical service use</td><td>0.92</td></tr>
<tr><td>Psychiatric service use</td><td>1.11</td></tr>
<tr><td colspan="2">Income</td></tr>
<tr><td>Medical service use</td><td>≤ 300.000: 1.00
>300.000: 1.00
>425.000: 1.10</td></tr>
<tr><td>Psychiatric service use</td><td>≤ 300.000: 0.91
>300.000: 1.00
>425.000: 1.06</td></tr>
</table></td></tr>
</table>

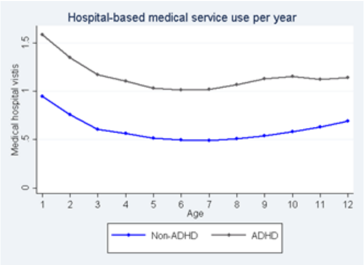
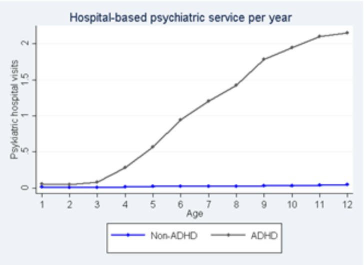
6.4.2. MIXED METHODS FINDING 2

Long term prospects of having concerns validated

This integrated finding covers the influence of ADHD on everyday life and service use prior to the child is diagnosed with ADHD. Study 2 showed that everyday life was difficult for a long period prior to the diagnosis as the parents were concerned and searched for help from numerous professionals. They described “treading water” as their concerns were sometimes dismissed. Study 3 expanded this understanding as trends in health care use prior to the diagnosis showed that children subsequently diagnosed with ADHD attended medical and psychiatric services in hospitals more frequently than children without ADHD. From Study 3, it is not possible to conclude that children with ADHD attend hospital services more frequently due to parental concerns or due to other health-related impairments. However, it may be that the parents even prior to the diagnosis were strained with an increased awareness of the child´s difficulties and health. Findings of Study 2 further revealed that the parents referred negatively to the time passed before their concerns were validated. They encountered diverse professionals who were not supportive of the parents’ concerns, which contributed to feelings of frustration and insecurity. The parents commonly felt left alone to deal with the everyday challenges and difficulties caused by the child later diagnosed with ADHD.

Study 3 showed that the needed support for the parents and their family may have long prospects as the mean age at time of diagnosis was 8.5 years in the child cohort studied. This suggests that the everyday lives of families with ADHD could have been impacted for several years before the diagnosis and support was provided. This seemed to burden the families. The syntheses of Study 1 revealed contradicting parental perceptions of receiving their child’s ADHD diagnosis. Some parents experienced relief about the diagnosis because it replaced their guilt and self-blame. For others, it was a short-term relief, as the diagnosis could be associated with beliefs of poor parenting. The findings of Study 2 complemented the experiences of being relieved when the diagnosis was provided, yet the findings add that relief was connected to meeting health care professionals who recognized the parents’ concerns and the symptoms of the child. Thus, parental concerns and early recognition of the symptoms of the child appears to be important for the parents when encountering a variety of health care services and professionals prior to the ADHD diagnosis.

Table 8: Joint display of mixed methods finding 2

<table>
<tr><th colspan="3"><i>Long prospects of having concerns validated</i></th></tr>
<tr><td>Study 1</td><td colspan="2"><i>Parental experiences in a crossfire of blame, self-blame and stigmatization</i>
• The significance of the ADHD diagnosis</td></tr>
<tr><td>Study 2</td><td colspan="2"><i>Treading water before and after the “ADHD bomb”</i>
• Drifting alone in health care and supporting systems
• Wasting time
• The meaning of getting the diagnosis</td></tr>
<tr><td>Study 3</td><td><i>Medical service use</i>
 </td><td><i>Psychiatric service use</i>
 </td></tr>
</table>

6.4.3. MIXED METHODS FINDING 3

The importance of health care in navigating the persistent challenges of everyday life
This integrated finding shows the importance of health care and health care professionals in managing the persistent challenges in everyday life. Study 3 sustained that ADHD independently affected hospital-based health care use and that children with ADHD use services more frequently than children without ADHD (IRR for medical service use: 1.55, IRR for psychiatric service use: 40.46). Thus, many families of children with ADHD encountered diverse health care professionals and settings as a part of everyday life. Study 2 added parental experiences to this knowledge by showing that parents depended on help and support to overcome the disruptive phases of everyday life and that health care was one of the elements in the variety of systems they rely on; for example, they described having back-up from their regular clinic when things were difficult at home. However, contrasting experiences were revealed. Study 1 showed that the parents met both supportive and non-supportive professionals. Study 2 expanded the understanding of feeling supported and displayed health care as a significant lifeline; for example, professionals and

services, who were accessible, cared for their entire family situation, considered their individual needs and provided knowledge on how to handle the situation at home were perceived to be supportive. Not being supported related to services or professionals who lacked understanding, information and knowledge of ADHD.

The effect of ADHD on both medical and psychiatric service use insinuates that the families attended hospital services because of the child's ADHD diagnosis but also because of co-existing problems. Regardless of the reason for referral, Studies 1 and 2 showed that ADHD impacted all aspects of everyday life and this needed to be acknowledged in every specialty in hospitals. The visits in health care influenced everyday life positively if health care professionals, unrelatedly of medical or psychiatric specialty, were capable of considering both medical and psychiatric issues in care and treatment plans and at the same time recognize how ADHD affected the whole family and everyday life. In contrast, the parents occasionally encountered difficulties in health care because of conflicting perspectives; for example, the parents came across professionals, who performed task-oriented care. The synthesized findings of Study 1 showed that having a child with ADHD required advocacy skills of the mothers and that they took on the role of coordinating between numerous professionals. This was confirmed by findings of Study 2 showing that the parents persistently fought for appropriate support for the child in health care and other settings and that health care professionals became allies in this fight.

Table 9: Joint display of mixed methods finding 3

<table>
<tr><th colspan="2"><i>The importance of health care in navigating the persistent challenges of everyday life</i></th></tr>
<tr><td>Study 1</td><td><i>Shuttling between supportive and non-supportive services and professionals</i>
• A need for more information and interventions
• Fighting for support in a variety of systems
• Parental collaboration with health care professionals and teachers
<i>An emotional roller coaster between hope and hopelessness</i>
• Disruption of family life
• Emotional burdens
<i>Mothers as advocates in a battlefield within the system and the family</i>
• Becoming professional parents – mother as advocates</td></tr>
<tr><td>Study 2</td><td><i>When the house of cards collapses</i>
• ADHD influencing everyday life
<i>Health care as a significant lifeline</i>
• Impact of health professionals' and the systems' support
• Conflicting or shared perspectives
• Essential relationships and interactions between child, parents and professionals
<i>Treading water before and after "The ADHD Bomb"</i>
• Drifting alone in health care and supporting systems
• Wasting time</td></tr>
<tr><td>Study 3</td><td><i>The adjusted effect of ADHD on medical and psychiatric service use</i><table><tr><td>Medical service use</td><td>IRR 1.55</td></tr><tr><td>Psychiatric service use</td><td>IRR 40.46</td></tr></table></td></tr>
</table>

CHAPTER 7. DISCUSSION

In this section, the integrated mixed methods findings are discussed with extended literature. This is followed by a methodological discussion, including a discussion of the mixed methods methodology and a discussion of the research process, methodology and methods of Studies 1, 2, and 3.

7.1. DISCUSSION OF THE MIXED METHODS FINDINGS

In response to providing new insights on the parental experiences, the complexities of everyday life, and hospital-based health care among children with ADHD, the findings encapsulate a vulnerable everyday life and point to the importance being met with acceptance and respect in hospital-based health care services from early childhood. The thesis reveals the effect of ADHD on health care use as well as potential risk factors of medical and psychiatric service use during the first 12 years of life in children with ADHD.

Family stressors influencing everyday life and health care use

The findings showed that the parental relationship was challenged by incompatible views of how to manage the child with ADHD and that the parents were more likely to be divorced than parents of children without ADHD. This is supported by previous studies reporting challenged interrelationships of the parents and low levels of marital quality (11,124). The interrelationship of the parents is likely to affect the child with ADHD and the rest of the family and it has been shown that a positive familial relationship may improve or enhance how the child benefits from care and treatment plans (125). In addition, Lingineni et al. found that children were less likely to have ADHD when living in two-parent families (126). Therefore, it may be important that health care professionals consider and address possible difficulties in the parental relationships to enhance the agreement between parents on how to manage and support the child with ADHD.

The difficulties in the parental relationship may relate to the strains on the parents as the findings showed that the parents felt burdened by the overwhelming responsibility for the child with ADHD. This left the parents with little time and resources to focus on their relationship as a couple. In line herewith, studies highlight that the families are burdened and strained by the challenges of having a child with ADHD (10,11,40). Furthermore, parental strain and parental stress are likely to be associated, and a meta-analysis reports that parents of children with ADHD experience higher levels of stress than parents of typically developed children (10,11,127). It is also important to notice that some conflicts, dysfunction, stress and strain may be pre-existing in the families which has been shown to be associated with increased risk of ADHD in children (47,128). Yet, this still calls for health care professionals of every specialty engaging with the families to understand the strains of the individual family. The strains may influence how they can manage care plans and their everyday lives. In contrast to the described burdens and strains, some families state that that they have close bonds and support each other (43). Furthermore, the parents over time adjusted to their situation and this thesis showed that parents regained hope for the future.

Hinojosa et al. found that mental health in the mothers was related to parental strain (129). In the present study, we found that 44.6% of the parents had a hospital registered psychiatric diagnosis. This percentage is likely to be underestimated, as parents who exclusively visited their GP's or the private health care sector with mental difficulties were not included. Yet, the findings support that mental health status of the parents may contribute to parental strain and it may provide difficulties with structure and the parent-child relationship. A study reports that when ADHD persists in parenthood, there is an increased risk of family conflict and negative parent-child interactions (5), meanwhile this thesis adds, that some parents with ADHD perceived it to be an advantage as they recognized the symptoms and needs of the child.

The presence of parental hospital registered mental illness was shown to increase rates of service use in medical and psychiatric hospitals in children with ADHD. Another study identified that mothers who had mental conditions were more likely to have children with ADHD and that they were more likely to seek help for their child in for instance mental health services or at the GP (50). It is likely that such families need extended support and it is suggested that health care professionals should remember to care for caregivers (130). In addition, it is important that health care professionals include the parental resources and consider ways of enhancing the families' resilient abilities to adapt or rebound in crisis (131,132). This thesis further found lower levels of education and income in families of children with ADHD compared to those without ADHD. This could suggest increased strain and low resources, and as reported by Russel et al., financial difficulties in parents are strong predictors of ADHD (6). However, complexities in health care use was revealed as high family income was associated with increased medical service use and low income was related to decreased psychiatric service use. Thus, the need of support in healthcare seems to vary within the individual family. Further, low income may be affected by several factors such as one parent working less because of the child´s ADHD, which is complemented by Flood et al (137). It may be difficult to completely characterize and identify families with increased healthcare needs. Previous studies also report an association between ADHD and increased visits at the GP, specialists and educational specialists among others (28,30,133), which stress the importance of the role of other systems to identify concerned families who need support.

Long prospects of having concerns validated

This thesis reveals increased medical service use in the first 12 years of life in children with ADHD, which indicates increased medical problems or parental awareness of the child´s difficulties from early childhood. Previous research complements that parents of children with ADHD are concerned before the child is diagnosed with ADHD and that ADHD symptoms may be present as early as 3 years of age (19,134-136). Parental concerns have been found to be important in detecting children at risk of developing ADHD and other developmental disorders (19,134-136). According to a study by Lemcke et al., the deviations in the first year of life that are associated with ADHD later in life are related to regulation of temperament and breastfeeding (19). Deviations in the child's second year can be described by impairments in relation to attention, impulsivity and activity (19). Identifying children at risk of ADHD was not the focus of this thesis, yet the findings complement previous research showing that everyday life of families of children with ADHD is impacted from very early childhood (5,32).

Some parents experience being dismissed when they seek professional assistance with their concerns for the child. To calm the parents, the professionals may dismiss parental worries, yet the findings showed that the parents felt left alone with their worries and question their own parenting competencies. In line herewith, studies show that some mothers are strained with taking care of their child already in early childhood and that support should be supplied as early as possible (19,137,138). This underlines the importance of recognizing the individual family's challenges when they attend health care settings. This study exclusively included hospital-based services, and it is acknowledged that this is just one element in the systems that the parents rely on support from. Previous studies suggest that a range of systems are integral to support the families and that it is important for these systems to collaborate, among those the GP, teachers and social systems are important (27,50,62,133,139).

With respect to support for the parents and the child with ADHD, parenting training programs have received great attention (138,140). Programmes comprising psychosocial interventions aiming at enabling parents to manage their children's challenging behavior may be beneficial for parents of children with ADHD (138,140). It is plausible that appropriate and early support considering the challenges of the individual family and child may both improve the children's development and potentially reduce parental stress and improve the families' well-being (138,140).

The importance of health care in navigating the persistent challenges of everyday life

As part of managing the persistent challenges of everyday life, the parents rely on support and back-up from health care professionals. Other studies complement this finding and add that teachers, specialists, public health nurses among others are equally important in care and treatment for the families (30,58,141). Yet, the parents rely on health care professionals from their regular clinic to help them navigate between the systems and secure consistency in care and treatment. It appears to be important that health care professionals acknowledge and support the advocacy skills of the parents (47). According to the findings of this thesis, support from health care professionals must build on respect for the entire family and acceptance of how ADHD affects every aspect of everyday life. A study by Moen and colleagues complements this finding showing that when one individual of a family is impaired, the whole family is impaired (43). Therefore, care and treatment should consider the whole family, including siblings and significant others apart from the child and the parents (43,47,142).

This thesis mainly focused on parental experiences, yet it might have been beneficial to perceive the whole family as a unit (43,47,142). Although, the focus was on the parents, it is possible to draw parallels to family-centered care (124,142,143). Family-centered care has been considered the standard care in numerous pediatric hospitals and is perceived to contribute to meeting the families' needs in health care (124,142,143). The concept of family-centered care is closely related to patient-centered care, and involves principles including information sharing, partnering, respect, collaboration, and negotiation (124,142,143). The present study demonstrated that families of children with ADHD meet health care services and health care providers who acknowledge and perform elements of family-centered care as they respectfully considered and recognized the individual families' challenges and needs. Meanwhile, parental experiences of lack of support in health care encounters were also revealed. This may be caused by various factors, yet in this study, the relationship with the health care professionals was consistently perceived essential for the parents' positive or negative experiences. These experiences are also reflected in previous studies and a systematic review stresses that nurses should be aware of their behaviors and attitudes as they not always align with the patient's values of the relationship (144). This is also in line with the core elements of Fundamentals of Care as described by Kitson et al. (145,146). To comply with Fundamentals of Care, it is essential for nurses to establish a trusting relationship (145,146). It is reported that a positive relationship increases the likelihood of the patients, or in this case, the family's fundamental needs being met appropriately (145,146).

The thesis shows that some children with ADHD possibly attend hospitals for both medical and psychiatric reasons and that some children enter hospitals frequently. This may be a strain for the parents as they need to coordinate between health care and other systems (53). Yet, the parents also looked forward to the health care meetings, as they were perceived essential lifelines regarding the difficulties of having a child with ADHD. Some of the health care visits are short and irregular and take place across medical and psychiatric services. This may challenge the relationship with professionals and be a barrier to receiving family-centered care as context and environment have been shown to influence the relationship (144).The parents occasionally encountered health care professionals who focused on the task instead of customizing care and treatment for the individual family, which also challenged the relationship with professionals.

7.2. METHODOLOGICAL CONSIDERATIONS

In this section, methodological considerations are discussed. In mixed methods research, considerations of the strengths and limitations of the integrative approach as well as the strengths and limitations of each single methods used should be made (76). Therefore, the mixed-methods approach and the methods of Studies 1, 2, and 3 are discussed, including various aspects of validity, reliability and credibility related to each research tradition (147-150).

7.2.1. MIXED METHODS

The methodology of this study was mixed methods, and a multistage mixed-methods framework with a core convergent design was applied (70-72). Three integrated mixed methods findings led to new insights on the parental experiences, the complexities of everyday life, and hospital-based health care among children with ADHD. The investigation of parental experiences and health care use necessitated that qualitative and quantitative data were treated as complementary. From a pragmatic point of view, research is concerned with meeting the goals that are framed in terms of research questions and as such, the investigation in this PhD thesis profited from a mixed methods methodology with pragmatism as the underlying philosophical assumption (73,75,77,78). However, the mixed methods methodology also presents limitations that need consideration.

An important point of discussion is the argument that it is difficult to carry out both qualitative and quantitative research in one single study and still acknowledge the diversities and enhance rigor of each tradition (72,78,151). There is a risk that the comprehensive aim of this mixed methods study may be to the detriment of a deeper understanding and exploration of each study or methods (72,78,151). Therefore, mixed methods studies are suggested to be undertaken in research groups to involve various research competencies (72,73). To acknowledge this potential disadvantage of mixed methods research, the supervisors of this PhD comprised diverse competencies with respect to qualitative, quantitative and mixed methods. Additional assistance was sought when needed, such as with respect to statistical analysis. Furthermore, in mixed methods, efforts should be made to acknowledge each research tradition (72,78,151). Thus, this research was conducted in three stages which included three studies. The results of each study are reported in individual papers, which promoted the opportunity to achieve and fulfill the requirements of each research tradition. Meanwhile, the researcher acknowledges that it is a challenge to completely cover the depth of each tradition when conducting mixed methods research.

It has been underlined that integration is the hallmark of mixed methods research and that it enhances the value of mixed methods studies (70). Yet, it has been evidenced that mixed methods studies frequently lack or pose difficulties with integration (70,150). In this thesis, integration was sought at the design level, at the methods level, and at the interpretation and reporting level to ensure the link between the studies. At the design level, a multistage framework with a core convergent design was found applicable as it consisted of more than two studies that were either sequential or convergent (72,73). This design was modified several times during the 3 years of this PhD study and represent an iterative process involving adjustments throughout the process. At the methods level, Study 1 linked to Study 2 through building. Although, building is not traditionally used between two qualitative studies in the mixed methods approach by Creswell (72,73), this was perceived beneficial for the design, aim and data collection of Study 2. To exemplify, the findings of Study 2 both complemented findings of Study 1 and provided enhanced knowledge on the everyday life and health care experiences of parents with children with ADHD.

At the interpretation and reporting level, the findings were initially reported in stages. Despite the advantage of accounting for the tradition of each research tradition, this also initiated challenges with respect to integrating the findings. Reporting the findings in individual papers necessitated that only selected and condensed findings were reported due to word counts in the papers, thus, the number of findings available for integration in this thesis was reduced. Potentially, this may exclude relevant nuances of findings that would have further induced new insights on the aim of this thesis. The process of integrating the findings of Studies 1, 2, and 3 was assisted by narrative weaving and joint displays as suggested by Fetters et al. (70). Joint displays are evolving as beneficial visual displays of integrating findings, and in this thesis, they provided structure and visualized the narrative weaving process (81). The aim of this thesis was not to validate findings of Studies 1, 2, and 3 but to provide new insights. To clarify the profit of the integration of findings, the process was undertaken by assessing the coherence of the findings through “fit” of integration (70). This process assisted the development of mixed methods findings as the three possible outcomes of confirmation, expansion or discordance were assessed and explained in the narrative weaving of the integrated findings.

7.2.2. STUDY 1

The systematic review sought to synthesize the best available evidence regarding parental experiences of living with a child with ADHD and their experiences of ADHD health care and other services. The main strength of this study was the systematic approach that was obtained by following the JBI guidelines (82,84). The process was assisted by the JBI software and standardized tools, which led to an extensive audit trail. The audit trail is published in Paper I, and it supported the important transparency of the study process (82,84). Two reviewers were involved in each step of the meta-synthesis, which further ensured rigor and validity of the process (82). Another strength is that the systematic review was based on an approved and peer-reviewed systematic review protocol to confirm thoroughness and minimize potential bias (82,84).

One important point of discussion is the challenge to capture all relevant studies in the literature search. As suggested by JBI, the search for literature was extensive and broad and assisted by a research librarian (82). Efforts were made to capture all relevant studies, nonetheless, this is most likely not possible (82,152). Further to this limitation is that in the process of screening and assessing more than 4000 articles, relevant articles may have been overlooked. Thereby, nuances may have been missed.

Munn and colleagues stress the importance of establishing confidence in the synthesized qualitative research findings by accessing the dependability and credibility of the primary authors’ findings (153). Dependability is aligned with reliability and can be achieved by critical appraisal of the studies included in the review (153). The reviewers independently assessed the quality of each study using the critically appraisal instruments in the JBI Manual (82). Overall, the reviewers found the studies to be of high quality, which support the reliability of the conducted meta-synthesis. Further, the credibility of the findings was assessed based on a ranking scale as suggested by JBI (82,153). The reviewers concluded that the findings of the primary authors were also of high quality as they were supported by credible illustrations or citations in the text (82) .

Another point of discussions is that the included studies in the review had different aims and they used a diversity of qualitative methodologies and methods. It has been discussed whether it is possible to synthesize findings developed within various qualitative research traditions (82,152,154,155). However, the JBI meta-synthesis adheres to a meta-aggregative approach, which is sensitive to the practicality and usability of the primary author's findings and does not seek to re-interpret the findings (82). This allows for different methodologies to be included and to aggregate findings into a combined whole that is more than the sum of parts. As such, the JBI approach seeks to enable generalizable statements (82). The majority of the meta-syntheses in Study 1 were complemented by the findings of Study 2, which points to some degree of generalizability.

7.2.3. STUDY 2

Conducting a focused ethnographic study with short-term field observations and interviews with 15 families of children with ADHD contributed to a deeper and more nuanced understanding of parental experiences in medical and psychiatric health care settings. The main strength of this study relates to the use of an ethnographic approach enabling explorations and descriptions of parental experiences in various settings in medical and psychiatric hospitals. Nevertheless, conducting a focused ethnography also poses some limitations.

Focused ethnographies have been criticized for being superficial when compared to traditional ethnographic or anthropological studies (102). It is important to notice that the purpose of Study 2 was not to holistically view the entire culture in medical and psychiatric settings as within traditional ethnographic and anthropological studies (102,103,108). Study 2 was restricted to a pre-selected aim and certain contexts, which is complimentary to the methodology of focused ethnography (102-105). The selection of aim and context in Study 2 was based on background knowledge from the conducted meta-synthesis. This is in line with the notion of focused ethnographies as background knowledge is important for selecting the aim and performing participant observations in a specific context (102-105).

An important point of discussion is that by being focused, the researcher may not open-minded towards new insights in the issue under investigation (102-105). However, the meta-synthesis did not reveal any details about the parents' experiences of health care meetings in medical and psychiatric hospital services, which opened for curiosity and continuous reflections. The researcher was aware that she used herself as a tool and that this may affect the generalizability of the findings (103,149). The researcher's role as an outsider or insider has been widely discussed and controversies exist in the literature (102,108). However, recognition of the researcher's pre-understanding is essential with respect to the reflexivity and thereby validity of the study (104,108). Being a registered nurse with experiences from clinical practice, a parent and having conducted a meta-synthesis in the area of interest constituted the researcher's pre-understanding during the participant observations and the interviews. Nevertheless, the health care meetings did not take place within her specialty and complete active participation was not possible. Thus, the researcher was both an insider with regards to being a nurse and an outsider in the area of caring for children with ADHD (108). An attempt was made to find a balance between engaging in the situations without losing the objectivity as suggested by Roper and Shapira (103). As an experienced nurse, the researcher may easily have understood the activities and interactions in the meetings, yet the researcher attempted to ask naïve questions in terms of not missing important aspects of the activities and behaviors being observed (108).

Another area for discussion relates to the sampling procedures and data collection of this study. Firstly, a combination of purposeful, convenient and maximum variation sampling procedures was used to seek unique, rich and various perspectives of the participants (80). Despite the effort to capture various experiences, this study suggests that contextual factors could be important considering parental experiences. Thus, it is possible that the findings cannot be generalized to the experiences of parents in different departments or hospitals. In addition, it can be questioned whether it is possible to collapse data from both general paediatric and psychiatric settings in one analysis of data as the focus and tasks of care and treatment may differ across the specialties. However, the intent of this study was not to compare one setting to another but to explore the experiences regardless of specialty. Secondly, the interview strategies represent both individual and dyadic interviews. This may include advantages as well as disadvantages; the interaction between the participants in dyadic interviews brings forth supplementary nuances whereas individual interviews add depth to the participant´s experiences (109,110).

With respect to the credibility of the findings of Study 2, it has been suggested to invite the participants to check the interpretations of data (149). This was not preferred in this study. Instead, the credibility of the findings was addressed during continuous discussions of the interpretations in the supervisor team and with fellow researchers. In addition, the informal and formal interviews contributed to validation of the participant observations and the participants' perspectives were continually summarized in the formal interviews leaving them a chance to elaborate or eliminate misunderstandings.

7.2.4. STUDY 3

Study 3 was designed as a population-based historical cohort study using data from nationwide Danish registers. The main strength of the study was the large sample size as it included the entire Danish Birth cohort of children born in 1995–2002. Within this cohort, we identified the entire cohort of children with ADHD who were in DPNR and DPCRR in this period. This enhanced the generalizability of the findings. In addition, an important strength is that the follow-up time began when the child was born and included a total of 12 years. The large sample size and long follow-up time are both likely to strengthen the representativeness of the population and minimize potential selection bias (156-158). Another strength is that information on potential explanatory variables were available for the entire birth cohort (156). Thus, we could adjust for a comprehensive set of explanatory variables, which may reduce the risk of potential confounders influencing the findings. Yet, the results revealed contradictory associations of explanatory variables and medical and psychiatric service use, which suggests that studying associations with services use in children with ADHD is complex and that additional variables may be worth considering. Another limitation is that DNPR and DPCRR include information about diagnoses given at public hospitals, which mean that service use for patients diagnosed by private psychiatrists or other specialists was not the focus of this study (156-158).

Register data may have higher validity than self-reported data as recall bias are avoided (156). In addition, the completeness of data, which is related to whether all individuals are included in the register minimizes potential selection bias and previous validation studies show high validity of the Danish national registers (156). With respect to the ADHD diagnosis in this study, a validation study of children diagnosed age 4 to 15 years during 1995 and 2005 concludes that the risk of misclassification of diagnoses of Hyperkinetic Disorder in the DPCRR is relatively low (159). However, the information available in the registers is not collected for research purposes meaning that researchers are limited to use definitions from administrative practices, and variation in coding practices is a potential limitation for all register-based studies (156-158). Further, the codes can change over time (156). In addition, missing data pose a possible limitation as registry data sometimes lack important information (156). An example is that missing information in the Danish Medical Birth Register was identified. There is a risk that missing data may under- or overestimate the results (156). The amount of missing data in this study was relatively small and did not inflate the results significantly.

CHAPTER 8. CONCLUSION

This PhD thesis aimed to integrate qualitative and quantitative data to provide new insights into the parental experiences, the complexities of everyday life, and hospital-based health care use among children with ADHD. Based on the findings from the meta-synthesis, the focused ethnographic study, the cohort study, and the integrated mixed methods findings, it is concluded that:

- Having a child with ADHD affects the whole family. Parents are burdened with the responsibility of the child. Parental experiences of living with a child with ADHD are complex and include experiences of guilt, hope, blame, stigmatization, exhaustion, and reconciliation.

- The everyday lives of families of children with ADHD are vulnerable, and the house of cards easily collapses, as ADHD pervades all aspects of everyday life. The parents depend on support from medical and psychiatric hospital-based health care services to manage everyday life.

- Accessibility to health care services and trusting relationships with health care professionals, who recognize the impact of ADHD on families and everyday life, are important. These resources provide a lifeline for parents to manage the complex challenges of everyday life. The variability in the health care settings may create difficulties in coordinating care and in the relationships between the parents and health care professionals.

- Children with ADHD use significantly more medical and psychiatric services in hospitals than children without ADHD. ADHD influences the amount of medical and psychiatric hospital-based service use in the first 12 years of life, also when adjusting for a comprehensive set of explanatory variables.

- Family stressors, such as a psychiatric disorder in a parent or conflicts between parents, contribute to the challenges of having a child with ADHD. The families may need extended support, yet they have their own resources that must be acknowledged in health care plans.

- During the first 12 years of life, parents often sense that something is wrong with their child, and they seek assistance to have their concerns validated. These concerns are frequently dismissed, which leads to parental frustrations.

- Parents rely on health care professionals to help them navigate the persistent challenges of everyday life. Although hospital-based health care is just one source of support for families, health care professionals in hospitals are important for the families to influence or coordinate between social and educational systems and to manage both ADHD and co-existing problems in everyday life.

In short, this PhD thesis shows that ADHD pervades everyday life and that children with ADHD use more medical and psychiatric services in hospitals during the first 12 years of life than children without ADHD. The findings encapsulate a vulnerable everyday life and point to the importance of the families being met with recognition, acceptance, and respect in hospital-based health care services from early childhood. It is important for health care professionals, regardless of specialty, to engage with individual families and to contribute to consistency of the health care experience.

CHAPTER 9. PERSPECTIVES AND IMPLICATIONS

In this section, perspectives on future research and implications for clinical practice are presented.

9.1. FUTURE RESEARCH

This thesis underlines the complexity of health care use in children with ADHD and the complexities of being a parent of a child with ADHD. Often, the parents need lifelines in health care services and among health care professionals to manage everyday life.

Conducting Studies 1 and 2 from the perspectives of the parents may have inhibited a full understanding of the culture of inquiry. For instance, the children with ADHD and the health care professionals' perspectives were not included in the systematic review or in the focused ethnographic study. Siblings and significant others in the family of a child with ADHD may also be burdened by the challenges in everyday life, which is complemented by other studies (38,43,47). Considering these limitations, further research should include additional perspectives, such as the perspectives of other family members, the child with ADHD, and health care professionals. Such research should pertain a family-focused perspective and involve participant observations, individual interviews and family interviews to enhance the understanding of how to support the whole family of a child with ADHD, and to identify the challenges in providing supportive care for the families of children with ADHD.

Furthermore, this thesis focused on hospital-based health care. This is just one element in the systems that the families of children with ADHD rely on. There is a need for studying the use of other health care services, such as the GP, who is likely to be among the first to meet the children and the parents. It is relevant to examine service use at the GP in other studies to identify trends in service use outside the hospitals. Studies show that the GP´s feel incompetent with respect to ADHD, thus, it would be valuable to examine health care use in combination with the families' perspectives in a future mixed methods study.

This thesis showed that the parents are concerned about the symptoms seen in their child before the diagnosis is applied. In this period, they appear to fight for support and use more hospital-based health care services than children without ADHD. It is of great importance to further investigate the concerns of the parents to inform health care professionals of what to be aware of and how to supply early support for the parents and the family. Firstly, it is relevant to examine early parental concerns in a systematic review, which could initiate interviews and surveys.

The parental experiences of being acknowledged and supported depend on the relationship with health care professionals. Thus, it would be of interest to further explore the enablers and barriers of the parent-professionals relationship in diverse specialties. Fundamentals of Care could be a relevant framework for such an investigation (145,146). Furthermore, future interventions in health care services are requested to enhance knowledge among health care professionals on how ADHD affects everyday life and how to facilitate a positive relationship with the parents of children with ADHD.

9.2. IMPLICATIONS FOR CLINICAL PRACTICE

Children with ADHD are more frequently in contact with medical and psychiatric hospital services than children without ADHD and the parents perceive health care to be a lifeline in a disruptive everyday life. Yet the findings of this thesis also show that the families of children with ADHD are burdened and that some health care professionals lack understanding of how ADHD pervades all aspects of everyday life. Therefore, it is important for health care professionals:

- To recognize the strains of the families of the child with ADHD and to acknowledge that ADHD pervades all aspects of everyday life and all other health care issues.
- To meet the child with ADHD and the parents with respect and facilitate a positive relationship by addressing how the child´s ADHD can be taking into considerations in (other) health care plans. This includes involving the parents and acknowledge that they are the most important experts on their child’s difficulties.
- 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 health care.
- To recognize that early ADHD symptoms of the child are of great concern for the parents. To acknowledge these concerns and consider ways of establishing support for the families.
- To enhance professional knowledge of ADHD and the impact on family life. Consultancy and interventions should be provided for health care

professionals who feel inadequately prepared to engage with families of children with ADHD. This involves developing services with multiple competencies, such as establishing multidisciplinary teams with competencies across medical and psychiatric care and treatment.

- To improve communication with other health care settings and other systems, such as schools, social systems, and GPs, and help parents communicate within and between various systems.
- To be aware that the parents need allies in health care to understand and translate the language in and between various systems. This includes supporting and respecting the advocacy skills of the parents.
- To acknowledge that regardless of specialty, the health care professionals play an important role in contributing to consistency in health care issues of the child with ADHD. This includes professionals taking on the responsibility for their particular role in the care pathway.

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APPENDICES

A: Search strategy

B: Interview guide

C: Participant information

D: Informed consent

APPENDIX A. SEARCH STRATEGY

The search strategy was separated in four facets:

- Family/parents
- Child/adolescence
- ADHD
- Experiences

The literature search was customized for each database using both controlled thesaurus terms and natural language terms for synonyms. Below is an example of the search conducted in CINAHL.

CINAHL:
1. (MH "Family+") OR (MH "Parents+") OR (MH "Caregivers") OR (MH "Family Attitudes+")
2. family OR families OR parent* OR father* OR mother* OR caregiver* OR relative*
3. 1 OR 2
4. (MH "Child+") OR (MH”Adolescence+”)
5. child* OR adolescen* OR teenager*
6. 4 or 5
7. (MH "Attention Deficit Hyperactivity Disorder")
8. attention deficit* OR adhd
9. 7 OR 8
10. MH "Life Change Events+") OR (MH "Life Experiences+")
11. (MH "Attitude to Illness+") OR (MH "Attitude to Mental Illness") OR (MH "Attitude to Life")
12. (MH "Psychosocial Aspects of Illness+") OR (MH "Adaptation, Psychological+") OR (MH "Coping+") OR (MH "Attitude to Health+")
13. psychosocial factor* OR perception* OR perspective* OR experience* OR attitude*
14. 10 OR 11 OR 12 OR 13
15. 3 AND 6 AND 9 AND 1

APPENDIX B. INTERVIEW GUIDE

To explore the overall aim of study, a semi-structured interview guide was constructed. The guide was structured by the three research question of study 2.

Semi-structured interview guide

Indledende spørgsmål:

Jeg vil gerne starte med at spørge, om du/I vil fortælle lidt om jeres familie og jeres hverdagsliv.

- Hvem består jeres familie af?

Kan du/I fortælle lidt om dit barns møder i hospitalsvæsnet

- F.eks. hvor og hvor ofte? Psykiatri/pædiatri eller begge?
- Hvad handler møderne på hospitalet om?
- Hvordan er sammenhængen mellem kontakterne på hospitalet? Eller mellem de øvrige kontakter i skole og andre systemer?

Research question 1: How do parents of children with ADHD experience collaboration with healthcare services and healthcare professionals?

Hvad har betydning for dig/jer i samarbejdet med sundhedsprofessionelle?

- Hvordan oplevede du/I det møde, som undertegnede var med til? Herefter uddybende spørgsmål i forhold til deltager observationer.

Jeg vil gerne bede dig/jer fortælle om jeres første møde med hospitalsvæsenet i forbindelse med dit/jeres barns ADHD?

- Hvor var det (pædiatri eller psykiatri?), hvorfor var du/I der, hvad oplevede du/I, hvilke følelser var forbundet med mødet?

Jeg vil gerne høre om jeres sidste kontakt på hospitalet

- I hvilken anledning var du/I der, hvordan var det at være der?

Hvordan oplever du/I samarbejdet med sundhedsprofessionelle?

- Hvad har betydning for dig/jer i samarbejdet med sundhedsprofessionelle?
- Hvordan oplever du/I relationen med de sundhedsprofessionelle

Research question 2: How do parents of children with ADHD feel supported in everyday life?

Vil du/I fortælle om, hvordan det er at have et barn med ADHD?

- Kan du/I prøve at beskrive hvordan jeres hverdag ser ud - gerne et eksempel?
- Hvem henvender du/I jer til når I har brug for vejledning eller støtte i hverdagen?
- Hvordan oplever du/I, at den pleje og behandling, der gives på hospitalet støtter/støtter ikke i jeres hverdagsliv? Eksempler?

Research question 3: How do parents of children with ADHD perceive barriers and enablers in healthcare?

Hvad er vigtigt for jer som familie, når I kommer på hospitalet?

- Hvad har betydning for, om det er en god eller dårlig oplevelse? Eksempler fra psykiatri/pædiatri?
- Har du/I nogle forventninger til samarbejdet?
- Kan du/I komme I tanke om nogle specifikke eksempler på, hvornår forventninger blev indfriet/ikke indfriet?

APPENDIX C. PARTICIPANT INFORMATION

Information om deltagelse i forskningsprojekt

Børn med ADHD

Forældres oplevelser af deres børns forløb i hospitalsvæsenet

Projektansvarlig
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AALBORG UNIVERSITETSHOSPITAL
AALBORG UNIVERSITET
REGION NORDJYLLAND

Deltagerinformation

Jeg henvender mig til dig, idet du er forælder til et barn med ADHD i alderen 5-12 år. Jeg vil spørge, om du har lyst til at indgå i en undersøgelse af, hvordan forældre til børn med ADHD oplever deres barns forløb forskellige steder i hospitalsvæsenet.

Formål med projektet

Projektet er en del af et ph.d. projekt, der har til hensigt at undersøge forældres oplevelse af at leve med et barn med ADHD og deres oplevelse af den pleje og behandling, der foregår på børneafdeling samt på børne- og ungdomspsykiatrisk afdeling. Projektet forventes at bibringe viden om, hvordan der i hospitalsvæsenet kan ydes bedst mulig støtte og hjælp til familier, der har børn med ADHD.

Hvad kræver det af dig?

Som projektansvarlig sygeplejerske vil jeg gerne møde forældre til børn med ADHD forskellige steder i hospitalsvæsenet. Du skal give tilladelse til, at jeg deltager og observerer og registrerer, hvad der sker i en enkelt situation, hvor dit barn tilses eller behandles ved en kontakt på hospitalet. Efterfølgende vil der være et interview af ca. 45-60 minutters varighed omhandlende dine oplevelser med hospitalskontakter og samarbejde med sundhedspersonale. Interviewet kan planlægges på et tidspunkt og sted, hvor det passer dig.

Det er frivilligt at deltage

Det er frivilligt at deltage i projektet. Deltagelse sker kun efter såvel skriftlig som mundtlig information, samt når du har underskrevet en skriftlig samtykkeerklæring. Det er til enhver tid muligt at fortryde deltagelse i projektet.

Anonymitet

Alle oplysninger behandles anonymt og projektet er omfattet af Region Nordjyllands paraplyanmeldelse ved Datatilsynet – Sundhedsvidenskabelig forskning i Region Nordjylland (2008-58-0028).

Kontakt

Hvis du har lyst til at deltage eller har yderligere spørgsmål, må du meget gerne kontakte mig, se venligst kontaktoplysninger på forsiden**.**

Med venlig hilsen

Britt Laugesen

APPENDIX D. INFORMED CONSENT

Informeret samtykke til deltagelse i sundhedsvidenskabeligt forskningsprojekt

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Forskningsprojektets titel:

Børn med ADHD – patientforløb i psykiatrisk og somatisk sundhedsvæsen

Erklæring fra informanten (deltageren):

Jeg har fået mundtlig og skriftlig information, og jeg ved nok om formål, metode, fordele og ulemper til at sige ja til at deltage.

Jeg ved, at det er frivilligt at deltage, og at jeg altid kan trække mit samtykke tilbage uden at miste mine nuværende eller fremtidige rettigheder til behandling.

Jeg giver samtykke til at deltage i forskningsprojektet og har fået en kopi af dette samtykkeark samt en kopi af den skriftlige information om projektet til eget brug.

Informant/deltagers navn:
____

Dato:__________________
Underskrift:____

Erklæring fra den, der afgiver information

Jeg erklærer, at informanten (deltageren) har modtaget mundtlig og skriftlig information om forskningsprojektet.

Efter min overbevisning er der givet tilstrækkelig information til, at der kan træffes en beslutning om deltagelse i projektet.

Navn på den, der har afgivet information: ____

Dato:__________________

Underskrift:____

Projektidentifikation:

Projektet er omfattet af Region Nordjyllands paraplyanmeldelse ved Datatilsynet – Sundhedsvidenskabelig forskning i Region Nordjylland (2008-58-0028).

ISSN (online): 2246-1302
ISBN (online): 978-87-7112-866-6

AALBORG **UNIVERSITY PRESS**