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BY
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AALBORG UNIVERSITY
DENMARK

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CV

Helle Enggaard graduated as a registered nurse from the nursing program in Aalborg in 2002. Afterward she worked as a registered nurse at what is now known as Aalborg University Hospital from 2002 to 2007, first in the hematology ward and subsequently in the thorax surgery ward. Parallel to her job at Aalborg University Hospital, Helle completed supplementary education and achieved a bachelor's degree in nursing in 2004. These studies raised Helle's awareness of the many opportunities nurses have to contribute to the development of nursing practice through clinical research. It was therefore natural for Helle to pursue further education, and she obtained her Master's of Nursing Science in 2006. In 2007 Helle accepted a position at the school of nursing at was is now known as the University College of Northern Denmark, where she taught and supervised many nursing students until 2017, when she enrolled as a PhD student in the Department of Clinical Medicine at Aalborg University. Helle has a special interest in nursing care for patients with long-term or chronic diseases, as their healthcare needs require empowerment-inspired nursing. Empowerment has always been of special interest to Helle, both in her clinical work and at the school of nursing. This PhD project was funded through a collaboration between University College Northern Denmark and Aalborg University Hospital—Psychiatry and provided Helle with a unique opportunity to focus on development of nursing care and empowerment.

ENGLISH SUMMARY

Background

Attention deficit/hyperactivity disorder (ADHD) in adolescents is a common mental disorder and associated with impaired academic, social, emotional, and family functioning. Furthermore, adolescents with ADHD are at risk for suffering from a co-existing medical disorder (MD) such as asthma, allergy, diabetes, enuresis, epilepsy, incontinence, obesity, insomnia, or migraine. Living with ADHD is complex, and a co-existing MD presumably adds to that complexity. Studies argue that adolescents with co-existing ADHD and MD require special approaches to treatment and care.

Adolescents strive for independence from their parents, and they make more independent decisions about their lives, which is likely to influence their disease-management choices. It is therefore important to support adolescents in order to empower them in their management of co-existing ADHD and MD. Thus, there is a need to develop and evaluate the impact of an intervention supporting adolescents' self-management of co-existing ADHD and MD.

Guided Self-Determination (GSD) is an empowerment-based intervention that supports patients' disease self-management by facilitating patient involvement and patient-centered care. The GSD intervention may be suitable for supporting adolescents' self-management of co-existing ADHD and MD.

Aim

This PhD project consisted of three studies that aimed to:

- Explore adolescents' perceptions of living with co-existing ADHD and MD (Study 1). The findings of Study 1 formed the basis for the adaptation of the GSD intervention to adolescents with co-existing ADHD and MD (GSD-ADHD-MD)
- Evaluate the impact of the GSD-ADHD-MD intervention on support from nurses, support from parents, and the adolescents' self-management of co-existing ADHD and MD (Study 2)
- Evaluate feasibility and acceptability of the GSD-ADHD-MD intervention received by adolescents with co-existing ADHD and MD (Study 3)

Methods

Adolescents' perception of living with co-existing ADHD and MD was explored in a qualitive semi-structured interview study and included 10 adolescents with co-existing ADHD and MD (Study 1). The GSD-ADHD-MD intervention was evaluated in an outpatient ADHD hospital clinic and an outpatient pediatric hospital clinic and included 10 adolescents with co-existing ADHD and MD. The impact of the intervention was evaluated in a mixed methods convergent study (Study 2).

Feasibility of the intervention was evaluated on the basis of registration of the adolescents' recruitment, retention, and participation rates, and acceptability was evaluated on the basis of semi-structured interviews with the adolescents (Study 3).

Results

The findings show that living with two disorders creates a dual task that cannot be handled by dealing with ADHD and MD separately. Evaluation of the GSD-ADHD-MD suggests that the intervention may have an impact on self-management and support from nurses but not on support from parents. Additionally, the acceptability and feasibility of the intervention depended on the adolescents' and the nurses' use of the reflection sheets and the collaborative sessions.

Conclusion

The GSD-ADHD-MD intervention has the potential to improve adolescents' management of co-existing ADHD and MD by helping them become aware of the dual task and by supporting their active involvement in their outpatient visits. However, some elements of the intervention were more feasible and acceptable than others; for this reason, the intervention needs further adjustments.

DANSK RESUME

Baggrund
ADHD er en hyppigt forekommende psykisk lidelse blandt unge, og den er forbundet med faglige, sociale, følelsesmæssige og familiemæssige udfordringer. Ydermere har unge med ADHD en øget risiko for også at lide af en fysisk sygdom såsom astma, allergi, diabetes, enuresis, epilepsi, inkontinens, overvægt, søvnbesvær eller migræne.

Unge stræber efter uafhængighed fra deres forældre, og de begynder at træffe selvstændige beslutninger, herunder også beslutninger vedrørende håndtering af egen sygdom. Det er derfor vigtigt at støtte unge for at empower dem i deres håndtering af sameksisterende ADHD og fysisk sygdom. Der er behov for at udvikle og evaluere indvirkningen af interventioner, der støtter unges håndtering af ADHD og en sameksisterende fysisk sygdom.

Guidet Egen-Beslutning (GSD) er en empowerment-baseret intervention, der støtter patienters håndtering af sygdom igennem patientcentreret kommunikation og patientinvolvering. Guidet Egen-Beslutning er måske egnet til at støtte unge med ADHD og en sameksisterende fysisk sygdom.

Formål
Dette ph.d.-projekt bestod at tre studier, der havde til formål at:

- Udforske unges opfattelse af at leve med sameksisterende ADHD og fysisk sygdom (Studie 1). Fundene fra Studie 1 dannede grundlag for tilpasningen af Guidet Egen-Beslutning til unge med sameksisterende ADHD og fysisk sygdom (GSD-ADHD-MD).
- Evaluere indvirkningen af GSD-ADHD-MD interventionen på støtte fra sygeplejersker og forældre og de unges håndtering af sameksisterende ADHD og fysisk sygdom (Studie 2).
- Evaluere gennemførbarhed og accept af GSD-ADH-MD interventionen hos de unge med sameksisterende ADHD og fysisk sygdom som modtog interventionen (Studie 3).

Metode
Unges opfattelse af at leve med sameksisterende ADHD og fysisk sygdom blev udforsket gennem semi-strukturerede interviews og inkluderede 10 unge med sameksisterende ADHD og fysisk sygdom (Studie 1). GSD-ADHD-MD interventionen blev evalueret i hospitalsregi på et ADHD ambulatorie og et pædiatrisk ambulatorie og inkluderede 10 unge med sameksisterende ADHD og

fysisk sygdom. Et mixed metode konvergentdesign blev anvendt til at evaluere indvirkningen af interventionen (Studie 2). Registreringer af rekruttering samt de unges deltagelse i interventionen blev anvendt til at evaluere gennemførbarheden af interventionen, og semistrukturerede interviews med de unge blev anvendt til at evaluere de unges accept af GSD-ADHD-MD interventionen (Studie 3).

Resultater

Fundene viser, at det at leve med to sygdomme skaber en dobbeltopgave, der ikke kan klares ved at håndtere ADHD og den fysiske sygdom hver for sig. Evalueringen af GSD-ADHD-MD viser, at interventionen måske kan have en indvirkning på håndtering af ADHD og fysiske sygdom samt støtte fra sygeplejersker, men ikke på støtte fra forældre. Ydermere er gennemførbarheden og accept af interventionen afhængig af, hvordan de unge og sygeplejerskerne sammen anvender refleksionsarkene og sessionerne.

Konklusion

GSD-ADHD-MD interventionen har potentiale til at forbedre de unges håndtering af sameksisterende ADHD og fysisk sygdom ved at hjælpe de unge med at blive bevidste om den dobbelte opgave og ved at støtte dem til at være aktivt involveret i deres ambulante besøg. Der er dog elementer i interventionen, der er mere acceptable og gennemførbare end andre, hvorfor der er behov for yderligere justering af interventionen.

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Helle Enggaard, June 2020

LIST OF PAPERS

Paper I
Enggaard, H., Laugesen, B., Zoffmann, V., Lauritsen, M. B., & Jørgensen, R. (2020). Adolescents' perceptions of living with co-existing ADHD and medical disorder in Denmark. *Journal of Pediatric Nursing, 53*, e129–e135. https://doi.org/10.1016/j.pedn.2020.03.004
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Paper II
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Paper III
Enggaard, H., Laugesen, B., DeJonckheere, M., Fetters, M. D., Lauritsen, M. B., Zoffmann, V., & Jørgensen, R. Feasibility and acceptability of the Guided Self-Determination intervention for adolescents with co-existing ADHD and medical disorder**.** Submitted June 3 2020 to *Issues in Mental Health Nursing*.
(The paper is in review)

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ABBREVIATIONS

ADD:	Attention deficit disorder
ADHD:	Attention deficit/hyperactivity disorder (In this thesis "ADHD" covers both attention deficit hyperactivity disorder and attention deficit disorder unless otherwise indicated)
GSD:	Guided Self-Determination
HCCQ:	The Health Care Climate Questionnaire
ICD-10:	International Classification of Disease, Tenth Revision
MD:	Medical disorder
MRC:	The United Kingdom Medical Research Council
PAM:	The Patient Activation Measure
POPS:	The Perception of Parents Scale

CHAPTER 1. BACKGROUND

1.1. ADHD IN CHILDREN AND ADOLESCENTS

Attention deficit/hyperactivity disorder (ADHD) is one of the most common mental disorders affecting children and adolescents worldwide. Several studies have estimated the global prevalence of ADHD among children and adolescents with differing results, ranging from 3.4% (Polanczyk et al., 2015) to between 5.9 and 7.2% (Thomas et al., 2015; Willcutt, 2012). The inconsistencies in these findings are presumed to relate to differences in research methods and diagnostic criteria (Sayal et al., 2018). Additionally, ADHD is reported to occur two to four times more often in boys than in girls (Polanczyk et al., 2007; Sayal et al., 2018; Thapar & Cooper, 2016).

Between 2006 and 2016, the prevalence of ADHD in children and adolescents in Denmark has grown threefold, from around 7,000 ADHD diagnoses to around 25,000 (SST, 2017). A recent Danish study also demonstrated that the risk of being diagnosed with ADHD before the age of 18 is 5.6% in boys and 3% in girls, making ADHD the second most prevalent mental disorder among Danish children and adolescents after anxiety disorder (Dalsgaard et al., 2020).

The etiology of ADHD is complex and not fully understood. The assumption is that the disorder is multifactorial, composed of genetic, biological, and environmental factors such as prematurity, low birthweight, and prenatal exposure to smoking, alcohol, and other toxins (Millichap, 2008; Thapar & Cooper, 2016). ADHD is a heterogenetic disorder, the core symptoms of which are inattention, impulsivity, and hyperactivity (WHO, 2016). According to the diagnostic criteria of International Classification of Diseases, Tenth Revision (ICD-10), inattention is characterized by having a short attention span, being easily distracted, having difficulty organizing tasks, and appearing to be unable to listen to or carry out instructions. Impulsivity is characterized by excessive talking and acting without thinking. Finally, hyperactivity is characterized by leaving one's seat in situations when staying seated is expected, the inability to engage in activities quietly, excessive physical movement, and constant fidgeting (WHO, 2016). The symptoms of ADHD are associated with impaired functioning in academic, social, emotional, behavioral, and family settings (Caci et al., 2014; Cormier, 2008; Langley et al., 2010; Sikirica et al., 2015; Thapar & Cooper, 2016), as well as with negative impacts on quality of life for both children and adolescents (Lee et al., 2016; Peasgood et al., 2016). ADHD is also proven to persist into adulthood (Abecassis et al., 2017) and is associated with antisocial behavior, emotional problems, self-harm (Sayal et al., 2018), adverse social, occupational, or economic outcomes, substance misuse (Barbaresi et al., 2013; Klein et al., 2012), criminality (Mohr-Jensen & Steinhausen, 2016), and increased mortality (Dalsgaard et al., 2015).

The recommended treatment for ADHD in children is a combination of medication and parent training interventions (NICE guideline, 2018). Parent training consists of psychoeducational and behavioral elements. The psychoeducational elements aim to give parents information about ADHD to help them understand their child's difficulties. The behavior elements aim in different ways to provide parents with strategies and confidence that can help them raise their child with ADHD (Daley et al., 2018). In adolescents, it is recommended that ADHD be treated with medication supplemented with cognitive behavioral therapy if the adolescent has problems with social skills, problem-solving, self-control, and active listening (NICE guideline, 2018). Cognitive behavioral therapy consists of cognitive and behavioral elements. The assumption in cognitive behavioral therapy is that behavior, feelings, and thoughts are interconnected and that changes in one will lead to changes in the other as well. The cognitive elements often consist of psychoeducation where the adolescents learn about ADHD and its symptoms as well as reconstruction of how the adolescents feel and think about themselves and their problems. The behavioral elements focus on practicing skills known to be difficult for adolescents with ADHD such as social skills, planning skills, and self-regulation. In addition, there is often homework between sessions so the adolescents can transfer the learned skills to their everyday life (Antshel & Olszewski, 2014). Overall, cognitive behavioral therapy is problem-focused and behavior-oriented.

1.2. EXPERIENCES OF LIVING WITH ADHD

Qualitative research has explored children's and adolescents' experiences of living with ADHD, with two recently published systematic reviews gathering the findings of this literature. The first of these reviews focuses on the experiences of adolescents (Eccleston et al., 2019), while the other highlights both children's and adolescents' experiences (Ringer, 2020). The review by Eccleston et al. (2019) included 11 qualitative studies on adolescents aged between 13 and 18 who had been diagnosed with ADHD. This review included studies with multiple types of participants, including parents, with the inclusion criteria that the experiences of the adolescents could be distinguished from those of the other participants. The review by Ringer (2020) covers 16 qualitative studies that looked at children and adolescents under the age of 19 with ADHD. Only two of the 16 studies had samples that exclusively included children under the age of 13, while samples for the other 14 studies were composed of either adolescents and children or adolescents only. Together, the two systematic reviews represent 22 qualitative studies of children's and adolescents' experiences of living with ADHD, and the studies conclusively establish that ADHD influences all aspects of children's and adolescents' everyday lives.

These reviews reveal that children and adolescents associate having ADHD with their difficulties in controlling emotions and behaviors, and with their attention and concentration problems, which in turn negatively affect their relationships and create difficulties at school. However, some also reported that having ADHD was

associated with certain advantages, such as having more energy, or being fun, creative, and outgoing. Despite perceiving ADHD as a disorder, they also perceived ADHD to be an intrinsic part of their personality; that is, they described themselves in terms of their ADHD, rather than as children or adolescents who experienced ADHD symptoms.

On the one hand, children and adolescents strove to accept themselves for who they are, difficulties and all. On the other hand, they felt that they had to adapt to the demands of their surroundings and regulate themselves by taking medication and finding ways to manage their thoughts, behaviors, and emotions. Additionally, they had negative experiences in terms of personal relationships, since their ADHD-related difficulties made it harder to meet others' expectations. Not being able to meet the expectations and rules of their surroundings led to negative feelings, such as anger, frustration, and sadness. It also made them feel stigmatized or feel that they did not "belong" because they were different. In contrast, they experienced positive relationships with others when other people acknowledged and accepted their difficulties in living with ADHD. Such experiences made them feel supported and helped, which they emphasized as important for everyday functioning.

Finally, the two reviews show that adolescents in particular felt ambivalent about their experiences with ADHD medical treatments. While medication was associated with improved achievement in school, it was also associated with side effects, from loss of appetite and weight loss to headaches, nausea, and loss of energy. Additionally, some adolescents found that the medication altered their sense of self, for example, by making them less social. Likewise, most adolescents expressed a wish to discontinue their ADHD medication. However, they felt that taking medication was not a choice, but something that their parents and physicians expected them to do. Consequently, adolescents often do not tell their parents or physicians when they consider—or act upon—the urge to take their medication selectively, for instance, only on school days.

1.3. **ADHD AND CO-EXISTING DISORDERS**

It is known that children and adolescents with ADHD often have co-existing mental disorders, such as conduct disorder, oppositional defiant disorder, anxiety disorder, intellectual disability, attachment disorder, tic disorder, affective disorder, or autism spectrum disorder (Jensen & Steinhausen, 2015; Larson et al., 2011; Reale et al., 2017). A Danish register-based study found that 52% of children and adolescents diagnosed with ADHD have one co-existing mental disorder and that approximately 25% have two or more (Jensen & Steinhausen, 2015).

Moreover, the literature reveals that children and adolescents with ADHD are at risk for having a co-existing medical disorder (MD). The prevalence of asthma, allergy, enuresis, epilepsy, obesity, type 2 diabetes, gastrointestinal diseases, insomnia,

headaches, or migraine has been shown to be higher in children and adolescents with ADHD when compared to those without the disorder (Chen et al., 2013; Cortese & Tessari, 2017; Gillberg et al., 2004; Jameson et al., 2016; Kutuk et al., 2018; Park et al., 2017). There is also evidence that the prevalence of ADHD is higher in children and adolescents with asthma, allergy, incontinence, cerebral palsy, epilepsy, and type 1 diabetes than in those without these MDs (Bjorgaas et al., 2013; Kapellen et al., 2016; Muskens et al., 2017; von Gontard & Equit, 2015).

Living with ADHD is complex, and a co-existing disorder presumably adds to that complexity. Some children and adolescents may therefore require additional support. The focus of this PhD project is on ADHD and co-existing MDs, as these patients face additional health services challenges in Danish hospitals, which are organized in silos according to medical specialty (DHMA, 2015). This means that ADHD is diagnosed, treated, and monitored at clinics housed within child and adolescent psychiatry facilities at psychiatric hospitals (Danish Health Authority, 2019b), while MDs are managed at clinics within pediatric departments at general hospitals (Danish Health Authority, 2019c). Consequently, children and adolescents with co-existing ADHD and MD receive treatment and care for each disorder in isolation.

Studies investigating the impact of living with co-existing ADHD and MD in children and adolescents are limited. However, studies have shown ADHD to be a risk factor for increased blood glucose levels (Yazar et al., 2019), hypoglycemia (Lin et al., 2019), diabetes ketoacidosis, and poor metabolic control (Hilgard et al., 2017) in children and adolescents with diabetes. These outcomes are most often related to the person's daily diabetes self-management, and because ADHD is associated with disruptions to planning and organizational skills, ADHD is presumed to be an additional challenge for diabetes management (Yazar et al., 2019). This corresponds with the findings of a qualitative study that reported that in adolescents with co-existing ADHD and type 1 diabetes, ADHD added complexity to their diabetes management, and that suggested that healthcare professionals take ADHD-related difficulties into account when treating diabetes (Lindblad et al., 2017). ADHD has also been shown to complicate asthma self-management in adolescents with co-existing ADHD (Wenderlich et al., 2019). These findings suggest that ADHD adds complexity to the management of any co-existing MD. However, there has been little written about the ways in which an MD might influence the lives of children and adolescents with ADHD.

Additionally, adolescents with co-existing ADHD and various chronic MDs are reported to have fewer protective factors than those with only ADHD or only a chronic MD (Nylander et al., 2015). Protective factors such as high self-esteem, optimistic thinking, wellbeing at school, and good relationships with peers and family members all improve adolescents' resistance to health risk behaviors. Nylander et al. (2015) demonstrated that adolescents with co-existing ADHD and chronic MDs have fewer protective factors and an increased engagement in health

risk behaviors such as smoking, drinking, experimenting with drugs, violent behavior, criminal acts, early sexual activity, and self-harm than those with only ADHD or only a chronic MD. Taken together, these findings indicate that living with co-existing ADHD and MD is complicated and may need special attention in the context of hospital-based treatment and care. This is in line with studies suggesting that children and adolescents with co-existing ADHD and MD require special approaches to treatment and care (Arango, 2011; Gillberg et al., 2004; Jameson et al., 2016; von Gontard & Equit, 2015). However, there is a gap in the literature regarding children's and adolescents' experiences of living with co-existing ADHD and MD. Investigating this question will be necessary if healthcare professionals are to develop new approaches to treatment and care that are tailored to these patients' needs and preferences.

1.4. **ADOLESCENTS**

The focus of this PhD project is limited to adolescents with co-existing ADHD and MD, as the health issues relate not only to the disorder the adolescents suffer from but also to the combination of the disorder and being a teenager (Sawyer et al., 2007). This section provides a brief overview of the developmental changes that occur during adolescence in order to demonstrate that adolescents with co-existing ADHD and MD need special attention when receiving hospital-based treatment and care.

Adolescence is a time of great biological, cognitive, and psychosocial development (Spano, 2004). Biological development includes sexual maturation, physical changes toward a more "adult" body, and hormonal changes (Christie & Viner, 2005; Suris et al., 2004). Cognitive development includes advancement in reasoning skills, hypothetical thinking, and use of logical and abstract thinking. Abstract thinking is the ability to envisage things that are not experienced or seen, which for some adolescents can lead to them overestimating their own abilities and thus encourage more risk-taking behaviors. However, more "concrete-thinking" adolescents may also engage in risk-taking behaviors because they are unable to understand or predict the consequences of their actions. Adolescence also sees the development of metacognition, which is a person's ability to think about thinking, i.e. the ability to reflect on themself and how they imagine others might view them (Sanders, 2013). Psychosocial development in adolescents involves steps toward autonomy and self-identity. Adolescents will gradually seek independence from their parents, as evidenced in decreasing interest in parental advice and family activities and an increase in conflicts with parents (Sanders, 2013; Steinberg & Morris, 2001). Adolescents start to develop their own identity by making their own decisions about things that matter to them. This process is often influenced by peers, as adolescents become increasingly concerned with how they appear to their peers (Sanders, 2013). Peer acceptance is important to adolescents, and they are influenced by peers whom they admire or respect, often adjusting their behavior and

opinions in accordance with the behavior and opinions of those peers (Sanders, 2013; Steinberg & Morris, 2001). Adolescence is also the time when young people start to develop their own identity, which involves the development of self-concepts and self-esteem. An adolescent's self-concept refers to the ways in which they perceive their own capabilities, goals, values, and experiences. Self-esteem reflects how an adolescent perceives their self-worth (Sanders, 2013).

The fact that adolescents generally strive for autonomy and independence from their parents, coupled with the fact that their decision-making is often indirectly influenced by peers, means that they begin to make more independent decisions about their lives. This is in turn likely to influence an adolescent's disease-management choices (Patton et al., 2016; Sawyer et al., 2007). For this reason, it is recommended that healthcare professionals support adolescents' decision-making processes in order to empower them in their management of a disorder (Patton et al., 2016). On top of this, some argue that management of ADHD is more complex for adolescents than it is for children, since the former face higher expectations and adolescents have less-structured daily lives as adult involvement is gradually decreased (Young & Myanthi Amarasinghe, 2010). This underscores the need for additional support for adolescents managing co-existing ADHD and MDs.

Despite adolescents seeking autonomy and independence from their parents, it is parents who remain the most important allies in health management (Christie & Viner, 2005). However, the parents' ability to manage conflicts with adolescents influences the adolescents' engagement in health risk behaviors (Patton et al., 2016). Healthcare professionals must therefore also help parents form and maintain supportive relationships with their adolescent children in order to promote wellbeing and positive disease-management practices (Michaud & Suris, 2004; Nielsen & Bronwen Players, 2009, p. 22). This is particularly relevant to parents of adolescents with ADHD, since these parents experience increased levels of conflict once their child enters adolescence (Laugesen et al., 2016), and they also experience difficulties in providing a balance between parental guidance and letting their adolescent child become independent (Moen et al., 2014). This is another reason for healthcare professionals to act as important allies to parents whose adolescent children have co-existing ADHD and MDs.

1.5. **LITERATURE REVIEW**

A literature review was conducted in order to clarify whether there are existing interventions to support adolescents' management of co-existing ADHD and MDs in healthcare settings. A search of existing studies was performed in PubMed, Cinahl, and PsycINFO. The detailed search strategies are described and documented in Appendix A.

1.5.1. INTERVENTIONS FOR ADOLESCENTS WITH CO-EXISTING ADHD AND MD

The literature search identified two studies on interventions for adolescents with co-existing ADHD and MDs (Brown et al., 2015; Sciberras et al., 2011). One study evaluated a sleep intervention in children and adolescents with co-existing ADHD and insomnia (Sciberras et al., 2011); the other evaluated a weight-loss treatment in children and adolescents with co-existing obesity and cognitive disabilities (including ADHD) (Brown et al., 2015).

Sciberras et al. compared brief and extensive behavioral interventions designed to improve management of sleep problems in children and adolescents aged between 5 and 14 who had co-existing ADHD and insomnia (Sciberras et al., 2011). The brief intervention consisted of a 45-minute face-to-face session between a child psychologist and the child's parents. The extensive intervention included another session two weeks after the first, as well as the possibility of a third session if the child's sleep problems persisted. A total of 27 families were included, of which 13 received the brief intervention and 14 received the extensive intervention. The study showed that both interventions reduced sleep problems in children and adolescents. However, the extensive intervention also improved the participating children's psychosocial quality of life and daily functioning while decreasing the levels of parental anxiety. The study concluded by recommending that the extensive sleep management intervention be further researched (Sciberras et al., 2011).

Brown et al. investigated a weight-loss treatment called Families in Training (FIT), which was provided at a pediatric weight management clinic in the US for patients aged between 2 and 18 years (Brown et al., 2015). They evaluated the effect of FIT on children and adolescents with co-existing obesity and cognitive disabilities (including ADHD) and compared this to the effects on children and adolescents with obesity but no cognitive disabilities. The study included 453 patients, of whom 24% had cognitive disabilities. Two-thirds of those with cognitive disabilities had ADHD. The study reported that children and adolescents with cognitive disabilities (including ADHD) achieved similarly positive weight-loss results, measured as changes in body mass index, blood pressure, pulse, and cholesterol and insulin levels, as those without cognitive disabilities. FIT is a yearlong family-centered treatment program based on motivational interview techniques. The healthcare professionals support families in choosing and setting personalized goals and solutions that help children and adolescents achieve their weight-loss goals. In addition, children and adolescents are encouraged to participate in discussions regarding goal-setting and behavioral changes. Brown et al. (2015) concluded that the positive weight-loss results in children and adolescents with co-existing obesity and cognitive disabilities are a result of the flexibility of the family-based FIT treatment, which allows for a focus on each family's strengths and challenges, and on the use of motivational interview techniques.

These two interventions both target a specific co-existing MD, and only the weight-loss program treats adolescents directly, while the sleep intervention is delivered to parents only. However, as mentioned above, it is important to target both adolescents and their parents when trying to support adolescents' disease management. Additionally, such interventions should be tailored to adolescents with a range of co-existing MDs to reflect clinical practice in Danish hospitals.

One intervention that may be suitable for supporting adolescents' self-management of co-existing ADHD and MDs is Guided Self-Determination (GSD). GSD is an empowerment-based intervention that improves patients' abilities to manage their disorder by facilitating patient involvement and patient-centered care (Zoffmann & Kirkevold, 2012). The empirical and theoretical underpinnings of GSD and the GSD intervention are presented in the following section.

1.6. THE GUIDED SELF-DETERMINATION INTERVENTION

The GSD intervention was developed by Vibeke Zoffmann in a four-phase research program. First, a grounded theory study of difficult problem-solving in diabetes care in 11 patient–nurse relationships was conducted. This study resulted in three grounded theories identifying and explaining why barriers for empowerment were or were not overcome in the patient–nurse interactions (Zoffmann & Kirkevold, 2005, 2007; Zoffmann et. al., 2008). Second, GSD was developed on the basis of the three grounded theories using participatory research involving 12 nurses and 25 adult patients with type 1 and type 2 diabetes (Zoffmann, 2004). Third, GSD was evaluated in one-to-one settings in 11 patient–nurse relationships using qualitative methods (Zoffmann & Kirkevold, 2012). Last, GSD was tested in a clinical randomized controlled trial with 50 adults with type 1 diabetes, documenting its effect on developing life skills in living with diabetes including improved glycemic levels (Zoffmann & Lauritzen, 2006).

1.6.1. EMPIRICAL BASIS OF GUIDED SELF-DETERMINATION

The three grounded theories underpinning the GSD intervention are summarized in this section with particular attention to the processes leading to shared decision-making or effective problem-solving in patient–nurse interactions. The summaries are based on the three papers in which the grounded theories are published (Zoffmann & Kirkevold, 2005, 2007; Zoffmann et al., 2008).

Life versus disease: Conflicting perspectives disempower patients and professionals in problem solving

The main finding in this theory was keeping life and disease-management apart (see Appendix B), which created conflicts within and between patients and nurses (Zoffmann & Kirkevold, 2005). Conflict within patients occurred when they tended

to live life as normally as possible while keeping the disease at a distance by resisting or unwillingly making changes in life on account of the disease. Hence, the patients tended to prioritize life over disease-management. Conflicts within nurses occurred, as the nurses tended to prioritize disease-management over life. Although the nurses wanted to support the patients in living with disease, they often had a disease-specific focus on problem-solving. Conflicts between patients and nurses occurred if they had opposite priorities of life and disease-management. Three different approaches to problem-solving determined whether the conflicts remained unchanged, worsened, or resolved. The conflict remained unchanged in *the compliance-expecting approach*, the conflicts worsened in *the failure-expecting approach*, and the conflicts resolved in *the mutual-expecting approach*. In the latter, patients are the problem solvers, and professionals are interested in knowing about the patients' difficulties in living with disease and want to support them in managing these difficulties. Different viewpoints of the patients' difficulties in connecting life and disease-management are exchanged that resolve the conflicts by combining disease-oriented and life-oriented knowledge. This approach demonstrates the positive potential of effective problem-solving.

Relationships and their potential for change

The main finding in this theory was the relational potential for change and the identification of three types of relationships between patients and nurses (Zoffmann & Kirkevold, 2007). The relationships were called *I-you-distant provider dominance*, *I-you blurred sympathy*, and *I-you sorted mutuality* and differed in scope of problem-solving, roles assigned to the patient and nurse, use of difficult feelings and differences in viewpoints, and quality of knowledge achieved as the basis of problem-solving and decision-making. All relationships have the possibility to create change but depend on how tension created by difficult feelings and different viewpoints was handled in the relationship (see Appendix B). The relationships *I-you-distant provider dominance* and *I-you blurred sympathy* both failed to take advantage of the potential for change. *I-you-distant provider dominance* seldom discovered difficult feelings or different viewpoints because the nurses used their disease-specific knowledge to identify patients' problems and come up with solutions, which patients were expected to follow. In the *I-you blurred sympathy* relationship, nurses were not comfortable with tension, which was why sources of tension were covered up or neutralized by seeking similarities between patients and professionals. However, these similarities were seldom verified or corrected by the patient. In the *I-you sorted mutuality* relationship, nurses and patients explored difficult feelings and exchanged different viewpoints. Disagreements on patients' difficulties were mutually explored and verified, and a person-specific knowledge was co-created by patient and nurse working together. Furthermore, this person-specific knowledge was utilized in problem-solving.

A person-centered communication and reflection model: Sharing decision-making in chronic care

The main finding of this theory is the advantage of *co-creating person-specific knowledge* (Zoffmann et al., 2008). Person-specific knowledge about the individual patient's difficulties in living with disease was co-created by patients and nurses when the communication was focused and included situational reflection at a mutual level. A person-centered communication and reflection model was developed. The model shows that the choices made by nurses and patients determined whether a focused communication with situational reflection at the mutual level was achieved; see Appendix B. Communication was focused when they talked about issues that were currently difficult for patients in living with disease and not just relevant for the disease in general. Situational reflection is based on the individual patient's situation, and mutual reflection means that both the patient and the nurse know what issues they are reflecting on, so they are able to exchange ideas, thoughts, and experiences on that specific issue. This leads to the co-creation of a person-specific knowledge about the individual patient's difficulties in living with disease.

1.6.2. THEORETICAL FRAMEWORK OF GUIDED SELF-DETERMINATION

The theoretical framework of GSD consists of empowerment philosophy, self-determination theory, and life skills, which are presented in the following sections.

Empowerment

GSD is consistent with the philosophy of empowerment as described by Anderson and Funnel (Zoffmann, 2004). Empowerment is defined as:

> *"The discovery and development of one's inherent capacity to be responsible for one's own life. People are empowered when they have sufficient knowledge to make rational decisions, sufficient control and resources to implement their decisions, and sufficient experience to evaluate the effectiveness of those choices"* (Anderson & Funnell, 2005, p. 11)

According to this definition, empowerment is both a process and outcome and an inherent capacity. For this reason, healthcare professionals cannot empower patients. Instead, the role of healthcare professionals is to inspire, inform, support, and facilitate patients' efforts to identify and achieve their own goals (Funnell & Anderson, 2003). This requires that the patients have knowledge, skills, and self-awareness about their own values, needs, and goals in order to influence their own behavior, thoughts, and attitudes to achieve their own goals and improve quality of life (Funnell & Anderson, 2003). Furthermore, empowerment recognizes the expertise of both patients and healthcare professionals in developing self-

management strategies, meaning that professionals are not the problem solvers. Instead, patients and professionals collaborate to identify and implement relevant and realistic problem-solving strategies (Funnell & Anderson, 2003). The philosophy of empowerment is patient centered, as it is focused on patients' experiences in living with disease.

Healthcare professionals acknowledge the relevance of empowerment in caring for patients with chronic or long-term conditions (Paterson, 2001). However, empowerment can be difficult to practice in busy clinical settings (Anderson & Funnell, 2005, 2010; Paterson, 2001). Anderson and Funnell write that this may be due to professionals also being trained in compliance, which is an approach that attempts to make patients comply and adhere to treatment regimens and health recommendations, which is highly relevant when patients have acute or short-term healthcare needs (Anderson & Funnell, 2005). For this reason, healthcare professionals, including nurses, seem to need support to practice empowerment when interacting with patients.

The philosophy of empowerment is in line with the positive types of relationships and approaches to problem-solving identified in the three grounded theories. GSD was developed to overcome the barriers to empowerment described and explained in the three grounded theories by supporting both patients and nurses in practicing empowerment in their relationships.

Self-determination theory

Self-determination theory is a theory on human motivation based on empirical research. Self-determination is identified as: *"A quality of human functioning that involves the experience of choice, in other words, an internal perceived locus of causality….Self-determination is the capacity to choose and to have choices being the determinants of one's action"* (Deci & Ryan, 1985, p. 39).

Self-determination theory differentiates between three types of motivation. The first is *amotivation*, in which individuals act without intent or do not act at all. They feel hopeless, and their actions are halfhearted because they do not value the actions or they do not expect to achieve the desired outcome (Ryan & Deci, 2000). *Controlled motivation* is when individuals do not experience a real sense of choice, as their actions are based on pressure or fear, which can be derived from external factors in the surroundings or internal factors within themselves (Ryan & Deci, 2000). *Autonomous motivation* or *self-determination* is when individuals experience that they have a choice and where they make choices to achieve self-selected goals.

Self-determined motivation requires fulfillment of the three basics needs: competence, relatedness, and autonomy. Competence occurs when an individual faces challenges and is able to overcome them. Autonomy is when people

experience a sense of choice and will to act in agreement with their values and interests. Relatedness is the caring that is received through interactions with other people, creating a sense of belonging (Ryan & Deci, 2000). The three basic needs can be supported or threatened by internal as well as external factors. This means that others, such as nurses, can facilitate development of autonomous/self-determined motivation by supporting the individual's sense of competence, autonomy, and relatedness (Ryan & Deci, 2000). For example, nurses should strive to understand the individual's perspective and encourage the individual's initiatives, provide choices and reasons when giving recommendations, and respect their right to make their own choices (Ng et al., 2018; Ryan & Deci, 2000).

Self-determined motivation is consistent with the philosophy of empowerment and the aim of GSD. Furthermore, the self-determination theory describes how external factors such as nurses can support patients in being self-determined by supporting the patients' sense of competence, autonomy, and relatedness.

Life skills

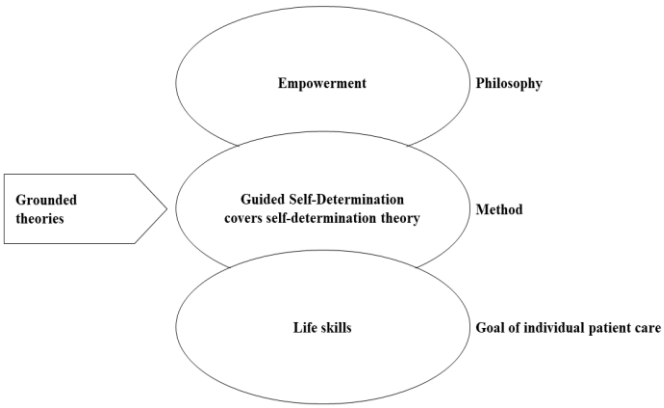
GSD was developed to support patients' development of life skills in living with diabetes. Life skills is a goal for health promotion and defined as *"those personal, social, cognitive and physical skills that enable people to control and direct their lives and develop the capacity to live with and produce change in their environment"* (Nutbeam, 1998, p. 360).

Individuals have life skills when they are able to solve problems in their own life in a balanced, self-determined way (Mullen, 1985, p. 9). *Balanced Self-Determined individuals* practice their rights without denying the rights of other people (Mullen, 1985, p. 9). In contrast, *Other-Determined individuals* wait for others to make decisions on their behalf. *Selfish-Determined individuals* achieve their goals at others' expense (Mullen, 1985, p. 9). The latter two reduce the sense of personal worth, whereas a sense of self-worth is increased in Balanced Self-determined individuals.

Additionally, problem-solving consists of the ability to recognize the problem, define the problem, choose an alternative, implement the alternative, and evaluate the results (Mullen, 1985, p. 40). Developing the ability to solve problems in one's own life is a cyclic process. The process begins with self-exploration, leading to self-understanding, which becomes evident in the individual's behavior in daily life, and feedback from these new initiatives can lead to further exploration, which again can be used to develop new and more efficient solutions in problem-solving (Mullen, 1985, p. 42). Thus, developing life skills is about learning the problem-solving processes that can be used in managing the problems of everyday life (Mullen, 1985, pp. 50–51) including management of disease in daily living.

GSD is based on the philosophy of empowerment and developed to support the patients' need of autonomy, competence, and relatedness to achieve the goal of developing life skills so they are able to manage their everyday life with disease. Figure 1 shows the empirical and theoretical framework of GSD.

Figure 1. The empirical and theoretical framework of the GSD intervention (Zoffmann, 2004, p. 10)



1.6.3. COMPONENTS OF THE GUIDED SELF-DETERMIANTION INTERVENTION

GSD support the patient's management of difficulties in living with diabetes through the use of reflection sheets and communication with nurses. Together, the reflection sheets and the conversations with the nurses move the patients through a cyclic process of problem-solving by facilitating self-exploration, self-understanding, and actions and feedback from actions. Furthermore, the reflection sheets and the communication skills support patients' sense of competence, autonomy, and relatedness, which according to the self-determination theory are important for improving or maintaining patients' motivation for disease self-management activities.

The original GSD intervention consisted of 21 reflection sheets divided between eight one-to-one consultations with the nurse. The semi-structured reflection sheets focus on the patient perspective and prompt the patient to reflect on different issues of their life with disease (Zoffmann, 2004, pp. 91–94).

The communication skills used in GSD are mirroring, active listening, and value clarification. Mirroring is when the nurses tell the patient what they have heard or observed, followed by a pause (Clabby & O'Connor, 2004), for example, by

repeating the patient's last word or by describing the patient's non-verbal expressions. Mirroring makes the patients feel heard and gives the patients the opportunity to hear themselves. In addition, the pause in speaking encourages reflection and gives the patient an opportunity to elaborate (Clabby & O'Connor, 2004). Active listening starts with mirroring and is followed by the nurse telling the patient how they understand what the patient has said. The purpose of active listening is to have the patient validate or correct the understanding (Mcnaughton et al., 2008). Active listening facilitates a common understanding of the topic being discussed between the patient and the nurse. Finally, values clarification is about starting a process where the patients clarify and reconsider their own values by asking questions that cannot be answered with facts or factual knowledge (Steinberg, 1986). Value clarification encourages reflection and self-insight. For example, instead of asking, "Do you take medication for ADHD?" the nurse could ask the patient, "Why is it important for you to take (or not to take) medication for ADHD?" In the latter question, the patient needs to reflect in order to respond.

The combination of the reflection sheets and communication skills supports the patient and the nurse in practicing the positive type of relationships and approaches to problem-solving identified in the three grounded theories. When enrolled in the intervention, the patient is expected to fill out the reflection sheets before consultations with the nurse. By filling out the reflection sheets the patient is systematically guided through a process of exploring difficulties related to disease self-management in their own life. Working with the reflection sheets at home is assumed to enhance the patient's ability to self-reflect and to consider the content of the reflection sheets in peace. In doing so, patients are assumed to provide more self-determined responses on the sheets that identify and express the challenges they face while living with disease (Zoffmann, 2004, p. 94).

Furthermore, the reflection sheets are the starting point of the conversations in which the nurse uses the three communication skills (mirroring, active listening, value clarification). This facilitates the mutual-expecting approach (Zoffmann & Kirkevold, 2005) because the nurse is supported in being patient-centered as the reflection sheets focus the perspective of the patient. In addition, conversations based on the reflection sheets will lead to conversations about what is relevant and important to the patient (Zoffmann, 2004, pp. 92–94). As a result, the nurse and the patient can co-create mutual knowledge on the person-specific difficulties of the individual patient (Zoffmann & Kirkevold, 2007), which are used as the base for further problem-solving (Zoffmann et al., 2008). These processes empower the patient to be self-determined in handling difficulties in disease self-management.

1.7. SUMMARY AND RATIONALE FOR THIS RESEARCH

Given the high prevalence of ADHD in children and adolescents both globally and in Denmark, as well as the disorder's impact on all aspects of children's and

adolescents' everyday life and its persistence into adulthood, it is clear that successful ADHD treatment and support is vital during childhood. Additionally, children and adolescents have been shown to be at risk for having co-existing MDs, adding further complexity to their lives. However, there is currently a lack of research on the experiences and perceptions of children and adolescents living with co-existing ADHD and MDs.

In addition, adolescents with co-existing ADHD and MDs may require more specialized care, since adolescent healthcare needs are not exclusively determined by their disorders. Adolescence is associated with striving for autonomy and independence, as well as with peer acceptance. These factors influence adolescent decision-making and can in turn affect any patient's abilities to manage co-existing ADHD and MDs. It is therefore imperative that adolescents receive support in their management of co-existing disorders. In addition, parents of adolescents with ADHD struggle to find the right balance between controlling and regulating their children and letting them become independent. This emphasizes the importance of providing support to parents as well, since they are often the most important allies for successful adolescent health management. In spite of this, there is still a lack of appropriate interventions to support adolescents in their management of co-existing ADHD and MD. Such interventions should target adolescents with a range of co-existing MDs, reflecting real-world clinical practice (in Danish hospitals, at least), where ADHD and MD are treated separately. GSD may represent just such an intervention: one that is able to integrate both disorders because it facilitates patient involvement and takes patients' perspectives into account when supporting development of self-management abilities. The rationale for this PhD project is therefore to provide insight into adolescents' perceptions of living with co-existing ADHD and MD and to further investigate whether the GSD is a suitable intervention to support adolescents' self-management of living with co-existing ADHD and MD.

CHAPTER 2. AIM AND OBJECTIVES

The aim of the PhD project was to evaluate the impact of the GSD intervention on living with co-existing ADHD and MD among adolescents.

The objectives of the PhD project were threefold:

1. To explore adolescents' perceptions of living with co-existing ADHD and MD (Study 1).
   The intent of this exploration was to gain knowledge on the perspectives of adolescents with co-existing ADHD and MD to assess the relevance of the GSD intervention for this group of adolescents, and to form the basis for the adaptation of the GSD intervention to adolescents with co-existing ADHD and MD (GSD-ADHD-MD)
2. To evaluate clinical outcomes of the GSD-ADHD-MD intervention in adolescents with co-existing ADHD and MD (Study 2)
3. To evaluate implementation outcomes of the GSD-ADHD-MD intervention in adolescents with co-existing ADHD and MD (Study 3)

Study 1

The aim of Study 1 was to explore how adolescents with co-existing ADHD and MD perceive living with co-existing ADHD and MD (Paper I).

Research questions:

- How do adolescents with co-existing ADHD and MD perceive everyday life?
- How do adolescents with co-existing ADHD and MD perceive support from parents and support from healthcare professionals?

Study 2

The aim of Study 2 was to evaluate the impact of the GSD-ADHD-MD intervention on support from nurses, support from parents, and the adolescents' self-management of co-existing ADHD and MD (Paper II).

Research questions:

- How can integration of quantitative self-reported data with qualitative interview data from the adolescents who received the GSD-ADHD-MD intervention expand our knowledge of the impact of the GSD-ADHD-MD intervention on 1) support from nurses; 2) support from parents; and 3) the adolescent's self-management?

Study 3

The aim of Study 3 was to evaluate the feasibility and acceptability of the GSD-ADHD-MD intervention received by adolescents with co-existing ADHD and MD (Paper III).

Research Questions:

- How do the adolescents engage with the GSD-ADHD-MD intervention in regard to recruitment, retention, and participation rate?
- How do the adolescents perceive the GSD-ADHD-MD intervention in regard to its content, complexity, and comfort?

Definitions

ADHD

For the purpose of this PhD project, the term "attention deficit/hyperactivity disorder" includes both individuals with ADHD and individuals with ADD, all referred to as ADHD in this thesis unless otherwise indicated. To identify adolescents with ADHD for participation in the studies, the diagnostic criteria of the ICD-10 were used. This mean that the adolescents were diagnosed with one of the following ICD-10 diagnostic codes of ADHD: F90.0, F90.1, or F.98.8 (WHO, 2016).

Medical disorder

"Medical disorder" was broadly defined for the purpose of this PhD project, as there were no restrictions as to what type of medical disorder the adolescents should have co-existing with ADHD. To identify adolescents with a medical disorder, the ICD-10 criteria were used, and a diagnosis was considered medical when the diagnosis code started with E, G, I, J, or K (WHO, 2016).

Adolescents

The World Health Organization defines adolescents as individuals aged 10–19 (McIntyre, 2002). For the purpose of this PhD project, adolescents were defined as individuals aged 13–17 due to the cultural understanding of adolescents in Denmark and because adolescent patients are transferred to adult healthcare settings when they turn 18 (Danish Health Authority, 2019c, 2019b).

CHAPTER 3. RESEARCH DESIGN

The overall research methodology of this PhD project is the mixed methods and the philosophical position is pragmatism.

3.1. **MIXED METHODS**

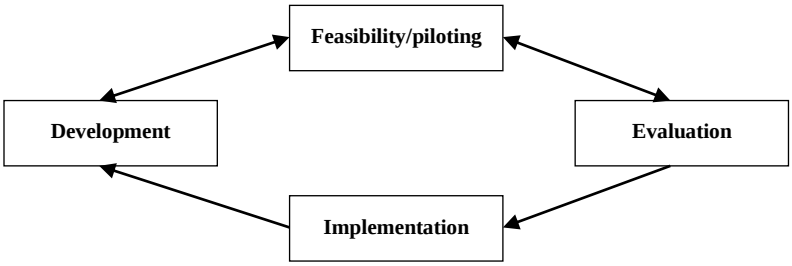
The rationale for choosing a mixed methods research design was the complexity of the aim of the PhD project, which intends to provide knowledge about the GSD intervention in adolescents with co-existing ADHD-MD. Mixed methods research is the collection and analysis of quantitative and qualitative data and the integration of the two forms of data to draw out interpretations to gain a better understanding of the research problem than could be achieved by either form of data alone (Creswell, 2014, p. 2; Creswell & Plano Clark, 2018, pp. 8, 13; Fetters & Freshwater, 2015). Fetters and Freshwater state that the integration produces a whole greater than the sum of individual quantitative and qualitative parts (2015), which indicates that mixed method research is suitable for investigating complex research problems.

The GSD intervention was not originally developed for adolescents or patients with co-existing disorders. The GDS-ADHD-MD intervention is therefore considered a "new" intervention under development. The United Kingdom Medical Research Council (MRC) has developed a framework for developing and evaluating complex interventions in health. According to the MRC framework, an intervention is considered complex when it consists of several interacting components and when the context and implementation is likely to have an impact on the effect of the intervention (Craig et al., 2008; Richards, 2015). Based on this definition, the GSD intervention was considered a complex intervention because it consisted of semi-structured reflection sheets and professional communication skills. Additionally, the effect of the GSD intervention is influenced by the nurses' and patients' use of the components together and individually (Olesen et al., 2015). Here follows a short introduction to the MRC framework to justify the choice of a mixed methods research design.

The MRC framework consists of a four-stage process: development, feasibility/piloting, evaluation, and implementation (Craig et al., 2008; Richards, 2015), as visualized in Figure 2. It is a non-linear process with important learning loops between the stages (Richards, 2015). It is recommended that developing interventions be based on existing research literature, the theory behind the intervention, and knowledge about the needs of the target population. The purpose of the feasibility and piloting stage of the intervention process is to investigate uncertainties about the intervention, and to evaluate the feasibility and acceptability of the intervention and the research procedures. The stage of evaluating the intervention is where the actual effect of the intervention is tested. Furthermore, this

stage often includes process and economic evaluations. Implementation is the stage in which an effective intervention is embedded into routine practice in healthcare systems (Craig et al., 2008; Richards, 2015). As mentioned earlier, the GSD intervention was considered a new intervention for adolescents with co-existing ADHD and MD; therefore, the PhD project falls within the two first stages of the MRC framework. Specifically, Study 1 and the process of adapting the GSD intervention for adolescents with co-existing ADHD and MD is part of the development stage. Study 2 and Study 3 are part of the feasibility/piloting stage according to the MRC framework. The MRC framework emphasizes the learning loops between stages, and it is assumed that preliminary evaluation of the clinical and implementation outcomes will enhance the understanding of the GSD-ADHD-MD intervention's potential among adolescents with co-existing ADHD and MD as well as point to which elements of the intervention need further adjustments.

Figure 2. MRC framework for the research and development of complex interventions (Craig et al., 2008)



The MRC framework accepts any research methods when developing and evaluating complex interventions if they embrace the complexity within the intervention and the process of developing the intervention (Craig et al., 2008). As a result, mixed methods research is argued to be useful for developing complex interventions (Borglin, 2015). According to Creswell and Plano Clark, the procedures used to integrate the quantitative and qualitative data should be organized into a specific mixed methods research design providing the logic and procedures for conducting the study and framing these procedures within theory and philosophy (2018, p. 5). This PhD project used a multiphase mixed methods evaluation design to frame Studies 1, 2, and 3 in response to the overall aim of the PhD project.

3.2. **PRAGMATISM**

The PhD project was philosophically positioned in pragmatism, and this section presents central features of pragmatism and how they correspond with the aim and methods used in this PhD project. First, there follows a short introduction to philosophy of science.

Philosophy of science concerns ontological and epistemological assumptions about the nature of reality (ontology) and how knowledge of this reality can be obtained (epistemology) (Mesel, 2013). The ontological and epistemological assumptions within a philosophical position provide a worldview through which the research problem is viewed, questions asked, and methods chosen (Mesel, 2013). That said, most applied research starts by identifying a problem in clinical practice from which questions are raised and the research project designed (Mesel, 2013). Again, the choices made in designing and conducting research are influenced by philosophical assumptions. Being explicit about the philosophical assumptions and showing how they relate to the research questions and research design enhance the transparency of the research.

Pragmatism is concerned with real-world problems and how to contribute to the solution of these problems (Bacon, 2012, p. 49; Creswell & Plano Clark, 2018, p. 37; Johnson & Onwuegbuzie, 2004). The dualism between subject and object is rejected (Bacon, 2012, p. 52) as the ontological assumption of pragmatism is that reality is singular and multiple at the same time (Creswell & Plano Clark, 2018, p. 37). This means that both objective and subjective knowledge are valued (Creswell & Plano Clark, 2018, p. 38). Furthermore, there are no clear perceptions of how to obtain knowledge about reality, because pragmatism is not based on definite epistemological assumptions. According to pragmatism, the value of procedures is not determined in themselves but by their ability to work in the real world, as shown by their ability to solve the problem (Bacon, 2012, p. 49; Creswell & Plano Clark, 2018, pp. 36–38; Johnson & Onwuegbuzie, 2004). Thus, pragmatism focuses on "what works," meaning that the methods that best address the problem should be used (Creswell & Plano Clark, 2018, pp. 37–38). This is not the same as "everything goes," but instead, pragmatism acknowledges the epistemological assumptions within different methods (Mesel, 2013).

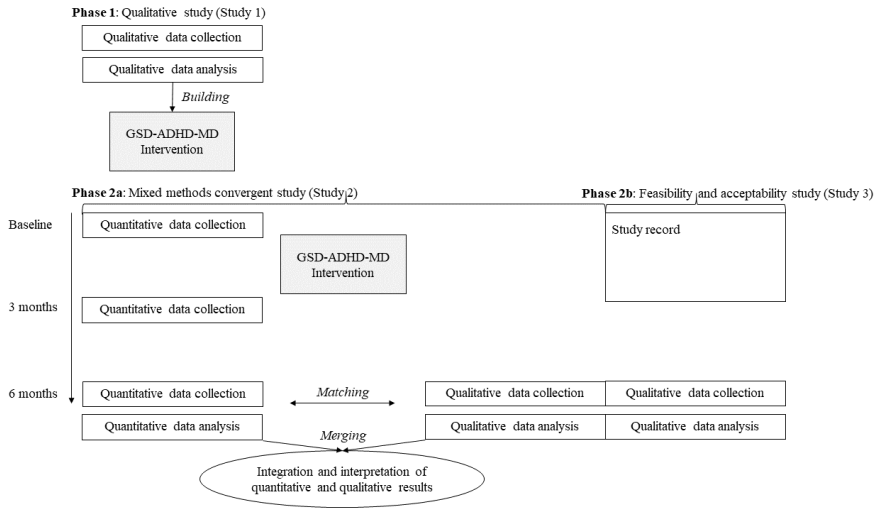
This PhD project is consistent with the principles of pragmatism. First, the project began with identifying the clinical problem concerning adolescents with co-existing ADHD and MD. Given the applications of GSD, this raised questions about GSD as a suitable intervention for supporting adolescents' self-management of living with co-existing ADHD and MD. Second, pragmatism corresponds well with mixed methods research because its ontological assumptions acknowledge objective and subjective knowledge, and allow both to be obtained through quantitative and qualitative methods (Creswell & Plano Clark, 2018, p. 37; Johnson & Onwuegbuzie, 2004; Morgan, 2007).

3.3. MULTIPHASE MIXED METHODS EVALUATION DESIGN

To reach the overall aim of the PhD project, a multiphase mixed methods evaluation project design was chosen to connect Studies 1, 2, and 3, and the GSD intervention was adapted to adolescents with co-existing ADHD and MD. "Multiphase" means

that each phase or part of the mixed methods evaluation can be presented as an individual study (Creswell, 2014, p. 46). In addition, the individual studies within a mixed methods evaluation design can either be quantitative, qualitative, or mixed methods studies (Creswell, 2014, p. 46). This multiphase mixed methods evaluation design consisted of three individual studies and a process in which the GSD intervention was adapted to adolescents with co-existing ADHD and MD (GSD-ADHD-MD); see Figure 3.

Figure 3. Multiphase mixed methods evaluation design



The hallmark of mixed methods research is the integration of quantitative and qualitative research, which occurs at the design, methods, interpretation, and reporting levels (Fetters, 2020; Fetters et al., 2013). The following section presents how integration was managed at the design, methods, and interpretation and reporting levels in this PhD project.

3.3.1. INTEGRATION AT THE DESIGN LEVEL

Integration at the design level can occur using core mixed methods designs or advanced mixed methods designs. According to Creswell and Plano Clark (2017), there are three core mixed methods designs: explanatory sequential design, exploratory sequential design, and convergent design. There are several advanced mixed methods designs that all incorporate one or more of the core designs (Creswell, 2014; Creswell & Plano Clark, 2018). The multiphase mixed methods evaluation design is an advanced mixed methods design that incorporates at least one core mixed methods design in one of the phases (Creswell & Plano Clark, 2018, p. 132).

This PhD study uses a multiphase mixed methods evaluation design with a mixed methods convergent component and two qualitative components. Phase 1 consisted of Study 1, in which the adolescents' perceptions of living with co-existing ADHD and MD were explored qualitatively. Study 1 provided the basis for deciding to move forward with the GSD intervention and adjusting the intervention for adolescents with co-existing ADHD and MD. Phase 2 consisted of phase 2a and phase 2b because the data collection for Studies 2 and 3 were conducted simultaneously even though they are considered individual studies. Study 2 was a mixed methods convergent study evaluating clinical outcomes of the GSD-ADHD-MD intervention, and Study 3 was a qualitative study evaluating implementation outcomes of the GSD-ADHD-MD intervention.

3.3.2. INTEGRATION AT THE METHODS LEVEL

Integration at the methods level occurs through linking the methods of data collection and analysis (Creswell, 2014, pp. 82–87; Creswell & Plano Clark, 2018; Fetters et al., 2013). In this multiphase mixed methods evaluation design, integration at the methods level occurred through *building*, *matching*, and *merging*, which is represented by the arrows in Figure 3.

Study 1 and Study 2 are integrated through *building*. The intent of building is to use the findings of one form of data to build or develop the data collection of the other from of data (Fetters, 2020, p. 124; Fetters et al., 2013). The findings of Study 1 were used to assess the relevance of the GSD intervention. The decision to adapt the GSD intervention to adolescents with co-existing ADHD and MD was confirmed by the findings of Study 1. The findings of Study 1 were therefore used to "build" the GSD-ADHD-MD intervention. Subsequently, the intervention was evaluated in the second phase of this multiphase mixed methods evaluation project (Study 2 and Study 3).

Study 2 used a mixed methods convergent design to evaluate the clinical outcome of the GSD-ADHD-MD intervention. *Matching* was the integration strategy used during the data collection to collect quantitative and qualitative data on the same constructs of interest (Fetters, 2020, p. 126). The advantage of matching is that it enables *merging*, which occurs when the quantitative and qualitative findings are brought together for comparison to gain a better understanding of the aim of the study (Creswell, 2014, p. 83; Fetters et al., 2013).

Integration at the methods level also included sampling strategies (Onwuegbuzie & Collins, 2007). The aims of Studies 1, 2, and 3 were all investigated in samples consisting of adolescents with co-existing ADHD and MD recruited from the same settings. However, the adolescents participating in Study 1 did not participate in Studies 2 and 3 because objectivity is an important feature in quantitative research.

3.3.3. INTEGRATION AT THE INTERPRETATION AND REPORTING LEVEL

Integration at the interpretation and reporting level occurred through joint displays and narrative weaving (Fetters et al., 2013). The integration of quantitative and qualitative findings that occurred in the mixed methods convergent study (Study 2) are described in detail in section 5.4. Here follows a presentation of how the integration occurred in this thesis. The findings of Studies 1, 2, and 3 were integrated to expand the knowledge on the impact of the GSD-ADHD-MD intervention on living with ADHD and MD among adolescents.

The integration was managed in four steps. In step one, the procedure recommended by Fetters was followed (2020, pp. 202–203): Findings were placed in a matrix to look for similarities across studies. A row was created for the findings of each study, so that visual comparisons could be made. Lines were drawn to connect related findings across the studies. These lines reflected overarching ideas based on commonality in the findings of the studies and were labeled as constructs (Fetters, 2020, pp. 203–204). This step of the integration resulted in three constructs: 1) the dual task in living with co-existing ADHD and MD; 2) involvement of the adolescents; and 3) parental support. These three constructs framed the further integration, in which joint display analysis (Fetters, 2020, pp. 206–207; Guetterman et al., 2015) and narrative weaving (Fetters et al., 2013) were used. In step two, joint displays were created, one for each of the three constructs. These joint displays contained a row for the findings of each study that were relevant for the construct. In step three, the findings in each of the joint displays were investigated in a back-and-forth process with the intent of drawing out new knowledge beyond the knowledge gained from the studies individually in response to the overall aim of the PhD project (Fetters et al., 2013; Guetterman et al., 2015). In addition, the "fit" of integration was assessed through *confirmation* (the findings confirm one another), *expansion* (the findings diverge and expand insight on the construct in question), and *discordance* (the findings are inconsistent, incongruous, disagree, conflict, or contradict with each other) (Fetters et al., 2013). In step four, the narrative-weaving approach was used to describe the findings of the integration (Fetters et al., 2013). Narrative weaving meant that the findings of Studies 1, 2, and 3 were written together to describe the integrated findings, organized by three constructs. Although steps two through four are described as a linear process, it was an iterative process in which joint displays were created and recreated to develop a more comprehensive understanding of the findings of all three studies (Fetters, 2020, p. 206; Fetters et al., 2013; Guetterman et al., 2015). A similar process occurred for the development of the narratives as they were written and rewritten alongside the iterative changes to the joint displays. The final joint displays and narratives of the integrated findings (Fetters et al., 2013; Guetterman et al., 2015) are presented in section 6.4.

CHAPTER 4. THE GSD-ADHD-MD INTERVENTION

The GSD-ADHD-MD intervention was adapted to adolescents with co-existing ADHD and MD based on the findings of Study 1 (summarized in section 6.1). The findings show that living with co-existing ADHD and MD is complex, since ADHD interferes with the MD and vice versa in everyday life. This creates a dual task, as the two disorders cannot be managed separately. Furthermore, the adolescents seemed not to take this fact into consideration—instead, they imagined that their difficulties would go away if they did not have a co-existing MD. Additionally, the adolescents perceived that the healthcare professionals only focused on one of the two disorders without taking the other into account. These findings supported the decision to adapt GSD for this group of adolescents, since GSD was believed to support both the adolescent patient and the nurse in recognizing the need to consider both disorders. This is because the core principle of GSD is to facilitate self-exploration and self-understanding, in turn creating a basis for further problem-solving. Study 1 also showed that adolescents take a passive role in encounters with healthcare professionals, whereas they take an active role in their relationships with peers, parents, and teachers. Thus, adolescents need help in order to become active in their encounters with healthcare professionals—something that GSD is designed to facilitate.

The intent was to adapt GSD in collaboration with registered nurses from the two participating outpatient clinics. However, both clinics were, at the time, in the process of implementing budget cuts that led to the nurses being laid off. Consequently, the clinical nurses could not participate in the process of adapting the GSD intervention. Furthermore, clinic management did not approve eight sessions that were used in the original version of the GSD intervention (Zoffmann, 2004) and in the version that was used to evaluate adolescents with type 1 diabetes (Husted et al., 2014). The pragmatic solution was to adapt GSD to make it consistent with the core principles of the intervention and to require as few sessions as possible. This meant that the GSD-ADHD-MD sessions were limited to four per adolescent. The four sessions were presumed sufficient to guide the adolescent through the process of self-exploration, self-understanding, and action and feedback from action. Parents were given one session. The decision on the number of sessions was not based on research as recommended by the MRC framework (Craig et al., 2008); however, the theoretical and empirical basis of the GSD intervention was still put into practice with the four sessions. This also meant that the selection of reflection sheets was based on the core principles of GSD rather than on the findings of Study 1. Adapting the reflection sheets meant that the word “diabetes” was replaced with the word “disorder”. Because the word “disorder” was used, the adolescents were allowed to address the issues they found most relevant without prioritizing one disorder over

the other. Only sheets 2.a and 2.b were diagnosis specific. The reflection sheets are presented in Appendix C, and the topic and objective for each session and the accompanying reflection sheet for the GSD-ADHD-MD intervention are presented in Table 1.

Two nurses from each outpatient clinic were trained by the PhD candidate to deliver the GSD-ADHD-MD intervention. The creator of the GSD intervention has developed online video presentations that delve into the theory underpinning the intervention, as well as the three communication skills, and an overall introduction to the GSD intervention. The nurses were provided with links to the online videos so they could watch them at a convenient time. Subsequent classroom activities (which lasted for 14 hours over two days) included discussion and review of the video content as well as the content and purpose of each reflection sheet, and exercises in which the nurses and the researcher used roleplay to deploy the reflection sheets and the three communication skills. The nurses were encouraged to practice the reflection sheets and the communication skills with patients in clinical practice before the study began. One nurse completed three practice GSD sessions; two nurses completed two practice GSD sessions; and one nurse did not practice the skills in clinical practice prior to the study. The researcher offered supervision throughout the practice and study period; the nurses primarily sought supervision during the practice period and with their first study participant.

Three of the four nurses who delivered the GSD-ADHD-MD intervention had been registered nurses for more than twenty years and worked in the pediatric and/or child and adolescents psychiatry specialties for nearly as long. One nurse had two years of experience as a registered nurse and had always worked in pediatric or in child and adolescent psychiatry specialties.

Table 1. The GSD-ADHD-MD intervention sessions and reflection sheets (Enggaard et al., n.d.)

Session topic	Session Objective	Content of reflection sheet
Session 1 Your life with two disorders	To support the adolescent's self-awareness of living with co-existing ADHD and an MD	1.a Invitation to collaborate 1.b Important events and periods in your life with two disorders 1.c What do you currently find challenging or difficult in living with two disorders? 1.d Unfinished sentences—values, experiences, and needs 1.e A picture, metaphor, or an expression you would use to describe how it is for you to live with two disorders
Session 2 Focus for change	To support the adolescent in identifying and prioritizing which difficulties of living with ADHD and MD they would like to problem-solve	2.a Plans to change your lifestyle with ADHD/ADD 2.b Plans to change your lifestyle with [medical disorder] 2.c Your experiences of different types of treatment 2.d Your reality in living with two disorders 2.e Room for disease in your life 2.f List of challenges or problems in your life with the disorders
Parent session Your life as a parent of an adolescent with co-existing disorders	To support parental development of self-awareness in parenting an adolescent with co-existing ADHD and an MD	P.a Invitation to collaborate (mom/dad) P.b Unfinished sentences—values, experiences, and needs (mom/dad) P.c Room for disease in your life (mom/dad)
Session 3 Working with change	To support the adolescent's problem-solving by exploring their existing approach as a basis for developing and testing new problem-solving strategies	Your existing approach to problem-solving 3.a Your observations 3.b Your thoughts and feelings 3.c Your goals and intentions 3.d Your actions 3.e Dynamic problem-solving
Session 4 Working with change	To support the adolescent in evaluating and adjusting their problem-solving	3.e Dynamic problem-solving (sheets from Session 3) 4.a New strategies and long-term plan 4.b Whom to involve in further problem-solving

CHAPTER 5. METHODS

This chapter presents the methods of Studies 1, 2, and 3. First, the setting and recruitment are presented, as they were identical in all three studies. Next, the participants and methods for data collection and data analysis are presented for each study, followed by ethical reflections and reflections on the researcher's role across all three studies. This presentation is primarily based on the three papers (Enggaard et al., n.d.; Enggaard et al., 2020b; Enggaard et al., 2020a).

5.1. SETTINGS

The setting for all three studies was an outpatient ADHD clinic and an outpatient pediatric clinic at a Danish public university hospital. Usual practice at the two clinics was that after the physician made the diagnosis and initiated treatment, most follow-up visits were managed by a nurse. These follow-up visits were supported when needed by physicians or other healthcare professionals. An outpatient visit managed by a nurse generally lasted between 45 and 60 minutes. Patients usually had between two and six visits at the outpatient clinic per year depending on the diagnosis and the severity of the individual patient situation.

5.2. RECRUTIMENT

All three studies utilized the same recruitment strategies to include eligible participants for each of the studies. Purposeful sampling strategies were used to recruit participants with experiences or characteristics relevant to the study aim (Creswell & Poth, 2017, p. 148). The inclusion criteria were adolescents (13–17 years of age) diagnosed with ADHD who were currently receiving treatment and care at one of the two outpatient clinics and who were diagnosed with an MD as well. Excluded were adolescents diagnosed with intellectual disabilities or inability to read, write, and speak Danish; the latter was assessed by healthcare professionals at the clinics. The ability to read and write Danish was not an exclusion criterion for Study 1. Furthermore, convenient sampling strategies were used, as adolescents who fulfilled the inclusion criteria were recruited on a first-come-first-served basis (Robinson, 2014).

The healthcare professionals at the two clinics assisted with the recruitment process. The healthcare professionals contacted the parents of eligible adolescents. If the parents were interested in the study, they were contacted by the PhD candidate by phone, at which time the parent was provided with oral information about the study. If the parent was still interested in the study, written information about the study was sent to the parents and the adolescents (Appendix D). The parents then informed their young child about the study, and if the child was interested in participating, a

meeting was arranged. At this meeting the adolescent and the parent(s) were informed about the study and their rights, and their questions were answered before the adolescent decided whether to participate in the study or not.

5.3. **STUDY 1**

This study provides a thematic analysis of semi-structured interviews with adolescents with co-existing ADHD and MD concerning their perceptions of everyday life with co-existing disorders and support from parents and healthcare professionals.

Participants

Fifteen parents were approached. Three parents declined the invitation on behalf of their child because they wanted to protect their child from further demands in a challenging everyday life. Two adolescents declined without any reasons provided. Ten adolescents consented to participate in the study of which five were males and five females, aged between 13 and 17 years (mean age 15 years). Nine adolescents had ADHD and one had ADD. In total, they had eight different MDs: type 1 diabetes (3), obesity (1), allergy (1), migraine (1), scoliosis (1), insomnia (1), ventricular extrasystoles (1), and precocious puberty (1). Five adolescents were recruited from the ADHD clinic, and five were recruited from the pediatric clinic.

Data collection

Data were generated through semi-structured interviews (Brinkmann & Kvale, 2018) at a time and location chosen by the adolescents. The interviewer (the PhD candidate) was unknown to the adolescents in advance.

A semi-structured interview guide with open-ended questions was used to capture the adolescents' perceptions of everyday life with co-existing ADHD and MD and the support received from parents and healthcare professionals. The interview guide is presented in Paper I (Enggaard et al., 2020a). The questions were phrased or rephrased based on the adolescents' responses and in different order according to the flow of the conversation (DeJonckheere & Vaughn, 2019). Additionally, the answers to the open-ended questions were probed by mirroring and follow-up questions specific to place, time, or person (Christian et al., 2010). The interviews lasted between 47 and 70 minutes (on average 58 minutes) and were audio recorded.

Data analysis

The interviews were transcribed verbatim and analyzed using thematic analysis. The analysis was driven by the data content and consisted of a six-phase, non-linear process (Braun & Clarke, 2006, 2013). The PhD candidate became familiar with the

data in the first phase. The PhD candidate listened to the interviews and read the transcripts several times to get to know the content of the data. Codes were generated in the second phase. The transcripts were read line by line, and data relevant to the research questions were extracted. Extracted items were allocated one or more codes capturing the essence of the text. This was done with all transcripts and resulted in many distinct codes. All codes were compared in order to find similarities and differences between the codes. This process resulted in development of a new set of codes that were broad enough to capture similarities and narrow enough to show differences across data. The new set of codes was used to recode all the data. The search for themes began in the third phase. Codes were examined to understand what the content meant in relation to the research questions. This examination generated patterns between the codes, which were conceptualized into candidate themes. This was an iterative process, as ideas on patterns and themes called for further exploration of data, which refined the patterns and altered the candidate themes. The themes were reviewed in the fourth phase. Codes assigned to each theme were examined to determine if data were coherent and meaningful. Furthermore, themes were compared to define the boundaries between themes. The themes were defined and named in the fifth and sixth phases. Codes allocated to each theme were interpreted and transformed into narratives and illustrated by selected quotes and examples from data. The PhD candidate discussed all analysis phases with the supervisors. Moreover, NVivo qualitative data analysis software, QSR International Pty Ltd. Version 12 Pro (Edhlund & McDougall, 2019) was used to manage the analysis of data.

5.4. **STUDY 2**

A mixed methods convergent design was used to evaluate the clinical outcome of the GSD-ADHD-MD intervention. Quantitative and qualitative data were collected from the same participating adolescents and analyzed separately. (Creswell & Plano Clark, 2018; Fetters et al., 2013). The mixed methods convergent design is visualized in Figure 3 (Phase 2a). This design used matching to ensure that the quantitative and qualitative data related to the same key constructs (support from nurses, support from parents, and self-management) (Fetters, 2020, p. 126; Moseholm & Fetters, 2017). The quantitative and qualitative findings were integrated through merging to achieve a more comprehensive understanding of the impact of the GSD-ADHD-MD intervention (Creswell & Plano Clark, 2018, pp. 68–71, 187–191; Fetters et al., 2013). The quantitative and qualitative strands are described in more detail in the sections that follow.

Participants

Twenty-two eligible adolescents were invited to participate in the study evaluating the GSD-ADHD-MD intervention, and 10 adolescents with co-existing ADHD and MD volunteered to participate. The participants are presented in section 6.2

Quantitative strand

Data collection

Quantitative data were collected using three self-reported questionnaires at three points in time: baseline, after three months, and after six months. The quantitative data was collected at the adolescents' family homes using the RedCAP electronic data capture tool hosted by the Region of Northern Denmark (Harris, 2012).

The Health Care Climate Questionnaire (HCCQ) was used to measure support from nurses (Center for Self-Determination Theory, 2020b). HCCQ measures the degree of autonomy support that patients perceive from healthcare professionals. HCCQ consists of six items assessed on a 7-point Likert scale where 1 represents "strongly disagree," 4 "somewhat true," and 7 "strongly agree." The total score is the average of the item scores, and higher scores indicate higher support for autonomy. In this study, the midpoint of the Likert scale (4 = somewhat true) was used as the cut-off for perceived autonomy support (Keogh et al., 2018). HCCQ has previously been used to evaluate the GSD intervention (Husted et al., 2011; Karlsen et al., 2016; Mohn et al., 2017; Olesen et al., 2016; Zoffmann & Lauritzen, 2006; Zoffmann et al., 2015).

The Perception of Parents Scale (POPS) was used to measure support from parents (Center for Self-Determination Theory, 2020a). POPS measured the adolescents' perceptions of the degree to which they experienced parental support. POPS consists of 42 items divided into six subscales, each representing a dimension of parental support: maternal autonomy support (nine items), maternal involvement (six items), maternal warmth (six items), paternal autonomy support (nine items), paternal involvement (six items), and paternal warmth (six items). The adolescents were instructed only to respond to items referring to a parent or stepparent with whom they have a relationship—meaning that if they did not have a relationship with their father or a stepfather, they did not respond to items on the three paternal subscales. POPS uses a 7-point Likert scale where 1 represents "strongly disagree," 4 "somewhat true," and 7 "strongly agree". The subscale scores were calculated by averaging the items scores within a given subscale, but before doing so the scores of certain items was be reversed. This meant that the item score for these items were subtracted from eight and the result was used as the item score. Higher score on the subscales signifies higher levels of perceived autonomy, involvement, and warmth. As with the HCCQ, the midpoint of the Likert scale (4 = somewhat true) was used as the cut-off for autonomy support, involvement, and warmth. POPS has previously been used to evaluate a GSD intervention (Husted et al., 2011).

The Patient Activation Measure (PAM) was used to measure perceived self-management (Hibbard et al., 2005; Maindal et al., 2009). The items in PAM address the patient's knowledge, confidence, skills, and behaviors for self-management of

health. PAM consists of 13 items, and each has five response options ranging from "disagree strongly" to "agree strongly," including the possibility to respond "not applicable." Responses are mechanically converted to a score ranging from 0 to 100, classifying the patient into one of four levels of patient activation: Level 1: The patient is overwhelmed and passive in managing their own health; level 2: The patient lacks knowledge and confidence to manage their own health; level 3: The patient takes action but still lacks skills and confidence to support management of their own health; level 4: The patient has developed new behaviors to manage their own health but struggles to maintain the new behavior under stress. PAM has previously been used to assess adolescents' self-management of various chronic medical disorders (Haas et al., 2017; Huang et al., 2014; Schmidt et al., 2016) and in a study evaluating the GSD intervention (Simonsen et al., 2019).

Statistical analysis

The distributions of PAM levels and HCCQ levels were visualized on a swarm plot at the three time points: baseline, three months, and six months. HCCQ scores were rounded to the nearest integer to provide the HCCQ level. POPS scores were reported as medians together with the 25% and 75% quartiles, thus giving the interquartile range, and the distribution was compared visually on a boxplot distinguishing mothers and fathers at each of the three points in time. The analyses were performed using the software program STATA 16 (StataCorp, 2019).

Qualitative strand

Data collection

Qualitative data were generated through individual semi-structured interviews (Brinkmann & Kvale, 2018; DeJonckheere & Vaughn, 2019) with the adolescents in their private homes just after they completed the questionnaires (PAM, HCCQ, and POPS) at six months. The interview guide included open-ended questions reflecting the adolescents' experiences with the GSD-ADHD-MD intervention, including their perceptions of how the intervention impacted support from the nurse and their parents and their management of co-existing ADHD and MD. Additionally, the interview guide comprised open-ended questions that were matched, to explore, from a qualitative approach, constructs that were measured in the quantitative questionnaires (PAM, HCCQ, and POPS). See Table 2, for example. The interviews lasted between 14 and 84 minutes (average of 52 minutes).

Thematic analysis

Transcripts of the audio-recorded interviews were subject to thematic analysis as described by Braun and Clarke (Braun & Clarke, 2006, 2013). The transcripts were coded using predefined codes equivalent to the three constructs assessed in the

quantitative questionnaires. Additionally, it was important to code data that did not align with the predefined codes. Table 3 shows the connection between constructs, questionnaires, and the deductive and inductive codes. All the codes were explored to identify themes describing the adolescents' perceptions of the impact of GSD-ADHD-MD intervention. Phases three to six of the thematic analysis follow the process as the one described for Study 1. The software program NVivo (12 pro) (Edhlund & McDougall, 2019) was used to manage the analysis of data.

Table 2. Examples of matching interview guide questions to the HCCQ questionnaire

HCCQ item	Interview questions
	• In your experience, has the nurse done things differently than during your usual visits to the clinic? • How did you use the reflection sheets in conversations with the nurse? • What were the pros and cons of bringing your parents/being alone with the nurse during the meetings?
• I feel understood by my nurse. • My nurse encourages me to ask questions	• How was your relationship with the nurse?
• My nurse listens to how I would like to do things • My nurse tries to understand how I see things before suggesting a new way to do things • I feel that my nurse has provided me choices and options	• What has it been like to work with the nurse during the sessions?
• My nurse conveys confidence in my ability to make changes	• How would you describe the nurse's confidence in your ability to manage difficulties in living with ADHD and [specific MD]?

Table 3. Qualitative analysis: Matching constructs, questionnaires, and codes (Enggaard et al., 2020b)

Construct	Source	Qualitative Codes
Support from nurses	Deductive (HCCQ)	Support for autonomy Support for relatedness Support for competence
	Inductive	Don't like to talk about myself with adults
Support from parents	Deductive (POPS)	Mom/Dad support for autonomy Mom/Dad involvement Mom/Dad warmth
	Inductive	Mom and Dad are as they usually are
Self-management	Deductive (PAM)	Self-management knowledge Self-management confidence Self-management skills and behavior
	Inductive	I have no difficulties to manage I want to come to the clinic, but I can't if I don't take the recommended medication

Mixed methods integration

Integration of the quantitative and qualitative findings was achieved through merging; that is, the quantitative and qualitative findings were compared to assess how they confirmed, expanded, or contradicted each other and to draw out metainferences about each of the three main constructs (support from nurses, support from parents, and self-management) (Creswell & Plano Clark, 2018, p. 71; Fetters et al., 2013). *Confirmation* occurred if the findings of the one type of data confirmed the findings of the other. *Expansion* occurred if the findings of the two data sources diverged and expanded insights on the construct in question by describing complementary aspects of that construct. *Discordance* occurred if the quantitative and qualitative findings conflicted or disagreed with each other (Fetters et al., 2013).

To merge the findings, qualitative themes and descriptive statistics were compared in a back-and-forth process framed by the three main constructs (support from nurses, support from parents, and self-management) (Moseholm & Fetters, 2017). Joint display analysis was used to achieve integration of the two types of findings. Specifically, the analysis was facilitated by constructing and restructuring joint displays to best elucidate a full understanding of both types of information, when carefully considered together (Fetters, 2020, pp. 206–207; Fetters et al., 2013; Guetterman et al., 2015). The final joint displays are presented in Paper II and section 6.2 in this thesis, alongside an integrated narrative of the mixed methods inferences (Fetters et al., 2013; Guetterman et al., 2015). The narratives used a weaving approach where the quantitative and qualitative findings were written together on a concept-by-concept basis (Fetters et al., 2013).

5.5. STUDY 3

This study evaluated the feasibility and acceptability of the GSD-ADHD-MD intervention. The study was conducted parallel with Study 2 and with the same participants as in Study 2. The connection between Studies 2 and 3 are visualized in Figure 3.

The methods used to evaluate feasibility and acceptability were different. Thus, the data collection and data analysis used to evaluate feasibility and acceptability will be presented separately in the following.

Data collection and data analysis

Feasibility

Feasibility was in this study defined as "*the extent to which a new treatment, or an intervention, can be successfully used or carried out within a given agency or*

setting" (Proctor et al., 2011). Feasibility was evaluated in relation to recruitment, retention, and participation rates (Proctor et al., 2011) to understand how the intervention was used by the adolescents with co-existing ADHD and MD in the two outpatient clinics. The PhD candidate monitored the recruitment process, the nurses who delivered the intervention logged (study record) name of the participant, additional attendees such as mother or father, duration of the session in minutes, and whether the reflection sheets had been filled out beforehand. Basic descriptive statistics were used to summarize data on recruitment, retention, and participation rate.

Acceptability

Acceptability was in this study defined as *"the perception among implementation stakeholders that a given treatment, service, practice, or innovation is agreeable, palatable, or satisfactory"* (Proctor et al., 2011). To understand if the intervention was acceptable to those receiving it, acceptability was evaluated based on adolescent perceptions of the GSD-ADHD-MD intervention after the intervention had ended. The evaluation examined three dimensions; content, complexity, and comfort. The *content* of the GSD-ADHD-MD intervention included the dual focus on co-existing ADHD and an MD, flexibility of attending sessions alone or with parents, the four sessions for the adolescents, the single session for parents, and the reflection sheets. *Complexity* and *comfort* were interpreted based on the adolescents' perceptions of the content elements.

Individual semi-structured interviews were used to collect data, and nine adolescents participated in an interview of which seven had completed the GSD-ADHD-MD intervention. To capture the adolescents' perceptions of the content of the intervention, a semi-structured interview guide was used. The interview guide is presented in paper III (Enggaard et al., n.d.).

A thematic analysis was conducted on the transcribed interviews (Braun & Clarke, 2006, 2013). This analysis was driven by an interest in capturing the adolescents' perceptions of the content of the intervention, meaning that data on that was coded. Subsequently, the coded data were organized in subcodes according to the content elements of the intervention. Phases three to six of the thematic analysis follow the process as the one described for Study 1. In addition, the adolescents' perceptions of the content of the intervention were used to interpret the intervention's complexity and comfort. The software program NVivo (12 pro) (Edhlund & McDougall, 2019) was used to handle the analysis.

5.6. **ETHICAL CONCIDERATIONS**

Prior to the start of the PhD project, the research was approved by the Child and Adolescent Psychiatry Administration and Pediatric Administration at Aalborg

University Hospital. Furthermore, Study 1, Study 2, and Study 3 were approved by and registered at the Danish Data Protection Agency (2008-58-0028). In accordance with Danish law (Sundheds- og Ældreministeriet, 2017), Study 2 and Study 3 were exempted from full review and approval by the ethics committee of Northern Denmark because biological material was not collected as part of these studies.

The studies were carried out in accordance with the Declaration of Helsinki (WMA, 2013) and Ethical Guidelines for Nursing Research (Northern Nurses' Federation, 2003). The parents were gatekeepers for the adolescents to protect the adolescents from feeling pressured to participate by the presence of the healthcare professionals or the PhD candidate (Grady et al., 2014; Savage & McCarron, 2009). The participants were provided with written and oral information about the study prior to their written consent (Appendixes D and E) to ensure that they were fully informed about the purpose of the study, the extent of participation, and the gains or risks of participating (Savage & McCarron, 2009). Additionally, the participants were informed that participation was voluntary and that they were guaranteed anonymity and could withdraw their consent at any time without consequences (WMA, 2013). All adolescents were involved in the consent process to respect the adolescents' decisions on participation (Grady et al., 2014; Kirk, 2007). However, the written consent of adolescents younger than 15 years was only valid when written consent was also obtained from the parents (Sundhedsministeriet, 2018). The parents and the nurses participating in Studies 2 and 3 also signed written consent prior to their participation in the study.

5.7. RESEARCHER ROLE DURING DATA COLLECTION

Data for this PhD project was collected with quantitative and qualitative methods, which are based on different ontological and epistemological assumptions, affecting the researcher role differently.

Quantitative research views reality as singular and independent from the researcher (Creswell & Plano Clark, 2018, p. 37). Thus, the researcher strives for independence between the researcher and the object being investigated to obtain objective knowledge on the phenomena of interest. These assumptions influenced the design of Study 2 and Study 3 in that the collection of quantitative data (Study 2) was prioritized over the collection of qualitative data (Study 2 and Study 3).

The PhD candidate visited all adolescents at their family home with a tablet to collect the quantitative data on an online link to the RedCAP electronic database (Harris, 2012). The process of collecting the quantitative data was attempted to be made as systematic as possible to minimize the inflation of the data. For example, the adolescents were given the option of having the questions read out loud by the PhD candidate or of reading them themselves. When the adolescents asked the PhD candidate which response option matched their experience or opinion best, they

were all given the same answer that they should choose the response option they thought fitted best.

In contrast, qualitative research views reality as multiple and dependent on the researcher (Creswell & Plano Clark, 2018, p. 37), meaning that the researcher influences the generation of qualitative data. Qualitative data on the phenomena of interest is subjective and a product of the interactions between the researcher and the participant and in this PhD project generated through individual semi-structured interviews with adolescents.

Efforts were made to establish a relationship with the adolescents prior to the interviews. During the enrolment, the PhD candidate interacted primarily with the adolescent and the parents secondarily to show the adolescents that their opinions, experiences, and viewpoints matter to the PhD candidate and the research project.

Furthermore, during the interviews, the PhD candidate was aware of the power she had in relationships to the adolescents and efforts was made to ensure that the adolescents were comfortable and not pressured to share things they were not comfortable with (Flanagan et al., 2015; Savage & McCarron, 2009). For example, the researcher was attentive to pauses, which on one hand allow the participant to reflect (Brinkmann & Kvale, 2018, p. 70), but on the other hand can be a sign of discomfort. The PhD candidate therefore often addressed pauses to reassure the adolescents that they were not obligated to answer all questions. Furthermore, the PhD candidate explained what went on during the interviews, for example that follow-up questions were asked to make sure that the PhD candidate did not misunderstand the adolescents' experiences and opinions. The PhD candidate also reassured the participants during the interviews that there were not any right or wrong answers to the questions, as she was interested in the adolescents' experiences and opinions (Brinkmann & Kvale, 2018, p. 76). Although these matters were included in the oral information about the study prior to the written consent, it was important to concretize them during the interviews to ensure that the adolescents were comfortable during the interviews. These strategies led to a relaxed and trusting atmosphere in which the adolescents expressed themselves freely and told the PhD candidate if questions became too personal. Furthermore, the interview guides consisted of open-ended questions to allow the adolescents to give voice to their own experiences with their own words. However, open-ended questions are often more abstract, and the ability to think abstractly is being developed during adolescence (Sanders, 2013). The PhD candidate was therefore attentive to the adolescents' ability to elaborate on the questions and strove to use mirroring and probing questions (Brinkmann & Kvale, 2018, p. 67; DeJonckheere & Vaughn, 2019) that were specific as to time, place, or persons to concretize questions. These strategies were experienced to support the adolescents in elaborating further without leading the adolescents' responses.

CHAPTER 6. FINDINGS

This chapter presents a summary of the main findings of Studies 1, 2, and 3, and the summaries are based on papers I, II, III (Enggaard et al., n.d.; Enggaard et al., 2020a; Enggaard et al., 2020b).

6.1. STUDY 1

The analysis of data resulted in four themes: 1) ADHD perceived as part of the adolescent's self-understanding—yet with daily frustrations; 2) MD perceived as an interruption in everyday life; 3) ADHD and MD—an overlooked dual task; and 4) the need for supportive relationships in navigating ADHD and an MD.

ADHD perceived as part of the adolescent's self-understanding—yet with daily frustrations

This theme illustrates that the adolescents perceived ADHD as creating difficulties as well as advantages in their everyday life, and at the same time they also perceived ADHD as part of their self-understanding. They did not appear to distinguish themselves from the ADHD, as they described the difficulties as well as advantages of having ADHD as their personal traits. Despite perceiving ADHD as a part of their self-understanding, they were frustrated when ADHD influenced their everyday life negatively. However, the frustrations were often directed toward themselves rather than to the ADHD disorder. The adolescents seemed to expect and accept the consequences of having ADHD in their everyday life, as ADHD was perceived as part of their self-understanding and as something they could not do anything about.

MD perceived as an interruption in everyday life

This theme reflects the perceptions of living with an MD. The adolescents' everyday lives were affected in different ways depending on the type of MD they had. There were MDs such as overweight that did not present with direct symptoms but that made the adolescents stand out from their peers in terms of their physical ability or physical appearance. They longed to be like everybody else, and the sense of being different was intruding on their everyday life as it affected their self-understanding negatively. Others were limited in everyday life due to the symptoms of the MD, as they had to withdraw from activities until the symptoms disappeared or decreased, which caused frustration. Those with an MD such as diabetes or migraine had to monitor and respond to symptoms continuously to maintain their physical wellbeing. In all cases, the adolescents perceived the MD as interrupting everyday activities by creating limitations in daily life.

ADHD and MD—an overlooked dual task

This theme reveals the complex dual task of living with co-existing ADHD and MD, as the two interfere with each other in everyday life. Being limited in everyday life by the MD could elicit the symptoms of ADHD. Additionally, ADHD-related difficulties such as memory problems or inattention became more noticeable to the adolescents when these abilities were needed in management of their MD. Conversely, having ADHD often adds complexity to having an MD by making management of the MD more challenging. Mismanagement of the MD could affect their physical wellbeing or lead to guilt and shame when failing to follow treatment regimens of the MD. ADHD and the MD were connected with each other in daily life, creating a dual task, as a change in one of the disorders would influence everyday life with the other disorder. Despite being aware of the mutual interference between ADHD and the MD, the adolescents stated that they would rather be without the MD. This indicates that they overlooked the dual task, as they believed their difficulties would disappear if the MD was eliminated.

The need for supportive relationships in navigating ADHD and MD

This theme highlights the fact that adolescents needed supporting relationships in navigating the complexities of living with ADHD and MD. The adolescents sometimes imitated behavior and attitudes of peers or changed behavior when peers reacted negatively to them. In addition, they strove to be accepted by their peers, and some found peers to be more inclusive and understanding when they knew about their difficulties. By imitating and involving peers, the adolescents created supportive relationships that enabled their participation in youth activities.

The adolescents perceived parents and teachers as essential sources of support in managing the challenges of living with ADHD and MD. However, it was important that parents and teachers acknowledged their attempts to manage ADHD and the MD. It was also important for the adolescents to be involved in decisions related to the management of ADHD and the MD. The adolescents described how they often initiated conflicts if they felt devaluated by their parents and teachers by not being acknowledged or involved. On the other hand, the adolescents were more responsive to their support when they felt acknowledged and involved.

The adolescents found that healthcare professionals were willing to talk about any subject. However, they rarely initiated conversations with the healthcare professionals regarding their lives with ADHD and MD. They preferred to be passive and listen to the parents discussing their treatment with the healthcare professionals. In addition, the adolescents noticed that healthcare professionals either focused on their ADHD or their MD, but they had never questioned this practice.

6.2. **STUDY 2**

The baseline characteristics of the ten adolescents who initially started the GSD-ADHD-MD intervention are presented in Table 4. Seven adolescents completed the intervention, and three discontinued the intervention at the outpatient ADHD clinic.

Table 4. Baseline characteristics of participating adolescents

Sex	
(n = 7)	Male
(n = 3)	Female
Age	
(n = 6)	13 years
(n = 1)	14 years
(n = 1)	15 years
(n = 2)	17 years
Living situation	
(n = 3)	Mother and father
(n = 2)	Part-time with mother and father
(n = 3)	Mother
(n = 1)	Institution
(n = 1)	Own apartment
School/occupation	
(n = 4)	School, regular class
(n = 5)	School, special class
(n = 1)	Work, full time
Diagnosis of ADHD[1]	
(n = 9)	Attention deficit disorder with hyperactivity
(n = 1)	Attention deficit disorder without hyperactivity
Diagnosis of MD[1]	
(n = 3)	Obesity
(n = 1)	Epilepsy
(n = 1)	Allergy
(n = 1)	Constipation
(n = 1)	Migraine
(n = 1)	Cerebral palsy
(n = 1)	Ulcerative colitis
(n = 1)	Malnutrition (underweight)

[1](WHO, 2016)

Quantitative findings

The quantitative findings are given visually in the joint displays (Tables 7, 8, and 9) starting on page 58 in this thesis.

All of the participating adolescents had HCCQ levels of 4 or above at baseline, which indicated that all adolescents perceived their nurse to be autonomy-supportive before the intervention. Furthermore, the distribution of HCCQ levels at three months is comparable to baseline, with a small increase. Also, after six months, HCCQ levels were comparable to the levels at the three-month assessment except

for two adolescents who scored below level 4. The POPS scores did not change considerably from baseline to three and six months. The median is above 4 at baseline, three months, and six months on all six subscales, which means that the adolescents perceived their parents to be supportive, involved, and showing warmth before and after the intervention. There seems to be a slight increase in PAM-level over time with a higher frequency of PAM-level 3 and 4 at six months compared to baseline.

Qualitative findings

The analysis of the interview data resulted in four themes: 1) feeling recognized and supported; 2) developing confidence in self-management abilities through support and involvement; 3) gaining insight into living with co-existing ADHD and MD; 4) developing and maintaining strategies suitable for everyday life.

Feeling recognized and supported

During the intervention, adolescents noticed change of content in their encounters with the nurses, moving from discussing ADHD or the MD to discussing everyday life with both disorders. Talking about everyday life with both disorders made the adolescents feel recognized and supported, and they described nurses as attentive and engaged. This led to trusting relationships, in which they felt they could be themselves and talk about what was important to them. However, few adolescents were not comfortable talking about themselves or their difficulties with the nurse. The reflection sheets changed the content of the conversations with the nurses and prompted the adolescents to express their perceptions and experiences of living with co-existing disorders. In addition, the sheets facilitated the exchange of viewpoints between the adolescents and the nurses. By exchanging viewpoints, the adolescents found that a mutual understanding of their situation was created. Being understood by the nurses was essential to the adolescents' feelings of being recognized for and supported in their individual difficulties.

Developing confidence in self-management abilities through support and involvement

The adolescents found that the nurses trusted in their self-management abilities, which in turn made them gain greater confidence in their abilities to manage co-existing ADHD and MD. They noted that the nurses were interested in hearing their suggestions on how to manage living with ADHD and MD before the nurses shared their knowledge or ideas. Being involved by the nurses had a positive influence on their confidence and motivated them to develop new strategies in managing ADHD and MD. However, constructive and positive feedback was important to the adolescents, as it helped them maintain confidence in their self-management

initiatives. In contrast, a few disapproved of being involved, as they had expected the nurses to provide solutions to their difficulties without their participation.

Gaining insight into living with co-existing ADHD and MD

The adolescents found that the intervention supported them in gaining insight into their lives with co-existing ADHD and MD that was also insight into their difficulties as well as own role in managing these difficulties. The adolescents highlighted that the intervention focused on issues they had been unaware of. The adolescents described how they had to think and reflect about their lives with the co-existing disorders when they filled out the reflection sheets. This process and the conversations with the nurses helped them to understand how ADHD and the MD influenced their everyday life, which in turn increased their insight and awareness into their current difficulties in living with co-existing ADHD and MD. Insight into their current situation made the adolescents aware of their own role in managing co-existing disorders in daily living. The adolescents started to reflect about what they could do themselves in regard to their difficulties. In contrast, a few adolescents did not perceive themselves as having gained any new insight into their lives, as they did not feel any need to change.

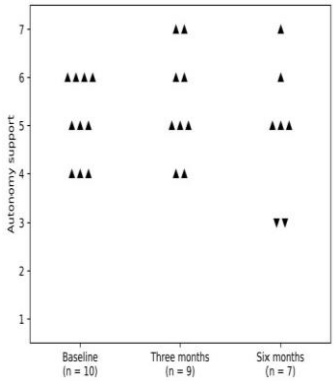
Developing and maintaining strategies suitable for everyday life

The adolescents developed self-management strategies that addressed the difficulties they had identified in their own life with co-existing ADHD and MD, and further, the strategies were developed to fit with their everyday life. These strategies were most often developed in collaboration with their parents and the nurse. Further, it was important to the adolescents that the strategies not only supported management of the distinct difficulty in living with co-existing ADHD and MD but that the strategy also made sense or added value to their life. The adolescents were engaged in developing self-management strategies as they took ownership of the strategies developed. However, they found it difficult to maintain their self-management strategies if routines or circumstances in everyday life changed.

Mixed methods integration

Three joint displays (Tables 5, 6, and 7) arrange quantitative findings beside qualitative findings for each of the three constructs. Subsequently, the mixed methods inferences are presented.

Table 5. Joint display of adolescents' assessments and experiences of support from nurses (Enggaard et al., 2020b)

Quantitative findings	**Qualitative findings**	**Mixed methods metainferences**
Extent to which adolescents experienced nurses as autonomy-supportive (HCCQ).  	**Feeling recognized and supported** ▲ Visits changed from a focus on ADHD or MD to talking about everyday life with co-existing disorders. The use of reflection sheets created opportunities for adolescents and nurses to exchange viewpoints. Being understood was essential to feeling recognized and supported in respect to individual difficulties. ▼ A few adolescents did not feel comfortable talking to their parents or other adults about themselves and their challenges. **Developing confidence in self-management through support and involvement** ▲ Being involved in developing strategies to manage everyday life had a positive effect on adolescents' confidence. Positive and constructive feedback was important for maintaining confidence in self-management initiatives. ▼ A few adolescents disapproved and expected nurses to identify solutions without participating in the decisions themselves.	▲ *Expansion* The qualitative results *expand* on the higher HCCQ levels over time by highlighting the importance of content change and involvement. ▼ *Discordance* The lower HCCQ levels at six months are *discordant* with the qualitative finding that a few adolescents disapproved of involvement and change of content.

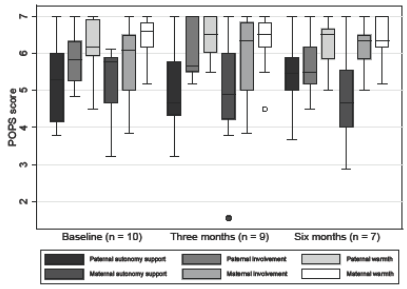
Support from nurses

The quantitative findings show a slight increase in high HCCQ levels at three and six months, suggesting that nurses were perceived to be more autonomy-supportive when delivering the intervention. This finding was *expanded* by qualitative findings highlighting the importance of talking about life with co-existing ADHD and MD, which was enabled by the reflection sheets. Being involved in developing self-

management strategies and getting feedback influenced adolescents' confidence in their self-management abilities positively.

At six months there were two lower levels at the HCCQ suggesting that two adolescents perceived the nurses to be uninterested in their perspectives about their issues and that the nurses provided solutions without involving them. These findings *diverged* from the qualitative findings, where a few adolescents expressed discomfort talking about themselves and said that they had expected the nurses to come up with the solutions without their participation in the decisions. Therefore, the additional insight from this interpretation is that these adolescents did not feel the nurses to be less autonomy supportive—rather, these adolescents were averse to being the center of the nurses' attention and involved in decisions regarding management of their co-existing disorders.

Table 6. Joint display of adolescents' assessments and experiences of support from parents (Enggaard et al., 2020b)

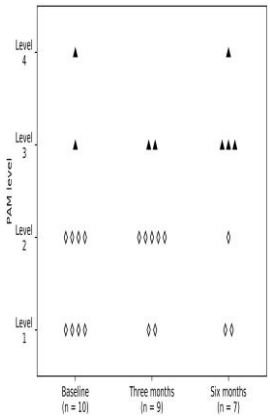
Quantitative findings	**Qualitative findings**	**Mixed methods metainferences**
Extent to which adolescents experienced parents as supportive*(POPS) 	**Feeling recognized and supported** Overall, the adolescents experienced no change in support from parents.	*Confirmation* POPS scores were high throughout the intervention, confirming the finding that adolescents did not experience parental change.

*The bottom edge corresponds to the 25% quartile and the top edge corresponds to the 75% quartile. The horizontal line is the median.

Support from parents

The quantitative findings on POPS show little variation among the three assessments within all six subscales. There was no clear trend over time, which suggests that the intervention had no impact on support from parents. This *corresponds* with the adolescents expressing that their parents had not changed. In conclusion, the integration shows that the GSD-ADHD-MD intervention does not influence parental support when assessed and explored from the adolescents' perspective.

Table 7. Joint display of adolescents' assessments and experiences of self-management (Enggaard et al., 2020b)

Quantitative findings	**Qualitative findings**	**Mixed methods metainferences**
Self-reported data on self-management (PAM*)  	**Gaining insight into living with co-existing ADHD and MD** ▲ Insight into their own lives enabled the adolescents to identify and describe their difficulties in living with co-existing ADHD and MD. ▲ Insight also helped them to understand their own role in managing everyday life with co-existing ADHD and MD. ◊ Few adolescents did not experience changes in insight following the intervention. **Developing and maintaining strategies suitable for everyday life** ▲ The adolescents developed self-management strategies that were tailored to align with their everyday lives and to address their personal challenges. ▲ New strategies supported management of a current difficulty but also had to make sense of or add value to their everyday lives. ▲ Adolescents took ownership of the self-management strategies developed during the intervention. ◊ It proved difficult to maintain strategies because the adolescents were not able to adjust their chosen strategies to changes in everyday life. **Developing confidence in self-management through support and involvement** ◊ A few adolescents disapproved of being involved in developing strategies in self-management. They expected the nurses to come up with solutions.	▲ *Expansion* Slight improvement in PAM levels at the three and six months are *expanded* upon by the qualitative results. ◊ *Confirmation* The PAM scores at level 1 are *confirmed* by the qualitative results.

*PAM: Level 1: Patient is passive and overwhelmed by managing own health. Level 2: Patient lacks confidence and knowledge to manage own health. Level 3: Patient takes action but still lacks confidence and skills to support management of own health. Level 4: Patient has developed behaviors to manage own health but struggles to maintain those behaviors under stress.

Self-management

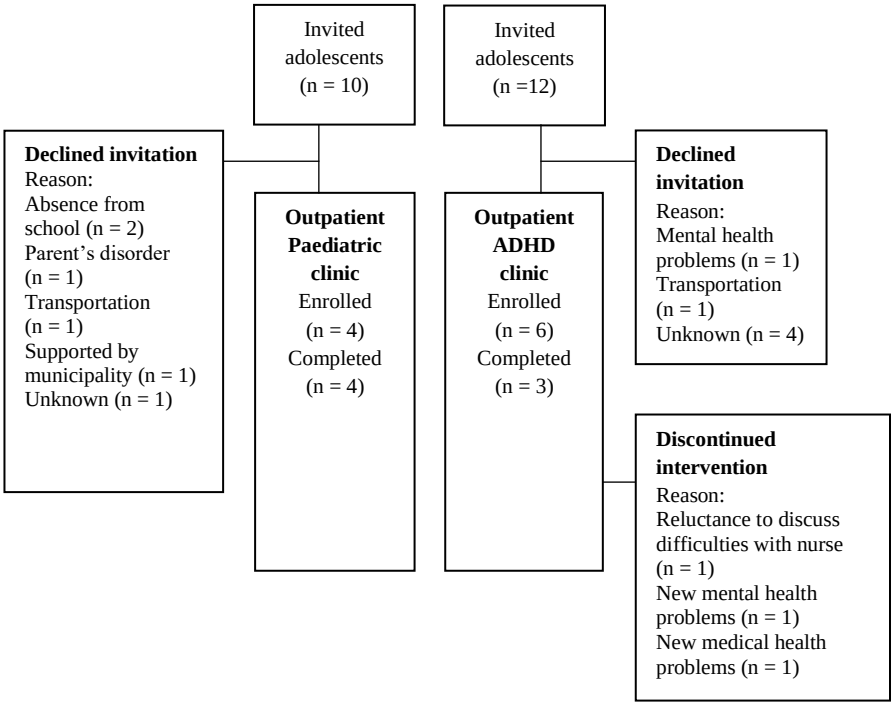
The quantitative findings on PAM show that more adolescents scored at PAM level 3 and 4 at six months compared to baseline, suggesting an increase in the adolescents' confidence, knowledge, and skills in managing co-existing disorders. This finding was *expanded* by the qualitative findings. The adolescents highlighted that gaining self-insight helped them to identify and describe their current difficulties in living with ADHD and MD. Further, this insight led to awareness of their own role in developing self-management strategies to handle these difficulties. Furthermore, the PAM level 4 findings reflect that it can be a struggle to maintain self-management strategies under stress. The qualitative findings *expanded* this finding, as the adolescents found it difficult of maintain self-management strategies if routines of their everyday lives changed. Finally, after three and six months, there were some adolescents who remained at PAM level 1, which indicated a passive approach to self-management which was *confirmed* by the qualitative findings. For example, a few of the adolescents mentioned that they expected the nurses to come up with the solutions without their involvement. Overall, the integration enhanced the understanding by showing that insight into one's own life is essential for developing self-management strategies that fit with their daily living.

6.3. **STUDY 3**

Feasibility

The recruitment and retention rate are presented in Figure 4. Twenty-two adolescents were approached, and 10 volunteered to participate in the evaluation of the GSD-ADHD-MD intervention. The participants are presented in Table 4 in section 6.2. Three adolescents dropped out of the intervention, and seven completed it. The intervention was completed in 11 weeks by three adolescents, one used 15 weeks to complete the intervention, and three adolescents used between 20 and 23 weeks to complete the intervention. Four adolescents used longer than the recommended three months to complete the intervention due to rescheduling sessions. In two cases, one session was rescheduled because the appointment did not fit the families' schedules. In one case, the nurse rescheduled one session due to illness. In the last case, a family rescheduled two sessions, and further one session was rescheduled due to no-show of the adolescent.

Figure 4. Flowchart on participant recruitment and retention (Enggaard et al., n.d.)



The adolescents' engagement with the GSD-ADHD-MD intervention is presented in Table 8. Half of the adolescents aged 13 to 17 participated in the intervention sessions alone, and the other half of the adolescents aged 13 to 15 participated in the intervention sessions with a companion. Session 1 and Session 2 lasted about an hour on average, while Session 3 and Session 4 lasted approximately half an hour on average. Generally, more adolescents had filled out the reflection sheets for Session 1 and Session 2 compared to Session 3 and Session 4, and one adolescent had not prepared any reflection sheets before any of the four sessions. Parents of seven of the adolescents attended the intervention session for parents. In four cases, both the mother and the father attended, and in three cases only the mother attended the Parent Session. The duration of the Parent Sessions was nearly an hour on average.

Table 8. Engagement with the GSD-ADHD-MD intervention (Enggaard et al., n.d.)

Session **Participants** (n) **Duration:** min—max (mean)	**Reflection sheet**	**Completed** * (n)	**Incomplete** ** (n)
Session 1 Adolescents (n = 10) Mother present (n = 5) Duration: 35–80 minutes (60 minutes)	1.a Invitation to collaborate***	-	-
	1.b Important events and periods in your life with two disorders	9	1
	1.c What do you currently find challenging or difficult in living with two disorders?	9	1
	1.d Unfinished sentences—values, experiences, and needs	9	1
	1.e A picture, metaphor, or an expression you use to describe how it is for you to live with two disorders	6	4
Session 2 Adolescent (n = 8) Mother present (n = 2) Social worker present (n = 1) Duration: 30–68 minutes (48 minutes)	2.a Plans to change lifestyle with ADHD/ADD	7	1
	2.b Plans to change lifestyle with [name of the medical disorder]	7	1
	2.c Your experiences with different types of treatment	5	3
	2.d Your reality living with two disorders	7	1
	2.e Room for disease in your life	6	2
	2.f List of challenges or problems in your life with the disorders	6	2
Parent session Mother only (n = 3) Mother and Father together (n = 4) Duration: 27–70 minutes (58 minutes)	P.1 Invitation to collaborate (mom/ dad)***	-	-
	P.2 Unfinished sentences—values, experiences, and needs (mom/dad)	6/2	1/2
	P.3 Room for disease in your life (mom/dad)	5/2	2/2
Session 3 Adolescents (n = 7) Mother present (n = 2) Social worker present (n = 1) Duration: 25–45 minutes (35 minutes)	3.a Your previous approach to problem-solving—your observations	5	2
	3.b Your previous approach to problem-solving—your thoughts and feelings	5	2
	3.c Your previous approach to problem-solving—your goals and intensions	3	4
	3.d Your previous approach to problem-solving—your actions	4	3
	3.e Dynamic problem-solving	4	3
Session 4 Adolescent (n = 7) Mother present (n = 2) Social worker (n = 1) Duration: 10–35 minutes (23 minutes)	4.a New strategies and long-term plan	5	2
	4.b Whom to involve in further problem-solving	4	3

*Completed beforehand; ** Incomplete (not completed beforehand); ***Sheets that are not meant to be filled out beforehand

Acceptability

The analysis of the adolescents' perceptions of the content, complexity, and comfort of the intervention yielded four themes: 1) embedding the intervention in daily life; 2) appreciating the flexibility of the intervention; 3) discussing reflection sheets induced a change of content and engagement; 4) being supported or challenged by the content of reflection sheets.

Embedding the intervention in daily life

The adolescents participated in the intervention at different paces. Some preferred having sessions once a month, whereas others preferred having their sessions weekly or biweekly. If the sessions were planned too far apart, the adolescents worried that they would not remember topics discussed at the previous session. On the other hand, they were concerned that the GSD-ADHD-MD intervention would create too many interruptions in everyday life if sessions were held too often. Altogether, they appeared to accept the intervention, but it was more comfortable for the adolescents when the sessions were planned in accordance with their everyday life.

Appreciating the flexibility of the intervention

The flexibility of the intervention was important to the adolescents. Attending sessions in the way they preferred made participation more comfortable for them. Five adolescents participated in the sessions without their parents. Meeting with the nurse alone made them more involved and active in the conversations, which they accepted and appreciated. The other five adolescents participated in the sessions with a companion—often a parent. Having a companion seemed to make interactions with the nurse more comfortable for these adolescents, as the parent helped them to interact with the nurse as well as keep track of what was discussed or decided at the sessions.

The adolescents agreed to fill out reflection sheets before the sessions but did it in different ways. Four adolescents had a parent write their responses on the reflection sheets as they were uncomfortable writing, which indicates that it was a demanding task. Five adolescents filled out the sheets independently, and they did not share the reflection sheets with their parents, because they did not want their parents to propose changes to their answers on the sheets. In summary, even though these adolescents were comfortable preparing the sheets by themselves, it was a difficult task. Some were concerned about the sheets being misunderstood, and others found it challenging to put their thoughts into writing.

Furthermore, the adolescents accepted the parent session. They said that parents needed counseling on how to help their child in the best possible way. The

adolescents therefore saw the parent session as beneficial to themselves and accepted that the parents met with the nurse without their presence.

Discussing reflection sheets induced a change of content and engagement

The reflection sheets were an important part of the conversations with the nurses. Generally, the adolescents found that the reflection sheets changed the content of the outpatient visits into focusing on their everyday life with both ADHD and MD, which induced them to talk about issues important to them. Despite their acceptance of the dual focus of the intervention, it also caused uncertainty about what they could discuss with the nurse. The adolescents assumed that issues surrounding ADHD would be discussed with the nurses at the ADHD clinic, and issues relating to the MD would be discussed at the pediatric clinic because they were used to receiving healthcare for ADHD and their MD in separate clinics.

Furthermore, the sheets made conversations more focused, even when they were not prepared beforehand, as they helped the adolescents be aware of the topic being discussed. Those who had prepared reflection sheets further said that doing so prepared them to take an active role in the encounters with the nurse, as they knew what to say and what they wanted the nurse to understand about their situation. In contrast, some adolescents sometimes felt that the nurse hurried though the reflection sheets, which made the adolescents more reluctant to share their reflections regarding the sheets. This shows that the adolescents' engagement in the sessions depended on the nurses' approach to the conversations and the reflection sheets.

Being supported or challenged by the content of reflection sheets

The content of the reflection sheets seemed to support or challenge the adolescents, depending on the sheet. Overall, the sheets for Sessions 1 and 2 were more popular among the adolescents, whereas they did not have much to say about the sheets for Sessions 3 and 4.

The adolescents were especially comfortable with the reflection sheets focusing on everyday life: 1.b (Important events and periods in your life with two disorders), 1.d (Unfinished sentences—values, experiences, and needs), 1.e (A picture, metaphor, or an expression you use to describe how it is for you to live with two disorders), and 2.e (Room for disease in your life). These sheets were described as helping them gain a better understanding of their life with co-existing ADHD and MD because they provided an overview of their life or because the sheets made them reflect on their lives with co-existing disorders, which were both enlightening and fun. The adolescents found that some of the sheets for Session 2 were more difficult to work with. For example, the layout of reflection sheets 2.a and 2.b (Plans to change lifestyle with ADHD/MD) confused the adolescents because they had to do several

things on the same sheet. In addition, reflection sheet 2.c. (Your experiences with different types of treatment) and 2.d (Your reality living with two disorders) challenged the adolescents, as they did not know or remember what kinds of treatment they have tried over the years or they did not know how to describe the influence of symptoms of ADHD and the MD on their everyday life. This indicates that reflection sheets were complex to the adolescents if the layout did not make sense to them or if the content related directly to the disorders and their treatment.

6.4. **MIXED METHODS FINDINGS**

The overall aim of the PhD project was to evaluate the impact of the GSD-ADHD-MD intervention on living with co-existing ADHD and MD among adolescents. The integration of findings of Studies 1, 2, and 3 led to three mixed methods findings: 1) becoming aware of the dual task of living with co-existing ADHD and MD; 2) being involved in managing co-existing ADHD and MD during outpatient visits; and 3) increasing awareness of parents' need of support. The following section presents the mixed methods findings in joint displays and narratives.

Mixed methods finding 1

Table 9. Joint display on mixed methods finding 1

<table>
<tr><th colspan="3">Becoming aware of the dual task of living with co-existing ADHD and MD</th></tr>
<tr>
<td>Study 1
ADHD perceived as part of the adolescents' self-understanding – yet with daily frustrations
• ADHD as part of who I am
ADHD and MD—an overlooked dual task
• Living with co-existing ADHD and MD creates a dual task
• Overlooking the dual task of living with co-existing ADHD and MD
The need for supportive relationships in navigating ADHD and MD
• Healthcare professionals focus on either ADHD or the MD</td>
<td>Study 2
Feeling recognized and supported
• Change of content—talking about everyday life with ADHD and MD
• Reflection sheets and conversations with the nurses helped to understand difficulties in living with co-existing ADHD and MD
Gaining insight into living with co-existing ADHD and MD
• Reflection sheets helped the adolescents to think about aspects of their lives that they usually did not consider
• Insight into their own situation led to reflects on their own role in managing co-existing ADHD and MD in everyday life
• A few did not achieve new insight into their lives
Developing and maintaining strategies suitable for everyday life
• Developing strategies to manage the identified difficulties in living with co-existing ADHD and MD
PAM: Self-management
<table>
<tr><th>PAM level</th><th>Baseline (N010)</th><th>3 months (N=9)</th><th>6 months (N=7)</th></tr>
<tr><td>4</td><td>1</td><td>0</td><td>1</td></tr>
<tr><td>3</td><td>1</td><td>2</td><td>3</td></tr>
<tr><td>2</td><td>4</td><td>5</td><td>1</td></tr>
<tr><td>1</td><td>4</td><td>2</td><td>2</td></tr>
</table>
</td>
<td>Study 3
Discussing reflection sheets induced a change of content and engagement
• Talking about important issues in living with co-existing ADHD and MD
• Focusing on both disorders caused uncertainty in the adolescents
Being supported or challenged by the content of reflection sheets
• Enlightening to work with the reflection sheets focusing on everyday life</td>
</tr>
<tr>
<td colspan="3">Metainferences
The finding incorporates different perspectives on living with co-existing ADHD and MD. The adolescents in Study 1 seemed to overlook the dual task of living with co-existing ADHD and MD as they expected their difficulties to vanish if they did not have the MD whereas most of the adolescents participating in the GSD-ADHD-MD intervention became aware of the dual task. In addition, awareness of the dual task seemed essential for developing self-management strategies in living with co-existing disorders. The integration suggests that the GSD-ADHD-MD intervention focusing on both disorders has the potential to help adolescents become aware of the dual task of living with co-existing ADHD and MD.</td>
</tr>
</table>

Table 9 presents the joint display for the mixed methods finding 1. This integrated finding incorporates different perspectives on living with co-existing ADHD and MD and suggests that the GSD-ADHD-MD intervention focusing on both disorders has the potential to help adolescents become aware of the dual task of living with co-existing ADHD and MD.

Study 1 revealed that having co-existing ADHD and MD created a dual task, as the two interfered with each other in the adolescents' everyday life. However, the study also showed that the adolescents seemed to overlook the dual task, as they expected that their problems would disappear if they did not have the MD. Study 2 *confirmed* and *expanded* on this finding. Adolescents in Study 2 had also previously overlooked the dual task of managing the interrelationship between ADHD and MD, as evidenced by the shift in their outlook during the intervention. Specifically, adolescents in Study 2 described how the intervention changed the focus of the encounters with the nurse from either ADHD or the MD alone to both disorders. The change in focus while using the reflection sheets increased their awareness of and insight into their difficulties in living with co-existing ADHD and MD. Study 3 further *expanded* on the findings of Study 1 and Study 2 by showing that the dual focus of the intervention permitted them to talk about what mattered to them without needing to distinguish between their disorders. Study 3 further revealed that the sessions and reflection sheets addressing everyday life with co-existing disorders were feasible and acceptable to the adolescents, especially because they helped them gain a better understanding of their situation with both disorders. Overall, the finding from Study 1 that adolescents overlooked the dual task of managing ADHD and MD was *confirmed* and *expanded* through evaluation of the GSD-ADHD-MD intervention in Study 2 and 3. Study 2 and 3 revealed that the intervention supports adolescents in exploring their lives with co-existing disorders and thereby has the potential to help the adolescents become aware of the dual task of living with co-existing disorders.

Though adolescents accepted the dual focus of the GSD-ADHD-MD intervention, Study 3 also revealed that the dual focus of the intervention challenged them. The adolescents expressed the expectation that ADHD-related issues would be discussed with the nurse at the ADHD clinic and issues related to the MD would be addressed at the pediatric clinic. This indicated that the adolescents were not used to addressing the dual task during healthcare visits, which to some degree *confirms* findings from Study 1. Study 1 showed that while the adolescents noticed that healthcare professionals primarily focused on one of their disorders, they never questioned this practice. The healthcare system therefore appears to constitute a barrier for the adolescents in their way of integrating the two disorders, as the adolescents seemed used to separating their difficulties in respect to the specialty of the hospital clinic they visited. However, the GSD-ADHD-MD intervention has the potential to overcome this barrier and provide an integrated focus on the adolescents' lives with co-existing disorders.

In Study 1, adolescents did not express any need for change in their self-management strategies, maybe because they accepted ADHD-related difficulties as something they could not prevent or change in everyday life, since ADHD was perceived as part of who they are. The integrated mixed methods findings of Study 2 *expanded* this finding. In Study 2, insight into living with both disorders was

essential for developing self-management strategies in living with co-existing disorders. This was reflected in both the increase of PAM levels 3 and 4 at three and six months and the qualitative findings. Understanding how ADHD and the MD influenced each other in their daily lives made them aware of their own role in managing their individual difficulties, which again motivated them to develop strategies targeting these concrete difficulties. This indicates that awareness of the dual task is the prerequisite for discovering the potential for change in one's own life. In addition, Study 2 demonstrated that a few adolescents did not achieve new insight into their lives, as they felt no need for changes, which seemed to prevent them for discovering the dual task of living with co-existing disorders. Study 3 showed that preparing reflection sheets was a demanding task and that some sheets were too complex for the adolescents to work with. It could therefore be that some adolescents did not become aware of the dual task of living with co-existing ADHD and MD because some elements of the intervention were too demanding. On the other hand, it could also be hypothesized that the GSD-ADHD-MD intervention may only be effective for those who are willing to explore their perceptions of having ADHD.

Mixed methods finding 2

Table 10. Joint display of mixed methods finding 2

Being involved in managing co-existing ADHD and MD during outpatient visits

Study 1

The need for supportive relationships in navigating ADHD and MD

- Healthcare professionals are willing to discuss any matter
- Adolescents take a passive role

Study 2

Feeling recognized and supported

- The reflection sheets helped the adolescents to share their experiences
- The reflection sheets provided engagement in the adolescents' perspectives
- A few adolescents were not comfortable talking about themselves

Developing confidence in self-management abilities through support and involvement

- Being involved influenced the adolescents' confidence positively
- Adolescents need constructive feedback to maintain confidence in self-management
- A few adolescents disapproved of being involved

Developing and maintaining strategies suitable for everyday life

- Taking ownership of the developed self-management strategies
- Maintaining self-management strategies could be challenging

HCCQ: Perceived autonomy support from nurses

HCCQ level	Baseline (N=10)	3 months (N=9)	6 months (N=7)
7	0	2	1
6	4	2	1
5	3	3	3
4	3	2	0
3	0	0	2

Study 3

Appreciating the flexibility of the intervention

- Attending sessions alone or with companion
- Preparing reflection sheets with or without parental support
- Preparing reflection sheets - a demanding task

Discussing reflection sheets induced a change of content and engagement

- Reflection sheets made conversations tangible
- The nurses' approaches influenced the adolescents' engagement

GSD-ADHD-MD sessions (ses.)

Ses. 1: 60 minutes on average
Ses. 2: 48 minutes on average
Ses. 3: 35 minutes on average
Ses. 4: 23 minutes on average

Meta inferences

The finding covers various perspectives on adolescents' involvement in the encounters with healthcare professionals and nurses. Adolescents with co-existing ADHD and MD in Study 1 did not request to be actively involved, as they preferred to have a passive role in the encounters with the healthcare professionals. However, most adolescents became active collaborators during the intervention, which suggests that the GSD-ADHD-MD intervention has the potential to support adolescents' involvement in managing co-existing ADHD and MD during outpatient visits.

Table 10 depicts the joint display for the mixed methods finding 2. This integrated finding covers various perspectives on adolescents' involvement in the encounters with healthcare professionals and nurses and suggests that the combination of reflection sheets and conversations with the nurse has the potential to support adolescents' involvement in managing co-existing ADHD and MD during outpatient visits.

Study 1 showed that the adolescents preferred to listen passively while their parents talked with the healthcare professionals. In addition, they perceived healthcare professionals as willing to talk about any subject, but they rarely took advantage of that opportunity. Together, these findings indicated that the adolescents preferred being passive and that they did not request to be actively involved in their outpatient visits. Because these participants did not have the opportunity to participate in the GSD-ADHD-MD intervention, this finding was *expanded* in Study 2. Study 2 revealed that most adolescents became active collaborators with the nurse during the GSD-ADHD-MD intervention, which was evident in the increase in the high HCCQ levels at three and six months for most of the adolescents and in the qualitative findings of Study 2. The interplay between the reflection sheets and the conversations with the nurses on everyday life with co-existing ADHD and MD supported the adolescents in becoming actively involved. This indicates that the GSD-ADHD-MD intervention has the potential to involve adolescents actively in the outpatient treatment. Findings of Study 3 further *expanded* this finding by revealing that the sheets created a focus and structure for the conversations enhancing the adolescents' acceptability of the intervention. In addition, Study 3 showed that adolescents became more hesitant in sharing their experiences if the nurse hurried through the reflection sheets. This *confirmed* that the combination of the reflection sheets and nurses' approach to the conversations (Study 2) were important means for helping adolescents become actively involved in their outpatient visits. However, it is important to notice that Study 2 also showed that a few of the adolescents expressed that they were uncomfortable talking about themselves with the nurses, which indicates that they might have preferred a passive role as the adolescents in Study 1 did.

The integrated findings of Study 2 demonstrated that being involved and supported by the nurses improved their confidence in their self-management abilities. Study 3 *expanded* this finding by revealing that the flexibility of the GSD-ADHD-MD intervention was important for the adolescents. Five of the adolescents were more comfortable attending the GSD-ADHD-MD intervention with their parents, as they needed parental support during the sessions and needed help in preparing the reflection sheets. Four adolescents chose to prepare the reflections sheets themselves without involving their parents, and five chose to attend GSD-ADHD-MD intervention sessions without their parents. It therefore seems important to tailor the GSD-ADHD-MD intervention to the individual adolescent, as it influenced their acceptability of the intervention and thereby their engagement with the intervention. In addition, the facts that half of the adolescents chose to fill out the reflection sheets by themselves and chose to attend sessions alone also indicate that some adolescents actually want to take responsibility for their own treatment when given the opportunity, such as with the GSD-ADHD-MD intervention. However, it is important to note that Study 2 also showed that a few of the adolescents disapproved of being involved as they expected the nurse to come up with the solutions to their difficulties.

Study 2 further revealed that some adolescents took on additional responsibility by developing new strategies for managing difficulties in living with co-existing ADHD and MD, though still in collaboration with their parents and the nurse. In addition, the adolescents expressed the need for positive and constructive feedback from the nurse to maintain self-confidence in their own self-management strategies as well as it was challenging to maintain the new self-management strategies in daily living. Study 3 seemed to reveal *contradicting* findings, as it was evident that the session 3 and 4 focusing on developing new strategies for self-management only lasted around 35 and 23 minutes on average, although they were planned to last 45–60 minutes. It is surprising that these sessions were shorter, taking the findings of Study 2 into account. However, it is not possible to draw any conclusion about why it was difficult to maintain self-management strategies in everyday life, why these sessions were of shorter duration, or whether there is a connection, as the adolescents did not share specific experiences on these sessions during the interviews for Study 3. Nevertheless, the interventions' ability to involve and support the adolescents in the sessions seemed important for enabling the adolescents to intervene in their own lives with co-existing ADHD and MD.

Mixed methods finding 3

Table 11. Joint display on mixed methods finding 3

<table>
<tr><th colspan="3">Increasing awareness of parents need of support</th></tr>
<tr>
<td>Study 1
The need for supportive relationships in navigating ADHD and MD
• The importance of parental support in daily living
• The importance of being acknowledged and involved by parents</td>
<td>Study 2
Feeling recognized and supported
• Not noticing any change in parental support

POPS: Parental support
<table>
<tr><th></th><th>Baseline (N=10)</th><th>3 months (N=9)</th><th>6 months (N=7)</th></tr>
<tr><td>POPS (median [Q25, Q75])</td><td></td><td></td><td></td></tr>
<tr><td>Maternal warmth</td><td></td><td>6.5 [6.2, 6.8]</td><td>6.3 [6.2, 7.0]</td></tr>
<tr><td>Maternal involvement</td><td>6.1 [5.0, 6.5]</td><td>6.3 [5.0, 6.8]</td><td>6.3 [5.8, 6.5]</td></tr>
<tr><td>Maternal autonomy support</td><td>5.8 [4.7, 5.9]</td><td>4.9 [4.2, 6.0]</td><td>4.7 [4.0, 5.6]</td></tr>
<tr><td>Paternal warmth</td><td>6.2 [5.9, 6.9]</td><td>6.5 [6.0, 7.0]</td><td>6.5 [5.8, 6.7]</td></tr>
<tr><td>Paternal involvement</td><td>5.8 [5.3, 6.3]</td><td>5.7 [5.5, 7.0]</td><td>5.5 [5.2, 6.2]</td></tr>
<tr><td>Paternal autonomy support</td><td>5.3 [4.2, 6.0]</td><td>4.7 [4.3, 5.8]</td><td>5.4 [5.0, 5.9]</td></tr>
</table>
* Responses on paternal support were at baseline (n=8), three months (n=7), and six months (n=6).</td>
<td>Study 3
Appreciating the flexibility of the intervention
• Accepted that parents had a separate intervention session</td>
</tr>
<tr><td colspan="3">Meta inferences
This finding includes different perspectives on parental support. In Study 1 the adolescents describe parental support in terms of what they need for parents to feel supported, whereas the adolescents in Study 3 talked about parental support in terms of the parents' support needs. This suggests that the GSD-ADHD-MD intervention's focus on parents in terms of a single session has the potential to expand the adolescents' perspective on parental support.</td></tr>
</table>

Table 11 shows the joint display for the mixed methods finding 3. This integrated finding included different perspectives on parental support. Overall, the finding suggests that the intervention's focus on parents has the potential to expand adolescents' perspective on parental support. The adolescents become aware of parents' support needs as a prerequisite for the parental support they wish to receive.

Study 1 showed that parental support was important to the adolescents' management of co-existing ADHD and MD in daily life. The adolescents further described how they were more receptive to parental support when they felt acknowledged and involved in their healthcare by their parents, whereas conflicts often arose if they did not feel acknowledged or involved. The integrated findings of Study 2 demonstrated that the GSD-ADHD-MD intervention's single parent session did not have an impact on parental support when assessed and explored from the adolescents' perspective. However, the scores on parental support (POPS) were high on all subscales at baseline and subsequent assessments for both mother and father, indicating that the adolescents were satisfied with the support they received from their parents. Nevertheless, Study 3 revealed that the adolescents acknowledged that their parents needed support for themselves as they accepted that parents had a session alone with the nurse. This finding *expanded* on Study 2, indicating that although the adolescents perceived their parents to be supportive, they also became aware of their parents' support needs. In addition, the adolescents in Study 1

described parental support in term of what they needed to feel supported by parents, whereas the adolescents in Study 3 described parental support in terms of what parents need in order to be supportive of the adolescents. This indicates that the GSD-ADHD-MD intervention's focus on parents in terms of the single parent session has the potential to expand adolescents' perspective on parental support. The adolescents seemed to become aware of parents' support needs as a prerequisite for the parental support they wished to receive.

CHAPTER 7. DISCUSSION

In this chapter the three mixed methods findings are discussed. There follows a discussion of the methodological strengths and limitations of the PhD project.

7.1. DISCUSSION OF THE MIXED METHODS FINDINGS

The purpose of the PhD project was to expand knowledge on the impact of the GSD-ADHD-MD intervention on living with co-existing ADHD and MD among adolescents. Findings of Study 1 reveal that living with co-existing ADHD and MD is a complex dual task that adolescents seem to overlook. Furthermore, Study 1 pointed to the need for interventions supporting patient involvement to help adolescents as well as nurses to address the dual task of living with co-existing disorders. Study 1 thereby provided the basis for adjusting and evaluating the GSD-ADHD-MD intervention among adolescents with co-existing ADHD and MD. While Study 2 suggests that the GSD-ADHD-MD intervention may have an impact on self-management and support from nurses but not on support from parents, the findings of Study 3 indicate that the feasibility and acceptability of the intervention varied in relation to the nurses' and adolescents' use of the reflection sheets and conversations. The integration of findings across all three studies led to three mixed methods findings: 1) Becoming aware of the dual task of living with co-existing ADHD and MD; 2) Being involved in managing living with co-existing ADHD and MD during outpatient visits; and 3) Increasing awareness of parents' need of support. These are discussed in response to the overall aim of the PhD project.

Becoming aware of the dual task of living with co-existing ADHD and MD

The findings showed that the adolescents were not used to addressing the dual task in any healthcare settings prior to the GSD-ADHD-MD intervention. The Danish secondary healthcare system covering hospital-based health services is highly specialized and organized by medical specialty (DHMA, 2015). The negative consequence of this situation is that healthcare professionals' ability to see patients as a whole tends to be impaired (Seemann & Gustafsson, 2016). Mental health nurses perceive themselves to lack skills, knowledge, and confidence in addressing patients' physical health needs (Happell et al., 2012), and vice versa for nurses within medical specialties (Alexander et al., 2016). The organizational structures of the healthcare system thereby create barriers for nurses to seeing the patients' healthcare needs from a more holistic perspective (Constand et al., 2014). This corresponds with present findings that adolescents prior to the GSD-ADHD-MD intervention were used to the healthcare professionals only addressing one of their disorders, and they were used to separating their healthcare needs according to the specialty of the hospital clinic they visited. This indicates that the organizational structures of the healthcare system prevent both the nurses and the adolescents from

addressing the dual task, which is problematic, as this study shows that the healthcare needs of individual adolescents are a dual task. Nevertheless, the GSD-ADHD-MD intervention seems to overcome these structural barriers. It might be because the reflection sheets supported the focus of the nurses on the adolescents' perspective of living with co-existing disorders, but it cannot be determined with certainty, as the nurses' perspectives have not been investigated in this PhD project.

The findings revealed that the GSD-ADHD-MD intervention focusing on both disorders has the potential to support adolescents in becoming aware of the dual task of living with co-existing ADHD and MD, and that awareness of the dual task is essential for developing self-management strategies. This process in development of self-management strategies corresponds with the process and purpose of the GSD intervention. GSD aims to support patients' development of life skills, so they are able to manage difficulties in living with a disorder (Zoffmann, 2004, p. 9). Life skills are the ability to solve problems in one's own life, and they are achieved through the problem-solving process. The combination of the reflection sheets and conversations with the nurse guides the patient through the problem-solving process by facilitating self-exploration leading to self-understanding, providing the basis for new actions that again are evaluated through feedback from these actions (Mullen, 1985, p. 40; Zoffmann, 2004, p. 102). This indicates that the GSD intervention has the potential to work as intended in adolescents with co-existing ADHD and an MD, although it was developed for adults with one disorder (Zoffmann, 2004), as the awareness of the dual task (self-understanding) seemed essential for developing self-management strategies in living with co-existing ADHD and MD. In addition, the problem-solving process is cyclic, meaning the feedback from actions (experiences with new self-management strategies) can lead to further self-exploration, enhancing the patient's self-understanding, which again can lead to more efficient self-management strategies (Mullen, 1985, p. 40). However, the GSD-ADHD-MD intervention consisted of four sessions, which meant that the adolescents were only guided through the process once. Difficulties maintaining self-management strategies in everyday life and working with problem-solving in the GSD-ADHD-MD intervention could also be related to difficulties with attention and working memory problems due to their ADHD (Kasper et al., 2012; WHO, 2016). Difficulties processing information leads to problems with remembering. Repetition improves the possibility of information being processed successfully and stored in the memory so that it can be recalled later. Despite awareness of the dual task and the willingness to manage difficulties differently, adolescents with co-existing ADHD and MD may have difficulties putting intentions into practice, and they may therefore need to repeat the problem-solving process before self-management strategies become integrated in their everyday life. This implies that four intervention sessions may not be enough to support adolescents' management of co-existing ADHD and MD.

Being involved in managing co-existing ADHD and MD during outpatient visits

This finding showed that the GSD-ADHD-MD intervention supported most of the participating adolescents in becoming actively involved in exploring their life with ADHD and MD in outpatient visits through the means of the reflection sheets and nurses' approach to the conversations. This suggests that the GSD-ADHD-MD intervention has the potential to facilitate patient involvement in adolescents with co-existing ADHD and MD. This is in line with the GSD intervention, which aims to facilitate patient involvement. Completing the reflection sheets at home prepares the patient for the conversation with the nurse, and the sheets further focus the conversation on issues that are currently difficult for the patient in living with the disorder (Zoffmann, 2004, pp. 92, 94). Meanwhile, this study adds that the reflection sheets also supported the adolescents when the sheets were not prepared prior to the sessions. According to the adolescents, the reflection sheets created focus and structure for the conversations, and the sheets further helped them express their viewpoints. A systematic review reports that adolescents with ADHD appreciate structure that allows for flexibility (Eccleston et al., 2019), which may be provided by the GSD-ADHD-MD intervention. The reflection sheets provided structure, but at the same time the intervention was flexible, as it was the adolescents who decided the content.

Several guidelines recommend that healthcare professionals support adolescent patients from the age of 12 years in becoming involved in their treatment to help them build independence and confidence in their own abilities to manage their disorders (Arianto et al., 2019; Danish Health Authority, 2019a; NICE, 2016). This PhD study suggests that there is a need for interventions such as the GSD-ADHD-MD facilitating involvement, as involvement appears not to be part of usual practice prior to the GSD-ADHD-MD intervention. This may in part be supported by Lipstein et al. (2016), who reported that parents of children and adolescents with ADHD are less likely to have experienced shared decision-making in regard to their child's treatment compared to parents of children and adolescents with asthma. The study concluded that these differences may relate to the type of disorder. It could therefore be argued that healthcare professionals might be more cautious about involving those with ADHD due to their difficulties with, for example, attention. However, this study showed that the GSD-ADHD-MD intervention has the potential to support involvement of adolescents with co-existing ADHD and MD in the outpatient visits.

Involvement of adolescents in hospital-based treatment and care should be tailored to the maturity of the adolescent, which is not strictly correlated to the age of the adolescent (Arianto et al., 2019; Danish Health Authority, 2019a). This is consistent with the findings of this PhD project showing that some adolescents were more comfortable involving their parents with the GSD-ADHD-MD intervention, whereas others chose not to involve their parents. Although maturity tends to be delayed by a

few years in those with ADHD (Vaidya, 2012), the present study showed that adolescents as young as 13 years old were among those who chose to involve and not to involve their parents. This supports that the right time to involve adolescents with co-existing ADHD and MD cannot be determined by age alone. Generally, there is a lack of research on adolescents with co-existing ADHD and MD, but a study reports that parents are more involved in disease self-management activities when the adolescents have co-existing ADHD and asthma compared to those with asthma only (Wenderlich et al., 2019). This implies that the maturity to be involved in managing co-existing ADHD and MD is more influenced by the ADHD than the MD. However, the present study did not record the severity of the participating adolescents' ADHD, and it is therefore not possible to conclude if it was the severity of ADHD that impacted whether the adolescents were involved with the intervention alone or with support from their parents. Furthermore, a few of the participating adolescents disapproved of being involved in developing self-management strategies, and they were uncomfortable talking with the nurse about difficulties in living with co-existing ADHD and an MD. One possible interpretation is that these adolescents were not mature enough to be actively involved in developing self-management strategies, which may explain their aversion toward involvement. Nevertheless, some of the participating adolescents approved of being involved, and some developed new self-management strategies, which suggests that the GSD-ADHD-MD intervention has potential to support independence and confidence in adolescents' own abilities in managing co-existing ADHD and MD. This is an important finding, as it underscores that empowerment (Funnell & Anderson, 2003) is achievable for adolescents with co-existing ADHD and MD, as the intervention supported them in identifying and achieving self-selected goals in everyday life with co-existing ADHD and MD. But the study also showed that involvement should be tailored to the needs and preferences of the individual adolescent.

Increasing awareness of parents' need of support

When the GSD intervention was adapted for this PhD project, the clinical management of the two participating outpatient clinics questioned whether resources should be spent on parent sessions without the presence of the adolescents. They argued that the patients are their primary concern and that parents are important relatives and partners in the adolescents' treatment and care. It was therefore a pragmatic decision for parents to be provided with a single session. The single parent session in the GSD-ADHD-MD intervention did not impact parental support, which may be because the adolescents were satisfied with parents' support, reflected in the high scores on POPS. Nevertheless, parenting a young person with ADHD is shown to be stressful, as conflicts tends to escalate when the child becomes an adolescent (Laugesen et al., 2016; Wiener et al., 2016). This is supported by Edwards et al. (2001), who report that conflicts are more frequent and intense in adolescent–parent relationships when the adolescents have ADHD compared to when they do not have ADHD. This indicates that parents are challenged in their

parenting role. It is possible that the adolescents in the present study did not experience conflicts in the relationships with parents or that they did not question conflicts with parents, as Study 1 suggests that adolescents accept that ADHD affects everyday life including the relationships with parents. Although the GSD-ADHD-MD intervention did not impact parental support, it still seems relevant to support parents, as parents are important allies in the adolescents' health management (Christie & Viner, 2005). However, it can be questioned whether that is feasible in clinical practice, taking the arguments of the clinical management into account.

In the relationships between parents and adolescents with ADHD, conflicts are primarily triggered by arguments about homework, hygiene, and bedtime (Garcia et al., 2019), whereas Study 1 suggests that conflicts are triggered by the way adolescents perceive parental support. This finding is in line with a systematic review showing that adolescents tended to initiate conflicts if their knowledge or experiences were not acknowledged by their parents or other adults (Eccleston et al., 2019). The present study shows that the GSD-ADHD-MD intervention's focus on parents has the potential to expand the adolescents' perspective on parental support, including awareness of the parents' support needs. Acknowledging parents' support needs may have a positive influence on the adolescent–parent relationship, and the quality of the adolescent–parent relationships is related to adolescents' wellbeing and disease management (Michaud & Suris, 2004; Nielsen & Bronwen Players, 2009, p. 22). For instance, adolescents with type 1 diabetes participating in a GSD group intervention described how gaining insight into the parents' perspective had changed their relationships, resulting in fewer conflicts (Brorsson et al., 2017). However, the adolescents with diabetes participated together with their parents in six out of seven GSD group sessions (Brorsson et al., 2019), whereas the adolescents in the GSD-ADHD-MD intervention did not participate in the parent session. This means that the adolescents in the present study did not gain insight into the parents' thoughts, worries, and behavior with regard to their disorders, as the adolescents with diabetes appreciated doing in the GSD group intervention (Brorsson et al., 2017). The rationale behind choosing not to have the adolescents present during the parents' session was that research has shown that parents tend to withhold information during hospital visits if their child with ADHD is present (Laugesen et al., 2017). However, it is not possible on the basis of the PhD project to conclude how parents are best involved in the GSD-ADHD-MD intervention, as the thesis

7.2. **STRENGTHS AND LIMITATIONS**

Methodological considerations of mixed methods research address the strengths and limitations of the individual quantitative and qualitative strands that comprise it, as well as the strengths and limitations of the mixed methods approach itself (Creswell & Plano Clark, 2018, p. 251; Fetters, 2020, pp. 224–225). In these sections, the

strengths and limitations of the mixed methods approach are discussed, followed by those of the quantitative and qualitative strands.

7.2.1. MIXED METHODS APPROACH

When designing a mixed methods study, Creswell and Plano Clark (2018, p. 251) recommend evaluating the strategies used to overcome potential validity threats. This PhD project used a mixed methods evaluation design that contained a convergent mixed methods component. These two designs pose unique potential validity threats (Creswell & Plano Clark, 2018, pp. 251, 253), which will be discussed in turn below.

Mixed methods evaluation design

The potential validity threats in a mixed methods evaluation design include 1) the absence of a model to frame the evaluation; 2) a lack of integration between the phases in the evaluation process (so that one phase builds upon the previous one); and 3) the absence of a core mixed methods design (or designs) in the evaluation process (Creswell & Plano Clark, 2018, p. 253).

In this PhD project, the MRC framework for developing and evaluating complex interventions framed the evaluation of the GSD-ADHD-MD intervention in adolescents with co-existing ADHD and MD. The MRC framework stresses that interventions should be developed in accordance with the needs of the target population (Craig et al., 2008), justifying the aim of Study 1. The aim of Study 1 was to explore adolescents' perceptions of living with co-existing ADHD and MD, which goes beyond an exploration of their needs for support, which is recommended by the MRC framework. As described in the background section, the aim of Study 1 was chosen because of the general lack of knowledge about the perspectives of adolescents living with co-existing ADHD and MD. However, the qualitative findings on the adolescents' support needs would likely have been more nuanced and detailed if that had been the only aim of Study 1. The MRC framework also emphasizes the need for preliminary investigations of uncertainties about the intervention, as well as investigations of the feasibility and acceptability of the intervention (Craig et al., 2008), justifying the aims of Studies 2 and 3.

The second validity threat for the mixed methods evaluation design is lack of integration. In this PhD project, integration occurred between phases such that the findings of the first phase were used to build the intervention that was evaluated in the subsequent phases. In addition, this multiphase mixed methods evaluation design led to integrated findings (Creswell & Plano Clark, 2018, p. 13; Fetters et al., 2013), confirming the strength of the design in addressing the overall aim of the PhD project. However, it is important to note that since the three studies had different aims, not all of the study findings could be integrated.

Mixed methods convergent design

The potential validity threats in a mixed methods convergent design include 1) lack of parallel constructs in the quantitative and qualitative data collection; 2) not integrating the quantitative and qualitative findings; and 3) unequal sample sizes in the quantitative and qualitative strands (Creswell & Plano Clark, 2018, p. 251). The validity threat regarding lack of parallel constructs was averted by collecting quantitative and qualitative data on the same three constructs (support from nurses, support from parents, and self-management). In relation to the second validity threat, the quantitative and qualitative datasets were collected with the purpose of comparing them, which is a strength, as it made merging the data possible. The third validity threat is unequal sample size. The sample sizes of the quantitative and qualitative strands were equal, which was both a strength and a limitation. It was a strength that the same participants provided data for the quantitative and qualitative strands because it was possible to compare the findings at the group level. It was a limitation because only 10 adolescents participated in Study 2; for this reason, the study did not exploit the strengths of the method used in the quantitative strand, which would have required more participants.

Finally, Creswell and Plano Clark recommend that researchers develop quantitative and qualitative research skills before conducting mixed methods research (2018, p. 14). Prior to the PhD project, the PhD candidate had only novice experience with qualitative methods and no experience with quantitative and mixed methods research, which was a potential threat to the rigor of the qualitative strands, quantitative strand, and the mixed methods approach. However, this was balanced by the establishment of a team of supervisors and consultants composed of experts in quantitative, qualitative, and mixed methods research. Yet, the concern is that the mixed methods research design might have been used at the expense of developing a more in-depth understanding of the methods used in the individual studies.

7.2.2. QUANTITATIVE STRAND

Quantitative data for Study 2 was collected through self-reported questionnaires and analyzed with descriptive statistics. Quantitative findings on the impact of an intervention are valid when they are caused by the intervention only (internal validity) and when the findings can be generalized to the population in general (external validity) (Onwuegbuzie, 2000). The validity of the quantitative findings was compromised by two major limitations: The small sample size and the lack of a control group. Therefore, it cannot be ruled out that the answers were influenced by factors other than the intervention. Overall, these limitations mean that the findings cannot be generalized to adolescents with co-existing ADHD and MD in general. However, the purpose of Study 2 was not to determine the effect of the intervention through the quantitative data. Instead, the purpose was to integrate the quantitative and qualitative findings to evaluate whether the intervention showed promise in

terms of its potential impact on support from nurses, support from parents, and self-management.

Finally, none of the questionnaires (HCCQ, POPS, or PAM) had been validated in an adolescent population with co-existing ADHD and MD, posing yet another limitation and compromising the validity of the findings. Since the questionnaires were not validated for this population, it is uncertain whether they measured what they aimed to measure (Bolarinwa, 2015). However, as mentioned in section 5.4, the PhD candidate was present when the adolescents answered the questionnaires, and the participants often commented aloud when they answered the items. The adolescents often stated how they understood a question (item) and why they chose to respond as they did, indicating that the adolescents understood the questions (items) as intended, thereby supporting the face validity of the questionnaires (Bolarinwa, 2015). Their answers and comments were not discussed by the PhD candidate, to avoid influencing the participants' responses.

7.2.3. QUALITATIVE STRANDS

Data in Studies 1, 2, and 3 was collected through semi-structured interviews and analyzed thematically, although the thematic analysis was managed differently in each study. Due to these similarities, the strengths and limitations of the methods are discussed together in this section.

Malterud (2001) argued that the validity of qualitative research depends on reflexivity, interpretation during the analysis process, and transferability. Reflexivity is considerations on how the researcher influences development of knowledge. Reflexivity is important because researchers influence all aspects of the research process, including what they choose to investigate, which methods they use, which findings they decide most suitably address the study aim, and how they disseminate the findings and conclusions (Malterud, 2001). These choices are influenced by the researchers' backgrounds and positions, which constitute preconceptions. The aim of qualitative research is not to prevent such preconceptions from influencing the research process but to use reflexivity to account for these effects in order to ensure the credibility of the data and the findings (Whittemore et al., 2001).

The PhD candidate has a background as a nurse and a nurse educator and a special interest in empowerment and nursing care for patients with long-term or chronic disorders. The PhD candidate was not experienced with the nursing care of patients with ADHD or adolescent patients prior to this PhD project. Not being experienced in the nursing care of adolescents or in the field of ADHD can be considered both a strength and a limitation. On the one hand, this lack of experience helped the PhD candidate take an explorative approach when conducting the interviews instead of forming hasty conclusions about what it is like for adolescents to live with co-existing ADHD and MD (Study 1). On the other hand, the PhD candidate's lack of

experience with the population could have prevented her from asking follow-up questions on issues that were important to the adolescents. To address this concern, the PhD candidate used active listening to minimize the risk of misunderstanding the adolescents due to her own preconceptions. The PhD candidate summarized what was discussed in the interviews and explicitly invited each interviewee to confirm, add detail, or correct her interpretations, which enhanced the credibility of the data.

Furthermore, to improve reflexivity, Malterud (2001) recommends that researchers create meta-positions, which are strategies to establish an adequate distance from the participants and the data to allow reflexivity. For this reason, the PhD candidate discussed all methodological choices, as well as her experiences during the interviews, with the supervisors. In addition, during the interviews, the PhD candidate strove to be attentive and listen to the adolescents while simultaneously being reflexive about what was said and what needed to be addressed through follow-up questions, as well as how to ask these questions. Overall, a researcher needs to balance being engaged with the participants and their stories and maintaining a distance. Since the PhD candidate was a novice researcher, she sought to learn from her own experiences in order to improve her ability to balance attentiveness and reflexivity by re-listening to the previous interview before holding the next one and scrutinizing how she had managed her role as the interviewer.

Interpretation during analysis involves taking a systematic approach to data analysis, which is transparent to the reader (Malterud, 2001). Thematic analysis is described in the papers and the thesis, making it transparent to the reader. However, the analytical method does not guarantee the validity of the findings; researchers need to question the quality of the analysis, interpretations, and findings, as the analysis is inevitably influenced by their preconceptions (Malterud, 2001). The non-linear analysis process was deliberately applied to ensure the validity of the findings. The PhD candidate continually questioned her own understanding of the data by going back to the previous analysis phase to check the credibility of the interpretations and findings.

Malterud (2001) further argued that knowledge can never be derived from data alone but derived from the interactions between the data and the theories or concepts that are part of the researcher's preconceptions; therefore, Malterud recommend that the researcher display these theories and concepts prior to the analysis. This was not done in any of the three studies and therefore represents a potential threat to the validity of the findings, as the reader cannot assess which theoretical lenses have influenced the interpretation of the data.

The PhD candidate's background as a nurse educator for 10 years made it very difficult to display all the theories and concepts that may have influenced her interpretations. Nevertheless, the PhD candidate was aware of some theories that may have influenced her interpretation. For example, for Study 2, the PhD candidate

was aware of the theoretical framework behind the intervention and the three constructs under evaluation. This helped her question the analysis, findings, and interpretations being developed because she became extra alert when the findings seemed to fit with the theories, identifying a situation in which the analysis process might have been subverted by her preconceptions. To minimize this, checking the data in an iterative manner was important to ensure that the analysis and findings were consistent with the data even though the findings were a product of the PhD candidate's interpretations. In addition, the analysis, findings, and interpretations were continually discussed with the PhD candidate's supervisors, which helped her become aware of preconceptions she had been blind to herself.

Transferability concerns the application of qualitative findings beyond the context of the study, and it is related to the sampling approach (Malterud, 2001). To support transferability, researchers need to recruit participants who have experiences that are relevant to the study aim, and the sample needs to vary with respect to the factors studied to support the representativeness of the findings. Furthermore, contextual knowledge about the setting and the participants is needed because only the reader can judge whether the findings can be considered relevant for other contexts by considering both what and whom the study findings cover (Malterud, 2001).

The setting and the participants of the studies are described in papers I, II, and III and in this thesis. Although the reader may question whether there is enough contextual information to determine the transferability of the study findings, ethical considerations about the anonymity of the participants were prioritized and restricted how much information could be shared about the participants. Furthermore, it could be considered a limitation that the participants had different MDs co-existing with ADHD because it made the study samples heterogeneous. However, this could also be considered a strength because the study sample represents the types of adolescent patients that the nurses encounter, thereby enhancing the transferability of the findings.

The sampling approach also concerns the sample size. Brinkmann and Kvale argue that researchers must interview as many participants as needed to answer the research question, which they found to be between five and 25 participants (Brinkmann & Kvale, 2018, p. 49). In all three studies, the data were collected and subsequently analyzed, which meant that, at the time of data collection, the PhD candidate did not know whether enough participants had been included to generate the data needed to meet the study aim; this was a potential limitation. However, as written in Paper I, Delmar argues that there is something common within the participants' unique experiences (2010). The themes developed for all three studies reflected the similarities and differences in the qualitative data regarding the study aim. Still, it cannot be denied that the findings of all three studies might have been more nuanced and detailed if more participants had been included.

CHAPTER 8. CONCLUSION

This PhD project aimed to explore adolescents' perception of living with co-existing ADHD and MD and evaluate clinical and implementation outcomes of the GSD-ADHD-MD intervention among adolescents with co-existing ADHD and MD. In response to the overall aim, the findings of Studies 1, 2, and 3 were integrated. On the basis of the findings of Studies 1, 2, and 3 and the integrated findings, the following is concluded:

Adolescents living with co-existing ADHD and MD perceive both disorders to interfere with their everyday life. While the MD disorder is perceived as an interruption in daily living, the adolescents seem to accept that ADHD influences everyday life, as they perceive ADHD as part of their self-understanding.

Living with co-existing ADHD and MD is complex, as the two disorders interfere with each other in the adolescents' everyday life, creating a dual task that cannot be handled by dealing with the ADHD and MD separately. However, the adolescents seemed to overlook this dual task, believing that their difficulties would disappear if they did not have the MD.

The GSD-ADHD-MD intervention focusing on both disorders supported the adolescents and the nurses in having an integrated focus on living with co-existing ADHD and MD and thereby has the potential to help adolescents become aware of the dual task of living with co-existing ADHD and MD.

The combination of the reflection sheets and nurses' approach to the adolescents in the GSD-ADHD-MD intervention has the potential to support adolescents in becoming active collaborators with the nurse during their outpatient visits.

Evaluating the clinical outcome of the GSD-ADHD-MD intervention suggests that the intervention may improve adolescents' management of difficulties in living with co-existing ADHD and MD by increasing their understanding of the dual task and that support from nurses was essential for developing new self-management strategies. Additionally, the single parent session did not have an impact on parental support. However, the interventions' focus on parents may have the potential to expand the adolescents' perspective on parental support, including awareness of the parents' support needs.

Evaluating the implementation outcomes suggests that the intervention's ability to integrate both disorders and the use of the reflection sheets together with the nurse's involvement were feasible and acceptable to the adolescents. Additionally, the sessions and the reflection sheets focusing on everyday life were more feasible and

acceptable to the adolescents than those related to developing and evaluating strategies for managing difficulties in living with co-existing ADHD and MD.

Due to the positive aspects of the GSD-ADHD-MD intervention among adolescents with co-existing ADHD and MD, is it concluded that the intervention is recommendable for further research to forward the development of the GSD-ADHD-MD intervention for adolescents with co-existing ADHD and MD.

CHAPTER 9. PERSPECTIVES AND IMPLICATIONS

9.1. FURTHER RESEARCH

For the further development of the GSD-ADHD-MD intervention, it would be relevant to investigate the following:

Study 1 revealed that living with co-existing ADHD and MD is a complex dual task. However, the study showed differences in the adolescents' perceptions of living with MDs such as diabetes in which symptoms need to be monitored continuously and MDs like overweight that affect the adolescents' physical appearance or cause physical restrictions. Such differences may influence the dual task in living with co-existing ADHD and MD, and further research should therefore explore adolescents' perceptions of living with ADHD and a specific co-existing MD to enhance a more in-depth understanding of the dual task.

The intervention did not have an impact on parental support when investigated from the adolescents' perspective. Further research should explore the perspective of the parents to enhance the understanding of whether or how the GSD-ADHD-MD intervention best supports parents as important allies in adolescents' management of co-existing ADHD and MD.

Feasibility and acceptability of the intervention were only investigated from the perspective of the adolescents; further research should include the perspectives of the nurses delivering the intervention and the parents receiving the intervention to provide a more comprehensive understanding of the feasibility and acceptability of the intervention.

Evaluating the feasibility and acceptability of the intervention showed that sessions and reflection sheets focusing on everyday life were feasible and acceptable to the adolescents, whereas the sessions and sheets focusing on problem-solving were less feasible and acceptable to the adolescents. Thus, it would be relevant to explore how the nurses and the adolescents collaborate during the sessions and how they use the reflection sheets to identify potential reasons why sessions focusing on everyday life are more feasible and acceptable than sessions focusing on problem-solving.

The feasibility and acceptability study also showed that the layout and the content of some of the reflection sheets were complex for the adolescents to work with, which advocates for further adjustment of the sheets. We recommend that further adjustment of the reflection sheets apply participatory research methods involving

adolescents with co-existing ADHD and MD to ensure that the sheets target the needs and preferences of the adolescents and are easy to use for the adolescents.

9.2. IMPLICATIONS FOR CLINICAL PRACTICE

Living with co-existing ADHD and MD is a complex dual task that cannot be handled by dealing with the ADHD and MD separately, and adolescents seem to overlook this dual task. The findings also show that adolescents tend to take a passive role during usual outpatient visits, whereas the GSD-ADHD-MD has the potential to help the adolescents become aware of the dual task, to become actively involved in the encounters with the nurses, and to manage difficulties in living with co-existing ADHD and MD. This research provides several clinical implications for nurses who work with adolescents with co-existing ADHD and MD:

Nurses need to take the co-existing disorder into account when caring for adolescents with co-existing ADHD and MD, as the findings of this PhD project suggest that their individual healthcare needs are constituted by the dual task.

Nurses need to consider ways to support adolescents' active involvement in outpatient visits, as the present study shows that the adolescents want to be involved, but that they need support.

Nurses need to be aware that the "right" time for meeting with the adolescents without the presence of the parents is not exclusively determined by the adolescent's age.

The GSD-ADHD-MD intervention cannot be recommended to be integrated into usual outpatient visits in its current form as further adjustments are needed. However, the reflection sheets focusing on everyday life can be applied in clinical practice, as they support adolescents in exploring everyday life with co-existing disorders, and they provide a better understanding of their own situation. This is an important step toward empowerment.

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APPENDICES

Appendix A: Literature search
Appendix B: Empirical basis of GSD
Appendix C: GSD-ADHD-MD reflection sheets
Appendix D: Participant information
Appendix E: Consent form

Appendix A. Literature search

The purpose of the literature searches was to identify studies on interventions supporting adolescents' management of co-existing ADHD and MD in healthcare settings using the block search strategies in PubMed, CINAHL, and PsycINFO.

The blocks were ADHD, medical disorders, adolescents, and non-pharmacological intervention. ADHD was defined to include attention deficit disorder without hyperactivity (ADD). Medical disorders were not restricted to any particular medical disorders, and non-pharmacological interventions were defined as interventions that focused on psychological, social, or behavioral factors in order to support the adolescents' management of co-existing ADHD and MD (Kirk et al., 2012). However the interventions were allowed to be used in combination with pharmacological treatments, as the NICE guideline of ADHD recommend that patients are treated with a combination of medicine and non-pharmacological interventions (NICE guideline, 2018).

The block search organized search terms within each block. The search terms were a combination of thesaurus terms and free-text search. Search terms were first combined with the Boolean operator OR within each block. Subsequently the blocks were combined with AND. The search strategies applied in each database are documented below. However, the first search in PubMed (search 1) did not lead to any studies on interventions for adolescents with ADHD and a co-existing medical disorder. Thus, the search strategy was changed in regard to the block on medical disorder and adolescents. Search terms used in the block on medical disorders where replaced with thesaurus terms on the individual medical diagnoses that have been associated with ADHD in children and adolescents (see section 1.3). This is a potential limitation of the search, as there might exist studies on interventions for other medical diagnoses co-existing with ADHD than the ones included in these searchers. However, it was not feasible to search on all existing medical diagnosis prevalent in the pediatric population. Furthermore, the search was broadened to include children and adolescents to prevent excluding studies that target a wider age range then adolescence.

The search strategy was applied in PubMed, CINAHL, and PsycINFO, not restricted to a specific time frame. The search resulted in 25 studies. They were then screened at the title and abstract level, resulting in 21 studies being excluded. The remaining four studies were read in full text, resulting in three studies being excluded, one due to participants being under the age of 13 years, one because the participants did not have ADHD, and one because it was a systematic review on behavioral sleep interventions for children with co-existing ADHD and insomnia. The references of this review were searched for relevant primary studies, which resulted in identification of one relevant study. Furthermore, the reference list of all the studies relevant for full text reading were searched for additional studies, but without

identifying relevant studies. On the basis of this search, two relevant studies on interventions for adolescents with co-existing ADHD and MD were identified (Brown et al., 2015; Sciberras et al., 2011).

PubMed (search 1)

	AND			
	ADHD	**Medical disorder**	**Adolescents**	**Non-pharmacological interventions**
O R	"Attention Deficit Disorder with Hyperactivity" [MeSH]	"Comorbidity" [MeSH] "Chronic Disease" [MeSH] "Noncommunicable Diseases" [MeSH]	"Adolescent" [MeSH]	"Cognitive Behavioral Therapy" [MeSH] "Family Therapy" [MeSH] "Behavior Therapy" [MeSH] "Person-Centered Psychotherapy" [MeSH] "Patient Education as Topic" [MeSH]

Search preformed in PubMed
Terms: MeSH Restrictions: Years: none. Language: none. Date of last search: 17 April, 2020 Number of results: 73 Screening of title of abstract: None of the studies were on intervention for adolescents with co-existing ADHD and MD

PubMed (search 2)

	AND			
	ADHD	**Medical disorder**	**Adolescents**	**Nonpharmacological interventions**
OR	"Attention Deficit Disorder with Hyperactivity" [MeSH]	"Migraine Disorders" [MeSH] "Headache" [MeSH] "Diabetes Mellitus" [MeSH] "Pediatric Obesity" [MeSH] "Gastrointestinal Diseases" [MeSH] "Sleep Initiation and Maintenance Disorders" [MeSH] "Fecal Incontinence" [MeSH] "Enuresis" [MeSH] "Cerebral Palsy" [MeSH] "Asthma" [MeSH] "Allergy and Immunology" [MeSH])	"Adolescent" [MeSH] "Child" [MeSH]	"Cognitive Behavioral Therapy" [MeSH] "Family Therapy" [MeSH] "Behavior Therapy" [MeSH] "Person-Centered Psychotherapy" [MeSH] "Patient Education as Topic" [MeSH]

Search preformed in PubMed
Terms: MeSH
Restrictions: Years: none. Language: none.
Date of last search: 17 April, 2020
Number of results: 16 (When adolescents only were searched, there were only 8 hits)
Title of abstract: 13 studies were excluded
Full text reading: Three studies

CINAHL

	AND			
	ADHD	**Medical disorder**	**Adolescents**	**Nonpharmacological interventions**
OR	MM "Attention Deficit Hyperactivity Disorder"	MM "Pollen-Food Allergy" MH "Asthma+" MH "Cerebral Palsy" MH "Enuresis+" MM "Enuresis, Nocturnal" MH "Epilepsy+" MH "Incontinence+" MH "Insomnia+" MH "Gastrointestinal Diseases+" MH "Pediatric Obesity" MH "Diabetes Mellitus+" MH "Headache+" MM "Migraine"	MH "Adolescence+" MH "Child+"	MM "Nursing Interventions" MH "Patient Education+" MH "Cognitive Therapy+" MH "Behavior Therapy+" MM "Pediatric Physical Therapy" MM "Pediatric Occupational Therapy" MM "Family Therapy" TX "Psychosocial Intervention" TX "Self-management Intervention"

Search preformed in CINAHL
Terms: Cinahl Heading (MM) and free text (TX)
Restrictions: Years: none. Language: none.
Date of last search: 17 April 2020
Number of results: 6 hits
Title of abstract: 4 studies were excluded
Full text reading: Two studies. However, one of studies was also identified in search in PubMed

PsycINFO

	AND		
	ADHD	**Medical disorder**	**Nonpharmacological interventions**
OR	"Attention Deficit Disorder With Hyperactivity"	"Food Allergies"	"Self-Management"
		"Allergic Disorders"	"Client Education"
		"Headache"	"Online Therapy"
		"Migraine Headache"	"Personal Therapy"
		"Obesity"	"Narrative Therapy"
		"Gastrointestinal Disorders"	"Individual Psychotherapy"
		"Insomnia"	"Insight Therapy"
		"Epilepsy"	"Family Therapy"
		"Fecal Incontinence"	"Client Centered Therapy"
		"Urinary Incontinence"	"Cognitive Behavior Therapy"
		"Epilepsy"	"Cognitive Therapy"
		"Urinary Incontinence"	"Conversion Therapy"
		"Cerebral Palsy"	"Behavior Therapy"
		"Asthma"	"Digital Interventions"
		"Diabetes"	"Mindfulness-Based Interventions"
		"Physical Disorders"	"Video-Based Interventions"

Search preformed in PsycINFO
Terms: Thesaurus
Filter: Adolescences ages 13–17 years
Restrictions: Years: none. Language: none.
Date of last search: 22 April, 2020
Number of results: 3 hits
Title of abstract: 2 studies were excluded
Full text reading: 1 study. However, this study was also identified in the search in PubMed

Appendix B. Empirical basis of GSD

Grounded theory: Keeping life and disease apart

This figure was first published in Zoffmann, V., & Kirkevold, M. (2005). Life versus disease in difficult diabetes care: Conflicting perspectives disempower patients and professionals in problem solving. *Qualitative Health Research, 15*(6), 750–765. However, this version of the figure is published in Zoffmann, V., & Kirkevold, M. (2012). Realizing empowerment in difficult diabetes care: A guided self-determination Intervention. *Qualitative Health research, 22*(1), 103-118.

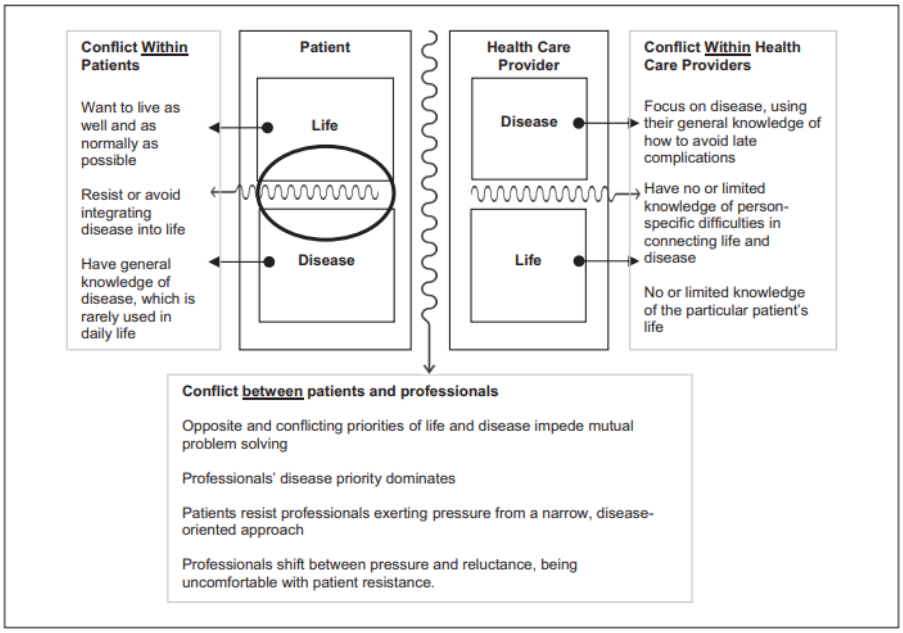
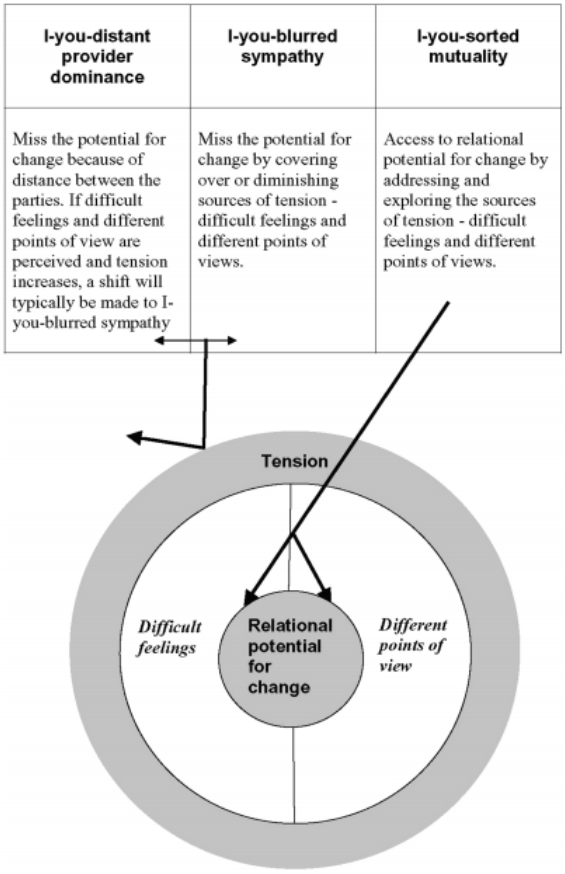


Figure 4. Resolving a life-versus-disease conflict by mutually focusing on the conflict within patients
From "Life versus disease in difficult diabetes care: Conflicting perspectives disempower patients and professionals in problem solving," by V. Zoffmann and M. Kirkevold, 2005, *Qualitative Health Research, 15*(6), p. 755. Copyright 2005 by Sage Publications. Reprinted with permission.

Grounded theory: Relational potential for change

This figure was published in Zoffmann, V., & Kirkevold, M. (2007). Relationships and their potential for change developed in difficult type 1 diabetes. *Qualitative Health Research*, *17*(5), 625–638.

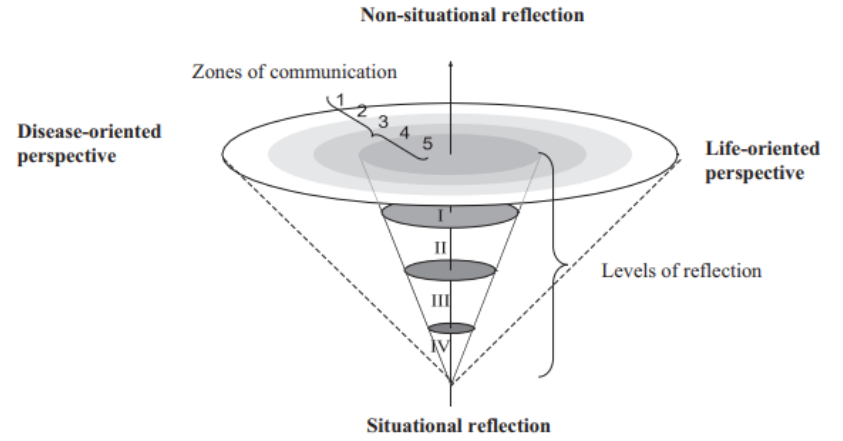
Figure 1
Relational Potential for Change and Its Connections With the Three Relationships



Grounded theory: Person-centered communication and reflection model

This figure was published in Zoffmann, V., Harder, I., & Kirkevold, M. (2008). A person-centered communication and reflection model: Sharing decision-making in chronic care. *Qualitative Health Research*, *18*(5), 670–685.

Figure 1
Person-Centered Communication and Reflection Model



Key: Zones of Communication 1-5

1. Addressing unrelated issues
2. Addressing general health-related issues
3. Addressing issues of general significance for the patient group
4. Addressing issues related to the patient but currently not difficult
5. Focused communication addressing issues currently difficult for the patient

Levels of Reflection	Situational Reflection	
	Health Care Professional's (HCP) Activity	Patient's Activity
I	Reflecting independently on observable signs of person-specific difficulties	Being observed; not engaged in HCP's reflection
II	Reflecting independently or with colleagues on non-observable aspects of person-specific difficulties; gathers information from the patient but does not inform the patient of the issues reflecting on or invite the patient to assess the difficulties; conjectures remain unverified	Contributing information, but not engaged in HCP's reflection or informed about the issues reflected on; not asked to verify or assess assumed difficulties
III	Engaged in mutual reflection with the patient, exchanging thoughts and ideas of explicit difficulties related to the patient's responses to living with the illness; conjectures verified and knowledge of person-specific difficulties is co-created; importance, causes, meanings and possible solutions clarified	Engaged in mutual reflection with HCP, verifying and exchanging thoughts and ideas of explicit difficulties related to living with the illness; co-creating person-specific knowledge of the importance, causes, meanings and possible solutions
IV	Though not participating in reflection, HCP can motivate the patient to start reflection, e.g., by asking value-clarifying questions or by pointing out possible inconsistencies in patient responses to illness	Reflecting independently; autonomously clarifying and reassessing own responses to and stand on specific difficulties

Appendix C. GSD-ADHD-MD reflection sheets

Guidet Egen-Beslutning

En ny begyndelse

Picture(colourbox.dk)

1

Kilde: Vibeke Zoffmann, 2004

Guidet Egen-Beslutning

Samtale 1 - Samarbejdsaftale & livet med sygdom

Dato: _____

Samtale 2 - Udfordringer i livet med sygdom

Dato: _____

Samtale 3 - Forandringsarbejde

Dato: _____

Samtale 4 - Forandringsarbejde

Dato: _____

Kilde: Vibeke Zoffmann, 2004

Samtale 1

Samarbejdsaftale & livet med sygdom

Invitation til samarbejde

Vigtige begivenheder og perioder før og nu

Hvad finder du svært og udfordrende at leve med for tiden

Ufuldendte sætninger

Billede, talemåde eller tilbagevendende tanker om livet med sygdom

3

Kilde: Vibeke Zoffmann, 2004

Invitation til samarbejde

Hvad skal vi samarbejde om?

- Vi vil udvælge noget, som opleves udfordrende eller svært for dig lige nu i livet med sygdom

Hvilken rolle har vi hver især?

- Både din, din mors, din fars og min viden og erfaring er nødvendig
- Vi skal bidrage aktivt og bruge tiden bedst muligt på noget, vi finder vigtigt
- Noget af tiden vil vi arbejde hver for sig, noget af tiden vil vi arbejde sammen

Hvordan skal samarbejdet være?

- Det er OK, at du, din mor, din far og jeg ser forskelligt på din situation
- Det er nødvendigt at vi kender hinandens opfattelser
- Det er OK, at du, din mor, din far og jeg er uenige
- Det er OK, at følelser kan opleves svære, og at de deles
- Det er **IKKE** OK, at nogen presser andre eller lader sig presse til at ændre mening

Hvad er fordelen ved arkene, og hvad skal de bruges til?

- Du kan bruge dem til i fred og ro at tænke over og blive klogere på din situation
- Vi kan bruge dem til at få overblik over, hvad der er vigtigt i din situation
- De kan gøre det lettere at snakke om det, der ellers kan være svært at snakke om
- De kan hjælpe dig til at tage beslutninger, der passer til dig
- Efter at du har brugt arkene, kan de fremover hjælpe dig med at holde fast i det, der er vigtigt for dig

Fra erfaringer med andre unge der har arbejdet med Guidet Egen-Beslutning, ved vi:

- At det er vigtigt, at du tager dig tid til udfylde arkene inden din aftale i ambulatoriet
- At du medbringer arkene til dine aftaler i ambulatoriet
- At det er vigtigt, at du deltager i de fire ambulante besøg over det næste halve år

Med venlig hilsen

_____

Sygeplejerske

Kilde: Vibeke Zoffmann, 2004

Vigtige begivenheder og perioder i dit liv med sygdom på livslinjen

Angiv de årstal, du oplevede de første symptomer på at have det svært fysisk og psykisk

Angiv de årstal, hvor du fik diagnosticeret ADHD/ADD og fysisk sygdom

Angiv perioder og begivenheder, som, du mener, har påvirket dine sygdomme positivt eller negativt

Begivenheder kan være eksempelvis være oplevelser i dit liv, personer, trivsel i skolen, hvem du bor hos og med, type af behandling for en af eller begge dine sygdomme, fritidsinteresser eller noget helt andet

Kilde: Vibeke Zoffmann, 2004

Hvad finder du svært og udfordrende at leve med for tiden?

Skriv nogle stikord:

Kilde: Vibeke Zoffmann, 2004

Reflection sheet 1.d

Ufuldendte sætninger

Om værdier, erfaringer og behov

De, som kender min måde at leve på, synes, at jeg _____

I forhold til min situation er jeg god til _____

En god dag for mig er _____

En dårlig dag for mig er _____

Det værste ved at være syg er _____

Det er svært for mig at _____

Når jeg skal snakke med andre om min situation _____

Sygdommene har forhindret mig i _____

Sygdommene må ikke forhindre mig i _____

Jeg bør ikke give sygdommene skylden for _____

Når jeg skal ind på hospitalet, tænker jeg _____

Noget, der giver problemer derhjemme, er _____

Jeg synes, mine venner _____

For min familie har sygdommene betydet at _____

Om fremtiden tænker jeg _____

Kilde: Vibeke Zoffmann, 2004

Reflection sheet 1.d

Jeg bliver ked af det, når _____

Jeg bliver glad, når _____

Jeg får god støtte af _____

Jeg får for lidt støtte af _____

Mine sygdomme har lært mig at _____

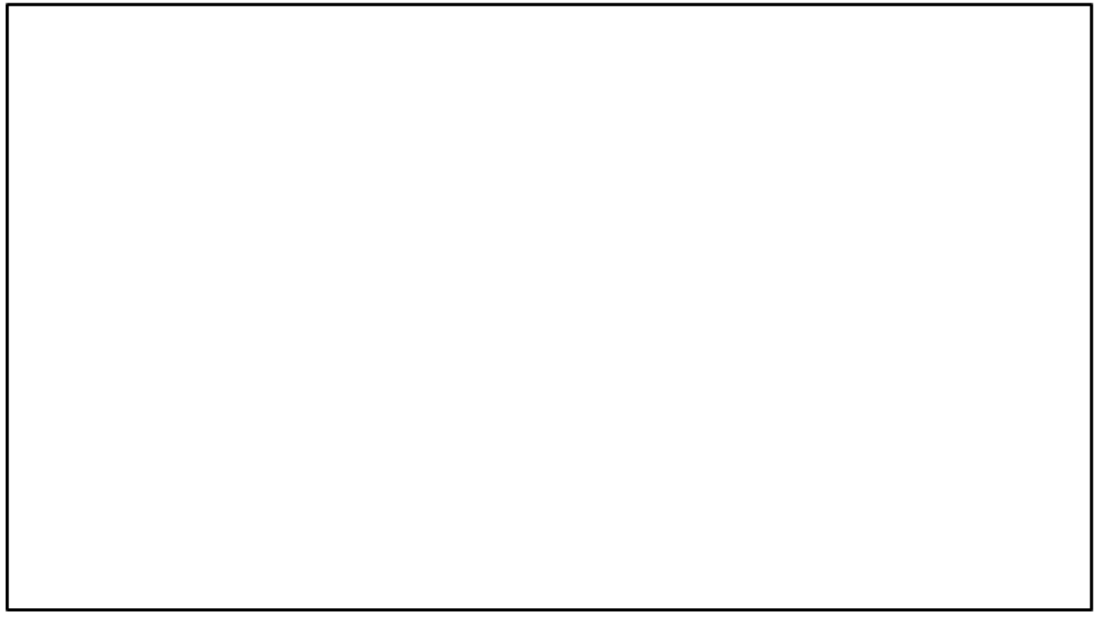
Det, jeg ønsker mig allermest, er _____

Om et år vil jeg _____

Kilde: Vibeke Zoffmann, 2004

Billede, talemåde eller tilbagevendende tanker om dit liv med sygdom

Tegn en tegning, skriv en historie, lav en billedcollage eller noget helt andet, du synes beskriver dit liv med sygdom



Kilde: Vibeke Zoffmann, 2004

Samtale 2

Udfordringer i livet med sygdom

Planer for ændring i din hverdag med ADHD/ADD

Planer for ændring i din hverdag med fysisk sygdom

Dine erfaringer med forskellige typer behandling for dine sygdomme

Din virkelighed med to sygdomme

Plads til sygdom i dit liv

Liste over problemer og udfordringer i livet med sygdom

10

Kilde: Vibeke Zoffmann, 2004

Planer for ændring i din hverdag med ADHD/ADD

Sæt kun kryds ved de sætninger, som du synes, passer på din hverdag

Det ***er*** en del af min hver-dag		Jeg ***vil*** ændre på det:		Jeg er i ***tvivl***, om jeg vil ændre på det	Jeg vil ***ikke*** ændre på det
		Inden en måned	Inden et ½ år		
	Jeg glemmer tit at spise morgenmad, middagsmad eller aftensmad				
	Jeg får ikke slappet af eller holdt pauser i løbet af dagen				
	Jeg trækker mig fra mine venner og bekendte				
	Jeg har svært ved gøre ting/opgaver færdige, som jeg er begyndt på				
	Jeg har svært ved at gå i gang med de opgaver/aktiviteter, som er en del af min hverdag (fx lektier og oprydning)				
	Jeg bruger ikke hjælpesystemer som fx kalender, alarm og smartphone til at huske ting og aftaler i min hverdag				
	Jeg er ikke fysisk aktiv i hverdagen				
	Jeg bliver vred og opfarende, hvis noget går mig imod				
	Jeg glemmer at tænke, før jeg taler/handler				
	Jeg taler ikke med andre om det, der er svært vedr. ADHD eller ADD				
	Jeg tager ikke den medicin, jeg har fået ordineret for ADHD eller ADD				
	Jeg sover ikke om natten eller først meget sent og har derfor svært ved at komme op om morgenen				

(Kilde: Arborelius)

Kilde: Vibeke Zoffmann, 2004

Reflection sheet 2.b
Example: overweight

Planer for ændring i din hverdag med overvægt

Sæt kryds ved de sætninger, som du synes passer på din hverdag

Det ***er*** en del af min hver-dag		Jeg ***vil*** ændre på det:		Jeg er i ***tvivl***, om jeg vil ændre på det	Jeg vil ***ikke*** ændre på det
		Inden en måned	Inden et ½ år		
	Jeg spiser store mængder (sund/usund) mad				
	Jeg spiser hurtigt				
	Jeg spiser store mængder fedtrig mad				
	Jeg spiser store mængder slik og søde sager				
	Jeg spiser ofte slik og søde sager				
	Jeg drikker kalorieholdige drikkevarer (juice, sodavand, energidrikke)				
	Jeg spiser ikke til alle 3 hovedmåltider				
	Jeg spiser ikke 3 mellemmåltider				
	Jeg spiser ofte om aftenen eller natten				
	Jeg er ikke fysisk aktiv i hverdagen				
	Jeg har svært ved at aflede mig selv, hvis jeg får trang til mad og drikke, som jeg ikke bør spise				
	Jeg undgår socialt samvær med andre pga. min overvægt				
	Hvis jeg af og til falder tilbage i mit gamle spisemønster, så har jeg svært ved at komme tilbage på sporet igen				

(Kilde: Arborelius)

Kilde: Vibeke Zoffmann, 2004

Dine erfaringer med forskellige typer behandling for dine sygdomme

Behandling kan eksempelvis være medicin, fysioterapi, undervisning, familiesamtaler, motion med mere

Behandlingstype:	Periode:	Fordele:	Ulemper:

Kilde: Vibeke Zoffmann, 2004

Din virkelighed med to sygdomme

Symptomer Symptomerne nævnes i rækkefølge, hvor den mest generende står først.	Hvor ofte er symptomerne til stede? (sæt kryds)					Er symptomerne til stede i bestemte situationer?		
	Konstant	Flere gange dagligt	Én gang dagligt	Et par gange om ugen	Én gang ugentligt	Nej	Ja	Nævn hvilke situationer
1) _____								
2) _____								
3) _____								
4) _____								
5) _____								
6) _____								
7) _____								
8) _____								

Kilde: Vibeke Zoffmann, 2004

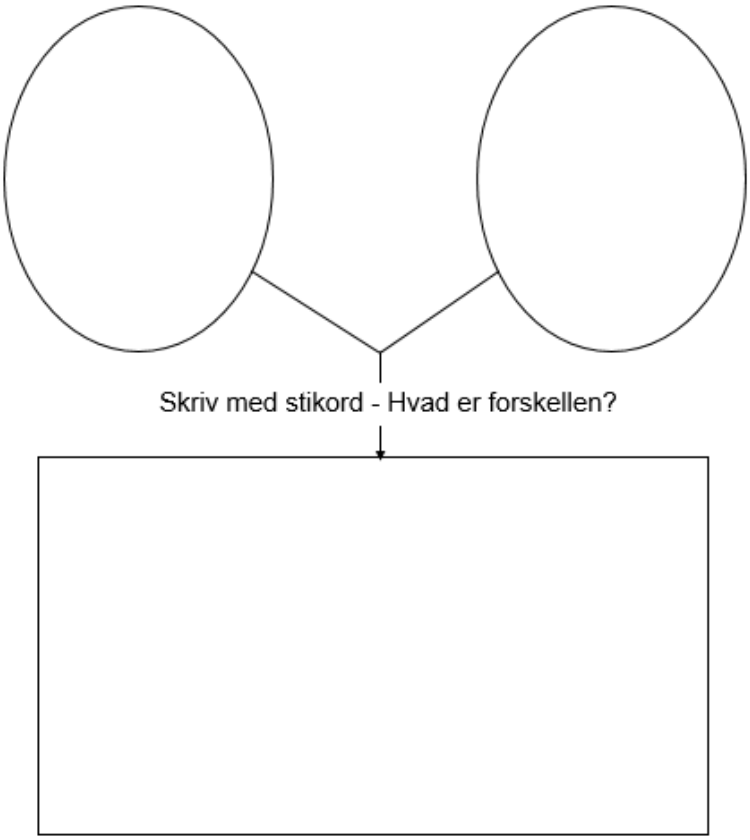
Plads til sygdom i dit liv

Så meget har mine sygdomme fyldt indtil nu

(udfyld **cirklen**, *som sygdommene fylder nu)*

Så meget må mine sygdomme fylde fremover

(udfyld cirklen, som sygdommene må fylde frem over)



15

Kilde: Vibeke Zoffmann, 2004

Liste over problemer og udfordringer i livet med sygdom

Du skal lave en liste over det, du mener, er dine udfordringer/problemer med at håndtere sygdommene i din hverdag. Jeg (sygeplejersken) laver en liste over det, jeg mener, er dine udfordringer/ problemer med sygdommene. Vores lister må gerne være forskellige.

Til samtalen viser vi listerne til hinanden og drøfter ligheder og forskelle. Formålet er, at vi i fællesskab finder frem til én udfordring/et problem, som du ønsker at arbejde videre med. Den udfordring/det problem skrives nederst på dette ark. Det er også den udfordring/det problem, du skal arbejde videre med til næste samtale (samtale 3).

Din liste:	**Sygeplejerskens liste:**
_____	_____
_____	_____
_____	_____
_____	_____

Ønskes forandret

Vores fælles benævnelse af én udfordring/et problem, og som du ønsker at forandre. Formuleres på en måde som du kan lide, og som vi begge finder dækkende.

Det, der er et problem eller en udfordring, er:

_____

_____

_____

Kilde: Vibeke Zoffmann, 2004

Samtale 3

Forandringsarbejde

Måde at løse problemet/udfordringen på indtil nu:

- Dine oplevelser
- Dine tanker
- Dine mål og intentioner
- Dine handlinger

Dynamisk problemløsning

17

Kilde: Vibeke Zoffmann, 2004

Måde at løse problemet/udfordringen på indtil nu

Det, der er et problem eller en udfordring, er?
(Her noteres den udfordring/det problem, vi i fællesskab fandt frem til ved sidste samtale)

_____

_____

• Dine oplevelser

Hvor længe har du oplevet problemet/udfordringen?

_____

_____

Hvor tit oplever du problemet/udfordringen?

_____

_____

Er problemet/udfordringen blevet større eller mindre med tiden?

_____

_____

Hvornår mærker du problemet mest?	Hvornår mærker du problemet mindst?

Kilde: Vibeke Zoffmann, 2004

• Dine tanker om

Hvad tænker du, at problemet eller udfordringen hænger sammen med?

_____

_____

Hvad gør det sværere?	Hvad gør det nemmere?
Hvad forhindrer det dig i?	Hvad opnår du ved det?

Hvor meget påvirker problemet/udfordringen dig?
0= jeg er slet ikke påvirket
10= jeg er meget påvirket

0_____10

19

Kilde: Vibeke Zoffmann, 2004

Reflection sheet 3.c

• Dine mål og ønsker

Hvad kan du/andre vinde ved, at problemet/udfordringen løses?	Hvad kan du/andre tabe ved, at problemet/udfordringen løses?
På kort sigt?	På kort sigt?
På lang sigt?	På lang sigt?

Har du sat dig for at løse problemet/udfordringen helt eller delvist?

_____

_____

Hvis delvist – hvilke dele?

_____

_____

20

Kilde: Vibeke Zoffmann, 2004

• Dine handlinger

Hvad har du gjort indtil nu for at kunne klare problemet eller udfordringen?

_____

_____

Hvornår/i hvilke situationer?

_____

_____

Hvor tit?

_____

_____

Hvad har du gjort, som ikke lykkedes?

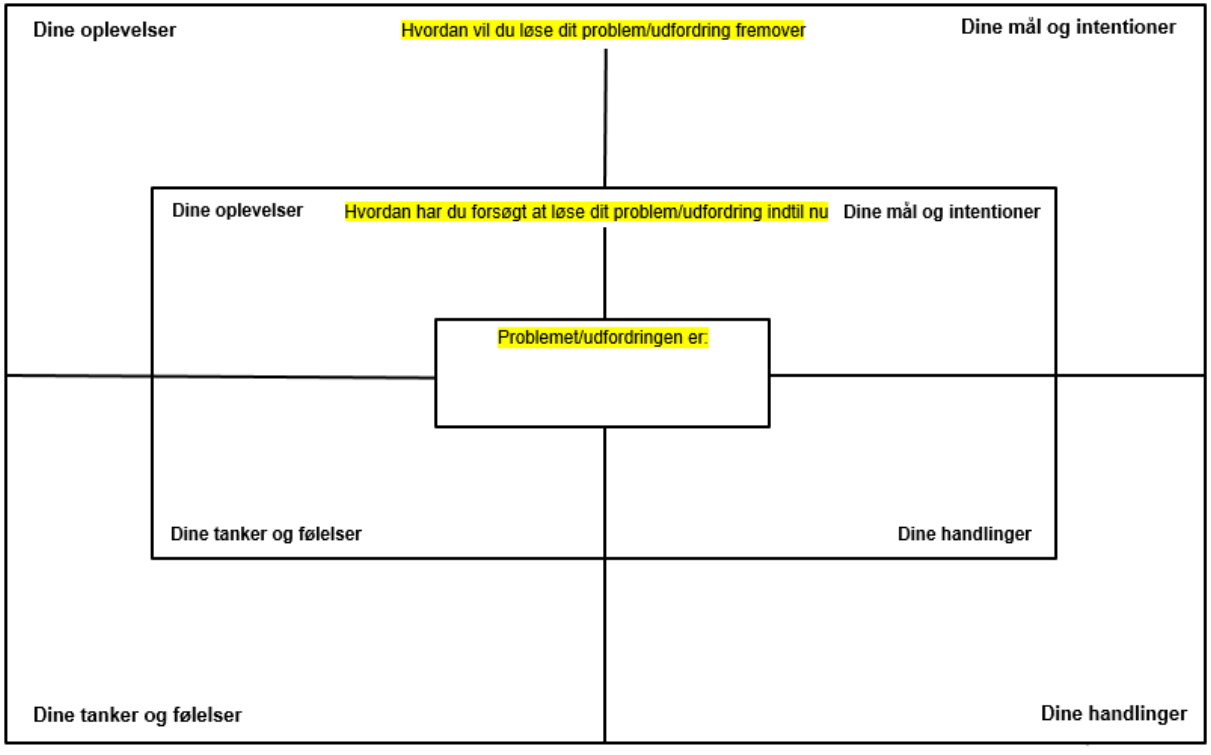
_____

_____

Hvem har du fået hjælp af?	Hvem har du savnet hjælp fra?
Hvem har du bedt om hjælp?	Hvem ville du gerne have bedt om hjælp?

Kilde: Vibeke Zoffmann, 2004

Dynamisk problemløsning



Samtale 4

Forandringsarbejde

Dynamisk problemløsning (medbring arket fra sidste samtale)

Nye strategier og langsigtet plan

Punkter du ønsker videregivet

23

Kilde: Vibeke Zoffmann, 2004

Nye strategier og langsigtet plan

Hvad har du opnået indtil nu?

_____

_____

_____

_____

Hvilke problemer/udfordringer arbejder du stadig med?

_____

_____

_____

_____

Reflection sheet 4.b

Punkter du ønsker videregivet

Er der nogle af de problemer/udfordringer, du har arbejdet med, som du ønsker at videregive til andre?

Det kunne f.eks. være dine forældre, dine lærere, din egen læge, en hospitalslæge eller sygeplejerske.

Sedlen her kan også anvendes som en slags huskeliste.

_____

_____

_____

_____

Kilde: Vibeke Zoffmann, 2004

Guidet Egen-Beslutning

At være forældre til en ung, der har ADHD/ADD og fysisk sygdom

Invitation til samarbejde

Ufuldendte sætninger (mor/far)

Plads til sygdom i vores liv (mor/far)

Samtale i ambulatoriet den _____

Reflection sheet P.a (mom/dad)

Invitation til samarbejde (forældre)

Hvad skal vi samarbejde om?

- Vi har fokus på det, I oplever som svært og udfordrende i forhold til at være forældre til en teenager, der skal håndtere to sygdomme

Hvilken rolle har vi hver især?

- Både din, din partners og min viden og erfaring er nødvendig
- Vi skal bidrage aktivt og bruge tiden bedst muligt på noget, vi finder vigtigt
- Noget af tiden vil vi arbejde hver for sig, noget af tiden vil vi arbejde sammen

Hvordan skal samarbejdet være?

- Det er OK, at vi ser forskelligt på jeres situation
- Det er nødvendigt, at vi kender hinandens opfattelser
- Det er OK, at vi er uenige
- Det er OK, at følelser kan opleves svære, og at de udtrykkes
- Det er **IKKE** OK, at nogen presser andre eller lader sig presse til at ændre mening

Hvad er fordelen ved arkene, og hvad skal de bruges til?

- Du kan bruge dem til i fred og ro at tænke over og blive klogere på din rolle som forælder
- Vi kan bruge dem til at få overblik over, hvad der er vigtigt i jeres situation
- De kan gøre det lettere at snakke om det, der ellers kan være svært at snakke om
- De kan hjælpe dig til at tage beslutninger, der passer til jeres situation
- Efter at du har brugt arkene, kan de fremover hjælpe dig med at holde fast i det, der er vigtigt for jer

Med venlig hilsen

_____

Sygeplejerske

Ufuldendte sætninger (Mor)

Om værdier, erfaringer og behov

De, der kender min måde at håndtere mit barns sygdomme på, tænker at

_____

Det, jeg er bedst til i relation til mit barns sygdomme, er_____

Det værste ved at have et barn, der er syg, er _____

Det, jeg er værst til, er_____

Mit barns sygdomme har forhindret mig i _____

Jeg må ikke forhindre mit barn i at _____

Jeg tror, mit barn har svært ved at modstå pres fra _____

Vi bør ikke give sygdommene skylden for _____

Når mit barn skal til ambulant kontrol, tænker jeg _____

Jeg vil gerne lære mere om _____

Noget, der kan give problemer derhjemme, er _____

Reflection sheet P.b (mom)

Jeg synes, at mit barns venner _____

Noget, jeg gerne vil, at mit barn ændrer hos sig selv, er _____

Noget, jeg gerne vil ændre ved mig selv, er _____

Noget, jeg gerne vil, at min partner ændrer ved sig selv, er _____

Om et år vil jeg _____

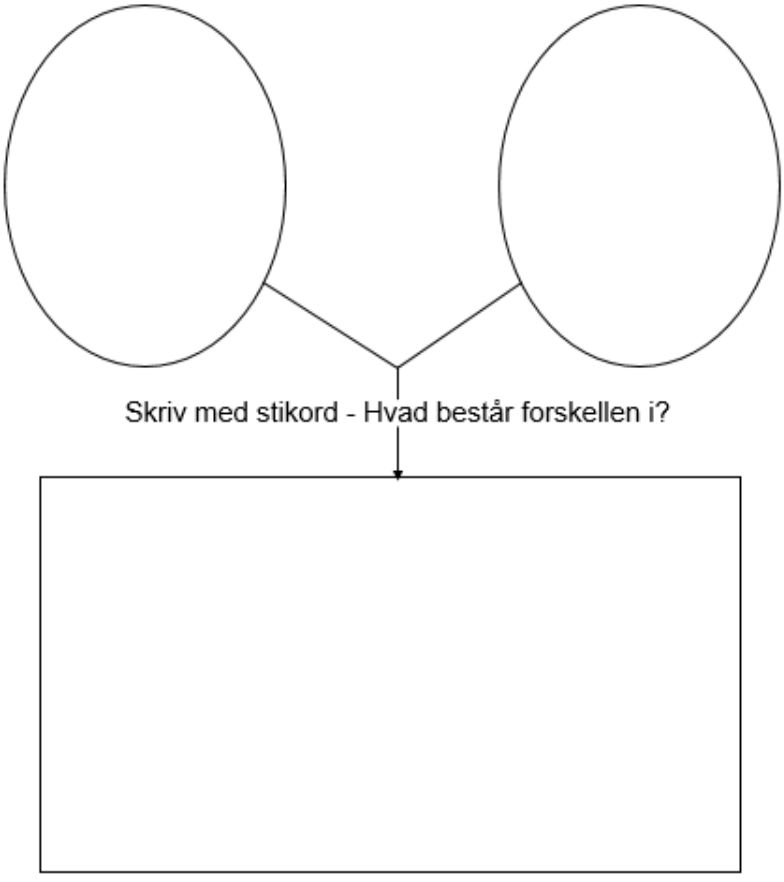
Plads til sygdom i mit liv (Mor)

Så meget har mit barns sygdomme fyldt indtil nu

(udfyld **cirklen**, *som sygdommene fylder nu)*

Så meget må mit barns sygdomme fylde fremover

(udfyld cirklen, som sygdommene må fylde fremover)



Reflection sheet P.b (dad)

Ufuldendte sætninger (Far)

Om værdier, erfaringer og behov

De, der kender min måde at håndtere mit barns sygdomme på, tænker at

_____

Det, jeg er bedst til i relation til mit barns sygdomme, er _____

Det værste ved at have et barn, der er syg, er _____

Det, jeg er værst til, er _____

Mit barns sygdomme har forhindret mig i _____

Jeg må ikke forhindre mit barn i at _____

Jeg tror, mit barn har svært ved at modstå pres fra _____

Vi bør ikke give sygdommene skylden for _____

Når mit barn skal til ambulant kontrol, tænker jeg _____

Jeg vil gerne lære mere om _____

Noget, der kan give problemer derhjemme, er _____

Reflection sheet P.b (dad)

Jeg synes, at mit barns venner _____

Noget, jeg gerne vil, at mit barn ændrer hos sig selv, er _____

Noget, jeg gerne vil ændre ved mig selv, er _____

Noget, jeg gerne vil, at min partner ændrer ved sig selv, er _____

Om et år vil jeg _____

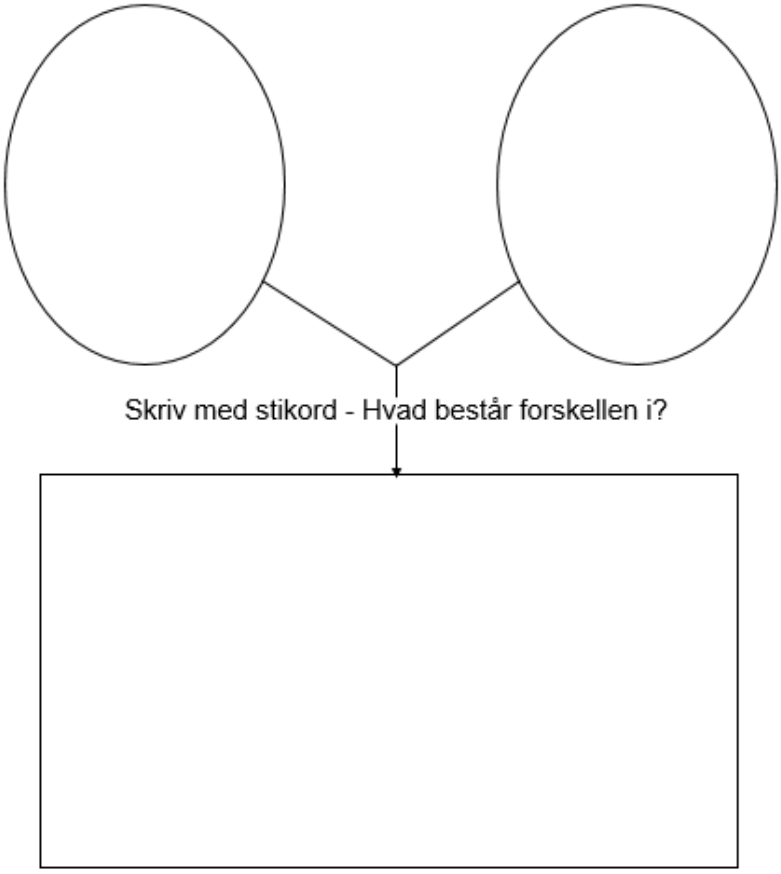
Plads til sygdom i mit liv (Far)

Så meget har mit barns sygdomme fyldt indtil nu

(udfyld cirklen*, som sygdommene fylder nu)*

Så meget må mit barns sygdomme fylde fremover

(udfyld cirklen, som sygdommene må fylde fremover)



Appendix D. Participant information

Written information to the parents (Study 1)

Information til forældre om forskningsprojekt

Unges oplevelser af at leve med ADHD/ADD og anden sygdom/tilstand i hverdagslivet

Projektansvarlig
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AALBORG UNIVERSITETSHOSPITAL
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AALBORG UNIVERSITET

Uddannelse i virkeligheden

Deltagerinformation

Jeg henvender mig til dig, idet du er forælder til et barn med ADHD/ADD og anden sygdom/tilstand i alderen 13-18 år. Jeg vil spørge, om dit barn har lyst til at indgå i en undersøgelse af unges oplevelser af at leve med ADHD/ADD og anden sygdom/tilstand i hverdagslivet.

Formål med undersøgelsen

Denne interview- undersøgelse er en del af et ph.d. projekt. Formålet med ph.d. projektet er, at skabe ny viden om hvordan sundhedsprofessionelle i hospitalsvæsnet bedst muligt kan hjælpe og støtte unge, der har ADHD/ADD og anden sygdom til at håndtere sygdom og hverdagsliv.

Hvad kræver det af dig?

Som projektansvarlig sygeplejerske vil jeg gerne interviewe unge med ADHD/ADD og anden sygdom/tilstand, som har kontakt til hospitalsvæsnet. Du og dit barn skal give tilladelse til, at jeg interviewer dit barn. Interviewet vil have en varighed af ca. 30-60 minutter og omhandle dit barns oplevelser af at leve med ADHD/ADD og anden sygdom i hverdagen. Interviewet planlægges til et tidspunkt og sted, som passer dit barn.

Det er frivilligt at deltage

Det er frivilligt at deltage i projektet. Deltagelse sker kun efter såvel skriftlig som mundtlig information, samt når du og dit barn har underskrevet en skriftlig samtykkeerklæring. Det er til enhver tid muligt at fortryde deltagelse i projektet, uden at det har konsekvenser for dit barns fortsatte behandling og kontakt til sundhedsvæsenet.

Anonymitet

Alle oplysninger behandles anonymt og projektet er omfattet af Region Nordjyllands paraplyanmeldelse ved Datatilsynet – Sundhedsvidenskabelig forskning i Region Nordjylland.

Kontakt

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

Med venlig hilsen

Helle Enggaard

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Uddannelse i virkeligheden

Written information to the adolescents (Study 1)

Information til unge om deltagelse i forskningsprojekt

Unges oplevelser af at leve med ADHD/ADD og anden sygdom/tilstand i hverdagslivet

Projektansvarlig
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AALBORG UNIVERSITET

Uddannelse i virkeligheden

Deltagerinformation

Jeg henvender mig til dig, idet du har ADHD eller ADD samt anden sygdom/tilstand og er i alderen 13-18 år. Jeg vil spørge, om du har lyst til at indgå i en undersøgelse, hvor du interviewes om dine oplevelser af at leve med ADHD/ADD og en anden sygdom/tilstand i din hverdag.

Formål med undersøgelsen

Denne interview undersøgelse er en del af et ph.d. projekt. Formålet med ph.d. projektet er, at skabe ny viden om hvordan sundhedsprofessionelle i hospitalsvæsnet bedst muligt kan hjælpe og støtte unge, der har ADHD/ADD og anden sygdom til at håndtere sygdom og hverdagsliv.

Hvad kræver det af dig?

Som projektansvarlig sygeplejerske vil jeg gerne interviewe flere unge med ADHD/ADD og anden sygdom/tilstand, som har kontakt til sundhedsvæsnet. Du skal give tilladelse til, at jeg må interviewe dig. Interviewet vil have en varighed af ca. 30-60 minutter og handle om dine oplevelser af at leve med og håndtere ADHD/ADD og anden sygdom i din hverdag. Interview er en samtale, hvor jeg stiller spørgsmål, men hvor du også fortæller om det, der er vigtigt for dig. Du kan ikke svare forkert i et interview, da jeg er interesseret i at forstå *dine* oplevelser af at leve med sygdom. Interviewet planlægges til et tidspunkt og sted som passer dig, det kan fx være hjemme hos dig, på mit kontor eller et helt andet sted.

Det er frivilligt at deltage

Det er frivilligt at deltage i projektet. Inden du beslutter dig for, om du vil interviewes, så vil jeg mødes med dig og dine forældre. Her vil jeg fortælle lidt mere om undersøgelsen og svare på eventuelle spørgsmål. Du kan til enhver tid fortryde din deltagelse i undersøgelsen, uden at det har konsekvenser for din fortsatte behandling og kontakt til sundhedsvæsenet.

Anonymitet

Alle oplysninger behandles anonymt. Anonymisering betyder at oplysninger omskrives, så det ikke er muligt for andre at genkende din deltagelse i undersøgelsen. Eksempler på anonymisering er, at dit navn erstattes med han/hun. Fortæller du om konkrete personer og steder, omtales de som ven/veninde, mor/far, bror/søster og skole, cafe, fritidsinteresse, mindre/større by osv. Ydermere er undersøgelsen omfattet af gældende regler for forskning.

Kontakt

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

Med venlig hilsen

Helle Enggaard

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Uddannelse i virkeligheden

Written information to the parents (Study 2 and Study 3)

Forskningsprojekt om unge med ADHD/ADD og fysisk sygdom

Hvorfor? Vi kontakter dig, idet du er forældre til en ung med ADHD/ADD samt anden fysisk sygdom i alderen 13-18 år. Vi vil gerne invitere jer til at deltage i et forskningsprojekt. Formålet er at undersøge, hvordan sygeplejersken kan støtte og hjælpe den unge og forældrene bedst muligt med de udfordringer, der kan være hos unge med både ADHD/ADD og fysisk sygdom.

Hvordan? Vi vil bruge en metode, der hedder Guidet Egen-Beslutning. Metoden består af forskellige papirark, som den unge udfylder før og mellem besøg i ambulatoriet. Der findes ikke rigtige og forkerte svar. Disse ark hjælper den unge og sygeplejersken til at blive klogere på den unges hverdag med ADHD/ADD og fysisk sygdom. Forældre vil også udfylde nogle ark, som handler om at være forældre til en ung med ADHD/ADD og fysisk sygdom. Vi vil undersøge, om Guidet Egen-Beslutning kan hjælpe den unge, forældrene og sygeplejersken til at opdage og samarbejde om det, der kan være svært og udfordrende i den unges hverdag med ADHD/ADD og fysisk sygdom.

Hvor længe? Forløbet varer et halvt år, hvor den unge har fire besøg i ambulatoriet af ca. 45 minutters varighed. Forældre har ét besøg i ambulatoriet. Forældre er velkomne til at deltage i den unges ambulante besøg. Det er en beslutning I træffer i fællesskab.

Guidet Egen-Beslutning er et supplement til den unges nuværende forløb i ambulatoriet. Det betyder for eksempel, at målinger og kontroller fortsat vil være en del af de ambulante besøg i forløbet med Guidet Egen-Beslutning.

Hvor meget? Hvis I vælger at deltage, skal du give tilladelse til at:

Den unge skal:

- Udfylde et spørgeskema før, under og efter forløbet med Guidet Egen-Beslutning.
- Deltage i et interview om hans/hendes oplevelser i forhold til Guidet Egen-Beslutning. Det er den projektansvarlige sygeplejerske, der interviewer den unge, og den unge bestemmer tid og sted.

Du skal:

- Deltage i et interview, som handler om dine erfaringer med Guidet Egen-Beslutning. Du interviewes af den projektansvarlige sygeplejerske, og du bestemmer tid og sted.

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Uddannelse i virkeligheden

Sygeplejersken i ambulatoriet må:

- Optage en lydfil af de ambulante besøg, som den unge og du har i forløbet med Guidet Egen-Beslutning
- Tage en kopi af de ark, den unge og du udfylder i forbindelse med Guidet Egen-Beslutning
- Slå den unges diagnoser op i hans/hendes journal.

Hvem? Alle oplysninger behandles anonymt, hvilket betyder, at oplysninger omskrives, så det ikke er muligt for andre at genkende din og dit barns deltagelse i Forskningsprojektet.

Det er den projektansvarlige sygeplejerske, der opbevarer og behandler alle data. Forskningsprojektet er omfattet af Region Nordjyllands Paraplyanmeldelse ved Datatilsynet – Sundhedsvidenskabelig forskning i Region Nordjylland (2008-58-0028).

Spørg Det er frivilligt at deltage i forskningsprojektet. Deltagelse sker kun efter såvel skriftlig som mundtlig information, samt når du og dit barn har underskrevet en skriftlig samtykkeerklæring.

Det er til enhver tid muligt at fortryde deltagelse, uden at det har konsekvenser for dit barns nuværende eller fremtidige behandling og kontakt til sundhedsvæsenet.

Hjælp andre Ved at deltage bidrager I til at afprøve metoden Guidet Egen-Beslutning. Hvis metoden kan bruges til at hjælpe unge med at håndtere et liv med ADHD/ADD og fysisk sygdom, vil viden og erfaring fra dette projekt kunne hjælpe andre unge i samme situation. Metoden Guidet Egen-Beslutning har tidligere hjulpet andre patientgrupper til at håndtere deres sygdom i hverdagen. Ingen har oplevet ubehag ved at arbejde med Guidet Egen-Beslutning. Vi har derfor vurderet, at der ikke er risici forbundet med at deltage i forskningsprojektet.

Vi håber, at du har fået indblik i, hvad det betyder at deltage i dette forskningsprojekt. Har du eller dit barn spørgsmål, er I velkomne til at kontakte den projektansvarlige sygeplejerske.

Med venlig hilsen

Helle Enggaard

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Enhed for Psykiatrisk Forskning, Aalborg Universitetshospital
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AALBORG UNIVERSITET
Uddannelse i virkeligheden

Written information to the adolescents (Study 2 and Study 3)

Forskningsprojekt om unge med ADHD/ADD og fysisk sygdom

Hvorfor? Vi kontakter dig, fordi du er mellem 13 og 18 år og har ADHD eller ADD samt anden fysisk sygdom. Vi vil gerne invitere dig til at deltage i et forskningsprojekt. Formålet er at undersøge, hvordan sygeplejersken kan støtte og hjælpe dig og din familie bedst muligt med de udfordringer, der kan være hos unge med både ADHD/ADD og fysisk sygdom.

Hvordan? Vi vil bruge en metode, der hedder Guidet Egen-Beslutning. Metoden består af forskellige papirark, som du udfylder før og mellem dine besøg i ambulatoriet. Der findes ikke rigtige og forkerte svar. Disse ark hjælper dig og sygeplejersken til at blive klogere på din hverdag med ADHD/ADD og fysisk sygdom. Dine forældre vil også udfylde nogle ark, som handler om at være forældre til en ung med ADHD/ADD og fysisk sygdom.

Hvor længe? Forløbet varer et halvt år, hvor du har fire besøg i ambulatoriet af ca. 45 minutters varighed. Dine forældre har ét besøg. Du bestemmer sammen med dine forældre, om de skal deltage i dine besøg i ambulatoriet. Guidet Egen-Beslutning er et supplement til dit nuværende forløb i ambulatoriet. Det betyder for eksempel, at målinger og kontroller fortsat vil være en del af dine ambulante besøg i forløbet med Guidet Egen-Beslutning.

Hvor meget? Hvis du vælger at deltage, siger du ja til at:

Du skal:

- Udfylde et spørgeskema før, under og efter forløbet med Guidet Egen-Beslutning
- Deltage i et interview om dine oplevelser i forhold til Guidet Egen-Beslutning

Sygeplejersken i ambulatoriet må:

- Optage en lydfil af de fire ambulante besøg i forløbet med Guidet Egen-Beslutning
- Tage en kopi af de ark, du udfylder i forbindelse med Guidet Egen-Beslutning
- Slå dine diagnoser op i din journal

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AALBORG UNIVERSITET
Uddannelse i virkeligheden

Hvem? Alle oplysninger behandles anonymt. Det betyder, at det ikke vil være muligt for andre at genkende din deltagelse i projektet. Eksempelvis bliver dit navn erstattet med han/hun osv.

Det er den projektansvarlige sygeplejerske, der opbevarer og behandler alle data. Forskningsprojektet er omfattet af Region Nordjyllands Paraplyanmeldelse ved Datatilsynet – Sundhedsvidenskabelig forskning i Region Nordjylland (2008-58-0028).

Spørg Det er frivilligt at deltage i projektet. Inden du beslutter dig for, om du vil deltage, mødes du og dine forældre med den projektansvarlige sygeplejerske, så I kan høre mere om projektet og få svar på eventuelle spørgsmål. Du kan altid fortryde din deltagelse, uden at det får konsekvenser for din nuværende eller fremtidige behandling og kontakt til sundhedsvæsenet.

Hjælp andre Ved at deltage bidrager du til at afprøve metoden Guidet Egen-Beslutning. Hvis metoden kan bruges til at hjælpe unge med at håndtere et liv med ADHD/ADD og fysisk sygdom, vil viden og erfaring fra dette projekt kunne hjælpe andre unge i samme situation. Metoden Guidet Egen-Beslutning har tidligere hjulpet andre patientgrupper til at håndtere deres sygdom i hverdagen. Ingen har oplevet ubehag ved at arbejde med Guidet Egen-Beslutning. Vi har derfor vurderet, at der ikke er risici forbundet med at deltage i forskningsprojektet.

Vi håber, at du har fået indblik i, hvad det betyder at deltage i dette forskningsprojektet. Har du eller dine forældre spørgsmål, er I velkomne til at kontakte den projektansvarlige sygeplejerske.

Med venlig hilsen

Helle Enggaard

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AALBORG UNIVERSITET
Uddannelse i virkeligheden

Appendix E. Consent form

Study 1

Forskningsprojektets titel: Unges oplevelse af at leve med ADHD/ADD og anden sygdom/tilstand i hverdagslivet

Erklæring fra indehaveren af forældremyndigheden:

Jeg/vi har fået skriftlig og mundtlig information og jeg/vi ved nok om formål, metode, fordele og ulemper til at give mit/vores samtykke.

Jeg/vi ved, at det er frivilligt at deltage, og at jeg/vi altid kan trække mit/vores samtykke tilbage uden, at min/vores datter/søn mister sine nuværende eller fremtidige rettigheder til behandling.

Jeg/vi giver samtykke til, at _____ (datter/søns navn) deltager i forskningsprojektet. Jeg/vi har fået en kopi af dette samtykkeark samt en kopi af den skriftlige information om projektet til eget brug.

Navnet eller navnene på forældremyndighedens indehaver(e):

_____ _____

Dato: _____ Underskrift: _____

Dato: _____ Underskrift: _____

Erklæring fra den unge:

Jeg har fået skriftlig og mundtlig information og jeg ved nok om formål, metode, fordele og ulemper til at give mit samtykke.

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

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

Navnet på den unge, som indgår i forskningsprojektet

_____ Fødselsdato og alder _____

Dato: _____ Underskrift: _____

Erklæring fra den, der afgiver information:

Jeg erklærer, at forældrene og den unge har modtaget mundtlig og skriftlig information om forskningsprojektet.

Efter min overbevisning er der givet tilstrækkelig information til, at forældrene og den unge kan træffe beslutning om den unges deltagelse i forskningsprojektet.

Navnet på den, der har afgivet information: Helle Enggaard

Dato: _____ Underskrift: _____

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

Kontaktes efter dette interview:

Må projektansvarlig sygeplejerske Helle Enggaard kontakte familien efter dette interview? JA_____ Nej_____

Study 2 and Study 3

Samtykke om deltagelse i et sundhedsvidenskabeligt forskningsprojekt.

Forskningsprojektets titel: Guidet Egen-Beslutning til unge med ADHD/ADD og fysisk sygdom

Erklæring fra indehaveren af forældremyndigheden:

Jeg/vi har fået skriftlig og mundtlig information, og jeg/vi ved nok om formål, metode, fordele og ulemper til at give mit/vores samtykke.

Jeg/vi ved, at det er frivilligt at deltage, og at jeg/vi altid kan trække mit/vores samtykke tilbage, uden at min/vores datter/søn mister sine nuværende eller fremtidige rettigheder til behandling.

Jeg/vi giver samtykke til, at jeg og _____ (datters/søns navn) deltager i forsknings-projektet. Jeg/vi har fået en kopi af dette samtykkeark samt en kopi af den skriftlige information om projektet til eget brug.

Navnet eller navnene på forældremyndighedens indehaver(e):

_____ _____

Dato: _____ Underskrift: _____

Dato: _____ Underskrift: _____

Erklæring fra den unge:

Jeg har fået skriftlig og mundtlig information, og jeg ved nok om formål, metode, fordele og ulemper til at give mit samtykke.

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

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

Navnet på den unge, som indgår i forskningsprojektet

_____ Fødselsdato og alder _____

Dato: _____ Underskrift: _____

Erklæring fra den, der afgiver information:

Jeg erklærer, at forældrene og den unge har modtaget mundtlig og skriftlig information om forskningsprojektet.

Efter min overbevisning er der givet tilstrækkelig information til, at forældrene og den unge kan træffe beslutning om deres deltagelse i forskningsprojektet.

Navnet på den, der har afgivet information: Helle Enggaard

Dato: _____ Underskrift: _____

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

Kontaktes efterfølgende:

Må projektansvarlig sygeplejerske Helle Enggaard kontakte familien, efter alle data er indsamlet? JA_____ Nej_____

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