INTERNET-BASED SUPPORT AND COACHING

- *Exploring the feasibility of an intervention for young people with ADHD and autism spectrum disorder*

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To my loving family

Abstract

Background: For individuals with Neurodevelopmental Disorders (NDDs), such as Attention-Deficit/ Hyperactivity Disorder (ADHD) and autism spectrum disorder (ASD), adolescence and young adulthood can be a vulnerable period associated with a loss of significant structure and support. They can also have a difficult time taking advantage of available support- and treatment options, due to their core deficits. There is limited research into support and treatment specifically targeting individuals with ADHD and/or ASD in this age group, and into how it can be tailored to fit their experienced needs. **Methods:** With the aim of evaluating the feasibility of an internet-based support and coaching model (IBSC) encompassing 8 weeks of twice weekly chat sessions (and two clinic visits), two studies were conducted using complementary methodological perspectives. *Study I* used a non-randomized controlled design, including 50 individuals with ADHD and/or ASD ages 15-32 years old in two naturalistic clinical settings. Participants received the intervention (n=30) or Treatment-As-Usual (TAU) (n=20). Six participants dropped out from the Intervention group. Self-report questionnaires were administered at baseline, at the end of the Intervention and after 6-months, including assessments of quality of life, sense of coherence, self-esteem, anxiety and depressive symptoms. *Study II*, sought to investigate the experiences of the participants taking part in IBSC, using semi-structured interviews with 16 individuals who had received IBSC and analysing data using qualitative content analysis. **Results:** Results from *study I* showed significant between-group effects regarding anxiety at post intervention and at 6-month follow-up, and for depressive symptoms at post intervention. A deterioration in the TAU group partly explained these results. The Intervention group experienced a significant increase in self-esteem and a decrease in anxiety at 6-month follow-up. *Study II* generated three themes; Deciding to participate, Taking part in the coaching process, and The significance of format with a total of ten subthemes. In summary, there was an appreciation of several aspects of the format that corresponded with their needs, e.g. being text-based and accessible from one´s home environment. Participants voiced unmet needs and underscored the importance of coaches' knowledge about NDDs. Incomplete personal interaction and a desire for increased flexibility in regard to frequency and form of communication were also voiced. **Conclusions:** IBSC shows promise as a feasible approach to supporting adolescents and young adults with ADHD and/or ASD. Future studies should determine for which diagnostic category the model is best suited and to what degree.

KEYWORDS: attention-deficit/hyperactivity disorder; autism; coaching; internet-based intervention; social support, adolescent, adult, qualitative, experiences

Sammanfattning på svenska

Tonåren och åren som ung vuxen kan vara sårbara perioder för individer med utvecklingsrelaterade funktionsavvikelser såsom ADHD och autism, och är ofta behäftade med en förlust av tidigare viktiga stödstrukturer. På grund av kärnsymtomen vid ADHD och autism, kan dessa individer också ha svårt att tillgodogöra sig traditionella stöd- och behandlingsinsatser. Forskning, som rör stöd och behandling för personer med ADHD och/eller autism i denna åldersgrupp, är begränsad. Det saknas även studier kring hur stödet bäst kan anpassas till individernas upplevda behov.

Syftet med denna uppsats var att studera genomförbarhet och preliminär effekt av en intervention; Internet-baserat stöd och coaching (IBSC), som inkluderar 8 veckors stöd och coaching via ett särskilt utformat chatprogram, två gånger i veckan (inklusive två klinikbesök). Interventionen studerades från två metodologiska perspektiv. ***Studie I***, en icke-randomiserad kontrollerad studie, inkluderade 50 individer med ADHD och/eller autism i åldrarna 15-32 år i två naturalistiska kliniska miljöer. Deltagarna erhöll antingen IBSC (n=30) eller sedvanlig vård (Treatment as Ususal: TAU) (n=20). Sex deltagare fullföljde inte IBSC. Självskattningsformulär som mätte livskvalitet, känsla av sammanhang, självkänsla, ångest- och depressionssymtom administrerades före och efter interventionen (8 veckor) samt efter 6 månader. ***Studie II*** avsåg undersöka hur de som erhållit IBSC upplevde interventionen. Sexton individer deltog och intervjuades med semistrukturerad intervju, som sedan analyserades med kvalitativ innehållsanalys.

Resultat från ***studie I*** visade signifikanta mellangruppseffekter för ångestsymtom direkt efter interventionen och efter 6 månader, samt för depressiva symtom direkt efter interventionen. Resultaten förklarades delvis av en försämring i TAU-gruppen. Interventionsgruppen upplevde en signifikant förbättring avseende ångest och självkänsla vid 6-månadersuppföljningen. ***Studie II*** genererade tre teman; Att besluta sig för att delta, Att ta del i coaching-processen och Formatets betydelse, med totalt tio subteman. Sammanfattningsvis uppskattade deltagarna flera aspekter av formatet då det uppfattades gå i linje med deras behov, bland annat det text-baserade formatet och tillgängligheten i hemmiljön. Deltagarna beskrev också ouppfyllda behov och underströk vikten av coachernas kunskap kring utvecklingsrelaterade funktionsavvikelser. En upplevelse av att en del av den personliga kontakten gick förlorad och önskemål om mer flexibilitet i förhållande till frekvens och kommunikationsform delgavs också.

IBSC förefaller som ett lovande stöd för unga individer med ADHD och autism. Framtida studier får visa om en specifik diagnosgrupp lämpar sig bättre för IBSC.

List of papers

This thesis is based on the following studies, referred to in the text by their Roman numerals.

I

Sehlin H, Hedman Ahlström B, Bertilsson, I, Andersson G, Wentz E. Internet-Based Support and Coaching With Complementary Clinic Visits for Young People With Attention-Deficit/Hyperactivity Disorder As Autism: Controlled Feasibility Study. *Journal of Medical Internet Research.* 2020; 22(12): e19658

II

Sehlin H, Hedman Ahlström B, Andersson G, Wentz E. Experiences of an Internet-Based Support and Coaching Model for adolescents and young adults with ADHD and Autism Spectrum Disorder: a qualitative study. *BMC Psychiatry,* 2018; 18(1):15

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Abbreviations

ADD	Attention Deficit Disorder
ADHD	Attention-Deficit/Hyperactivity Disorder
ANCOVA	Analysis of Covariance
ASD	Autism Spectrum Disorder
ASQoL	Autism Quality of Life measure
CBT	Cognitive Behavioural Therapy
DAMP	Deficits in Attention, Motor control and Perception
DSM	Diagnostic and Statistical Manual of Mental Disorders
ESSENCE	Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations
GAF	Global Assessment of Functioning
HADS	Hospital Anxiety and Depression Scale
IBSC	Internet-Based Support and Coaching
ICBT	Internet-delivered Cognitive Behaviour Therapy
MADRS-S	Montgomery-Åsberg Depression Rating Scale -Self-reported
MBD	Minimal Brain Damage; Minimal Brain Dysfunction
NDD	Neurodevelopmental Disorder
QoL	Quality of Life
SD	Standard Deviation
RCT	Randomized Controlled Trial
RSES	Rosenberg Self-Esteem Scale
SCID I	Structured Clinical Interview for DSM Axis I Disorder
SCID II	Structured Clinical Interview for DSM-IV Axis II Disorder
SOC	Sense of Coherence
TAU	Treatment as Usual
WHOQOL-BREF	World Health Organizations Quality of Life - Brief Scale

1 INTRODUCTION

Attention-Deficit/Hyperactivity Disorder (ADHD) and Autism Spectrum Disorder (ASD) are neurodevelopmental disorders (NDDs) characterized by an onset early in the developmental period. They both affect functioning within domains such as social interplay, communication, learning, and executive function - including attention and memory [1, 2]. Clinical presentations are heterogeneous with varying severity of symptoms and level of impairment, meaning that the time for diagnosis can differ from very early in life up until adulthood [3, 4]. Furthermore, disorders often co-occur and symptoms may fluctuate over the life span [5].

Historically, research concerning ADHD has focused on children. However, the last two decades' follow-up studies have shown repeatedly that ADHD in most cases persists with disabling symptoms into adulthood [3]. In ASD, most individuals diagnosed in childhood still meet diagnostic criteria in adulthood and an increased recognition contributes to a higher rate of individuals being diagnosed [6, 7]. Individuals with ADHD and ASD now constitute a growing group of patients in need of support from psychiatric services in adolescence and adulthood.

Adolescence and emerging adulthood are distinct and sensitive periods in life, acknowledged to often result in increased psychosocial stress [8]. This is especially so for youth with ADHD and ASD. For these individuals, adolescence and young adulthood can be a period with experienced changes in symptoms as well as increased responsibilities [4, 9]. A loss of important structure and support both from school and in the home environment is common, and the transitioning between child and adult services can also result in less support [10-12]. In spite of this, research on support for this age group is still limited. Moreover, interventions for individuals with NDDs need to be carefully tailored to their specific needs, as the core characteristics of their disorder (such as sensory sensibilities, lack of initiative or motivation, procrastination and poor communication skills) may well result in difficulties in taking advantage of conventional care [4].

For individuals with NDDs, access to treatment and support can improve the ability to function and reduce the risk of developing comorbid psychiatric disorders [13]. Treatment targeting ADHD has mostly focused on medication, which can provide symptom relief for the majority, but does not address challenges in all areas of life [2]. ASD is not "treatable" and there is no medication targeting the core symptoms of the disorder [1]. Support and management for ASD mainly involve early intervention- and social skills training, environmental interventions, and pharmacological treatment targeting comorbidity including insomnia, anxiety, temper tantrums, and seizures [1, 14-16]. There is still a limited amount of research concerning psychosocial interventions for adolescents and young adults with ASD [16, 17].

1.1 Attention Deficit Hyperactivity Disorder

1.1.1 SHORT HISTORY OF THE DISORDER & THE DIAGNOSTIC CRITERIA

ADHD is characterized by impairments in attention, impulsivity and in the regulation of activity level/hyperactivity [2]. The first descriptions of a disorder that resembles what we today call ADHD date back to the late 18th century. The Scottish physician Sir Alexander Chichton (1798) then described individuals with abnormal inattention and mental restlessness that could be present from birth and impact negatively on, among other things, education [18]. Similar accounts have followed, and in 1902, the British paediatrician Sir George Frederic Still marked what has been thought of as the beginning of the scientific study of the disorder within the framework of "defect of moral control in children". Within this category, he defined difficulties in delay of gratification, impulsivity as well as an "abnormal incapacity for sustained attention" in children with otherwise normal intellectual capacity [18]. Over time, the conceptualizations and proposed etiology of the disorder has changed, from assuming a causality between discrete brain damage and the described behaviour patterns (MBD; Minimal Brain Damage) to underscoring a functional disturbance of the brain (MBD; Minimal Brain Dysfunction) [18]. In the 1980s, the diagnosis of Attention Deficit Disorder (ADD) (with or without hyperactivity) was included in the DSM-III with operationalized diagnostic criteria [19]. During roughly the same period, the concept of DAMP (deficits in attention, motor control, and perception) was introduced and came into clinical use in Scandinavia, where in addition to the difficulties described in ADD - deficits of motor control, perception and speech-language impairments could be included [20].

The current definition of ADHD according to the Diagnostic and Statistical Manual of Mental Disorders 5th edition (DSM-5) [21] characterizes ADHD as the presence of symptoms of inattention and/or of hyperactivity–impulsivity, appearing before the age of twelve and apparent in more than one environment (e.g. social- or academic activities) (Table 1). Symptoms must have been present for at least 6 months and show evidence of negatively impacting social, academic or occupational functioning [21]. Different presentations reflect the fact that symptoms can also vary with age, dividing ADHD into a predominantly inattentive type, hyperactive-impulsive type or combined type. Severity level is also to be specified (mild, moderate or severe) [21].

ADHD is today one of the most common neurodevelopmental disorders, with prevalence rates estimated to between 5.0% and 7.1% in the young population and with more males than females meeting the diagnostic criteria in childhood (male-to-female ratio 2.4:1) [22, 23]. The exact etiology of ADHD is still not fully known, however results of family, twin and adoption studies show that the disorder has a strong underlying genetic component and estimates into the heritability of ADHD suggest it to be 70–80% [24]. ADHD is a disabling disorder that effects most areas of life and it is common with psychiatric comorbidity such as substance use disorders, anxiety- and mood disorders [25].

Table 1. Diagnostic criteria for ADHD according to DSM-5

Diagnostic criteria for Attention Deficit Hyperactivity Disorder, DSM-5
Inattention: Six (or more) of the following symptoms have persisted for at least 6 months to a degree that is inconsistent with developmental level and that negatively impacts directly on social and academic/occupational activities: *Note*: The symptoms are not solely a manifestation of oppositional behaviour, defiance, hostility, or failure to understand tasks or instructions. For older adolescents and adults (age 17 and older), at least five symptoms are required. a) Often fails to give close attention to details or makes careless mistakes in schoolwork, at work, or during other activities (e.g., overlooks or misses details, work is inaccurate). b) Often has difficulty sustaining attention in tasks or play activities (e.g., has difficulty remaining focused during lectures, conversations, or lengthy reading). c) Often does not seem to listen when spoken to directly (e.g., mind seems elsewhere, even in the absence of any obvious distraction). d) Often does not follow through on instructions and fails to finish schoolwork, chores, or duties in the workplace (e.g., starts tasks but quickly loses focus and is easily side-tracked). e) Often has difficulty organizing tasks and activities (e.g., difficulty managing sequential tasks; difficulty keeping materials and belongings in order; messy, disorganized work; has poor time management; fails to meet deadlines). f) Often avoids, dislikes, or is reluctant to engage in tasks that require sustained mental effort (e.g., schoolwork or homework; for older adolescents and adults, preparing reports, completing forms, reviewing lengthy papers).

g) Often loses things necessary for tasks or activities (e.g., school materials, pencils, books, tools, wallets, keys, paperwork, eyeglasses, mobile telephones).
h) Is often easily distracted by extraneous stimuli (for older adolescents and adults, may include unrelated thoughts).
i) Is often forgetful in daily activities (e.g., doing chores, running errands; for older adolescents and adults, returning calls, paying bills, keeping appointments).

Hyperactivity and Impulsivity: Six (or more) of the following symptoms have persisted for at least 6 months to a degree that is inconsistent with developmental level and that negatively impacts directly on social and academic/occupational activities:

Note: The symptoms are not solely a manifestation of oppositional behaviour, defiance, hostility, or a failure to understand tasks or instructions. For older adolescents and adults (age 17 and older), at least five symptoms are required.

a) Often fidgets with or taps hands or feet or squirms in seat. Often has difficulty sustaining attention in tasks or play activities (e.g., has difficulty remaining focused during lectures, conversations, or lengthy reading).
b) Often leaves seat in situations when remaining seated is expected (e.g., leaves his or her place in the classroom, in the office or other workplace, or in other situations that require remaining in place).
c) Often runs about or climbs in situations where it is inappropriate. (Note: In adolescents or adults, may be limited to feeling restless.)
d) Often unable to play or engage in leisure activities quietly.
e) Is often "on the go," acting as if "driven by a motor" (e.g., is unable to be or uncomfortable being still for extended time, as in restaurants, meetings; may be experienced by others as being restless or difficult to keep up with).
f) Often talks excessively.
g) Often blurts out an answer before a question has been completed (e.g., completes people's sentences; cannot wait for turn in conversation).
h) Often has difficulty waiting his or her turn (e.g., while waiting in line).
i) Often interrupts or intrudes on others (e.g., butts into conversations, games, or activities; may start using other people's things without asking or receiving permission; for adolescents and adults, may intrude into or take over what others are doing).

Several inattentive or hyperactive-impulsive symptoms were present prior to age 12 years.

Several inattentive or hyperactive-impulsive symptoms are present in two or more settings (e.g., at home, school, or work; with friends or relatives; in other activities).

There is clear evidence that the symptoms interfere with, or reduce the quality of, social, academic, or occupational functioning.

The symptoms do not occur exclusively during the course of schizophrenia or another psychotic disorder and are not better explained by another mental disorder (e.g., mood disorder, anxiety disorder, dissociative disorder, personality disorder, substance intoxication or withdrawal).

1.2 Autism spectrum disorder

1.2.1 SHORT HISTORY OF THE DISORDER & THE DIAGNOSTIC CRITERIA

ASD encompasses deficits in the areas of communication and interaction, as well as restricted interests and repetitive behaviours that cause impairment in several areas of life, such as school or work [1]. In the first decades of the 1900´s, the term autism was first used by German psychiatrist Eugen Bleuler to describe symptoms of so-called childhood schizophrenia, i.e. hallucinations and excessive fantasy [26]. In the 1940s, Leo Kanner, however, described what he called early infantile autism in a group of children [27]. Kanner's description of early infantile autism closely resembles what we today recognize as ASD including obsessiveness, stereotypies, literal use of language and difficulties in relating to other people [26]. Austrian paediatrician Hans Asperger had made similar observations during this period, but was most noticed for this when his work was highlighted by the British psychiatrist Lorna Wing in 1976, as she coined the term Asperger's Syndrome [28]. As of Kanner's recognition of infantile autism and throughout the 1960´s, leading theorists within child psychology conceptualized symptoms of autism as mainly stemming from early experiences and maternal insufficiency, so called "refrigerator mothers" [29]. From the 1960´s and onward the term autism has however evolved into being viewed as a disorder of communication and social impairment and to being defined as a developmental condition [26]. Autism accordingly replaced childhood schizophrenia in the DSM-III (1980) under the umbrella term 'pervasive developmental disorders', with four different subcategories ('infantile autism', 'childhood onset pervasive developmental disorder', 'residual autism' and an atypical form) [19]. The DSM-IV continued the use of pervasive developmental disorders but with somewhat revised subcategories [30]. However, scientific debate as to whether subcategories showed diagnostic stability and were distinguishable diagnostic entities (versus on a continuum of presentations from mild to severe cases) resulted in using the overarching category Autism Spectrum Disorder when the DSM-5 was published in 2013 [21].

ASD, as defined in the DSM-5 [21], is demarcated as symptoms from two domains, namely “persistent deficits in social communication and social interaction” and symptoms of “restricted, repetitive patterns of behaviour, interests, or activities” (Table 2). Symptoms must have had an early onset and cause social and occupational impairment [21]. An important addition in the DSM-5 is the inclusion of atypical sensory processing. Current severity for each domain is also specified from level 1 ("Requiring support”) to level 3 (“Requiring very substantial support”) [21].

The prevalence rates for ASD have increased over the years. From having been believed to affect around 0,05% of the population, current estimates show a lifetime prevalence of between 1% and up until approximately 2,5%. However, actual symptoms (the autism phenotype) seem to have remained stable over time [6, 7] and effects are likely due to increased recognition and broadened criteria [6]. ASD is more common in males than in females, with a gender ratio of about 3:1 [31]. The etiology of the disorder seems to be largely explained by genetic factors with a heritability of up to 0.93 [32]. Co-occurring psychiatric disorders, such as mood and anxiety disorders are very common, as well as intellectual disability [4].

Table 2. Diagnostic criteria for Autism Spectrum Disorder according to DSM-5

Diagnostic criteria for Autism Spectrum Disorder, DSM-5

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive; see text):
    1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
    2. Deficits in nonverbal communicative behaviours used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
    3. Deficits in developing, maintaining, and understand relationships, ranging, for example, from difficulties adjusting behaviour to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

B. Restricted, repetitive patterns of behaviour, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):
    1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypes, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
    2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behaviour (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).
    3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
    4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g. apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

1.3 Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examination (ESSENCE)

ESSENCE is an umbrella acronym coined in 2010 as an attempt to elucidate the complexity and vast overlap among NDDs [5]. Research has clearly shown that it is rule rather than exception that children who present with impairing symptoms within areas of general development, communication and language, social inter-relatedness, motor coordination, attention, activity, behaviour, mood, eating, and/or sleep before the age of five, often have problems within the same and/or related areas some years later [5]. There is also a higher likelihood of meeting criteria for not only one, but several NDDs including ADHD, oppositional defiant disorder, ASD, Tic disorders/Tourette syndrome, learning disability, language impairment, developmental coordination disorder, seizures and other neurological syndromes later in life [5]. This was reflected in the publication of the DSM-5 in 2013, where ASD and ADHD were officially recognized as co-occurring conditions [21]. As follows, this is a group of individuals requiring services with a holistic approach, taking into account all of the related problems [4, 5]. The overall prevalence for difficulties within the ESSENCE group is approximated to about 5 - 7 % with a male- female ratio of about 2-3:1 [5]. It has also been proposed that there may be a somewhat shared etiology among the disorders [33].

1.4 Treatment & Support

1.4.1 PHARMACOLOGICAL TREATMENT

Pharmacological treatment (stimulant or non-stimulant) is the most widely offered treatment option for individuals with ADHD [2]. Although able to reduce the effects of core symptoms of the disorder, medication has been shown to be inadequate for up to 50% of adults, as well as sometimes presenting with unwanted side effects [34, 35]. In the subgroup of adolescents and emerging young adults with ADHD, medication is still insufficiently studied [36]. For individuals with ASD there is no pharmacological treatment option available, aside from treatment of co-existing psychiatric and somatic disorders [4].

1.4.2 NON-PHARMACOLOGICAL TREATMENT

For both ADHD and ASD, current treatment recommendations comprise the use of so-called multimodal approaches, including non-pharmacological treatment options [14, 15, 37]. This is especially relevant in cases of co-occurring ADHD and ASD [4]. For both conditions, a basic approach of vital importance is adjusting the social and physical environment (such as stimuli reduction, enhanced structure and use of visual support) and to the processes of health care (e.g. minimising waiting time) in order to reduce stress. Support in developing coping strategies to deal with core difficulties associated with the disorders are also emphasised in most treatment guidelines [14, 15, 37].

1.4.3 PSYCHOEDUCATION

Psychoeducation – directed both at the individual and at next of kin and other important persons (e.g. teachers) is seen as essential, and is often a first step in the support of individuals with ADHD and ASD [4, 14, 15, 37]. Psychoeducation involves improving understanding and acceptance in relation to difficulties, and to offer basic management skills [4, 38]. Psychoeducation is an accepted and evidence-based intervention for a number of psychiatric disorders and can be provided in several formats (group format, individually, single session or continuously, internet-based) [4, 38, 39]. It should be a precursor to, as well as an integrated part of, most interventions for individuals with NDDs [4]. A few specific psychoeducational interventions targeting individuals with ASD as well as ADHD have been studied with positive results [40-44]. At least one for ASD was conducted through the internet and showed to be a promising and feasible intervention for adolescents and young adults [45]. It has been suggested that psychoeducation in young people with ADHD and ASD needs to take into account individual circumstances, general ability and age [4]. Furthermore, psychoeducation should not be considered a 'one-off' intervention. It should be a recurrent and integrated part of support for individuals throughout the lifespan, especially during critical periods of transition [4].

1.4.4 COGNITIVE BEHAVIOUR THERAPY

When it comes to psychotherapeutic interventions there is increasing evidence for the use of cognitive behavioural therapy (CBT) as part of a multimodal approach in managing the core symptoms of adult ADHD [3, 46]. Only a few studies exist concerning CBT for adolescents with ADHD, but they seem to demonstrate some initial efficacy [47, 48]. CBT is usually highly structured and involves psychoeducation, goal setting, and practicing specific skills through homework. Psychotherapy for adolescents or young adults with ASD is still in its early stages, but some studies have focused on adapted CBT for concomitant mental health problems, such as anxiety, and/or with elements targeting for example social impairment [16]. Such studies have revealed some promising results [49-51]. In addition, social skills training has been used with what seems to be at least moderate effects in adolescents with ASD [16, 52].

1.4.5 PROGRAMMES TARGETING TRANSITIONING INTO ADULTHOOD

In later years, a few programmes specifically focused on supporting young individuals with NDDs in the transition into adulthood have been studied with preliminary encouraging results. These include a pilot module-based group intervention for young adults with ASD drawing on techniques from CBT and social skills training [53]; a 10 week group program focusing on social communication, self-determination, and working with others for young adults with ASD [54], a family-centred group programme for school-aged adolescents with ASD and their parents [55] as well as an unassisted, self-directed 12-month online transition planning program for adolescents with ASD (preparation for leaving school)[56]. The latter concluded that including support from trained professionals might be an important accommodation as many participants did not complete the program in its entirety. Finally, a recent feasibility study targeting transitioning young adults with ASD and/or ADHD combined goal-focused manualized group- and individual sessions to empower individuals within different life domains (e.g. work, education, finance, housing, health, relationships and society etc.)[57]. Preliminary results pointed to the intervention as feasible.

1.4.6 COACHING

Coaching is an intervention that has gained interest and is increasingly recommended as a way to support individuals with ADHD [3]. As yet, there is no single operationalized definition of its methodology or process, but overarching aims of coaching for ADHD include it being a collaborative endeavour that integrates psychoeducative elements, building skills for managing daily life, as well as empowering (building on strengths) and providing structure and support [3, 58]. Coaching resembles other psychosocial treatments to some extent, borrowing its theoretical framework in part from CBT, psychoeducation, and positive psychology [59, 60]. However in coaching, emphasis is put on mentor- or partnership, striving to be pragmatic, flexible and highly accessible and to have a focus on day-to-day struggles [59]. Pre-requisites for ADHD coaching include it being well-versed in the disorder and its outcomes, including a distinct focus on executive function deficits [60, 61]. Most models do not directly address comorbid clinical problems such as anxiety or depression [61]. As such, coaching is seen as complementary to other treatment plans [61].

A number of studies have specifically focused on coaching for adolescents and adults with ADHD. In these, coaching has here been used in a variety of contexts (academic and non-academic), with coaches with different backgrounds (e.g. trained/certified coaches, school personnel, peer coaches, school psychologists, doctoral students) and varying in frequency/duration (2-27 sessions; daily – weekly), format (individual or group) and communication modality (in person, telephone, videoconference) [61, 62]. A clear majority has however involved individual coaching for college students with a primary focus on school achievements [59]. To our knowledge, only two studies have involved adults; one of these was an observational study of group coaching which showed positive outcomes on a number of ADHD symptoms [61], while the other was an exploratory study involving individual coaching for college students which yielded significant improvement in learning and study strategies, self-esteem and quality of life [60]. Comparisons between studies are hampered due to different study designs and outcome measures. However, there seems to be preliminary support for the use of coaching as a supplement in multimodal treatment approaches for ADHD with positive outcomes on measures such as symptoms of ADHD and well-being [3, 59]. When it comes to ASD, no research seems to exist on corresponding coaching models, except for within the framework of other interventions (such as social skills training or in the vocational area) [63, 64]. One review of support for adults with ASD concluded however that there needs to be research into interventions also providing broad individualized support and mentoring for this group [65].

1.4.7 INTERNET-BASED SUPPORT AND TREATMENT

Internet-based interventions within mental health have become an important contribution to the field, and offer new ways of delivering evidence-based treatment and support [66]. There are several benefits, not least being able to reach individuals independent of geographical location [66]. Internet-delivered cognitive behaviour therapy (ICBT) has been proven as effective as face-to-face CBT in the treatment of for example anxiety and depression [67]. A 2017 review [68] also suggests that synchronous chat-based communication shows promise as an effective and feasible communication modality for mental health interventions (often equal to- or more beneficial than Treatment-As-Usual (TAU) conditions. Studies included showed however great variability in terms of both intervention objective, design and duration and therefore need to be interpreted with caution. For adolescents and young adults with NDDs, internet-based interventions could prove particularly helpful, possibly eliminating some experienced difficulties with physical appointments (e.g. having to interpret non-verbal cues, being in unfamiliar and/or sensory overwhelming environment, difficulties with time management etc.)[9, 69]. Furthermore, adolescents and young adults are largely accustomed to web-based communication [70]. Thus far, very few studies have focused specifically on web-based psychosocial interventions targeting core deficits for adolescents and young adults with ADHD and/or ASD [69, 71, 72], but promising results have been seen for ICBT for adults with ADHD [73] and for a structured psychoeducative intervention targeting adolescents and adults with ASD [45]. Significant improvement in inattention symptoms were also found by Moëll et al. [74] (following a guided online (using smartphones) course for adults with ADHD symptomatology which focused on organization skills. This study, however, included participants with subclinical or "probable" ADHD diagnosis. Finally, a case report showed how using tele-psychiatry (through an internet voice application) was helpful in being able to establish therapeutic alliance with a socially isolated 16-year old male with Asperger Syndrome and depression [75].

In 2012, Wentz et al. [76] published a paper on the development of a model for chat-based support and coaching. The background to the model was an experienced need to offer support to adolescents and young adults with NDDs, in a time in life where they were perceived as especially vulnerable, and in a form that could appeal to them. A user-centred design was adopted in cultivating the model, and the final version was tested in a small validation study with ten participants. Significant improvement in sense of coherence, self-esteem and subjective Quality of Life was seen at 6-month follow-up and the model was viewed as useful and valuable by participants [76].

2 AIMS

The overarching aim of this thesis was to evaluate the feasibility of an internet-based support and coaching model (IBSC). The thesis entails two sub-studies with the following specific aims:

I. To explore the effectiveness of the intervention in two naturalistic clinical settings, using a larger sample size than in the validation study and including a comparison group.

II. To investigate the subjective experiences of the individuals taking part in the internet-based support and coaching intervention.

3 METHODS

The included sub-studies are both part of the IBSC project, for adolescents and young adults with ADHD and/or ASD. The IBSC model is examined from two methodological viewpoints, quantitatively (study I) and qualitatively (study II). Shared features will first be described, followed by the specific details of each sub-study. An overview of methods, participants and the analyses used in each sub-study are outlined in Table 3.

Table 3. Overview of the included studies

	Design	**Study group**	**Data collection**	**Data analysis**
Study I	Non randomized controlled feasibility study	50 individuals with confirmed diagnosis of ADHD and/or ASD at two study centres in Region Västra Götaland were allocated to the intervention IBSC (*n*=30) or Treatment as usual/TAU (*n*=20). *Six* individuals in the intervention group did not complete their participation in IBCS.	Patient self-report questionnaires	Descriptive and inferential statistics
Study II	Qualitative interview study	All 30 individuals who had participated in the intervention/IBCS (including dropouts). 17 out of 30 agreed to participate, one of which could not be reached to complete the interview.	Single semi-structured narrative interviews	Qualitative content analysis

3.1 Design

Study I: A non-randomized controlled design was employed, assigning participants to either the intervention (8 weeks of IBSC; n=30) or to Treatment as usual (TAU; n=20). Randomization was discarded due to recruitment experiences in the validation study, where individuals with ASD, by reason of difficulties with tolerating uncertainty, were unwilling to participate without knowing to which study group they would be allocated. It was also deemed unethical to withhold treatment from the comparison group during the intervention period. Self-assessment questionnaires were administrated to the intervention group and to the TAU group at baseline, after the intervention/after 8 weeks and at 6-month follow up in order to establish the effectiveness of intervention.

Study II: Semi-structured narrative interviews with the participants in the intervention group regarding their experience of taking part in the intervention were carried out from a minimum of 3 months after the end of the intervention.

3.2 Participants and procedure

The study was performed in two naturalistic settings; a Habilitation Centre serving children, adolescents and adults with ASD and other neurodevelopmental disabilities, and a psychiatric outpatient clinic specialized in adults with ADHD and ASD. Both study centres were located in the southwest of Sweden, Region Västra Götaland. They both had large catchment areas and reduced travel time could therefore be a motivating factor. The recruitment of participants to the intervention study was conducted consecutively between the autumn of 2010 and autumn of 2014 during regular visits at the two study centres.

Inclusion criteria comprised:

- 15 to 32 years of age
- confirmed diagnosis of ADHD, ASD or both according to the DSM-IV
- access to a computer with internet connection
- for intervention group: no other ongoing support or psychological treatment during the intervention period

Exclusion criteria encompassed:

- other serious or dominant disorders; ongoing psychosis, serious and ongoing alcohol and/or substance misuse, major depressive disorder (if unable to conform with the intervention or in need of other treatment), conduct disorder/antisocial personality disorder, severe dyslexia and known intellectual disability.

Participants were offered a small monetary compensation to cover any expenses associated with their involvement (such as travel costs). As both recruitment, effectuation and administration of the intervention took place in small routine care settings, by staff who were also involved in carrying out routine care at the treatment sites (and had a limited amount of time reserved for the study), the recruitment period spanned over a relatively long period of time. The internet-based support and coaching intervention was ongoing between the autumn of 2010 and winter of 2014.

3.3 Assessment

Participants who expressed interest and seemed to fulfil inclusion criteria were assessed for eligibility by a psychiatrist or licensed clinical psychologist making use of the Structured Clinical Interview for DSM Axis 1 Disorders (SCID 1)[77] - the alcohol/substance use and psychotic disorder modules, as well as the Structured Clinical Interview for DSM-IV Axis II Disorder (SCID II)[78] - the antisocial personality disorder module. The Montgomery-Åsberg Depression Rating Scale - Self-reported (MADRS-S) [79] was used to detect symptoms of depression at baseline in addition to being used as an outcome measure (see "Instrument Heading"). All outcome measures were completed by participants at baseline assessment. Table 4 shows the baseline demographics of participants in study I.

Study I: All individuals who were assessed for participation in the intervention fulfilled inclusion criteria and were included in the study (n=31). One individual refrained from participation before the start of intervention, leaving 30 in the intervention group. Of these, 24 participants completed the full 8 weeks of participation (dropout: n=6).

Comparison cases for the TAU group were recruited synchronously to the intervention group using the same assessment procedure. They were matched by age, gender and diagnosis. Due to recruitment problems (i.e. difficulties finding an exact match within the time frame) some cases were included even though they did not fully match participants in the intervention group. Twenty-one comparison cases were assessed. One individual who was judged in need of treatment for depression was excluded, leaving a total of 20 in the TAU group.

Study II: All participants in the intervention group (including dropouts) were invited to take part in the interview study after the post intervention follow up.

Seventeen individuals agreed to participate (reasons for declining were not shared). One individual failed to show up despite several scheduled interview dates, leaving 16 participants in study II. Fifteen had taken part in the intervention and one was a dropout. The age range of participants in the interview study was 15 to 32 years (mean = 23 [SD = 5]). Fifty-six percent were males and 44% were females. Six participants were recruited from the Habilitation Center and ten from the specialized psychiatric outpatient clinic. Seven had combined diagnosis of ADHD and ASD, 6 had ASD and 3 had ADHD.

Depending on time for enrolment in the intervention study, interviews took place between the autumn of 2012 and spring of 2015 at the recruiting clinic (median 8.5 months after the intervention). One interview took place in the participant's home at the participant's request (i.e. travel difficulties). Interviews were conducted individually, except for one where the participant requested a parent to be present. Ten interviews were performed by a senior female researcher with no previous connections to any of the involved study sites or participants. Six interviews were performed by the author. The latter had been involved in recruiting and as a coach at the specialized psychiatric outpatient clinic. For this reason she was excluded from performing interviews with participants from her own study site. Interviews varied greatly in length but had a median duration of 22 minutes. All interviews were recorded, anonymized and transcribed verbatim by professionals. For an overview of the studies and participants in the two IBSC sub-studies, please see Figure 1.

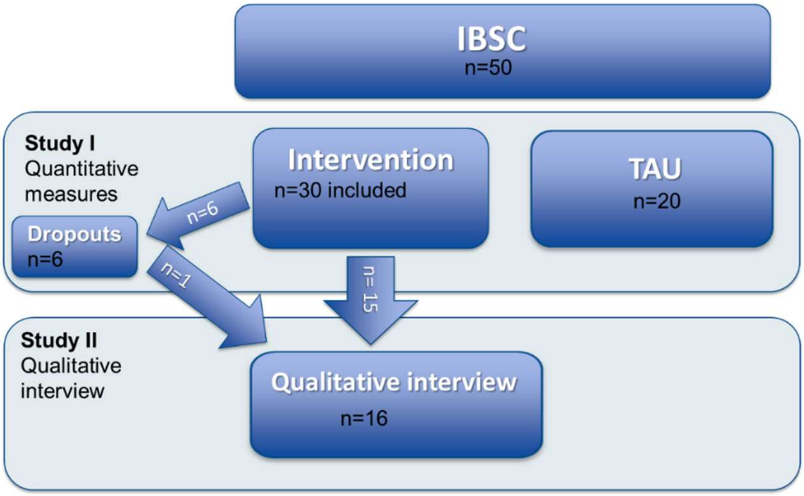

Figure 1. Overview of participants in IBSC sub-studies

3.4 Instruments

Study I: All outcome measures correspond with the ones used in validation study [76].

3.4.1 PRIMARY OUTCOME MEASURE

Pursuant to the validation study, the Manchester Short Assessment for Quality of Life (MANSA) was chosen as primary outcome measure. MANSA includes 16 items, of which 4 are objective QoL questions (answered with "yes" or "no") and 12 are subjective QoL satisfaction questions regarding occupation, financial situation, friendships, leisure activities, living situation, personal safety, family relations, physical- and mental health [80]. One question pertaining to satisfaction with sex-life was excluded for ethical reasons with regard to the age range of the participants (including participants as young as 15). The 11 remaining satisfaction items are rated on a 7-point scale ranging from 1= "could not be worse" to 7= "could not be better". An overall score is then calculated. The Swedish version of MANSA has shown satisfactory psychometric properties in terms of internal consistency and construct validity, when used among individuals with mental illness [81]. The first item of MANSA reflects subjective global quality of life. Besides being included into the total score, this item was also analysed separately in agreement with the validation study. It was however considered a secondary outcome measure.

3.4.2 SECONDARY OUTCOME MEASURES

The Hospital Anxiety and Depression Scale (HADS) was chosen to measure symptoms of anxiety and depression. The scale has a total of 14 questions, scored between 0 and 3, with higher scores suggesting higher symptom load. It comprises two subscales of 7 questions each measuring symptoms of anxiety and depression respectively. The HADS has been shown to have satisfactory psychometric properties, even among adolescents [82, 83]. The Montgomery-Åsberg Depression Rating Scale - Self-reported (MADRS-S) was used as a separate measure of depressive symptoms, as well as to detect depression in the initial inclusion process. MADRS-S consists of 9 items that are scored from 0-6 points. The total score ranges from 0-54 points, with higher scores indicating more severe depression. MADRS-S is constructed to be sensitive to change in depressive symptoms and has been shown to have good reliability [79, 84].

The Sense of Coherence scale (SOC 29) is a questionnaire that measures comprehensibility, manageability and meaningfulness –constituent parts of the concept of sense of coherence (SOC). Built on salutogenic theory, a stronger SOC has been shown to be positively related to perceived health, in particular mental health. It is also predictive of general health and resilience to stress [85]. The SOC 29 has 29 items, each scored from 1 to 7 with a higher score representing a higher sense of coherence. The SOC 29 has been shown be a valid and reliable instrument across cultural settings [86].

The Rosenberg Self Esteem Scale (RSES) measures aspects of self-esteem. It comprises 10 questions that are scored on a Likert scale between 0 and 3 –a higher score signifying an overall higher self-esteem [87, 88]. The RSES has been widely used and validated as an instrument to measure self-esteem.

Data on sociodemographic characteristics was collected through a self-report questionnaire inquiring about civil status, living situation, geographical area, level of education, occupation and support from social services. Medical records were used to collect data about diagnosis, ongoing and/or received treatment and support (medical as well as otherwise).

3.4.3 GLOBAL ASSESSMENT OF FUNCTIONING

A decision was made to assess retrospectively all participants' functioning at baseline (both intervention and TAU-group) according to the Global assessment of functioning Scale (GAF) from DSM-IV-TR [30]. The GAF takes into consideration the impact of psychiatric symptoms on a person's functioning within social, school and occupational domains. The GAF-scale ranges from 0 (severely impaired) to 100 (very high functioning) with defined anchor points for every ten point interval. Individual case presentations based on current diagnoses, sociodemographic information, level of anxiety and depression (based on HADS and MADRS-S), participants' item level responses on the MANSA and item level responses on a questionnaire measuring perceived caregiver burden [89] were summarized by the first author. The questionnaire measuring caregiver burden had been filled out by next of kin at baseline and evaluates the participants functioning within a number of different areas of daily living [Note: results on this questionnaire are not otherwise reported on in this study]. Each case was assessed for 10-point GAF-interval score by the first author. Then, omitting information on gender and study arm, cases were assessed blind by the second author. Inter-rater agreement was measured with Cohen's kappa (k) and found to be very good (k =.89). Results of GAF assessment for all individuals are shown in Table 4.

Study II:

3.4.4 SEMI-STRUCTURED INTERVIEWS

A semi-structured interview guide with open questions encompassing the participants' expectations and experiences surrounding receiving IBSC was used. The interview included inquiries about how participants perceived the support at different stages of the intervention, any experienced benefits and/or disadvantages with IBSC compared to other forms of support as well as what participants might have appreciated or would like to have changed with the IBSC. Furthermore, participants were asked about the significance of coaches' knowledge, experience and background and any ideas of their own they might have had regarding the use of chat-based support and coaching. In accordance with narrative interviewing, the participants were encouraged to relate freely to the interview questions and that the interview might be seen as a conversation with the intent of capturing their subjective experiences.

3.5 Intervention & treatment as usual

3.5.1 INTERNET-BASED SUPPORT & COACHING

The IBSC model was developed and validated by Wentz et al. [76]. The model aims to offer a combination of individualized psychoeducation, support and coaching focused on everyday life issues related to living with an NDD. It entails 8 weeks of internet-based support and coaching á 30 minutes to one hour, twice weekly, delivered through a specifically developed chat program ("Salut chat"). Live meetings with the coach at the clinic replace one chat session per week during week three and six of the intervention. The program also allows for brief communication through an email function. The focus of chat sessions is tailored to the individual´s own perceived needs and preliminary topics are decided on during a live meeting with the coach at the start of the intervention. Chat topics can entail subjects such as handling social situations, daily structure and routines, study technique and help with stress- and time management. Coaches validate participant's experiences, help provide possible explanations (psychoeducation) and alternate between encouraging participants to find their own coping strategies (building on strengths) as well as offering more specific advice. The support is deliberately general and supportive in nature set against more structured skill-based interventions. The coaching is provided by a health care professional with extensive knowledge and experience in the field of NDDs and relies heavily upon this knowledgebase. All coaches were employed at the study centres and were from different occupational background and included occupational therapists, social workers, special education teachers and a clinical psychologist. The fidelity to the model was encompassed by thoroughly informing the coaches about the principles of IBSC before the start of the intervention and making sure that the focus of chat sessions was daily life problems, while referring serious mental health matters elsewhere. The latter was also ensured by offering coaches supervision by the model developer/head of project every second week. During these meetings recruitment matters were also discussed.

3.5.2 TREATMENT AS USUAL

TAU encompassed any typically occurring treatment offered at the involved treatment sites such as pharmacological treatment and/or psychological treatment, occupational therapy (e.g. interventions targeting management of structure and time), and group psychoeducation. A majority of individuals received predominantly pharmacological treatment which encompassed check-ups with a psychiatrist and/or a nurse, and a few individuals did not receive any active treatment during the intervention period. The latter was mostly due to problems with compliance in offered support.

3.6 Data analysis

3.6.1 STATISTICAL ANALYSES

Study I: Statistical analyses were performed using the SAS Software version 9.4 (SAS Institute Inc., Cary, NC, USA). The Fisher´s Exact test for dichotomous variables was used to examine differences in baseline characteristics between the intervention- and the TAU group (Table 4), and to analyse potential differences between the intervention group and loss to follow-up. For ordered categorical variables, the Mantel-Haenszel Chi Square test was used. Non-ordered categorical variables were analysed using the Chi Square test and for continuous variables the Fisher´s non-parametric permutation test was used.

To assess the effect of the intervention on primary and secondary outcome measures, and for comparisons between groups, the Fisher´s non-parametric permutation test was used for continuous variables. In order to adjust for differences in baseline GAF scores between the groups, analyses of covariance (ANCOVA) models were calculated resulting in parameter estimates of between-group differences with adjusted means with 95% confidence interval and adjusted P-values. The first item of MANSA (overall subjective quality of life) was analysed separately based on the variable mean score using the same statistical procedure in order to adjust for GAF scores. Primary and secondary outcome measures were predefined before the start of the study and therefore not adjusted for multiple testing. The Wilcoxon Signed Rank Test was used for within group comparisons on primary and secondary outcome measures.

Missing data at eight weeks amounted to at most n=1 for all measures and n=1 for a single scale (HADS) at 6 months. To account for missing values at post-treatment and follow-up assessment mean substitution was used.

Effect sizes for between-group effects were calculated as Cohen's d based on the observed means and pooled standard deviations ((M2 - M1) / SDpooled).

3.6.2 QUALITATIVE ANALYSES

Study II: Interview data in the form of verbatim transcripts were analysed using qualitative content analysis. Content analysis is a method that has its roots in the systematical analysis of communication, such as texts or interviews, and can be used both quantitatively and qualitatively [90]. Qualitative content analysis involves the procedure of reading the relevant texts multiple times as to get sense of the data in its entirety. Both manifest and perceived latent content is regarded in this process [90, 91]. The text is subsequently broken down into so called meaning units, that is - analytical units of content that are perceived to capture the meaning of a portion of text. Meaning units are then condensed, and given a relevant code. Codes are examined and categorized into clusters that form subthemes and themes in a step-by-step procedure where the original text is continually re-considered so as not to lose original meaning. The analysis was principally performed manually. The software program NVivo v10 [92] was used to support the analysis process, mostly as an aid in structuring the data/codes. Furthermore, to get a sense of if any theme or code was completely dominated by a certain diagnostic category, a simple count was performed. The count showed no such absolute tendency.

3.7 Ethical considerations

The project obtained ethical approval by the Regional Ethical Review Board at the University of Gothenburg, Sweden (reference: 013-08; T364-10; T645-11; T436-12). Verbal and written information about the study was provided to all participants. Written informed consent was obtained during intake interviews for study I, and before the interview in study II. All participants were considered to have the necessary level of maturity to give their own consent. The guidelines of the World Medical Association Declaration of Helsinki (2008) were applied regarding ethical considerations.

4 RESULTS

4.1 Baseline characteristics and dropouts

The Intervention group and the TAU group were (as shown in Table 4) equal on most pre-treatment demographics, but the Intervention group had a significantly lower mean GAF-score than the comparison-group - a difference that was also echoed in Employment status. No differences in baseline outcome variables between groups were present before or after adjusting for differing GAF-baseline scores. Dropouts (n=6) did not differ in terms of demographic- or outcome variables at baseline from those that completed IBSC in the intervention group. Difficulties in prioritizing and/or adhering to the set-up of the model due to for example stress at school/work and/or memory issues were mentioned as reasons for dropping out.

Table 4. Demographics and sample characteristics at baseline, adapted from Sehlin et al. (2020).

Demographic	**IBSC n=24[a]**	**TAU n=20**
Age at inclusion (years)		
Mean (SD)	21.0 (5.1)	22.1 (5.1)
Gender, n (%)		
Male	13 (54)	10 (50)
Female	11 (46)	10 (50)
Diagnosis, n (%)		
ASD	9 (38)	7 (35)
ADHD	3 (13)	5 (25)
ASD + ADHD	12 (50)	8 (40)
GAF-score (10-point interval)*		
31-40	9 (38)	3 (15)
41-50	9 (38)	4 (20)
51-60	5 (21)	8 (40)
61-70	1 (4)	5 (25)
Geographical area, n (%)		
Urban	13 (54)	17 (85)
Rural	11 (46)	3 (15)

Demographic	**IBSC** **n=24**[a]	**TAU** **n=20**
Living situation, n (%)		
One person household	8 (33)	6 (30)
Living with partner and/or children	2 (8)	5 (25)
Living with parents and/or siblings	14 (58)	8 (40)
Living with friends and/or acquaintances	0 (0)	1 (5)
Level of education (completed or ongoing)		
Has not completed compulsory school [b]	2 (8)	0 (0)
Compulsory School	7 (29)	8 (42)
Upper Secondary School	11 (46)	9 (47)
Vocational education (after compulsory school)	0 (0)	1 (5)
University	4 (17)	1 (5)
Missing	0	1 (5)
Occupation, n (%)*		
Employed	0 (0)	7 (35)
Unemployed	6 (25)	3 (15)
Student [c]	13 (54)	7 (35)
Work experience placement	2 (8)	1 (5)
Sick leave	3 (13)	2 (10)
Support from social services [d]		
Yes	7 (29)	7 (37)
No	17 (71)	12 (63)
Missing	0 (0)	1 (5)

IBSC: Internet-based support and coaching; TAU: Treatment as usual; ASD: autism spectrum disorder; ADHD: attention-deficit/hyperactivity disorder; GAF: Global Assessment of Functioning.

[a] Only 24 out of 30 in the intervention group completed IBSC; therefore, only the 24 are presented in the table.

[b] No formal education or terminated compulsory school without complete grades.

[c] All levels of education (eg, compulsory school, secondary school, vocational education, and university studies).

[d] Support can include assistance through the Swedish Act concerning Support and Service for Persons with Certain Functional Impairments (LSS) or from Social Services, for example, so called contact person, relief service, or living support.

*$p < .05$.

4.2 Study I: Effect of the intervention

Results based on analyses with ANCOVA (adjusting for differing baseline GAF-scores between groups) showed a significant between-group effect on symptoms of anxiety (HADS) post intervention, based on a non-significant decrease in anxiety in the Intervention group and a significant increase in the TAU group. Anxiety measures at 6-month follow up likewise showed a significant between-group effect, at this point explained by a significant decrease in anxiety in the Intervention group and a significant increase in the TAU group. Between-group effect sizes for anxiety at post intervention/8 weeks as well as at 6-month follow up were large. Depressive symptoms according to HADS also showed a significant between-group effect at post intervention/8 weeks depending on a non-significant decrease in the intervention group and non-significant increase in the TAU group with a medium sized between-group effect size.

Regarding within-group changes, self-esteem (Rosenberg) had increased significantly in the Intervention group between baseline and 6-month follow up. No other significant results were found for primary or secondary measures.

Table 5 illustrates results on adjusted primary and secondary outcome measures at baseline, 8 weeks and 6 months for the two groups.

Table 5. Results regarding Rosenberg, HADS Anx and HADS Depr at baseline, after 8 weeks and at 6-moths follow up by treatment group (adjusted variables), adapted from Sehlin et al. (2020).

	IBSC (n=24)		**TAU (n=20)**			
Variable	Adjusted means[a] (95% CI)	*P* -value within group	Adjusted means[a] (95% CI)	*P*-value within group	*P* -value between groups: Adjusted [a]	Mean difference between groups (95% CI); Effect size
ROSENBERG						
Rosenberg Total score Baseline	17.3 (15.2-19.4)		17.1 (14.8-19.4)		.90	
Change Total score Baseline to 8 weeks	1.57[b] (-0.06-3.20)	.060	0.043 (-1.72-1.81)	.79	.23	1.53 (-0.98; 4.04); 0.332
Change Total score Baseline to 6 months	1.29 (-0.36-2.93)	.038	0.356 (-1.46-2.17)	.86	.47	0.930 (-1.64; 3.49); 0.388
HADS ANX						
HADS Anx Baseline	8.02 (6.34-9.69)		7.93 (6.08-9.78)		.95	
Change HADS Anx Baseline to 8 weeks	-0.432[b] (-1.68-0.813)	.44	1.80 (0.45-3.14)	.010	.024	-2.23 (-4.15; -0.31); 0.796
Change HADS Anx Baseline to 6 months	-1.52[b] (-2.85–0.20)	.003	1.55 (0.12-2.99)	.023	.004	-3.08 (-5.14; -1.02); 1.24

HADS DEPR						
HADS Depr Baseline	3.93 (2.57-5.29)		4.48 (2.98-5.99)		.60	
Change HADS Depr Baseline to 8 weeks	-0.502[b] (-1.77-0.760)	.41	1.58 (0.22-2.94)	.063	.036	-2.08 (-4.02; -0.14); 0.675
Change HADS Depr Baseline to 6 months	-0.081[b] (-1.38-1.22)	.80	1.14 (-0.26-2.55)	.091	.23	-1.22 (-3.24; 0.79); 0.491

[a]Adjusting for GAF intervall using Analysis of Covariance (ANCOVA)
[b]Based on 23 individuals

IBSC: Internet-based support and coaching; TAU: Treatment as usual; CI confidence interval, Rosenberg Rosenberg Self-Esteen Scale, HADS: Hospital Anxiety and Depression Scale (DEPRS: depression; ANX: anxiety)

4.3 Study II: Participant experiences

The qualitative analysis of interviews with participants who had taken part in the intervention (total 16 participants including one dropout) resulted in three themes, and a total of ten sub-themes portraying their subjective experiences of taking part in IBSC (se Figure 2).

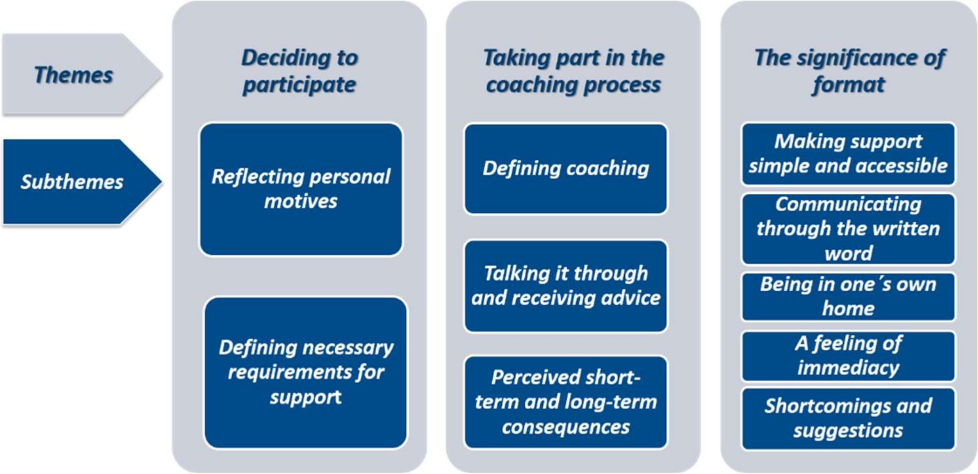

Figure 2. Overview of themes and subthemes in study II.

4.3.1 DECIDING TO PARTICIPATE

The theme reflects individual reasons for deciding to take part in the study, as well as the participant´s perceived requirements for receiving support. The subtheme Reflecting personal motives shows that the participants had a curiosity about the new model and the technique used (chat), viewing the technique as something familiar from their everyday life and having the potential to be better suited to their situation (both in terms of having an NDD as well as reducing time for travel in connection to appointments). A need for support that was previously unmet by health care and/or family was also voiced as a motive.

In order to feel secure and making the support feel meaningful, some requirements were mentioned (subtheme: Defining necessary requirements for support). These were mainly; adequate information about the model, data security and guaranteed confidentiality, as well as being familiar with and having a visual image of the coach. Some also stressed the importance of a high competence level in the coach regarding NDDs, based on previously negative experiences.

4.3.2 TAKING PART IN THE COACHING PROCESS

The analysis showed that the participants defined coaching (subtheme) as an easy-going form of help, comparable to a "social contact" from whom they could receive guidance and encouragement. The content of chat-conversations (subtheme; Talking it through and receiving advice) were mainly related to themes such as making sense of their diagnosis, specific practical advice concerning planning and organization, problem-solving, interpretation and management of social situations as well as discussing previous and current life events. There was a voiced reluctance against using the term "treatment" about the support.

Perceived short-term and long-term consequences (subtheme) of receiving the support were also mentioned. Short-term consequences could for example be an experienced relief in having someone to turn to with thoughts and questions especially in view of experienced thresholds for contacting healthcare (and/or family members, acquaintances etc.). This could contribute to anxiety reduction in the moment and/or being perceived as having a mood stabilizing effect. Also mentioned was that the structure of sessions in the short term was helpful in creating order in their everyday life.

When it came to long-term consequences, participants mentioned feeling empowered in different areas of life (such as social situations), experiencing improved planning skills and self-confidence and being better able to balance their everyday life so as to promote less stress and fatigue. Learning to use writing as a way of processing feelings in other areas was also mentioned. There was an expressed satisfaction with the intervention also concerning length and frequency of chat sessions. However there were also participants who were sceptical about the intervention having any lasting effects and who voiced having difficulties in implementing given advice. Some mentioned that more continuous support, longer than the 8 weeks offered, would probably have resulted in better effects.

4.3.3 THE SIGNIFICANCE OF FORMAT

In terms of the format of the intervention, and in what way participants viewed specific features as having an impact on their experience - several subthemes emerged. The support was viewed as simple and accessible (subtheme Making support simple and accessible), promoting flexibility and minimizing the effort and time used to obtain and receive help. However, the same aspect was considered by some as having the opposite effect, being associated with feeling less committed and/or forgetting about sessions. Some also mentioned that the internet-based form was less important, support being equally acceptable through other methods of communication such as telephone or physical meetings.

Being able to communicate through the written word (subtheme) was experienced as having several advantages. On the one hand, it allowed for time to reflect and make sure that what was written accurately conveyed what one wanted to express, reducing the risk of misunderstandings. Participants also said that they felt more secure in expressing thoughts and feelings through the written word, than they would have done in a physical meeting. Having access to what had been written on the screen furthermore alleviated memory problems. However, the opinion that part of the personal interaction was lost in the chat-sessions was also voiced.

Another aspect of communicating through a chat-program was being in one´s own home (subtheme). Avoiding some of the tension associated with social interaction, unfamiliar surroundings etc. seemed to reduce anxiety and stress. Nonetheless, the opinion also arose that while appreciating the opportunity to receive support at home, this could not entirely replace face-to face interaction.

Another perceived positive aspect of the format was "a feeling of immediacy" (subtheme) associated with the higher frequency (two times a week) and the possibility for brief communication through the email function, which meant being able to communicate feelings in real time (even though response was delayed). This endorsed rapid implementation of advice, rapid follow up and made it easier to stay focused on the topic for chat sessions. Some would however also have appreciated the opportunity to be able to vary the frequency of chat sessions in accordance with their experienced need for support that particular day or week.

Finally there were some expressed Shortcomings and suggestions (subtheme) in relation to the IBCS. Shortcomings were mostly related to failing technology that sometimes affected the support received (need for re-scheduling of chat-sessions etc). Suggestions from participants regarding improvements covered topics such as being able to vary form of communication (live meetings, computer-chat, mobile app, group chat, telephone, video conversations, on-call chat service and the like) and to have access to chat logs between sessions. There was also a voiced need for help in providing information to concerned parties (for example employer) if one needed time off work or school, or a private place to participate in chat sessions. The need to engage in activities outside of chat sessions and incorporate these into the support was also voiced, as a way to establish for example new strategies or practice new skills.

5 DISCUSSION

The 2020 COVID-19-pandemic rapidly increased the use of digital technology to a level not previously seen. Within psychiatry, this was mostly in the form of telephone- and video appointments [93]. The full implications of this are likely still not fully known. However, it seems probable that it has brought about a longstanding change that will prove to have had several positive outcomes, for example in the form of access to more individualized care. Digital visits might not suit everyone, but a greater inclination to make use of different treatment modalities is encouraging and offers the prospect of being able to reach more people with health care interventions. Chat-based support could be one such possibility.

5.1 Major findings

In this thesis, an internet-based support and coaching model for young people with ADHD and/or ASD, mediated through the use of a chat program and with complementary clinic visits, was explored. Two different methodological perspectives were adopted with the overarching aim of evaluating the feasibility of the model. In study I, a non-randomized controlled study conducted in two naturalistic settings, the main findings included a decrease in anxiety and an increase in self-esteem in the intervention group at 6-month follow up. There were also significant between-group differences immediately following the intervention as regards symptoms of anxiety and depression, as well as for anxiety at follow-up, both favouring the intervention group. The latter was however explained in part by a deterioration in the TAU group. Study II, a qualitative interview study, showed that participants were mainly positive to chat-based support. Several aspects of both the format, and of the support and coaching offered, seemed to fit in well with their experienced needs. It was however not seen entirely as a substitute for face-to face meetings, and participants voiced a number of requirements for receiving this kind of support.

5.2 Possible long-term effects on anxiety & self esteem

Both anxiety and low self-esteem are common among individuals with NDDs, often arising out of difficulties in coping with everyday life situations [94]. Anxiety might be reduced in this population by acquiring more adequate coping skills. Better ability to master everyday life, greater self-knowledge and a more accepting stance in relation to one´s own difficulties might likewise result in increased self-esteem. The finding that self-esteem increased and anxiety decreased at follow-up in the intervention group in study I is promising, and interesting in several regards.

The internet-based support and coaching did not include treatment techniques specifically targeting anxiety or low self-esteem. It was however focused on helping individuals comprehend their faced difficulties in perspective of also having a NDD, to support, empower and enable them to generate new coping-strategies and offer helpful advice when appropriate. The latter is to some extent a deviation from traditional ADHD-coaching techniques, that generally focus more on empowerment and are less directive in nature [58]. This accommodation was motivated by the inclusion of individuals with ASD, who can have a difficult time generating solutions in novel situations [95].

The fact that the effects on these measures were significant at 6-month follow-up, rather than directly after the intervention, could be interpreted as indicative of actual change rather than as an effect of short term reassurance. Short-term reassurance and subtle avoidance of anxious feelings or situations have often been proven to maintain anxiety in a longer perspective [96]. Our results are compliant with the validation study that likewise showed increased self-esteem after 6 months [76]. At least one other study evaluating an individual coaching program for college students (age 17 to 60) with ADHD has shown increased self-esteem as an experienced effect (according to RSES at post intervention, no follow-up was included) [60].

Few studies have otherwise specifically targeted self-esteem in individuals with ADHD and/or ASD. It has been proposed that compared to symptoms such as anxiety and depression, self-esteem in individuals with ASD might take longer to change considering enduring core difficulties, adverse life experiences and difficulties in generalizing skills [95]. A randomized controlled trial (RCT) [51] and a small pilot study [95], both evaluating CBT-based interventions specifically addressing low self-esteem in adults with ASD, seem to confirm this assumption. None showed an increase in self-esteem, even in the light of improvements on other ratings such as quality of life and general well-being. All considered, delayed effects on self-esteem might therefore be understandable in this group. In ADHD a sparse number of studies suggest that psychosocial interventions could have some effect on self-esteem [97]. These studies were mostly skills-based (e.g. CBT) but can presumably equally have had an effect on coping and self-awareness [97].

Results from the few previous studies that exist on purely psychoeducational interventions for individuals with NDDs are somewhat ambiguous, but seem to hold preliminary support for the notion that psychoeducation can result in preserved or possibly increased self-esteem in individuals with ADHD – if they also include advice on coping [42, 98]. Increased self-awareness succeeding psychoeducation alone might in contrast have adverse effects on self-esteem in this group, possibly due to a heightened awareness about difficulties in the absence of coping skills [44]. Using coaching for this population might therefore be a sympathetic approach as it includes both psychoeducation as well as support and strategies for managing daily life.

5.3 Quality of life & sense of coherence

We found no effects on measures that relate to quality of life, including MANSA (our primary outcome measure) and SOC (measuring sense of coherence, but also associated with subjective quality of life)[99]. MANSA was the primary outcome measure in the validation study in which there was a detected significant increase on the first item: subjective global quality of life [76]. The remaining questions in MANSA comprise satisfaction with work, leisure activities, quality of- and number of friends, economy, living situation etc - factors that might very well be unchanged even in the light of a greater self-acceptance and self-esteem. A study exploring QoL in individuals with ASD using MANSA has suggested that there might also be a more intricate relationship between severity of specific ASD symptoms and different QoL domains [100]. We have not had access to information on symptom severity in our sample, and can therefore not discard the possibility that such differences might be present in comparison with the sample in the validation study. As regards SOC, it has been noted that questions might in part relate to some of the basic difficulties found in individuals with NDDs; such as ability to accurately interpret and manage social communication, experience of situations as predictable, ability to be flexible and the tendency to have shifting ideas, thoughts and feelings. Also, it has been suggested that SOC might be more resistant to change after early adulthood [99]. As the present study included older individuals compared to the validation study, this might be a possible explanation for the lack of effect on this measure [76].

5.4 Opposite trajectories for the Intervention- & TAU-group

Significant between-group effects were found for depressive symptoms post intervention and anxiety at post intervention as well as at follow-up (according to the HADS). This was to a certain extent explained by TAU experiencing a worsening of symptoms across these measures, whilst the intervention group moved in the opposite direction. This outcome was unexpected and the probable cause is not evident. Results are for this reason interpreted with caution. A hallmark of the IBSC is a relatively high frequency of contact (twice weekly) and the intervention being delivered in the participants' everyday environment. This kind of frequency and delivery mode did not constitute the TAU condition, as it is rarely offered as part of standard care in Sweden. Struggling with executive functioning (especially intrinsic motivation), or having a diagnosis of ADHD, has been shown to increase the probability of dropping out from treatment [101, 102]. Repeated reminding and prompts are suggested strategies to increase adherence and decrease attrition [101]. As impaired executive functioning is often a cardinal difficulty among individuals with NDDs, it is likely that they might benefit more from support administered at a higher frequency, as it offers reminders and helps them keep on track. This is something that was also mentioned by some participants in study II. Having the support taking place in one's daily environment and being highly individualized might also be helpful for individuals with deficits in generalization, as is common in this group. It is known from previous studies that effects following for example psychological treatment can emerge over time as a result of new insights and changing behaviour patterns - especially when treatment is insight-based [103, 104]. It is possible that the effects of receiving IBSC could likewise be evident after some time had elapsed as an effect of a gradual change in thinking and behaviour. The intensity and mode of support received might therefore be one difference between the groups, possibly contributing to their dissimilar outcomes even after some time had elapsed.

5.5 How did participants experience the IBSC?

Study II revealed that there was an experienced need for support among participants to discuss everyday life issues relating to their diagnosis, with someone that was well-versed in their disorder. Confidence that the coach was trained and experienced in the field of NDDs was underlined as one of several pre-requisites for taking part in the intervention. For some, the need for support was previously unmet. Several studies have documented an unfulfilled need for support among individuals with NDDs, which seems to be particularly common during the period of transitioning into adulthood, as well as in the transition between child- and adult services [11, 12, 105]. There is however very little available research addressing support for individuals with NDDs during this specific period in life [11, 106]. At the same time, such interventions may be critical during emerging adulthood to prevent otherwise poor adult outcome in several areas of life for this group [11, 106]. Access to support and psychoeducation is also very important after recently undergoing a neuropsychiatric investigation, as shown in several qualitative studies and emphasized by most guidelines [3, 4, 107, 108]. This need was also mentioned by some participants in the interview study.

Study II indicated that the internet-based support was appealing in view of a hesitance or perceived barriers to seek help from health care or in their own social network, and was perceived as more available and better adapted to some of their needs. Participants professed it less stressful to communicate from one´s own home, and in some instances, it reduced the risk of appointment cancellations. Having access to support or activities from home has been mentioned as pivotal for some individuals with NDDs – sometimes as a way of being able to participate at all, or as a first step in establishing contact [75, 109]. Other aspects of the format viewed as helpful was the written communication. This offered visual support and relieved memory difficulties, allowed more time for the thought process, and made it easier to discuss subjects regarded as private. These collected experiences underscore the need to reduce barriers for receiving support and to offer alternatives that take into account characteristic difficulties such as stress resulting from working memory deficits, poor understanding of non-verbal communication and slow processing speed in some individuals with NDDs [110, 111]. Previous studies have highlighted the experience of insufficiently tailored treatment and support, and that clinic environments (such as waiting rooms) might be felt stressful for individuals with ADHD and/or ASD [12, 112]. Some of the advantages found with internet-based treatments are feelings of increased privacy, less shame and stigma and increased willingness to disclose private concerns [113].

Effects from getting the support mentioned in study II ranged from mostly short-term effects in the form of help and reassurance in the moment, to long-term consequences such as greater self-confidence, less stress and fatigue or better ability to plan. This is encouraging and agrees with findings in both the pilot study and in study I, in which increased self-esteem (which has been proposed to be an effect of accumulated self-confidence [114]) was observed as a long-term effect. Participants also viewed the coaching as less formal and emphasized this as a positive aspect of the support. The internet-based support was however not viewed as entirely positive. Some also voiced missing part of the personal interaction, acknowledged the long term benefits of having to leave the house, and in some cases admitted to not taking the support as seriously as one would a clinic appointment. A greater tendency to disengage has been previously mentioned as a potential disadvantage with internet-based support [113]. Views on the contact frequency also varied. Some appreciated the high frequency and saw it as making it easier to put advice into practice. Others would have preferred a more individually-tailored chat schedule or support for a prolonged period of time.

5.6 Clinical implications – can IBSC be a feasible support option?

Finding ways to support young individuals with NDDs should be a prioritized matter as they are a vulnerable group that often experience thresholds for receiving support. Narrow skill based interventions might sometimes prove too demanding and not all manage to adhere to and take advantage of standard care options. This is supported by views shared in study II. It is therefore of clinical relevance to have an array of support options and treatment modalities available. It has been put forward that broad and general support concerned with daily living and a focus on empowerment might be equally important for this group [65]. One qualitative study concerning adolescents and young adults with ASD, confirmed that successful transitioning into the community was facilitated by access to a supporting mentor [115]. Simpler counselling sessions ("clinical management") performed by health care personnel (psychiatrist), well-versed in the field of NDDs, proved to have equivalent effects to cognitive behavioural group psychotherapy for symptoms of ADHD in adults in a rather recent RCT [116]. Coaching also seems to have preliminary potential as one such option and has been suggested as a way to support at least individuals with ADHD [3]. It has been noted in previous studies that some individuals with ADHD seem also to prefer "coaching" to standard health care therapeutic interventions, which makes this kind of intervention important to study [117, 118]

All things considered, results from study I and II seem to suggest that IBSC holds promise as a feasible and acceptable option for supporting young people with ADHD and/or ASD. Participants seemed for the most part to be positive towards the support and coaching offered, and perceived as helpful aspects of the delivery mode (chat) to traditional clinic visits, considering their core difficulties. An internet-based intervention that provides psychoeducation, support and coaching and that manages to affect positively self-esteem and anxiety could be very valuable. Another advantage with the internet-based format is the chance to reach individuals located in rural areas where support can be difficult to access, increasing the outreach to these patients. Despite the relatively low functioning in the intervention group (as assessed by GAF), the dropout-rate in the intervention group was low (20%) compared to other studies involving individuals with NDDs and to studies concerning internet-based interventions such as ICBT [67, 73, 102, 119]. This is reassuring and suggests that the intervention was acceptable, not too demanding for participants, and delivered in a fashion that managed to keep up their motivation, which is important in this group. Attrition bias analyses showed no variables that were significantly related to dropout. It cannot however be ruled out that ADHD itself, alone or in combination with ASD, or the severity of the

NDD, might be contributing factors for dropout. We suspect that the text-based format and communicating from one's own home might have best suited individuals with ASD, even though no such conclusions can be drawn. It is also possible that the format or frequency of contact was not optimal for everyone, and might need further individualization.

5.7 Strengths and limitations

The foremost strength of study I and II is that they involve individuals largely representative of clinical reality, in settings where treatment and support usually take place. For instance, individuals with NDDs most often have overlapping difficulties within the ESSENCE spectrum, as well as other psychiatric co-morbidities [2, 5, 16]. Young individuals with NDDs are a group that can be difficult to recruit, and have few current treatment options. RCTs often have narrow inclusion criteria and include mostly high functioning individuals in stricter research settings, which it has been argued can make them less generalizable to psychiatric health care [120, 121]. As the thesis was mainly concerned with investigating the feasibility of the model as a precursor to a potential larger randomized study, this was an important aspect to consider. The advantages of representativeness must however be weighed against the limitations of non-randomization. Study I indeed included a matched control group receiving standard care. The risk of confounding by indication and the possibility that latent variables could have effected to which condition a participant was allocated to, cannot be entirely discounted and could account for differing GAF-scores although this was adjusted for in the statistical analyses. Furthermore, using a blended group of individuals with ASD, ADHD, or a combination of the two, is a limitation as it makes it difficult to say if one or the other diagnostic category may have benefited more from the support than the other.

A strength of the thesis is the application of both quantitative and qualitative methods. Using a combination of quantitative and qualitative methodology has been increasingly recommended in research as they complement each other and can provide a fuller understanding of the research topic at hand [120, 122]. This is particularly true in pragmatic trials and implementation research, where qualitative data can help explain or offer important dimensions to quantitative results [120].

Achieving trustworthiness in qualitative research involves considering aspects such as credibility and transferability [91]. To attain credibility in study II we asked all participants in the intervention arm to take part in the interviews, including dropouts. Not all of them accepted, and only one dropout took part. Our impression is however, that participants were open and provided us with a variety of important perspectives. We strove foster a mindful and vigilant approach when analysing interviews, so to capture meaningful and suitable meaning-units, codes and themes. We have tried to illuminate findings and support transferability by choosing representative quotations and through seeking agreement among co-researchers, as well as by offering adequate descriptions of participants, context, data collection and the analysis procedure. In qualitative research, the researcher´s understanding and interpretation of data are part of the process. Absolute neutral observation is not anticipated [123]. It is however important to consider how pre-conceptions can impact results, i.e. through reflexivity [123]. One of the researchers had been a coach and coordinator at a particular research centre, so she did not perform interviews at this site. To illuminate possible effects of this in the analysis phase, interpretations were also discussed with co-authors. Limitations in study II also include not being able to distinguish between different diagnostic groups as the sample was mixed (including ADHD and/or ASD). However, as argued above, this is however highly representative of clinical reality. Nevertheless, to explore this further, we performed a simple count to see if there were themes or codes that were totally dominated by a certain diagnostic category, which there weren't. Furthermore, a significant amount of time had elapsed for some of the participants before undertaking the interview. It is possible that not all aspects were remembered by them with absolute accuracy. However, we were concerned with capturing the implications of the participants' subjective experiences and our feeling was that participants could recall and provide important views on the questions asked.

5.8 Conclusions

In summary, the aim of this thesis was to investigate if IBSC could be a feasible and acceptable intervention for adolescents and young adults with NDDs. Initial development and validation of the model having been carried out, this thesis can be seen as a natural next step in gathering both qualitative and quantitative data that could inform a possible future larger RCT study. Drawing on the preliminary results presented, the support and coaching seem relevant and the chat-based format feasible for individuals with NDDs. The low dropout rate is also encouraging. If confirmed in future studies to be beneficial, IBSC could prove to be a welcome complement to other support options for a group of individuals where treatment alternatives are still scarce. Even though it was beyond the scope of this study, our impression is also that individuals with ASD were the ones that most benefited from and appreciated the support.

5.9 Future perspectives

Results from study I and II show promise for IBSC as a possible support option for individuals with NDDs. Future studies would benefit from using a randomized study design and significantly larger sample sizes to confirm these results. In order to shed more light over the assumption that IBSC might best suit individuals with ASD, it seems reasonable for a future study to include this group exclusively. It is possible that a pre-randomization design (i.e. assigning participants to one or the other of the two treatment conditions before seeking informed consent) might be one way of addressing the problems encountered in the validation study in randomizing individuals with ASD.

Future studies could also benefit from further operationalization of the coaching techniques e.g. creating a support manual with more detailed descriptions of techniques or potential themes for coaching. This could help to isolate treatment effects and potential moderating or mediating factors, and be helpful for coaches. However, it is considered important to sustain the initial intention of it being a low threshold and low demand option also suiting individuals who can have a difficult time complying with other forms of treatment, as well as upholding the high quality of knowledge and experience as a pre-requisite in coaches. With today's more advanced technology, there is furthermore the prospective of adding more visual content as an aid to participants, as well as being able to offer access to the support in smartphones etc. for even greater accessibility.

Finally, one could consider changing or adding some of the outcome measures. Quality of Life is an important outcome to include for individuals with ASD [16]. One might however consider using for example the World Health Organizations Quality of Life measure (WHOQOL-BREF) that now has an additional validated nine-item autism-specific module (ASQoL)[124]. One might also consider including participant ratings of supposed mediators such as increased knowledge about one´s NDD, ability to cope better with everyday situations etc., as well as a possible observer-rated scale such as the Clinical Global Impression Scale [125].

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