Mind the Gap Between CAMHS and AMHS—The Perspectives Of Patients with Anorexia Nervosa, Parents and Professionals

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Innhold

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I am grateful.

I am grateful for these years I have been able to immerse myself in a project that feels meaningful. I am grateful for those who came before me and laid the foundation for our project. As Mind the gap is a project based on service users' experiences and initiative – I have always – even in my more dark moments – mobilized inspiration from Lill Ann's engagement for better transitions and parental involvement. Lill Ann Wellhaven Holm has for years offered support groups for parents with children with eating disorders. Those parents' stories about the transition period laid the foundation for our project. From my perspective, it seems as if their despair lit a fire in Lill Ann, who has a character filled with energy and stamina. Together with her natural impatience and willingness to step up and influence practice, she made - "This have to change" – a common statement early in our collaboration. And with Liv Nilsen as the facilitator, there was no question if they could make it. Only when.

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ABBREVIATIONS

CAMHS: Child and Adolescent Mental Health Services

AMHS: Adult Mental Health Services

AN: Anorexia nervosa

PCP: Primary care doctor

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PAPER 1

Veronica Lockertsen, Liv Nilsen, Lill Ann Wellhaven Holm, Øyvind Rø, Linn May Burger, Jan Ivar Røssberg. (2020) Mental health professionals' experiences transitioning patients with anorexia nervosa from child/adolescent to adult mental health services: a qualitative study. BMC Health Services Research volume 20, Article number: 891 (2020) https://doi.org/10.1186/s12913-020-05740-2

PAPER 2

Lockertsen, V., Nilsen, L., Holm, L.A.W, Rø, Øyvind, Burger, Linn May, Røssberg, Jan Ivar. (2020). Experiences of patients with anorexia nervosa during the transition from child and adolescent mental health services to adult mental health services. *J Eat Disord* **8,** 37 (2020).

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PAPER 3

Veronica Lockertsen, Lill Ann Wellhaven Holm, Liv Nilsen, Øyvind Rø, Linn May Burger & Jan Ivar Røssberg (2021). The transition process between child and adolescent mental services and adult mental health services for patients with anorexia nervosa: a qualitative study of the parents' experiences. Journal of Eating Disorders volume 9, Article number: 45 https://doi.org/10.1186/s40337-021-00404-w

Summary

The transition from child and adolescent mental health services (CAMHS) to adult mental health services (AMHS) often represents a difficult period for patients with anorexia nervosa and their parents. They become disconnected from CAMHS and often have start-up challenges in AMHS. Together with former service users, we conducted a qualitative explorative study to explore experiences with the CAMHS-AMHS transition from three different perspectives, represented in each article included in this dissertation.

In this dissertation, we discuss three main themes collectively representing the different perspectives and anchored our theoretical understanding of transitions in Melisis` Transition theory. We used the transition theory to shed light on the contribution from the different perspectives. First, the fact that *unprepared transitions have systemic explanations but contribute to personal and health-related consequences*. Overall, the transition from CAMHS to AMHS is experienced as unprepared, without consideration of the patient's individual needs during the transition period. Being unprepared complicates the patients and parents' disconnection from CAMHS and makes the startup in AMHS difficult. Preparing the transition, should create a better chance of a successful transition. Preparations should explicitly describe the differences between services for both parents and patients. Good collaboration is essential in achieving continuity in treatment and closing the gap between the services. However, managing this collaboration is experienced as challenging due to systematic barriers. Second, *different treatment cultures between the services—implying a difference in attitudes toward patients' autonomy and parents' role in treatment—negatively affect treatment and recovery*. These manifested differences made it challenging to consider the individual patients' level of maturity and ability to be self-sufficient. With AMHS routinely not involving parents, they felt excluded from their adolescents' treatment. As they are often responsible for providing meal support and serving as their adolescents' care providers in this period, the lack of involvement was constraining and created stress for parents. The transition period was perceived as a very uncertain time, with potential consequences for both patients' health and parents' wellbeing. Third, *knowledge is one of the most important single factors in the transition*. From the patient's perspective, professional competence was vital for developing trust and feeling safe with the new professional in AMHS. From the professional's perspective, they felt overwhelming expectations toward their level of knowledge and felt that the patients had high demands, which created uncertainty and self-doubt. The parents experienced how important it was for them to have enough knowledge and that the professional must have competence in knowing when and how to use the parent's competence and collaborate in the transition.

NORSK SAMMENDRAG:

Overgangen fra Barne-og-ungdomspsykiatriske helsetjenester (BUP) og Voksenpsykiatriske helsetjenester (VOP) representerer ofte en vanskelig periode for pasienter med Anorexia Nervosa og deres foreldre. De frakobles BUP og har ofte oppstarts utfordringer i VOP. Sammen med medforskere med brukererfaring gjennomførte vi en eksplorativ kvalitativ studie med fokus på pasienters, foreldres og profesjonelles erfaringer med BUP-VOP-overgangen. Der de ulike perspektivene er representert i hver sin publiserte artikkel, belyser denne avhandlingen perspektivenes kollektive erfaringer. Her er vår teoretiske forståelse forankret i Melisis` overgangsteori. Overgangsteorien brukes til å belyse opplevelsene som de forskjellige perspektivene har bidratt med.

I denne avhandlingen diskuteres tre hovedtemaer som samlet representerer de forskjellige perspektivene. *1) Uforberedte overganger har systemiske forklaringer, men skaper personlige og helserelaterte konsekvenser.* Overgangen mellom BUP-VOP oppleves overordnet som uforberedt, uten særlig tilpasning til pasientens individuelle behov i denne overgangsperioden. Å være uforberedt kompliserer både avslutningen i BUP og behandlingsoppstarten i VOP. Dette gjør god forberedelse er viktig, og man bør eksplisitt beskrive forskjellene mellom BUP/VOP til både foreldre og pasienter. For å oppnå kontinuitet i behandlingen, er godt samarbeid mellom tjenestene essensielt. Å administrere dette samarbeidet oppleves imidlertid som utfordrende på grunn av systematiske barrierer. *2) Ulike behandlingskulturer mellom tjenestene - som innebærer en forskjell i holdningene til pasientenes autonomi og foreldrenes rolle i behandlingen - påvirker behandling og recovery negativt*. Disse manifesterte forskjellene gjorde det utfordrende å vurdere den enkelte pasients modenhetsnivå og evne til å være selvstendig. Med at VOP ikke rutinemessig inkluderte foreldrene, følte de seg ofte ekskludert fra sin unges behandling. Siden foreldrene ofte var ansvarlige for å gi måltidstøtte og være deres ungdoms omsorgspersoner i denne perioden, var mangelen på involvering begrensende og skapte stress for foreldrene. Overgangsperioden ble oppfattet som en veldig usikker tid, med potensielle konsekvenser for både pasientenes helse og foreldrenes velvære.

3) Kunnskap er en av de viktigste enkeltfaktorene i overgangen. Fra pasientens perspektiv var profesjonell kompetanse avgjørende for å utvikle tillit og føle seg trygg med den nye behandleren i VOP. Fra fagpersonens perspektiv følte de overveldende forventninger til eget kunnskapsnivå og følte at pasientene hadde høye krav. Dette skapte usikkerhet og dårlig selvtillit. Foreldrene opplevde hvor viktig det var for dem å ha nok kunnskap og hvordan den profesjonelle må ha kompetanse til å vite når og hvordan man kan bruke foreldrenes kompetanse og samarbeide i overgangen.

INTRODUCTION

Ensuring successful transitions between services is considered an overall challenge, not just in mental health care services but also in somatic care (van Staa et al., 2011; McManus et al., 2013; Hergenroeder et al., 2015). Treatment of and caring for patients with anorexia nervosa (AN) often includes somatic and mental health services. In addition, for patients with AN, treatment often implies a transition from child and adolescent mental health care services (CAMHS) to adult mental health care services (AMHS), as AN often occurs in adolescents with an average duration of 6 years (Treasure et al., 2005).

The transition from CAMHS to AMHS was a common theme brought up by parents in a support group our project initiator Lill Ann Welhaven Holm organized in collaboration with a nonprofit organization called ROS (Advice for eating disorders). Parents were concerned about their adolescents transitioning from CAMHS to AMHS and how that changed their role in caring for their child. They found that they received less information and had, in some sense, lost control over their adolescent's disease and treatment.

Being a parent to a child with AN, Lill Ann wanted to start a research project exploring this theme—the transition from CAMHS to AMHS—and how this period can be experienced. When exploring patients, parents, and professionals' perspectives, we could better understand the transition process and improve clinical practice. As I took my master's in an institution experienced with service user involvement in treatment and research, and found otherwise suited, I joined the project as a doctoral student.

We wanted to explore the transition between CAMHS and AMHS from a triagonal perspective. More specifically, we created the following research aims

- Exploring the experiences of professionals concerning the transition from CAMHS to AMHS
- Exploring the patients' experiences of the transition between CAMHS and AMHS
- Exploring the parents' experience of the transition process from CAMHS to AMHS

Most of the previous research on transitions for patients with AN has focused on specialized eating disorder programs. Thus, we found it valuable to focus on the transition period's experience, including all the present treatment facilities they had included in their experience.

We thought this would provide a more comprehensive understanding of what the transition comprises for the involved parties.

1 BACKGROUND

Co-occurring with the transition from CAMHS to AMHS, adolescents start on their own transition from adolescence to adulthood. This raises concerns about how patients deal with changes and loss of familiar objects, networks, social support, and co-occurring meaningful objects. Therefore, some central issues must be addressed when exploring the transition from CAMHS to AMHS for people with AN, parents, and professionals.

This background section provides context for understanding the treatment system and the diverse experiences and elements influencing the transition experiences. While the following section provides information about the age of adolescence and contemporary discussions on developmental and cultural factors, the latter focuses on giving a brief overview of the recent history and concept of AN. Lastly, it also focuses on the particular challenges concerning AN that patients, parents, and professionals' experience in the transition between CAMHS and AMHS.

1.1 The transition between CAMHS and AMHS

Approximately 50% of all mental disorders occur in adolescence (Kessler et al., 2007), and planning and health care management transitions are crucial elements in delivering health care services (Winters et al., 2007; Governmnent, 2009; Kennedy, 2010). Many adolescents require long-term professional care, including continuing treatment for AMHS (WHO, 2005).

A transfer refers to the actual point where the responsibility for the provided care and support to the adolescent moves from CAMHS to AMHS. Transfer does not include a perception of the complete process as therapeutic (McDonagh & Kelly, 2003). Transitions, on the other hand, are multidimensional. The means related to them are essential in shaping the intensity and nature of adolescents' experiences (Meleis, 2010b). NICE (2016) and Blum (1993) define transitions as movements between CAMHS and AMHS that are well planned and purposeful. The transition adapts to the individual's need for developmentally appropriate and psychosocially sound health care. The care should be coordinated across systems and address adolescents' medical, psychosocial, and educational or vocational needs.

A transition includes planning, actual transfer, and support (NICE, 2016). The underlying intent is an engagement in AMHS, with patients feeling safe and assured that their clinician has enough knowledge about them to provide them optimal care adapted to their needs. Recommended tools to achieve the latter include a period of joint care, involving the adolescent in the transition planning, and handover information, for example, in case notes co-written with the adolescent (NICE, 2016). Thereby, the adolescent comprehends the clinicians' understanding and is empowered in the potentially unsure setting of AMHS. Another important aspect involves including their families in the planning process, as it is possible to revoke the uncertainties and apprehension of the family experience (Jivanjee et al., 2009; NICE, 2016). Together, these attitudes toward the transition are vital to securing continuity of care (Forbes et al., 2001; NICE, 2016).

There is a vast difference in the treatment offers for patients transitioning from CAMHS to AMHS. In Norway, approximately 5% of children and adolescents receive professional help from CAMHS, with an increasing tendency for psychiatric diagnosis in adolescent girls (Krogh et al., 2019). Approximately 3% of the adult population receives treatment in AMHS. Those who receive treatment in AMHS tend to experience an overall decrease in in-and-out-patient contact both in length and time (Indergård et al., 2019). Other studies have shown that only one in six adolescents with mental health issues receive adequate care (Offord et al., 1989; Kataoka et al., 2002; Wagner et al., 2017). Consequently, there is a higher risk for illness progression, a more chronic outcome, and a negative effect on self-determination and psychosocial functioning (Lambert et al., 2013; ten Have et al., 2013).

Since Blum in the early 1990s started focusing on transition (Blum, 1993), knowledge on how a disruption of care in the CAMHS-AMHS interface can create long-term adverse effects on adolescents' health and wellbeing has increased worldwide, albeit at a slow pace (Richards & Vostanis, 2004; Singh, 2009; NICE, 2016). A review found that 81% of studies on the transition from CAMHS to AMHS were conducted after 2010 (Cleverley et al., 2018). Important studies such as the United Kingdom (UK) TRACK study (Singh et al., 2010; S. P. Singh et al., 2010), and later the European Union (EU) MILESTONE study (Tuomainen et al., 2018; Santosh et al., 2020) have provided and still provide knowledge about how to manage the transition between CAMHS and AMHS successfully.

As in our study, much of the research on the CAMHS–AMHS transition have defined transition in a manner similar to Blum (1993). A well planned and purposeful movement between CAMHS and AMHS that adapts to the individual's need for developmentally appropriate and psychosocially sound health care. The care should be coordinated across systems and address adolescents' medical, psychosocial, and educational or vocational needs. However, there has been little consensus on a successful transition's core components and process indicators. In Cleverley et al.'s (2018) review, they explore the literature on the transition from CAMHS to AMHS to do just that. After a full-text review, they selected 86 documents as being eligible. Six core components are briefly summed up in the following sections. First, transition policy, which includes addresses age (developmental readiness), service, and geographic boundaries. The organizational readiness should be enhanced and guided with distinct procedures, protocols, and staff training. Second, tracking and monitoring. The need for a formal transitioning process with specific criteria, including tracking the adolescent while in transition. Third, transition readiness includes identifying the individual and family's particular needs in the transition. It is also essential to inform adolescents and their families about the existing differences between CAMHS and AMHS. Fourth, transition planning, which includes identifying all stakeholders and ensuring role clarity among them. This includes collaboration between CAMHS, AMHS, and a suitable clinician to support the transition after entering AMHS. Fifth, transfer of care. This includes logistical components regarding the intake and discharge process. Sixth, transfer completion. This describes how studies recommend that the CAMHS clinician contact AMHS services after 3–6 months to follow up on how the adolescent has engaged in AMHS and clarify eventually raised questions. Singh and Tuomainen (2015) reviewed the effectiveness of different CAMHS-AMHS transitional care models and the experiences the stakeholders have with the transition. They state that there is no high-quality evidence of transitional care models. However, the data broadly support the development of models that address the broader transitional needs of adolescents. The practice-policy gaps must be addressed, and the provision should develop into an accessible, adaptable, responsive, and age-appropriate service.

1.2 The Organization of the Norwegian Mental Health Care System

In Norway, all citizens of the state have the right to government-provided health care services ("The Patients' Rights Act," 1999; Services., 1999; "Specialized Health Services Act," 1999). The Norwegian health care services are based on the Declaration of Alma Ata 1978, where the primary goal is to secure health care services for all in the patient's communities (WHO, 1978; Omsorgsdepartementet, 2015). In Norway, the health services are organized after the LEON principle, offering health care at the lowest sufficient care level. Therefore, the municipalities have developed their health care services so help can be given in their known surroundings. A principle is that most treatment of mental health disorders, including AN, should be offered in familiar outpatient treatment settings, consequently the number of hospital beds decreases.

For the treatment of patients with AN, the Norwegian health care services are divided into three levels: primary health care services, which include primary care doctors (PCPs), school nurses, and other offers of treatment in the municipalities; specialized health care services, which include CAMHS and AMHS in- and outpatient treatment; and regional specialized eating disorder in- and outpatient treatment services. Accordingly, where the patients receive treatment depends on the severity of the disorder, the individual’s overall physical and psychological condition, behavior, and social circumstances (Helsetilsyn., 2000; NICE, 2017). Treatment of patients with AN should always be based on knowledge and tailored to the individual.

1.3 Adolescence—From Childhood to Adulthood

While our study explored how adolescents experienced the service transition from CAMHS to AMHS, the age of adolescence can be categorized as a transition on its own (Meleis, 2015). The period defines the stage during which children transition to adulthood—intellectually, physically, hormonally, and biologically—and represents a period that is a critical life phase for achieving human potential (Patton et al., 2016). As the pubertal transition to adulthood involves both gonadal and behavioral maturation in addition to interference with social contacts and society’s expectations, adolescence is a tumultuous period (Erikson, 1968; Arain et al., 2013). The essential changes in psychosocial domains throughout the adolescent and young adult years are under-communicated and not as apparent as in the younger years. These changes can affect health care delivery as they determine their capacity to engage with an adult health care system. The services, to a degree, have to adapt to the adolescents’ development to be helpful in the transition (Kennedy et al., 2007).

The psychosocial development in adolescence makes the individual dependent on their careers and enables independence and autonomy. It is a time when individuals to develop a sense of identity separate from the birth family. They progress in their stances and create their own personally meaningful values. In these years, they cognitively acquire a higher capacity for abstract thinking and develop an ability to consider the consequences of their actions. They also develop higher levels of empathy and, thereby, deeper relationships. With a natural development in these years, the brain's capacities increase, allowing more complex problem solving, handling more information, and the opportunity to develop lifelong talents. However, the brain is heavily influenced by mental health disorders, nutritional status, stress, and the other factors illustrated in figure 1 below (Arain et al., 2013).

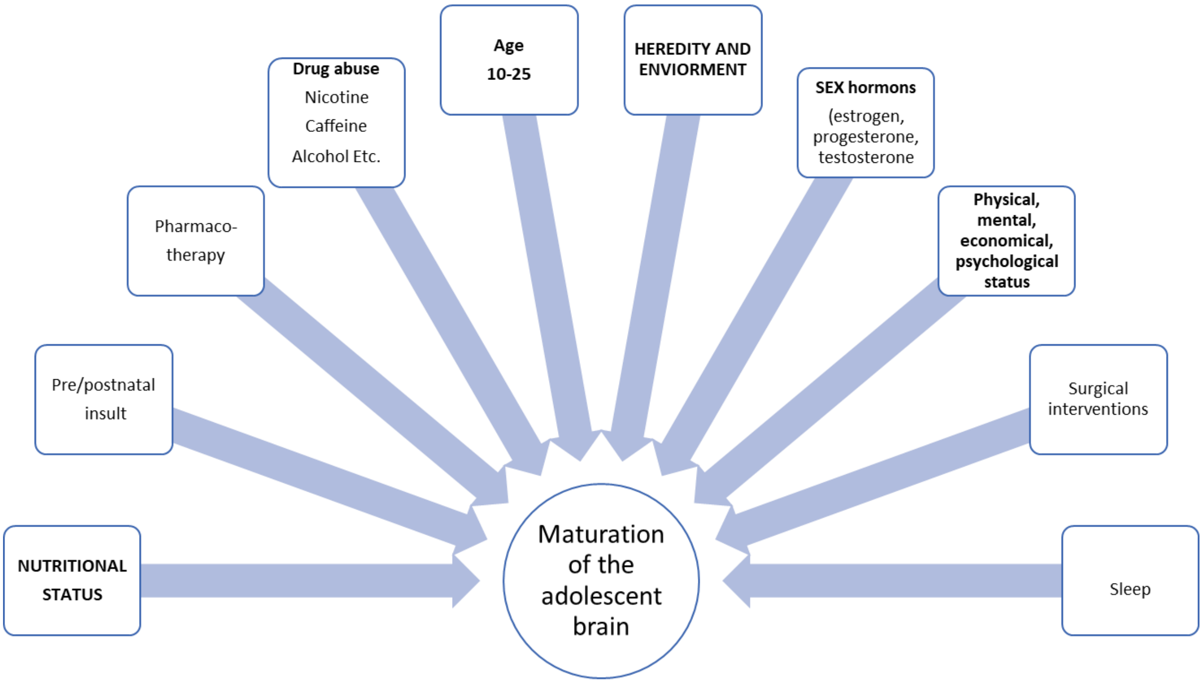

Figure 1 Modified from (Arain et al., 2013)

Adolescence comprises different labels and definitions. A16-year-old individual could be simultaneously labeled as a child, adolescent, or youth. These words convey distinctive meanings and expectations toward the individual. Therefore, the definition of adolescence influences the scope and focus of laws, policies, and programs intended to protect and empower adolescents (Sawyer et al., 2018). Consequently, the definition influences when the transition from CAMHS to AMHS is implemented. In a Lancet Viewpoint in 2018, Sawyer et al. (2018) argued that the age of adolescence should be altered and adapted to more contemporary patterns. While the UN defines adolescence as the period from 10 to 19 years, Sawyer et al. (2018) state that this classification originates from the mid-20th century and is out-of-date and wants to expand the definition up to the age of 25. In their view, the definition of adolescence should consider the existing empirical knowledge about puberty regarding undeveloped affect regulations, unmatured abilities to navigate relationships, and the understanding of social codes.

The common comprehension in most cultures is that adolescents should be supported to achieve the necessary educational and social assets. With support, they can maintain good health and individual well-being, as well as empowerment employment (WHO, 2013; Sawyer et al., 2018). This requires substantial investment in the health care system and prevention approaches (Patton et al., 2016). Patton et al. (2016) described how substantial investment in the health care system and prevention approaches are required to stop this trend of increasing mental health problems. An increased focus on adolescent health and well-being may bring a triple dividend of benefits now, into future adult life, and for the next generation of children. Our study views service transitions as a vital component that requires more attention since the transition often represents a risk of dropping out from treatment and an extended period of disease.

1.4 Conceptualization of Anorexia Nervosa

AN has severe physical and psychological consequences for the individual and their surroundings. Patients with AN often struggle with abnormal eating habits and severely restricted energy intake caused by an intense fear of gaining weight. AN often causes a distorted body image, entailing the person seeing themselves as overweight. While exercise and physical activity often have health benefits, many with AN exercise compulsively with subsequent health deterioration (Meyer et al., 2011; APA, 2013).

Hoek and van Hoeken (2003) reported an average prevalence rate for AN of 0.3% for young females. In their study, AN's incidence was eight cases per 100,000 population per year, with an increasing tendency. In a national context, Rosenvinge (2002) estimated that approximately 50,000 Norwegian women might suffer from eating disorders, and about 600 of them may need highly specialized services. The age of onset is typically between 14 and 19 years (Pinhas et al., 2011), with an average duration of 6 years (Treasure et al., 2005). Implicitly, many of these patients transfer from CAMHS to AMHS. While recommended treatment for young patients with AN is family-based (Lock, 2010; Hay, 2013; Helsedirektoratet, 2017), no specific approach has demonstrated superiority in treating adults with AN. However, treatment in AMHS is often based on individual psychotherapy.

1.4.1 Psychological, Social, and Biological Factors for AN

Even though the first contemporary medical case of an anorexic patient was already described in 1692, it is to this day difficult to pinpoint the etiology of AN, as a range of different coincidental factors contribute to its development. One regularly describes AN as multidetermined because of the combination of biological, psychological, social, developmental, and sociocultural factors that influence AN (Steinhausen, 2002; Striegel-Moore & Bulik, 2007; Keel & Forney, 2013). Often, patients diagnosed with AN have neurobiological changes, but it is difficult to determine if they are the cause or caused by malnutrition.

Studies have identified some individual factors that can contribute to a vulnerability to developing AN. Tending toward premorbid perfectionism and negative self-evaluation, a fear of growing up, a "negative urgency" implies how individuals manage strong feelings, anxiety, and intolerance of uncertainty (Cassin & von Ranson, 2005; Culbert et al., 2015). Additionally, patients with AN often have comorbid disorders, such as substance abuse, depression, obsessive compulsive disorder (OCD), anxiety, and post-traumatic stress disorder (PTSD), which complicate the recovery process (Arcelus et al., 2008; Franko et al., 2013).

Social factors such as family relationships, peers, societies' set norms of what to eat, and body size are essential factors (Geller et al., 2000; Gustafsson et al., 2011; Culbert et al., 2015). Some of the earliest etiological discussions understood mother-child attachment and interaction as one of the most critical risk factors. To this day, specialists discuss how family dynamics and relationships influence eating disorders (Eisler, 2005). In a review from 2013, Rikani claimed that previous research failed both at uncovering the exact etiology of eating disorders and understanding the interaction among the different causes of eating disorders (Rikani et al., 2013). Consequently, there are vast variances among treatment traditions and clinicians' views, which may ultimately confuse patients and their families. Furthermore, many parents have experienced both feelings of self-blame and being partially blamed by others for their child's AN (Whitney et al., 2005). Elucidating etiology is essential for efficacious treatment. Le Grange (2016) argued that a lack of understanding of AN's etiology creates suboptimal treatment. Moreover, the different interpretations may cause difficulties in the collaboration between professionals, parents, and patients.

A meta-synthesis compared patients, parents, and professionals' experiences and their views on AN (Sibeoni et al., 2017). They included 30 articles from seven countries and revealed two essential disparities between the different stakeholders' perspectives. One described the different beliefs the stakeholders had on AN’s etiology, and the second was the diverse experiences and beliefs they had living and working with AN. The three stakeholders had different ideas of why the AN occurred and consequently viewed the treatment differently. While professionals tended to believe the biomedical approach and focused on behavioral and bodily aspects, the parents criticized this as a rigid approach. They wanted a more holistic treatment framework that included care for their adolescents’ global distress. While the professionals distinguished between patient and disease to reduce patients’ guilt and improve treatment adherence, the patients rejected this approach. They favored a more psychological understanding, evoking AN’s individual causes related to their personality. In their view, personality traits such as excessive perfectionism, low self-esteem, poor body image, and a strong need for success drove them into AN. Besides, they described how their confusion about their own identity and how they felt alone contributed to AN's development.

The study did not identify that parents or professionals, to the same extent, had the same psychological beliefs as the patients. However, both parties included the impact of traumatizing events in childhood in their understanding. Parents tended to explain the AN using a background in sociocultural and family theory. They viewed the link between parental conflicts, communication issues, and relational disorders in their own families as necessary for the patients’ AN. The patients agreed and included parenting styles as being overprotective with excessing demands on them in the list of factors contributing to their AN. Reaching adolescence, the patients’ associated AN with sociocultural causes such as finding it difficult to fit into peer groups and normative social pressures. These different understandings are important to the present thesis, as they can be a factor in the difficulties patients and parents had when forming the many new relationships in the transition period.

1.4.2 How Does AN Affect Autonomy? A Theme of Agency and Ambivalence

Respect for people’s autonomous choices runs deep in society and is a shared moral principle (Beauchamp & Childress, 2001). One of AN’s key features is ambivalence and its ego-syntonic nature. Therefore, dilemmas concerning self-management and autonomy are common when treating AN. AN’s ego-syntonic nature plays a part in AN adolescents reluctance to seek, engage, and continue treatment (Gregertsen et al., 2017). Different studies underline how adolescents achieve a positive sense of control through their AN. Achieving control implies that the adolescent establishes a sense of stability and security through anorexic behavior. Commonly, this applies both in a practical sense, as through stringent time schedules and rules, and as a way of distancing from difficult emotions and anxiety (Westwood & Kendal, 2012). Moreover, mastering to follow such a strict diet and schedule could make them feel empowered. Also, some experienced getting confirmation from their surroundings when losing weight: They then felt worthy of compliments, and their confidence increased. Due to starvation of the brain, ambivalence becomes more prominent as the AN progresses. As the AN progresses, the balancing act of being in control and fighting for control over AN is bound to start (Serpell et al., 2003; Nordbø et al., 2006).

Although autonomy is not a univocal concept, there is agreement on these minimum features—an individual's self-rule and freedom from controlling interferences by others and one's own limitations. One interference can include the individual's inadequate understanding of their situation, so a meaningful choice is prevented (Beauchamp & Childress, 2001). Several studies have worked with the themes of ambivalence and autonomy (Garner & Bemis, 1982; Strauss & Ryan, 1987; Vitousek et al., 1998; Tan, 2003; D.J.O.A., 2006; Williams & Reid, 2012).

In qualitative interviews with 29 patients with AN, Hope et al. (2013) focused on how the disease may influence autonomy. They argued that the condition may compromise a patient's autonomy in the following ways: First, there is the issue of gaining weight and eating sufficiently. Although the patients exhibit the necessary competence to decide to eat, they often found it difficult. This lack of agency was exemplified in participants accepting treatment, which implied an increased intake of nutrition, but being unable to eat when food was placed in front of them. They also described a fluctuating state of emotions regarding gaining weight. There was a mismatch between the objective evidence as being dangerously underweight and the evidence from their affective responses and perceptions of their shape and weight. This negatively affected their motivation and ability to dedicate themselves to their own goal of recovery. Thus, the patients described substantial inner conflicts that caused a lack of stability in how they perceived themselves and how they felt threatened by the danger AN represents. The risk of death did not represent a higher threat to them than weight gain. As AN aggravates, the internal struggle for power increases. Clinically, this complicates how one relates to the patients' sayings and choices, as they can be inconsistent with the patients' agreement to treatment goals. In our study, the theme of ambivalence is essential, as the transition often represents an unstable time and change in supporting surroundings. Fassino et al. (2009) found that drop-out rates in inpatient treatment ranged between 20% and 51%, and premature drop-out rates in outpatient settings were up to 73%.

1.5 Research on Patients With AN Transitions from CAMHS to AMHS

After a comprehensive review of the literature, we found few studies that have been conducted focusing on transitioning patients with AN, and the studies are often conducted in a specialized eating disorder setting (Treasure et al., 2005; Arcelus et al., 2008; Winston et al., 2012; Dimitropoulos et al., 2012, 2013; Dimitropoulos et al., 2015; Dimitropoulos et al., 2016). However, there is no clear cut between treatment in specialized eating disorder units and treatment for adults in general mental health care services, as the state of disease determines the level of care. While outpatient clinics are often located in their municipality, specialized eating disorder clinics are often regional or localized and may be distant from patients' homes. As described in the earlier sections regarding the general mental health care system, consistent barriers to recovery are caused by the system (Dimitropoulos et al., 2015). The adolescents described having GPs lacking knowledge about AN, lack of access to AMHS, rigid admission criteria, geographical boundaries, and far-away distance to a specialized eating disorder clinic that competed with their desire to manage their education (Dimitropoulos et al., 2015). After receiving treatment in AMHS, some described that treatment modalities were inflexible and not tailored to their needs, making them feel they had no influence over the treatment. To improve the transition, the adolescents recommended more collaborative treatment approaches that promote greater autonomy in CAMHS. Being more included in one's own treatment in CAMHS would foster more realistic preparation for AMHS. They recommended having specific conversations about the cultural differences between CAMHS and AMHS prior to the transition with patients and their families. Then they could be better prepared for what the transition implies and experience less anxiety in the process.

When transitioning from CAMHS, the adolescent often leaves a family-based treatment. That implies that parents have a crucial role in managing adolescents' eating and facilitating change in CAMHS. However, in AMHS, they are introduced to an approach that expects the individual to take control and have responsibility for change (Helsetilsyn., 2000; NICE, 2017; Helsedirektratet, 2019). Dimitropoulus described how decreased parental involvement severely impacted adolescents' treatment and health. The parents' loss of control and influence in treatment generates difficulties both for parents and the patients. In their study, the professionals described that they understood how challenging the sudden difference in parental involvement must be for parents (Dimitropoulos et al., 2012). A particular concern is adolescents who refuse treatment or who do not have the skills to manage the illness without parental support. Arcelus et al. (2008) found that patients treated earlier in CAMHS had lower self-esteem and more maturity fears. Since AMHS`s approach emphasizes adult responsibility, Dimitropoulos et al. (2015) questioned whether the level of responsibilities should be increased in CAMHS. This would allow the adolescent to be more prepared for AMHS's demands of self-sufficiency and responsibility. By doing so, they would acknowledge how AN patients may lag behind their peers developmentally and psychologically (Dimitropoulos et al., 2013). The illness' interruption of the normative adolescent developmental process is highlighted as an important aspect of the transition. A transition initiated based on a chronicle age boundary does not consider how the adolescents' development may have been negatively influenced by early onset of illness and repeated and prolonged hospitalizations (Dimitropoulos et al., 2012). Most of these adolescents do not acquire the normal modes or practices of informed decision making about normative life changes without their parental assistance.

Two other barriers when preparing adolescents' transitions from CAMHS to AMHS are denial and ambivalence toward treatment. Therefore, ongoing parental involvement in AMHS outside the re-feeding process is recommended (Dimitropoulos et al., 2012). Dimitropoulos et al. (2016) sought to determine adolescents' expectations regarding parental support during the CAMHS-AMHS transition. They believed that increased knowledge might mitigate the often abrupt and uncoordinated transition. All through the conducted interviews, the adolescents expressed mixed feelings about the nature of parental involvement. They wanted more responsibility and control over the management of their AN but at the same time expressed a desire and/or need for external monitoring. Combined with ambivalence about recovery, they experienced anxiety about transitioning. For them, they separated family support into two groups: involvement in treatment and emotional support. They expressed how vital it was that parents distinguished between involvement and control (Dimitropoulos et al., 2016).

2 THEORETICAL PERSPECTIVES

2.1 Transition Theories

Transitions have been a research subject in many fields (e.g., psychology, organizational studies, education, and nursing), but the approach has often been empirical rather than theoretical. Before being conceptualized as a nursing phenomenon, the transition has been used in developmental and stress/adaptation theories since the concept can be applied to humans' life processes (Chick & Meleis, 1986). Over two decades, Afaf Meleis and colleagues have developed a global transition theory (TT). TT is based on the conviction that transitions are a central concept in a person’s lifeworld that contains much potential but also presents a vulnerability to health risks (Meleis, 2000; Meleis, 2010c; Meleis, 2015; Smith, 2015).

Although Meleis has concerned herself with conceptualizing TT within the nursing profession, the theory has vastly expanded and now provides comprehensive insight into what a transition comprises for each individual. TT can give more insight into potential consequences of faulted or successful transitions and bring context to our use of Blum’s (1993) definition, which states that transitions are movements between CAMHS and AMHS that are well planned and purposeful. The transition adapts to the individual’s need for developmentally appropriate and psychosocially sound health care. The care should be coordinated across systems and address the adolescents’ medical, psychosocial, and educational or vocational needs.

TT focuses on understanding and facilitating transition so the individual can remain or become healthy before, during, or at the end of the transition (Meleis, 2015). The transition process and experience have an earlier starting point than the actual event, which has a fluctuating ending point. The TT offers a framework to describe the “experience of individuals who are confronting, living with, and coping with an event, a situation, or a stage in growth and development that requires new skills, sentiments, goals, behaviors, or functions” (Meleis, 2015, p. s363). Transition involves changes in familiar objects and loss of networks, social support, and meaningful objects (Meleis, 2010c). The individual’s responses are formed by interactions with significant others, reference groups, and peers; the transition's prerequisites are unique. Therefore, the transition process needs to be formed after the individuals’ present needs. Patients with AN transitioning from CAMHS to AMHS often feel that they have lost contact with their peers as their disease contributes to disruption in school attendance from admissions to hospital. The forthcoming therapeutic action in the transition is shaped after the individual and their family's responses. As it defines the transition as “a passage from one life phase, condition, or status to another,” TT considers the transition to be a complex and multifaceted concept embracing several components, including process, time span, and perception (Meleis, 2015).

One of the key aspects of understanding transitions and the importance of preparing for it is understanding the concept of roles. Comprehending what the individual considers as their role and what that role implies for them are essential for assessing the adolescents’ needs in the transition process. It will provide a frame for understanding the individuals’ reactions and experienced problems in the transition. Role theory considers human behavior not as a simple matter of stimulus-response reaction but as a complex interaction between ego and society. It synthesizes the self, the social structure, and the culture by considering these aspects from the individual’s perspective (McCall, 2013; Meleis, 2010a). TT considers that effective health care requires a broader perspective of the individual’s interaction and role-taking in the present situation and understanding its self-conception. When transitioning roles, the person must incorporate new knowledge and alter their behavior and self-conception in new contexts. The transition denotes changing relationships and abilities to create new ones. The TT defines four different transition triggers, and the following characteristics clarify the insufficiencies and reactions to expect in the transition process.

2.1.1 The Transition Model

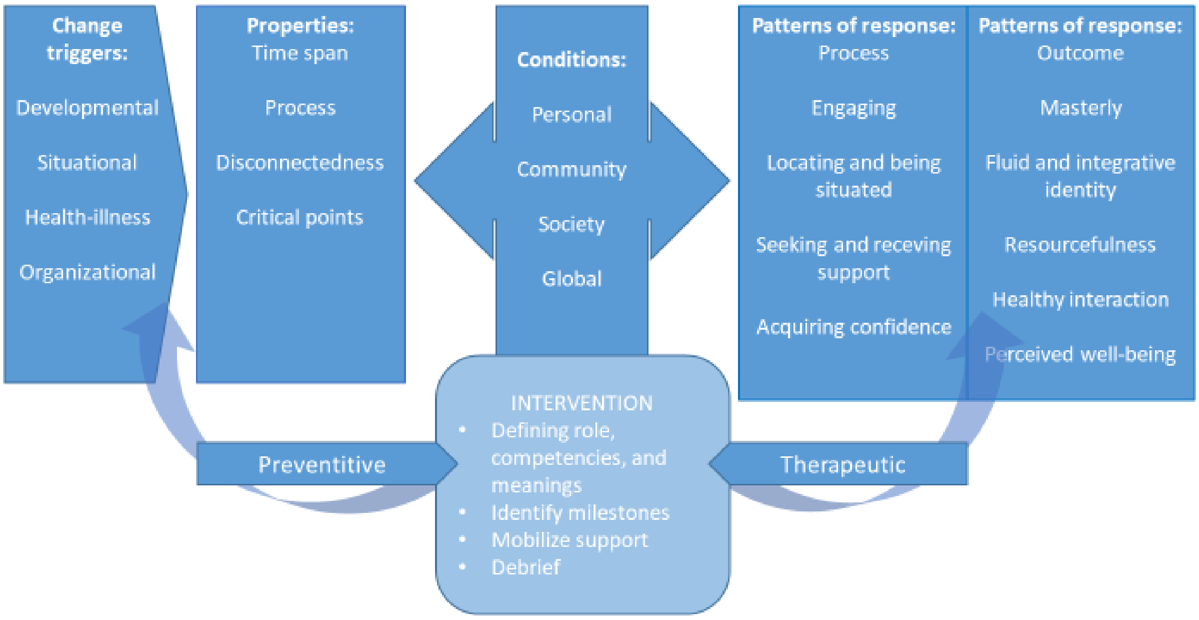

Figure 2

Modified after Meleis, A. I. (2015). Transitions Theory In M. C. Smith & M. E. Parker (Eds.), Nursing Theories and Nursing Practice (4th ed. ed., pp. 361–381). Philadelphia, Pennsylvania: F.A. Davis Company.

TT identifies four different transition triggers. They include developmental, that is adolescence to adulthood; situational, that is admission to or discharge from a hospital ward or change of therapist; health or illness, that is change in health or an illness situation that requires new behaviors, resources, and coping strategies; and organizational, that is changing to a different care system. For our study, all the transition triggers can occur simultaneously.

2.1.2 Transition Characteristics

In TT, the transition's time span extends from the first anticipation of transition until the attainment of stability in the new status. Unlike its beginning, the end of a transition is fluid and can be defined by reaching a defined goal. In other cases, it could be when the new role is intergraded, or the individual has re-achieved a sense of well-being and master their circumstances. There is a sense of movement and development associated with the transition. This process is described in three stages: 1) an ending, 2) a period of confusion and distress, and 3) a new beginning. How the individual is affected by the transition process varies, and consequently, there are vast differences to what extent and with what intensity the individual experiences their transition process (Bridges, 1980). TT underlines how awareness is essential for catching the changing event and the internal experience of transition. Awareness increases the possibility for change. With that, the transition can be a dynamic process that incorporates the interpretation of meaning and change over a timespan.

TT describes disconnectedness as one of the most pervasive characteristics of transitions. Bernat and Resnick (2009) emphasize that connectedness to others and institutions is important for adolescents' health and well-being. For our study, connectedness is important for both adolescents and parents. Connectedness provides adolescents with better outcomes as adults and protects against an array of health risk behaviors. As transitions create disconnectedness, the individual's sense of security is negatively affected. Besides, it can create incongruity between past, present, and future expectations. There is likely a discrepancy between their needs and access to satisfactory means. The loss of familiar surroundings may change how they respond to this incongruence. When TT underlines the importance of identifying critical points, the intention is to understand how the transition develops, which milestones have been reached, and identify appropriate assessment and intervention points. Overall, the TT's goal is to describe triggers, anticipate experience, predict outcomes, and provide interventions (Chick et al., 2010; Meleis, 2015). The responses occurring in the transition depend on the individual and on communal, social, and global conditions.

2.1.3 Process and Outcome—Two Ways of Assessing Responses

Since transition unfolds over time, focusing on process indicators can help assess when interventions are needed to facilitate healthy outcomes. These patterns of response include feeling connected, interacting, being situated, and developing confidence and coping (Meleis et al., 2010). They also include the following: helping individuals feel connected by assigning health care professionals to whom they could talk and have their questions answered and follow-up on how the individual interacts in the transition through patterns of questions, responses, and congruency between actions and goals; understanding how family and caregivers involvement can be ambiguous. Sometimes, experienced as a supportive gesture and other times as a signal of lack of belief in the individuals' ability to master their own situation; and understanding how location influences that response. Often, the transition implies movement from one place to another, and both distance and the difference are important.

To understand the new life, they compare it to the old. This use of “situating” is a way for the individual to integrate and make meaning of their experiences; furthermore, developing confidence is vital when handling the new, multiple, and sometimes conflicting demands on a person, family, or organization in the midst of attempting to deal with a triggering event (Meleis et al., 2010; Meleis, 2015). Developing confidence is manifested by understanding and comprehending their lives and situation. Consequently, this leads to developing strategies to manage their transition and afterlife. Changed responses can appear through how they identify their needs and seek help.

Outcome patterns

There is a subjective element in all transitions, regarding achieving balance in life and in situations. It may be considered too soon in the transition process to evaluate outcomes, but one may use the same elements to describe the transition process. TT describes five patterns of responses as outcomes: mastery, fluid integrative identities, resourcefulness, healthy interactions, and perceived well-being (Meleis et al., 2000; Meleis, 2015). Mastery describes how individuals have integrated their goals and sentiments, acting according to their identity, using their knowledge, and having confidence. They master their environment, understand their own needs, and require appropriate resources and co-opting supportive conditions. They can establish healthy relationships, maintain them, and improve their ability to self-care. The transition is then fulfilled and can alleviate the burden on caregivers and family members. Thus, their health is intertwined with the individual in focus and, therefore, part of the outcome response (Meleis, 2015). In our study, the TT was able to provide increased understanding to both parents and adolescents in the transition process.

2.2 Service User Perspectives and Initiative—A Core Figure in Mind the Gap

Strengthening patient and family engagement in care and research is a goal for different institutions, both internationally and nationally (WHO, 1991; Strand et al., 2003; NFR, 2014; Heaton et al., 2015; Helseforetakene, 2018). As part of a larger contemporary change in knowledge production, there is a now a more dynamic relationship between science and society, since the research being created in dialog with the public (Nowotny et al., 2003). A vital part of achieving this dialog pertains to including service users in research. By including service users' perspectives in research, one avoids health research that talks "to," "for," or "about" the public and instead promotes research that caters to social needs (Ives et al., 2013). The present study is service user-initiated. Initiating research in close collaboration with service users reduces the distance between direct experiences and their interpretation. Therefore, it may reduce the risk of unreliable, distorted, and inaccurate knowledge (Beresford, 2005). Regardless of the research methodology, service user involvement is justified several reasons that range between democratic and ethical justifications and quality and utility foundations, as service users' involvement may lead to better research, clearer outcomes, and faster uptake of new evidence (Secker, 1998).

In this thesis, we bore Heaton et al.'s (2015) five core elements in mind, working as a multi-perspective team: Users' knowledge and experience are valued as being on par with that of professionals, which creates greater equality in the relations between users and professionals. One is set on working together and taking advantage of each other's different backgrounds, and both find their relationship to be reciprocal and mutually beneficial. By including users, the public services develop a capacity to meet the users' emerging needs and possibly transform the services' design and delivery. Moreover, participation of users in the co-production of services is encouraged and facilitated by networks and organizations (Ostrom, 1996; Boyle & Harris, 2009; Needham & Carr, 2009; Boyle et al., 2010) . Making research more available for the public by changing the language in abstracts, leaflets, and other publications to more everyday language is one way to break down existing silos (Wieczorek et al., 2018). In 2017, the number of research projects in Norway that included service users increased to 60%. However, to what degree service users are involved has not been widely reported (Slørdah, 2018). There is a paucity of detailed accounts of the process of involvement and the challenges that appear throughout the process. More knowledge could guide collaboration between researchers and service users (Barber et al., 2011; Sims et al., 2013).

Including users in research arises from different traditions, and the related taxonomy is diverse. Commonly called "participatory research" as the umbrella term, collaborative, cooperative and participatory action research, action research, emancipatory research, community-based participatory research, participatory rural appraisal, participatory evaluation, co-production, co-creation, community and patient engagement are also used regularly (Beresford, 2013; Askheim et al. , 2019). Contrary to what one may expect, there is no clear understanding of what level users are involved in the research within these labels. Additional descriptions are needed to understand the extent to which the service users were actually involved (Beresford, 2013; Rose, 2003) (Pelikan et al., 2001). One can describe service users' involvement in research according to four levels: consultation, contribution, collaboration, and control (Sweeney, 2009). Even if research projects identify themselves at one of the four levels, involvement is not static but is instead a dynamic feature that varies throughout the various stages in the research process (Wallcraft et al., 2009). The latter is also the case in this study.

3 AIMS OF THE THESIS

In this thesis, the main purpose was to explore the transition from CAMHS to AMHS from three different perspectives: patients with AN, parents, and professionals. Transitions are considered a vulnerable time in treatment, with an increased chance of drop-out. AN is a severe mental disorder, and the negative impact it causes in the person's life increases with its duration. Continuity in treatment is a vital aspect of mental health care for these patients and a primary parental concern. Based on empirical knowledge represented by the service users, and the scarcity in research conducted on the topic of AN patients transitioning from CAMHS to AMHS, we conducted a qualitative study with the following aims:

1. To explore the experiences of professionals concerning the transition from CAMHS to AMHS (Paper I)
2. To explore the patients' experiences of the transition between CAMHS and AMHS (Paper II)
3. To explore the parents' experience of the transition process from CAMHS to AMHS (Paper III)

4 Methodological Positioning of the Thesis

Methodology refers to the framework by which our project has been informed and is the foundation that guided our research process (Smith, 2015). As a worldview guides all research, the researcher must make theirs evident so that the research can be transparent and open for critical examination (Creswell, 2014). Mind the Gap has explored professionals, patients, and parents' experiences for the transition between CAMHS and AMHS. We borrowed Ashworth's (2015) term and tried to make a "grasp of their world." Ashworth uses this large, somewhat figurative expression to avoid terminology as qualities, perceptions, meanings, or propositions, which all can be interpreted into different traditions within qualitative research. In Mind the Gap, the participants' "grasp of the world" lies in the spoken words that were transformed into the analyzed text. Although the material was of a semantic character, those words were expressed in a social context that influenced what was said and how (Smith, 2015).

By using a qualitative method, many assumptions have already been made. One assumption is the understanding of language as a fundamental property of human communication. We tend to make sense of our social world by expressing ourselves verbally, and that expression is colored by the context in which it is created. Therefore, the research needs to stay close to the symbolic system in which the material was created (Ashworth, 2015). As a conductor of research in a postmodernist paradigm, I acknowledge how my stance, values, and experiences have shaped the current research. Playing a crucial part in the interviews and the analysis, my background and my own context shape my interpretations (Creswell, 2014). Although no qualitative descriptions are free from the researchers' interpretation, our approach entails an interpretation that Sandelowski (2000) calls low-interference. With low-interference descriptions, one aims to convey events and sayings accurately and the participants' meanings attributed to such to ensure descriptive validity.

Acknowledging that one can never describe the whole meaning of the participants, we chose to describe what most observers would agree was in fact there. Although constructivism is a prominent factor in postmodernism, I am skeptical of a relativistic stance that denies the existence of any reality. With no common reality, there is no relationship between the studied phenomena and our research conclusions, and consequently any possibility to assess the study's validity (Maxwell, 2013). Although I think about our individual experiences as quite specific to us, our lifeworld has universal features, and both can be elucidated in a qualitative research context. I believe in a dialectic relationship between our ability to perceive and directly access our experiences and our tendency to conceive and construct the same experience. In our qualitative research project, we explored participants' experiences, meanings, and whatever affects, intentions, or similarities they viewed relevant when asked for their perspective. Some qualitative researchers would call this the participants' *constructions*, as individuals are quite active in their perception, and their attention is selective. Therefore their narrative in an interview is always related to their lifeworld and not *reality* (Ashworth, 2015). I rather think of how the participants made sense of their experiences and understood their situation, which was part of the reality I tried to understand (Maxwell, 2013).

5 Method

5.1 Research Design

The present study is a service user-initiated qualitative research project focusing on the transition from CAMHS to AMHS for patients, professionals, and parents. The project's preconception is based on experiences from parental support groups and inspired by how the theme of challenging transitions to AMHS repetitively appeared in groups for parents with children suffering from eating disorders. Therefore, our preunderstanding is that many parents of AN patients experience the transition between CAMHS and AMHS as difficult and straining. Future expansion of how professionals, patients, and parents experience the transition from CAMHS to AMHS is essential to improve clinical practice. Using a qualitative, explorative, and descriptive design, I, alongside service users, interviewed the stakeholders, focusing on their different experiences during the challenging period of transitioning between the two services. To investigate the transition between CAMHS and AMHS from different perspectives, we used qualitative techniques, including semi-structured individual interviews and multi-step focus groups (see Section 6.3) (Stebbins, 2001).

5.2 Recruitment and Participants

Our research's overall recruitment strategy was what Maxwell (2013) would call *purposeful selection.* We deliberately selected particular persons and treatment settings to provide us with relevant research about the transition from CAMHS to AMHS. With the use of specific inclusion criteria for each study, we aimed to represent the typical settings patients were treated in and a sample that accurately represented the population. The selection is presented as follows.

Study I

Eight participants with experience working with the transition from CAMHS to AMHS were recruited from the South-Eastern Norway Regional Health Authority. They consisted of seven women and one man. A variety of professions and workplaces were represented to provide a diverse perspective. Primary care doctors (PCP), school nurses, psychiatrists, psychologists, and psychiatric nurses were included to enlighten the transition from different treatment facilities and care levels. To ensure that we included experienced professionals, we contacted different units from in- and outpatient treatment facilities, seeking complexity and depth of thought. Using snowball sampling, we recruited clinicians with different inpatient and outpatient treatment experiences. Besides having experience with treating eating disorders, three participants had experience coordinating treatment and collaborating between different hospitals and departments. Recruitment of professionals occurred between February 2018 and April 2018.

Study II

Ten participants with experience as an AN patient receiving treatment in the transition from CAMHS to AMHS were included in study II. All participants had experience with the transition between CAMHS and AMHS in a specialized mental health care service. Six had experiences in inpatient units, and three had received treatment in a specialized eating disorder unit in CAMHS. Five of the participants had received treatment in a specialized eating disorder unit in AMHS. All participants were women struggling with AN in the transition period, with a median age of 22 (range = 19–29) years. The median time since the transition between CAMHS and AMHS was 4.5 years (range = 1–10 years). Six of the participants were working or studying at the time of the qualitative interview. Eight of the participants still received treatment. Six of them were invited to participate by current therapists who contacted participants they knew had experiences illuminating the research questions. The others contacted the project manager after finding project information on an Internet support site for eating disorders. Recruitment occurred between February 2018 and May 2019. Written consent was obtained from all participants.

Study III

A total of 12 participants with experience being a parent to a patient with AN transitioning from CAMHS to AMHS were included in the study through snowball sampling methods, that is three fathers and nine mothers. Eight of the participants were individual parents, and four were couples; thus, the transitions of 10 adolescents were discussed. Three participants were invited to participate by their adolescents' therapists, who contacted participants they knew had experiences regarding the research questions. The others contacted the project manager after finding project information on an internet support site for eating disorders. None of the parents had relations with the patients included in the study exploring the patient's perspective. The adolescents were aged 15 on average when they first contacted the CAMHS. All but two of the adolescents had experience with inpatient treatment, and all had some experience with specialized eating disorder units. All parents had the primary care of the adolescent while transitioning, and one had received assistance from child welfare services until age 18. Three of the parents were separated and had the main responsibility for the adolescent during the transition. All transitions occurred the year their adolescents turned 18. The average time from transition to the qualitative interview was 4.5 years. Recruitment to the study occurred between September 2018 and December 2019 in Norway. Written consent was obtained from all participants.

TABLE 1 OVERVIEW OF THE STUDY

STUDY PURPOSE	The overall aim of the thesis is to investigate the overreaching themes occurring, exploring patients, parents and professionals' experiences with the transition from CAMHS to AMHS		
	Paper 1	Paper 2	Paper 3
TITLE	Mental health professionals' experiences transitioning patients with anorexia nervosa from child/adolescent to adult mental health services: a qualitative study	Experiences of patients with anorexia nervosa during the transition from Child and Adolescent Mental Health Services to Adult Mental Health Services	The transition process between Child and adolescent mental services and Adult mental health services for patients with Anorexia Nervosa. A qualitative study of the parents' experiences

AIM	To explore the experiences of professionals concerning the transition from CAMHS to AMHS	To explore the patients' experiences of the transition between CAMHS and AMHS	To explore the parents' experience of the transition process from CAMHS to AMHS
DESIGN	Qualitative explorative study	Qualitative explorative study	Qualitative explorative study
DATA	Eight professionals in two individual interviews and one multistep focus group interview	Nine patients, five individual interviews, and one multistep focus group interview with four participants	12 participants, discussing 10 (two couples) in individual interviews
ANALYSIS	Systematic text condensation	Systematic text condensation	Systematic text condensation

5.3 Data Collection

Exploring the transition from CAMHS to AMHS from different perspectives requires a strategy that handles the themes' complexity while remedying for the possible experienced vulnerability revealing personal experiences in a new context. Additionally, we had to decide the best strategy considering the involvement of service users in collecting the data. While all three studies are based on individual interviews, I and II have also conducted focus groups. Focus group interviews can be stimulating with co-participants, positively triggering other participants' memories. Then, they are a suitable technique as they elicit people's understandings and views of their experiences (Wilkinson, 2015). We wanted to contemplate how complex the theme of transition is and make room for different reactions triggered by memories. Therefore, we conducted two focus groups with the same core group. In study I, one participant participated in only one of the groups. We considered the variation in the group as beneficial, as it could reveal new moments with the transition, and the already emerging themes could be seen in a new light. Multistep focus groups are considered a beneficial technique when working with service users in research (Hummelvoll, 2003). Repeated meetings give the participants an opportunity to inspect and challenge their own and others' experiences in a dialectic way. Before the second focus group, we handed out a summary of the first focus group to prepare and validate our understanding. The intention was to construct the main themes we wanted to focus on in the second group meeting.

Decisions regarding who attended focus groups and who should be interviewed individually were often decided in collaboration with the participant. It was a pragmatic combination considering the participants' ability to participate, adapting to the participants' requests, and choosing between the two. For example, the PCP had a rigorous schedule and had little opportunity to participate in the focus group due to practicalities. Therefore, it was natural to interview PCP individually. Interviewing patients for Study II, we wanted to include patients from other districts than the South-East of Norway. Due to practicalities, the patients from Tromsø and Bergen were interviewed individually. One participant wanted to participate in the focus group but experienced deterioration of health and had to cancel. After recovering, she wanted to share her experiences and was interviewed individually. For Study III, we had planned to conduct focus group interviews combined with individual interviews. Still, the recruitment stretched out in time, and to prevent drop-out, we decided to conduct the interviews consecutively organized as individual interviews. The focus group interviews were conducted in our research clinic, and the individual interviews were conducted in other appropriate settings decided by the participants.

With the help of an interview guide that followed the same structure for each group of informants (see appendix I), we conducted semi-structured interviews lasting 60–90 min. The participants were encouraged to describe their experience with the transition through specific examples. The questions focused on factors that influenced the transition process. Initially, the idea was that mainly four different aspects influenced the transition: the treatment system, the relationship with the therapist, family, and other significant persons, and factors concerning the disease and illness. While the interview guide was used to ensure all essential themes and topics were covered, new topics introduced by the participants were discussed further. To ensure validity, we restated and summarized our understanding throughout the interviews. Likewise, we quickly summed up the main futures of our understanding at the end of our interviews. The first author audio-recorded and transcribed the interviews verbatim for all studies. For me, the transcription is the bridge between the research questions' phenomenon and the analysis. It is the foundation of the study, and it has to be conducted in a manner that the possibilities for misunderstanding the content meaning are at a minimum. As I transcribed, I stayed as close to the written language as possible. This denaturalistic transcription technique is used to provide a written account of the easy-to-read interviews (Bourgeault et al., 2010). The text was slightly modified by taking out sounds and words used just in the spoken, not written conversation.

5.3.1 The Moderators

With my background as a nurse with a master's degree in psychiatric health care and clinical practice in acute psychiatry, I am used to meeting and talking to people about their world and experiences. For years, I have met people in their most vulnerable state and worked with them until they were ready to re-establish their home environment. Moreover, I have worked as a supervisor for other colleagues in helping them to manage and improve clinical practice. In acute psychiatry wards, we were obligated to offer treatment to all patients assessed in need, and through the years, many of them have struggled with AN. However, I felt like I was entering another world when I immersed myself in AN and the complex treatment experience faced by AN patients. As the project is based on the understanding that the transition is a difficult period, I tried to stay curious about my own clinical experience and thoughts on the transition. Together with the rest of the research group, our overall experience and thoughts were used to create the interview guide. Before the interviews, we prepared ourselves and shared our concerns and triggers. After each interview, we debriefed and summed up our own experiences and feelings and sorted out the situations we had experienced differently. This was useful for closing the finished interview and preparing for the following interview.

While I was a moderator in all three studies, I had three different co-moderators. For study I, JIR, a professor in psychiatry and an experienced researcher, co-moderated the focus group interviews. Although I had experience using qualitative interviews in an earlier project, I was inexperienced with focus groups. The support and JIR’s active attempt to maintain focus on the theme at hand were valuable in the interview setting. The individual interviews were conducted by me alone for pragmatic reasons.

For Study II, LMB and I moderated both focus group interviews and individual interviews. Besides having former user experiences, LMB has attended service user boards in hospitals and performed voluntary work in an interest group for eating disorders. She is an active advocate for animal therapy and had started a course in reactions to trauma in children. The interviews for Study II were characterized by the moderator’s abilities to create a good and safe environment and an open atmosphere. The participants quickly started sharing their experiences and complementing each other’s narratives. Especially with the focus groups, LMB expressed that her own experience with the disease interfered with her ability to stay attentive and attuned to the participant’s experiences. It became natural that we as moderators had a flexible role between us regarding guiding or managing the interviews. LMB has an intuitive way of providing warmth and giving support, which was often needed in the interviews.

For Study III, LAWH and I moderated the interviews. Besides being an experienced Gestalt therapist, she has vast experience meeting parents in voluntary support groups and was the studies initiator. Her preunderstanding of the challenge's parents endured gave room to share difficult experiences and feelings. Her ability to acknowledge and share some of the same complicated feelings created a safe environment. The parents expressed that it reduced their feelings of shame and instead provided feelings of recognition and companionship.

5.4 Data Analysis

Qualitative research is a non-linear and complex process requiring a systematic and structured approach (Holloway & Galvin, 2016). To guide the analytic process, we relied on Malterud`s systematic text condensation for all three studies (STC) (Malterud, 2001; Malterud, 2011, 2012). Heavily inspired by Giorgi, Malterud developed a modified phenomenological method—STC. Following Giorgi, STC holds an explorative ambition to present vital illustrations from peoples' lifeworlds, not cover the full range of possible phenomena. For Giorgi, the goal is to present the particular object reduced to its essence through phenomenological reduction (Giorgi, 1985a, 1985b).

STC has an inductive, descriptive approach, presenting the participants' experience as expressed by themselves, rather than exploring the possible underlying meaning of what was said. Using the participants' expressed semantic phrases, one extracts the "taken-for-granted" meanings that could have been overlooked in other contexts. For this study, Malterud described how the analytic process of STC was conducted by reducing text with specified shifts between decontextualization and recontextualization of data. STC is described as a stepwise approach, that is, 1) total impression; 2) identifying and sorting meaning units—from themes to codes; 3) condensation—from code to meaning; and 4) synthesizing—from condensation to descriptions and concepts. However, the data analysis is an interactive activity that requires that the researcher moves back and forth between the data and the analysis throughout the process. This alternation assures the connection between the data and the research question. To make the process transparent to the reader, I present our overall take on STC`s stepwise process and then elaborate on the different studies' specific approaches.

1.Total impression

STC`s first step includes becoming familiar with the data and creating a meta-perspective of the material (Malterud, 2012). I established an overview of the data by transcribing, re-listening, and reading the material. With STC, researchers should bracket our preconceptions and remain atheoretical and open to the participants' worldview. The research group met and discussed the material at hand. We elaborated on what each of us perceived as a pattern across the material. Discussing the material with fellow researchers facilitated a more expansive analytic space and a more precise description of our take on the material. SCT recommends three-six concrete preliminary themes at the end of the first stage.

2. Identifying and sorting meaning units—From themes to codes

Step two of SCT includes reading and working with the material to identify specific text segments relevant to the research question (Malterud, 2012). Using NVivo, I coded and recoded texts to identify meaning-bearing units. My approach to this decontextualization was flexible, and I had in mind that the labeling was preliminary, and the text was often coded under different labels and themes. I went back and forward in the material and developed an increased understanding of the text, themes, and the created codes. Often the rereading of the text presented a new understanding. As my understanding changed, the codes were developing and got more stringent as the coded text under multiple labels reduced, and the coding groups were more distinguished. The research group discussed and revised the preliminary findings and made the foundation for step three of the STC.

3.Condensation—From code to meaning

In this third step of STC, the meaning is to abstract the units in the code groups created in the previous step into fewer codes revealing aspects of the participants' experiences relevant for our study (Malterud, 2012). Reviewing the coding groups, I reduced the content into more of a condensed text by starting with what I perceived as the essence of the theme. Using a rich meaning unit as a focal point in the text, I built the remaining meaning units around this text. The parts of the text that did not fit into the condensation in this process were evaluated. The parts either found its place in another condensation or were not viewed as a meaning-bearing unit after this stage in the analysis. An essential part of this process was to outline the coding groups, as our understanding developed into more substantial and defined different themes.

4. Synthesizing—From condensation to descriptions and concepts

After decontextualizing and recontextualizing the text in previous stages, the purpose of Stage 4 in STC is to develop descriptions and concepts elucidating the study’s question (Malterud, 2012). Here, we created an analytic text that presented the meaning of the phenomenon in focus. The text was a mix of a third-person story and citations that underlined and illustrated the storyline. The research group reviewed the text and reconsidered how the content belonged under the specific theme or another, validating our synthesis according to how it reflected the original context. There were frequent discussions within the research group regarding how to name the different categories. Although the disagreement often surrounded nuances within the category and preferences regarding semantic choices, these discussions were meaningful. They kept us attuned to the coherence of the narrative and its core features.

5.4.1 Study I

After JIR and I had conducted the interviews and I transcribed them, the research group all read the transcripts of the interviews with the professionals. We used much time discussing the preliminary themes in Stage 1 of STC, as the group of participants were heterogenic and had several different experiences and perspectives on the transition. In addition, we had different perspectives internally in the research group. After the initial discussions, we all agreed on how the transition was treated more as a transfer than a transition between services. However, the interpretation of the reasons and how and why remained debatable. We had to go back to the material multiple times before the analytic process could proceed to the next step. Another difficulty encountered in the analysis was ensuring that the professionals’ experience was in focus, not the patients. Although the consequences of the experience often were the patients’, we asked about the professionals take on the transition and viewed this as a vital part of getting answers to the overall research question. After the initial discussions, the analysis moved on to the nuances in the material and labeling the categories. We wanted to obtain the essence of the categories and more clearly define them. For example, one of the finished articles’ categories was *mistrust between CAMHS and AMHS.* This category moved from the more loosely defined label, *attitudes toward each other*. This is a category that implies but does not explicitly let the reader know what the category contains. After the research group had reached some consensus on the categories, the quotations in use were translated into English. The process went back and forth between the whole text and the category at hand to ensure that the translated material represented the authenticity of the material. Lastly, our results were discussed and compared with the existing knowledge throughout the discussion section in the article and are examined in the discussion section of this thesis.

5.4.2 Study II

After LMB and I conducted the interviews and I transcribed them, LMB, JIR, and I conducted the first two steps of the analysis. In this study, my coding was to a large degree inspired by Tjora's (2017) concept of inductive empirical coding. With this method, one placed less meaning on the first impression one has after reading the material. The codes do not sort out the data but let us know what exactly is said. This process generated a longer list with codes since one stays closer to the transcripts for a longer time, but all three researchers had the same take on the material at all stages. The idea was that this coding method would reduce some of the tension experienced in collaboration with study I and make less room for premature conclusions. After the coding process, we agreed on some themes representing the material and started translating the essence of the text we selected for inclusion in the study. After this stage, all researchers were included in the following stages of the analysis. Lastly, our results were discussed and compared with the existing knowledge throughout the discussion section in the article and are presented in the discussion section of this thesis.

5.4.3 Study III

After LAWH and I had conducted the interviews and I had transcribed them, LAWH, JIR, and I conducted the first two steps of the analysis. The interviews were conducted over a more extended period, and LAWH had much experience with the parents' perspective of the transition. When asking for the parents' experiences with the transition, they were likely to respond by explaining how their young adults experienced it and the positive and negative elements regarding their recovery and disease. Although their experiences were closely linked, it became essential to distinguish the two to centralize the parent's experiences when analyzing the data. An additional challenge occurred when the parents described their situation. As we asked for their experience with the transition, the transition is not an action but a process. The parents' experiences were quite complex as they often described multiple transfers between different services over a long time. This was challenging primarily in the first steps of the analysis. However, after the themes were condensed, it became unclear if the theme describing their *Overwhelming multifaced responsibilities* was connected to the transition as we believed. Still, we all agreed that this theme was important when describing the transition. It was linked to the idea that the parents follow their children throughout this period, and the transition is described as more than a transfer from CAMHS to AMHS.

5.5 Ethical Considerations

A mother with a service user experience initiated the study. On the basis of a clinical challenge in care when transitioning from CAMHS to AMHS, the study is accepted as relevant as it contributes valuable knowledge about a theme few others have examined. Although the theme of transition between child and adolescent health services to adult services is studied in other contexts, the knowledge base on patients, parents, and professionals' experiences with the transition when focusing on AN remains sparse.

Approval from the local Data Protection Committee at the hospital (Personvernombudet) (2016/19732), and the study was performed in accordance with the Declaration of Helsinki. The Regional Committee for Medical and Health Research Ethics for the Southeast Region of Norway (2016/1259) saw the study as not being a medical or health-related research project regulated by the law of health research and was not therefore subject to presentation, cf. HFL. § 2.

All participants signed a written consent form prior to the interview. For the consent to be valid, the participants must understand the provided information. Therefore, the form was designed to be easy to comprehend. One participant who planned to participate in the focus group was unable to continue due to the state of her illness. However, she wanted to participate in an individual interview after she had recovered.

The data were managed and safely secured according to laws and guidelines regulating research. Only the researcher and supervisors had access to the complete data. Furthermore, only the researcher had the information that could identify the participants. When presenting the raw material, either in written or verbal form, principles of de-identification were followed.

6 RESULTS

Three different studies investigated the overall objective of the present dissertation. In the discussion section, I focus on overreaching themes extracted from the different studies. The following presents the results of each study.

6.1 Study I

Mental health professionals' experiences transitioning patients with anorexia nervosa from child/adolescent to adult mental health services: a qualitative study.

This article reports on an explorative, qualitative study conducted to obtain better insight into the professionals' experience handling transitions in different public health services. We classified the experienced barriers during the transition process into four categories. The first, *different treatment cultures*, describes two different ways cultural differences negatively influence the transition—first, how parents are included. Although AMHS often attempts to include parents in the treatment on the individual level, it is up to the patients, and it is not an integrated part of the treatment as in CAMHS. Therefore, the clinicians feel they have to prioritize between time with the patient and time with the parent. Second, patients are unprepared for the cultural differences between CAMHS and AMHS regarding patient autonomy and expected self-sufficiency. Although the clinicians acknowledge that there are individual differences in what patients need in this period, the clinicians lacked the time for the needed systematic follow-up to adjust to these in the transition process.

Mistrust between CAMHS and AMHS was a second issue. There is a lack of companionship between the services, making it easier to close the treatment in CAMHS rather than transitioning to AMHS. CAMHS are often unfamiliar with what therapy the patients receive entering AMHS. Both CAMHS and AMHS experienced a lack of mutual understandings of each other's systems and treatment ideologies.

Therapist factors was the third issue. This describe how competence and therapists' feelings of security can influence continuity of care for patients. When treating patients with AN, professionals experience a need for competence on many levels. However, clinicians experience low professional self-confidence. This lack of confidence can harm patients' transition from CAMHS to AMHS. Lastly, *transfer of alliance* is the fourth issue and describes how the professionals experienced a lack of transfer of alliance and trust between systems, clinicians, and the patients. The professionals explained that it appeared complicated for the patients to start therapy in AMHS. It also seemed difficult to achieve a good therapeutic relationship, as the patients quickly felt rejected due to unmet expectations.

6.2 Study II

Experiences of patients with anorexia nervosa during the transition from Child and Adolescent Mental Health Services to Adult Mental Health Services

This study reports on an explorative, qualitative study exploring patients' experiences of the transition between CAMHS and AMHS. We classified their experiences into four categories: The first was "Being unprepared and alone in the transition process," which describes how a lack of preparation for the transition between CAMHS and AMHS makes them feel overwhelmed. They experienced different levels of follow-up during unstable periods. With increased expectations of self-sufficiency combined with decreased involvement of parents, they felt alone and scared during the transition process. Consequently, they focused more on their eating habits to gain a sense of control in the situation. The second was "It takes time to create a trusting relationship," which describes how time is a factor in the transition. The patients felt afraid that the new therapists would not understand and acknowledge their situation. They often felt that therapists had a preconceived notion of them, and their first impression of therapists at the first meeting was essential to decrease that negative feeling. When establishing a new relationship, the participants needed time to open up about their weight and food issues. They felt that the new therapists expected them to simply open up and trust them, despite having experienced a rapid change in therapists. Often, there was a lack of information between CAMHS and AMHS, so they had to repeat themselves, making it difficult to develop motivation for their recovery. "We are not all the same" was the third category, and it described how adolescents developed differently but were not treated differently despite their diverse ability to be self-sufficient. While some felt ready for AMHS`s more individual, independent approach, others found this shift too demanding. Despite negative experiences with the transition, some viewed it as necessary for their recovery process. The transition made them aware of the changes they had to make regarding how they take responsibility. The fourth category was "How they see me and treat me affects my hope for the future." It highlights the interaction between adolescents and therapists. The participants often underlined that they felt powerless during the transition, depending on how the system and professionals related to them and perceived them during that period. When entering the transition phase, the participants often felt that AMHS had more interest in their illness than in them. In this therapy, evaluating and interpreting their symptoms and BMI were more frequent than talking with them about their well-being and experiences of their condition. CAMHS and AMHS were perceived evidently differently in how they verbalized their visions and hope for the adolescent patient. They felt that AMHS did not comprehend how frightening it could be to be admitted in an adult environment. They described a sense of resignation—“so I lost interest”—as AMHS lacked an understanding of the difficulties they experienced during the transition period. In their adolescent years, many of them only had social contact with people who were getting paid to be there or fellow inpatients. They had to protect themselves from becoming attached to the people surrounding them, which they felt changed how they related to people in their lives outside the mental health services.

6.3 Study III

The transition process between Child and adolescent mental services and Adult mental health services for patients with anorexia nervosa: A qualitative study of the parents' experiences

This study reports on an explorative, qualitative study that explored how parents experience the transition process from CAMHS to AMHS. The analysis found that six categories represent the parents’ experiences of the transition. The first was that the discharge when the child turned 18 years old was sudden. The parents described the transition from CAMHS to AMHS as an abrupt end to treatment defined by age rather than process. This caused stress, as they were unsure how to proceed in the treatment system when their daughter suddenly was discharged from CAMHS. The parents felt powerless and left out of what was happening with their adolescents in AMHS. The lack of continuity was a second issue, and it was often followed by deterioration and relapses in the patient. For parents, the transition went in circles between services, hospitalizations, and meetings with their PCP and themselves as facilitators and coordinators. The parents described how their adolescents’ health often deteriorated in these waiting periods, with some patients being admitted to an acute psychiatric ward. They found their adolescent’s ambivalence toward treatment highly frustrating during the transition period. The patients often dropped out of treatment, and the parents felt they were left responsible and followed up more closely as they were afraid of the consequences. The third was the lack of involvement and information causes distress. The parents experienced being unprepared for the change in roles as caregivers when their adolescents started receiving treatment from AMHS. They experience being left with the same responsibilities as in CAMHS, but with less information and less inclusion. The parents experienced that AMHS’s emphasis on the individual’s independence and self-sufficiency influenced the adolescents’ attitudes. They questioned why the health care services did not request their experience and knowledge. Often, the adolescents found it straining to connect with a new clinician; thus, a more involved parents’ role would be a positive bridging factor. knowledge—an essential factor for developing a trusting relationship between parents and clinicians—was the fourth issue. A successful transition often relied on trust in the clinician’s competence with eating disorders as the adolescents tended to lose motivation for treatment after sensing that the clinician knew less about eating disorders than they themselves. Often the clinicians seemingly lacked knowledge about what their caregiving role implied and how they could ease the transition. Fifth, parents had overwhelming and multifaceted responsibilities. It was challenging to find balance in their own lives, as they had so many obligations. In addition to being responsible for the adolescent and adapting to their needs, they also had responsibilities toward other children, their work, and their own lives. They emphasized how their adolescent still needed the same support from them as when they were underage. The transition period was characterized by much emotions, fear, and frustration. Some described difficulties in sleeping and increased mental health problems. Lastly, parents required professional support. The parents described how they always had to be on guard, available, and prepared during the transition period and needed support from the mental health care services. The parents were scared, as they knew how life-threatening the condition was and how unstable their adolescents became when standing their ground. Therefore, they often submitted to their adolescents’ wishes. They often lacked the support they needed to stand their ground and found it challenging to set boundaries. The support offered by the mental health care services, were inconsistent.

7 DISCUSSION

The overall objective of this dissertation was to explore the transition from CAMHS to AMHS through the different perspectives of patients, parents, and professionals. We anchored our understanding of transition in a transitional theory to enlighten the complexity of this period in treatment and the adolescent’s life. The dissertation includes three published papers, each representing the different perspectives. Overall, the papers provides essential aspects of the transition’s challenges for the involved parties. However, in this chapter, I want to discuss three overreaching themes abstracted from the different perspectives. These are illustrated in Figure 3.

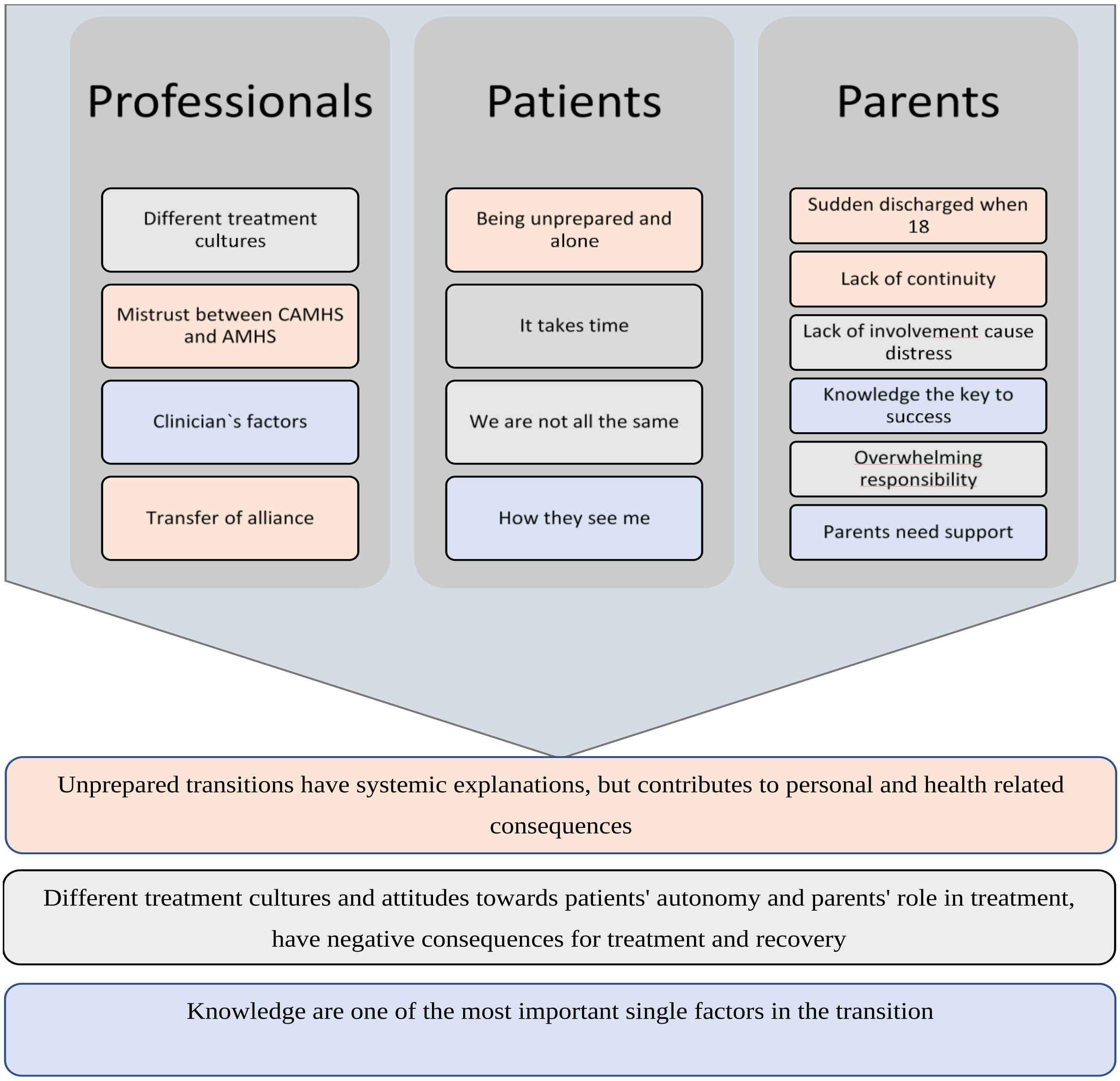

Figure 3

7.1 Unprepared Transitions Have Systemic Explanations but Contribute to Personal and Health-Related Consequences

The findings from the current study describe how patients, parents, and professionals seemed to agree that the transition often is unprepared, and the unpreparedness created a barrier in the transition process. Not only did it contribute to poor follow-up after discharge from CAMHS, but also to the problematic start-up in AMHS. Although some of the patients described the transition to AMHS as a necessary element in their recovery, they viewed their transition process as flawed. The patients felt they had no voice in the decision when and how the transition was carried out. Without their current maturity and readiness status being assessed, the patients felt lost and alone. Interviewing patients in pre-and post-transitioning groups in Canada, Cleverley et al. (2020) learned that many of the patients just resigned to the idea of transitioning, as they accepted that they had no part in the decision. This resignation is unfavorable for the transition process. We know from transition theory that being adequately informed and the degree of involvement in the transition planning are indicators of how patients will engage in the transition process (Meleis, 2015). In Cleverley et al.'s study, both pre-and post-transition youth advocated for earlier and more detailed preparation. In our study, from the parents' perspectives, there was no question if they viewed the transition as a hurdle in the patients' recovery process. They also perceived the transition process as a strain on their own situation and health. In our study, they described how they suddenly were left in a new system that expected them to enter a new role without guidance. They understood that their adolescent was to be treated as more of an adult, and their role therefore changed. However, their effort in taking care of the patient day and night was not acknowledged. They felt powerless, as they believed that AMHS defined them out of treatment and did not sufficiently involve or inform them of their adolescents' treatment. Thus, the lack of continuum between CAMHS and AMHS negatively influenced both patients and parents' situation.

Robinson et al. (2020) conducted a thematic analysis of qualitative data from an online survey of 616 caregivers' experiences of eating disorder treatment. In their study, the parents experienced the transition as predominantly disruptive, as their adolescents were simply excluded from CAMHS after turning 18. They experienced the disruptiveness of the transition process as a fertile ground for relapse. They expended much time searching for adequate treatment facilities, and in their study, as in ours, this was described as straining. They had a theme called "the wait and weight," implying rhetoric commonly describing adolescents as not thin enough to receive treatment. They were left without treatment and support. In line with our study, some patients described how they had to starve themselves to fit the current treatment facility thresholds. The transition period was perceived as unstable, leaving the parents responsible for the periods between therapy and for periods where patients felt alone during prolonged transition.

The reasons why the transition period is characterized by such disruptiveness are complex. However, in our study, the professionals provided some explanatory factors. Although CAMHS and AMHS, to some degree, collaborate in the transition period, the system is organized in such ways that the collaboration often collapses before the transition period ends. They described a lack of trust between the services. Disregarding the CAMHS`s long relationship with the patient, professionals in AMHS make their own assessment of the patients when entering AMHS. This routine makes the transition more difficult for patients who have to repeat much information and contributes to a feeling of mistrust between the services. Often were professionals in CAMHS unaware of what kind of care the patients with AN would receive when they entered AMHS. It could be difficult for the CAMHS professional to refer patients they had worked with for a long time to a system they did not trust. AMHS professionals picked up on this lack of trust and criticized CAMHS for not preparing the patient for the transition. In their view, the transition would have been a better success if patients were more prepared on what to expect and what was expected of them when entering AMHS. Another reinforcing factor was the lack of information flow between CAMHS and AMHS. Patients had to repeat information about their situation, which possibly enhanced the patient’s feelings of disconnectedness. Disconnectedness is identified by transition theory as one of the known properties of transitions (Meleis, 2015).

As inadequate preparation for the transition might enhance the feeling of being disconnected, patients may need more time to arrange the contradiction between past, present, and future expectations and support when navigating and connecting to AMHS (Meleis, 2015). Patients are transitioning from a familiar and often safe place to something new without being adequately supported in the process. The need to strengthen the transition with more collaboration between the services is evident, as it ensures that patients and parents are not alone in securing information. They should operate as one not two services to ensure a continuum of health care in the transition as the current way of organizing the transition enhances the feeling of disconnectedness. From the patient’s perspective, discontinuity created unnecessary instability for them, a fertile ground for disengagement, and possible drop-out from treatment.

7.2 Different Treatment Cultures Between the Services—implying a Difference in Attitudes Toward Patients' Autonomy and Parents' Role in Treatment—negatively Affect Treatment and Recovery.

The transition process has already been described as unprepared and too sudden after reaching the age boundary at 18 years. Although the transition method is problematic, the challenge becomes all the more difficult as we know how fundamental the differences are between CAMHS and AMHS treatment approaches. In our study, those differences contributed to the difficulty professionals faced in taking individual considerations toward patients and parents' needs in the transition process. The transition became more challenging for the parents and the patients. Much of the research conducted on transitions have focused on administrative challenges. Thus, Mulvale et al. (2016) wanted to explore how the differences in care philosophies may influence the transition since they can have a persisting influence on the transition even after administrative challenges are addressed. They conducted a systematic review followed by a thematic synthesis of the peer-reviewed literature to understand better the professionals' care philosophies and how they potentially could affect the patients' transition from CAMHS to AMHS. Of the 1,897 identified articles, 12 met eligibility criteria. They identified and contrasted three different philosophies from the articles.

The first was the differences between developmental versus diagnostic approaches. They found that CAMHS see patients' current problems in light of their developmental context. By contrast, AMHS takes a diagnostic approach, focusing on managing the symptoms of AN. Furthermore, they identified differences in who was likely to receive treatment, as CAMHS includes a broad range of health problems and needs that do not meet the diagnostic criteria in AMHS. Patients struggling with severe mood conditions and psychosis were found to have easier access to AMHS, which may underline AMHS's greater focus on a psychopharmacological approach. In addition, it can be a signal to which disorders are perceived as more severe and in need of treatment. The study suggests that these differences may lead to difficulties in the transition from CAMHS to AMHS for patients with eating disorders. They contribute to inconsistent referrals, lack of eligibility for AMHS, and discontinuation of needed services. Our study confirms the hypothesis, as the already discussed lack of continuity between services creates barriers for both patients and parents, as parents are left with much work trying to access adequate treatment for their adolescents.

Their second theme concerns differences between the CAMHS's more family-social approach versus AMHS's more individualistic approach (Mulvale et al., 2016). Where CAMHS had it in their culture to consider the adolescents' social context when understanding their presented problems and therefore took a networked approach to their service delivery, AMHS often took a more individualistic approach. There, the adolescent was considered an autonomous adult, and consequently, there was less focus on their family and social context. In the present study, all stakeholders had a similar impression. The AMHS professionals acknowledged the differences and were, to some degree, concerned over the lack of parental involvement. However, they found that sharing information with parents and including them in the treatment required more time than they had. In addition, they needed consent from the patients. The latter was not always easy to obtain, as many patients were perceived ambivalent to parental involvement in their treatment. Furthermore, for some, the involvement of parents was not advisable, as they did not have the personal resources to support their adolescent. Mulvale et al. (2016) discussed how not including parents made adolescents often feel alone and were less likely to continue treatment in AMHS. As parents had less knowledge about the received treatment, it was easier for them to drop out of treatment without the parents knowing. Our study shows differences in how the adolescents` wanted parents to be included in the transition and treatment. Regardless, they experienced an AMHS that did not try to convince them to include their parents. Some said they were asked if they wanted to include their parents but not asked a follow-up question when they answered no. Consequently, the professionals missed a conversation about their family life and additional information that the patients viewed as important for their current situation.

As in our study, Mulvale et al. (2016) described a difference between CAMHS's more protective approach versus AMHS's more individual approach, including how parents are involved in treatment. They found that CAMHS often had childish physical surroundings and a protective approach that did not help prepare youth for the responsibilities expected by AMHS. In AMHS, the adolescents were a minority among patients, and their specific needs were often unmet. Contrasting CAMHS's childish surroundings, AMHS`s inpatient facilities were experienced as frightening and confusing for the adolescent patient. From our study, we learned how the systems failed to take individual considerations into account regarding assessing maturity levels and readiness for adult responsibilities either in CAMHS or AMHS. Unfortunately, this leads to a transition process to which many patients do not feel ready for. They do not feel prepared or ready for the responsibility expected by AMHS and are left without any real possibility to master their situation.

Still living at home, the parents often are left with the responsibility for their health, but they do not receive information and do not feel involved in the treatment. This lack of involvement leads parents to being distressed as their concern for their adolescent's health is overwhelming. The transition period is perceived as a very uncertain time, with potential consequences for both patients' health and parental well-being. In Robinson et al.'s (2020) study of parent's experiences, they found that the services expected that their adolescent could make sound decisions, something the parents viewed differently. This was one reason their adolescents dropped out and experienced clinical deterioration in the transition period. As transitions create disconnectedness, the individual's sense of security can be severely eroded (Meleis, 2015). Thus, when these cultural differences are not explicitly discussed, adolescents are left unsure of what AMHS expects of them. AMHS often lacks the ability or awareness to adapt to the individual's particular needs in the transition. For a transition to be characterized as successful, transition theory has identified outcome measures concerning how adolescents have mastered and integrated their new role as adults (Meleis, 2015). Transition theory does not explicitly have self-sufficiency as a goal but rather emphasizes the individual's ability to be self-aware and know when to access help or support in their transition—creating new goals and having the ability to attempt reaching them with confidence. How the services organize the transition process creates a hurdle for this exercise. AMHS is likely to disregard the individuals or parents' attempt to reach out for help, as they are used to determining what services are to be provided. From our study, we learned how the patients and parents feel left without adequate support in this period.

Ideally, the transition period could be a therapeutic intervention where patients could practice being autonomous. Hope et al. (2013) see the development of autonomy for people struggling with AN as a therapeutic exercise, where clinicians enable the patients to develop their autonomy. Through exercising their autonomy, one can be independent of the controlling influences of AN and self-develop. The clinician must have enough time to cultivate the patient's autonomy. The transition can be an ideal exercise in practicing autonomy, but it requires awareness and an attending clinician.

7.3 Knowledge Is One of the Most Important Single Factors in the Transition

In our study, experiences from all three perspectives emphasize “knowledge” as an essential factor in the transition. From the patient’s perspective, professional competence is vital in this period as it often takes time to develop trust and feel safe with the professional. Although knowledge about AN and how to connect with people struggling with AN are vital in every level of treatment, it is especially essential when transitioning as the period causes stress and feels highly unpredictable. We know that competence and knowledge are important for establishing a trusting and fruitful relationship between the three stakeholders.

As already discussed, the lack of preparation for the cultural differences creates challenges for the patient in a transition. The patients lack knowledge about how the expectations toward them change in the transition. There are also differences in how the language used by professionals to describe their problems change into a stronger focus on their disease. In our study, this difference is apparent already in the first meetings. Patients view first impressions as important when describing their therapeutic relationship. Often, the patients felt being met as a diagnosis, not a person. When Sibeoni et al. (2017), in their meta-synthesis explored views about the treatment of AN from the perspectives of clinicians, patients, and parents, they found that “targeting symptoms” was important for all three stakeholders. Perhaps and as no surprise, the finding primarily explored the clinician’s perspective. Identifying disease and quickly diagnosing patients are key in the mental health care system. When entering AMHS, the clinician reassesses the patient’s situation and symptoms according to diagnostic criteria and AMHS thresholds for treatment. In our study, the patients experienced that the clinician used that information as their base of knowledge in the ongoing treatment, more so than their narrative about their psychological functioning or feelings of well-being. With this approach, clinicians signal that training habits and eating patterns are symptoms and signs of disease, which can be corrected as the object of treatment. Symptoms decreases, often measured in weight gain, and the patients return to their “normal” state and are declared recovered. Since the diagnosis manual ICD-10 emphasizes observable target symptoms, it is natural that clinicians focus on them. However, from the patient’s perspective, the psychological distress and illness are undermined with this approach, leaving them feeling treated as a disease instead of a person with a disease.

The incongruence between what clinicians and patients view as crucial in the first meetings creates a barrier in the transition that is difficult to overcome. Sibeoni et al. (2017) in their meta-synthesis describes how distrust between patient and clinician results in barriers to establishing a good therapeutic relationship. With clinicians using weight as a measuring tool for psychological functioning, they lose the opportunity to create an open and safe treatment environment. Although guidelines declare a goal in treatment is to help people to reach a healthy body weight or BMI for their age, and that weight gain is key in supporting other psychological, physical, and quality of life changes (NICE, 2017), the patients do not emphasize these symptoms the same way clinicians do. For patients, the psychological stress they experience is often described as the most important to discuss. The parents in our study describe some of the same focus on weight and food. Some of them understood that their adolescent wished to drop out of treatment as they had experienced how damaging it became for their adolescents' feelings of self-worth.

Since there are severe and life-threatening conditions associated with starving yourself and having low body weight, it is not surprising that the clinicians need to feel in control and focus on elements that can be easier to measure. Clinicians often have a sense of responsibility, not only for the patients but also to maintain a framework structured by the department's rules and protocols, emphasizing the control element in the relationship even more (Sibeoni et al., 2017). Patients with AN often struggle with ambivalent feelings toward treatment and recovery, which explain why they have such ambivalent feelings concerning the therapist's degree of control in the relationship. Although recognizing the therapeutic importance of continuous surveillance, Sibeoni et al. (2017) found that patients often experienced it as coercion and punishment. Although transition theory underlines that it is natural in the transition process to try to make sense of the changes inflicted upon them by comparing the old with the new (Meleis, 2015), others have found some similar tendencies. Mulvale et al. (2016) underline how studies have found that CAMHS has a broader range of medical and psychosocial interventions, while AMHS focuses more on psychopharmacology and reflects on how this difference in approaches may lead to the adolescent's disengagement following transfer to AMHS.

In our study, the patients want the professionals to know how important predictability is for them and be aware of how triggering the transition is for their anxiety and eating habits. As they have such difficulties trusting the new clinician, they find ways to test their devotion toward them, their competence, and their ability to endure and handle their way of behaving. For them, time was needed to create trust and a fruitful therapeutic relationship. However, they experienced a lack of focus in AMHS on building a relationship and using the time to create the necessary trust. From the professional's perspective, they felt overwhelming expectations toward their level of knowledge and feel that the patients have high demands. It often makes them question their own competence. One can assume that between the various expectations for clinicians from patients and parents and their obligations to the system framework, the pressure makes it challenging to navigate and use the necessary time to create a fruitful therapeutic relationship needed to make the transition process successful.

For the parents in our study, professional competence was paramount. In their view, competence on different levels is important. First, they felt as if their adolescent lost motivation for treatment if they were handed a clinician that, in their view, lacked an adequate level of competence and knowledge about AN. Moreover, the clinicians need competence regarding knowing when and how they use the parent's competence and how they all should collaborate in the transition. They need the professional to sense what they are handling in their difficult home life and their fears in terms of feeling responsible for an unstable adolescent. They must develop trust in the professional's competence to let go of their responsibilities for the adolescent. First, when that happens, they do not need to be involved – only informed.

Other studies have indicated that parents perceive clinicians' knowledge and expertise of AN as inadequate (Fox et al., 2017; Robinson et al., 2020). Apparently, parents have spent considerable time struggling with obtaining adequate care for their adolescents, and their interaction with the caring system has given them profoundly negative experiences. Robinson et al. (2020) found that many carers feel that not receiving support or help increased their levels of shame and an internalized feeling of self-blame and failure. Some had experienced being met with hostility by clinicians. It was a shared experience that the clinicians lacked understanding of AN and the impact living with the disorder had on the individual and their families. These findings are supported by our study: Both patients and parents felt as the complexity of their situation were not considered by the clinicians. It worries that the parents feel that the system induces shame and excludes them from the adolescent's treatment. As the patient's recovery often relies on parental support, and most therapies are delivered in outpatient facilities, home life is a vast part of the patient process. Transition theory identifies the level of health and well-being of the person and their family as an essential condition for the transition outcome (Meleis, 2015). Thus, the home environment can facilitate recovery or create a barrier to it that is difficult to reverse without trust between parents, clinicians, and patients.

7.4 Methodological Considerations

Conducting qualitative research relies on the researchers' ability to reflect and be open to what the material comprises. Studying experiences with the transition, I wanted to characterize those experiences, discuss them, and possibly explore some nuances that could shed light on how and why so many experience the transitioning in such a negative way. As the project manager, I saw it as my job to secure an atmosphere that allowed the research team to feel safe in a supportive setting. Thus, we could see and discuss the material as freely as possible. The following section elaborates our approach to secure this atmosphere.

7.4.1 Reflexivity in Process

Commonly, when conducting research, the researchers are engaged in the theme in focus. In the positivistic tradition, these engagements could be characterized as disturbance and contribute to researcher bias. Our study has chosen to use those engagements as a positive factor in the research process. Therefore, we had an intense focus on reflexivity to ensure our engagements positively contributed to the project and to avoid research bias and confirmation. Practicing reflexivity in the research process involves thinking about how we as researchers influence the analysis with our ideas and thinking. Reflexivity has to be an active process, sharing our pre-existing understanding and challenge them in the light of new understandings occurring in the research collaboration (Haynes, 2012). Thus, our potential biases and understandings did not get in the way of openly analyzing the material and understanding the topic in focus more broadly (Hummelvoll, 2010).

Since our project was user initiated (by LAWH) and the user who initiated the project refused the idea of managing the project herself, our collaboration started with clarification of roles and determining the project's mandate. Initially, the project had a more action research design. After assessing how the research question and design matched, we chose a more traditional qualitative design.

In the process of determining our research design, it became clear we had different research goals within the group. Expectations became the theme of many conversations. Whereas I came into the project wanting to understand and possibly find some key knowledge points about the transition, LAWH as the initiator, felt that knowledge was already gained and wanted the project to influence practice directly. These difference in expectations is characteristic when including service users in research. Often, when service users engage in research, they are interested in action and actively create change (Strier, 2007; Abma et al., 2009). I had great sympathy for her arguments, and she for mine. Thus, we decided to take the pragmatic choice of a traditional qualitative study as we would gain systematic knowledge we did not have and could follow a more realistic timeline. With these initial discussions, we started forming a collaborative atmosphere characterized through openness and honesty. In my view, accepting differences is essential to creating a creative and intuitive work environment needed to conduct qualitative research, as one constantly discusses one's own values and experiences. This open atmosphere was particularly important as our research group was composed of different backgrounds regarding academic experience and knowledge and service user experiences and knowledge. Using time to establish a safe, collaborative environment in a research group lays the foundation for the service users to become an equal part of a group set on the academic researchers' turf (Askheim & Høiseth, 2019). Although including service users in research is mainstream today, there is little focus on how they should be included. Many service users have reported feeling included in the paper, but not in the process (Minkler & Wallerstein, 2008; Tew, 2008; Cossar & Neil, 2015; Askheim & Høiseth, 2019).

As earlier mentioned, we had Heaton et al. (2015) in mind as we viewed the users' knowledge and experience as par with that of professionals, which created greater equality in the relations between users and professionals. Thus, we used the time to discuss and elaborate on our expectations and roles. This was meant to increase understanding of what the researcher's role implied. Such an approach allowed them to master their new role and use their experience as service users in the project's best interest. In the process, as a new researcher myself, I obtained a clearer understanding of my own role as a doctoral student and project manager. When the research process was initiated, we spend less time discussing the process and more time discussing the collected material. To smooth the collaboration process and secure an open dialog, we individually filled out a form that summed up experiences from our group meetings focusing on collaboration. It gave me, as the project manager, insight into service users' experiences in the process. I was the only one reading those reflections, and they guided me in my work as a project manager in the first months of collaboration.

7.4.2 The Concept and Review of Validity Threats

To demonstrate a study's credibility, agency, and topicality, the research must display transparency about potential pitfalls in the research process (Morse et al., 2002). For some, reliability and validity pertain to the quantitative paradigm and are unsuited for describing the quality of a qualitative study (Morse et al., 2002; Maxwell, 2013). Different semantic phrases underline one's philosophical stance. While I am sure that Gubas`s concept of "trustworthiness" would also help me demonstrate the value of our study (Guba, 1981), I have chosen to use the concept of validity. To me, validity is not linked to the qualitative stance of an "objective truth," but more as guidance in criteria our study can be tested against. In the following, I will demonstrate how we dealt with validity issues in our study inspired by how Maxwell (2013) identifies the two core validity threats to be researcher's biases and reactivity.

7.4.2.1 *Research's Bias*

Maxwell (2013) claims that there were two critical threats to the validity of qualitative conclusions. The researcher can select the data that fit the researcher`s existing theory, goals, or preconceptions and that the researcher could select the data that they found appealing.

For us, the concept of research biases was mainly demonstrated in study I. We had newly developed collaboration and had yet to establish trust in our research group. As study I explored the professional's perspective, JIR and I had conducted the interviews while the rest of the research group were handed out transcripts to read through before our group meetings. We chose to devote time to developing our personal understanding of the content before sharing it to the group. As such, we wanted to elicit various possible perspectives (Gillard, Simons, Turner, Lucock, & Edwards, 2012). However, it seemed we had underestimated the outplay of our different perspectives and the level of distrust toward the system that was integrated in service users. Our preconceptions had enhanced playground as the service users had not attended the interviews themselves. Provided with only a script, they imposed their preconceptions of distrust onto the material at hand. When I met their interpretations and understanding of the interviews, I felt the interviews became unrecognizable and started to defend the professional perspectives rather than be open to what was said. This process prolonged the analytical process. Thus, we reorganized the structure of the research meetings.

Instead of starting the discussion at once, we prepared our impressions in written form and presented them in turn, finishing with a discussion. That gave us more room for analytical work with the material. Although discussions can be fruitful for the creative process, they must occur in a facilitating atmosphere, where the reflective process co-exists with temperament. After those initial meetings, we found a structure that gave us exactly that. In addition, we had all read through the interviews multiple times and therefore had a more nuanced view of them. In retrospect, it could have been a good idea to deliver the interviews in written form and listen to the interviews with the service users. In addition to functioning as a preparation for the following studies where they were to be moderators, it could have contributed to another layer of information for study I.

7.4.2.2 Reactivity

Reactivity refers to the researchers' influence on the interviewees in the interviewing setting (Maxwell, 2013). In qualitative research in general, reactivity does not refer to control for the researchers' effect in the setting. Instead, it reflects over those influences and discusses these openly. Our study views reactivity as especially important, as we included service users in the interview setting. Some literature on participatory research underlines that one benefit of including service users in research is how they may provide different answers with their shared experience than a traditional academic researcher. Moreover, due to their shared experiences, they may allow themselves to ask the informants different questions. Although we support the possibility that service user involvement in the interview setting could give different answers to asked questions, we considered it an ethical dilemma. One hazard of using service users in the interview setting are utilizing similar experiences as a shortcut to creating an intimate atmosphere and the interviewees' sensitive experiences. Therefore, we carefully considered what to share of the service users' experiences in the presentation of the participants. Thus, the interviewees themselves had an idea of the similarities existing between them. However, we did not experience that the interviewees regarded the academically trained moderator differently from the service user moderator, as the conversations flowed fluently between all participating in the interview.

Rather than experience, gender and age can be important factors influencing the interviews. Interviewing parents for Study III, I was conscious that I, in my position regarding gender and age, could symbolize the life they still felt afraid their child would not get. In the same study, LAWH was often questioned about her daughter, how her daughter lived and had recovered to date. This to me, symbolizes how directly one influences the interview regarding reactivity and how moderators can become somewhat of a reference point of what is to come. Moreover, how it is important that service users' experiences must be a prepared narrative and that they, to some degree, they should have worked through their own often difficult experiences. In our study, the service users were experienced and had processed their experiences. However, for Study II, LMB expressed difficulties separating the interviewee's narrative and feelings from her own. We had prepared for that course of events and complimented each other in the interview setting, so the confusion did not play out in the group.

As a moderator of qualitative interviews, one relies on one's ability to stay empathic and in tune with the participants' narratives, not only to catch the essentials in their story but also to consider the participants. When describing one's own experiences, maybe for the first time, one can be caught off guard, unaware of feelings. The moderator's role implies a sensitivity regarding the use of time, so the participants can control their narrative and not reveal feelings and experiences they were unconscious of. In that regard, we also used the time to ensure that we, as moderators, were in control of our reactions for the shared difficult experiences.

One way of navigating complex narratives and other people's experiences is through member checking. Member checking or informant validation are used to improving the study's internal validity. Throughout the interviews, we conducted member checking by asking if we had perceived the statements accurately and summed up our understandings along the way. That way, we used the participants' experiences to lead the interview forward and reduce reactivity. In Studies I and II, we sent out a summary of the previous focus group session to comment on and discuss in the following focus group.

7.4.2.3 Additional Factors Regarding Validity

In qualitative studies relying on interview data, rich data implies detailed and varied data to reveal a picture of what the experiences contain. Regarding interview studies, such data are revealed from verbatim transcripts of intensive interviews, not only notes of what the researchers find relevant (Maxwell, 2013). Our study was based on material gathered from such intensive interviews, using various individuals and settings, often called triangulation. The purpose of triangulation can include setting the different materials against each other as a check, validating the study's conclusions. In our study, we mostly used the different perspectives to gain information about different aspects of the transition from CAMHS to AMHS. Although used as a validation technique, seeing the perspectives as complementary also expands the different aspects regarding the transition.

The study was based on the preconception that the transition from CAMHS to AMHS had room for improvement. However, we used the interviews to find at variance experiences. Searching for discrepant evidence is a vital part of validity testing in qualitative studies (Maxwell, 2013). In the interviews, we asked for the whole range of experiences in the transition period by starting the interview with open questions about how they would describe their experience with the transition and used that as our base for future questions.

As our analysis was based on de-contextualizing and re-contextualizing the material, the individual interviews are unknown to the reader. Compensating for that, we attempted to illustrate the authenticity of the interviews for the reader by including numerous accounts of citations from the interviews in our three studies.

Maxwell (2013) claims that many qualitative studies bases their conclusions on an implicit quantitative component. He states that one often underlines how important one theme is in a study by how typical, rare, or prevalent a phenomenon is in the material. This way of displaying prevalence is also present in our study, and in some sense, a part of our analysis. Deciding what a theme or category was, we sometimes referred to the "size" or how repetitive a phenomenon or code was identified in the material. Maxwell argues that the numbers allow you to test and support claims and thereby assess the amount of evidence you have to conclude the way you do, or in our case, categorize. However, we do not regard that prevalence alone can determine what is categorized as a theme. In Study II, interviewing patients, one specific interview made us aware of the theme: *How they see me and treat me affects my hope for the future*. After re-reading that interview, we had to return to the previous ones to consider closer if similar phenomena were present. Braun (2006) states that prevalence alone is not what determents what qualifies as a theme. They claim that the "keyness" of a theme is not dependent on quantitative measures but whether the theme captures something important concerning the overall question.

Qualitative research's transferability depends on different factors regarding the study's sample and context. In Study I, the professionals were well-qualified, experienced clinicians with experience transitioning adolescent patients with AN. With those qualifications, they were not per se representative for the general population of clinicians handling adolescents in the transition. However, using representability as a criterion when choosing participants for Study I could have left us with clinicians with no knowledge about transitions and unable to answer our research questions. The goal was to create knowledge about the transition that was transferable beyond our study, and we gathered participants with such experience. For Study II, interviewing patients that had undergone a transition from CAMHS to AMHS, we expected a broader sample regarding ethnicity and gender than were included in the study. Although we did not explicitly ask the participants about their cultural background, they all were white girls that spoke native Norwegian. Almost all patients treated for AN in Norway are native Norwegian girls. However, we reflect on how transferable our study is outside a western society and culture. As for Study III, the included parents were all parents to girls raised in Norway. One parent lived in a multicultural marriage. The participants described how caring for their child in this period demanded much use of their time and financial resources. It is a reasonable assumption that they can devote these resources since Norway is a welfare society and generally has reasonable welfare arrangements. Less privileged families in low-income countries would possibly be forced to prioritize differently. However, our findings support those found in international literature and can be assumed to have relevance in other contexts. For Studies I and II, the participants self-volunteered to participate. They had obtained information about the project through therapists or the internet. Although all participants qualified regarding our studies' set criteria for inclusion, one can question if the participants' experiences were biased toward the negative. Moreover, the retrospective nature of the interviews could represent a bias in material, as one often tends to remember the negative aspects better than the positive. One can expect that the current state of recovery or disease would impact their retrospective view on the transition.

8 Conclusions and Clinical Implications

Unprepared transitions have systemic explanations but contribute to personal and health-related consequences. It is essential to acknowledge the patients' needs during the transition period and consider their readiness for the transition. Doing so should create a better chance of a successful transition. Preparing patients and parents are CAMHS's responsibility, and a more gradual process of focusing on the patients' self-sufficiency and autonomy should be an integrated part of planning the transition. Preparations should explicitly describe the differences between the services to both parents and patients. As good collaboration is essential in achieving continuity in treatment, there should be a way for clinicians to get in touch with each other and communicate directly. Ideally, the theme of transition should be a discussion including all active parties. Doing so would empower the patients and give both CAMHS, parents, and AMHS a connection. Having a stronger focus on building an alliance with the patient in the first meetings could influence the patients' experience and compliance with treatment. Improving the transition by focusing on including parents and adolescents and preparing them for the transition period could ease parental distress and improve adolescents' compliance with treatment.

Clinicians should increase their focus on the important role of parents in the transition process. The system should implement routines and guidelines to offer caregivers support and guidance during the transition process. The parents often provide meal support in the transition, and they are the ones with the most information and knowledge about the patient's recovery process or disease. In addition, since adolescent patients often still live at home, parents are an essential part of their support system. Furthermore, when patients live at home but lack the personal resources to be supportive, the patients' recovery is also complicated and therefore are just as an essential factor. Therefore, we recommend future research on how to secure the transition, including the parents' perspective to gain more insight into what is needed in this treatment period. In addition, we recommend future research into when and for whom the transition is initiated up to the age boundary of 18, as CAMHS have authority to treat patients up to the age of 23.

Since CAMHS know the patients and can treat them up to the age 23, it can appear reasonable that they coordinate and secure the transition. CAMHS, in the coordinator role, provides multiple benefits for the transition of the patient. They know the patients' history and, therefore, can contribute to the flow of information that is currently missing. They often know the families and can help them navigate their new role as a parent to an adult. CAMHS also have the knowledge base regarding developmental issues many clinicians in AMHS feel are missing. Thus, the AMHS professionals can receive the support they now feel missing, and CAMHS can obtain more insight into AMHS, which they feel are lacking in preparing patients on the transition. This change in organizing the transition could contribute to a more positive relationship between the services and can reduce the existing distrust.

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10 Appendix

10.1 Intervjuguide pasienter

Overordnet forsøker vi å koble det sier opp mot BUP og VOP og deres forskjelligheter. Hvis de starter med å beskrive noe i BUP – spør vi etter hvordan dette var i VOP osv. Dette gjør vi ved å forøke å få tak i ekte historier om hva som faktisk hendte.

Husk:

Ikke konsensus

Selv om historier ligner, er det likevel forskjellige historier

Vi er her fordi vi er nysgjerrige på deres historie, ikke for å evaluere verken dere eller systemet

- Kan dere starte med å fortelle om hvordan dere opplevde overgangen mellom BUP/VOP?
    - Hvordan BUP/ hvordan VOP? (ettersom hvor pas begynner)
    - Eksempler på hva bra/Dårlig?

- Systemet?
    - Hva kan du si om hvordan behandlingssystemet hadde innvirkning på din behandling/bedringsprosess?

- Hvordan var relasjonene til behandlerne?
    - BUP/VOP
    - Familien
    - Ærlighet/støtte/oppfølging
    - kan dere fortelle om hvordan du fikk snakke om hvordan du hadde det på den tiden?
    - Hvordan vil du beskrive hvorfor du var/ikke var åpen?

- Deg selv?
    - Hvordan vil du beskrive ditt eget bidrag til at det gikk bra/dårlig?

Hvordan tenker du at overgangen preget din behandling/ sykdomsforløp?

10.2 Intervjuguide behandlere

Generell innledning om prosjektet og hensikten

I denne gruppa, er det mange ulike perspektiver, og det er med vilje. Her er det ikke om å gjøre å bli enige, men heller utforske så bredt som mulig de ulike momentene ved overgangen. Så alle stemmer er viktige og ingenting er rett eller galt.

Vi har frem til kl 15. Jan og jeg vil styre tiden, slik at vi kommer oss igjennom de temaene vi ønsker å snakke om.

I tiden mellom dette fokusgruppeintervjuet og neste skal jeg transkribere og ta en foreløpig analyse, den analysen får dere tilsendt kort tid før neste intervju, så lager det bakgrunnen for neste.

Tema: Opplevelsen til pasienter og pårørende

Hvordan tenker dere at pasientene opplever overgangen?

- eksempler

Hvordan tenker dere at pårørende opplever overgangen?

- Eksempler

Hva tenker dere er viktige aspekter ved en god overgang/momenter som er viktige for pasienter/pårørende?

Hvordan vurderer dere om hvor klare pasientene er når det kommer til overgangen?

- **Hvordan vurderer dere pasientenes modenhet «readyness» i forhold til alder?**
- Hvem blir holdt igjen/ hvem blir ikke?
- (våre antipatier/sympatier)

Tema: Opplevelsen av planleggingen av overgangen

Hva erfarer du som de vesentlige aspektene ved en god overgang?

Hvordan opplever du at dette er tilstede/ikke tilstede?

Hvordan arbeider du med pårørende /vurderer deres rolle?

Hvordan tenker du at pasientfaktorer spiller inn i overgangen (symptomer – relasjonelle vansker…)

Hvordan får du planlagt overgangen? Hvor forutsigbare er disse? Rutiner?

- Hva fungerer/ hva fungerer ikke?

Relasjonsbrudd

(hva er bakgrunnen for at du tenker disse aspektene er viktig?)

Tema: Opplevelsen av overgangen til terapeutene

Hvordan tenker du at din relasjon til pasienten har innvirkning på overgangen?

- hva kan ha positiv innvirkning/dårlig?
- Hvordan takler du selv overgangen?
- Redsel styrer overgangen?

Kan dere si noe om deres opplevelse a vi hvilken grad en vellykket overgang er på ders skuldre/ oppmot systemet / pasienten?

- Hva hjelper dere med å sikre overgangen?

Tema: Opplevelsen av samarbeidet mellom BUP/VOP

Hvordan er samarbeidet mellom bup/vop?

Tidsaspektet; Når starter planleggingen og hvordan går den? Kontakt mellom BUP/VOP!

Hva preger dette samarbeidet?

Samarbeidet med foreldre (BUP/VOP)

ANDRE:

Terapeutfaktorer

Systemfaktorer vs terapeutenes egen tanker/holdninger