

Mind the Gap: Parental Perspectives on Mental Health Service Transitions for Young Adults with Anorexia Nervosa

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Abstract

Introduction:

The transition from Child and Adolescent Mental Health Services (CAMHS) to Adult Mental Health Services (AMHS) is known to be difficult. For young persons (YP) with anorexia nervosa (AN) transitioning between services might be particularly challenging due to the timing, often coinciding with other key life changes. The potential consequences of inadequate transition are many: treatment dropout, heightened symptom load, and increased distress amongst patients and relatives. Furthermore, the parent-child relationship may be affected by the changes related to service transition. Parents are highly involved in treatment in CAMHS, but have a less central role in AMHS, therefore, their experience of transition is important to fully grasp potential problems or shortcomings of the transition processes and thereby improve it. The parental voice has not received much attention to date. This study aimed to describe common themes in parental experiences of their role, when their YP transitions from CAMHS to AMHS.

Methods

A total of seven parents were included, three fathers, three mothers and one stepmother. Parents were interviewed using a semi-structured interview guide focused on their experiences of the transition process. The data was analyzed using empirically testing thematic analysis.

Results

The analysis revealed 3 superordinate themes relating to the parental experience of transition: 1) The transition process, 2) Autonomy and independence, and 3) Shift in parental role. The parents' overall experience of the transition process was that it was unsatisfactory, and in their view a cause of increased anxiety and a worsening of symptoms in the YP. Furthermore, parents described feeling anxious and uncertain regarding the new personal and legal autonomy and independence that the YP had in the AMHS. Finally, the large shift in parental role was challenging, although, for some it improved the parent-child relationship.

Discussion

parents can be highly affected by the transition process and the shift in involvement, and the parent-child relationship can both improve or strain in this phase. Furthermore, several parents experienced their child having adverse outcomes of the transition process or lack thereof. Future research can benefit from including parental perspectives on transitioning in healthcare for YP with AN.

Introduction

The transition from Child and Adolescent Mental Health Services (CAMHS) to Adult Mental Health Services (AMHS) is a period of critical importance for young people (YP) with anorexia nervosa (AN)

(Lockertsen et al., 2020). AN typically develops between the ages 14 to 19 with approx. 85% having onset before the age of 20. AN is a severe mental disorder with serious negative physical, social and psychological consequences (Lockertsen et al., 2020). Individuals with AN often have a long and potentially chronic treatment course (Pinhas et al., 2011). Furthermore, the disorder is often characterized by poor insight into one's illness and into the severe consequences of eating disordered behaviors, which can lead to poor or shifting motivation for treatment (Dimitropoulos et al., 2015). As such, the transition period is of critical importance to YP with AN.

Inadequate transitions can compromise treatment outcomes and lead to increased distress and suffering amongst YP and their relatives. Previous studies have found that many YP experience the transition as a negative process that can lead to treatment drop-out (Broad et al., 2017). Thus, treatment continuity across the transition phase is highly important. In a qualitative synthesis investigating the transition for adolescents with chronic mental illness it was found that young adults felt unprepared for the transition and that the loss of familiarity with the people and surroundings in CAMHS led to increased anxiety (Fegran et al., 2014).

The divided structure of CAMHS and AMHS in many healthcare systems can leave YP with complex mental health problems without treatment, if they fall into the care gap between services (Campbell, O'Neill & While, 2012). Danish YP from CAMHS who later enter treatment in AMHS are more likely to have faced socio-economic challenges in childhood and are more likely to experience the same in adulthood compared to the YP who do not return to AMHS (The benchmarking unit of the Danish Ministry of Health, 2021). As such, this group of YPs is particularly vulnerable, and a good transition phase is an important step in ensuring continuity in treatment efforts and subsequently minimizing the risk of a socio-economic healthcare gap (Hill, Wilde & Tickle, 2019). To manage a successful transition, YP need support from both relatives and professionals (Lindgren, Söderberg, & Skär, 2013, 2014). Therefore, the need to assess and evaluate practice guidelines for transition is important.

The international standard treatment for AN in children and adolescents, Family-based Treatment (FBT), involves parents taking a key role in supporting recovery (Hay et al., 2014; Helsedirektoratet, 2017; Sundhedsstyrelsen, 2016). FBT is rooted in systemic and behavioural therapeutic approaches and has parent empowerment as the main initial therapeutic focus. YP are treated in their own home, parents are supported to take responsibility for the YP's eating and ensure a stable weight gain in the initial phases of treatment (Lock & Le Grange, 2012). Hence in FBT parents are seen as the primary agents of change. When entering AMHS treatments are often different and parents are no longer systematically involved in treatment.

Transitioning to treatment of AN in AMHS is set at a certain age (often 18 years) and not based on the individual YPs maturity, level of independence, motivation, illness or progress of treatment in CAMHS. A qualitative study found that patients with AN felt unprepared for the transition into AMHS. They felt alone in the process and felt that they were not taken seriously in AMHS (Harboe et al., 2025; Lockertsen et al., 2020). Other studies have investigated therapists' experiences of transition for young adults with AN and

results indicated that the transition process was particularly difficult as the patients often lacked independence and self-sufficiency, alongside facing challenges with motivation and treatment adherence (Dimitropoulos et al., 2015). In another study on physicians' experiences of transition of patients with AN, the transition process was described as "*a malfunctioning and violent event*" that was unsatisfactory for all parts (Stocker et al., 2022). Recommendations for a smoother transition between CAMHS and AMHS include overlapping treatment in both services, ensuring flexibility in the transfer process, and providing thorough information and involvement to both patients and their families.

The aim of the current study was to explore parents' experiences after the transition of their offspring from CAMHS to AMHS. Using qualitative methods, we set out to answer the following research question:

How do parents of young adults with Anorexia Nervosa experience the treatment course before, during and after the transition from Child and Adolescent Mental Health Services to Adult Mental Health Services?

Methods

Context: Danish MHS and transitioning

Danish mental health services are publicly financed hospital-based services providing inpatient and outpatient treatment. Referral happens through general practitioners, and the criteria for treatment in MHS is severe, complex, or treatment resistant mental health disorders. In the Danish system care for eating disorders is offered at tier 3, in specialist services, typically one CAMHS and one AMHS eating disorder service per region. There is very limited access to other lower tier eating disorder services in Denmark.

This project was carried out in the Capital Region of Denmark, where the transition to adult care takes place at the age of 18. In CAMHS, parents participate in FBT. In AMHS the treatment approaches are not family-based, and parents are much less involved. Hence, the transition of treatment AN in CAMHS to AMHS is a change in treatment center, staff, and treatment approach. Furthermore, patients decide whether they want their relatives involved.

Participants & Recruitment

Participants were seven parents of female YP between 18–22 years of age who were in treatment for AN (typical or atypical according to ICD-10). The sample consisted of three fathers, three mothers, and one stepmother all of whom had a child who had been treated in CAMHS and later transitioned to the specialist AMHS eating disorders treatment center. In this paper transition is defined as either having had a transition meeting at CAMHS and a) been referred to AMHS directly from CAMHS or b) through self-referral within 2 years of ending treatment in CAMHS. Hence, we will refer to all as having a transition although a coordinated transition effort was not conducted for all.

Five of the seven interviews were conducted by phone due to COVID-19 restrictions. Carrying out interviews over the phone did not impact on the quality or length of the interviews compared to the interviews carried out in person. Parents were asked to participate if their child met the following criteria:

- Gave informed consent to participate in research at Mental Health Center Ballerup, Capital Region of Denmark
- Primary diagnosis of AN
- Previous treatment in CAMHS for AN
- Maximum age of 22 years

Contact to the relatives was established through the YP. Therefore, the YP knew and approved of their relatives' participation in the study.

Interviews

Qualitative data were collected by carrying out semi-structured interviews following an interview guide. The interview guide was developed by the research team and was based on topics that emerged in prior studies on transitioning between services, see supplementary material for the interview topic guide. The interviews were carried out by a MSc student who was not employed in the services. The interviews were audiotaped and transcribed verbatim.

Analysis

The data was analyzed using empirically testing thematic analysis (ETTA) (Gildberg et al., 2015). In ETTA the interview guide is developed through systematic literature searches, in which common empirically founded themes are identified and used to generate research questions. Once the data is collected, the researcher goes through several steps to obtain results. The steps are as follows:

1. Familiarization with the data
2. Development of analysis process questions: these questions are based on the original research question combined with a set of inclusion and exclusion criteria related to data extraction. Our analysis process questions were:

What characterizes the experiences of parents to YP with AN before and after the transition from CAMHS to AMHS?

How do the parents experience the autonomy and legal rights associated with becoming adult in regard to their child's treatment course in AMHS?

3. Coding: with the research process questions in place, the transcripts are coded sentence by sentence with weight given to sequences central to the research process questions.

4. Condensing: the codes are condensed by merging similar codes and duplicate codes, the frequency of codes is registered to keep track of the 'strength' of the code group.
5. Categorizing: the code groups are gathered into initial categories.
6. Thematization: The categories are merged and divided into themes that are distinct from one another, the research process questions steer the development of themes based on initial categories.
7. Comparison with previous empirical findings: the themes are compared to the findings of previous studies and similarities and differences are noted. The researchers identify what results support existing literature and what results provide novel information.

Step 1–7 was carried out by the same author who conducted the interviews, step 6 + 7 was revisited by two other authors to ensure that themes and comparisons represented the raw data in a meaningful way. This was done to minimize the risk of focus drifts or skewed emphasis due to subjectivity.

Results

In the following section we will present the main themes identified in the analysis. The analysis found three main themes: 1) The transition process 2) Autonomy and Independence and 3) Shift in parental role.

The transition process

The parental experience of transition was generally characterized by poor communication, confusing processes, and mistrust towards healthcare staff. Several parents described that communication leading up to the transition process varied across health care staff. This led to perceptions of services as untrustworthy and the transition process as an unsafe procedure. In general, parents experienced feelings of insecurity and powerlessness and wanted health staff to take more responsibility for the transition.

According to parents, the transition had a crucial impact on the treatment courses for the YP involved. All parents experienced that the YP' treatment course in CAMHS ended before the transition to AMHS took place. As such, no coordinated transition process was carried out. Some of the participants had been to one meeting about transition, but treatment ended from CAMHS before the necessary transfer took place in AMHS. The sudden interruption of treatment made some of the YP symptoms worsen shortly before the transition to AMHS, according to the parents.

Some parents explained that they were instructed to get a new referral to the AMHS, which resulted in a discontinuity in treatment, leaving an extended time gap where the YP was left without treatment. One parent recalled that their YP was not offered treatment in AMHS based on a management decision concluding that the YP was not 'ill enough', although they recalled some contradictory statements by CAMHS staff. Such examples of conflicting communication made parents feel insecure and unsafe in the transition of their child's treatment. Finally, a few parents stressed that the transition went well

enough but elaborated that they felt that CAMHS was associated with a greater sense of security than AMHS.

Autonomy and independence

Throughout the interviews, challenges related to the YP's autonomy, ability, and right to make decisions for themselves when turning eighteen was highlighted by the parents. There was an overall feeling of anxiety, and feeling that the YP was not able to handle the newly gained autonomy due to the impact of AN. The parents explained how it was stressful to have 'less control' with the YP's activities including their eating and exercise habits.

Several of the parents experienced that their child discontinued treatment, discharged themselves prematurely, and refused treatment after turning 18. Parents struggled with being sidelined and felt that the YP was making decisions that *'were not in their best interest'*. Parents also struggled with the change in information flow. Where they were previously the first point of contact, the healthcare staff in AMHS would communicate directly to the YP and only involve parents if the YP allowed it. One parent explained how the newfound autonomy was used as a 'threat' and 'negotiation tool' by the YP, who would threaten to discontinue treatment. This caused a heavy strain on the family relations.

Across the interviews, there was agreement that parents' possibilities of acting, helping, and contributing to their offspring's care were strongly reduced, which led to the parents struggling to support the autonomy and independence of the YP. Parents felt without influence and in a position where they had to accept that the YP may make *'bad decisions'*. As the parents transitioned into their new role, it appeared that they learned to *'have to accept that their child can learn from poor choices'*, and that in their new role, it was central to be supportive and encouraging of *'good choices'*. Two of the parents described how they experienced the autonomy and independence of the YP developing in positive directions once they *'let go'*. The YP took responsibility for their treatment course, they gained weight and became increasingly skilled at expressing their needs. Across this theme, it was evident that the parents had severe anxieties related to stepping back and leaving responsibility to the YP who they considered to be *'very vulnerable'* and *'not ready to leave the nest'*. The parents were conflicted as to whether the new autonomy would *'inflate the AN'* or *'be part of the solution'*.

Shift in parental role

The final theme was centered around changes in the parental role during the YP's transition. Central to the topic of the parental role was that the parents found it extremely difficult to be parents to a YP with AN. Expanding on that, they explained how it was particularly difficult to experience a shift in their ability to provide help and support regarding treatment to their child, and to witness their child suffering. Parents highlighted different challenging aspects of their changed parental role. For some it was hearing the YP talk about suffering or suicidal thoughts, for others it was witnessing the impact AN had on the

YP's life, and in addition to that, they described a feeling of '*defeat*' and '*guilt*' attached to being a parent of a YP with AN. All the parents described '*feeling like a bad parent*'.

The shift in parental role was centered both around their changing role in the treatment system, but also largely around activities in the home. In the transition phase, home activities may also be affected as some of the YPs moved out to live independently, increasing parental perceived powerlessness. Some parents' described disagreements with their co-parent regarding how to '*deal with AN*' and the YP. Across the sample, parents described that there were large discrepancies in how the two parents perceived their role after CAMHS treatment finished. Some of the parents described how their partner did not acknowledge the AN or that they discarded their parental role totally. One parent explained how these disagreements surrounding the parental role had led to divorce and subsequent conflict between the two parents. Whilst parents generally found the transition and their new role extremely difficult, some also expressed that being less involved with treatment enabled them to have a better relationship with their child.

The shift in parental role often affected the whole family. One participant reflected that having a YP go through the entire treatment process made the whole family prioritize the matters that are most important to them as a family. As such, the parental role and family structure seemed to go through a parallel transition, affecting each family member, the family as a whole and the relationship between the parents in fundamental ways. The overall experience of going through this transition was different for each of the parents and whilst some found it to be beneficial for family function, others found it had detrimental effects such as divorce between parents and strained relationship with the YP with AN.

Discussion

The present study emphasizes that the transition from CAMHS to AMHS is challenging for parents of YP with AN. Three distinct themes describing different aspects of parental experience of the transitioning from CAHMS to AMHS emerged. The three themes were 1) *Transition Process* 2) *Autonomy and Independence* and 3) *Shift in Parental Role*. We will discuss the findings in that order.

Transition process

According to the Danish Health Authorities, a structured and coordinated transition process is recommended for YPs with AN where the parents are included as an important part of the transition process (Sundhedsstyrelsen, 2019). The purpose of the transition process is to include the YP preferences, needs and goals, as well as parental support to form the foundation for treatment in AMHS (Sundhedsstyrelsen, 2017).

In the present study, we found that parents generally felt the young adults' treatment in CAMHS concluded without a thoroughly coordinated transition to AMHS. In Danish MHS the referral process from CAMHS to AHMS is initiated by CAMHS. When referral is not considered relevant, the YP's treatment course is terminated in CAMHS. This decision is based on clinical judgement and the YP's

own motivation and wish for treatment. This decision-making process, however, is only initiated if the CAHMS staff considers it relevant. If the YP's treatment course is terminated, but YP wish to continue treatment after age 18, they must seek a re-referral from their GP, who refers to specialist services that may have waiting times, as such this can be a longer process. This leads to a treatment gap, where the AN may intensify. Consequently, there is a risk of discontinuing treatment for YPs who both need and want treatment, and those who might be ambivalent. While this may present a whole range of new challenges if transition was standardized for everyone, it might allow a more seamless approach.

Such approaches have been developed, i.e., an all-age integrated care model has been proposed to accommodate the disrupted transition process between CAHMS and AHMS (Wade, 2024) and is available in some countries (e.g. UK). However, to date, there is no quantitative evaluation of this approach (Wade, 2024; Ragnhildsdottir et al., 2024).

A Canadian qualitative study, investigating the experience of impending transition from CAHMS to AHMS, found that patients with ED were positive towards a facilitation intervention for transition, i.e., the use of a transition coordinator or a health care transition passport to communicate information regarding the patient (Nadarajah et al., 2022). However, the participants also expressed concerns regarding such transition facilitating tools, such as time constraints, concerns regarding securities when using phone applications or not feeling safe sharing personal information with a health care professional introduced at the time point of transition (Nadarajah et al., 2022). Transition coordinators have been used successfully in other patient groups with YP with special health care needs (Annunziato et al., 2013).

Similarly, in the care pathway program, the British First Episode Rapid early Intervention for Eating Disorders (FREED) program have assigned a case manager to encourage early referral from primary care or through self-referral, thereby decreasing the waiting time between first referral and specialist services (Schmidt et al., 2016). FREED is described as a service model and care path, where the main goal is to reduce the average duration of untreated illness (Schmidt et al., 2016). YP with a first episode of ED receiving FREED have significantly less intensive treatment requirements compared to TAU. Further, 59% of FREED patients reached a healthy weight after 12 months, compared to 17% of TAU (McClelland et al., 2018). These significant improvements in clinical outcomes as well as the reduction of intensified treatment were maintained both at a two-year follow-up (Fukutomi et al., 2020), and in an upscaled version of the program (Austin et al., 2022). While FREED does not specifically target transitions between CAMHS and AMHS, it underscores the importance of minimizing the duration of untreated illness, and a similar care pathway might help prevent young people from falling into treatment gaps during transitions. The outcomes of FREED suggest that early, efficient referrals between services can positively influence clinical outcomes and healthcare costs. Additionally, having a case manager or transition coordinator could help smooth this process.

Common for all parents in our study was, that there was a treatment gap for the YP whether the transition efforts took place or not. The gap and changes in treatment led to a sense of loss of safety

and security for the parents. Parents described worrying intensely about the potential worsening of eating disorder symptoms and well-being of their child. Having established that the transition process for YP with AN is at a particularly critical time (Dimitropoulos et al.,2015) the transition between CAMHS and AMHS should be personalized and take place when relevant for the individual YP in relation to maturity, severity of AN, motivation, independence etc. rather than at age 18 inflexibly.

Further, there is a need for thorough preparation and information regarding the impending changes in treatment. The results of the current study indicate that it may be beneficial to involve parents in these preparations, especially considering the big shift in their role in treatment. The results underscored the anxiety and fear pertaining to the decrease in involvement, however, some parents also explained, that the exact same led to a better relationship with the YP. As such, the transition could well accommodate parents by providing information and reassurance before, during and after, rather than necessarily aiming at more parental involvement in the treatment.

Furthermore, parents interviewed in the current study gave several examples of breakdowns in communication that might hinder successful transitioning. Thus, several parents recalled being told that there were fewer resources in AMHS and that '*a lot of treatment options*' would disappear upon the entry to AMHS. Whilst these reflections most likely come from a place of trying to level expectations, they may be problematic for a transition process. That is because the constructs of motivation, hope, and belief in good treatment outcomes are closely linked (Laranjeira & Querido, 2022). The main intervention delivered in AMHS is psychotherapy, and it is well established that a trusting relationship, agreement on treatment approach, and hope are distinctly important factors related to the outcomes of psychotherapy (Wampold, 2015). Therefore, the instillation of skepticism may have long and serious consequences for the YP and their treatment course. Mental health care staff must be cautious when attempting to decrease expectations. Ideally, communication to parents and YP about AMHS should be made by an AMHS representative who can communicate the details of the treatment, whilst instilling hope and discussing expectations for the new treatment program in a positive way.

Parental role

Parents initially struggled with their new role. Whilst in CAMHS they were central figures in the treatment and the recovery process, they found themselves somewhat detached and without influence in AMHS. In a previous qualitative study investigating professionals' experiences of the transition from CAMHS to AMHS for YP with AN, results showed that professionals identified the same issue (Lockertsen et al., 2020). Eating disorder professionals from AMHS services explained how in CAMHS parents are involved from day one, and how this was hard to prioritize in AMHS due to resources. They further expressed that they found it meaningful and to the benefit of the YP if there was more involvement of parents, but that culture, guidelines, and resources made it difficult to implement this in practice. Professionals also hypothesized that the lack of parental involvement could lead to mistrust towards services (Lockertsen et al., 2020). Supporting this, our study found that parents were mistrusting towards the AMHS and felt '*pushed out*' in an abrupt way. On the other hand, other participants in Lockertsen et al. (2020) indicated that in some instances it is good for the YP to create independence from the parents. This point was

also shown in our sample, where some of the parents saw the benefits of being less involved after the initial transition.

Autonomy & Independence

Parents had strong anxieties related to the autonomy and independence given to the YP with AN when turning 18 years. The parents' primary concern was that the YP was not in a 'mental place' to make healthy decisions for themselves. As such, it was frightening for the parents to have to 'let go' and let the YP take on the responsibility. The dilemma of AN and autonomy is not a new topic. Hope and colleagues (2013) described how YP with AN often describe AN as something separate from themselves, with its own autonomy. These YPs described a power battle between themselves and AN, which is a powerful metaphor for the experienced interference with personal autonomy that AN can produce. However, many YPs also described AN as an integral part of themselves and with the integration of AN into the self, the ability to make treatment decisions regarding engaging in treatment involving weight gain become extremely difficult. As such AN can be seen as a disorder that disturbs personal autonomy through various routes (Bergamin et al., 2022). Moreover, while FBT benefits from the strong parental care and involvement, it may not sufficiently prepare the YP for taking responsibility for their improvement process when they approach the age of 18. This challenge could potentially be mitigated if families were adequately supported in preparing for the transition. Hence it is no surprise that parents experienced the independence and autonomy over treatment decisions as a frightening process. Furthermore, previous studies (Nadarajah et al., 2021) have emphasized the importance of parental involvement during the transition process to facilitate a successful transition. In addition, previous qualitative studies have shown that parents felt excluded during the transition process and unprepared regarding the YPs increasing autonomy (Hovish et al., 2013; Lindgren et al., 2016; Lockertsen et al., 2021; Islam et al., 2016). This demonstrates the need to investigate how we can best support YPs and relatives during the time of transitioning between services and emphasizes the importance of a thorough and overlapping transition phase that involve parents to a greater extent.

Barriers and facilitators?

Overall, our study underlined the importance of parental involvement during the transition process to prevent the YP from falling through the treatment gap and help relieve parental anxiety. It further underlines the need for a tailored transition process including both CAHMS and AMHS, as this is critical for the parents' ability to support the YPs in a successful transition during such an unpredictable and fragile time in the young adults' lives (Islam et al., 2016). Our findings suggest clear benefits of making the transition phase a period of shared care between CAMHS and AMHS, giving the parents and YPs the opportunity to understand the way AMHS work to be fully prepared for the change (Lockertsen et al., 2020).

The present study also showed that parents were unprepared and with unrealistic expectations about AMHS due to perceived lack of or mixed information from health professionals. Parents felt alone and distressed by the lack of support they experienced. Previous research (Prizant, 2008) has highlighted the

importance of providing information about AMHS, differences in services, issues of confidentiality prior to transition. However, parents in this study experienced conflicting information about AMHS, and that professionals did not follow up on agreements made in interdisciplinary transfer planning meetings leading to a lack of trust in the parent-professional relationship. According to Prizant (2008) an optimal transition is facilitated by developing trusting relationships, clear communication systems between parents and health professionals, and specification of follow-up responsibilities. These were not successfully experienced by the parents in our study. As such, interventions targeting this problem may help transition processes for parents and YPs alike.

The organizational division between CAHMS and AMHS and a lack of resources may explain some of the barriers to successful transitions. The symptom severity threshold for entry into AMHS is generally higher than CAMHS which can lead to abrupt termination of services. CAMHS supports moderate conditions and AMHS tend to offer services only to those with severe and long-term mental health illnesses (Samantha Minchin, 2018). Therefore, transition can be hindered by health professionals' assessment of whether YPs meet the criteria for treatment in AMHS. In addition, one study (Islam et al., 2016) showed that general practitioners were often left with the responsibility for the ongoing treatment of YPs, resulting in minimal support after leaving CAMHS. Another study (Belling et al., 2017) emphasized the ethical concerns related to the focus on narrow range of conditions in AMHS, leading to only individuals with the most severe forms of mental illnesses receiving treatment.

Thus, a lack of continuity of treatment can increase the risk of YPs falling through the cracks and not transitioning to AMHS, thereby reducing their chances of recovery, or that individuals in partial recovery deteriorate until 'ill enough' to enter AMHS. Further, the changes in parental involvement in treatment may be a barrier for some and a facilitator of good outcomes for others, as seen in our study. An earlier study (Broad et al., 2017) highlighted that while some YPs valued independence, other YPs continued to prefer parental support. Therefore, the needs of both parents and YPs must be recognized and considered in the transition process to facilitate a successful transition.

Limitations & future directions

The current study had various limitations that should be considered when interpreting results.

First, the number of participants was small and sampled from one service. The results should therefore be seen as indications of patterns for further research in samples from different contexts.

Secondly, our participants had all had a YP with a transition meeting at CAMHS, but not all had been directly referred, meaning the participants had different routes to AMHS with more or less coordinated transition, this is a limitation due to heterogeneity in the service provided, but a strength in terms of highlighting some of the issues related to the transition process overall.

Finally, our study only included parents of YPs who had actually begun treatment in AMHS. Therefore, we have not investigated perspectives of parents to YPs who chose to discontinue treatment completely.

We recommend that future studies investigate the experience of the lack of transition for YPs with a treatment need who do not proceed to receive treatment in AMHS.

Conclusion

Parents of YP with AN described many challenges during the transition from CAHMS to AMHS, including inadequate or lack of coordination and information during transition processes, shifts in parental roles both at home and in treatment, and concerns about premature independence and autonomy of the YP. Parents importantly experienced increased anxiety and insecurity as well as worsened AN symptoms in the YP due to abrupt treatment changes or gaps, suggesting the need for future research into concrete interventions that can help provide thorough and overlapping transition process benefitting parents and ultimately patients with AN.

Declarations

Human Ethics and Consent to Participate Declaration

This qualitative project was approved as a sub-study to a larger related research project with the Danish Medical Ethics Board, approval number: H-15012537. All participants gave informed consent. Data was handled in accordance with GDPR law and was approved by the regional data protection agency.

Competing Interest declaration: there were no competing interests for any of the authors involved in the study.

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Authors' Contributions declarations

AB: manuscript responsible and primary writer, secondary analyses, editing and correspondence with journal.

SV: concept, recruitment, data collection, initial analysis.

AS: manuscript writing, editing.

DW: manuscript writing, editing.

AAH: manuscript writing, editing.

MB: manuscript writing, editing.

SHP: manuscript writing, editing.

NM: manuscript writing, editing and supervising.

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