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Transition From Pediatric to Adult Care in Duchenne Muscular Dystrophy: Lived Experiences of Youths and Their Caregivers from the GrowDMD project

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Abstract

Background Duchenne Muscular Dystrophy (DMD) is a rare neuromuscular disease characterized by progressive muscle degeneration leading to severe disability. Therapeutic advances in recent years have significantly increased life expectancy, making it necessary to update clinical management strategies. Consequently, the transition from pediatric to adult care has become a crucial challenge, as DMD care was traditionally centered within pediatric services.

Mehtods This qualitative study, part of the GrowDMD project ("Growing into Adulthood with DMD - Comparing Patient Experiences and Systems to Optimize Care"), explored the experiences of transition of care among youths with DMD and their caregivers in Italy, Germany, and Canada.

Between 2022 and 2023, semi-structured interviews were conducted. The data were analyzed using thematic analysis with NVivo, allowing the identification of common and country-specific topics, as well as differences between youths' and caregivers' perspectives.

Results The study included 18 youths with DMD aged 15-25 years and 26 caregivers. Participants consistently reported gaps between pediatric and adult services, fragmentation of adult care, and insufficient information about the transition process that often resulted in emotional distress and relational difficulties for both youths and their caregivers.

Conclusions Overall, the transition to adult care is a complex, multifaceted process requiring a biopsychosocial approach. Structured, coordinated, and multidisciplinary transition pathways are needed, including psychological support and strategies that progressively balance youths' desire for autonomy with their increasing need for assistance. Such pathways are essential to ensure continuity of care and to inform the development of international guidelines adaptable across healthcare systems and applicable to other rare chronic conditions.

Introduction

Duchenne Muscular Dystrophy (DMD) is a rare X-linked neuromuscular disease with an estimated global prevalence of less than 10 cases per 100,000 males [1]. It is characterized by progressive muscle degeneration that ultimately leads to severe disability. Symptoms usually have an onset between three and five years of age, and the disease course follows distinct stages. Early signs include difficulties with gross motor skills, gait abnormalities, frequent falls, and difficulty getting up from the ground [2]. Some people with DMD may also present cognitive, language, or developmental delays, reflecting the multisystemic nature of the disease. Children often experience a temporary improvement in motor abilities until around six years of age, followed by a steady functional decline. By the ages of 10–12 years, most individuals require a wheelchair [2]. As the disease progresses, cardiac and respiratory complications emerge, and many youths with DMD require assisted ventilation by the age of 20–25 years [1, 3].

In recent years, significant therapeutic advances have prolonged the life expectancy of people with DMD, making it necessary to re-evaluate and update global approaches to clinical management. In fact, while in past decades people with DMD were mainly managed within pediatric services due to their limited life expectancy, today one of the main challenges is to ensure a smooth transition from pediatric to adult-centered care. Transition is not merely a transfer of medical records, but a structured, multidisciplinary process tailored to evolving physical, psychological, and social needs [4, 5].

The transition process in rare neuromuscular diseases such as DMD is particularly complex. It requires close coordination across multiple specialties, including neurology, cardiology, pulmonology, physical therapy, rehabilitation, and psychosocial support [6, 7, 8].

This complex process poses challenges not only for healthcare professionals (HCPs) but also for youths and caregivers, who often experience a profound life change during transition [9].

Barriers to successful transition include the tension between the patient's growing desire for independence and their increasing need for assistance, inadequate psychological support, and the emotional difficulty of leaving a familiar pediatric

team, often perceived as well-coordinated. By contrast, adult services are frequently experienced as fragmented and less prepared to meet the multifaceted needs of people with DMD [9]. Additional barriers, such as limited information, poor coordination, and feelings of abandonment, have been consistently highlighted in recent literature [10].

To address these challenges, we launched the GrowDMD project: “Growing into Adulthood with DMD - Comparing Patient Experiences and Systems to Optimize Care”, funded by the European Joint Programme on Rare Diseases 2020 (N°825575). The project is a collaboration between the IRCCS Carlo Besta Neurological Institute Foundation (Italy), the Pediatric Center of the Faculty of Medicine at the University of Freiburg (Germany), the McMaster University’s Ron Joyce Children’s Health Centre (Canada), and the CHU Sainte-Justine: Mother and Child University Hospital of Montreal, together with national patient advocacy organizations: Parent Project APS (Italy), Deutsche Gesellschaft für Muskelkranke e.V. (Germany), and Muscular Dystrophy Canada (Canada).

The GrowDMD project aims to evaluate the lived experiences of individuals with DMD as they transition from pediatric to adult care. Specifically, it seeks to identify both facilitators and barriers to successful transition by exploring the perspectives and unmet needs of people with DMD, caregivers, and HCPs.

Using a mixed-methods design, we compared the experiences of people with DMD across three countries with advanced yet differently organized healthcare systems. This approach allows us to examine both similarities and contrasts across youths, caregivers, and care organizations, and to assess how current transition guidelines are applied in practice.

For the qualitative component, we conducted semi-structured interviews with people with DMD, caregivers, and HCPs to explore their experiences of transition, expectations, and challenges. The interviews explored also interpersonal relationships, environmental enablers and barriers, and the daily activities of young people with DMD. Six months later, we conducted follow-up interviews with HCPs to gather additional insights.

For the quantitative component, we developed a survey that incorporated validated questionnaires for people with DMD and their caregivers. The aim was to capture transition-related experiences, challenges, and expectations. Questionnaires administered to youths included the World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0) [11], the Psychological General Well-Being Index (PGWBI) [12] and the Transition-Q [13], while caregivers completed the Participation and Environment Measure - Children and Youth (PEM-CY) [14].

To complement these data, we organized two focus groups with youths and caregivers to share preliminary results and gather their feedback and reflections.

The goal of the GrowDMD project is to identify barriers and enablers of successful transition, formulate policy recommendations, and improve social participation opportunities for people with DMD. Beyond its immediate scope, the outcomes of this project are expected to provide valuable insights applicable to transition processes in other rare neuromuscular diseases and healthcare contexts.

In this paper, we focus on comparing the findings from semi-structured interviews with young people with DMD and caregivers conducted in the three participating countries.

Methods

This study was conducted within the GrowDMD project, analyzing results from semi-structured interviews to investigate the experience of transition from pediatric to adult care among people with DMD and their caregivers in Germany, Italy, and Canada.

Eligible participants were people with a confirmed diagnosis of DMD, aged 15–25 years, and their primary caregivers. Recruitment took place through specialized clinical centers and local patient advocacy organizations (PAOs).

Interviews were carried out between 2022 and 2023, either face-to-face or remotely (via Webex, Zoom or Microsoft Teams), depending on participants' preferences, distance from the clinics, and health conditions. A semi-structured interview guide was developed based on a systematic review of the literature on transition in DMD [15]. The interviews explored the following main themes: experiences related to care management and the transition of care, environmental barriers and facilitators, interpersonal relationships, and activities of daily living. Although the interviews covered several aspects of participants' lived experiences, the present study adopted a specific analytical focus on reporting and comparing experiences related to the transition of care. The guide was adapted and translated into local languages (English, Italian, French, and German), following cross-cultural validation standards [16] (See supplementary for the full interview guideline). All interviews were audio-recorded with informed consent and transcribed verbatim.

Transcripts were de-identified and stored in secure repositories at the three research sites, with file transfers conducted exclusively through protected channels.

The qualitative analysis was conducted using thematic analysis, following Braun and Clarke's framework [17], adopting a combined deductive-inductive approach to develop the coding system.

In the first phase, the researchers across the three countries familiarized themselves thoroughly with the data by reading all transcripts. This step enabled the team to develop a shared knowledge of the topics and start the analytical reflection that shaped the coding scheme.

The coding process was conducted flexibly, integrating the inductive identification of themes that emerged directly from the transcripts, with a deductive approach focused on key elements relevant to the research questions, the interview guide and previous research on the components of the transition. Then, the international research group discussed the preliminary themes and defined an initial set of core codes. Two researchers per country independently coded the transcript, and discrepancies were discussed until consensus was reached within the international team.

During the coding process, each country was able to incorporate additional country-specific codes whether relevant aspects emerged within their sample.

This approach enabled identification of common themes and cross-national differences, as well as distinctions between patient and caregiver perspectives.

Data were organized and analyzed using qualitative data analysis software Nvivo [18].

This study was approved by the Lombardy 4 Regional Ethics Committee (CET Lombardia 4) on 27 September 2023, by the Ethics Committee of the University of Freiburg (Albert-Ludwigs-Universität) on 26 April 2022 (Reference No. 22-1092_1), and by the Hamilton Integrated Research Ethics Board (#14872 and #16658). The study is a prospective observational study not involving medication, and all procedures were conducted in accordance with ethical standards. All participants (or legal guardians, for minors) gave written informed consent to participate in the study before taking part. Psychological support was made available to participants in case of emotional distress during the interviews.

Results

A total of 18 interviews with young people with DMD aged between 15 and 25 years, and 26 interviews with caregivers were conducted (see Table 1 and Table 2 for the sociodemographic information of the sample). With a specific focus on the transition of care, the qualitative analysis explored key topics, highlighting young people with DMD and caregivers' experiences. Across Italy, Canada, and Germany, common topics emerged: "Changes" from pediatric to adult care, "Information" on transition, "Outlook" such as expectations, feelings and thoughts, "Transition Criteria" and "Transition Goals". Based on this shared coding framework, further topics were identified inductively as the data spontaneously revealed new country-specific topics. In Italy emerged the importance of "Involvement" of families in healthcare", while German and

Canadian interviews reported additional aspects of the transition, including the “Retrospective Evaluation” of the process, and “Transition Policies”.

Country	N	Medium age (standard deviation)	Geography (rural /small town / urban)	Lives alone/ with parents / other options	Education level	Student/employed/unemployed	Pediatric / adult center or specialists
Italy	6	21 (2.9)	4 small town, 2 urban	4 with parents, 1 with brother and assistants, 1 with parents and 3 days/week alone with assistant	4 high school, 1 middle school, 1 university	4 students, 1 employed, 1 unemployed	3 adult center, 2 pediatric center, 1 paediatric center with adult specialists
Germany	7	18.1 (3.9)	NA	5 with parents, 1 with his roommates, 1 “other option”	1 high school, 6 middle school	4 students, 3 unemployed	3 adult center, 4 pediatric center
Canada	5	16.8 (4.4)	2 small town, 3 urban	5 with parents	4 high school, 1 university	1 student, 1 part-time job/university, 3 unemployed	2 adult center, 2 pediatric center, 1 transitioning to adult center
TOT	18						

Table 1. Sociodemographic Characteristics of Youths with DMD; NA: not asked because of data protection

Country	N	Medium age (standard deviation)	Geography (rural / small town / urban)	Living with their son or not	Employed / unemployed	Relationship with the patient
Italy	9	54.9 (4.5)	7 small town, 2 urban	8 with their son, 1 does not live with the son	7 employed, 2 unemployed	5 mothers, 4 fathers
Germany	8	48.6 (8.7)	NA	6 with their son, 2 do not live with the son	8 employed	5 mothers, 1 father, 1 sister and 1 stepfather
Canada	9	52.4 (4.3)	2 rural, 1 small town, 6 urban	9 with their son	8 employed, 1 “other”	5 mothers, 4 fathers
TOT	26					

Table 2. Sociodemographic Characteristics of Caregivers; NA: not asked because of data protection

Changes

Young people with DMD and their caregivers reported significant challenges faced during the transition from pediatric to adult care, including changes in care settings, relationships with HCPs, appointment scheduling, and in the management of the condition in daily life.

Continuity of care

A primary issue concerned the continuity of care between pediatric and adult services. In pediatric centers, youths with DMD and caregivers often received integrated and tailored care, with multiple clinical appointments taking place in the same location and on the same day. This continuity was frequently disrupted upon entering adult care.

In Italy the transition often represents a point of discontinuity, requiring relocation to new care settings and the establishment of new therapeutic relationships. In Germany, the separation from the pediatric team was described as distressing for young adults with DMD, as these HCPs had long served as a trusted reference point for families. Similarly, in Canada, the transition was often experienced as abrupt: *"Here in Quebec… for children with major disabilities… the government gives you so much, and then at 18 years old that just stops"* (Caregiver, Canada).

Fragmentation of adult healthcare services

In all three countries, adult care was perceived as fragmented, requiring young people with DMD and their caregivers to navigate multiple clinics and specialists with limited coordination among them: *"You have to go one day for the neurological appointment, another day for the pulmonary check… everything is somewhat disconnected"* (Caregiver, Italy). This fragmentation increased the burden on families, who had to manage appointments, communication, and administrative tasks, further complicated by regional and institutional differences. Caregivers also reported longer intervals between appointments and bureaucratic barriers: *"It has already been a year, and they still have not contacted us"* (Caregiver, Italy).

In Germany, young people and caregivers faced difficulties finding adult HCPs experienced in DMD. In Canada, geographic factors added further challenges: urban areas generally offered more structured care pathways, whereas young people in rural regions often needed to travel to multiple clinics, frequently without financial support.

Participants in all three countries emphasized the need for a single care coordinator to organize appointments and reduce fragmentation.

Emotional and relational challenges

The transition involved not only organizational changes but also emotional and relational challenges. Across all three countries, participants reported a loss of trust in care management after entering the adult care setting, describing it as less engaging and more bureaucratic: "*I'm starting to think that nobody cares about us. Nobody cares about my son*" (Caregiver, Canada). This contributes to feelings of abandonment, uncertainty, loneliness, and detachment: *"I miss the pediatrician… the relationship feels different now"* (Patient, Italy).

Information

Across all three countries young people with DMD and caregivers reported substantial variability in the clarity, comprehensiveness, and timing of information regarding the transition from pediatric to adult care.

In Italy, a recurring theme was the lack of clear and timely communication about the transition to adult care. Many participants described facing significant changes without adequate information, leading to feelings of uncertainty and unpreparedness: *"We found ourselves in the middle of it… we had no sense beforehand of what would happen"* (Caregiver, Italy). In some cases, information was provided through structured meetings, such as joint appointments with pediatric and adult specialists or anticipatory discussions with HCPs. However, many participants reported that information was fragmented or communicated only verbally.

In Canada, information about the transition to adult care was also described as inconsistent and sometimes inaccurate. Discussions about disease progression were often limited, partly because some caregivers and young people with DMD preferred to focus their interactions with HCPs on current challenges rather than the future: *"I guess what I'm trying to say is not thinking too much about the future is one of the ways in which we get through the day of today"* (Caregiver, Canada).

In Germany, information was similarly heterogeneous, ranging from a single conversation to more structured information events for families. The timing of transition-related discussions varied, from six months before the transfer to adult care to multiple appointments over an extended period: *"It was actually the first time I started thinking about it or even considered the fact that at some point the care at the pediatric clinic could come to an end when I read about it in one of the brochures we get from our PAO."* (Caregiver, Germany).

Networking with other families emerged as an essential source of both information and practical guidance across all three countries.

Outlook

Young people with DMD and their caregivers expressed a range of emotions and reflections regarding both the present and the future.

In Italy, participants described feelings of anxiety, fear of the unknown, and psychological strain associated with the transition from pediatric to adult care. Despite these concerns, several participants emphasized the importance of focusing on the present rather than becoming overwhelmed by future uncertainties.

The psychological burden associated with the disease was frequently mentioned, with both young people with DMD and caregivers expressing a clear need for more structured psychological support. Caregivers also noted that discrepancies between youths' chronological age and physical appearance sometimes led HCPs to treat them as younger children, thereby undermining their sense of maturity: *"My son is 17, but he looks more like a 13-year-old. People still treat him as a child, and this also happens in medical settings"* (Caregiver, Italy).

In Canada, caregivers emphasized their desire to promote their children's autonomy while acknowledging ongoing concerns about continued involvement in care: *"We want him to live independently in terms of support from us"* (Caregiver, Canada).

In Germany, caregivers similarly questioned whether young people with DMD were sufficiently mature to assume responsibility for their own care, reflecting the broader tension between providing necessary support and fostering independence: *"As a concerned mother, I wonder whether, at 18, he's really mature enough to take care of all that"* (Caregiver, Germany). Caregivers also highlighted the importance of preserving autonomy for as long as possible, emphasizing young people's personal abilities rather than disease-related limitations.

Transition Criteria / Characteristics

Across the three countries, the typical transition age was around 18 years. Pediatric HCPs often recommended follow-up within adult care centers, and in some cases, joint consultations involving both pediatric and adult HCPs were arranged. These joint sessions were perceived as valuable for ensuring continuity of care and for familiarizing young people with the adult healthcare system prior to full transfer.

Transition goals

In Germany, young people with DMD and their caregivers reported that an effective transition should aim to identify key contact persons within adult care, establish therapeutic relationships with adult healthcare professionals, and ensure continuity and coordination within an often-fragmented adult care system.

In Italy and Canada, participants expressed similar priorities, emphasizing the need for a coordinated healthcare approach that minimizes disruption to daily life. They stressed that transition should focus primarily on supporting people with DMD overall quality of life rather than concentrating exclusively on medical aspects: *"The main goal is to have the best possible day-to-day life and future and not focusing on medical side of life when this is not required"* (Caregiver, Canada).

Involvement in the transition process

In Italy, many young people with DMD and caregivers reported a high level of involvement in clinical decision-making, describing open dialogue and collaboration with HCPs. Participants appreciated receiving information about treatment options and clinical trials and valued opportunities to ask questions: *"They always ask us, they involve us"* (Caregiver, Italy); *"Since I turned 18, the doctor speaks directly with me"* (Patient, Italy). However, in some cases, involvement was more limited, with young people or caregivers delegating decision-making to HCPs while remaining informed: *"If they tell me I need a treatment, I just do it"* (Patient, Italy).

Retrospective evaluation of the transition process

In both Germany and Canada, many participants who had already undergone the transition reported that limited attention had been given to transition planning. They noted that they had initially assumed adult care would mirror the structure and coordination characteristic of pediatric services: *"The fact that the doctors are so dispersed and that there are no longer any coherent centers… that hit me when the transition had already been more or less completed"* (Caregiver, Germany).

Across both countries, participants emphasized the absence of holistic, family-centered care pathways and expressed a strong desire for clearer and more gradual processes to support them throughout the transition: *"Well, I think I'd have liked to know if there was a clear plan for what comes next"* (Caregiver, Germany). *"That is something which is required-a multidisciplinary approach for these rare diseases, a multidisciplinary team and approach that is required… We were worried"* (Caregiver, Canada).

Transition Policies

In Germany, the transition process was facilitated when pediatric and adult clinics were co-located within the same university hospital. This proximity helped the continuity of care and enabled closer communication between pediatric and adult specialists.

In Canada, transition policies varied across institutions. Some young people with DMD continued to attend pediatric clinics for routine monitoring, while receiving treatment within adult care services: *"He still goes to pediatrics, but not for treatment. Just to check up"* (Caregiver, Canada).

Discussion

This qualitative study conducted within the GrowDMD project explored the experiences of young people with DMD and their caregivers during the transition from pediatric to adult healthcare in Italy, Germany, and Canada.

Five overarching topics emerged across all countries: "Changes", "Information", "Outlook" "Transition Criteria," and "Transition Goals". Additional country-specific topics included "Involvement" (Italy); "Retrospective Evaluation" and "Transition Policies" (Germany and Canada).

It is important to note that the country-specific topics do not indicate issues that uniquely concern certain countries or that are irrelevant in the others. The presence of a topic in only one country should not be interpreted as its absence elsewhere; rather, it reflects what emerged from the interviews, which represent only a partial snapshot of a more complex reality.

Based on the coding scheme, the following areas of tension can be identified across all three countries.

Autonomy vs. independence

A recurring theme was the tension between the emerging wish for autonomy and the increasing need for support and dependence during adolescence. Nowadays people with DMD are witnessing the adult life chapter, introducing new aspirations such as independent living, employment, romantic relationships, and new psychosocial challenges. It seems crucial to address these questions and help young adults live the life they aspire to. At present there aren't appropriate support structures to enable youth to exercise autonomy in ways that are important to them.

Discontinuity in care

Another theme was the discontinuity between pediatric and adult healthcare system. The shift from the familiar environment of pediatric services to the more fragmented and bureaucratic adult system often creates feelings of loss and detachment. Both, young people with DMD and caregivers, described the pediatric team as a trusted reference point, while adult services were perceived as less coordinated and more impersonal. These experiences echo previous research in DMD and other chronic conditions, where the transition to adult services has been associated with uncertainty, discontinuity, and emotional strain [15].

Transition is not only medical

In the past years the research and clinical practice tried to find the best way to "transfer" the youths from the pediatric to the adult healthcare services, but it's crucial to find a way to a successful "transition" instead. While "transfer" is a procedural shift between services, "transition" represents *"a passage from one life phase, physical condition, or social role to another, resulting in a temporary disconnectedness of the normal way of living, which demands an adjustment of the person and the environment"* [19]. Recent findings suggest that a successful transition is a broader process that requires attention to both medical and psycho-social and environmental aspects [8, 15].

In this context, psychological support is an issue that deserves greater attention for young people with DMD and their caregivers. In interviews across countries, the issue of receiving psychological support at all stages was raised, and the desire to receive such support also emerged.

Caregivers as care coordinators

Caregivers play a central role throughout the whole process in the three countries. They often become informal care coordinators, and they are key advocates for their children, ensuring continuity and communication across services. This responsibility often comes at a cost in terms of emotional burden and exhaustion. As previously reported, the balance between supporting autonomy and maintaining necessary assistance for youth with DMD represents a recurring tension across all countries. Many caregivers expressed ambivalence about their level of involvement: while they wish to foster independence, they also struggle with concerns about their child's readiness to manage care autonomously. This tension between promoting autonomy and providing support has been observed across different chronic conditions such as muscular dystrophies, cerebral palsy, and congenital heart disease [20, 21, 22], underscoring the need for transition models that explicitly define caregivers' roles, as both active and supported partners of the transition process.

These differences suggest that, although some specifics vary between countries, fundamental needs such as continuity, information, coordination, and emotional support are universal.

These results might suggest the following practical implications (Fig. 1). According to our data, there seems to be a clear need for specific training of adult healthcare professionals to increase their competence in managing rare neuromuscular disease like DMD and to enhance their sensitivity to the psychosocial aspects of transition (1). Establishing a dedicated care coordinator could help reduce fragmentation and improve communication between services (2). Psychological support should be systematically offered to both young people and families, not only at the moment of transition but throughout adolescence and early adulthood (3). Furthermore, building interprofessional and inter-institutional networks that connect pediatric and adult services supported by shared guidelines, protocols, and communication tools could foster greater consistency and equity across regions (4). Finally, transition planning should go beyond medical management, addressing education, employment, and independent living to promote full participation and quality of life in adulthood (5).

Some limitations should be acknowledged. In the present study, the sample size was relatively small, which limits generalizability, although the qualitative study design aims to capture depth and diversity of experiences, rather than representativeness. Moreover, this study included only the perspectives of young people with DMD and their caregivers; healthcare professionals' views, which are being explored in other components of the wider GrowDMD project, would add further insights into systemic barriers and facilitators from the healthcare management point of view. Integrating these

qualitative findings with quantitative data within the project's mixed-methods framework will reduce the qualitative data limitations and provide a more comprehensive understanding of transition dynamics.

Conclusion

Despite advances in medical care that have extended life expectancy, the transition from pediatric to adult care for youths with DMD is still a challenging phase. The GrowDMD project aimed to evaluate the experiences of youths with DMD and their caregivers during this phase. The transition emerged as a multi-faceted process, characterized by issues in care continuity, fragmented services, limited support, and emotional strain, along with difficulties in managing the balance between independence and ongoing dependence. These findings highlight the need for a biopsychosocial approach, integrating clinical with psychological and social support to ensure continuity of care and quality of life. In this context, the development of internationally transition guidelines, adaptable to the healthcare systems of different countries and generalizable to other rare chronic diseases, represents a key step toward supporting youths with DMD and their families throughout the transition process.

Strengthening collaboration between pediatric and adult services and promoting tailored transition pathways is crucial to address these challenges and support youths with DMD and their caregivers throughout this period.

Local patient advocacy organizations (PAOs) play a crucial role in this process, representing a fundamental partner throughout the entire transition pathway by acting as facilitators, fostering networking among families and services, and often contributing to make the overall experience smoother and more supportive.

Future research should focus on actively translating this knowledge into practice, developing and validating updated standardized tools to evaluate transition readiness for youths with DMD and transition quality. Such instruments could guide clinical practice, support individualized planning, and facilitate international comparison. By addressing both organizational and emotional aspects, future interventions can contribute to building more coordinated, structured, sustainable, and personalized transition programmes for young people with DMD and their families, supporting autonomy, continuity and overall well-being.

Declarations

Author contributions

Conceptualization: All authors worked on the conceptualization of the study; Methodology: All authors designed the methodology; Formal analysis and investigation: An.M., Al.M., G.T., E.G., B.B., S.F., J.W., K.P., A.S.; Writing - original draft preparation: An.M., Al.M., G.T.; Writing - review and editing: All authors have read and agreed to the published version of the manuscript; Funding acquisition: T.L.; Resources: N/A; Supervision: T.L., I.M., M.L., N.N., O.K.d.C..

Fundings and Competing interests

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Availability of data and materials

The datasets used and analysed during the current study are available from the corresponding author on reasonable request.

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Figures

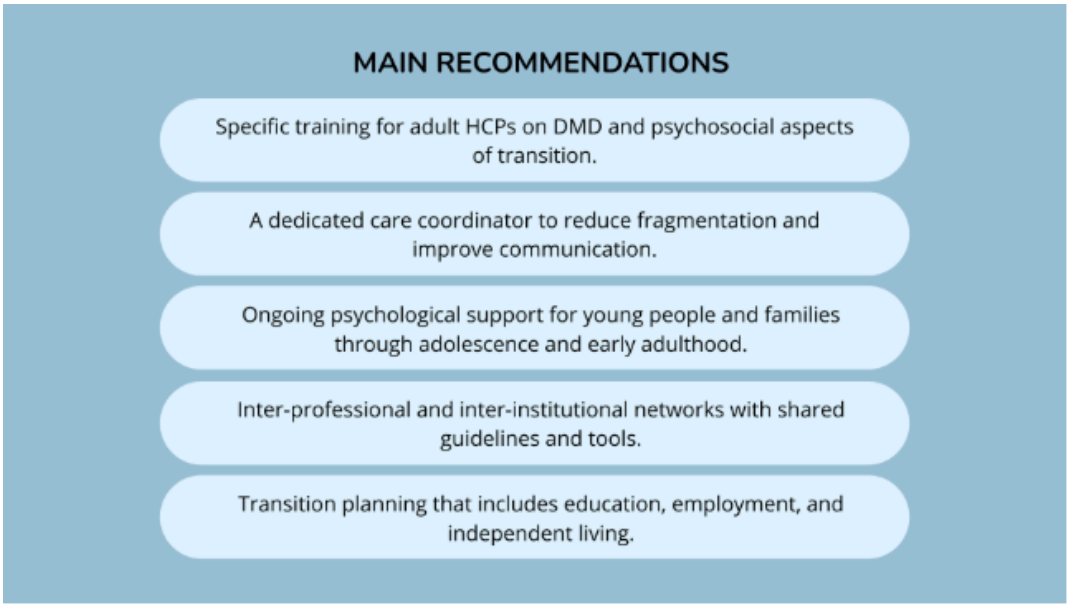


Figure 1

Main Recommendations