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Research Article

Perception of the Transition from Pediatric to Adult Care in Patients with Epilepsy and Their Comorbidities: Experience Report from a Brazilian University Center

Carvalho BM[1]*, Hernandez JG[1], Costa AKB[1], Ribeiro AS[1], Rocha DF[1], Brito HAR[1], Alessi R[2], Wajnsztejn R[3] and Bezerra DF[4]

[1]Pediatric Neurology course at ABC Faculty of Medicine University Center, Santo André, São Paulo, Brazil

[2]Coordinator of the Adult Epilepsy Servic at ABC Faculty of Medicine University Center, Santo André, São Paulo, Brazil

[3]Coordinator of the Pediatric Neurology Service at ABC Faculty of Medicine University Center, Santo André, São Paulo, Brazil

[4]Coordinator of the Pediatric Epilepsy and Transition Service at ABC Faculty of Medicine University Center, Santo André, São Paulo, Brazil

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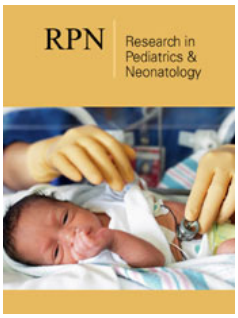

***Corresponding author:** Carvalho BM, Pediatric Neurology course at ABC Faculty of Medicine University Center, Santo André, São Paulo, Brazil

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Abstract

Introduction: The transition from pediatric to adult care in patients with epilepsy is a critical and challenging process, given the significant impact of the disease on the patients' physical, psychological, and cognitive development. Epilepsy, in addition to being a chronic neurological condition, is often associated with comorbidities that complicate disease management, particularly during adolescence.

Objective: This study aims to identify and understand the challenges faced by adolescents with epilepsy during the transition from pediatric to adult care, assessing their comorbidities, autonomy, and perceptions, as well as those of their caregivers.

Methods: Between 2019 and 2023, structured and validated questionnaires were administered to 31 adolescents aged 12 to 18 years diagnosed with epilepsy at the ABC Faculty of Medicine University Center, in Santo André, São Paulo, Brazil. The questionnaire included 55 questions and was administered to both patients and their caregivers, focusing on disease understanding, promotion of autonomy, and analysis of psychosocial influences.

Results: The results indicated a high prevalence of psychiatric and behavioral comorbidities, such as anxiety (46%), ADHD (33%), depression (6%), and OCD (3%). It was also observed that 53% of adolescents did not fully understand their health condition, and 45% were not actively involved in their medical care. Additionally, 87% of patients did not have a career plan, reflecting the significant impact of epilepsy and its comorbidities on their future perspectives.

Discussion: The discussion highlights the complexity of the transition process and the need for a multidisciplinary and personalized approach, including education about the disease, psychosocial interventions, and promotion of autonomy. The lack of patient understanding and engagement, combined with the high prevalence of comorbidities, underscores the need for policies and guidelines that integrate these aspects to ensure a successful transition.

Conclusion: The study concludes that the transition from pediatric to adult care in patients with epilepsy requires careful planning and continuous support to improve health outcomes and long-term quality of life. An integrated approach that prioritizes the patient's overall well-being is crucial to ensure that these adolescents achieve full autonomy and a successful transition to adult life.

Introduction

Epilepsy is a chronic and stigmatizing disease, belonging to a heterogeneous group of neurological conditions, characterized by a persistent predisposition to epileptic seizures. It

is estimated that 50% of epilepsy cases begin in childhood and adolescence, profoundly affecting both children and adults. This condition, in addition to directly impacting neurological health, is surrounded by myths and beliefs that hinder patients' normal lives, exacerbating the associated stigma.

In the pediatric population, any disease can represent a significant risk to physical, psychological, and cognitive development. However, epilepsy, due to its neurological impact, seems to affect children more deeply than other chronic diseases, with psychosocial consequences that may limit quality of life more than the epileptic seizures themselves [1].

The transition from pediatric to adult care

The transition of care, defined as the planned process of transferring patients with childhood-onset epilepsy to adult care, is a critical milestone in disease management [1]. This process involves transferring the follow-up from a pediatric neurologist to an adult neurologist. A failed transition can result in loss of follow up, poor treatment adherence, and adverse outcomes, including disease relapse and, in extreme cases, death. Each patient requires an individualized approach during this transition, from childhood to adult care [2].

Objective

This study aims to identify and understand the challenges faced by patients with epilepsy during the transition from pediatric to adult care, assessing their comorbidities, autonomy, and collecting their views and opinions on the subject, as well as those of their caregivers.

Method

Between 2019 and 2023, a cross-sectional study was conducted with 31 adolescents diagnosed with epilepsy, aged between 10 and 18 years, at the ABC Faculty of Medicine University Center, in Santo André, São Paulo, Brazil. The study aimed to investigate psychiatric comorbidities and psychosocial factors that influence the quality of life of these patients and their caregivers.

Participants were selected based on specific inclusion and exclusion criteria. To be included, participants needed to be between 10 and 18 years old and have a confirmed diagnosis of epilepsy according to the criteria of the International League Against Epilepsy (ILAE). Additionally, the diagnosis must have been made at least six months prior to ensure there had been sufficient time for the development of potential psychiatric comorbidities. Only those with complete clinical records, which included comprehensive information on mental health, behavior, cognitive development, and medical history, were eligible for the study. Ethical consent was obtained from the parents or legal guardians, with assent requested from the adolescents when appropriate.

Exclusion criteria were also rigorously applied. Patients with an unclear or inconclusive epilepsy diagnosis were excluded, as well as those with severe neurological conditions such as moderate to severe intellectual disabilities, degenerative diseases, or significant genetic anomalies, which could confound the assessment of comorbidities. Patients with serious medical conditions, including advanced cancer or renal failure, were not included in the study. Additionally, individuals with incomplete medical records or insufficient clinical follow-up were excluded from the research.

Data collection was conducted through structured and validated questionnaires containing 55 questions, administered to both the patients and their caregivers. The questionnaires were designed to gather information regarding mental health, behavior, social and economic factors, and environmental influences that might impact the quality of life.

The diagnosis of psychiatric comorbidities, such as anxiety, depression, and attention-deficit hyperactivity disorder (ADHD), was performed by pediatric neurologists using the criteria outlined in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). This clinical diagnosis was supported by interviews with patients and their caregivers.

In addition to data collection, a psychosocial intervention was implemented. This In addition to data collection, a psychosocial intervention was implemented. This intervention focused on educating both patients and caregivers about epilepsy, including its symptoms and treatment options, with the goal of promoting better disease management. The intervention also encouraged the development of autonomy and self-care among the adolescents, helping them acquire the skills needed to manage their condition independently where possible. Furthermore, the study included an analysis of psychosocial factors, assessing how environmental, social, and economic circumstances affected both the development and the quality of life of the patients and their caregivers.

Result

Of the 31 patients who responded to the questionnaire, all met the inclusion and exclusion criteria. A significant clinical heterogeneity was observed, with 63% of patients and caregivers not understanding the type of epilepsy. The most common comorbidities were anxiety (46%), ADHD (33%), depression (6%), and OCD (3%). Regarding adolescents' understanding of their health condition, 53% reported not fully understanding their condition. Additionally, 45% of adolescents do not actively participate in their health care, and 87% do not have a career plan and cannot assess the impact of the disease on their future (Table 1) (Figure 1) (Table 2).

Table 1: Prevalence of epilepsy according to age group and number of subjects in each group.

Age group	Prevalence	N
10 a 12 years old	129	4
13 a 15 years old	484	15
≥16 a 18 years old	387	12
Total	1.000	31
Prevalence per 1000 population		

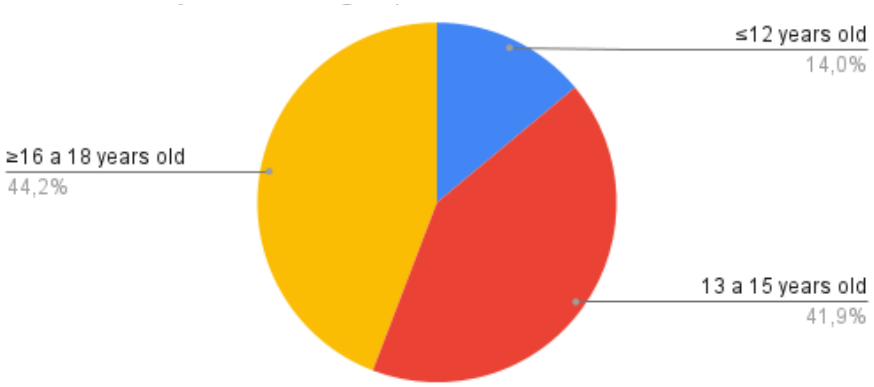

Figure 1: Prevalent of epilepsy according to age group and number of subject in each group.

Table 2: Incidence of comorbidities in the pediatric population undergoing epilepsy transition.

Comorbidity	Frequency (%)	N
Anxiety	46	14
ADHD	33	10
Depression	6	2
TOC	3	1
Others	12	4
Total	100	31

Discussion

The results of this study underscore the complexity of the transition process from pediatric to adult care in patients with epilepsy, particularly when considering the high prevalence of associated comorbidities [3]. Epilepsy, in addition to being a chronic neurological condition, is often accompanied by psychiatric and behavioral disorders that further complicate disease management, especially during the critical period of adolescence.

The most common comorbidities identified in this study, such as anxiety (46%), ADHD (33%), depression (6%), and OCD (3%), reveal a significant psychosocial burden among adolescents with epilepsy. These conditions not only directly affect patients' quality of life but also interfere with treatment adherence, self-care, and the ability to transition to independent and functional adult life (Figure 2).

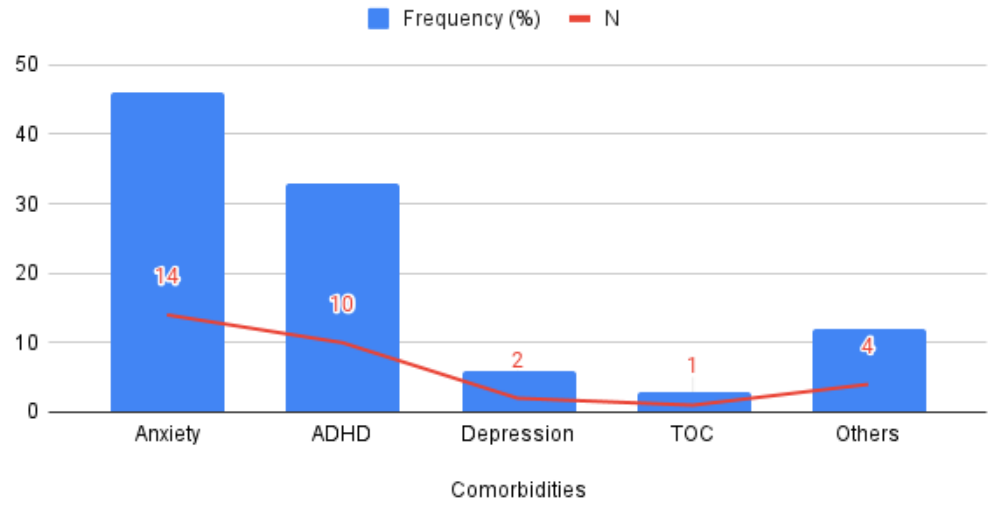

Figure 2: Incidence of comorbidities in the pediatric population undergoing epilepsy transition.

Anxiety, which was the most prevalent comorbidity in our study at 46%, can be both a consequence of epileptic seizures and a factor that exacerbates them. Constant worry about the occurrence of seizures, social stigma, and lack of understanding about the disease contribute to high levels of stress and anxiety in patients. These factors can lead to a vicious cycle, where increased anxiety worsens seizure control and, in turn, seizures increase anxiety, creating a clinically challenging scenario. Adolescents with epilepsy often grapple with the fear of seizures occurring unexpectedly, which can significantly impact their daily activities and social interactions, further compounding their anxiety.

The literature underscores the high prevalence of anxiety in this population. For instance, studies indicate that the prevalence of anxiety disorders in patients with refractory partial epilepsy is

approximately 19% [3]. This statistic highlights that a significant proportion of individuals with epilepsy, particularly those whose seizures are not well controlled by medication, experience anxiety. Additionally, anxiety disorders are commonly found alongside mood disorders in epilepsy patients. Those with comorbid anxiety and major depressive disorder (MDD) or subsyndromal depressive episodes (SSDE) tend to have a markedly worse quality of life compared to individuals with either anxiety or depressive disorders alone. This suggests that the combination of anxiety with mood disorders exacerbates the negative impact on the patient's overall well-being, leading to more severe functional and emotional challenges [3,4].

Our findings of a 46% prevalence rate of anxiety among adolescents with epilepsy align with the literature, emphasizing the critical need for comprehensive mental health evaluations in this population. The high incidence of anxiety in our study indicates that these patients are at significant risk of experiencing heightened emotional distress, which can interfere with both seizure management and overall quality of life. Addressing anxiety through targeted interventions, such as cognitive-behavioral therapy and other supportive measures, could be crucial in breaking the cycle of anxiety and seizures, ultimately improving both psychological and epilepsy-related outcomes [3,4].

ADHD, present in 33% of patients in our sample, adds an additional layer of challenge, particularly regarding treatment adherence and the ability to follow care plans. Adolescents with ADHD may struggle with medication adherence, active participation in consultations, and understanding the implications of their health condition. Moreover, ADHD can contribute to academic and social difficulties, potentially exacerbating the negative impact of epilepsy on the patient's life. These patients often face difficulties in focusing, organizing tasks, and managing time, which can lead to missed doses of epilepsy medications and incomplete follow-up of care plans, thereby increasing the risk of seizures and poor disease control.

The literature supports this association, as evidenced by Wang's findings, which indicate that the prevalence of comorbid ADHD is significantly higher in children with epilepsy (24.76%) compared to controls (5.17%). The inattentive subtype (ADHD-I) was the most prevalent, affecting 14.1% of children with epilepsy. Wang also noted that ADHD in children with epilepsy is associated with younger age, early first onset of seizures, and a higher frequency of epileptic episodes. These factors suggest that the neurological impact of early and frequent seizures may exacerbate the cognitive and behavioral challenges linked to ADHD, making it more difficult for affected children to manage both conditions simultaneously.

This comorbidity, especially prevalent in younger patients, adds complexity to the clinical management of epilepsy, as ADHD-related inattention and hyperactivity can impair the adolescent's ability to engage in treatment regimens and understand the consequences of irregular medication use. Furthermore, the presence of ADHD in children with epilepsy is likely to lead to additional academic and social difficulties, compounding the stress and functional limitations already imposed by epilepsy. Thus, the dual burden of epilepsy and ADHD requires a comprehensive, multidisciplinary approach to care, focusing not only on seizure control but also on addressing the cognitive and behavioral challenges associated with ADHD.

Depression, although less prevalent (6%) in our study, must be carefully monitored as it can have devastating consequences if left untreated. Depression in adolescents with epilepsy may be underdiagnosed due to the overlap of symptoms with epilepsy and its medications. Common side effects of antiepileptic drugs, such as fatigue, mood swings, and cognitive impairment, can mask or be mistaken for depressive symptoms, making accurate diagnosis challenging [5]. The presence of depression can lead to a lack of motivation for self-care, increased suicidal ideation, and, in extreme cases, may worsen the prognosis of epilepsy by negatively affecting adherence to treatment plans and increasing seizure frequency [6].

The literature highlights the significant prevalence of depression, especially among patients with drug-refractory epilepsy. In these populations, depression rates can reach as high as 50%, a stark contrast to the approximately 10% observed in patients whose seizures are controlled [3,6]. This dramatic increase suggests that the inability to manage seizures effectively contributes to emotional distress and depression, further complicating the overall treatment of the patient. Depression is reported to be 3 to 10 times more common in patients with drug-resistant epilepsy compared to the general population, emphasizing the profound mental health burden carried by those with poorly controlled seizures.

The high incidence of depression in drug-refractory epilepsy may stem from the chronic stress of living with uncontrolled seizures, the social isolation that can accompany the condition, and the frustration of not finding effective treatment. This combination can severely impact the quality of life, exacerbating both the physical and psychological challenges these patients face. Consequently, the management of depression in adolescents with epilepsy should be prioritized, as addressing their mental health needs is crucial not only for improving emotional well-being but also for enhancing treatment adherence and overall disease outcomes [3,6].

OCD, identified in 3% of patients, is another comorbidity that can complicate epilepsy management. Obsessive-compulsive disorders can lead to repetitive behaviors and rituals that interfere with the treatment routine and may create additional obstacles to a successful transition to adult care. These compulsions and obsessions can exacerbate stress and anxiety, potentially complicating both the management of epilepsy and the adherence to prescribed treatment regimens.

The literature suggests that obsessive-compulsive symptoms (OCS) can be quite prevalent in children and adolescents with epilepsy, often emerging soon after the onset of the condition [7]. Although specific prevalence rates for comorbid OCD in epilepsy patients are not widely documented, interictal obsessive-compulsive symptoms have been observed in this population. This indicates that OCD may be a common issue among young patients

with epilepsy, affecting their ability to manage both their condition and their daily lives effectively.

The lack of detailed prevalence data on OCD specifically in patients with epilepsy means that our findings contribute valuable insights into this area. Identifying OCD in 3% of our patient population highlights the importance of considering this comorbidity in the management of epilepsy. Obsessive-compulsive behaviors can complicate adherence to treatment plans and disrupt the overall management of epilepsy, necessitating a multidisciplinary approach to address both the neurological and psychological aspects of the condition. Further research into the prevalence and impact of OCD in epilepsy patients is needed to better understand this relationship and to develop targeted interventions that can improve overall treatment outcomes and quality of life [7].

One of the most concerning findings was that 53% of adolescents do not adequately understand their health condition, and 45% do not actively participate in their health care. This low level of engagement is worrisome because the transition to adult care requires the patient to take greater responsibility for managing their condition. Lack of understanding and participation can result in poor treatment adherence, discontinuity of care, and worsening health outcomes.

Furthermore, the absence of a career plan in 87% of patients reflects the significant impact that epilepsy and its comorbidities have on adolescents' future perspectives. Uncertainty about the disease's impact on adult life, combined with the limitations imposed by comorbidities, can lead to feelings of helplessness and lack of direction, which need to be addressed during the transition process.

These results highlight the need for a multidisciplinary and personalized approach to care transition. The simple transfer of responsibility from a pediatric neurologist to an adult neurologist is not enough; continuous support is required, including education, psychological guidance, and interventions that promote autonomy and self-care. Health teams should work closely with patients and their families to ensure that all aspects of mental and physical health are addressed, minimizing the risk of negative outcomes during and after the transition [8,9].

In summary, the high prevalence of psychiatric and behavioral comorbidities in adolescents with epilepsy highlights the importance of careful planning and an integrated approach to care transition. By focusing on the early identification and management of these comorbidities, we can significantly improve health outcomes and facilitate a smoother transition to adult care, contributing to better long-term quality of life for these patients [9].

Conclusion

The transition from pediatric to adult care in patients with epilepsy is a complex and multifaceted process that involves much more than the simple transfer of medical care. When well-planned and executed, this process can significantly determine the success of epilepsy management in adult life, affecting not only seizure control but also the quality of life and autonomy of patients.

Our study reveals that although epilepsy is a chronic neurological condition common in childhood, its psychosocial comorbidities and impact on patients' cognitive, physical, and emotional development are often underestimated during the transition. The high prevalence of comorbidities such as anxiety, ADHD, depression, and obsessive compulsive disorder among adolescents with epilepsy highlights the need for a more holistic and integrated approach that goes beyond seizure control.

Furthermore, data show that a significant number of adolescents do not fully understand their health condition or actively participate in medical care. This not only limits their ability for self-care and disease management but also affects their future career and personal life prospects. The lack of career planning among these adolescents indicates that epilepsy and its comorbidities can have a lasting and limiting impact on their lives, compromising their ability to achieve full autonomy and social integration.

Therefore, the transition from pediatric to adult care should be seen as a critical opportunity to intervene early and effectively, ensuring that adolescents with epilepsy and their families are well informed, prepared, and supported throughout the process. This includes not only education about the condition and treatment but also the development of self-care skills, promotion of autonomy, and psychological support to cope with comorbidities and the stigma associated with epilepsy.

The success of the transition also depends on collaboration between healthcare professionals, patients, and their families. It is essential that pediatric and adult neurologists, psychologists, social workers, and other professionals involved in the care of these patients work together to create a personalized transition plan that takes into account the individual needs of each patient. The integration of psychosocial and educational support services can help mitigate the adverse effects of comorbidities and improve long-term outcomes.

Finally, the findings of this study suggest the need for more comprehensive policies and guidelines for the transition of care in patients with epilepsy. These guidelines should include clear recommendations on the timing and strategies for transition, as well as the integration of psychosocial care into the treatment plan. By investing in the effective transition of these patients, we can improve not only epilepsy control but also the overall development and quality of life of adolescents as they become adults.

This focus, which prioritizes the patient's overall well-being, can be crucial in reducing health disparities, promoting autonomy, and ensuring that adolescents with epilepsy reach their full potential as adults. It is our responsibility as healthcare professionals to ensure that this transition is conducted in a way that provides the best possible outcomes, both medical and psychosocial, for this vulnerable population.

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