PSYCHOSOCIAL NEEDS OF YOUNG PEOPLE WITH EPILEPSY: ILLNESS EXPERIENCE AND TRANSITION FROM PAEDIATRIC TO ADULT HEALTHCARE

Dissertação apresentada à Universidade Católica Portuguesa para obtenção do grau de mestre em Psicologia do Bem-estar e Promoção da Saúde

Por

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Faculdade de Ciências Humanas

Setembro 2023

UNIVERSIDADE CATÓLICA PORTUGUESA

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Sob orientação de Professora Bárbara Nazaré e Professora Teresa Mendes

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Resumo

A relationship entre doença mental e epilepsia tem sido amplamente estudada, juntamente com o reconhecimento de que o momento de transição dos cuidados de saúde pediátricos para os cuidados de saúde de adultos é um ponto crítico na vida das pessoas com epilepsia. Assumindo uma abordagem qualitativa com um desenho exploratório, os objetivos deste estudo é compreender a experiência de doença de jovens adultos com epilepsia antes e durante a transição dos cuidados de saúde. Embora existam pesquisas substanciais sobre as necessidades desta população, faltam investigações qualitativas para caracterizar as suas experiências e programas de intervenção para atender às suas necessidades psicossociais. O estudo incluiu seis participantes com epilepsia (três mulheres e três homens) que atualmente recebem cuidados de saúde para adultos em Portugal. Cinco deles fizeram a transição dos cuidados de saúde pediátricos para os de adultos. Os participantes foram recrutados boca a boca e posteriormente entrevistados remotamente para realizar uma análise temática. Os resultados reforçaram a investigação existente relativa às necessidades psicossociais dos adolescentes com epilepsia durante a sua transição.

Palavras Chave: Epilepsia, Jovens Adultos, Adolescentes, Transição de Cuidados de Saúde, Experiência de Doença, Necessidades Psicossociais, Experiência de Transição de Cuidados de Saúde.

Abstract

The relationship between mental illness and epilepsy has been widely studied, along with the recognition that the moment of transition from paediatric healthcare to adult healthcare is a critical point in the lives of people with epilepsy. Taking a qualitative approach with an exploratory design, the objectives of this study are to understand the illness experience of young adults with epilepsy before and during their healthcare transition as there is a lack of qualitative investigations to characterize their experiences and intervention programs to address their psychosocial needs. Although there is substantial research on the needs of this population,. The study included six participants with epilepsy (three women and three men) who are currently receiving adult healthcare in Portugal. Five of them transitioned from paediatric to adult healthcare. Participants were recruited through word of mouth and subsequently interviewed remotely to conduct a thematic analysis. The results reinforced existing research pertaining to the psychosocial needs of young adults with a retrospective look into their transition experience.

Keywords: Epilepsy, Young Adults, Adolescents, Healthcare Transition, Illness Experience, Psychosocial Needs, Healthcare Transition Experience,

Introduction

Over time, there have been numerous investigations on the impact of living with chronic illnesses on mental health and well-being. It is well known within the scientific community that physical well-being highly correlates with psychological well-being. Additionally, there are many external factors of suffering from an illness that can contribute to poor mental health, beyond physical consequences or pain (Araújo and Carvalho, 2015; Chew at., 2017; Collins, 2011; Johnson & Shorvon, 2011; Michaelis et al., 2018; Shafran et al., 2020; Verhaak et al., 2005).

The transition of healthcare from paediatrics to adults in the population of young people with epilepsy, a population with challenges and needs very particular consequences arising from having to manage a disease (and its comorbidities in many cases) with the characteristics of epilepsy (unpredictable, heterogeneous in terms of presentation-severity, symptomatic control, psychosocial correlates; still loaded with stigma; which carries increased risks in terms presence of psychopathology, neurocognitive problems, with predictable correlates in emotional, behavioral, social, academic/vocational, family terms, at the same time as they have to deal with the normative challenges of the adolescence transition (identity, autonomy, peers, body) for the emerging adult phase (intimacy, commitment to professional projects…); It is important to clarify why it is important to know more about this; which is an emerging topic, also and even more so in the Portuguese reality (innovation factor of the study),….

More specifically, there is a strong association between chronic illnesses and mental disorders, such as clinical anxiety, depression, and suicide ideation (Araújo and Carvalho., 2015; Shafran, 2020; Verhaak et al., 2005). Thus, much like other chronic illnesses, epilepsy has also been highly studied in terms of its various impacts on patients' well-being, quality of life, and mental health, which will be discussed throughout this literature review. Since within the population of people with epilepsy in general, people are more predisposed to have poorer mental health, when looking into adolescence as a stage of development, and, more specifically during the transition from paediatric to adult healthcare, these concerns are even more prevalent (Andrade et al., 2017).

This investigation will start by providing a theoretical background in the first chapter showing what literature exists today about the psychosocial needs and experiences of adolescent with epilepsy and their transition from paediatric healthcare and the objectives of the study. The

following chapter will have the methodology of the study, which will the type of investigation, the design and how it will be carried out. Here the sample, instruments and procedures of recruitment and analysis of data, along with ethical procedures will be outlines in detail. The third and final chapter will include the presentation and discussion of the main results, categorized in the relevant themes identifies in the qualitative analysis. In parallel this section will also discuss the results attained, the relationship of the results with existing literature and objectives of the results and outline any limitations the study had. The conclusion will then be presented in the last section, having a broader approach to the investigation, providing final contributions and implications for future studies.

Chapter I - Theoretical Framework

1.1 Background: Epilepsy

According to the World Health Organization (WHO), epilepsy is one of the world's most common neurological illnesses, and in many countries is the most prevalent neurological disorder in adolescents (Collins, 2011; Marin, 2005). In Portugal, it is estimated that 1 in 200 people have epilepsy, which can translate to roughly 40,000 to 70,000 people (Liga Portuguesa Contra a Epilepsia, 2022). Epilepsy is a brain disorder defined by having a history of at least one seizure and experiencing alterations in the brain that increases probability of future seizures; an epileptic seizure is a temporary event caused by abnormal and intense brain activity, resulting in specific signs and symptoms. (Fisher et al., 2005)

Epilepsy can impact people from birth to adulthood – whether individuals are born with it, it appears throughout their life, or is caused by a brain injury (Chew et al., 2017). The main symptoms are seizures that vary in type, ranging from light 'spacing out' to uncontrollable episodes with loss of consciousness, and uncontrollable shaking of the body. These physical symptoms of epilepsy and its interference in daily life will differ from person to person depending on the type and the seizure control status (i.e., by taking medication that is effective in seizure control).

Most people with epilepsy experience their first seizure or epileptic episode, before the age of 20 (Mendes, 2018), and with the use of medication for two to five years, most children and young people will no longer experience any epileptic symptoms, as such reaching remission, with only 20% of children that seizure control is not attained even with the use of medication (Sillanpaa & Schmidt, 2008).

Authors state Lee et al (2019, p.1), "intellectual functioning is definable as the global ability that allows the individual to understand reality and interact with it" and this can frequently be reflected by a lowered IQ. Intellectual disabilities impact the intellectual functioning of individuals, with different manifestations such as behaviours, thought, and emotions (Lee et al., 2019). A high rate of people with intellectual disabilities, estimated at 22.2%, have comorbid epilepsy, and vice versa (Robertson et al., 2015).

Managing epilepsy is difficult in nature; when coupled with cognitive impairment, managing the condition becomes even more difficult. Intellectual disabilities correlate with

increased levels of mental disorders; therefore, living with both disorders further increases the risk of developing anxiety and depression.

1.2 Illness Experience of Adolescents with Epilepsy

Adolescence is a stage in development that is known for its instability and rapid changes in various ways such as physical, physiological, psychological, and social. This stage in life is where adolescents develop their sense of self and expand their cognitive abilities, social skills, and various other dimensions including transitioning into adulthood and a more autonomous life (Collins, 2011; Marin, 2005). Key markers of adolescence such as drinking, driving, going to parties, discovering own sexuality, taking contraceptive measures. For children and adolescents, adapting to a diagnosis of epilepsy can be a difficult process and a source of psychological distress (Chew et al., 2017). Adolescents with epilepsy frequently have to reduce or eliminate alcohol intake due to its interference with certain medication type; be more aware? of sleep schedules; also, medication may interfere with the efficacy of contraceptive methods (Chew et al., 2017; Goselink et al., 2022).

Young people, which encompass individuals ages 15 to 30, with epilepsy have higher rates of several psychiatric comorbidities compared to individuals of the same age group without epilepsy (Johnson & Shorvon, 201; Shafran, 2020), greater difficulties establishing interpersonal relationships (Chew et al., 2017; McEwan et al., 2004), lower subjective well-being as well as the quality of life (Michaelis et al., 2018). We will explore the impact of epilepsy on adolescents' mental health. This impact of epilepsy is noticeable in areas such as academic performance for those in school, drinking restrictions during a phase in life where this experience is emphasized, restrictions in going out at night with friends (i.e. clubs and bars) and in getting a driver's license, and fewer job opportunities (McEwan et al., 2004; MacLeod, 2009; Ragni et al., 2020).

Epilepsy can have a variety of consequences ranging from cognitive or neurobiological to psychological or social impacts. On a psychological level, epilepsy can be briefly portrayed by its unpredictability regarding seizure occurrence and the control the individuals have over their own body, which has various implications. Epilepsy can have implications impacting young people's lives at school, future work life (employment), socialization, safety, and overall general lifestyle (Chew et al., 2017; Collins, 2011; Shafran, 2020).

Additionally, we will also explore what procedures or preventative interventions are in place for young people when transitioning from paediatric e to adult healthcare that address such psychosocial needs risen in the literature.

1.2.1 Social Needs

Social needs consist of the fundamental requirement that humans have when it comes to interactions, relationships, and connection with others (Pichère & Cadiat, 2015) Meeting social needs contributes significantly to an individual's mental and emotional well-being, and their fulfilment often has a positive impact on physical health as well. Failure to meet these needs can lead to feelings of isolation, loneliness, depression, and decreased overall quality of life (Kerr et al., 2014). The factors that will be explored are stigma, interpersonal relationships, peer relationships, family relationships, romantic relationships, and psychosocial needs.

1.2.1.1. Stigma

Many generations ago, epilepsy had many negative connotations, ranging from being perceived as a psychiatric disorder and patients being treated as ‘insane’ (at a time when psychiatric disorders were treated with invasive procedures such as lobotomies and mental disorders were seen as insanity), to religious or spiritual meanings such as seizures being bad omens or dangerous messages. Currently, these inferences have changed substantially along with modern medicine. However, stigma and negative stereotypes take a long time to disappear and may still harm certain aspects of the lives of individuals with epilepsy (e.g., decreased job opportunities and offers) (Jacoby and Auston (2007).

Stigma is when individuals tend to place more value on what others’ think about themselves (Collins, 2011) and feelings of being different from their peers have negative implications on self-esteem (Chew at al, 2016). This stigma is prevalent in adolescents and young adults with epilepsy.

There is a clear relationship between perceived stigma and decreased psychosocial abilities. Quality of life may be negatively impacted by three types of stigma: internalized stigma, such as having feelings of shame or embarrassment due society’s portrayal of epilepsy; interpersonal stigma, such as verbal harassment or abuse by others pertaining to the condition; and institutional stigma, where people with epilepsy often face job discrimination or face negative public perceptions of the condition (Jacoby and Auston (2007).

Consequences of perceived stigma on patients with epilepsy are positively associated with psychological (e.g., helplessness, depression, anxiety, low self-esteem) and physical problems (e.g., somatic symptoms and other health problems), as well as lower quality of life. Furthermore, stigma negatively impacts the frequency of seizures in addition to the impact on the trajectory and treatment of the chronic illness, such as worsening severity of seizures and causing an increase in medication needed thus growing its side effects. (Jacoby and Auston, 2007)

1.2.1.2. Interpersonal Relationships

As mentioned above, living with epilepsy can have various negative aspects that contribute to a lower quality of life and psychosocial function; one of those aspects stems from poor development and greater difficulties in establishing interpersonal relationships (McEwan et al., 2004). Relationships with implied commitment and emotional connection (e.g., peer relationships and romantic relationships) can have both a protective (if positive and healthy) or a detrimental impact (if toxic or negative) on the well-being of people with epilepsy (Gesselman et al., 2021).

1.2.1.2.1 Peer Relationships

Having epilepsy at these ages can highly affect social function, the ability to develop and maintain peer relationships, self-esteem, mood, and cognition, thus impairing not only their interpersonal relationships, but also their own development. This has potential consequences such as depersonalization, leading to clinical disorders such as anxiety and depression, as well as feelings of loneliness and behavioural issues. (McEwan et al., 2004)

As reported by Wilde and Haslam (1996), a common concern of young people with epilepsy is disclosing their illness to their peers; therefore, most peers only find out about their condition when they have a seizure in front of peers. The decision to disclose the diagnosis is based on factors like the closeness of the relationship with the peers, seizure frequency, and safety concerns of the young person. The apprehension stems from many concerns such as embarrassment, fear of being bullied, made fun of, or rejected, and overall negative peer reactions to their condition (McEwan et al., 2004).

As a result, peer relationships for young people with epilepsy are often associated with bullying, discrimination, and labelling. Additionally, young people tend to express a lack of close friends and difficulties regarding social activities, feeling left out or different from their peers (Chew et al., 2017; McEwan et al., 2004; Wilde and Haslam, 1996). In a sample of 24

Adolescents, 71% reported having experienced bullying and teasing due to their condition; also, many participants complained that their psychosocial needs were not met appropriately by medical professionals or support services (Wilde and Haslam, 1996).

When assessed as positive, peer relationships are a source of support for young people, who report feeling protected from discriminatory or teasing behaviour and perceiving loyalty within their friendships (Chew et al., 2017; McEwan et al., 2004; Wilde and Haslam, 1996).

1.2.1.2.2. Family Relationships

Family relationships can either help or hinder adaptation to the illness, depending on factors such as parental knowledge of epilepsy and its risks, independence from parents, and parental concerns (Chew et al., 2017). Young people report experiencing significant support from parents and siblings. Parents use different styles. On the one hand, some parents aiming to promote autonomy and independence, without posing restrictions whilst still being protective and helpful. Usually, young people put more restrictions on themselves than their parents do, due to concern over injuries. As young people adapt to the illness and parents learn more about epilepsy, parental protectiveness tends to decrease, as they get accustomed to their child's new reality. This type of support helps young people adapt to their condition.

Contrastingly, some parents adopt a stricter approach, imposing restrictive rules and being too vigilant, leading to a negative reaction from young people. This type of parental style can make adolescents feel deprived of autonomy and privacy, making them feel angry and creating a hostile family environment. (Chew et al., 2017)

1.2.1.2.3. Romantic Relationships

Intimacy is an important element of romantic relationships; within the model of intimacy, self-disclosure is one of its dimensions (Prager, 2000). In the present study, the main focus is self-disclosure of having epilepsy, and its positive or negative outcomes.

For some, opening up about their condition to their girlfriends/boyfriends can be a slow and difficult process, especially for those with previous experience regarding stigma or negative reactions concerning their medical conditions (e.g., negative or awkward responses at work or in interpersonal relationships) (Sprecher & Hendrick, 2004). When one of the elements of the couple do not reveal the illness to the other, it can be detrimental not only to their own self, but to their relationships with others, be it romantic or otherwise. On a relational level, disclosure in romantic relationships is highly associated with better relationship esteem, responsiveness, and

overall quality of said relationship (Sprecher & Hendrick, 2004).On an individual level, sharing this aspect of a person's life has a positive association with a person's self-esteem. Moreover, even though this type of disclosure may not predict relationship length, girls/women are less likely to breakup with their partners' following their illness disclosure (Sprecher & Hendrick, 2004).

Moreover, healthy romantic relationships have a positive impact on various aspects of people's health and well-being, such as decrease instances of mental disorders, less injury, higher quality of life, better adherence to medical treatment, and a decreased mortality risk (Gesselman et al., 2021). This highlights the importance of evaluating how people with epilepsy experience romantic relationships and obstacles in this context, to be able to better understand and support their needs, so that adolescents are not further at risk of low levels of well-being or mental illnesses.

These psychosocial needs in adolescents coincide at a critical period: the transition from pediatric to adult healthcare. Adolescence is a time period associated with many developmental, social, and psychological challenges. However, when dealing with a chronic illness at the same time, these two aspects may collide, as managing this illness and transitioning often goes against what is considered typical of adolescence (Goselink et al., 2022).

1.2.1.3. Psychosocial Needs

Psychosocial needs include psychological and social needs individuals experience throughout their lives (Upton, 2013). The social aspect includes anything related to social structures or social processes that have an impact on individuals. Psychological needs encompass any need that is critical for individuals' mental health, such as self-esteem, self-actualization, support systems, etc.

Psychosocial needs of adolescents with epilepsy are different from those of young people without chronic illness. Psychosocial needs encompass a variety of psychological and social factors. Psychological factors include aspects such as mental health, self-esteem, and subjective well-being, whereas social attributes refer to social support system, interpersonal relationships, external environments (such as work conditions). and overall social interaction skills (Macleod, 2003).

1.2.2. Adaptation

In psychology, adaptation means changing how you act or think to deal with new situations or challenges and stay mentally healthy, thus being the absence of mental health disorders or symptoms (Stanton & Hoyt, 2017). As expressed by Mendes (2018), adaptation when faced with extensive challenges and stressors, can be viewed as spectrum than can range from either very good or very bad results.

1.2.2.1. Mental Health

As reported by numerous studies, depression is the most predominant psychological disorder amongst young people with epilepsy with studies reporting ranges from 23% to 70% of people with epilepsy having a pathology of depression (Araújo &. Carvalho; Ekinci et al., 2009). The relationship between epilepsy and depression can be described as a "transitory phenomenon" which can happen before the occurrence of seizures (peri-ictal) or in between seizures (i.e. inter-ictal), that is more persistent (Araújo & Carvalho, 2015).

However, among individuals with temporal lobe epilepsy, which is characterized by focal seizures that occur in one area of the brain but can spread to other areas (Asadi-Pooya et al., 2007), there is an exceptionally high chance of developing depressive disorders. This is due to its origin within the limbic system, which plays a large role in emotional and behavioural regulation, which, in turn, is a common denominator regarding epilepsy and depression. Aside from this theory, which is highly disputed (Araújo & Carvalho, 2015), it is concluded that the factors with a larger impact on the probability of developing a depressive disorder are the psychosocial impacts of the illness on the individuals' lives.

The consequences of developing depression go beyond psychological symptoms or outcomes. Specifically, depressive disorders can impact how the patient responds to epilepsy treatment, including response to pharmaceuticals. People with both epilepsy and depression have a higher rate of seizures and worse response to anti-seizure medication, which is highly linked to the frequent sleep deprivation among patients with depression (Hitris et al., 2007). In sum, depression affects an individual's epilepsy treatment negatively whilst simultaneously, increased frequency of seizures also increases depressive symptoms.

As previously mentioned, anxiety is the second most widespread psychological disorder with an estimated 15 to 20% prevalence of anxiety in people with epilepsy (Ekinci et al., 2009); however, much like depressive disorders, it is highly underdiagnosed and treated (Brandt & Mula, 2016). According to Brandt and Mula's (2016) study concerning anxiety disorders in

patients with epilepsy, younger ages (children and adolescents) are more likely to develop clinical anxiety. However, this comorbidity is seen as a "forgotten comorbidity", as the literature tends to focus on psychoses and depressive disorders.

Chew et al (2017) carried out a qualitative review on the experiences of young people with epilepsy, which helps to pinpoint the origins of their lower quality of life. These adolescents frequently express feelings of fear, regarding injuries, brain damage, or death caused by seizures; anger, sadness, and frustration due to restricted activities, and feeling different compared to their friends or peers and the dependence on anti-seizure medication; loneliness, embarrassment, and self-pity about having seizures in public, which may be unavoidable due to the unpredictable and uncontrollable manifestations of the illness.

Clinical anxiety in the presence of epilepsy has copious negative consequences that diminish patients' quality of life (Brandt & Mula, 2016). Author Brandt & Mula (2016) attribute the predisposition to develop anxiety to high levels of external health locus of control. In brief, health locus of control concerns how much patients place blame or perceive having control over their illness, for example, attributing it to a higher power, doctors, family, etc. Thus, the perception the patient has over who has control over their lived experience of having epilepsy. External locus of control means seeing the illness as controlled by others, whereas internal locus of control is the perception that the illness is controlled by oneself.

Patients with epilepsy can have greater difficulties that people without epilepsy, in adapting to their diagnosis due to a higher external health locus of control, which is associated with less active coping mechanisms and lower rates of adaptive behaviours, such as rushing and taking less time when assessing problem situations and not using active and goal-directed problem solving (Asadi-Pooya et al., 2007). On the other hand, an internal locus of control over their condition is correlated with positive psychological and physical adaptation to epilepsy and promotes adaptive behaviours.

1.2.2.2. Academic performance

As previously mentioned, epilepsy often has some impact on individuals' cognition and has a high comorbidity rate with neurocognitive disorders (Kanner et al, 2020). For adolescents and young adults in academic contexts (high school or university), this cognitive impact can lead to a significant decline in academic results or increased difficulties in schools and universities (Ragni et al., 2020).

1.2.2.3. Psychopathology in Adolescents with Epilepsy

According to a critical review by Araújo and Carvalho (2015), the prevalence of psychiatric pathology in patients with epilepsy can range from 15% to 70%, with the main disorder being depression, followed by anxiety disorders. The review highlights many reasons for this correlation including poor interpersonal relationships, the unpredictable nature of seizures and mild episodes, the stigma associated with epilepsy, as well as the impact of those comorbidities on epilepsy itself and pharmaceutical treatments.

Although there is a clear relationship between chronic and mental illness, epilepsy-related healthcare does not adequately address the psychological needs of young people with epilepsy, so much so that they often go undetected and untreated (Araújo e Carvalho, 2015; Shafran et al., 2020).

The development of comorbid psychiatric illnesses is positively correlated with the frequency and severity of seizures that the patient experiences (Johnson & Shorvon, 2011).These factors influence not only mental health but their quality of life, interpersonal relationships, and perceived stigma (Araújo and Carvalho., 2015; Collins, 2011; Johnson & Shorvon, 2011).

1.3 Transition: Paediatric to adult health care

When children with epilepsy transition from adolescence to adulthood, they most commonly develop in three different manners (Camfield & Camfield, 2014): some patients find that their seizures continue into adulthood and remain for the rest of their lives; some enter in remission in childhood yet still have social problems resulting from the illness, and finally, for very few people, they reach remission without the negative social impacts of the condition. Hence, there are often many psychosocial issues, beyond comorbidities, that can impact patients as they reach adulthood, whether their physical condition has improved.

The moment of transition from paediatric to adult healthcare comes with various challenges and, as described by Camfield et al. (2019), is a “purposeful and planned process that addresses the medical, psychosocial, educational, and vocational needs of young adult patients…” during their transfer from a “family-centred model of care to an adult care model”. This is especially important in the case of young people with epilepsy, as they have a high likelihood of needing medical support for seizure management.

The transition from paediatric brings many challenges, such as the loss familiarity and often rebuilding relationships and trust in doctors, a new level of autonomy and responsibility,

insufficient knowledge about own condition and their comorbidities, thus requiring the right processes and support in place for adolescents (Camfield et al., 2012). This transition should be a continuous, extensive process that extends beyond the moment a child reaches 18 years of age and transfers from paediatric to adult healthcare (Andrade et al., 2017). A transition that is done poorly, without providing adolescents the support that they need can have serious long-term psychosocial and medical repercussions such as increased seizure frequency, unstable family environment (Geerlings et al., 2015).

However, there is little to no interdisciplinary support or procedures in place to accompany people going through this transition. Camfield et al. (2019) concluded that having neurologists be the sole medical support system provided to patients during this transition is inadequate, as they do not have all the resources to best help such process. The authors highlighted that this limitation would keep proving to be detrimental to patients' healthcare as transition programs often include only one health professional.

People with comorbid epilepsy and intellectual disorders have higher chances of experiencing a poor transition to adulthood healthcare, and overall poor social outcomes in stem from the condition (Camfield et al., 2019). This can be due to many reasons, including greater difficulty in keeping up with the medical procedures needed to assess the development of the condition (i.e. EEG, blood tests, MRI, etc.), as well as many health workers not being equipped or trained in dealing with people with cognitive difficulties or behaviours that are not representative of the patient's age.

1.3.1. Preventative Interventions

What is more concerning, however, is the absence of preventative interventions for this population, aiming to prevent the development or deterioration of psychiatric comorbidities or to improve quality of life. Three papers (Michaelis et al., 2018; Reger et al., 2018; Shafran et al., 2020) present recommendations and guidelines for early screenings; this was the closest to an intervention that could be found for this population, the first two articles promoting a healthcare transition related intervention and the latter a preventative mental health intervention that is not specific to healthcare transition.

There are several possible explanations for these lapses in healthcare, namely the fact that patients with epilepsy are followed by health professionals such as neurologists, among other specialists, and often do not have contact with psychologists or psychiatrists, especially young

people (Shafran et al., 2020). Thus, Shafran et al (2020) argue that psychological treatment should be integrated into the health services offered to patients with epilepsy, in the context of a multidisciplinary team. An alternative would be to provide training for the medical team supporting young epilepsy patients to deliver psychological evidence-based interventions when needed. The authors suggested optimizing and adapting one type of therapy, the Modular Approach to Treatment of Children with Anxiety, Depression or Conduct Problems (MATCH-ADTC), to the needs of young people with epilepsy. Four key components need to be addressed in an intervention: education about mental health and patients' relationship with their condition; stigma and coping mechanisms; parental mental health (as parents of children with epilepsy are more likely to suffer from anxiety and other mental health issues); and transition to adulthood. Authors asked users of this program to evaluate their experiences with the program and provide suggestions of improvement and overall feedback to assess its efficacy.

Michaelis et al (2018) presented a program for people with epilepsy who will transition do adult healthcare based on a model intervention with four key components: psychological intervention; self/family management and adherence interventions; and educational interventions. More specifically, that there should be a screening process for patients diagnosed with epilepsy, to determine their risk of developing psychological comorbidity and provide mental health support for those who need it. Lastly, the authors emphasise that there needs to be action where epilepsy healthcare providers are concerned (e.g., doctors, clinicians) to promote these psychological treatments and look out for these concerns so that patients know what support they can receive and resources they have access to.

Lastly, Reger et al (2018), outlines a pilot program called the Transition Age Program (TAP) for children aged at least 17 years old to prepare them for their transition to adult healthcare. The program consists of a team of a paediatric neuropsychologist, paediatric psychologist, and a social worker. The goals are to have this multidisciplinary team to asses patient's readiness to transition, their comorbid psychosocial issues than can impact transition or quality of life using instruments such as the health related quality of life questionnaire (HRQOL), provide psychoeducation regarding epilepsy care and challenges during transition, promote readiness in family and patients for the transition and offer a summary developed collaboratively be the team for the patient and family outlining the patient's psychosocial needs.

The three programs outlined above present various aspects the address various psychosocial needs of young people with epilepsy both in general and specifically during the transition period, and although they differ in how they approach, they have many aspects in common and others that diverge, hence combining their key aspects could provide a more thorough intervention.

1.4. Limitations of Existing Research

Although there is a considerable amount of literature breaching the topic of epilepsy in young people and its psychosocial impact on their quality of life, there is a lack of qualitative studies where the researcher hears directly from the young person in question to understand their experiences and needs (McEwan et al., 2004; Chew et al., 2017).

Additionally, both Chew et al. (2017) and McEwan et al. (2004) emphasise that many studies focus on exploring the impact of paediatric epilepsy on family members and do not explore the lives of young people. When addressing the needs of young people with epilepsy, it is necessary to investigate directly from the source, concerning descriptions, perceptions, and definitions of lived experiences. It is also important to note, as highlighted by Chew et al. (2004), people's illness experience will be different depending on the population's culture or country. A lot of literature mentioned above is based internationally, with a lot of evidence coming from USA and Canada, where as investigation based in Portugal is still limited.

Bai et al. (2023) conduct a thorough systematic review of 17 qualitative studies ranging from 1996 to 2022 about the experiences of adolescents and young adults with epilepsy and found 3 overarching themes; the impact of epilepsy, emotions associated with epilepsy and self-management of epilepsy. Of those 17 studies, only one focuses on the healthcare transition from paediatric care to adult care. In the review, authors highlight various psychosocial needs prevalent in the papers analysed

Furthermore, previous quantitative studies used scale that had been designed for adults and were adapted to young people, instead of being specifically designed for them. This can lead to questionable conclusions, as not all aspects of this stage of development are considered. Likewise, the instruments used should also consider the medical contexts of the population. For young people with epilepsy, it is necessary to consider clinical characteristics (e.g., severity and frequency of seizures, type of epilepsy, medication), and not solely age (McEwan et al., 2004).

In sum, McEwan et al. (2004) argue that the most appropriate methodology for exploratory papers is qualitative. This allows for greater validity of results, facilitates deeper examination, and provides a bottom-up approach to research that allows young people first, define what quality of life means to them, and second, to explore their experiences.

1.5. Objectives

The objective of the study was to describe the experiences of young adults with epilepsy regarding (1) epilepsy management and (2) the transition from paediatric to adult healthcare, identifying their needs and the barriers and facilitators of a positive transition.

The findings of the present study will contribute information to provide factors for structuring intervention programs that meet identified needs, based on the reports of young people with epilepsy that were interviewed. Targeting their needs, as expressed directly from the source (the young people), allow for an accurate depiction of experiences on which to base an evidence-based psychological intervention. Providing young people with this support aims to promote better adaptation to their condition, which in turn would have multiple other benefits, on parents, clinical characteristics, their developmental trajectories etc, as mentioned in the studies presented above. Considering the vast amount of evidence showing that this population suffers in multiple domains, there should be processes in place to help increase their well-being.

Chapter II - Method

2.1. Design

The present study had a cross-sectional, exploratory design, with a qualitative approach. This was found to be the most appropriate method to address the experiences and psychosocial needs of young people with epilepsy in depth and providing participants the opportunity to raise new aspects of their experiences without being restricted to close-ended questions.

2.2. Sample

The sample consisted of young adults from 19 to 30 years old with epilepsy, four women and three men, currently in treatment in adult healthcare settings. All participants were Portuguese (N = 7), with six living in mainland Portugal and one living in Madeira Island. Four participants were employed, two were students, and one was unemployed.

Participants had different types of epilepsy, including focal epilepsy, and juvenile myoclonic epilepsy. Not all participants knew which type of epilepsy they had or disclosed such information, explaining solely the type of seizures they experienced. The types of seizures ranged from absences, generalized tonic clonic seizures to focal seizures. Seizure frequency varied, from one participant reporting no seizure activity (due to medication), to individuals with absences reporting multiple seizures per day. Five participants were cared for in public hospitals, whereas the two remaining individuals were currently accompanied in the private sector.

Regarding participant's healthcare transition, five participants transitioned from paediatric to adult healthcare, have any seizure activity and their epilepsy was technically no longer present, only to return already in adulthood, therefore did not have a normatic transition experience.

2.4. Instruments

To fully understand the participants' experiences and needs, interviews were conducted. We used a semi-structured interview script (cf. Appendix A), which was developed by the research team based on the study's objectives. The script is organized in three section: 1) sociodemographic questions; 2) illness experience; and 3) healthcare transition.

2.5. Data Collection

The sampling method was non-probabilistic, including convenience and snowball sampling. For participant recruitment, and as this is a challenging population to reach, eight institutions were contacted, including epilepsy and neurology foundations, clinics, hospitals, and

corporations; online support groups (six Facebook support groups) and word of mouth were also used. A letter was developed (cf. Appendix B) to present the study, to ask for help recruiting participants. Once an answer was obtained from institutions or groups, a brief meeting occurred to further explain the study and its objectives and to discuss inclusion criteria. Although two institutions (a hospital and a clinic) showed interest in collaborating with this investigation, due to time constraints, this was not possible. Therefore, all participants were reached from individual contacts through word of mouth from the 26th of April 2023 to the 1st of June.

The sample was difficult to recruit, and some participants expressed this was due to stigmatization and personal nature of their experience; therefore, the inclusion criteria was revised to be as expansive as possible to facilitate recruitment: young adults with any type of epilepsy between the ages of 19-30, having a medical support system, having experienced any form of seizures in the past or presently and having been diagnosed with epilepsy during childhood to ensure they experienced a healthcare transition.

Participants were presented with an information sheet and consent form (cf. Appendix C) and the interview was scheduled according to their availability and preferred method. Finally, when interviewing participants who met the criteria, there was a brief conversation where the researcher shared why this investigation was being developed, answered any questions from participants, and asked them to sign a consent form.

Aiming to put participants comfortable and at ease, the researcher took a flexible approach in the interview process, adapting to what the participant was sharing (e.g., changing the order of questions when needed and engaging in casual conversation about the investigation pre or post interview).

The interviews were carried out remotely, two over Zoom and the remaining five through phone; participants were free to choose their preferred method. The duration of the interviews varied from 20 minutes to an hour, with an average of 28 minutes.

The data collection adhered to all its respective ethical procedures, in terms of the qualitative analysis ethical standards, and the institution responsible for enabling the investigation.

Before the interview process, participants were asked to read an information sheet that outlined the key components and objectives of the investigation and signed an informed consent

form, which highlighted any risks they could experience, provided emergency contacts in case of any negative reactions, and included the information contact of the research team.

Anonymity and confidentiality were ensured for all participants in every step of the presentation of the investigations and its process. The names of participants were displayed as numbers and any identifiable data (such as specific locations hospitals, clinics, or schools) of the participant were replaced with fabricated locations.

2.6. Data Analysis

The data was analysed using thematic analysis (Braun & Clarke, 2022), adopting a deductive and inductive reasoning. The deductive approach implies that the themes and codes identified in the data were guided through the existing literature regarding this topic and population, in other words, it is based on key themes found in the theoretical knowledge section reflected in this investigation. The inductive approach implies drawing conclusions based on the participant's self-reported experiences.

After transcribing the interviews, following the steps defined by Braun & Clarke (2022) there was an in-depth familiarization with the data, re-reading said texts and identifying codes, using the MAXQDA data analysis software.

As the codes were identified, it was possible to create an organisation system, by understanding which codes would be incorporated under each other, in subsections, and thus identifying the key themes in the data, defining those themes clearly, and establishing their connection with the existing codes.

This was followed by reviewing and validating the themes, reading every excerpt that was coded and categorized into a theme, to verify its adequacy. These processes are highly recursive, therefore this sequence of steps required going back and forth and re-evaluating the previous steps multiple times.

Taking that into consideration, once the themes were perfected, defined and had a final label that best characterized it, the following step was understanding the relationship between the identified categories and the theoretical framework and the investigation's objectives. Once this was concluded, the final step was identifying excerpts to develop the analysis report.

Chapter III - Presentation and Discussion of Results

When conducting the thematic analysis, after creating over 20 codes and rearranging them in a hierarchy, two overarching themes were categorized which were developed according to the investigation's objectives: *illness experience* and *healthcare transition process*.

The theme of *illness experience* aims to evaluate people's experience of dealing with epilepsy, considering psychological, social, and physical domains. Two themes were considered: *management of illness*, and *impact of illness*. *Impact of illness* includes any positive or negative impact the illness has on participants' quality of life and/or psychological, physical, financial, or social health. It included four subthemes: *concerns*, *stigma*, *interpersonal relationships*, *professional/academic difficulties*. *Management of illness* concerns what the participants need to do, take into consideration, or adapt to because of epilepsy, and included five subthemes: *precautions to adopt*, *resources*, *obstacles*, *public lack of knowledge*, and *patient's lack of knowledge*.

The overarching theme of *healthcare transition process* concerns the second objective of the study, aiding in the outline of a preventative strategy for this population by tackling individuals' experiences during their transition between paediatric and adult healthcare and, more specifically, exploring facilitators and barriers to a successful transition and how it impacted their lives. This overarching theme was organized in four subthemes: *current autonomy managing the illness*, *degree of perceived changes in transition*, *resources*, and *change in communication with doctors*.

3.1. Illness Experience

Within this overarching theme, the most prevalent theme was *impact of illness* which accounted for 57% , followed by *management of illness* which constituted only 43% of excerpts reference in the theme, with both themes being mentioned in all interviews.

3.1.1. The Impact of Illness

This subtheme was the most prevalent in the overarching theme of illness experience, which included any type of impact, whether it be negative or positive that epilepsy had on participants lives, at various dimensions such as psychologically, physically, financially, socially, and professionally.

The most common dimension referenced was *concerns* representing 46% of mentions within the theme and being mentioned in all interviews. *Concerns* reported by participants were

increased anxiety about maintaining a strict medication regimen and memory loss as a medication side effect; pregnancy (among women with epilepsy), due to uncertainties regarding the process, higher risks, fear of reducing medication and birth control specificities; health fears; financial concerns; and fear of reduced job opportunities due to the illness. *Concerns* are often linked to negative emotional s such as anxiety, fear, stress, frustration, and embarrassment.

> (...)vai ganhando sempre alguma preocupação, sendo os medicamentos, que tem o seu lado bom mas também tem o seu lado mau, as medicações a seguir também acabam, por exemplo, noto que estou a ficar um pedacinho mais esquecido, por causa da questão da medicação. (L.M., 28 years old, refractory epilepsy)

> Preocupo-me que apareça alguém que nunca dê emprego por causa disto (Participant 1., 27 years old, epilepsy unknown)

> (...)quando eu estou a querer falar e a querer tipo, expressar raciocínio ou dizer alguma coisa e estou cansado ou enquanto a ter crises, me impedem de fazer, tá sempre voltar atrás e a raciocinar. Isso deixa-me muito irritado(...) (Participant 2, 26 years old, epilepsia focal)

Stigma and *professional/academic difficulties* have both 25% of the subtheme, and are both referenced in four interviews. When talking about stigma, mentions broaching this refer to internalized and externalized stigma (Jacoby & Austin, 2007). *Stigma* and *professional/academic difficulties* are very frequently referenced in conjunction because stigma associated with epilepsy is frequently the cause of experienced job/academic difficulties. However, regarding academic or professional difficulties, different types of epilepsy impact people differently. Participants with absence seizures report difficulties in maintaining trains of thought or not keeping up with school material; however, participants with myoclonic seizures report fear of embarrassment when they have seizures at work and being the center of attention.

> Quando vou à procura de trabalho, não me dão (...) eles perguntam sempre, 'tem alguma doença', e eu digo 'tenho epilepsia, mas está controlada'... e ele diz 'ah então eu ligo-te a dizer sim ou não'... e ainda estou à espera das chamadas de todos. (Participant 3, 25 years old, focal epilepsy)

Finally, representing 11% of the subtheme, and being referenced in four interviews, was references to *interpersonal relationships*. This includes any mentions of the impact of illness on participants social life and relationships. Participants had mixed experiences regarding the

impact of epilepsy on their relationships. Some participants, more specifically those with absence seizures, experienced a greater impact because that specific type of seizures can go undetected thus when interacting with new people. Other impacts included limitations to social life due to not being able to have a driver's license, or to do activities that friends do, such as playing certain sports, staying up late at night, or going to clubs.

> Não posso jogar bola com os amigos ou com familiares. Eu não posso ficar muito agitado e esforçar muito (Participant 1., 27 years old, epilepsy type unknown)
>
> Não tenho namorado... não posso sair com os meus amigos, porque ainda não tenho carta de condução. (Participant 3., 25 years old, focal epilepsy)
>
> A nível social, a minha maior preocupação, é, de repente, ser eu que estraga naquele momento, o ambiente (Participant 4., 22 years old, juvenile myoclonic epilepsy)

Participants' experiences, were consistent with the psychosocial needs found in this population, highlighting the need for psychoeducation, which is a dimension present in all three preventative intervention programs refered in this investigation (Michaelis et al., 2018; Reger et al., 2018; Shafran et al., 2020). Participants raised many sources of distress regarding stigma, career, mental health, and lack of knowledge, which are encompassed as an aspect of psychoeducation in the interventions. Including these key themes in psychoeducation actions could reduce the impact these stressors have on individuals' lives.

Regarding mental health, the most frequently mentioned complaints concerned increased anxiety and memory deterioration due to epilepsy medication, as well as anxiety about taking medication in the long-term. Although previous literature has addressed this need to prevent mental health disorders and reduce stress levels, it can be important to dive deeper into this specific anxiety towards medication and its side effect and increase education about it, to reduce the cycle of anxiety.

3.1.2. Management of Illness

The most referenced subtheme was *resources*, with 70% of excerpts references within this category, and being mentioned in all six interviews. Resources concern any factor participants mention as a facilitator or helpful factor in managing the illness. The most frequently mentioned resources were family support (psychological and financial), followed by the support of doctors or other medical professionals; less mentioned were friends to whom participants disclosed their condition and exercise.

> (...)acho que é a minha família, especificamente os meus pais, que ainda me ajudam financeiramente com a medicação, estão sempre em cima de mim sobre as consultas anuais, de ir sempre ao médico fazer o eletroencefalograma (EEG) todos os anos... também ajudam financeiramente em relação a essas consultas (...) (Participant 6, 26 years old, juvenile mioclonica epilepsy)
>
> (...) não são todos os dias iguais, coisa que eu noto imenso, é que exercício faz uma diferença descomunal no próprio controlo (...) Eu faço levantamento de pesos, e é uma coisa que me tem ajudado imenso (...) (Participant 7, 28 anos, epilepsia refratária)
>
> Os meus amigos, foi sempre uma questão de haver uma pessoa mais próxima, e essa pessoa mais próxima tem sempre o contacto da minha família, e vivemos a nossa vida normalmente. Eles sabem o que eu tenho, o que eu tomo, para darem aos paramédicos (...) (Participant 4, 22 years old, juvenile mioclonic epilepsy)

The second most mentioned subthemes were *precautions to take* (14%), and *lack of public knowledge* (12%), both of which are mentioned in three interviews. *Precautions to take* include any life adaptation participants found necessary to decrease the probability of having seizures, such as decreasing alcohol intake, prioritizing sleep (at times impacting social life), using specific contraceptive methods (among women), taking medication consistently, attending medical appointments and exams, and avoiding certain events or places such as concerts or clubs.

> (...) parece que não, mas acaba por ser um constrangimento a vários níveis, não é? Nós acabamos por ter que ter atenção à quantidade de bebida que vamos estar a ingerir, o tipo de álcool que vai ser...As horas a que eu me vou deitar. Eu não posso porque já sei que amanhã tenho que levantar cedo. Eu sei que depois não vou dormir, então eu não posso estar este tempo todo sem dormir. (Participant SC, 26 years old, juvenile mioclonic epilepsy)
>
> Condiciona-me em algumas coisas, por exemplo, em conduzir, métodos contraceptivos, a questão de ser muitos exames médicos, muita ressonância, tomografia computadorizada, eletroencefalograma etc. Muita medicação. (Participant 4, 22 years old, juvenile myoclonic epilepsy)

The category of *lack of public knowledge* (12%) was often linked to the public's perception of epilepsy and misconception that all seizures are the same (i.e., standard dangerous myoclonic seizures).

> E quando nós dizemos que temos a epilepsia, mas está controlada, eles só deduzem às convulsões, não conhecem os outros tipos de epilepsia que há. (Participant 3, 25 years old, focal epilepsy)

The final two subcategories which accounted for 9% of the references each, were *barriers* and *patient's lack of knowledge*, having both been mentioned in two interviews. *Barriers* are obstacles or difficulties patients have faced whilst trying to manage their epilepsy (e.g. seizures, medical appointments etc.). The most common *barrier* (9%) mentioned by two participants concerned a misdiagnosis from doctors. Both participants were told by doctors that they were suffering from anxiety, which prevented them from receiving adequate treatment and caused negative psychological experiences. Additionally, another barrier mentioned was a general lack of support and aid for people with epilepsy.

> E eu insistia que era crises, porque era exatamente igual a quando não estava medicada.. mas ele não acreditou em mim e continuou a insistir que era ansiedade (...) eu estava muito chateada, por isso insisti em parar de tomar o medicamento e voltar a fazer o exame, para lhes mostrar que quando tenho os espasmos, iria aparecer no exame (...) estava tão revoltada... ainda estou até este dia honestamente (...) (Participant 6., 26 years old, juvenile myoclonic epilepsy)

> Não temos soluções. As pessoas com epilepsia deviam ter ajudas, só que não são praticamente ajudadas com nada. (Participant 3, 25 years old, focal epilepsy)

Regarding the *patient's lack of knowledge* (9%), their own health conditions can be detrimental in terms of how patients are able to convey their experiences, express themselves, and their sense of control over their condition.

> Por exemplo, eu quando era adolescente não sabia que tipo de epilepsia tinha, ninguém me tinha dito sequer que havia diferentes tipos de epilepsia... por isso, tinha imensa dificuldade em explicar o que eu sentia, como eram as crises e tal (...) acho que conhecia-me melhor a mim própria (Participant 6, 26 years old, juvenile myoclonic epilepsy)

3.2 Healthcare Transition Process

The most mentioned aspect of the healthcare transition process was a *change in communication with doctors* which accounted for 35% of references in this theme and being mentioned in all interviews. Often, communication became more patient-centered instead of family-centered, with patients gaining more autonomy and the relationship with their doctors shifting and becoming closer.

> A comunicação mudou muito porque eu comecei a falar com o médico em vez de ser a minha mãe a falar com o médico (...) e não é só o facto de ser eu a falar, foi também a maneira que falava com o médico mudou porque estava muito descontraída e confortável para colocar perguntas e de responder às perguntas dele
> consegui expressar-me muito melhor, em termos do que eu sinto quando tenho crises, quando acontecem etc. (Participant 6, 26 years old, juvenile myoclonic epilepsy)

> (...) antes basicamente quem fazia a comunicação a ponte eram os meus pais, eu não dizia tanto. O que é que acontecia porque não tinha tanta noção. (N.A., 26 years old, focal epilepsy)

The two following categories are highly interlinked, *perceived changes in transition* (27%) and *resources (27%),* both mentioned in four interviews. They are interconnected because most resources influence *perceived changes in transition*. Most participants experienced the transition as easy; however, it should be noted that two participants did not have epileptic activity during the period where they would have transitioned from pediatric to adult healthcare (one as a result of a medical procedure that eliminated seizure activity completely for a few years). Consequently, those participants did not experience the transition in healthcare characteristic of other participants. Nonetheless, most participants' experiences with the transition were positive, many reporting there were no changes that impacted them during the transition or that they did not feel there was a transition at all.

> Claro médico para médico também vai variando algumas coisas. Mas, no fundo eu não achei muita diferença (Participant 4, 28 years old, focal epilepsy)
> Não foi preciso muita preparação, porque quase nada mudou. (Participant 1, 27 years old, epilepsy type unknown)

> (...) a médica deu-me sempre mais ênfase ao que eu sentia como é que eu devia fazer, o que explicar à minha mãe para depois a minha mãe me explicar a mim... o que foi

> essa essa questão aí ou seja não houve uma diferença em termos do que eu sabia de um profissional para outro. (Participant 4, 22 years old, juvenile myoclonic epilepsy)

Regarding *resources*, many participants identified their trust in their doctors as a facilitator of the transition, along with maintaining the same doctors, staying in the same medical facility, and having the support of parents when participants are unready to make the transition.

> Só fico feliz que pelo menos depois mudei de médico e encontrei um que gosto, e ter o médico que tenho agora que gosto muito, faz toda a diferença no mundo (Participant 6, 26 years old, juvenile myoclonic epilepsy)

> A minha transição foi de transitar os tratamentos que tinha cá, para lá...claro que nisso a família tem sempre um papel importante. (Participant 7, 28 years old, focal epilepsy)

The final category was *current autonomy managing illness* (12%) which was mentioned in four interviews. Wen participant's lacked autonomy it was considered a downfall of a transition, however higher levels of autonomy were a promoter of a healthy transition. For participants with no autonomy before transitioning, and a feeling of being incapable of having the autonomy that comes with adulthood, the transition either does not take place with the normative characteristics of patients taking on a bigger role or does not take place at all. Additionally, participants also viewed their relationship with their doctors, their support and family support as a *resource*. When participants express the transition as something gradual, for example, in relation to their family support, this is also seen as a significant resource.

> (When participant was asked if they felt ready to transition) No. (When participant was asked if anything helped with the transition) No. (When participant was asked if they feel ready to deal with their epilepsy autonomously) No. (Participant 3, 25 years old, focal epilepsy)

> (...) por isso sinto muito que tenho apoio tanto médico como de família... e que pronto, soa um bocado estranho, mas não estou a lidar com a doença sozinha de repente, continuo a ter esse apoio, especialmente o médico, faz uma grande diferença. (Participant 4, 26 years old, juvenile myoclonic epilepsy)

Overall, the results are in accordance with existing interventions with this population during the transition, as there is a need for people with epilepsy to feel prepared before the transition process and to have the adequate support system to promote feelings of capability,

much like Reger et al (2018) pilot TAP program. Moreover, participants highlighted the support of doctors as a resource, a sense of security which supports the three existing interventions (Michaelis et al., 2018; Reger et al., 2018; Shafran et al., 2020) emphasise the importance of a multidisciplinary team, where medical providers take on a more active and present role in their processes, enabling individuals to feel like they have all the resources they need.

Individuals also had differing experiences according to their type of epilepsy and seizures. Considering these differences and their impact could result in a better understanding of whether there is a necessity to adapt interventions to better suit everyone's experiences, or to simply equip family member, doctors, or support systems with a better view of their condition and its repercussions. For example, results showed that individuals with absence seizures have a greater impact on their interpersonal relationships (specifically, establishing new relationships, as they are not yet comfortable to disclose their condition) compared to individuals with myoclonic seizures, who are more concerned about having seizures around colleagues or professionals they know for fear of embarrassment. Thus, there should exist a certain level of flexibility within programs objectives, to adapt to patients' specific concerns, and not follow a strict set of guidelines or goals.

It is important to note that due to the high comorbidity of intellectual disabilities with people with epilepsy, a limitation of this investigation was that although participants were asked initially whether they have any associated conditions, they still may not have disclosed the existence of an intellectual disability if one existed, and thus their responses may not have been as comprehensive as the interview script was not designed and measures were not in place to accommodate people with cognitive disabilities. Some participants found it more challenging than others to understand questions and articulate their experiences than others, therefore this type of differentiation should be a key aspect in the recruitment procedure, making it certain that if participants have a cognitive or intellectual disability that they have adapted interview questions, time and any further accommodations needed, possibly also speaking with caretakers. Future investigations should these specifications into considerations and go further, adapting intervention program specification for the needs of people with intellectual disabilities. As Goselink et al. (2022) emphasise, the psychosocial needs of people with epilepsy during healthcare transition are different to those with epilepsy and comorbid intellectual disabilities, as individuals with this comorbidity will have lower expectations regarding independent living and

general autonomy. Hence the importance of having a tailored program for people with intellectual disabilities, as currently, existing programs do not provide this (Goselink, 2022).

It is important to consider that participants had quite some difficulty remembering certain experiences or recalling how they felt regarding certain domains of their lives. Future investigations should explore the experiences of adolescents during this transition and before, ins order not to rely on retrospective accounts of situations. Furthermore, the recruitment process was a big challenge, therefore the sample size is a significant limitation as results may not be an accurate representation of the population.

3.3. Conclusion

In conclusion, this investigation explores the experiences of young adults with epilepsy regarding epilepsy management and their transition from paediatric to adult healthcare, to understand their psychosocial needs and identify barriers and facilitators for a successful transition. The study's findings illuminated experiences and psychosocial impact of individuals with epilepsy, shedding light regarding specific challenges they face during this life stage.

The investigation encompasses the population of young adults with epilepsy, aiming to understand their illness management and illness experience as well as the transition process from paediatric to adult healthcare. This research corroborated the existing body of literature, adding to existing qualitative research into this topic. The importance of a well-prepared and studies transition process emerged as a common theme, resonating with interventions like the TAP program by Michaelis et al. (2018) and Reger et al. (2018) and Shafran et al. (2020)’s studies and guidelines. More specifically the combination of various aspects of the three programs as the proposed intervention to foster a positive transition experience.

In a context where the evidence is clear that this population faces multifaceted challenges, improving well-being is crucial. In summary, this thesis aims to voice experiences, psychosocial needs, and potential pathways to better healthcare transitions for adolescent and young adults.

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Appendix A

Semi-Structured Interview Script

Tema	Perguntas
Dados demográficos e clínicos	• Que idade tem? Quais são as suas habilitações literárias? O que faz profissionalmente? • Que tipo de epilepsia tem? Há quanto tempo recebeu o diagnóstico? Com que frequência tem crises? As crises estão controladas? Tem outras doenças associadas? Que tratamentos médicos faz atualmente? É acompanhado em instituições de saúde públicas e/ou privadas?
Impacto e gestão e da epilepsia	• Que impacto tem a epilepsia e/ou outras doenças associadas no seu dia a dia (por exemplo, nas relações com família, amigos, namorados; no bem-estar; no percurso escolar/profissional)? ○ No caso de a epilepsia e/ou outras doenças associadas terem um impacto negativo, como gere esse impacto? • Tem alguma preocupação sobre o futuro por ter epilepsia e/ou outras doenças associadas? Qual/Quais? • O que precisa de fazer, no dia a dia, para gerir a epilepsia e/ou outras doenças associadas (por exemplo, tomar medicação, ter um estilo de vida saudável)? • Que dificuldades sente em relação à gestão da epilepsia e/ou outras doenças associadas? • Quem lhe dá apoio para gerir a epilepsia e/ou outras doenças associadas? De que forma?

Transição dos cuidados de saúde	• Como tem sido a sua comunicação com os profissionais de saúde acerca da epilepsia e/ou outras doenças associadas, desde o diagnóstico até hoje?
	• Como descreve a sua transição dos cuidados de saúde pediátricos para os cuidados de saúde de adultos? O que mudou? O que correu melhor? O que poderia ter corrido melhor?
	• Sentiu-se preparado/a para gerir os cuidados de saúde sozinho/a, antes e durante a transição?
	  o Se não se sentiu preparado/a, o que poderia tê-lo/a ajudado a sentir-se mais preparado/a para fazer a gestão da epilepsia?
	  o Se se sentiu preparado/a, o que o/a ajudou a sentir-se preparado/a para fazer a gestão da epilepsia e/ou outras doenças associadas?
	• De que forma é que os profissionais de saúde (e.g., médicos, psicólogos) podem ajudar mais os adolescentes e jovens adultos com epilepsia e/ou outras doenças associadas?

Appendix B

Project Presentation Letter

Carta de apresentação de projeto "Necessidades psicossociais de jovens com epilepsia na fase de transição de cuidados de saúde pediátricos para cuidados de saúde para adultos"

Caro(a) _____,

O meu nome é Inês Costa e sou aluna na Universidade Católica Portuguesa, no Mestrado de Psicologia do Bem-Estar e Promoção da Saúde.

Contacto-vos para apresentar o estudo que estou a desenvolver no âmbito da minha dissertação de Mestrado, orientada pelas Professoras Bárbara Nazaré e Teresa Mendes.

O objetivo do meu estudo é investigar as necessidades de jovens com epilepsia na fase de transição de cuidados de saúde pediátricos para cuidados de saúde para adultos. Pretendo recolher os dados para, futuramente, desenvolver um programa de intervenção para adolescentes e jovens adultos com epilepsia, com o objetivo de facilitar esta transição.

Para conseguir atingir os meus objetivos, necessito de angariar participantes dispostos a falar sobre a sua experiência na transição de cuidados de saúde. Irei realizar uma entrevista individual (por telefone ou via zoom/online) com a duração de cerca de 30 minutos.

Os participantes devem pertencer ao seguinte grupo:

- Ter entre 19 e 30 anos, ter epilepsia e ser acompanhado em consultas médicas para adultos.
- Ter sido diagnosticado com epilepsia durante a infância e ser acompanhado pela neuro pediatria no passado.

Neste sentido, uma vez que trabalham com pessoas com epilepsia, gostaria de solicitar a vossa ajuda para contactar possíveis participantes para este estudo. Atendendo à política de proteção de dados, compreendo que não possam partilhar dados de utentes connosco. Tendo isso em consideração, segue anexo o documento de consentimento informado, o qual podem partilhar com possíveis participantes, e que contém o meu contacto.

Desde já, agradeço a disponibilidade e encontro-me ao dispor para todos os esclarecimentos adicionais que desejem.

Appendix C

Information Sheet and Consent Form

Necessidades psicossociais de jovens com epilepsia na fase de transição de cuidados de saúde pediátricos para cuidados de saúde para adultos

Consentimento Informado

Esta investigação está a ser realizada pela estudante de Mestrado Inês Costa e orientada pelas Professoras Doutoras Bárbara Nazaré (Universidade Católica Portuguesa) e Teresa Pompeu Mendes (Universidade Lusófona - Centro Universitário de Lisboa), ambas psicólogas. Pretendemos conhecer as necessidades de jovens com epilepsia na fase de transição de cuidados de saúde pediátricos para cuidados de saúde para adultos, de modo a desenvolver um programa de intervenção para adolescentes e jovens adultos com epilepsia.

Para participar no estudo, deverá pertencer no seguinte grupo:

- Ter entre 19 e 30 anos, ter epilepsia e ser acompanhado em consultas médicas para adultos.

A participação é voluntária, pelo que pode recusar participar e pode deixar de participar a qualquer momento, sem ter de se justificar.

Se decidir participar, será entrevistado, de forma individual, por telefone ou videochamada, conforme a sua preferência, em dia e hora a agendar. A investigadora irá fazer-lhe algumas perguntas sobre o impacto da epilepsia na sua vida e a maneira como gere a doença. A entrevista durará aproximadamente 30 minutos.

A entrevista será gravada em áudio, ficando acessível apenas para as investigadoras e sendo usada só para fins científicos. As suas respostas serão transcritas e analisadas e, posteriormente, a gravação será apagada. Os resultados mais relevantes poderão ser

apresentados em congressos e conferências, e publicados em dissertações de mestrado ou artigos científicos, sem identificar os participantes.

A participação no estudo não tem custos e não é remunerada. O único risco que pode advir da sua participação no estudo é sentir algum desconforto por falar sobre a epilepsia. Se recear que isto aconteça, deve considerar não participar no estudo. Caso sinta necessidade de apoio psicológico, sugerimos que contacte as investigadoras e/ou o seu médico assistente.

Se quiser discutir algum aspeto relacionado com o estudo, poderá contactar as investigadoras responsáveis (s-isccosta@ucp.pt; barbara.nazare@ucp.pt).

Ao aceitar participar, declara que tem entre 16 e 30 anos, que tem epilepsia e que leu e compreendeu as informações referentes à sua participação no estudo.

□ Aceito participar

□ Não aceito participar