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The impact of epilepsy on adolescence: a quali-quantitative investigation using focus group

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Abstract

Adolescents with epilepsy live with a chronic illness that influences their relationships with peers and the development of their autonomy. Questions have been raised as to whether quantitative research approaches can adequately capture patients' experiences of living with epilepsy. By comparison, qualitative research methodologies support a more in-depth exploration of patients' personal experiences, enabling epilepsy researchers to obtain meaningful and valuable insights into patients' unique point of view. Participants in the present study were eight adolescents with epilepsy (five females, three males) aged between 15 and 20 years. The data were collected via a standard focus group procedure and self-report measures (Patient Health Questionnaire for Depression; PHQ-9**;** Generalized Anxiety Disorder Scale; GAD-7 and Quality of Life Inventory for Adolescents; QOLIE-AD-48**)**. Qualitative analysis of the focus group data yielded four key categories defining the psychosocial impact of epilepsy on adolescence: "Peer relationships and acceptance", "Autonomy", "School," and "Future". These outcomes suggest that epilepsy research may be significantly enhanced by the use of mixed-method approaches: adopting qualitative techniques such as focus group discussions to explore epileptic adolescents' thoughts and feelings and the psychosocial impact of epilepsy during adolescence, can inform clinical practice and promote the empowerment and quality of life of teenagers with epilepsy.

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1. Introduction

Epilepsy is the most common neurological disorder in child and adolescent patients with a prevalence of 1.5-2% (Appleton et al., 2005; Baker et al., 2005; MacLeod & Austin, 2003; Paolicchi, 2002). It is characterized by a tendency to have recurring seizures (*i.e.,* "transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain"; Falco-Walter et al., 2017), and is typically treated with antiepileptic medications.

Epilepsy chronicity and unpredictability (Chew et al., 2017b), together with antiepileptic medications' side effects, are often associated with cognitive, social, and psychological issues that can lead to significant challenges for adolescents and their families (Crudgington et al., 2019).

Epilepsy affects patients' psychological health, independence, emotional adjustment, and planning for the future (Kwong et al., 2016; Taylor et al., 2008). Moreover, one of every three patients with epilepsy experiences mood and anxiety disorders in the course of life (Tombini et al., 2020), which are associated with increased seizure severity (Cramer et al., 2003) and side effects of antiepileptic drugs (Mula et al., 2016). Specifically, pediatric subjects with epilepsy are five times more likely to develop depressive and anxiety symptoms (Caplan et al., 2005, 2008) than patients with other chronic illnesses. Moreover, in children and adolescents, anxiety, depressive and somatic symptoms resulted related to the deterioration of both the family's and child's QoL (Cianchetti et al., 2018)

Studies have suggested that 'active' epilepsy, greater seizure severity (Austin et al., 1996; Devinsky et al., 1999; Hoare & Russell, 1995; Sabaz et al., 2000), a higher number of medications (Camfield et al., 2001; Devinsky et al., 1999) and longer duration of illness (Hoare & Mann, 1994) represent risk factors for poor quality of life (QoL) in adolescence, defined as "the individual's evaluation of the quality of their lives as it relates to their own personal expectations"(Andelman, 2000). Adolescents with epilepsy reported a poorer QoL of life in comparison to both healthy peers and adolescents with other chronic illnesses such as diabetes and asthma (Austin et al., 1996; Hoare & Mann, 1994).

Notably, in adolescence, this chronic illness impacts on both peer relationships and autonomy, influencing social functioning and self-esteem (Gebauer-Bukurov et al., 2015; Kwong et al., 2016; Thomson et al. 2014). In a scoping review, Thomson and colleagues (2014), found that adolescents and emerging adults with epilepsy cite various impairments to their body functions and structures: sadness, irritability, anxiety, fatigue, lower vitality, appetite changes, side effects of antiseizure medication on memory, attention, mental functions. Furthermore, epilepsy places limits on activities such as driving and carrying out daily routines (daily routines were disrupted by the need for regular sleep, eating, and medication habits) (Thomson et al., 2014).

Adolescence is marked by physical, psychological, emotional, and social change, identity formation, and self-definition (Baker et al., 2005; Steinberg & Morris, 2001; Taylor et al., 2008). During this developmental period, adolescents focus on peer acceptance and acquire social skills enabling them to integrate into society and attain independence (Baker et al., 2005; Erikson, 1963; Siegel, 2014). Thus, adolescents with epilepsy not only have to face the challenges of living with a chronic condition but also need to accomplish the normative tasks of their developmental period; in other words, they are required to simultaneously manage a large number of stressful demands (Camfield et al., 2012; Chew et al., 2017b, 2019; Lee et al., 2019; Mohamed & Mohamed, 2020).

Questions have been raised as to whether quantitative research approaches can sufficiently capture patients' experiences of living with epilepsy (Baca et al., 2010; Chew et al., 2019; Harden et al., 2016; McEwan et al., 2004a, 2004b). Furthermore, researchers have tended to overlook children's and adolescents' views of their illness, using quantitative tools primarily with parents (Harden et al., 2016; Moffat et al., 2009). Qualitative research methodologies, on the other hand, support more in-depth exploration of patients' personal experiences, enabling epilepsy researchers to obtain meaningful and valuable insights into patients' unique point of view, in relation to what it means and how it feels to live with this chronic illness, and how subjects manage certain situations (e.g., how adolescents negotiate peer relationships)(McEwan et al., 2004a, 2004b; Moffat et al., 2009; Rapport et al., 2015; Willing, 2013). To date, few studies have used qualitative research methods to investigate the psychosocial impact of epilepsy during adolescence. In 2011, Kerr and colleagues published a systematic review of qualitative epilepsy research on "the impact of epilepsy on adult and pediatric patients' lives," identifying only three studies that had examined the experiences of adolescents. In 2017, Chew and colleagues conducted a scoping review of qualitative studies on "young people's perspectives of living with epilepsy", identifying 17 studies with adolescents. Among these, only two studies (Chew et al., 2017a; Kerr et al., 2011; McEwan et al., 2004a, 2004b; Moffat et al., 2009; Rapport et al., 2015; Willing, 2013) examined epilepsy's impact on adolescents using focus group methods (FG).

FG can be a particularly appropriate qualitative research methodology to implement with adolescents because it reproduces the setting where they are often most comfortable discussing their issues: the peer group (McEwan et al., 2004b). Furthermore, this technique can help healthcare researchers to understand the illness from the adolescents' own perspective, by eliciting their point of view and encouraging discussion in a non-threatening environment among patients facing the same health conditions (Heary & Hennessy, 2006; Moffat et al., 2009; Rapport et al., 2015). Sharing one's thoughts and feelings with others living the same experiences and challenges can improve psychological adjustment to illness, enhancing coping strategies, and improving perceived social support (Plante et al., 2001).

1.1 The current study

While quantitative studies have shed light on seizure-related factors, illness perception and family functioning as risk factors for adolescents' self-esteem and psychological health (Austin et al., 2010; DiMatteo, 2004; Lee et al., 2008; Räty et al., 2003; Rodenburg et al., 2005), little is known about the experience of living with epilepsy from adolescents' own perspective (Chew et al., 2019).

The main aim of our quali-qualtitative pilot study was to advance our understanding of the psychosocial impact of epilepsy in a group of adolescents living with this disorder, using both self-report quantitative measures and the FG technique, with a view to informing patient-centered intervention and guiding clinical practitioners to enhance patients' quality of life and social autonomy.

Specifically, we hypothesize that could emerge, from adolescents' own perspective, a negative impact of epilepsy on their life. In particular, according to previous literature (Austin et al., 2010; Chew et al., 2019; McEwan et al., 2004), we hypothesize that epilepsy would be described as an additional challenge to adolescents in completing their normative developmental tasks, such as social development, relationships with peers, independence, and autonomy.

2. Methods

2.1 Participants

Eight adolescents with epilepsy (five females, three males) aged between 15 years and 20 years (M=17y., SD=1.51) were recruited to take part in this study. In terms of their clinical characteristics, four participants experienced generalized seizures, and four of them focal seizures (three were candidates for surgery). The length of illness duration ranged between 1 and 17 years (M=10.75, SD=5.65).

Seven participants were receiving polypharmacy, and all had pharmaco-resistant epilepsy. In terms of their cognitive and behavioral profiles, four patients had a mild intellectual disability, and five were affected by mild adaptive disability. Participants were selected from the epilepsy database of the Neurology Division and of the Unit of Clinical Psychology of a pediatric hospital in Rome, Italy: "Bambino Gesù Children's Hospital" and were included in the research sample if: a) they had a diagnosis of epilepsy and were adolescents; b) were able to verbally participate in a group discussion.

A psychologist contacted potential participants' parents; those interested in participating were given a written brief explaining the nature and purpose of the research and asked to complete an informed consent form. Adolescents were informed that they could refuse to participate even if their parents had given their consent. We obtained separate approval from each participants' consultant pediatric neurologist. The study was approved by the Ethics Committee of Bambino Gesù Hospital, in compliance with the Declaration of Helsinki. All participants provided informed consent to the anonymous use of their data for this study.

2.2 Measures

Data were collected using the standard FG procedure (Barbour, 2007) and participants completed the following self-report measures in Italian:

Patient Health Questionnaire for Depression - PHQ-9 (Kroenke et al., 2001)

The PHQ-9 is a self-report rating scale composed of 9 items investigating depression symptoms. It is based on the Diagnostic and Statistical Manual of Mental Disorders fourth edition (DSM-IV) criteria for major depressive disorder and scores of 5 to 9, 10 to 14, 15 to 19, and 20 to 27 correspond to mild, moderate, moderately severe, and severe depressive symptoms respectively. The scale was used in several studies with Italian samples (Lucchesi et al., 2016; Menchetti et al., 2013; Picardi et al., 2005; Teymoori et al., 2019) and the internal consistency (Cronbach’s α) ranges from .86 and 89 (Kroenke et al., 2001).

Generalized Anxiety Disorder Scale - GAD-7 (Spitzer et al., 2006)

GAD-7 is a 7 items self-administered rating scale investigating anxiety symptoms. It is based on the Diagnostic and Statistical Manual of Mental Disorders fourth edition (DSM-IV) criteria for generalized anxiety disorder and scores of 5 to 9, 10 to 14 and 15 to 21correspond to mild, moderate, and severe anxiety symptoms respectively. The scale was used in several studies with Italian samples (Ambrosi et al., 2019; Lucchesi et al., 2016; Teymoori et al., 2019) and showed a good internal consistency (Cronbach’s α .92) (Spitzer et al., 2006).

Quality of Life Inventory for Adolescents - QOLIE-AD-48 (Cramer et al., 1999)

The QOLIE-AD-48 is a self-report questionnaire investigating epileptic adolescents' quality of life. It consists of 48 items and eight subscales. Considering participants’ cognitive difficulties in completing lengthy questionnaires, we selected only three subscales, ("Epilepsy Impact", "Social Support" and "Stigma"). Each subscale has a total score, and higher T-scores indicate a more favorable quality of life. The QOLIE-AD-48 has been shown to be a reliable and valid measure with good internal consistency for all the three subscales (Cronbach's α Epilepsy impact = .94, Social support = .80, Stigma = .75) (Cramer et al., 1999) and was used in several studies with Italian samples (Beghi et al., 2012; Cianchetti et al., 2015).

Ad-hoc semi-structured interview

Adolescents completed a semi-structured interview created ad-hoc in order to investigate the importance of informing people about epilepsy. Two questions compose the interview: "In your opinion, is it important to talk about epilepsy with people who do not know it? If yes, why?"; "In your opinion, could it be useful to create a book for patients and families receiving epilepsy's diagnosis for the first time?".

2.3 Procedure

The group was held one day a week, 15 times in a room of the outpatient Clinical Psychology Unit of "Bambino Gesù Children's Hospital" in Rome, Italy. Each meeting lasted 1 hour, and it was audio-taped to enable verbatim transcription. A moderator (a psychotherapist), facilitated the discussion and the reflections, and a psychologist supported the moderator's work. When the group started, adolescents were given badges with their names, they were informed about confidentiality issues, and everybody was invited to introduce themselves and talked about their hobbies and interests. Following this moment and during the other meetings, participants were asked to take part in two types of activities:

a) Discussing issues, identified in the previous literature, about the psychosocial impact of epilepsy on adolescence (the first eight meetings). Firstly participants, encouraged by moderators' participation, wrote on sticky notes one or more words related to the theme discussed. Secondly, sticky notes were attached to the wall divided into thematic areas in order to provide a visual prompt for eliciting discussion; finally the moderator, through reflective techniques, started the group discussion, summarizing the resulting opinions and asking the participants to find possible solutions to the problems emerged (issues discussed are summarized in Table 1).

b) Drawing medical procedures related to epilepsy in order to explain them to patients receiving the first diagnosis (the last seven meetings). Participants were asked to create drawings for a book designed for patients and families receiving epilepsy's diagnosis for the first time. Drawing allows people's fears, fantasies, and frustrations to be revealed (Got & Cheng, 2008). It provides a way for children and adolescents to release their impulses positively (Moon, 2012). Moreover, art activities may help people to understand themselves better and to both feel their emotions and emotions expressed by others and, as a result, to establish better relationships with others (Got & Cheng, 2008).

While adolescents were in the focus groups, parents were invited to sit in a different room of the unit. They were asked to complete a questionnaire providing information about adolescents' epilepsy and their quality of life. Considering that the focus of the study was on adolescents' perspectives, it was decided not to include these data.

2.4 Data analyses

For each self-report measure, total scores were analyzed using SPSS software version 24.0 (Armonk, NY: IBM Corp), and percentages related to the answers of the semi-structured interview were reported. Regarding FG, audio-taped data from each meeting were transcribed, and thematic coding was used to code data. Codes that emerged from the text were studied and used to produce relevant and meaningful central categories (Denzin & Lincoln, 2011). In order to increase the validity and reliability of findings and reduce bias on the identification of categories, data were analyzed by two independent researchers. Qualitative analysis of FG data identified four main central categories highlighting the psychosocial impact of epilepsy on adolescence: "Peer relationships and acceptance", "Autonomy", "School", and "Future".

Table 1. Issues discussed during the FG

Issues discussed	Selected answers
Places in which you had a good or bad experience of epilepsy	*Bad places* "Once I was at home alone, I had a seizure, and I saw the image of my dead grandfather, he was watching me, and then I woke up. It was unpleasant because I was alone."; "Daddy once left me alone at home because he wanted to buy cigarettes…I had the seizure, and I fell, it was terrible."; "It's annoying to stay at the hospital.., it's worse than other places."; "I remember a distressing seizure at the hospital...it was when I also had depression. I was in tears." "I had just entered the classroom when I had the seizure, and everything falls from my hands. All my classmates were laughing. I got angry because epilepsy is not something I want...”;"I had a seizure at school, and my classmates took a picture of me. It made me angry!” "When I had seizures on holiday, I'm afraid of ruining the holiday to everyone."; "On holiday, because if it happens, I become depressed, and I ruin the holiday to the others." "On the bus, while I was on a trip ... some friends knew I was sick, but I was afraid other people notice me." "The worst of my life was at the gym because I broke my wrist." *Good places* “Home is the better place to have a seizure.” "At school every time I have seizures, I fall, and I get hurt, but I'm never alone...my teachers and my classmates know what to do in order to help me."

	"I'm less scared at the gym because I expect there is someone more qualified who can help me."
Peers and teachers’ reactions to epilepsy disclosure	“They think you are crazy.”; “They push you away because you are different." “When I tell them about epilepsy, they made many questions."; "Questions, they made many questions." “When I told my classmates and my teachers, I have epilepsy, they were in shock!; "People become afraid when you talk about epilepsy, and they left you alone."; “At the beginning, when I explained to them what seizures are, they become anxious and afraid.”; "They made fun of me, took pictures of me, and published it on social networks."
	"When I explained what to do and how to help me when I have a seizure, they reassured themselves" “At school, they are worried about me, they look at me. I thank them”.
Things or activities you cannot do because of epilepsy	"Taking the driving license is difficult if you have epilepsy."; "I cannot go out with my friends until midnight...there are many issues...for example, with drugs' schedules "; "Going out with my friends alone."; "One thing we cannot do is drink alcohol and smoke."; "Travelling, going around the world...it's difficult when you have epilepsy, for example, I cannot lose hours of sleep.."; "Mathematics at school."; "Remember what are you doing and where you are."; "When I found I have epilepsy, I had to stop swimming. It was my greatest passion, but it cannot swim because there must always be someone close to me"; "For me, the most difficult activity is relating to others. Stay with peers, find friends alone without my parents' mediation."
Worries about future	"I would like to take a degree, to find a job and start to work"; "I would like to become a chef"; "I'm afraid not to find my place in the world, not to find a job"; "I'm worried about the surgery"; "Will we have seizures forever?"; "Will epilepsy disappear?"; "I'll always be afraid that seizures would come back"; "In the future, I would have a beautiful car"; "Could we drive? .. I have been waiting for so many years"; "Stay alone ... I am afraid of loneliness."

3. Results

3. 1 Self-report measures

Concerning PHQ-9 (M = 1.88; DS = 2.1) and GAD-7 (M = 2.88, DS = 1.46), mean total scores showed no clinical significant results. QOLIE-AD-48 subscales mean total scores were analyzed "Impact of epilepsy" (M = 76.13; DS = 13.03), "Social Support" (M = 83.13; DS = 14.36), "Stigma perceived" (M = 72.25; DS = 13.09) and converted in T-scores "Impact of epilepsy" (T = 52), "Social Support" (T = 50), "Stigma" (T = 54), not showing an impairment of the perceived quality of life.

3.2 FG Qualitative analysis

3.2.1 Peer relationships and acceptance

All participants described adverse experiences with peers. Although some of their friends appeared to be capable of offering them affection and support, they often felt rejected and isolated: "*They distance themselves from you because you are different. Differences scare [people], it's a form of discrimination*". One girl even reported being bullied: during a seizure, she was mocked by classmates who took photographs of her and shared them on social networks: "*I was at school, in my classroom when I had a seizure… my classmates began to take photos [...] it makes me very angry, it's not a joke!*".

Diagnosis disclosure appeared to be crucially related to peer relationships and acceptance. Telling peers about having seizures was challenging because it involved relying on them to accept and understand the situation: "*The teachers stress me out because they say: you have to tell your roommates on the school trip about your epilepsy!; I don't want to have to explain the same things a hundred times over. It's difficult to explain*". Diagnosis disclosure appeared to be influenced by several other factors such as the type of seizures suffered, their frequency, and also the quality of the friendship in question: "*I didn't tell my new classmates about [my] epilepsy...I don't trust them yet. My old classmates know about it*". One girl also cited the presence of a special education teacher in the classroom as a factor driving disclosure: "*When I changed schools, I felt I had to justify her presence to my classmates*".

Disclosing a diagnosis of epilepsy seemed to elicit a variety of reactions from peers. Initially, negative emotions, such as anxiety and fear, tended to come to the fore: "*[Your] peers are scared, and they ask you a lot of questions*"; "*In the beginning, it was frightening for them: 'Who should we call when you get a seizure? What do we need to do?'*". However, once the disorder had been described to them in greater depth, peer reactions typically changed, and diagnosis disclosure even proved to be a helpful strategy in some cases: "*At school, all my classmates check on me, they look out for me. I'm thankful to them*". When participants discussed their epilepsy in sufficient detail with their close friends, it became possible for these boys and girls to offer them understanding and support: "*Now they know what to do and how to help me. They support me*".

3.2.2 Autonomy

Limitations and restrictions on the development of autonomy were recurring themes. Participants expressed the desire to engage in activities such as driving independently, going out with friends, traveling, practicing sport (e.g., swimming): *Epilepsy is big trouble! Even at school, I can't* *go to the bathroom alone, somebody's got to come with me! I'm forced to go to the toilet with the anxious thought that there is someone else there with me!*"," *I can't stay out with friends until midnight every night; there would be issues, for example, with my medication schedule*". It was difficult for participants to attend parties and drink alcohol like their peers. This contributed to feelings of rejection and isolation from the peer group: "*For me, it is a dangerous situation...I rarely say "no" to my classmates...Managing to spend time with them is very challenging, so I always try to say "yes" if they offer me something*".

Participants wished to affirm their autonomy actively, but this stood in apparent conflict with their need to have someone constantly at hand. Specifically, they sought the presence of someone who was well prepared and knew what to do during a seizure: "*At school, I'm never alone, the headmaster explained everything to my teachers, and I to my classmates*"; "*Once, my father left me alone at home because he had to go out and buy cigarettes... I had a seizure, and I fell... it was horrible!* ". They also felt the need for emotional support from others: "*I think it takes a lot of strength and courage to live with this illness... we need a person by our side, [who is] willing to support and help … you can't get on alone*"; "*Everyone needs to be strong... I trust some people like [my] parents and some friends because I know that when I have seizures, they won't discriminate against me; even if they feel panicky, they'll be there for me*".

3.2.3 School

Participants described the school as one of the least reassuring places to have a seizure, given the risk of adverse reactions on the part of other students and even teachers. They reported that teachers can feel shocked when a student discloses a diagnosis of epilepsy, and are not always skilled at providing reassurance and support: "*At school, the big problem is my classmates... but, actually, even some anxious teachers... they make me feel panicky*".

Furthermore, with regard to their academic achievement, three participants shared difficulties with the discussion group concerning both specific subjects, such as mathematics and memory loss: "*sometimes I can't remember what I'm doing or where I am*".

3.2.4 Future

Autonomy was the dominant theme when participants discussed their future plans. They aspired to have a family, driving a car, traveling, graduating from high school and attending university, and also finding employment (e.g., as a cook or a policewoman). Only one boy said: "*I can't see anything in my future; I don't know what the future holds*". This statement is revealing of the participants' underlying worry about a future characterized by uncertainty and unpredictability. They wish to know if, and when, they will be able to drive: "*Will we ever be able to drive? I have been waiting for so long*"; whether they will complete their studies or find a job: "*I'm afraid of not being able to find a position in life*"; and whether they will be able to travel alone and start their own family. Five adolescents expressed concerns about their epilepsy itself, wondering if they would ever be definitively cured of it: "*I am afraid it will never go away* ", "*Even if the seizures went away, you would always be afraid they might come back* ". Two participants were afraid of dying and two of ending up alone: "*Being on my own ...loneliness is one of my biggest worries"*. One girl also expressed her concerns about a surgery she was due to undergo some weeks later.

3.3 Ad hoc semi-structured interview outcomes: The importance of informing people about epilepsy

When the moderator asked the group to discuss solutions to the problems they had raised, all participants emphasized the importance of informing people about epilepsy: "*Raising awareness at school… last year, a course was organized at our school. I believe that things like this can be useful. Schools must be informed.* "or "*a solution for traveling alone, is to go with friends* […] *it should be explained to them what to do when seizures occur*". There was general agreement among participants about the need for information, which was further borne out by the results of the ad-hoc semi-structured interview. Specifically, in the eyes of this sample of adolescents, explaining epilepsy is key to challenging negative beliefs and prejudices (50%) and educating people about how to manage seizures (37.5%): It is crucial to "*helping people understand that we are like everyone else, despite having this illness*"; "*showing people what to do and bringing epilepsy out into the open, so we don't look crazy*"; "*making it clear that we're not abnormal or weird people but that we simply have to follow certain rules to be well.. a seizure is like a cold, it's something that we have to live with..*"; "*so that people can understand what they have to do when I have a seizure*"; "*so that people can understand that not everybody in the world is healthy and so maybe can help you*".

Moreover, in the semi-structured interviews, a majority of participants (87.5%) stated their opinion that an illustrated booklet could be a valuable means of offering helpful information and reassurance to patients and their families: "*it could be of comfort to families because what the doctor says is often frightening*"; "*It could be helpful, by giving them an idea of what to expect and making their lives easier by providing important information and useful advice*"; "*When you get your diagnosis at first, you have a lot of questions and fears, and it can be confusing. An explanatory book could help you to get your ideas straight and feel supported; [and it could create an occasion for sharing information and feelings with your family members*", "*In the beginning, we were all scared and searching for answers. It would have been useful*".

When the moderator asked participants to represent routine medical procedures related to seizures graphically, the adolescents decided to draw an electroencephalogram procedure, magnetic resonance imaging, blood tests, and antiepileptic drugs.

4. Discussion

Our hypothesis was partially confirmed. Results from self-report questionnaires did not show an impairment of the perceived quality of life. However, despite the positive QOLIE-AD-48 results, qualitative analysis of the FG data yielded four main categories mapping out the psychosocial impact of epilepsy in adolescence: "Peer relationships and acceptance," "Autonomy," "School" and "Future."

FG appears to be a valid method for exploring adolescent perspectives on epilepsy: the peer group setting puts participants at their ease when discussing how they experience their illness (McEwan et al., 2004a, 2004b; Moffat et al., 2009) and gives researchers the opportunity to observe interactions among peers (Barbour, 2007).

Epilepsy represents an additional challenge to adolescents who are trying to complete the normative developmental tasks of adolescence, such as social development, independence, and autonomy (Chew et al., 2019). Our findings suggest that the areas of adolescents' lives most significantly impacted by epilepsy are their peer relationships and the development of their autonomy.

With regard to peer relationships, diagnosis disclosure appeared to be crucially related to peer acceptance. Previous studies (McEwan et al., 2004b; Moffat et al., 2009) indicated that it is problematic for teenagers with epilepsy to disclose their diagnosis to peers, a step that is often associated with rejection and nonacceptance (Benson et al., 2015; Chew et al., 2017a). The fear of stigmatization and discrimination, due to the disclosure of their medical condition, is common among patients with chronic illnesses (Davidson et al., 2004; Graetz et al., 2000; MacLeod & Austin, 2003; Michaud et al., 2009). Both peers and teachers can react negatively when they first learn about the diagnosis, potentially worsening the patients' cognitive and neuropsychological school problems, such as difficulties with memorization (Elliott et al., 2005).

Issues relating to the development of autonomy were frequently discussed among our participants. Adolescents expressed concern about the impact of epilepsy and the restrictions it imposed on them. They appeared to be aware of these limitations and feeling frustrated by them (Moffat et al., 2009). Participants saw these restrictions as preventing them from achieving full independence, and this negatively influenced their expectations concerning their future lives and their chances of attaining personal and professional fulfillment (McEwan et al., 2004b).

Epilepsy has an impact on social participation, for example, adolescents with epilepsy are often unable to obtain the driver's license, or they do not participate in activities with peers for fear of having seizures in front of others (Thomson et al., 2014). Seizures and their effects played a role in limiting young people's participation (Thomas, 2004). The reduced participation in activities with their friends and peers contributed to feelings of difference and inadequacy. Moreover, their inability to participate in these activities reduced opportunities for them to develop friendships and sources of support (Chew et al., 2019).

While highlighting their fear of seizures and worry about their prognosis, these adolescents also explained how their families and friends could play a key role in the emotional and practical management of their illness (Chew et al., 2017a). Results from a review of Pai & Ostendorf (2011) showed that parental involvement is associated with better treatment adherence and health outcomes among adolescents with chronic illnesses (Helgeson et al., 2008). However, parental restriction, which occurs as a result of parents' perception of their child's vulnerability to injury or death, is likely to negatively affect young people's sense of independence and autonomy (Chapieski et al., 2005). Thus, it is important to maintain a balance between adequate supervision and facilitating young people's autonomy (Chew et al., 2019).

Hence, interventions that aim to support adolescents with epilepsy should also be directed at reducing socially imposed barriers (e.g., parental restrictions and institutional policies), and at promoting appropriate responses from family members, peers, and other significant others (Chew et al., 2019; Jantzen et al., 2009; King et al., 2003).

Using a mixed-method research approach appears to yield more multifaceted information than patients' clinical outcomes alone. If we had analyzed our participants' PHQ-9, GAD-7, and QOLIE-AD-48 scores only, we would not have accessed the participants' own perspectives on how the illness was impacting their psychosocial development. Qualitative research methods facilitate an in-depth exploration of participants' thoughts and feelings (Rapport et al., 2015), and techniques such as FG can help patients to cope with their illness, increasing their awareness about it (Kerr et al., 2011), and giving them the opportunity to experience – jointly with others facing similar health conditions – understanding without stigmatization (McEwan et al., 2004a, 2004b). It is known that sharing the same clinical conditions as others enhances individuals' perceived social support and quality of life (Elafros et al., 2013), and this is particularly true for adolescents in search of stable friendships. Higher quality research of this kind will enhance the validity of findings and translate into better health, education, and social practices in the care of epileptic adolescents and their families (Harden et al., 2016).

5. Conclusions

This pilot study confirmed the effectiveness of qualitative research methods, and specifically FG techniques, in investigating adolescents' experience of living with epilepsy, a chronic illness characterized by uncertainty and unpredictability.

Group sessions may offer the optimum setting for epileptic adolescents to share their thoughts and feelings, become more aware of their coping and problem-solving skills, and experience social support from peers affected by the same health conditions (Plante et al., 2001). Our results confirm the value of extending epilepsy research to include mixed-method approaches. Specifically, adopting qualitative techniques such as focus group discussions to explore epileptic adolescents' thoughts and feelings and the psychosocial impact of epilepsy during adolescence, can inform clinical practice and promote the psychoeducation, the empowerment and quality of life of teenagers with epilepsy (Cappelletti et al., 2020; Perkins & Zimmerman, 1995). Moreover, our mixed-method pilot study offers a starting point for the design of future epilepsy research that is similarly aimed at developing a more patient-focused view of the illness and providing a more comprehensive understanding of what it means to live with a chronic condition (Rapport et al., 2015). In clinical practice, the group setting implemented in the present study may be usefully reproduced, with a view to offering adolescents with epilepsy the opportunity to discuss their fears and anxieties and overcome social isolation (Moffat et al., 2009). Finally, qualitative outcomes can inform clinical intervention and guide practitioners to enhance their adolescent patients' quality of life by helping them to identify strategies for becoming more independent and coping with challenges in their peer relationships.

The study is not without limitations. The small sample size in the present study implies that the results may not be generalizable to other populations of adolescents with epilepsy. Further studies using FG with a more substantial number of participants should be conducted. Furthermore, participants' evaluation before FG participation begins (pre-test), and at the end of the program (post-test), could provide useful information about FG effectiveness. Future research should also include cohorts from different ethnic groups and locations (e.g., both urban and rural), and simultaneous FG with patients' parents. Nevertheless, this study can usefully inform the design of future epilepsy research psychoeducation projects and empowerment combining quantitative and qualitative approaches to offer a stronger overall methodology (Moffat et al., 2009).

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