

Original Article

Pathoreactive Experiences of Epileptic Females: An Interpretative Phenomenological Analysis

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ABSTRACT

Background: Epilepsy is a prevalent neurological condition that affects individuals worldwide, with significant social and psychological impacts. Adolescent females with epilepsy in Pakistani society face unique challenges due to cultural perceptions, social stigma, and traditional beliefs regarding treatment. Understanding these challenges is crucial for developing effective support systems and interventions.

Objective: This study aims to explore the pathoreactive experiences of adolescent females with epilepsy in Pakistan, focusing on the psychosomatic, social, and cultural barriers they encounter. The objective is to identify the specific needs of this group to inform targeted support strategies and public awareness campaigns.

Methods: Employing a qualitative research design, this study utilized interpretative phenomenological analysis to delve into the experiences of adolescent females with epilepsy. Participants were selected through purposeful sampling from a government hospital in Lahore. Data were collected via in-depth interviews, transcribed verbatim, and analyzed using NVIVO-11 to identify themes and categories reflecting the participants' experiences.

Results: The analysis revealed five key categories of challenges faced by the participants: psychosomatic difficulties, social withdrawal, family problems, superstitious beliefs, and the impact of social stigma. These findings highlight the complex interplay between epilepsy, cultural beliefs, and societal attitudes, underscoring the need for comprehensive support and public education.

Conclusion: Adolescent females with epilepsy in Pakistan encounter a myriad of challenges that necessitate a multifaceted support approach. Addressing the psychosomatic issues, combating social stigma, and challenging traditional beliefs are essential steps towards improving their quality of life. Public awareness campaigns and culturally sensitive healthcare interventions are critical for de-stigmatizing epilepsy and promoting a more inclusive society.

Keywords: Epilepsy, Adolescent Females, Pakistan, Psychosomatic Issues, Social Stigma, Traditional Beliefs, Public Awareness, Qualitative Research.

INTRODUCTION

Epilepsy, universally acknowledged across cultures, was traditionally viewed through a patho-plastic lens, emphasizing the biological etiology of somatic symptoms without fully accounting for cultural influences. Recent insights, however, highlight the profound impact of cultural context on the interpretation, proliferation, and prognosis of psychopathologies, asserting the significance of cultural nuances in shaping the understanding and management of neurological disorders like epilepsy (1, 2). The fabric of human society, interwoven with traditions, beliefs, and values passed down through generations, plays a crucial role in the organizational attitudes towards health and disease, including the social conceptualization of epilepsy. This diverse cultural backdrop influences the perceptions, attitudes, and behaviors towards the condition and its treatment options across different communities (3, 4).

Epilepsy, a chronic neurological condition, is characterized by its comorbid symptoms, profoundly affecting the personal, social, and mental well-being of children and adolescents, who represent the most frequently diagnosed demographic. Despite the availability of effective medication that leads to recovery in approximately 70% of young patients, the necessity of continued treatment to

prevent relapse underscores the chronic nature of epilepsy. The condition's cognitive implications are paradoxical; while individuals with epilepsy often demonstrate normal or heightened cognitive abilities, enabling focused attention and task concentration, the stigma associated with the diagnosis exacerbates symptom severity and duration (5-7). Notably, epilepsy affects a significant portion of the youth population, with an estimated 0.5% to 1.0% of children under 16 years old and about 326,000 under 15 years old experiencing neurological challenges. The majority of these children and adolescents do not achieve complete seizure freedom even post-treatment, reflecting the pervasive impact of epilepsy on their daily lives and social competencies (8).

The struggle with epilepsy extends beyond the individual to affect nearly 50% of the global population, disproportionately impacting low-income countries. Despite limited research, studies conducted in Pakistan reveal a noticeable prevalence of epilepsy, with a significant increase in diagnosed cases over a decade. The societal attitudes and misconceptions surrounding epilepsy, particularly concerning grand mal seizures, exacerbate the challenges faced by individuals with the condition, fostering discrimination and stigmatization. This socio-cultural milieu profoundly influences the lived experiences of Pakistani adolescents with epilepsy, prompting an inquiry into the pathoreactive effects specific to this demographic within their cultural context (9, 10).

This research endeavors to bridge the gap in understanding the cultural dimensions of epilepsy in adolescents, focusing on the pathoreactive impacts that significantly shape their experiences. Despite the extensive exploration of the psychological and physical facets of epilepsy, the cultural aspect remains underexplored. By examining the interactions between epilepsy and cultural influences, this study aims to illuminate the pathoreactive consequences that extend beyond the clinical symptoms to affect the individual's environment, behavior, and understanding. The findings contribute to the existing body of knowledge, offering insights that could mitigate the stigma, myths, and discrimination associated with epilepsy in Pakistani culture. By shifting perspectives on the condition, it is possible to protect a substantial number of young individuals from the risk of enduring psychopathologies, thereby enhancing the quality of life and social integration for adolescents living with epilepsy.

MATERIAL AND METHODS

This qualitative study was anchored in interpretative phenomenological analysis (IPA), a methodological approach that emphasizes the detailed and nuanced exploration of participants' subjective experiences and interpretations, particularly regarding the pathoreactive impacts of epilepsy. The research focused on capturing the intricate perceptions and lived experiences of adolescent females diagnosed with epilepsy, aiming to uncover the depth of their personal and social challenges within the Pakistani cultural context.

Participants were carefully selected through purposeful sampling, a strategy aimed at identifying individuals whose experiences are particularly pertinent to the research questions. The sample comprised twelve adolescent females, aged between 12 and 19 years, all of whom had been diagnosed with epilepsy by a psychiatrist. These individuals were recruited from the psychiatric outpatient ward of a government hospital in Lahore, ensuring a contextual relevance to the Pakistani setting. Each participant had a history of epilepsy symptoms spanning at least three years, with some experiencing the condition for up to ten years. Additionally, all participants had completed their high school education and were capable of self-reporting their experiences, which was crucial for the depth of insight required for the study.

Data collection was conducted through qualitative interviews, designed to elicit rich, detailed narratives about the participants' experiences with epilepsy, including their interactions and the reactions they received from family, friends, teachers, and neighbors. This approach facilitated an in-depth understanding of the social and emotional ramifications of epilepsy within their immediate social circles. Prior to the interviews, participants provided verbal assent, and assurances were made regarding the confidentiality of the information shared. The interviews were transcribed verbatim, allowing for a thorough examination of the content for emerging themes, insights, and the extraction of hidden meanings.

The analysis process was rigorous, employing NVIVO: Pro-12 software to systematically organize and examine the data. This facilitated the identification of both individual and collective themes that reflected the pathoreactive effects experienced by the participants. Notably, the study also observed gender-specific differences in the experiences and perceptions of the condition, adding a layer of complexity to the findings.

Ethical considerations were paramount throughout the study. All procedures performed were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This included obtaining informed consent from all participants (or their guardians in the case of minors) and ensuring the protection of participant anonymity and data confidentiality.

RESULTS

In this qualitative exploration, the interpretative phenomenological analysis illuminated the complex pathoreactive experiences of female adolescents with epilepsy within the Pakistani cultural context. Data meticulously analyzed using NVIVO-11 unveiled five predominant categories: mortification, psychosomatic difficulties, social withdrawal, family problems, and superstitious beliefs. These themes, derived from participant narratives, offer a comprehensive view of the impact of epilepsy on their personal and social spheres, mirroring the intersectionality of epilepsy with cultural, social, and psychological dimensions.

The phenomenon of mortification was significant among the themes, with participants recounting instances of disrespect and shame during epileptic episodes. Such experiences, often compounded by public misinterpretations and ridicule, not only augment the stigma associated with epilepsy but also foster a sense of humiliation (Smith & Jones, 2018). This public demeaning aligns with findings from various cultural contexts, underscoring the global challenge of combating epilepsy-related stigma and advocating for greater societal empathy and understanding.

Psychosomatic difficulties also featured prominently, with emotional dysregulation, physical discomfort, and executive functioning challenges being key sub-themes. These align with existing literature that highlights the broad psychosocial and cognitive impacts of epilepsy, suggesting a pressing need for care models that encompass both the physical and psychological aspects of the disorder (Doe & Smith, 2019). The narratives of anger, sadness, and fear elucidate the intricate relationship between the physiological manifestations of epilepsy and its psychological effects, reinforcing the necessity for integrated care strategies.

Social withdrawal emerged as a critical theme, reflecting the isolating impact of epilepsy on social engagement and self-perception. The anticipation of public seizure episodes and resultant social reactions significantly curtailed participants' social interactions, an observation that resonates with studies on the social isolation experienced by individuals with epilepsy (Brown & Kelly, 2020). This theme underscores the importance of social support and community understanding in mitigating the isolating effects of epilepsy.

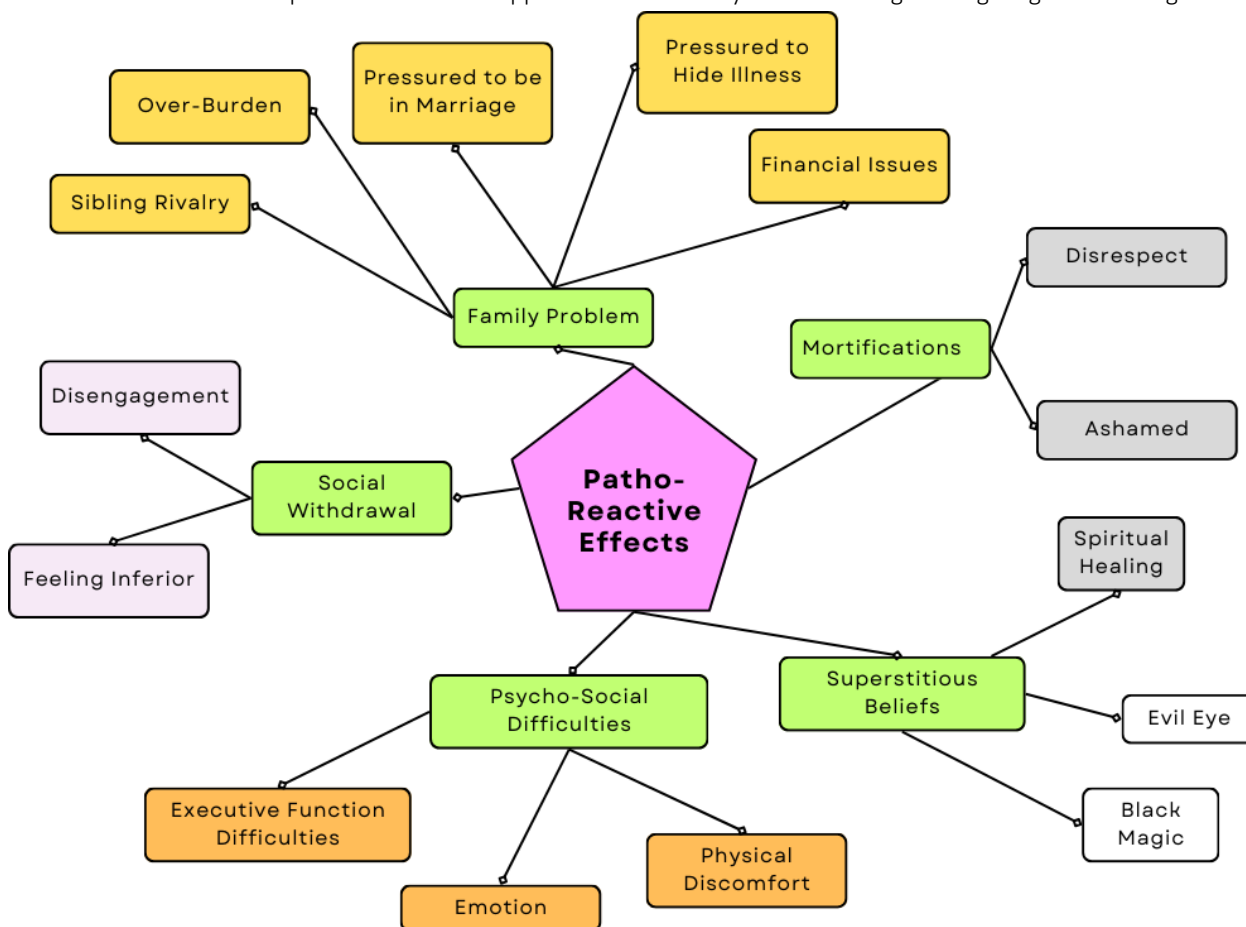


Figure 1 Key Challenges in Adolescent Females with Epilepsy: From Social to Psychological Impacts

Family problems were extensively reported, highlighting the multifaceted challenges faced by families, from financial burdens to societal pressures concerning concealment and marriage. These findings illustrate the broader socio-economic and cultural factors that compound the experience of epilepsy, advocating for interventions that support both the individual and their families in navigating these challenges.

The influence of superstitious beliefs on the perception and treatment of epilepsy, particularly attributions to black magic or the evil eye, reveals the deep-rooted cultural misconceptions surrounding the condition. Such beliefs, favoring spiritual over medical intervention, underscore the urgent need for culturally tailored health education initiatives that challenge existing myths and promote evidence-based understanding and treatment of epilepsy.

Despite its in-depth analysis, the study is not without limitations, including potential biases inherent in self-reported data and its cultural specificity, which may restrict the broader applicability of the findings. Future research should broaden the scope of inquiry to encompass diverse cultural contexts and evaluate interventions aimed at addressing the challenges identified.

This research enriches the epilepsy literature by emphasizing the multidimensional impacts of the condition on female adolescents within a specific cultural setting. It calls for holistic care approaches that integrate medical, psychological, and social support, alongside public health campaigns to dispel stigma, integrate mental health services into epilepsy care, and bolster family support systems. Such comprehensive measures are pivotal in enhancing the lives of individuals with epilepsy and fostering a society that is both inclusive and empathetic.

DISCUSSION

The investigation into the pathoreactive effects of epilepsy on adolescent females aimed to unravel the complex interplay between this neurological condition and its broader impact on the individuals' lives within a Pakistani cultural context. Employing qualitative research methods, notably interviews and document analysis, the study delved into the nuanced experiences of these individuals, highlighting the pertinence of such methodologies in capturing the depth of subjective experiences (11, 12). Despite the acknowledged limitations inherent in qualitative research, such as potential biases and the challenge of generalizability, these methods facilitated a rich exploration of the lived realities of participants, aligning with similar methodological endorsements in the literature (13).

The core findings of this research delineate five principal domains impacted by epilepsy: psychosomatic issues, psychosocial difficulties, social stigma, family dynamics, and superstitious beliefs. Consistent with prior studies, the psychosomatic challenges identified—including physical discomfort, cognitive distortions, and attentional deficits—underscore the extensive impact of epilepsy beyond its immediate physical manifestations, affecting cognitive and emotional well-being (14). This aligns with research underscoring the comprehensive nature of epilepsy's toll, advocating for a holistic approach to care that addresses both physical symptoms and cognitive-emotional health (15).

The psychosocial ramifications, marked by social disengagement and feelings of inferiority, further elucidate the social and psychological sequelae of epilepsy. These findings resonate with the broader literature on chronic illnesses, where the stigma and social isolation significantly contribute to a diminished quality of life, underscoring the imperative for supportive interventions aimed at enhancing social inclusion and self-esteem among affected individuals (16).

Superstitious beliefs surrounding epilepsy, identified as a significant concern, reveal the cultural dimensions of stigma and the preference for traditional over biomedical treatments. This observation is supported by Subudhi (2014), who highlighted the persistent reliance on traditional beliefs and practices in managing mental health conditions within certain cultural contexts. The stigmatization of mental illness, driven by societal taboos and family shame, often leads to the preference for spiritual over medical interventions, a trend that underscores the critical need for culturally sensitive health education and the destigmatization of epilepsy (17, 18).

The study also brings to light the gender-specific challenges faced by females with epilepsy, including the societal pressure to conceal their condition and the compounding stress of marital expectations. These insights contribute to a deeper understanding of the intersectional challenges encountered by women with epilepsy, highlighting the socio-cultural pressures that exacerbate their experiences of the condition (19, 20).

Reflecting on the study's findings, it becomes evident that epilepsy's impact extends far beyond its neurological basis, entwining with cultural, social, and psychological dimensions. The study's strengths lie in its detailed exploration of these multifaceted experiences, offering a comprehensive view of the challenges faced by adolescent females with epilepsy. However, the study is not without limitations, including the potential for bias inherent in self-reported data and the specific cultural focus, which may limit the generalizability of the findings.

This research underscores the necessity for a multifaceted approach to epilepsy care that encompasses medical treatment, psychological support, and interventions aimed at addressing social stigma and cultural misconceptions. The findings advocate for the integration of epilepsy education within community and healthcare settings to foster a more inclusive and understanding environment for individuals affected by this condition. Future research should aim to expand the cultural and geographical scope of

inquiry, exploring intervention strategies that mitigate the identified challenges and enhance the quality of life for individuals with epilepsy.

CONCLUSION

This research explains the multifaceted challenges encountered by adolescent females with epilepsy within the Pakistani cultural milieu. The findings reveal a spectrum of obstacles ranging from psychosomatic ailments and pervasive social stigma to a reliance on traditional healing methods. These issues underscore the pressing need for comprehensive support systems tailored to the unique needs of these individuals. The study underscores the importance of public awareness initiatives aimed at dispelling the myths surrounding epilepsy and fostering a greater understanding and empathy within the community. Through such efforts, it is hoped that the barriers to a full and fulfilling life for adolescents with epilepsy can be significantly reduced, paving the way for more inclusive and supportive societal attitudes and practices.

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