

ORIGINAL RESEARCH ARTICLE

Coping experiences in individuals with
drug-resistant epilepsy and functional/
dissociative seizures: A qualitative study**Lucila Gonzalez Molina**^{1,2*}, **Camila Wolfzun**^{1,2}, **Mercedes Sarudiansky**^{1,2},
Nahuel Pereira de Silva³, **Luciana D'Alessio**^{1,3}, and **Guido P. Korman**^{1,2}¹National Scientific and Technical Research Council (CONICET), Buenos Aires, Argentina²Institute for Psychological Research, Faculty of Psychology, University of Buenos Aires, Buenos Aires, Argentina³Epilepsy Center, J.M. Ramos Mejía Hospital, Buenos Aires, Argentina**Abstract**

Individuals diagnosed with drug-resistant epilepsy (DRE) and functional/dissociative seizures (FDS) face multiple social, economic, and psychological difficulties. Coping is central to adaptation and psychological well-being in chronic health conditions. This study explores and describes the coping strategies of patients with DRE and FDS from Buenos Aires, Argentina. To our knowledge, this is one of the first studies in Latin America to pursue this objective. A qualitative exploratory design was used for this study. Eight adult participants (four with DRE and four with FDS), aged 33–56 years, were recruited from the J.M. Ramos Mejía Hospital between 2021 and 2023. Data were collected through semi-structured interviews, based on the McGill Illness Narrative Interview, and analyzed using thematic analysis principles to capture patients' experiences. Four coping strategies were identified from the analysis. First, both groups perceived social support from relatives and friends through emotional and practical assistance. Second, religiosity provided meaning, hope, and emotional relief through faith and religious practices. Third, participants reported seeking distraction as a way to distance themselves from intrusive negative thoughts. Finally, engaging in meaningful daily activities promoted autonomy and improved mood. This study offers a preliminary exploration and contributes to understanding the coping strategies of patients with DRE and FDS in Argentina. These strategies were perceived as valuable for managing the challenges and consequences of their seizures. Understanding these narratives enhances the professional–patient relationship and provides a more comprehensive perspective on living with seizures.

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Citation: Molina LC, Wolfzun C, Sarudiansky M, de Silva NP, D'Alessio L, Korman GP. Coping experiences in individuals with drug-resistant epilepsy and functional/dissociative seizures: A qualitative study. *J Clin Basic Psychosom.* 2026;4(3):025370070.
doi: 10.36922/JCBP025370070

Received: September 12, 2025**Revised:** September 19, 2025**Accepted:** September 23, 2025**Published online:** October 14, 2025

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Keywords: Drug-resistant epilepsy; Functional/dissociative seizures; Coping strategies; Qualitative research; Argentina

1. Introduction

Epilepsy is one of the most common neurological diseases, affecting individuals of any age, sex, social class, and culture.¹ It is characterized by an excessive or hypersynchronous brain activity that produces a recurring tendency toward unprovoked

seizures.² Although prevalence and incidence vary globally, they are estimated at 6.38/1,000 and 61.44/100,000, respectively.³ Across treatment with antiseizure medication, approximately 70% of patients achieve adequate control of their seizures (i.e., seizure freedom).¹ However, 36.3% of the overall prevalence of patients are estimated to develop drug-resistant epilepsy (DRE).⁴ DRE is defined as the lack of response to at least two appropriately chosen and tolerated antiseizure drugs to achieve sustained seizure control.⁵

Functional/dissociative seizures (FDS) are frequently misdiagnosed as DRE, leading to the referral of approximately 20–30% of patients to specialized epilepsy centers.^{6,7} Furthermore, 22% of individuals with FDS present comorbidity with epilepsy.⁸ FDS is defined as paroxysmal events characterized by sensory, cognitive, and motor alterations, which occur from a complex interaction between psychosocial and biological factors,^{9,10} with an incidence estimated at 3.1/100,000 individuals.¹¹

Both groups of patients present high rates of psychiatric comorbidities, mainly with anxiety and depressive disorders,^{12–14} and their quality of life is significantly affected.^{15,16} For these patients, living with seizures implies facing economic, social, family, and psychological challenges.¹⁷ The stigma and discrimination associated contribute negatively to their quality of life and self-esteem.^{15,18,19}

The importance of coping strategies and their impact on psychosocial well-being, prognosis, and adaptation to the illness has been recognized by several studies in patients with epilepsy and with FDS.^{20–23} Coping is a complex process of cognitive and behavioral responses to deal with a situation evaluated as stressful or exceeding personal resources.^{24,25} Although the studies, as mentioned earlier, focused on the quantitative evaluation of coping, a few studies have opted for an approach centered on analyzing patients' narratives. Pretorius and Sparrow²⁶ explored the coping challenges and resources of a South African population diagnosed with FDS, highlighting the availability of several resources, such as family support, religion, and spirituality, which allowed them to lead a satisfactory life despite many difficulties. Deegbe *et al.*²⁷ found that people living with epilepsy in West Africa combined different forms of treatment (e.g., traditional, spiritual) to try to control their seizures, in addition to pharmacological treatment. The authors highlighted that beliefs about the causes of epilepsy play a key role in shaping patients' coping strategies.

These investigations were conducted in countries whose cultural contexts differ from those of the Latin American population, thus limiting their direct transferability.²⁸ In Argentina and Latin America, there are a few qualitative studies in these patient groups, focusing on understanding the perspectives and explanatory

models of the illness.^{29–31} Regarding DRE, patients reported significant consequences of the illness in their daily lives, including physical, cognitive, social, and occupational limitations that affect their autonomy and well-being. At the same time, they expressed diverse beliefs about the origin of their seizures (i.e., biological, psychosocial, and supernatural) and a frequent use of traditional medicine practices (e.g., consultations with healers).³⁰ Individuals with FDS attributed the causes of their seizures primarily to psychosocial factors, often drawing on folk explanations (e.g., *daño*, witchcraft). In addition, patients often combined biomedical treatment with religious, traditional, and alternative practices.^{29,31}

This article aims to explore and describe the coping strategies of patients with DRE and FDS from the Argentine population, in relation to the challenges of living with seizures. Thus, a greater understanding would be achieved regarding the role of individual experience in coping with chronic health problems and its relevance for professional care. Furthermore, to our knowledge, this is one of the first articles in Latin America to explore coping strategies in patients with DRE and FDS from a qualitative perspective.

2. Methodology

2.1. Sample and participants

This study consisted of a consecutive sample with the following inclusion criteria: (i) Adult patients (> 18 years), (ii) Patients of both sexes, (iii) Patients diagnosed with DRE or FDSS and referred to the J.M. Ramos Mejía Hospital, one of the leading referral hospitals in the country in the field of neurology, and (iv) Patients who completed the semi-structured McGill Illness Narrative Interview (MINI).³² Participants were recruited between 2021 and 2023 and were invited to participate during hospitalization in the video-electroencephalogram (vEEG) unit. The vEEG, considered the gold standard, established the differential diagnosis between FDS and DRE.³³ All patients evaluated in this unit underwent a clinical protocol that included a neurological, psychiatric, neuropsychological, and neuroimaging assessment. Participants were excluded if they presented (i) Both types of seizures (epileptic seizures + FDS), (ii) Psychotic symptoms at the time of assessment, and (iii) An IQ <70 according to the Wechsler Adult Intelligence Scale.³⁴

A total of 24 patients were evaluated in the vEEG unit. Eight were eligible and included in the study. All participants signed an informed consent form in which the objectives of the study were explained, ensuring the confidentiality of the information provided. This study was approved by the Ethics Committee of the J.M. Ramos Mejía Hospital.

2.2. Data collection

This is a qualitative, exploratory, cross-sectional study. To achieve the study's objective, the Spanish version of the MINI was used.^{30,32} This is a semi-structured interview that enabled the exploration of patients' beliefs and perspectives regarding the illness, as well as health-seeking behaviors.³² For this study, we focused on the questions from Section 5, "Impact on life," which specifically inquire about coping strategies and resources. The questions included:

- (i) What things helped you during this period of your life?
- (ii) In what way did your family or friends help you through this challenging period of your life?
- (iii) How did your spiritual life, faith, or religious practice help you get through this period of your life?

Two psychologists (LGM, CW) conducted the interviews. The interviews were conducted individually and lasted approximately 50 minutes each. All interviews were recorded and transcribed to be analyzed according to the principles of thematic analysis.³⁵

2.3. Analysis

For the analysis, a deductive approach was initially employed, identifying the pre-defined conceptual themes (coping strategies and resources), as reflected in the questions described in the MINI. Then, an inductive approach was applied, in which the interview segments were read repeatedly, and codes were subsequently assigned to the relevant segments, which were reviewed several times by the authors to reach consensus. The codes were then grouped into themes. Given the nature of the thematic analysis method, special care was taken to reduce bias in data analysis through peer discussion of the original material. The analysis was supported by the qualitative data analysis software ATLAS.ti (version 9). Pseudonyms were assigned to the participants to ensure anonymity.

3. Results

A total of eight participants were interviewed, four diagnosed with FDS and four with DRE. [Table 1](#) presents the sociodemographic data of the participants.

Analysis revealed that both groups of participants perceived the support of different resources and strategies to cope with the difficulties of the illness. These themes are reflected in four categories: Social support, religiosity, distraction-seeking, and meaningful daily activities.

3.1. Social support

This theme encompasses the perception of emotional support, assistance, and companionship provided by family members, partners, and friends to face the

challenges implied by the illness. Both groups reported this coping strategy, highlighting support mainly through the company of a loved one, concern for their health, and concrete assistance in carrying out activities.

Patients with DRE and FDS mentioned their family as the primary source of support. For example, Romina, a patient with DRE, mentioned how her family helps by assisting her every time she has a seizure, "Yes, my family. My mother, my brother. Every time I have an absence, they have to run..."

Roberto, a patient with FDS, related the importance of his wife's company during his health treatments, despite their conflicts.

(...) when I underwent treatment, my son was by my side... My wife was always... for better or worse, she was always by my side. Whether we were separated or not, she was always with me; in the worst moments, she was with me. (Roberto, FDS)

Norma emphasized her family's company, which prevented her from feeling alone: "By accompanying me, by being there... they keep me company at home. Not being alone."

Support from friends involves assistance with activities that are limited by the illness. For example, Romina said that her friends helped her with mobility due to the limitations she experiences in her autonomy as a result of her seizures.

Like, "Romi, I will pick you up, Romi, I will take you, Romi..." The other day I asked a friend if she wanted to come with me to buy some clothes. And she said, "OK, Romi, I will pick you up and leave my bike at your house, and then we will walk to the town center." And that is fantastic for me. Actually, I do not tell my friends, "Pick me up and let's go to a place." We usually meet in town directly. But today, I would need them to pick me up and take me there. (Romina, DRE)

Assistance through friends' care to prevent injuries was also noted. Lola, a patient with FDS, talked about the importance of her friends' care in preventing her from getting hurt during a seizure.

I lived with a friend and her boyfriend for two or three months, and every night they were checking to make sure I did not have a seizure. Luckily, they never saw me have one, but they are always concerned, alert, watching out for me, taking care of me. (Lola, FDS)

Moreover, friends also provided emotional support. In Julio's case, he disclosed his diagnosis to one of his friends

Table 1. Sociodemographic characteristics of participants

Participant	Diagnosis	Age ^a	Gender	Residence	Level of education	Employment status
Norma	FDS	50	Female	A.M.B.A.	Did not complete secondary school	Unemployed
Roberto	FDS	56	Male	C.A.B.A.	Did not complete secondary school	Unemployed
Lola	FDS	34	Female	A.M.B.A.	Complete tertiary education	Employed
Matías	FDS	40	Male	A.M.B.A.	Did not complete secondary school	Unemployed
Domingo	DRE	50	Male	C.A.B.A.	Completed tertiary education	Employed
Romina	DRE	39	Female	A.M.B.A.	Completed tertiary education	Unemployed
Julio	DRE	19	Male	A.M.B.A.	Did not complete tertiary education	Student
Juan	DRE	33	Male	A.M.B.A.	Completed secondary school	Unemployed

Note: ^aAge at the time of assessment (years).

Abbreviations: A.M.B.A.: Área Metropolitana de Buenos Aires; C.A.B.A.: Ciudad Autónoma de Buenos Aires. DRE: Drug-resistant epilepsy;

FDS: Functional/dissociative seizures.

and emphasized that he can always count on his support: “And... a few friends know. And maybe one that I talk to now always tries to support me.”

3.2. Religiosity

This theme is defined by the experience of faith in God and its effects and the exercise of faith through religious practices. Religiosity is a coping strategy used by patients with DRE and FDS. According to Juan’s perspective, the experience of faith allowed him to view the illness as part of a divine plan for his life, and how his improvement or worsening is related to that plan. In addition, faith is connected to the hope for a cure for his illness.

And... regarding spirituality, well... my faith in God helped me a lot. It helped me a lot because, for me, it was progress from God. Because everything is based on God’s plan for my life, right? Whether I get worse or better, right? I believe in God that at some point I will be cured, that is... when God says, “Well, this is as far as you go,” and then I can show those who are sick that there is a way out, not that there is not. (Juan, DRE)

Moreover, mystical experiences, such as Romina’s, affect faith in a way related to the hope of a cure.

What helped me, I always say, is that one day (...) I saw Jesus’s face in the wardrobe, and it never disappeared. So, I think he appeared to tell me, “Well, Romi, yes, I am here, have faith, things will work out.” (Romina, DRE)

Coping strategies related to the practice of faith involved specific actions, such as prayer, petitions, and reading biblical passages, which patients engaged in to seek strength and relief from discomfort. For example, Romina asked for strength to tolerate her illness, hoping to find a solution to her seizures: “Uh... and I ask Him for strength to, to tolerate

all this that I have to tolerate until a solution is found.” Roberto shared his experience of feeling the priest’s words as a personal message that gave him strength to think positively while praying to God: “It was as if sometimes what the priest said was meant for me... As if he were saying to me... ‘you have to be stronger,’ eh... do not think about the bad, think about the good, I prayed to God.” Lola resorted to reading biblical passages in times of stress because they allowed her to feel calm: “(Faith) helps me because it keeps me calm. Believing, or perhaps, in moments of great tension, reading a verse from the Bible, also helped me to calm down.”

3.3. Distraction-seeking behavior

Seeking distraction is a theme defined by performing complex manual activities to shift the focus of attention away from negative thoughts, and it was present only in the group with FDS.

I always look for things that are very difficult to fix, so that my brain thinks about that and does not think about my past, what happened to me... or what happened to me yesterday, or what might happen to me tomorrow... Do you understand? I look for distraction, I look to be distracted. (Roberto, FDS)

3.4. Meaningful daily activities

This theme, identified among participants with FDS, encompasses daily activities that positively impact mood and well-being. It involved actions contributing to a sense of self-efficacy and autonomy, such as helping in the kitchen or going for a walk. It also included daily activities, such as traveling to the hospital for medical appointments, which represent a change of environment that positively impacts the patient’s mood.

Norma said, “For me, it helped me to start doing some things, to be able to do things, to walk, to

help with the kitchen here..." Matías said, "And coming here helps me a lot, I clear my head by looking outside. (The trip to the hospital) Sure, it clears my head a little. Before being there, always in the same place."

4. Discussion

This study explored how patients with DRE and FDS cope with the challenges of living with seizures. A qualitative analysis of the experiences reported found that both groups resorted to different strategies to cope with the difficulties related to a chronic health problem. Social support from family and friends was a frequent coping resource, through companionship, emotional support, care to prevent seizures, and concrete assistance in performing certain activities that are limited by the illness. These findings are consistent with other qualitative studies emphasizing social support as a frequent coping strategy in both groups across different cultures.^{17,26,27,36} Social support is relevant because, as a consequence of experiencing seizures, patients undergo stigmatization and social rejection, and often feel that they are a burden to their relatives and significant others.^{17,19,37} In addition, their lives are considerably affected, both by the possibility of injury and the consequent limitations in their autonomy.^{26,30} In individuals with epilepsy, social support is associated with the ability to cope with stressful situations through more adaptive resources, facilitating acceptance and problem-solving.³⁸ Similarly, it is a positive factor for patients with FDS, and it has been shown to favor recovery and adaptation.²⁶ In this regard, the patients in this study received emotional support and assistance from their loved ones. Seeking social support among individuals with FDS can also be explained by the desire to maintain interpersonal interaction and the positive value of socializing. A study reported that most patients sought weekly telephone interaction with family and friends and spent considerable time on face-to-face interactions.³⁹ This can positively impact the patient's life, improving their tolerance to distress and psychosocial well-being.⁴⁰ For example, Lola, a patient with FDS, felt cared for by her friends, who were watching out for the possibility of a seizure. Similarly, Juan (another patient with FDS) emphasized the importance of the support of his wife and son during the treatments he underwent, and how this helped him to overcome the difficult moments of the illness.

Religiosity was another way of coping with the challenges of the illness for both groups. Religious coping is related to the search for meaning, the perception of greater control, strengthening closeness to God, and achieving life change through religious practices.⁴¹ Engaging in religious beliefs and spirituality is a coping

strategy identified in several studies on patients with epilepsy and with FDS.^{26,27,36,41} In a study on epilepsy and religion, religious attitudes characterized by belief in a punitive God and lack of control over the condition made treatment adherence difficult and were associated with greater psychological distress.⁴¹ However, in the study by Deegbe *et al.*,²⁷ turning to God represented the search for a source of healing whose power is believed to transcend any other form of treatment. In this study, faith in God and religious practices allowed patients to find emotional relief from the distress of the illness and gave them the strength to continue despite the difficulties. This experience was similar to that reported in the study by Pretorius and Sparrow,²⁶ in which spirituality had a buffering effect on seizures, and placing trust in a non-judgmental higher power provided a cathartic sense of relief. In addition, similar to Deegbe *et al.*,²⁷ some patients trusted that they might find a cure for their condition through faith. Faith in the intervention of a higher power to obtain healing could be understood as the search for an alternative solution in response to the perceived failure of biomedical treatments to control seizures. In other qualitative studies conducted in Argentina, patients with DRE and FDS resorted to religious practices as supplementary methods to conventional biomedical treatments.^{29,30} In Africa, seeking support from religious groups and traditional medicine healers is also common.^{25,26} According to some studies, these strategies may be related to the belief that seizures are caused as part of God's plan for their lives, by possession, or by a "curse."²⁹⁻³¹ In fact, Juan described how his faith in God helped him trust in the possibility that his epilepsy would improve, according to God's plan for his life.

In this study, only patients with FDS resorted to seeking distraction as a coping strategy to deal with the negative thoughts. In patients with FDS, the tendency to worry and ruminate is often common and can sometimes present as an intrusive or uncontrollable experience.⁴⁰ According to the biopsychosocial model that explains FDS, these processes can play a role as a precipitating or maintaining factor of seizures,^{9,42-44} which is why they are often the target of some psychological treatment models.⁴⁵⁻⁴⁷ The most recent reviews on coping in FDS suggest that strategies, such as cognitive disengagement or distancing may be associated with greater psychological distress.^{48,49} However, distraction techniques are frequently employed as interventions within psychotherapeutic models for FDS (e.g., cognitive-behavioral therapy), aiming to redirect attention away from physical symptoms, intense emotions, or negative thoughts toward external stimuli (e.g., sensory stimuli).^{46,48} Although avoidance as a primary coping strategy may hinder effective problem-solving, distraction techniques have proven helpful in managing seizures while other therapeutic goals

are addressed.^{46,50} In addition, in a review of qualitative studies, distraction strategies were identified as one of the coping approaches in this group of patients.³⁷

Individuals with FDS experience different limitations in daily life, such as being unable to drive, perform household chores, or work.^{18,39,51} This may lead to social isolation, shame, and low self-esteem.^{37,51} In contrast to the findings of Pretorius and Sparrow,²⁶ in this study, some participants with FDS perceived a sense of well-being when they could carry out activities at home or when traveling to medical appointments. Performing meaningful daily activities was a strategy that had a positive impact on their mood and allowed them to cope with the distress associated with the loss of autonomy due to seizures. People with FDS experience a significantly greater impairment in their quality of life compared to patients with epilepsy, and their prognosis is generally poor.^{15,16,52} It has been demonstrated that academic or occupational engagement despite seizures is a positive prognostic factor,^{52,53} so the well-being experienced by these patients could be attributed to the increased sense of autonomy and self-efficacy that comes with performing these daily activities. In this regard, individuals with FDS have reported a preference for spending their free time on activities, such as watching television, reading, exercising, being outdoors, or spending time with friends.³⁹ Therefore, psychotherapeutic interventions could consider these lifestyle choices to improve the quality of life of patients with FDS.

Finally, to the best of our knowledge, this is one of the first Latin American studies to address coping strategies in these patients from a qualitative perspective. Studies that use quantitative methods to assess coping, although effective in enabling group comparisons and facilitating large-scale data collection, scarcely reflect individual perspectives regarding the coping experience. This study made it possible to gain an understanding of the way in which patients with epilepsy and FDS face life with seizures. Using a qualitative approach provides individuals with the opportunity to communicate their personal experience, conveying the meanings they attribute to their condition, which cannot be fitted into pre-defined categories.^{18,37}

5. Limitations

One limitation of this study is the small sample size. However, this study is part of a broader research project that will allow for a more in-depth exploration of the coping strategies used by patients with DRE and FDS in the future. Another limitation was using the interview section with questions aimed at exploring coping resources, which could represent a bias in the range of possible responses. In addition, this study focused exclusively on coping strategies, without inquiring into the challenges

experienced; therefore, future studies could explore the difficulties perceived by these patients and the resources available to face them. Finally, the analysis in this study described the coping strategies used, without performing a comparative analysis between the two groups. Nevertheless, this study could serve as a starting point for other studies, with a larger sample of participants, focusing on comparing the coping strategies of these patients based on their narratives.

6. Conclusion

This study aimed to qualitatively analyze the coping strategies of patients living with DRE and FDS, based on narratives about their experiences of dealing with the challenges imposed by seizures. Different themes related to the coping strategies of both groups were identified. Both groups perceived social support from relatives and friends as an emotional and practical resource. Religiosity, through faith in God and religious practices (such as prayer and petitions), provided meaning to the illness and hope in the possibility of finding a cure. Seeking distraction was a strategy used to create distance from recurring negative thoughts, and was reported only in the FDS group. Finally, engaging in meaningful daily activities was another strategy used by participants with FDS that positively impacted their mood by increasing their sense of well-being. Understanding these experiences is relevant for the professional-patient relationship, as it provides a more comprehensive view of personal experiences when dealing with the condition.

Acknowledgments

The authors would like to acknowledge the Functional Neurological Disorders and Clinical Psychology Research Team (INePSI) for their contribution to this study.

Funding

This research was funded by the UBACyT research project (20020220200070BA) under the University of Buenos Aires.

Conflict of interest

The authors declare they have no competing interests.

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Ethics approval and consent to participate

This study was approved by the Ethics Committee of the J.M. Ramos Mejía Hospital. All participants signed an informed consent form explaining the study's objectives, ensuring the confidentiality of the information provided.

Consent for publication

All participants signed an informed consent form explaining the purposes of the study to agree to participate, which included consent to use the data for research purposes.

Availability of data

Data used in this work are available from the corresponding author upon reasonable request.

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