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METHODOLOGY

Developing and Validating an Epilepsy Awareness and Education Program: Bridging Gaps in Knowledge and Support for People Living with Epilepsy and Their Families

Ofhani Prudance Musekwa[1], Lufuno Makhado[2], Angelina Maphula[1]

[1]Department of Psychology, Faculty of Health Sciences, University of Venda, Thohoyandou, Limpopo, South Africa; [2]Office of the Deputy Dean Research and Postgraduate Studies, Faculty of Health Sciences, University of Venda, Thohoyandou, Limpopo, South Africa

Correspondence: Ofhani Prudance Musekwa, Department of Psychology, University of Venda, Private Bag X5050, Thohoyandou, Limpopo, South Africa, Tel +27 15 962 8828, Email ofhanimusekwa@gmail.com

Abstract: Various epilepsy studies on epilepsy awareness and knowledge highlight underlying myths, misconceptions, stigma, and discrimination associated with epilepsy, People Living with Epilepsy (PLWE), and their families. This study aimed to develop an epilepsy awareness and education programme to enhance epilepsy awareness and support among individuals living with epilepsy and their families. Participatory Action Research (PAR) laid the ground for the programme's investigation, development, and implementation. The study stakeholders (co-researchers) included PLWE, family members and caregivers (FMCs), community members, and health care providers (HCPs) who participated in the inception of the study, data collection, programme development, and validation. The study included four phases: phase one was a systematic review, phase two was an empirical phase that included an explanatory sequential mixed method, phase three was meta-inferences and conceptualization, and the last phase was the development and validation of the programme. All phases of the study informed the development of the programme (using a step-step guide to programme development). From these, the gaps and potential education needs were identified. Gaps such as insufficient knowledge about epilepsy in rural communities, negative attitudes and satisfactory awareness, and a need for support and care for PLWE and FMCs. Implementation of this programme will improve epilepsy knowledge, care, and support in marginalised communities, establishing a more conducive environment and ultimately improving the quality of life for patients and their families.

Keywords: epilepsy, awareness programme, epilepsy education, programme development, quality of life

Introduction

Epilepsy is a common neurological condition that affects millions of people across the world.[1] The disease is characterized by abnormal discharge of neurons.[2] South Africa, like other regions across the world, struggles with the adverse consequences of epilepsy, from treatment to social consequences such as discrimination and stigma.[3,4] There are several myths and misconceptions held that are maintained by poor levels of knowledge, attitudes, and awareness of epilepsy. These myths and misconceptions include false information about epilepsy first aid, epilepsy causes, management, and the impact that epilepsy generally has on a person's life.[5,6] Myths about epilepsy are also common in other African countries, as shown by Osungbada et al[7] who did a study on epilepsy misconceptions and myths in Nigeria, and Mbelesso et al[8] who did a door-to-door survey on epilepsy knowledge in central Africa and found that misconceptions are still prevalent.

Above disease burden, misconceptions, and stigma-driven behaviours result in negative experiences for PLWE and their families. It was reported that the above family members and caregivers needing epilepsy care and support from health care providers experience psychological burdens, feelings of inadequacy, caregiver burden, financial strains, as well as lack of support.[9–14] On the other hand, PLWE need support and epilepsy information from health care providers

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as they often report that to alleviate their experiences of anxiety, depression, physical limitations, and social isolation, more intentional awareness needs to be carried out.[15–17] These experiences have an impact on the overall quality of life for patients and their families and caregivers.

Some studies highlighted that these misconceptions are held by Health Care Providers (HPC), People Living with Epilepsy (PLWE), and community members (including traditional leaders, teachers, and school learners).[18–21] This paints a picture that misconceptions about epilepsy are widespread among different people and groups. This further motivates the importance and great need for an intervention to discard epilepsy misconceptions, stigma (which mostly constitutes above 30% of either felt or experienced stigma[22–25]), and discrimination (whose impact was reported to be above 35%[22,26] on epileptic patients' quality of life). It is more evident that raising awareness and dismissing myths surrounding epilepsy are imperative steps toward establishing a more inclusive and knowledgeable society.

Previously developed epilepsy awareness interventions have reported an improvement in population knowledge and awareness. For instance, Goel et al,[27] conducted a study in India evaluating the impact of an epilepsy awareness programme for school teachers. Their study found that although the change was short-term, the programme had improved epilepsy knowledge, attitudes, and skills, further acknowledging the necessity for continued training and reinforcement. In addition, other studies conducted in Palestine,[28] rural Bolivia,[29] and rural Malaysia (Sabah)[30] assessing the impact of epilepsy education programmes corroborate the positive impact these have on attitude, behaviours, and patient coping skills. This reported impact is despite global initiatives for epilepsy awareness and public campaigns such as World Epilepsy Day and Epilepsy Month, initiated by the International League Against Epilepsy and the International Bureau for Epilepsy.[31] Although the idea behind these is to have continuous epilepsy knowledge and awareness, there are no known accessible programmes on epilepsy that can be used to draw material for public campaigns. As far as the researchers are aware, in South Africa, there is no known epilepsy awareness programme that was developed and informed by an extensive scientific investigation. This is supported by a systematic review conducted by Kaddumusa et al[18] which concluded that there is a need for a stigma reduction intervention in Sub-Saharan Africa. For this reason, this study developed and followed a planned step-by-step guide to programme development to raise awareness and influence positive attitudes, increase epilepsy knowledge, and improve epilepsy practices. Essentially, what this will do is eliminate misconceptions about epilepsy, discrimination, prejudice, and stigma. This programme aims to drive targeted education, foster collaboration and capacity building, and raise epilepsy awareness. It carries within it the overarching goal of improving epilepsy knowledge, attitudes, practices, and quality of life for PLWE and FMCs by establishing a supportive, inclusive, and engaged society for PLWE and their families. This programme seeks to mend the academic and healthcare gap by integrating basic research into an informed and contextualized intervention.

Materials and Methods

This study aimed to develop an epilepsy awareness programme. It was conducted from February 2020 – January 2024, embedded within a Participatory Action Research (PAR) approach to research. It involved stakeholders (considered co-researchers) such as general community members, HCPs, PLWE, and their Family Members and Caregivers (FMCs). In this study, healthcare providers refer to primary caregivers (professional nurses, auxiliary nurses, registered nurses, and community health workers) who are the first point of contact and are accessible to PLWE and their families. The co-researchers were part of the study's research process (development of the study, development, and validation of the programme).

The scientific aspect of the research included four phases: a systematic review phase, an empirical phase (explanatory sequential mixed method), a meta-inferences and conceptualization phase, and lastly, the development of a programme. The systematic review describes the level of epilepsy knowledge and awareness and assesses the impact and availability of epilepsy awareness guides from research conducted between 2014 and 2020. The empirical phase of the study involved collecting data quantitatively and qualitatively. Four questionnaires were developed to collect data from the study participants, and SPSS was used to analyse the findings. The analysis included chi-square cross-tabulation, descriptive statistics, and Pearson correlation analysis. The findings of this stage informed the interview guides used in the qualitative stage. Focus groups and one-on-one interviews were conducted, and data were analysed thematically. The participants involved in this study (N= 5074) were PLWE (n=163), FMCs (n=519), community members (n=4290), and HCPs (n=102) from Limpopo and Mpumalanga provinces in South Africa. For conceptualisation and meta-inferences, a conceptual framework collated the empirical phase findings and the theoretical framework that guided the study. The preceding phases assessed needs and identified gaps and potential epilepsy education goals. In the end, needs assessment and identifying gaps and goals were the first two stages of the step-by-step guide to programme development. These two stages were followed by intervention design (based on knowledge gaps and education needs as shown by study findings) and key stakeholders' validation of the programme. Validation involved conveniently sampling and snowballing participants from individuals who participated in the empirical phase of the study as well as other experts in the field (epilepsy experts and researchers) who read the programme content and evaluated factors such as applicability, relevance, and clarity by scoring each variable from 1 (poor) – 5 (excellent) and added overall comments on the overall programme. The researchers recruited participants who could read to avoid bias associated with a researcher's presence during evaluation.

Results

Step-by-Step Programme Development and Validation Guide

The researchers adopted and moderated the steps to programme development by Kowalski and Fallon,[32] crafting them into a step-by-step guide to developing and validating a programme (as demonstrated in Figure 1) outlined below. Kowalski and Fallon propose a comprehensive framework for community education programmes encompassing four stages associated with specific activities. The initial stage is characterized by an emphasis on assessment, entailing activities such as identifying needs and interests. The second stage involves planning, wherein activities are aligned with identified needs and interests. The third stage, implementation, is making the program publicly available for utilization. The fourth stage, evaluation, assesses the extent to which identified needs and desires have been met. The final stage, reassessment, involves cyclically revisiting the entire process.

In the context of this guide, specifically directed toward developing and validating research output programmes, the researchers have selectively incorporated elements from the initial stages outlined by Kowalski and Fallon.[32] The first stage is slightly different, focusing on needs assessment and gap identification. The planning stage has been refined and reformulated as intervention design, and another fourth stage, validation, has been introduced. Consequently, this guide articulates a structured progression through four pivotal steps: needs assessment, identification of gaps and goals, intervention design, and validation.

Figure 1 Step-by-step awareness programme development and validation guide.

Step One: Needs Assessment

A needs assessment systematically gathers and analyses data based on a need.[33] In addition, it involves collecting data to understand a problem/phenomenon and specific gaps between what is current and what is expected. As mentioned, this study was embedded within the PAR methodology; in its inception, a need assessment was initiated through conversation with community members, family members, and PLWE, who alluded that there is little knowledge about epilepsy as a disorder, stigma, discrimination, and prejudice toward PLWE and their families. The researchers then developed a study protocol to thoroughly assess the problem and need, aiming to develop an awareness programme. To achieve a solidified assessment, the researchers did a systematic review study, an empirical investigation of the research problem, and conceptualized the findings. Through this, the researchers attained scientific evidence for the research problem and gap and set goals to foster change.

Stage Two: Identified Gaps and Goals

In addition to the findings of the needs assessment, the systematic review showed that there is generally poor epilepsy knowledge, relatively positive attitudes, and poor practices towards epilepsy.[9] What's more, according to the search, no public programmes were available.[9] This further strengthened the researcher's aim of developing an epilepsy awareness programme that can be adapted to different contexts. Through conceptualizing the empirical investigation findings,[10] the needs assessment revealed specific gaps and potential intervention goals. According to the findings, there is a need for epilepsy support and care for PLWE and their families.[11] PLWE and FMCs often reported not feeling prepared to handle a seizure and psychological burden.[12,17] The support needed includes counselling, information sharing, and training (specifically first aid). In addition, there were reported negative attitudes, moderate to low levels of knowledge, and poor epilepsy practices, which often resulted in misconceptions, stigmatization, discrimination, and ill-treatment of epileptic patients.[6,9–12] This further warranted epilepsy education for all stakeholders to increase awareness and knowledge, improve practices, and encourage positive attitudes. In addition, HCPs expressed a need for continuous training and information sharing.[10] There is a need for these interventions to be intentional and sustainable. All participants in the study expressed a need for epilepsy first-aid training. Therefore, the goal of this programme is to create awareness, educate, and build capacity for epilepsy care and support, as well as ascertain programme sustainability. The results from data collected from PLWE,[17] HCPs, and FMCs[11,12] mostly advised the content of package 1, which, in essence, focuses on epilepsy empowerment and support. On the other hand, the results from the conceptual framework,[10] data collected from community members,[6] and HCPs guided package 2, which focused more on epilepsy knowledge and awareness.

Stage Three: Programme Design

In this stage, the researchers used the needs assessment findings (gaps) and recommendations (programme goals) which include the need for epilepsy information sharing and education (first aid, training, and knowledge sharing for attitude, awareness, knowledge increase, and practice improvement) and support and care (continuous education and psychological burden alleviation) to design the programme content. During the investigation, the researchers found that three aspects are intertwined (Agents, Intervention, and recipients) see Figures 2 and 3.

Roczniewska and Marszałek[36] explain an agent as "one who takes action" and the recipient as the one whom an action is directed towards and ultimately experiences the outcome of the particular action. In addition, the intervention accompanies and informs the action and ushers in outcomes. However, in context specifically, agents are individuals responsible for implementing and administering the intervention to the recipients. Regarding the intervention, the assessment showed that different recipients need different interventions. PLWE and FMCs require first aid training and counselling as a form of support. In contrast, community members and FMCs require knowledge sharing (epilepsy facts), first aid training, and capacity building to better support and care for PLWE and their FMCs. This meant that this programme would incorporate two packages as follows:

Package 1

Package 1 as shown in Figure 4 below, is an epilepsy care and support package (incorporating epilepsy first aid, counselling, and mental health wellness). This package is aimed at encouraging positive attitudes and practices toward epilepsy and increasing epilepsy knowledge. Package 1 is structured into three sections labelled 1a, 1b, and 1c, each

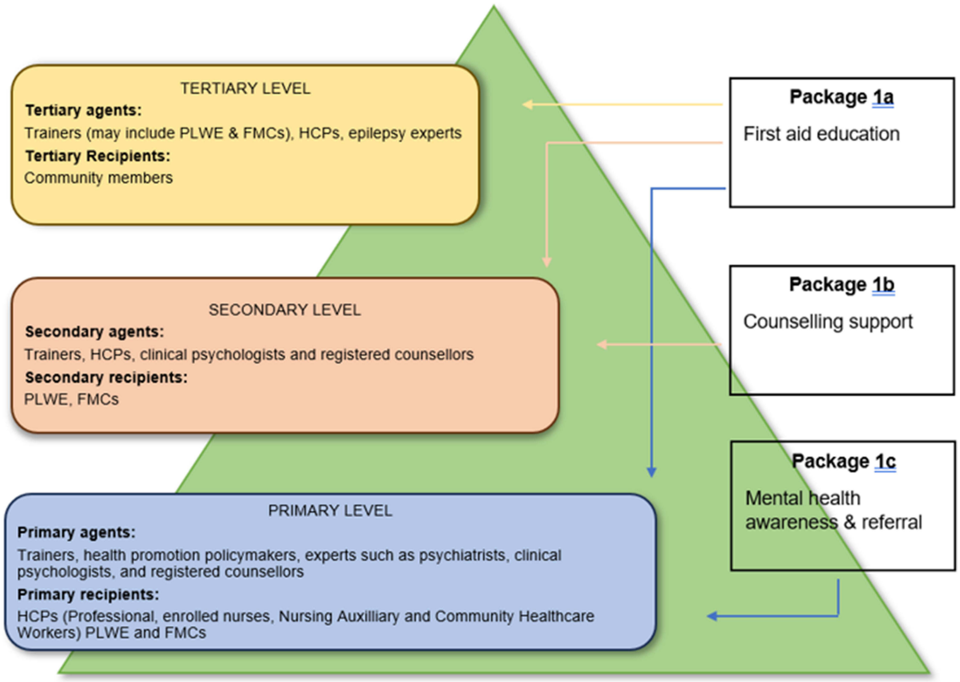


Figure 2 Epilepsy needs-based education approach.

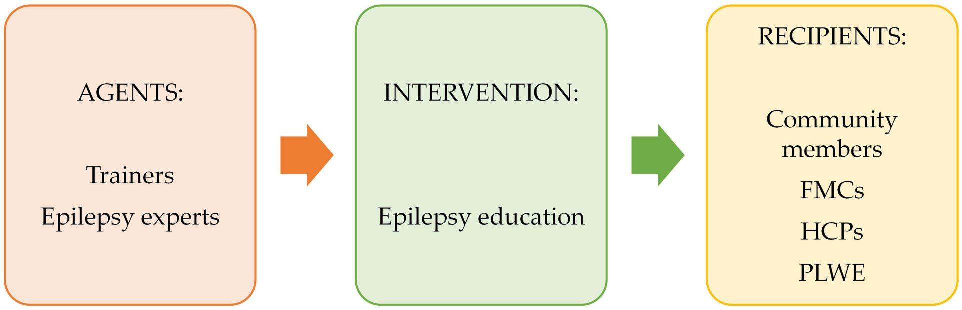
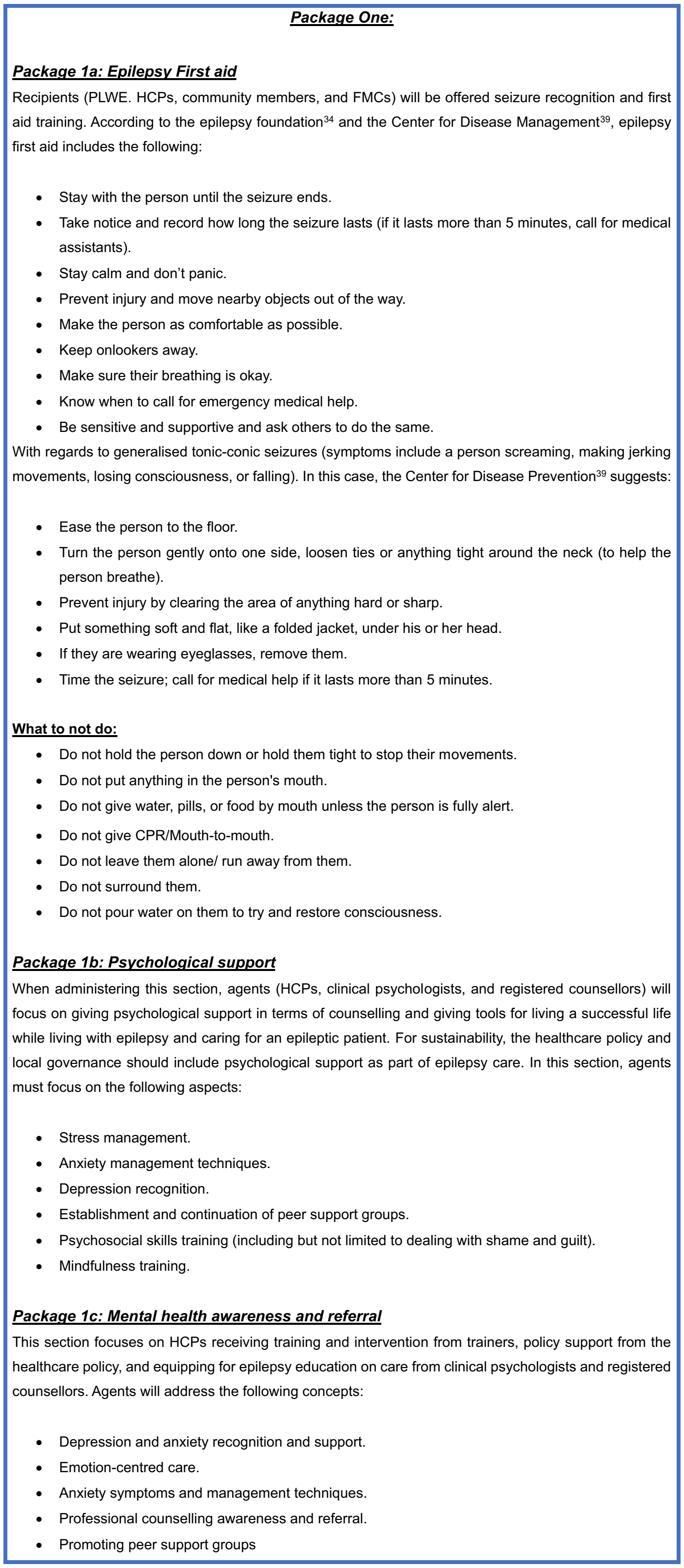


Figure 3 Epilepsy community education approach.

addressing its own categories of agents and recipients. These categories are categorized as primary, secondary, and tertiary levels, adhering to no chronological order of significance. The first level, the primary level, encompasses primary agents, including trainers, health promotion policymakers, and experts such as clinical psychologists and registered counsellors. These primary agents are linked with HCPs, who serve as primary recipients within this tier. The second tier involves secondary agents, comprising HCPs empowered from the previous primary level, clinical psychologists and counsellors, and trainers. This group caters to secondary recipients, PLWE, and FMCs. Although the tertiary level will be open to PLWE and FMCs who would like to participate, the target agents are trainers, epilepsy experts, and HCPs and community members as recipients. Package 1a includes epilepsy first aid and will be applicable on all tiers (primary, secondary, and tertiary). Package 1b includes counselling support for the secondary recipients (PLWE and FMCs). Lastly, package 1c, which speaks to mental health awareness and referral, is packaged for the primary recipients (HCPs).

Package 2

Package 2 as shown in Figure 5 below, includes general knowledge and information about epilepsy as a disorder. Its content focuses on increasing epilepsy knowledge, awareness, and attitudes. The content comprises epilepsy facts/truths and myths. The agents for this package are trainers and experts in the field, such as epilepsy researchers. These will



Package One:

Package 1a: Epilepsy First aid

Recipients (PLWE. HCPs, community members, and FMCs) will be offered seizure recognition and first aid training. According to the epilepsy foundation[34] and the Center for Disease Management[39], epilepsy first aid includes the following:

- Stay with the person until the seizure ends.
- Take notice and record how long the seizure lasts (if it lasts more than 5 minutes, call for medical assistants).
- Stay calm and don't panic.
- Prevent injury and move nearby objects out of the way.
- Make the person as comfortable as possible.
- Keep onlookers away.
- Make sure their breathing is okay.
- Know when to call for emergency medical help.
- Be sensitive and supportive and ask others to do the same.

With regards to generalised tonic-conic seizures (symptoms include a person screaming, making jerking movements, losing consciousness, or falling). In this case, the Center for Disease Prevention[39] suggests:

- Ease the person to the floor.
- Turn the person gently onto one side, loosen ties or anything tight around the neck (to help the person breathe).
- Prevent injury by clearing the area of anything hard or sharp.
- Put something soft and flat, like a folded jacket, under his or her head.
- If they are wearing eyeglasses, remove them.
- Time the seizure; call for medical help if it lasts more than 5 minutes.

What to not do:

- Do not hold the person down or hold them tight to stop their movements.
- Do not put anything in the person's mouth.
- Do not give water, pills, or food by mouth unless the person is fully alert.
- Do not give CPR/Mouth-to-mouth.
- Do not leave them alone/ run away from them.
- Do not surround them.
- Do not pour water on them to try and restore consciousness.

Package 1b: Psychological support

When administering this section, agents (HCPs, clinical psychologists, and registered counsellors) will focus on giving psychological support in terms of counselling and giving tools for living a successful life while living with epilepsy and caring for an epileptic patient. For sustainability, the healthcare policy and local governance should include psychological support as part of epilepsy care. In this section, agents must focus on the following aspects:

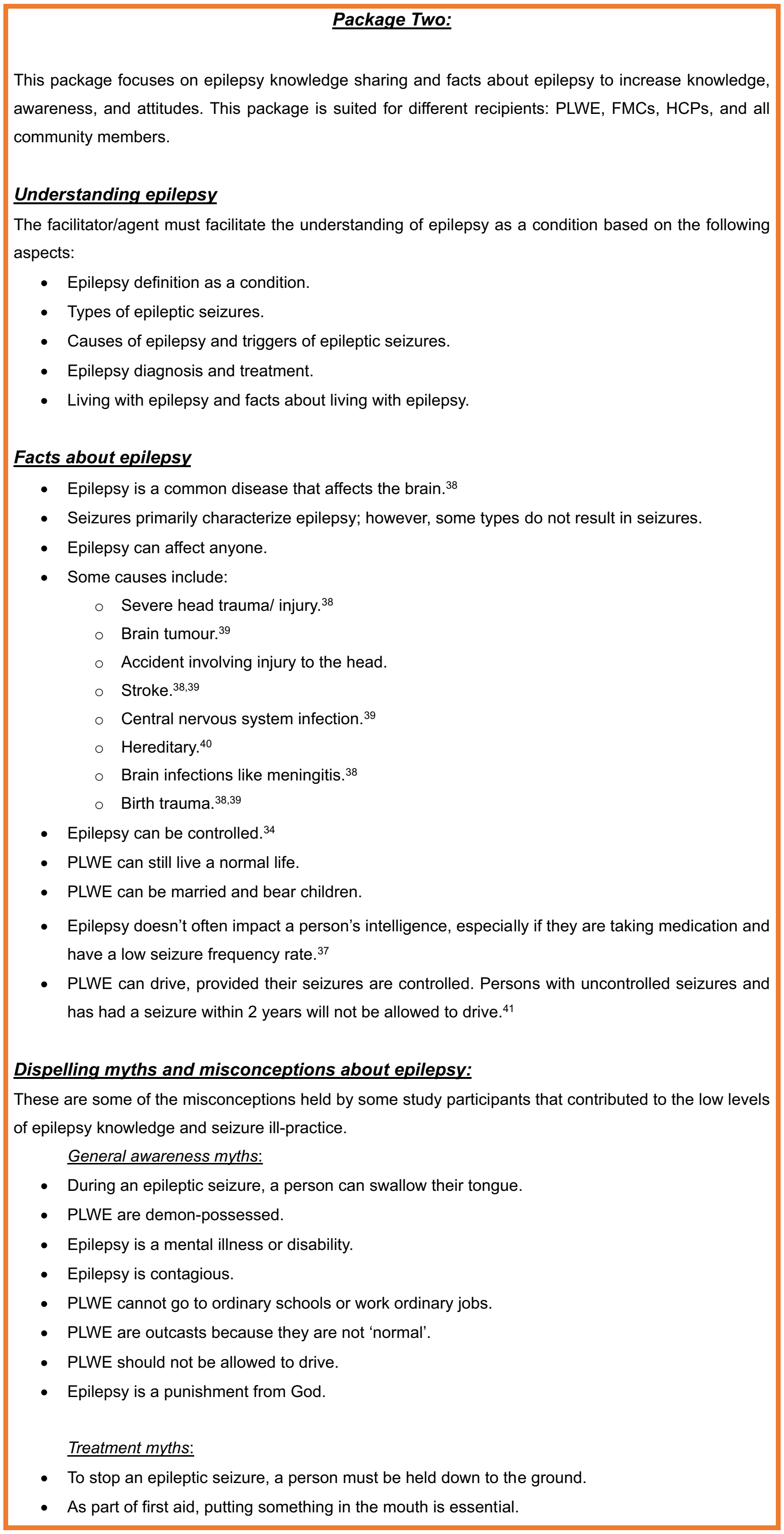
- Stress management.
- Anxiety management techniques.
- Depression recognition.
- Establishment and continuation of peer support groups.
- Psychosocial skills training (including but not limited to dealing with shame and guilt).
- Mindfulness training.

Package 1c: Mental health awareness and referral

This section focuses on HCPs receiving training and intervention from trainers, policy support from the healthcare policy, and equipping for epilepsy education on care from clinical psychologists and registered counsellors. Agents will address the following concepts:

- Depression and anxiety recognition and support.
- Emotion-centred care.
- Anxiety symptoms and management techniques.
- Professional counselling awareness and referral.
- Promoting peer support groups

Figure 4 Epilepsy Awareness Programme Package 1.



Package Two:

This package focuses on epilepsy knowledge sharing and facts about epilepsy to increase knowledge, awareness, and attitudes. This package is suited for different recipients: PLWE, FMCs, HCPs, and all community members.

Understanding epilepsy

The facilitator/agent must facilitate the understanding of epilepsy as a condition based on the following aspects:

- Epilepsy definition as a condition.
- Types of epileptic seizures.
- Causes of epilepsy and triggers of epileptic seizures.
- Epilepsy diagnosis and treatment.
- Living with epilepsy and facts about living with epilepsy.

Facts about epilepsy

- Epilepsy is a common disease that affects the brain.[38]
- Seizures primarily characterize epilepsy; however, some types do not result in seizures.
- Epilepsy can affect anyone.
- Some causes include:
  - Severe head trauma/ injury.[38]
  - Brain tumour.[39]
  - Accident involving injury to the head.
  - Stroke.[38,39]
  - Central nervous system infection.[39]
  - Hereditary.[40]
  - Brain infections like meningitis.[38]
  - Birth trauma.[38,39]
- Epilepsy can be controlled.[34]
- PLWE can still live a normal life.
- PLWE can be married and bear children.
- Epilepsy doesn't often impact a person's intelligence, especially if they are taking medication and have a low seizure frequency rate.[37]
- PLWE can drive, provided their seizures are controlled. Persons with uncontrolled seizures and has had a seizure within 2 years will not be allowed to drive.[41]

Dispelling myths and misconceptions about epilepsy:

These are some of the misconceptions held by some study participants that contributed to the low levels of epilepsy knowledge and seizure ill-practice.

General awareness myths:

- During an epileptic seizure, a person can swallow their tongue.
- PLWE are demon-possessed.
- Epilepsy is a mental illness or disability.
- Epilepsy is contagious.
- PLWE cannot go to ordinary schools or work ordinary jobs.
- PLWE are outcasts because they are not 'normal'.
- PLWE should not be allowed to drive.
- Epilepsy is a punishment from God.

Treatment myths:

- To stop an epileptic seizure, a person must be held down to the ground.
- As part of first aid, putting something in the mouth is essential.

Figure 5 Epilepsy Awareness Programme Package 2.

administer the intervention to FMCs, Community members, HCPs, and PLWE. In contrast to package 1, which attended to unique content, this package addresses all stakeholders as it provides universal knowledge about epilepsy, which may increase epilepsy understanding (awareness and knowledge) and attitudes.

Epilepsy Awareness and Education Programme Sustainability

The epilepsy awareness and education programme's potential for sustainability can be attributed to its adaptability and versatility regarding available tools and resources. This adaptability is particularly valuable because it enables the programme to address a variety of misconceptions and cater to diverse requirements related to epilepsy care and support. This versatility renders the programme applicable in various contexts, thereby enhancing its effectiveness in meeting the distinct needs of various populations. Furthermore, the existing community engagement is an encouraging factor for long-term sustainability. The active involvement and commitment demonstrated by stakeholders, including community members, PLWE, and FMCs, throughout the study process, along with their proactive recruitment of fellow participants, predict the programme's continued success. Documenting the tool's development and evaluation is also pivotal in facilitating knowledge sharing and ongoing monitoring, further strengthening the program's long-term sustainability prospects. In addition, the long-term involvement of diverse stakeholders who hold different positions within the communities may encourage programme personalisation, adoption and continuous monitoring and evaluation of the programme. Monitoring and evaluation post-intervention implementation or training will ensure the programme stays relevant and applicable to different populations at different times.

Stage Four: Validation

As previously alluded to, all stakeholders within this study were involved in designing and validating the epilepsy awareness and education programme. Stakeholders representing each participant group were selected to engage in the programme development to ensure validity and representativeness. Simultaneously, the programme was validated by other stakeholders who did not form part of the validation process to ascertain further validity of the programme process and content. The stakeholders also had to answer whether the program truly reflected their needs and whether the intervention would meet them. This stage is continuous because it will validate the impact against context and agent. This allows continuous improvements of the programme and ensures contextual relevance. The researchers designed a validation tool for both the agents and recipients.

Validation Method

To ensure the trustworthiness of the epilepsy awareness and education programme, the researchers invited participants to validate the tool. This was done in a period of one month. The researchers aimed to attain PLWE, FMCs, community members, HCPs representing participants from Limpopo and Mpumalanga provinces, and researchers as experts in the field for programme validation. Convenient and snowball sampling was applied to recruit participants. Participants were invited to participate in the validation via Email and WhatsApp messenger. All participants who agreed to participate received a Word document with the proposed program and a Google Forms link starting with a consent question; all participants had to agree to participate before evaluating the program (See Table 1 for evaluation tool scoring). The validation tool was an open-ended survey with seven questions, each with a scale ranging from 1–5 (1 being poor and 5 excellent). The completed tool was then downloaded to an Excel spreadsheet; an Excel formula was used to calculate the mean scores of each question. The concluding part of the survey invited the participants to share their inputs or additional comments.

Validation Findings

This study recruited 40 participants; thirty-six agreed to participate in the evaluation. Table 1 describes the demographics of participants. This group comprised epileptic patients (n= 8%) and their families (n= 11%), community members (n= 53.4%), healthcare providers (*n*= 11%), and researchers (*n*= 16.6%). From these, *n*= 69.4% were females, 25% were males, and n= 5.6% proffered not disclosing their gender. Most participants were within the 29–33 age group (*n*= 25%), and the minority were aged 44 and above (*n*= 8%), while *n*= 25% included participants from ages 24–28.

Table 1 Participant Demographics

Demographic Category		**Total (*n*)**	**Total (*n*%)**
Gender	Male	9	25%
	Female	25	69.4%
	Prefer not to say	2	5.6%
Age group	18–23	5	14.4%
	24–28	9	25%
	29–33	13	36%
	34–38	4	11%
	39–43	2	5.6%
	44- above	3	8%
Participant group	PLWE[a]	3	8%
	FMC[b]	4	11%
	Community member	19	53,4%
	HCP[c]	4	11%
	Researcher	6	16.6%

Notes: [a]People Living With Epilepsy (PLWE). [b]Family Member and Caregiver (FMC). [c]Health Care Provider (HCP).

Table 2 Evaluation Scoring and Average

Assessment item	**Score (*n*)**	**Average**
Clarity and Coherence.	1 = 0	4
	2 = 0	
	3 = 2	
	4 = 14	
	5 = 20	
Innovation and Creativity.	1 = 0	4
	2 = 1	
	3 = 2	
	4 = 15	
	5 = 18	
Relevance and Need.	1 = 0	5
	2 = 0	
	3 = 0	
	4 = 9	
	5 = 27	

(*Continued*)

Table 2 (Continued).

Assessment item	Score (*n*)	Average
Feasibility and Sustainability.	1 = 0	4
	2 = 0	
	3 = 4	
	4 = 14	
	5 = 18	
Partnerships and Collaboration.	1 = 0	4
	2 = 0	
	3 = 5	
	4 = 14	
	5 = 17	
Evaluation and Measurement.	1 = 0	4
	2 = 0	
	3 = 4	
	4 = 16	
	5 = 17	
Credibility and Expertise.	1 = 0	5
	2 = 1	
	3 = 1	
	4 = 8	
	5 = 26	

The evaluation tool had seven questions for assessing the epilepsy awareness and education programme. Question one assessed quality and coherence, for which participants scored a four on average. This was the same for questions two, four, five, and six, which assessed programme innovation and Creativity, feasibility and sustainability, partnerships and collaboration, and evaluation and measurement. The average score for questions three and seven, which assessed relevance, need, and credibility and expertise, was an average of five. See Table 2 for participant scoring details.

The evaluation survey included a concluding aspect that invited participants to share their overall impression of the tool. Applicable suggestions were implemented in the final programme. Some of the suggestions included expanding on the programme sustainability and mental health intervention specifications, clarity on how stakeholders will be involved in the implementation, and specifications on who will be the targets of each package. Generally, participants were favourable towards the programme, recognizing strengths in clarity, comprehension, community involvement, and practicality. These impute strengthened the developed programme, giving it a greater chance of impact and making it more feasible.

Implications

This paper has significant implications for epilepsy awareness, education, and the broader healthcare community. First and foremost, the development and validation of epilepsy awareness and education programmes have the potential to bring about a tangible reduction in the stigma and discrimination faced by PLWE and their families by increasing knowledge, awareness, attitudes, and improving practices. Furthermore, by dispelling myths and misconceptions surrounding epilepsy and fostering a better understanding of the condition among the general public, these programmes can create a more inclusive and empathetic society. The study's emphasis on tailoring interventions to meet the distinct needs of various stakeholders, including PLWE, family members, community members, and healthcare providers, underscores the significance of customized approaches in achieving meaningful change. This approach recognizes that more than a one-size-fits-all strategy may be needed. Thus, it advocates for personalized support and education to address the specific challenges faced by each group.

Moreover, the study's utilization of the participatory action research (PAR) methodology is a valuable example of how community engagement and collaboration can enhance the development and implementation of health education programs. The study fosters a sense of ownership and commitment by involving PLWE, family members, and healthcare providers as co-researchers throughout the process. It ensures that the resulting programme resonates with the real-life experiences and needs of the target audience. Furthermore, the study's emphasis on sustainability, achieved through the programme's flexibility and ongoing community engagement, highlights the potential for lasting positive impacts. This sustainability aspect is particularly important for long-term success, as it allows for continuous monitoring, adaptation, and growth of the programme to meet evolving needs and challenges. Thus, the study's implications underscore the power of collaborative, tailored, and sustainable health education programmes in making a substantial difference in the lives of individuals affected by epilepsy and in fostering a more informed and compassionate society.

What is known about epilepsy is the dynamics of the condition, its impact, and misconceptions, and recognising that to mitigate some of the psychosocial challenges PLWE and their families face, epilepsy education needs to be put into place. However, according to the authors' knowledge, there are no known community epilepsy education programme, specifically one that focuses on raising awareness, increasing knowledge, and reducing stigma and misconception. This study bridges this gap by adding to the body of knowledge and evidence-based education and awareness programme. Confidence can be placed in this intervention based on its proven validity and sustainability, which invites the possibility of applying the base of either the step-by-step guide (which promotes scientific investigation) and/or programme itself to other conditions that require psychosocial intervention and education.

Conclusion, Limitations, Strengths, and Recommendations

In conclusion, this study sought to develop an awareness programme that would ultimately influence positive attitudes, behaviour change, and epilepsy care and support as alluded to by the empirical and conceptualisation phases that preceded the development of the programme.[6,15] This current study achieved its goal by systematically adopting an informed step-by-step guide highlighting co-researchers role and importance in academic research. Furthermore, it helped to synthesize the study findings into an applicable and practical programme. The scientific findings of the empirical studies were confirmed by research experts (statistical expert and qualitative co-coder). What's more, it is essential to develop a tailored, scientifically informed intervention that suits the unique needs of the recipients. These interventions, from first-aid training to counselling and knowledge dissemination, aim to eliminate misconceptions and reduce the stigma and discrimination associated with epilepsy. The PAR method employed in the study promotes research and output personalisation for stakeholders involved in the study. This influences stakeholders to ensure the success and sustainability of the programme. In addition to empowering agents and having recipients become future agents, the availability of a validated education materials ensures the longevity of impact and the potential for an increased quality of life for PLWE and FMCs.

The current study's limitations include having limited PLWE, HCPs, and FMCs to evaluate the programme What may have contributed to this may be participant fatigue, as these were the same group of individuals involved in the conception of the study and both stages of the empirical phase. What's more, the program was developed based on the findings of a study, limiting the interventions to the gaps identified. However, the empirical investigation gave the programme more strength to ensure it caters to clear needs and has clear goals and design. The programme's validity and sustainability pose a strength as it may be flexible to adapt to different contexts, although it may require evaluation to ensure proper contextualization. In addition, the researchers recommend that the four steps to programme development should be implemented in programme development and planning. This may ensure a well-defined intervention for policymakers, researchers, and Non-Governmental Organisations. In addition, the evaluation aspect of the programme allows for the integration of basic research that has been done elsewhere in different contexts, with different findings to be adopted into the programme and implemented in that particular context.

Abbreviations

PLWE, People Living With Epilepsy; HCPs, Health Care Providers; FMCs, Family Members and Caregivers; UNHCR, United Nations High Commissioner for Refugees; WHO, World Health Organization; CDC, Center for Disease Control.

Ethics Approval and Informed Consent

The study was conducted following the Declaration of Helsinki and approved by the Human and Clinical Trial Research Ethics Committee of the University of Venda (SHS/20/PSYCH/12/2710, approved 30 October 2020).

Consent for Publication

Authors consent that the details disclosed in this study can be published as is.

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Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis, and interpretation, or in all these areas; took part in drafting, revising, or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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Disclosure

The author(s) report no conflicts of interest in this work.

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