EDID-GHDI Research/Thematic Report

Survey: The Roles, Needs, and Experiences of Women Caregivers of People with Epilepsy & Neurological Disorders in South Africa

EDID-GHDI

Engendering Disability-Inclusive Development | Genre, handicap et développement inclusif

Authors: Written and prepared by K. Robinson and S. Cassel of Epilepsy SA National Office

Cite this paper as
Robinson, K., and Cassel, S. (2026). *Survey: The Roles, Needs, and Experiences of Women Caregivers of People with Epilepsy & Neurological Disorders in South Africa* [Report]. EDID-GHDI, University of Guelph.

NATIONAL OFFICE
epilepsy™
SOUTH AFRICA
Igniting the Flame of Potential
NPO 001-911 | PBO 930007484

Acknowledgements

We would like to extend our gratitude to the Epilepsy South Africa (Epilepsy SA) Branches that participated in the carer research. We extend our appreciation to the social workers and other supportive staff who coordinated participant recruitment, conducted the online surveys, and facilitated the follow-up interviews with women caregivers.

Our heartfelt thanks go to the following branches for their commitment and collaboration:

- Epilepsy South Africa South Cape/Karoo Branch
- Epilepsy South Africa Western Cape Branch
- Epilepsy South Africa Gauteng Branch
- Epilepsy South Africa Mpumalanga Branch
- Epilepsy South Africa Free State & North West Branch

We also wish to acknowledge the invaluable leadership and guidance of Sharlene Cassel, National Director of Epilepsy South Africa, and Karen Robinson, National Office Liaison, for facilitating this study on behalf of the Engendering Disability-Inclusive Development (EDID/GHDI) project.

Finally, we extend our deepest appreciation to the women caregivers who generously shared their time, experiences, and insights. Their voices form the heart of this research and continue to guide efforts toward more inclusive and gender-responsive support systems across South Africa.

Table of Contents

Table of Figures

Executive Summary

Caregiving for people living with epilepsy and other neurological disorders in South Africa is largely undertaken by women, most of whom are unpaid family members. Despite their crucial role in sustaining health and well-being, these caregivers remain under recognised in policy and service delivery. Cultural norms continue to define caregiving as a woman's responsibility, leaving many exposed to economic vulnerability, emotional exhaustion, and social isolation. This study forms part of an ongoing effort by Epilepsy South Africa (Epilepsy SA) to document and understand the lived realities of women caregivers and to inform gender-responsive support interventions at community and policy levels.

Building on survey findings and follow-up interviews, this report highlights that caregivers navigate a complex intersection of love, faith, exhaustion, and resilience, often describing caregiving as both a calling and a burden. Their stories underscore the urgent need for structural support systems that recognise unpaid care as both social and economic labour.

Background

In 2024, Epilepsy South Africa conducted a Carer and Peer Support Group Training Needs Assessment Survey nationally. Three branches participated (Epilepsy South Africa South Cape/Karoo, Epilepsy South Africa Mpumalanga, Epilepsy South Africa Western Cape), and a total of 35 participants took part, including 19 carers and 16 social development staff members. The assessment identified critical needs in mental health support, seizure management, communication skills, and self-care strategies for carers.These findings led to the development of a Carer Training Module, introduced as a stand-alone component of the Development Hub Training Programme, that will be rolled out nationally in 2026. The current 2025 Carer Survey and Interviews build upon that foundation, combining quantitative and qualitative methods to explore the lived experiences, motivations and burdens of women carers across the five provinces.

This expanded study intentionally included branches not previously part of the 2024 survey, Gauteng and Free State & North West, to ensure geographic and socio-economic diversity. The inclusion of both urban and rural carers revealed striking similarities in emotional strain, stigma, and resource constraints, despite differing local contexts. Insights from this study will directly inform the design and implementation of the National Carers Roadshow (2026), ensuring that support strategies remain evidence-based, locally relevant, and responsive to the realities of unpaid carers.

Aim and Objectives

The study aimed to explore the roles, challenges, and support needs of women caregivers supporting individuals living with epilepsy and neurological disorders. Specific objectives included:

- ✓ Profiling the socio-economic characteristics of caregivers;
- ✓ Assessing how caregiving affects employment, education, and well-being;
- ✓ Understanding emotional and psychosocial impacts of care; and
- ✓ Evaluating awareness, accessibility, and satisfaction with existing caregiver programmes.

Alongside the qualitative interviews, an online carer survey gathered quantitative data on demographics, economic status, caregiving duration, and access to support and training. This combination of survey and interview data allowed the study to triangulate statistical trends with lived experiences, providing a fuller understanding of caregivers' realities across provinces.

Methodology

Data were collected between August and September 2025 from 37 women caregivers across five Epilepsy SA branches: Western Cape, South Cape/Karoo, Gauteng, Free State & North West, and Mpumalanga (see Figure 1). A mixed-methods design was employed, using both structured online surveys and semi-structured follow-up interviews. The survey provided quantitative data on demographics, caregiving duration, income, and training, while the interviews provided qualitative insights into caregivers' emotional journeys, coping mechanisms, and community relationships. Interviews were conducted by social workers in English or local languages.

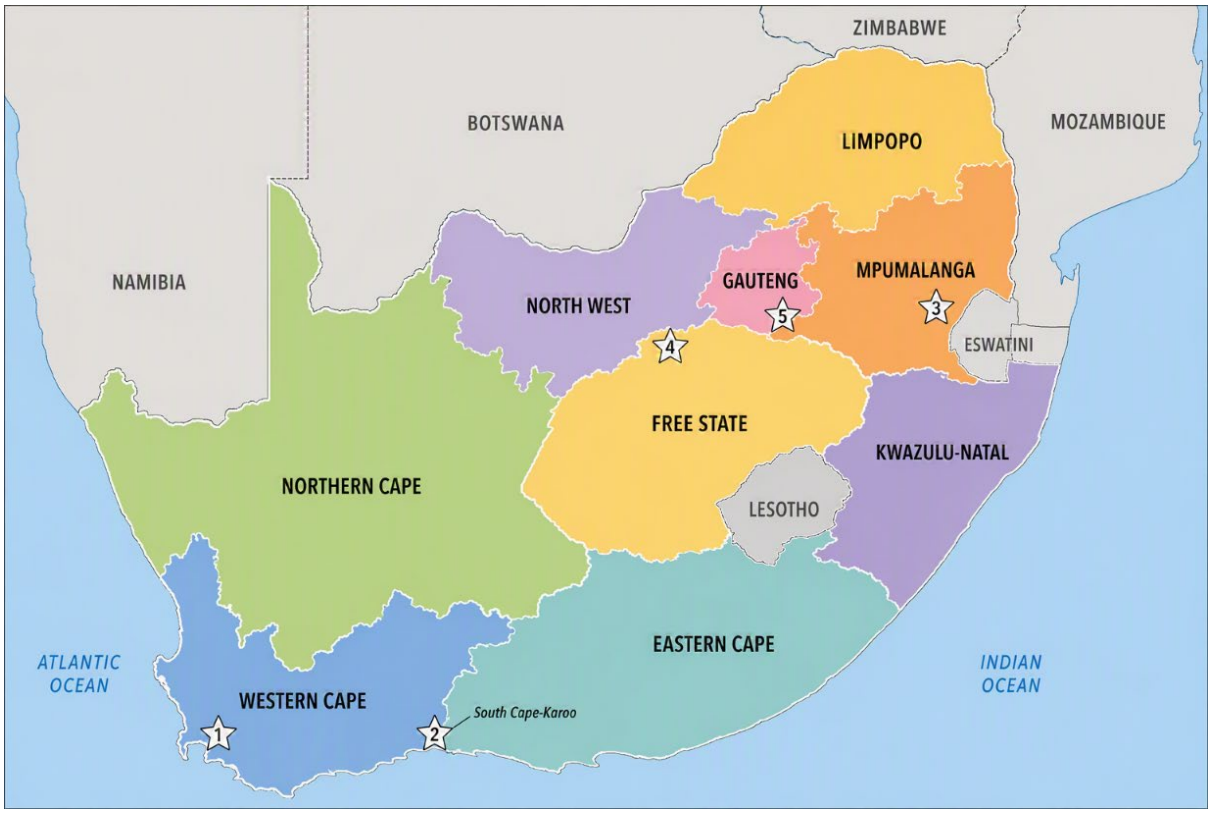


Figure 1: South Africa map indicating the location of Epilepsy South Africa branches involved in the study

(1 = Epilepsy South Africa Western Cape Branch; 2 = Epilepsy South Africa South Cape/Karoo Branch; 3 = Epilepsy South Africa Mpumalanga Branch; 4 = Epilepsy South Africa Free State & North West Branch; and 5 = Epilepsy South Africa Gauteng Branch). Generated using Microsoft Copilot (GPT-5-based image generation), July 2026.

Descriptive statistics were used to summarise quantitative results, and thematic analysis identified recurring patterns and deeper meanings within carers' narratives. A total of 35 interviews were successfully completed, with two interviews in the Free State & North West Branch concluded early due to emotional distress. These partial interviews were still ethically included, as they illustrate the intensity of emotional strain many carers experience when recounting their stories. Data saturation was achieved across provinces, with strong thematic consistency emerging in the areas of faith, isolation, resilience, and the need for psychosocial and financial support.

Key Findings

Demographics and Caregiving Roles

- ✓ 100% of caregivers were women, underscoring the gendered nature of unpaid care work.
- ✓ Most respondents cared for their own child (54.9%), followed by other family members.

- ✓ Caregivers ranged widely in age, but the majority were between 31 and 60 years old.
- ✓ Many had been caregivers for more than a decade, with several beginning their caregiving journey when their child or partner first developed seizures or experienced a stroke.

Economic Vulnerability

- ✓ 64.9% were unemployed and 73% reported significant financial strain.
- ✓ Caregiving responsibilities often restricted employment opportunities and income generation.
- ✓ Caregivers reported using personal or family resources to cover medical and transport costs.
- ✓ Several interview participants described the emotional toll of poverty: one mother in the Free State said, “Some days we both go to bed without supper, but I cannot rest because he still needs his tablets.”
- ✓ Many women expressed a desire for small income-generating opportunities, noting that “even selling food or sewing at home would help, because we can’t leave our loved ones alone.” (Mpumalanga participant)

Access to Support and Training

- ✓ 58.3% were aware of caregiver programmes, though availability varied widely by province.
- ✓ 50% had received some form of training, primarily through Epilepsy SA branches or local clinics.
- ✓ Among those trained, 69% expressed satisfaction, citing increased confidence in managing seizures.
- ✓ Interview data revealed a strong desire for refresher courses and emotional support sessions, highlighting that carers value spaces where they can share experiences and learn.
- ✓ Carers in Gauteng and Mpumalanga praised Epilepsy SA’s workshops as “the only place we are seen and heard,” yet also requested continuous mentorship rather than once-off sessions.
- ✓ In the Western Cape and South Cape/Karoo, carers stressed that training should include mental health, self-care and communication skills to manage stigma within families and communities.

Emotional and Social Wellbeing

- ✓ Caregivers frequently described exhaustion, anxiety, and social isolation.
- ✓ Many linked resilience to faith, family support, and witnessing small improvements in their loved ones.
- ✓ Interviewees across provinces emphasised that spirituality and prayer were essential coping tools: “Prayer gives me strength to face another day,” shared one carer from Mpumalanga.
- ✓ Stigma associated with epilepsy continued to impact community acceptance and caregiver mental health. Several participants during the interviews across provinces recounted community gossip and avoidance: “People stare when my child has a seizure in public,” noted a caregiver from Gauteng.
- ✓ Carers often described loneliness in vivid terms: “Even family doesn’t understand; they say I’m overprotective, but they don’t see what I see at night.” (Free State carer)
- ✓ In the South Cape/Karoo, women highlighted that caregiving reshaped their identity: “It changed who I am. I forget myself sometimes because everything is about him.”

Priority Support Needs

Respondents consistently requested:

- ✓ Financial assistance and stipends for caregivers to ease household burden.
- ✓ Expanded training in epilepsy management and safety.

- ✓ Regular counselling and support groups for emotional well-being.
- ✓ Community-based respite services and weekend relief care.

One carer from the South Cape/Karoo summarised: “We need a place where someone can look after him just for a weekend, so I can rest and feel like myself again.”

Carers also recommended peer-support circles facilitated by social workers, with one Gauteng participant noting: “Sometimes we just need to talk without being judged that alone helps.”

Across all provinces, participants called for recognition within government programmes: “We work like nurses and counsellors, but no one pays us.” (Western Cape participant)

Policy Context

While several frameworks acknowledge the role of caregivers, including the White Paper on the Rights of Persons with Disabilities (2016), the Social Assistance Act (2004), and the National Development Plan 2030, implementation remains fragmented. Informal caregivers are excluded from social protection measures such as stipends or pension benefits, leaving many in financial precarity.

The Intersectoral Global Action Plan (IGAP) on Epilepsy and Other Neurological Disorders and the National Mental Health Policy Framework (2023–2030) provide opportunities to strengthen caregiver inclusion through coordinated, cross-sectoral action. The combined survey and interview findings highlight the policy gap between formal recognition of disability rights and the lived economic and emotional realities of caregivers. Despite awareness of caregiver programmes in some provinces, access remains inconsistent, underscoring the need for implementation frameworks that explicitly address unpaid care work.

The study’s findings align with national advocacy efforts led by Epilepsy South Africa, which has locallised the World Health Organisation’s Intersectoral Global Action Plan (IGAP) into the South African Intersectoral Action Plan (SAINAP). SAINAP, developed in collaboration with government departments and civil society partners, is being prepared for presentation to Cabinet in 2026. It provides a strategic roadmap to strengthen neurological care, promote gender equity, and formalise caregiver support across sectors. Integrating caregiver perspectives from this study into SAINAP will ensure that gender-responsive and community-based caregiver support becomes a measurable policy outcome rather than a peripheral commitment.

Discussion

Findings confirm that caregiving for people with epilepsy and other neurological disorders in South Africa is gendered, under-supported, and economically invisible. The convergence of poverty, stigma, and gender inequality compounds caregiver burden, echoing national research (Keikelame & Swartz, 2016; Silaule et al., 2023; Yakubu & Schutte, 2023).

The qualitative interviews add depth to these findings revealing how women negotiate daily stress, faith, and love within systems that offer little formal assistance. Across provinces, caregivers described their work as both emotionally draining and profoundly meaningful, reflecting strength, spirituality, and resilience amid hardship. These lived realities reinforce the urgent need for policies and programmes that recognise caregiving as essential social and health infrastructure.

The integrated analysis identified five dominant themes: (1) Faith and Spirituality as a source of strength; (2) Emotional and Physical Burnout; (3) Persistent Poverty and Lack of Formal Support; (4) Stigma and Social Exclusion; and (5) Love, Resilience, and Identity. Quotes from every province

illustrated these cross-cutting issues, showing that despite context differences, the emotional landscape of caregiving is universally complex and deeply gendered.

The quantitative survey findings mirror these themes, revealing that more than 70 percent of caregivers experience chronic financial strain, and over half reported that caregiving limits their ability to work or study. Emotional exhaustion and social isolation were also prominent in both data sets, confirming the intersection between unpaid care, economic marginalisation, and gender inequality. By integrating survey and interview data, the study demonstrates that caregiving is not only a private act of compassion but a structural public-health and social-justice concern requiring coordinated national response.

Recommendations

- ✓ Formally recognise unpaid caregivers within national policy and programme framework.
- ✓ Provide targeted financial assistance or stipends to reduce economic hardship.
- ✓ Expand training and psychosocial counselling through Epilepsy SA and other Non-Profit Organisations and primary healthcare clinics.
- ✓ Create peer support networks and community respite programmes for ongoing relief.
- ✓ Integrate caregiver perspectives into the rollout of SAINAP and the National Mental Health Policy Framework.
- ✓ Promote public awareness campaigns to reduce stigma and celebrate caregivers' contributions.
- ✓ Establish a national caregiver registry linked to Epilepsy SA and the Department of Social Development to enable tracking, referral, and equitable access to support services.
- ✓ The findings serve as evidence to support the development and refinement of the Carer Training Module, guide the 2026 National Carers Roadshow, and inform the integration of caregiver perspectives into the national SAINAP rollout.

Conclusion

Women caregivers play a vital yet largely invisible role in South Africa's health and social support ecosystem. Their unpaid labour sustains families and community well-being but comes at significant personal cost. Strengthening support systems for these women through training, financial assistance, emotional support, and policy recognition is both a gender and public health imperative.

The interviews revealed that caregiving is not only an act of duty but also of profound love, faith, and endurance. Many women described finding strength in prayer, small victories, and the gratitude of those they care for. They also expressed fatigue, isolation, and the longing to be recognised not only as caregivers, but as women who also need care. Recognition, rest, and respect emerged as recurring needs that must underpin all future interventions.

Introduction

Caring for a family member with epilepsy or another neurological disorder demands substantial emotional, physical, and financial commitment. In South Africa, this responsibility is most often carried by women, many of whom provide care informally and without pay. Despite their essential contribution to the well-being of affected individuals and the broader health system, women caregivers remain largely invisible within national health policies and social support frameworks. As one participant from the Free State reflected, “Some days we both go to bed without supper, but I cannot rest because he still needs his tablets.” This simple statement captures both the devotion and economic strain that define much of women’s caregiving in South Africa.

This study draws on both an online national survey and follow-up qualitative interviews conducted with 37 women caregivers across five Epilepsy South Africa Branches - Western Cape, South Cape/Karoo, Gauteng, Free State & North West, and Mpumalanga. The survey provided quantitative insights into caregivers’ demographics, income, and training, while the interviews captured the emotional realities and gendered meanings of care. Two interviews in the Free State had to be stopped because participants became too distressed to continue a powerful indication of the emotional burden associated with long-term unpaid caregiving.

This study seeks to document and analyse the roles, needs, and lived experiences of women caregivers who support individuals living with epilepsy and other neurological disorders in South Africa. For the purposes of this research, a caregiver is defined as a woman who provides unpaid assistance to a family member, friend, or community member affected by such conditions. This support may involve managing medication, accompanying individuals to medical appointments, offering emotional care, or assisting with daily living activities.

Interview narratives from across provinces reveal how such care is not merely a set of tasks, but a deeply personal commitment shaped by love, faith, and resilience. One caregiver from Mpumalanga explained, “Prayer gives me strength to face another day,” while another from the South Cape/Karoo noted, “We do everything from bathing to making sure medicine is taken even when we are tired, we carry on.”

Quantitative findings further showed that 64.9% of caregivers were unemployed, 73% experienced significant financial strain, and over half reported emotional exhaustion. Yet, despite this hardship, most described caregiving as a spiritual calling and an expression of unconditional love. This convergence of quantitative and qualitative data illustrates that women’s care labour sustains not only individuals with epilepsy but also the moral and social fabric of their communities.

The research further explores how caregiving experiences are shaped by intersecting factors such as gender, socio-economic status, rural or urban context, and social isolation. By centering the voices of women caregivers, the study aims to contribute to a deeper understanding of their challenges and to inform the development of more inclusive, gender-responsive support systems for caregivers in South Africa. The voices of women interviewed highlight how poverty, gender norms, and stigma compound their daily realities. As one woman from Gauteng put it, “People stare when my child has a seizure in public… they think it’s something we caused.”

Background

Globally, more than 50 million people live with epilepsy, with approximately 80% residing in low- and middle-income countries (LMICs) (World Health Organization [WHO], 2021). In South Africa, the

estimated prevalence of epilepsy ranges between 7 and 10 per 1,000 people, making it one of the more common neurological disorders in the country. Due to limited access to specialist neurological and mental health services, care for people living with epilepsy and related neurological disorders is frequently community-based and largely dependent on informal caregivers.

Caregiving within these contexts often falls on women—particularly mothers, grandmothers, and other female relatives—who provide unpaid care in the home. These caregivers face multiple intersecting challenges, including financial strain, emotional and physical fatigue, stigma, and inadequate institutional or community support (Keikelame & Swartz, 2016). The experience of caregiving is further shaped by broader socio-cultural and economic factors, such as poverty, unemployment, and limited access to health information.

Survey findings confirmed these patterns, with nearly three-quarters of participants reporting difficulty affording transport and medication. Less than 60% were aware of available caregiver programmes, and only half had received formal training, typically through Epilepsy SA branches or local clinics. Interview data reinforced this gap, with many carers describing how they "learned by doing," relying on intuition, advice from social workers, or faith-based guidance rather than structured support.

Interview narratives from the five participating Epilepsy South Africa Branches (Western Cape, South Cape/Karoo, Gauteng, Free State and North West, and Mpumalanga) reinforced these realities. Many women described caregiving as "something expected of us," deeply tied to traditional gender roles and cultural obligation. Several participants shared that they often balanced caregiving with household chores or informal income-generating activities, saying, "I cook, clean, and take care of my son-there's no rest even when I'm tired." Others spoke of feeling isolated and emotionally drained, particularly in rural communities where access to health or psychosocial support was limited.

In South Africa's patriarchal cultural systems, caregiving continues to be regarded as "women's work," reinforcing gendered divisions of labour and contributing to social and economic inequality (Silaule et al., 2023). The interviews revealed how these cultural expectations persist across generations: one caregiver from the Free State noted, "My mother cared for my brother with seizures, now I care for my child-it's just what women do." Female caregivers, especially those in rural or low-income communities, often balance their caregiving duties with household responsibilities and informal employment, leading to heightened vulnerability and isolation.

Together, the survey and interview findings underscore that caregiving is not only a private act of compassion but also a form of invisible labour that sustains the health system. The dual burden of care and poverty places women caregivers at the intersection of social exclusion, gender inequity, and economic vulnerability, highlighting the urgent need for coordinated national support mechanisms.

Literature Summary

Recent empirical studies provide valuable insight into the multidimensional nature of caregiving among South African women, particularly those supporting individuals with chronic neurological disorders.

Sabo et al. (2020) found that caregivers of children with epilepsy at Charlotte Maxeke Johannesburg Academic Hospital experienced significantly reduced health-related quality of life, with financial strain and seizure frequency identified as key stressors. Similarly, Keikelame and Swartz (2016) reported that caregivers of people with epilepsy in Cape Town often face psychosocial stress, cultural

stigma, and social isolation, which compound their caregiving responsibilities. Echoing these findings, results from both the online survey and qualitative interviews in this study confirmed that emotional exhaustion and social isolation remain pervasive among women caregivers across provinces. One caregiver from the Western Cape said, “Sometimes I feel I cannot talk to anyone- people don’t understand what we go through.”

Silaule et al. (2023) examined caregivers of individuals with mental illness and found that 83% of female caregivers experienced moderate to severe burden, primarily due to the lack of respite care and limited access to health and social services. This same need for rest and psychosocial relief was strongly expressed in the interviews; as one participant in the South Cape/Karoo Branch explained, “There is no time for me-if I could have one weekend off, it would help so much.” Further survey data showed that more than half of respondents (52%) had never accessed any form of respite or emotional support, despite expressing high levels of stress and burnout.

Yakubu and Schutte (2023) further proposed a multidimensional model of caregiver burden encompassing environmental, economic, and emotional predictors, underscoring the complex and context-specific challenges that shape caregiving outcomes. This model resonates with the present study’s integrated findings, which revealed how economic insecurity, stigma, and gender roles interact to shape women’s caregiving experiences in South Africa.

At a global level, the World Health Organization (WHO, 2021) highlighted that unpaid care work predominantly performed by women represents labour equivalent to approximately 9% of global GDP. This finding underscores the economic invisibility of women’s caregiving contributions and the need for systemic recognition and support. Similarly, South African caregivers interviewed across provinces spoke of the financial and emotional invisibility of their work. As one woman from Mpumalanga stated, “We do everything, but nobody sees us or pays us for it.”

Together, these studies demonstrate that caregiving burdens are influenced by gender norms, economic inequality, and structural limitations within health systems. The present study builds on this body of evidence by documenting the lived experiences of women caregivers of people with epilepsy and other neurological disorders across South Africa, revealing similar patterns of financial hardship, emotional fatigue, and social exclusion reflected in both the online survey and the interview narratives. Despite these challenges, many caregivers expressed resilience grounded in faith and family. A Gauteng participant shared, “Prayer keeps me strong. When I feel tired, I ask God for strength to keep going.”

Relevant Policies

South Africa’s policy framework offers partial but fragmented recognition of the needs of informal caregivers, including those caring for people with epilepsy or neurological disorders. While several national instruments acknowledge disability rights and community-based support, few provide direct, comprehensive guidance on supporting unpaid caregivers.

Interviews and survey data confirm that caregivers are aware of some existing disability-related policies but often perceive them as inaccessible or irrelevant to their everyday realities. Many described a gap between policy promises and on-the-ground support, particularly regarding financial assistance and access to respite care.

White Paper on the Rights of Persons with Disabilities (2016)

This policy aligns South African legislation with the UN Convention on the Rights of Persons with Disabilities and affirms the inclusion, participation, and non-discrimination of persons with

disabilities. It recognises the diversity of disability and the responsibilities of the state and stakeholders to provide coordinated, barrier-free services. However, it does not include detailed provisions specifically focused on support mechanisms for informal caregivers, such as training, financial support, or respite care. Caregivers in interviews emphasised this gap, with one woman from the Free State noting, “We are the ones doing the work, but government policies talk only about people with disabilities- not those who look after them.”

National Mental Health Policy Framework and Strategic Plan (2023–2030)

This framework emphasises rights-based, community-oriented mental healthcare, integration of services, and intersectoral collaboration. It highlights partnerships between service providers, carers, and communities but lacks clear operational mechanisms or dedicated resources for supporting informal caregivers within mental health and neurological care pathways. As one caregiver in the South Cape/Karoo Branch said, “We hear about these plans, but on the ground, we are still alone with no help.” Survey results supported these perceptions, as only 58% of participants were aware of any caregiver-related programmes, and less than half reported any direct contact with government or social workers for ongoing support.

Social Assistance Act (2004)

The Social Assistance Act establishes South Africa’s social grant system, including the Care Dependency Grant, which provides financial support to primary caregivers of children up to 18 years with severe disabilities requiring full-time care. This grant offers some economic relief but is means-tested and not universally accessible to all caregivers, particularly those caring for adults or without formal income. Several interviewees voiced frustration about this limitation; one woman in Mpumalanga said simply, “We need a stipend for caregivers too.” Both survey and qualitative findings confirmed that financial insecurity is the most pressing concern across all provinces, with 73% of respondents reporting serious economic strain related to caregiving responsibilities.

National Development Plan 2030

The National Development Plan calls for the strengthening of community health worker programmes and improved health system performance, which can indirectly benefit caregiving environments. However, the plan does not directly address the specific needs of unpaid caregivers or propose targeted social support for caregiving roles. A participant from the Western Cape summarised the gap: “They speak about development, but how can we develop if we cannot even rest or feed our families?”

Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (2022–2031)

At the global level, the World Health Organization-led Intersectoral Global Action Plan (IGAP) provides a comprehensive roadmap for improving care, services, and quality of life for people with epilepsy and other neurological disorders and their families. Endorsed by the World Health Assembly, the IGAP outlines strategic objectives to enhance policy prioritisation, access to treatment, integrated care, and participation of carers and people with lived experience in health systems planning and implementation. The IGAP offers an international benchmark and targets that can inform national policy development and advocacy for caregiver support.

Building on the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (2022–2031), Epilepsy South Africa developed the South African Intersectoral Action Plan (SAINAP) to

localise global commitments within the national context. SAINAP was co-developed with government departments, civil society, and advocacy organisations, and is being prepared for presentation to Cabinet in 2026. The plan outlines coordinated, multi-sectoral actions to improve access to care, strengthen community-based rehabilitation, and recognise caregivers as key contributors to national health and social systems. This research contributes direct empirical evidence to SAINAP's advocacy priorities, particularly those related to gender equity, caregiver recognition, and the integration of psychosocial support services into community-based epilepsy programmes.

Despite these frameworks, the gap between policy rhetoric and the lived realities of women caregivers remains significant. Informal caregivers often navigate fragmented systems with limited psychosocial support, inadequate financial assistance, and no formal recognition of their essential contributions to family and community health. As one caregiver stated, "We love our children, but love doesn't pay for food or transport." Our carer research aligns with SAINAP's advocacy goals on community-based rehabilitation and caregiver recognition. It also aligns with Epilepsy SA's ongoing advocacy to bridge this gap by formalising caregiver support through evidence-based recommendations and national policy engagement.

Study Approach

A mixed-methods design was used to gather comprehensive evidence about the experiences of women carers supporting people living with epilepsy or other neurological disorders. This approach combines both quantitative and qualitative methods to provide a fuller understanding of the research topic.

The survey component allowed for the collection of measurable information from a larger group of participants, while the follow-up interviews provided deeper insight into carers' personal experiences and perspectives. Using both methods together helped to strengthen the findings, as the quantitative data highlighted general patterns and the qualitative data added meaning and context to those patterns.

This triangulation of methods provided both breadth and depth with survey findings quantifying the scope of issues such as financial strain, training access, and emotional fatigue, and interviews revealing how these challenges are experienced in daily life. For example, while 73% of survey respondents reported financial stress, interview narratives showed how this translates into real choices about food, transport, and medication.

The interviews, conducted across five provincial Branches, allowed carers to describe in their own words how they cope with emotional fatigue, stigma, and the lack of financial and social support. For instance, participants shared stories of resilience, faith, and family solidarity, revealing nuanced experiences that could not be captured through the survey alone. This mixed-methods integration also enabled comparison across provinces showing that while provincial contexts differ in available services, the emotional realities of caregiving are strikingly similar nationwide. Mixed-methods research is widely recognised as useful in social and health studies because it allows researchers to explore both numerical trends and lived experiences within the same study (Johnson, Onwuegbuzie, & Turner, 2007).

Participant Recruitment

Women caregivers were recruited through Epilepsy South Africa Branches across the country. Recruitment was coordinated by the social workers at each Branch, who were responsible for

identifying and inviting eligible participants. Eligible participants were required to meet the following inclusion criteria:

- ✓ **Gender**: Female
- ✓ **Age**: 18 years or older
- ✓ **Role**: Informal carers (family members, friends, or neighbours) providing regular, unpaid care or support to a person of any gender living with epilepsy or another neurological disorder.
- ✓ **Connection to Epilepsy SA**: Currently accessing or linked to services offered by one of the participating Epilepsy SA Branches.
- ✓ **Availability**: Able to attend a scheduled appointment at the Branch to complete the online survey and a follow-up interview.
- ✓ **Language**: Able to understand English, as both the survey and interview were conducted in English.
- ✓ **Consent:** Willing and able to provide informed consent to participate in the study, including consent for the recorded interview.

Potential participants were identified by social workers based on their existing knowledge of carers accessing Branch services. Identified carers were contacted directly and informed about the study's purpose, process, and voluntary nature. Each received an information sheet and consent form outlining the research procedures. Social workers scheduled appointments for eligible women to visit the Branch, where they completed the online survey and took part in a follow-up interview.

Efforts were made to ensure diversity among participants in terms of race, age, and socio-economic background, in order to reflect the local communities served by each Branch. Initially, six Epilepsy SA Branches were invited to participate, with a target of recruiting approximately eight eligible carers per Branch (total n = 48). However, the Eastern Cape Branch was unable to participate due to limited staff capacity and competing project commitments. As a result, five Branches (Epilepsy SA Western Cape, Epilepsy SA South Cape/Karoo, Epilepsy SA Gauteng, Epilepsy SA Free State & North West, and Epilepsy SA Mpumalanga) took part in the study. A total of 37 women caregivers completed the online survey, and 35 participated in the follow-up interviews. Two participants who initially consented were unable to complete their interviews, one due to family concerns and another owing to conflicting commitments.

Coordination and Implementation

Prior to participant recruitment, the Epilepsy South Africa National Office engaged with Branch Directors and social workers to coordinate the implementation of the carer research. An initial email was circulated to Branch Directors providing details of the research, outlining its objectives, and indicating areas where Branch assistance was required.

Following this, the National Office met with the Branch Directors and the designated social workers identified to participate in the study. A subsequent series of follow-up meetings were held with social workers from each Branch to discuss the research process in greater detail, including the online survey and follow-up interview components. During these sessions, social workers received clarification on the study procedures and were encouraged to raise questions regarding implementation at their respective sites. At the request of the social workers, a short introductory script was developed to complement the interview guide and ensure consistency when introducing the research and conducting interviews with women carers across all participating Branches.

Social workers played a key facilitating role throughout the research process not only in recruitment but also in providing a safe and trusted environment for carers to share their stories. Their involvement ensured that the interviews were culturally sensitive and that carers felt comfortable

discussing personal experiences, including emotional strain, stigma, and the daily realities of caregiving. In several cases, social workers had to pause or discontinue interviews when participants became too emotional, particularly in the Free State and North West Branch, underscoring the sensitivity of the topic and the importance of trauma-informed interviewing approaches.

Regular feedback was provided by the Branches to the National Office during data collection to ensure that logistical and ethical challenges were promptly addressed. This two-way coordination not only strengthened data quality but also fostered ownership of the process among local teams. This collaborative model also strengthened the reliability and ethical grounding of the study.

Data Collection

Quantitative data was collected through structured surveys administered via the Google Forms platform (see Appendix A: Carer Survey Instrument: Google Form Questionnaire). The survey captured demographic information, caregiving duration, sources of support, and perceived levels of caregiving burden. A total of 37 women caregivers participated in the survey, representing five Epilepsy South Africa Branches: Western Cape, South Cape/Karoo, Gauteng, Free State & North West, and Mpumalanga (see Figure 1). Of these, 35 caregivers also participated in follow-up qualitative interviews conducted by trained social workers at their respective Branches. Two participants who had initially consented were unable to complete interviews, one due to family opposition and another owing to unforeseen personal commitments. Interviews followed a ten-question guide that explored caregivers' daily routines, emotional well-being, stigma, and support needs (see Appendix B: Semi-structured Interview Guide). The guide ensured consistency across the provinces while allowing for open- ended and context-specific responses.

Interviews were conducted in English or local languages and transcribed verbatim using Microsoft Teams. Two interviews in the Free State & North West Branch were discontinued at the participants' request due to emotional distress; these cases were noted as evidence of the emotional intensity of caregiving experiences. Across all Branches, interview duration ranged from 20 to 45 minutes, with social workers recording non-verbal cues and contextual observations in field notes to support thematic analysis. The qualitative component provided rich, contextual insights that deepened understanding of the quantitative findings and illuminated the complex intersection of gender, poverty, and emotional resilience that characterises caregiving in South Africa.

Data Analysis

Quantitative survey data were analysed using descriptive statistics to summarise key variables, including caregiver age, relationship to the person with epilepsy, length of care, and perceived burden. Frequencies and proportions were calculated to identify common patterns across provinces. Qualitative data were analysed thematically following the approach outlined by Braun and Clarke (2006). Transcripts were reviewed and coded to identify recurring patterns in participants' narratives. Themes were inductively developed from the data and refined through team discussion to capture the shared and divergent experiences of carers across all five Branches.

Emergent themes included:

- ✓ Faith and Spirituality as a Source of Strength
- ✓ Emotional and Physical Burnout
- ✓ Persistent Poverty and Lack of Formal Support
- ✓ Stigma and Social Exclusion
- ✓ Love, Resilience, and Identity

These themes were triangulated with quantitative survey results such as reported levels of financial stress, training access, and emotional well-being and compared against existing literature to ensure analytic validity and contextual depth.

Ethical Considerations

This study was conducted in accordance with ethical research principles, including respect for participants, voluntary participation, and confidentiality. Informed consent was obtained from all participants prior to data collection.

Access to the online survey data collected through Google Forms was restricted to two designated staff members from the Epilepsy South Africa National Office that are part of the Engendering Disability-Inclusive Development (EDID) SA research team. Interview data were collected in person at the Branches by the social workers, with the interviews recorded via Microsoft Teams to ensure accuracy and secure storage. Audio recordings and automatically generated transcripts were stored in a OneDrive folder managed by Epilepsy SA. Only members of the EDID SA research team had access to these files.

Given the sensitive nature of caregiving experiences, particularly those involving emotional distress, stigma, and family challenges, social workers were trained to conduct interviews with empathy and cultural awareness. Participants were reminded that they could pause or stop the interview at any time and were encouraged to omit any questions they did not wish to answer. In two cases within the Free State and North West Branch, interviews were respectfully discontinued when participants became visibly distressed. Social workers provided immediate emotional support and follow-up check-ins to ensure participants' well-being, demonstrating a trauma-informed and participant-centred approach.

Transcripts were reviewed and anonymised prior to analysis to remove any identifying details, including names, locations, or references that could reveal participant identity. Quotations used in the report were carefully selected to protect confidentiality while preserving the authenticity of participants' voices. All consent forms and related documentation were securely stored in accordance with Epilepsy SA's data protection policies. Participant names and any other identifying information were not included in any reports or analyses, ensuring that all data remained confidential and anonymised.

In cases where participants disclosed emotional distress or a need for psychosocial support, referrals were made to Epilepsy SA's social development services for follow-up care. This ensured that research participation not only respected confidentiality but also promoted participant well-being beyond the interview process. Ethical oversight for the project was provided internally by Epilepsy South Africa through the EDID SA framework, in alignment with the organisation's standards for responsible research and participant protection.

Profile of Women Carers

Gender Identity

Figure 2 illustrates the gender identity of participants who completed the online survey. The survey was designed for women who provide care to individuals living with epilepsy or other neurological disorders. A total of 37 participants completed the survey. Of these, 37 selected "woman," and one respondent also selected "man" in addition to "woman." As the study specifically focused on women carers, and the survey instructions indicated that the study was intended for women participants, this response was interpreted as a possible input error or multiple selection made in error. The

overall sample was therefore treated as 37 women carers in accordance with the study's inclusion criteria.

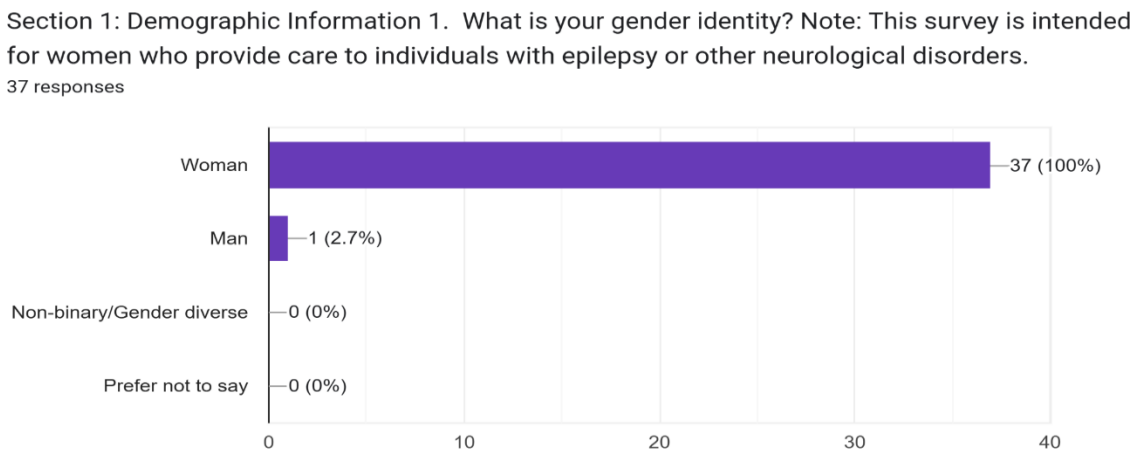


Figure 2: Gender identity of women carers (n=37)

Age Group of Women Carers

Figure 3 presents the age groups of the women carers who completed the online survey (n = 37). The largest proportion of carers fell within the 35–44 years age group (9 participants, 24.3%), followed by the 45–54 years group (8 participants, 21.6%) and 55-64 years old (8 participants,21.6%). Both the 18–24 and 25–34 age groups included 4 carers each (10.8%), and another 4 carers (10.8%) were 65 years and above. This distribution shows that caregiving roles span a wide range of adult ages, with most carers in this study situated in early to middle adulthood.

Research on caregiver demographics similarly highlights that caregiving is common across different life stages. According to the Family Caregiver Alliance (2021), nearly half of informal caregivers are between 18 and 49 years old, while a significant proportion are 65 years and older, demonstrating that caregiving responsibilities extend across multiple adult age groups. This finding is consistent with broader caregiving literature, which suggests that individuals often assume caregiving roles during their most active working and family years (Lantano et al., 2025).

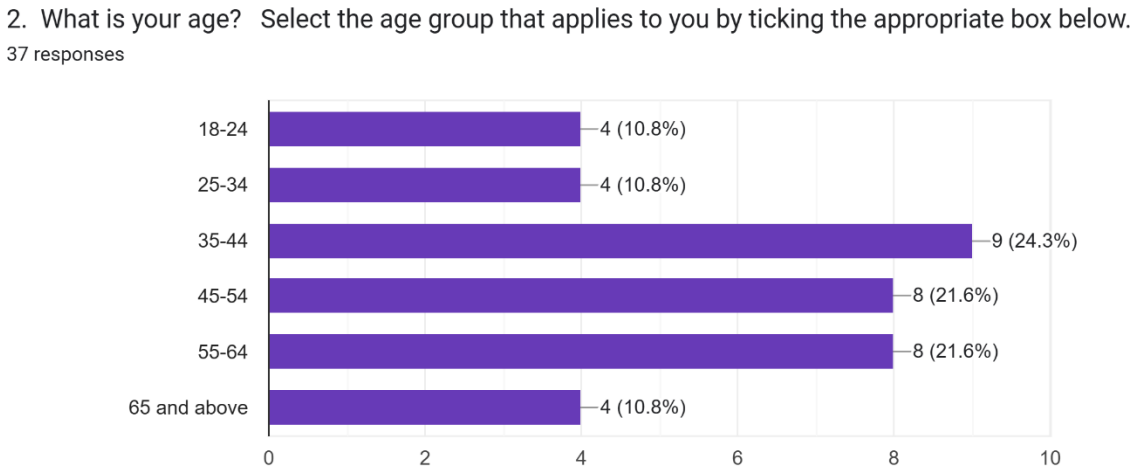


Figure 3: Age groups of women carers (n=37)

Area of Residence

Figure 4 shows the residential locations of the women carers who completed the online survey (n = 37). Just over half of the participants (51.4%) reported living in urban areas, while 27% lived in rural areas, and 21.6% lived in peri-urban settings. This indicates that most carers in the study were based in towns or cities, with a smaller but notable proportion providing care in rural or peri-urban communities.

This distribution aligns with national caregiving patterns, where caregiving is found across all geographical settings, though access to support services often differs. Studies have shown that urban caregivers may have greater access to health and social services, while rural caregivers often face challenges such as limited transportation, fewer specialist resources, and social isolation (Phillipson et al., 2016).

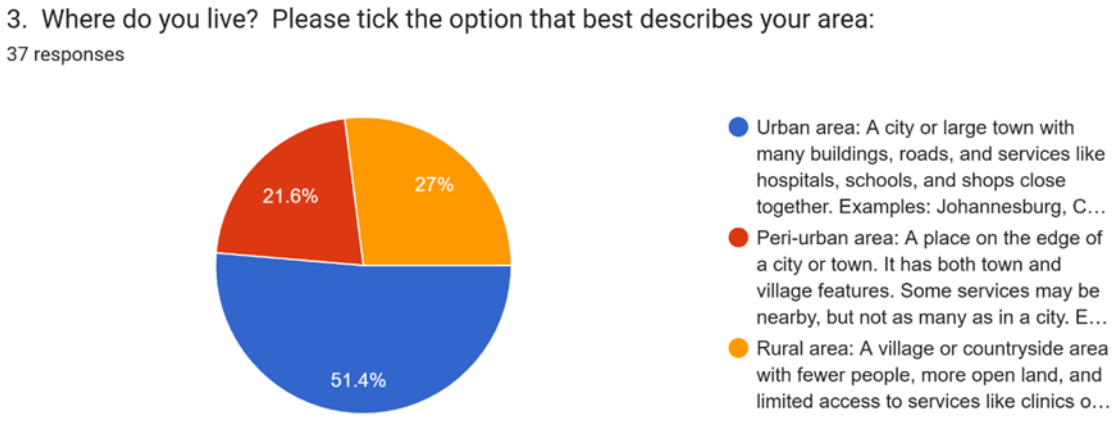


Figure 4: Area of residence of women carers (n=37)

Employment Status

Figure 5 presents the employment status of the women carers who completed the online survey (n = 37). Most participants were unemployed (24; 64.9%), while 9 carers (24.3%) were employed full-time, 3 carers (8.1%) retired, and 1 carer (2.7%) reported being self-employed.

This distribution indicates that most women carers were not formally employed, suggesting that caregiving responsibilities may limit opportunities for paid work or reflect the socio-economic challenges faced by many carers in South Africa. Previous studies have found similar patterns, noting that unpaid carers—particularly women—often experience employment disruption, reduced working hours, or withdrawal from the labour force due to caregiving duties (van den Berg et al., 2020).

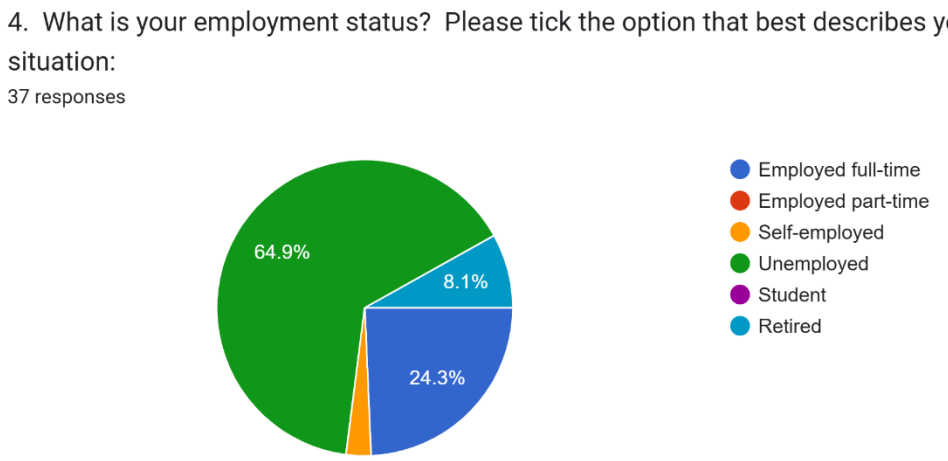


Figure 5: Employment status of women carers (n=37)

Highest Level of Education

Figure 6 shows the highest level of education reported by the women carers who completed the online survey (n = 37). Nearly half of the participants (18 carers; 48.6%) reported having secondary education, while 13 carers (35.1%) had attained tertiary education. Smaller proportions completed primary education (3 carers; 8.1%), held a diploma (1; 2.7%), or had completed Grade 10 (1; 2.7%). One participant (2.7%) reported having completed a Beauty Therapy course.

This distribution shows that most carers had at least secondary-level education, with a significant proportion achieving tertiary qualifications. However, similar to findings in broader caregiving research, educational attainment among carers varies widely, reflecting diverse socio-economic backgrounds. Research suggests that while higher education may help carers access information and resources, caregiving responsibilities can also interrupt educational and training opportunities, particularly among women (Pinquart & Sörensen, 2006).

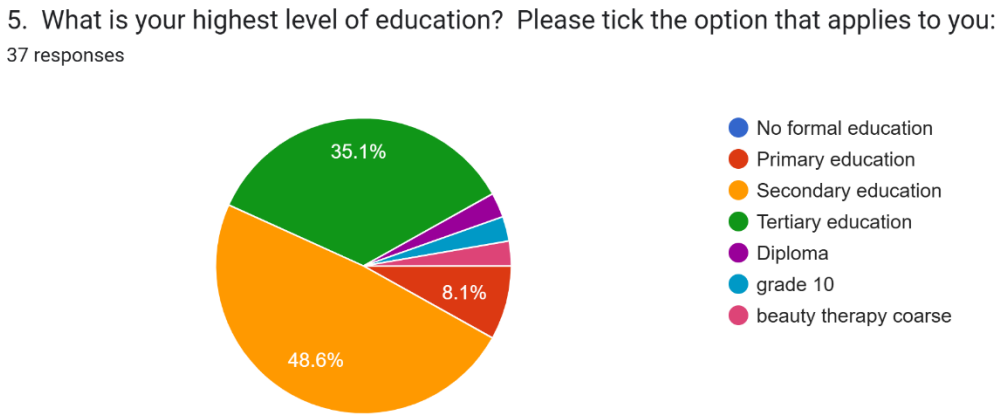


Figure 6: Highest level of education of women carers (n=37)

Relationship to the Person Cared For

Figure 7 presents the relationship of the women carers to the person living with epilepsy or another neurological disorder (n = 37). Over half of the participants were parents (20; 54.1%), followed by extended family members (5; 13.5%), and friends (3; 8.1%). Smaller proportions were sons (2; 5.4%), spouses or partners (2; 5.4%), or had other caregiving roles such as being a member of a non-profit organisation (1; 2.7%), daughter (1; 2.7%), client (1; 2.7%), resident where I work (1; 2.7%), and child's father (1; 2.7%).

This distribution highlights that most carers were immediate family members, particularly parents, reflecting the central role of families in providing unpaid care for individuals with chronic neurological disorders. Previous research has shown that parents, and especially mothers, often assume long-term caregiving responsibilities, balancing emotional, financial, and physical demands. Family-based care remains the primary source of support for people with epilepsy in many low- and middle-income contexts, where formal care systems are limited (Austin et al., 2014).

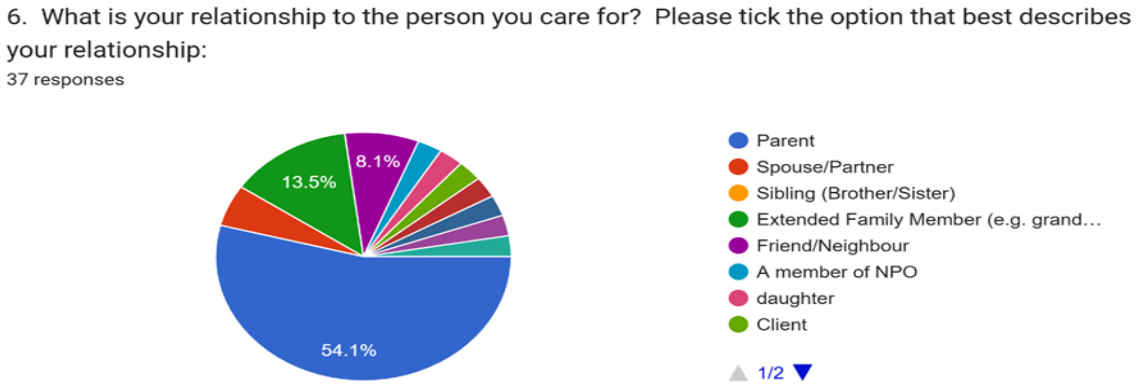


Figure 7: Relationship of women carers to the person living with epilepsy or another neurological disorder (n = 37)

Key Findings

Impact of Caregiving on Financial Situation

Figure 8 illustrates how caregiving has affected the financial situation of the women carers who completed the online survey (n = 37). Most participants (27 carers; 73%) reported that caregiving negatively affected their financial situation, while 8 carers (21.6%) indicated no financial impact, and 2 carers (5.4%) responded "maybe."

This finding highlights the significant economic strain faced by women carers, who often incur additional costs for transportation, medical expenses, and lost income opportunities due to reduced work availability. Similar patterns have been observed globally, with unpaid carers frequently experiencing financial hardship linked to out-of-pocket costs and reduced employment participation (Arno et al., 2014).

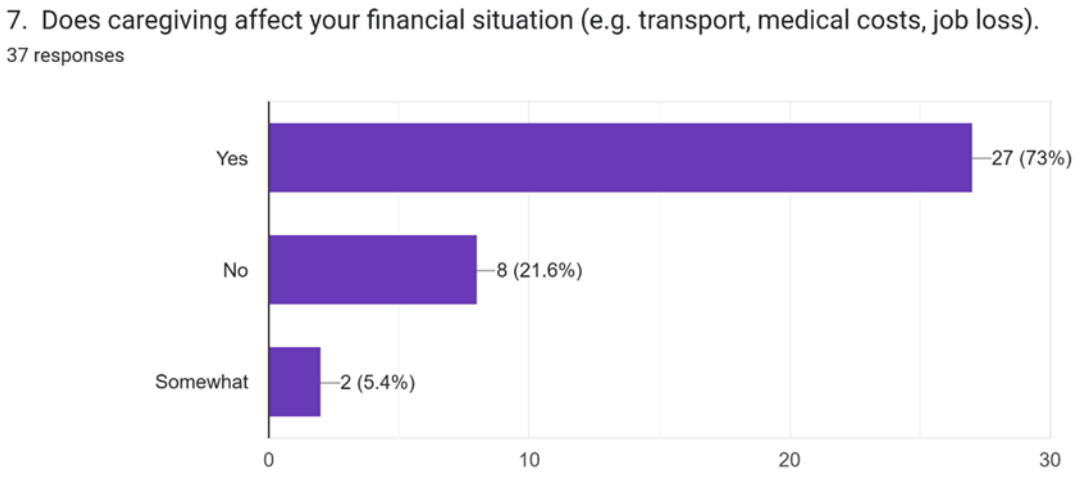


Figure 8: Impact of caregiving on the financial situation of women carers (n = 37)

Financial Impact: Participant Perspectives

A follow-up open-ended question was asked to explore how caregiving affects women carers' financial situations. Thirty participants provided narrative responses describing the financial pressures associated with transport, medical expenses, unemployment, and the costs of daily care needs.

Three key themes were identified from participants' open-ended responses regarding the financial impact of caregiving: increased costs, loss of income opportunities, and dependence on social grants. Representative quotations are included below, and full verbatim responses are provided in Appendix C. A thematic review of their comments revealed three recurring themes:

- ✓ **Increased financial costs related to caregiving** – Many carers mentioned additional spending on transport, medical care, and daily necessities.
    - "If it's raining, I have to get a taxi and I don't get paid, so no transport fee."
    - "I have to use most of my money to buy him nappies; in the end, we run short on money for other things."

- ✓ **Loss of income or limited employment opportunities** – Carers frequently described being unable to work or having to give up job opportunities due to their caregiving responsibilities.
    - "It's difficult finding full-time employment since I have to be away from work to attend check-ups or be there when my son gets hospitalized."
    - "Because I have to stay indoors all the time instead of going out to look for work."
- ✓ **Dependence on social grants and financial strain** – Several participants reported relying on disability or social relief grants, which were often insufficient to cover household and care-related expenses.
    - "I rely on the disability grant - it's low and I can't cover daily costs."
    - "I'm compelled to give my uncle the grant of my child to go to the clinic and also my R350 SRD grant as the situation is not well at home."

Overall, the responses portray significant financial vulnerability among carers, consistent with global evidence showing that unpaid caregiving often leads to economic hardship and reduced labour participation, particularly among women Schultz & Eden, 2016).

Caregiving Roles and Responsibilities

Neurological Disorders of Care Recipients

Figure 9 shows the neurological disorders of the individuals cared for by the women participants (n = 37). Most carers reported providing care to a person living with epilepsy (26; 70.3%), followed by traumatic brain and spinal cord injury (7; 18.9%) and headache disorders (5; 13.5%). Smaller proportions cared for individuals with cerebrovascular diseases such as stroke (3; 8.1%), neuroinfectious or neuroimmune disorders (2; 5.4%), and neurodevelopmental disorders (2; 5.4%). A few participants indicated caring for individuals with neurodegenerative conditions, intellectual or cognitive disabilities, or multiple comorbidities (each 2.7%). Two carers (5.4%) reported that they were unsure of the exact diagnosis.

This distribution reflects the diverse neurological disorders managed by informal carers supported through Epilepsy South Africa, with epilepsy being the most prevalent condition. Similar patterns are observed globally, where epilepsy and post-traumatic neurological injuries represent major causes of long-term disability and reliance on informal caregiving, especially in low- and middle-income settings (World Health Organization, 2023).

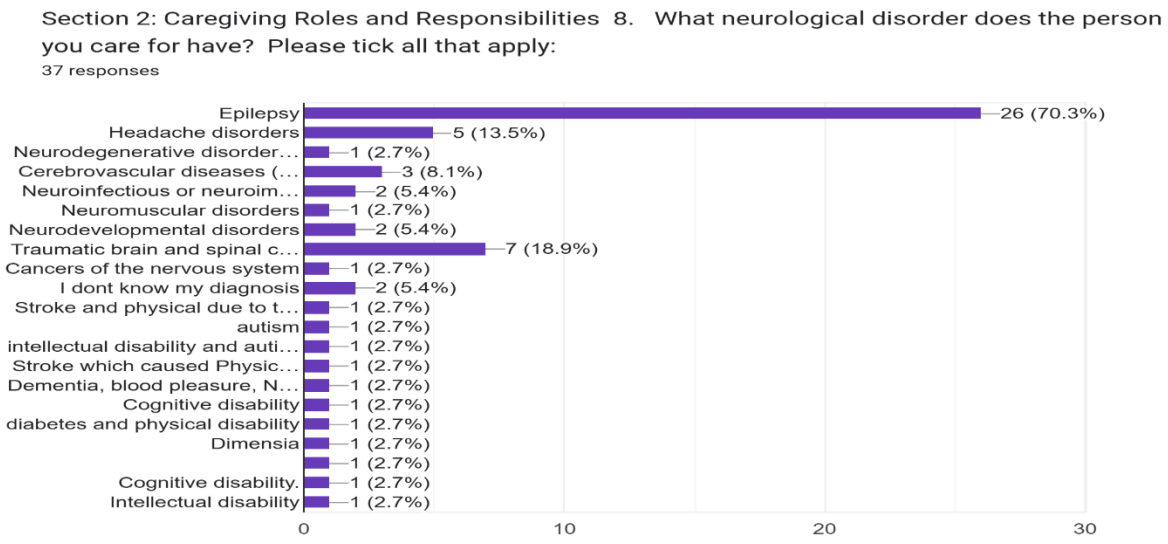


Figure 9: Neurological disorders of persons cared for by women carers (n = 37)

Duration of Caregiving

Figure 10 illustrates how long participants have been providing care for a person living with epilepsy or another neurological disorder (n = 37). Just under one-third of the carers (12; 32.4%) reported providing care for more than 10 years, while 8 carers (21.6%) had been caring for 7–10 years. A smaller group (9 carers; 24.3%) had been caring for less than one year, 5 carers (13.5%) for 1–3 years, and 3 carers (8.1%) for 4–6 years.

This distribution indicates that a large proportion of participants were long-term carers, with over half having provided care for seven years or more. Long-term caregiving is common in families affected by chronic neurological disorders such as epilepsy, where ongoing medical management and supervision are required. Research has shown that extended caregiving duration is often associated with greater emotional strain, financial burden, and risk of burnout, particularly among women who are the primary caregivers (Schulz & Eden, 2016).

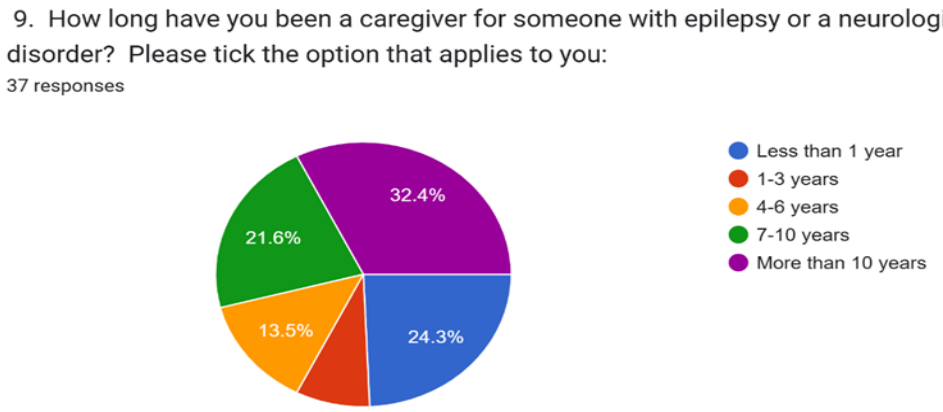


Figure 10: Duration of caregiving among women carers (n = 37)

Time Spent on Caregiving Duties

Figure 11 shows the average number of hours participants reported spending on caregiving each day (n = 37). Most carers (24 participants; 64.9%) indicated that they provided full-time care, while 7 carers (18.9%) spent 5–8 hours per day on caregiving duties. A smaller number reported providing care for 2–4 hours (5 carers; 13.5%), and only 1 participant (2.7%) spent less than two hours per day in a caregiving role.

These findings suggest that most participants were highly involved in daily caregiving, often providing around-the-clock support. Full-time caregiving is common in families supporting individuals with epilepsy or neurological disorders, where continuous supervision and assistance with daily activities are frequently required. Studies have shown that high-intensity caregiving is associated with greater physical and emotional strain, particularly among women who balance multiple household and family responsibilities (Pinquart & Sörensen, 2003).

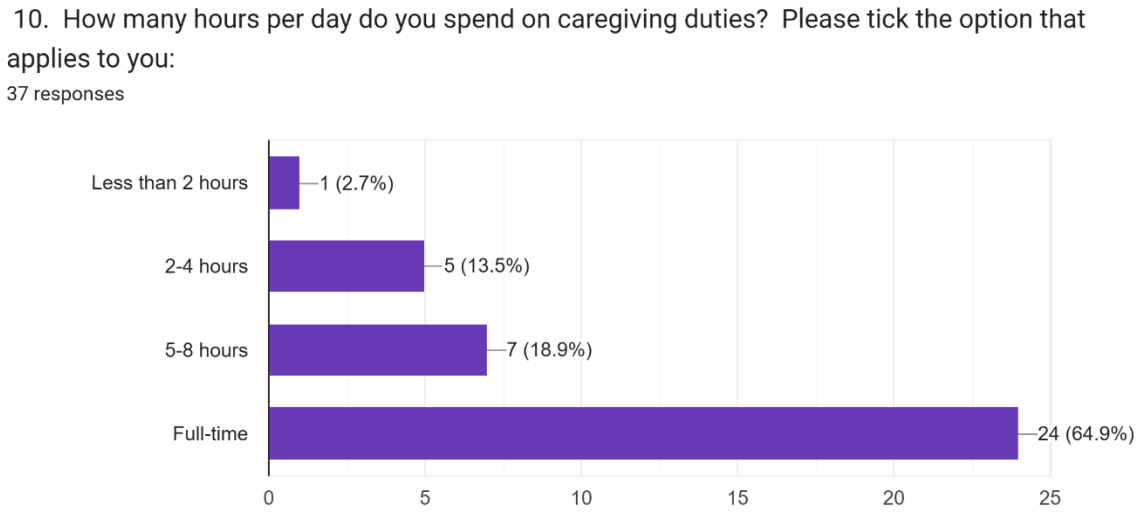


Figure 11: Average hours per day spent on caregiving duties (n = 37)

Caregiving Responsibilities

Figure 12 summarises the main caregiving responsibilities reported by participants (n = 37). The most frequently reported role was providing emotional support (30 participants; 81.1%), followed by managing medication (24; 64.9%) and advocacy or coordination of care (24; 64.9%). Around three-fifths of carers (22 participants; 59.5%) assisted with daily living activities (such as bathing, feeding, and dressing) and managing finances (22; 59.5%). Night-time supervision and transporting care recipients to medical appointments were reported each by 20 participants (54.1%), while helping with mobility was mentioned by 7 participants (18.9%). A small number of carers described additional responsibilities such as using traditional medicine or providing post-stroke care.

These findings indicate that the women carers in this study perform a wide range of intensive and multidimensional caregiving tasks—emotional, practical, and medical. This pattern aligns with evidence that family carers of people with neurological disorders often assume complex, unpaid responsibilities comparable to professional care roles (Rigby, Gubitz, & Phillips, 2009). Emotional and medication management tasks are particularly demanding in epilepsy care, where seizures and treatment side effects require constant monitoring and psychosocial support (de Oliveira, G. N., et al. 2020).

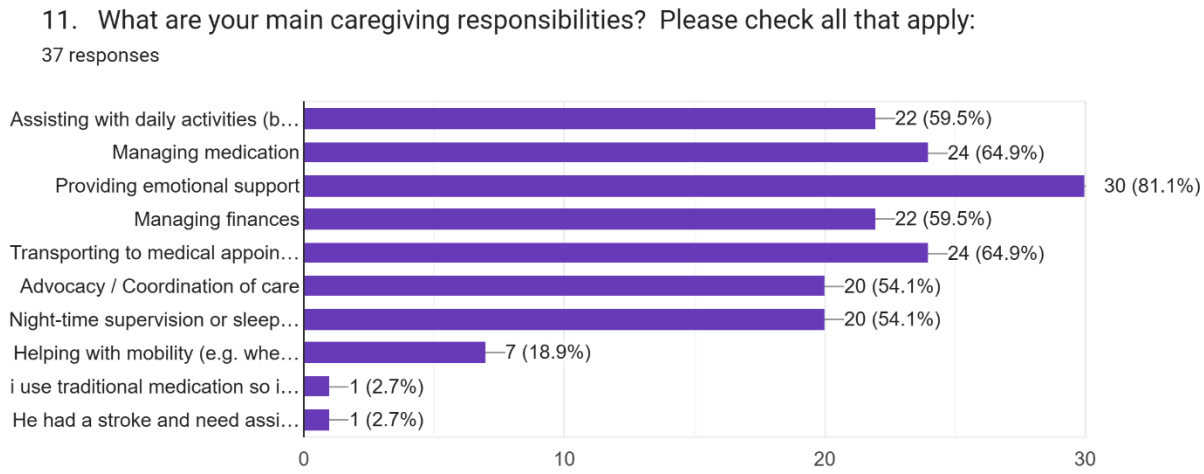


Figure 12: Primary caregiving responsibilities among women carers (n = 37)

Access to Support and Resources

Figure 13 illustrates the types of support that participants reported currently receiving (n = 37). Most carers (27 participants; 73%) identified family support as their primary source of help, followed by disability grants (21 participants; 56.8%) and support from friends (13 participants; 35.1%). Smaller numbers mentioned receiving support from community or church groups (2.7%), government assistance (5.4%), or formal support groups (13.5%). Notably, four participants (10.8%) reported receiving no support at all.

These findings suggest that most caregiving support is informal and family-based, with limited access to structured or institutional resources. This pattern reflects broader research showing that in many low- and middle-income contexts, care for individuals with chronic neurological disorders is largely sustained by families, often without adequate state or professional support (World Health Organization, 2022). The heavy reliance on family networks, combined with limited government or community support, may increase carers' vulnerability to stress, financial hardship, and social isolation (Camfield et al., 2018).

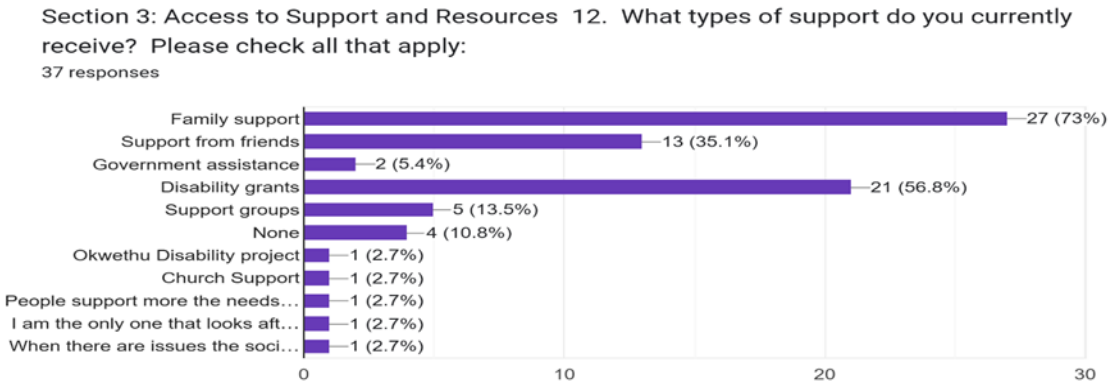


Figure 13: Types of support currently received by women carers (n = 37)

Awareness of Caregiver Support Programmes

Figure 14 presents participants' awareness of formal or informal caregiver support programmes (n = 36). Just over half of the respondents (21 participants; 58.3%) reported that they were aware of existing caregiver support initiatives, such as those offered by NGOs, churches, or clinics. However, a substantial proportion (13 participants; 36.1%) indicated no awareness of such programmes, while 2 participants (5.6%) were unsure.

These findings highlight a mixed level of awareness and accessibility of caregiver support resources. Although some carers knew of available programmes, over one-third remained unaware of services that could potentially provide emotional, informational, or financial assistance. Limited awareness may reflect communication gaps between service providers and community members, as well as the uneven distribution of caregiver resources across provinces.

Similar trends have been observed globally, where family carers of people with neurological disorders often report low visibility of formal support systems, particularly in rural or resource-limited areas (Lloyd et al., 2018). Enhancing outreach and information sharing through local clinics, social workers, and community networks could therefore play a crucial role in improving carers' access to assistance.

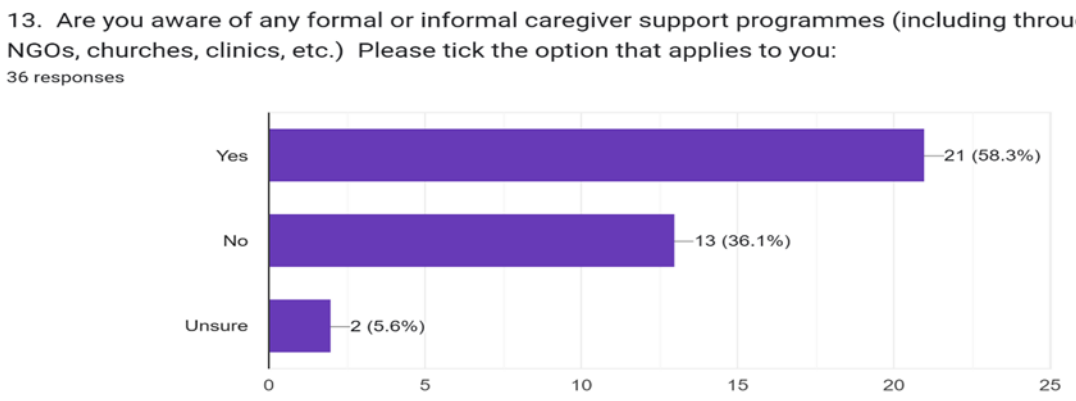


Figure 14: Awareness of caregiver support programmes (n = 36)

Types of Caregiver Support Programmes Accessed

Figure 15 illustrates the types of caregiver support programmes accessed by participants who reported awareness of such initiatives (n = 24). The most frequently accessed form of support was counselling (14 participants; 58.3%), followed by training or educational programmes (12 participants; 50%). A smaller number of participants reported involvement in peer support groups (3 participants; 12.5%) or receiving financial assistance (2 participants; 8.3%).

A few respondents identified other forms of assistance, including opportunities for socialising (4.2%), access to medical supplies (4.2%), and non- emotional support initiatives (4.2%).

Overall, these findings suggest that while emotional and educational supports are the most common, formal and structured financial or practical assistance remains limited. This pattern aligns with prior research showing that caregivers of people with neurological disorders often receive psychosocial rather than economic support, despite ongoing financial pressures (Brodaty & Donkin, 2009).

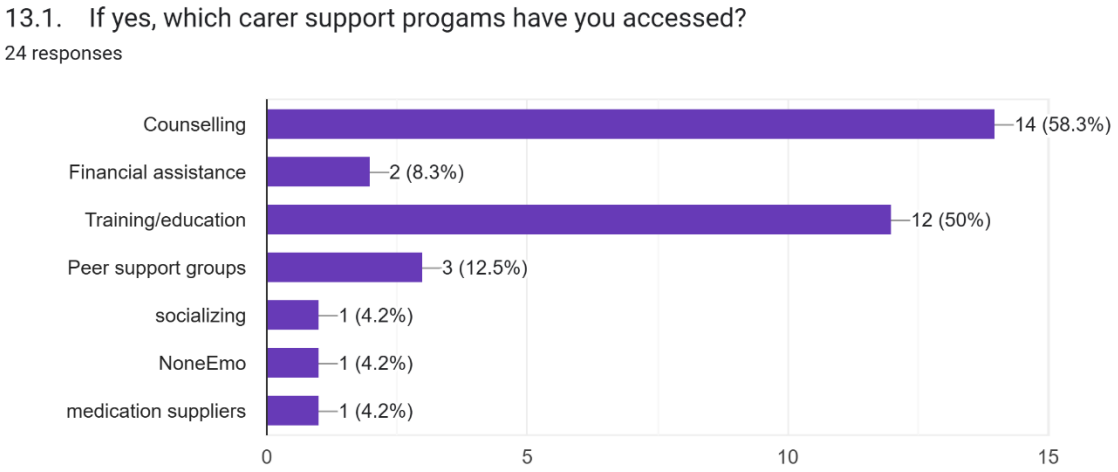


Figure 15: Types of caregiver support programmes accessed (n = 24)

Satisfaction with Caregiver Support Services

Among the 29 participants who had accessed some form of caregiver support, the majority reported being very satisfied with the services received (20 participants; 69%). A smaller group expressed a neutral level of satisfaction (7 participants; 24.1%), while only 2 participants (6.9%) indicated that they were not satisfied. See Figure 16.

Overall, these findings suggest that most carers viewed the available services, particularly counselling and training opportunities positively. However, the small number of participants reporting dissatisfaction points to the ongoing need to ensure that support services are accessible, relevant, and responsive to the diverse needs of women carers. Recent evidence shows that structured, multi-component support programmes addressing both emotional and practical needs can significantly improve caregiver satisfaction and wellbeing (Gemito et al., 2024). Furthermore, the perceived quality of social support plays a critical role in shaping carers' overall satisfaction, highlighting the importance of sustained peer and professional engagement (García-Mochón et al., 2019).

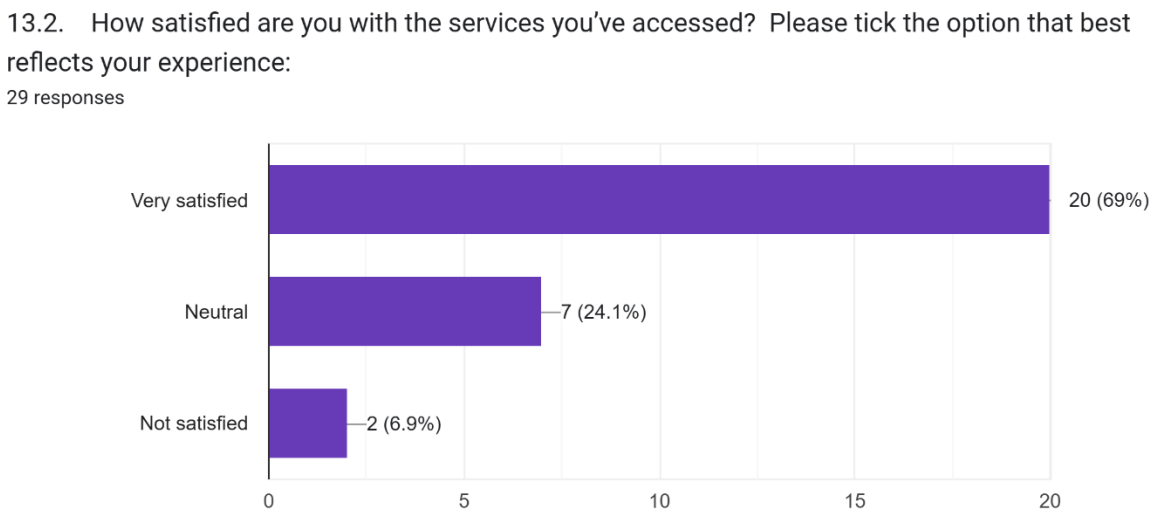


Figure 16: Satisfaction with caregiver support services (n = 29)

Unmet Needs of Caregivers

Participants were asked to identify their top three unmet needs as caregivers (n = 37). The responses revealed a range of recurring challenges, which were grouped into five primary themes:

- ✓ **Emotional support** – Many carers described a need for greater understanding, counselling, and spaces for emotional expression.
- ✓ **Information and training** – A strong need for accessible, accurate information about neurological disorders, treatment options, and caregiving skills was reported.
- ✓ **Transportation support** – Transport to medical appointments or support groups was frequently identified as a major barrier, especially in rural areas.
- ✓ **Financial and material assistance** – Numerous carers mentioned difficulty affording medication, medical supplies, and basic needs such as food or clothing.
- ✓ **Respite and self-care opportunities** – Several participants highlighted exhaustion and a desire for rest, time alone, or short breaks from caregiving.

Representative quotations include:

- ✓ "Emotional support, transportation and information."
- ✓ "House, job, and financial assistance."
- ✓ "Rest, alone time, self-care."
- ✓ "Need nappies, assistance with transport, information, clothes and bedding."

These findings underscore the multidimensional strain of unpaid caregiving and the interconnectedness of emotional, financial, and informational needs. The pattern aligns with broader literature showing that carers of individuals with neurological disorders often experience overlapping gaps in formal support, economic stability, and self-care opportunities (Ploeg et al., 2020).

(Full verbatim responses are provided in Appendix D.)

Additional Resources Help Needed

Figure 17 illustrates the additional resources that women carers identified as most helpful in supporting their caregiving roles. Most carers (32; 86.5%) indicated a need for training on caregiving and managing neurological disorders, while 27 carers (73%) highlighted the importance of financial assistance. A substantial number also expressed the need for counselling or emotional support (26; 70.3%) and mental health support (21; 56.8%). More than half of the respondents (25; 67.6%) reported that transportation assistance would ease their caregiving responsibilities, and 19 carers (51.4%) requested access to peer support groups or caregiver networks.

Additional needs included information about available services (16; 43.2%), access to medications and medical supplies (12; 32.4%), and respite care for temporary relief (8; 21.6%). One respondent specifically mentioned the need for housing support (2.7%). Overall, these findings highlight a consistent pattern of insufficient psychosocial, financial, and informational support for women carers—issues echoed in international literature, which emphasizes that training, mental health support, and respite opportunities are among the most unmet needs of family caregivers (Adelman et al., 2014).

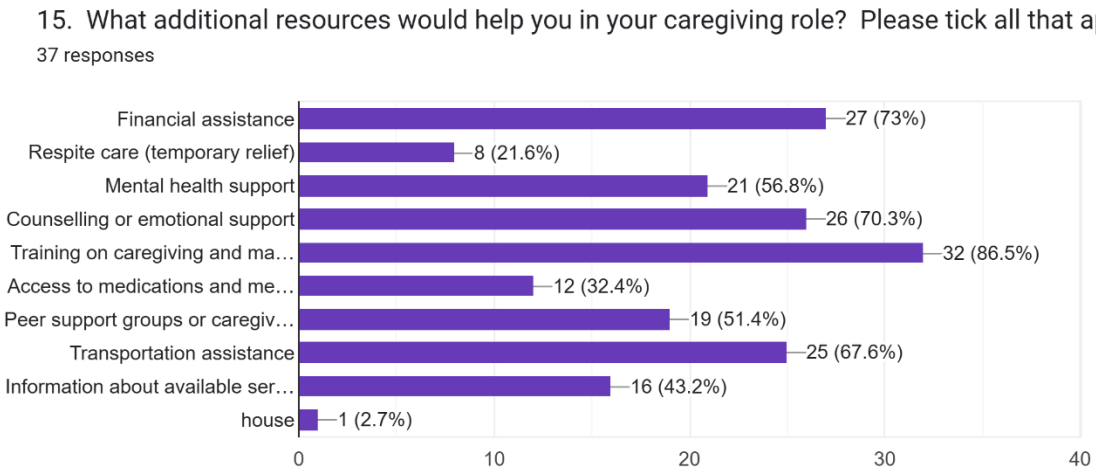


Figure 17: Additional resources needed

Gender and Caregiving Expectations

As shown in Figure 18, most participants (23; 62.2%) reported that being a woman had not affected the caregiving expectations placed on them by their family, community, or culture. However, 13 participants (35.1%) indicated that their gender had influenced these expectations, suggesting that some women experience additional social or cultural pressure to assume caregiving responsibilities. A smaller number (3 participants; 8.1%) were unsure whether their gender played a role in shaping caregiving expectations.

These findings highlight a mixed perspective among carers: while many did not perceive gendered expectations explicitly, more than one-third acknowledged that being a woman contributed to societal or familial expectations to provide care. This reflects broader literature indicating that caregiving is still strongly gendered, with women more likely to be viewed as natural or expected caregivers due to social and cultural norms (Schultz & Eden, 2016).

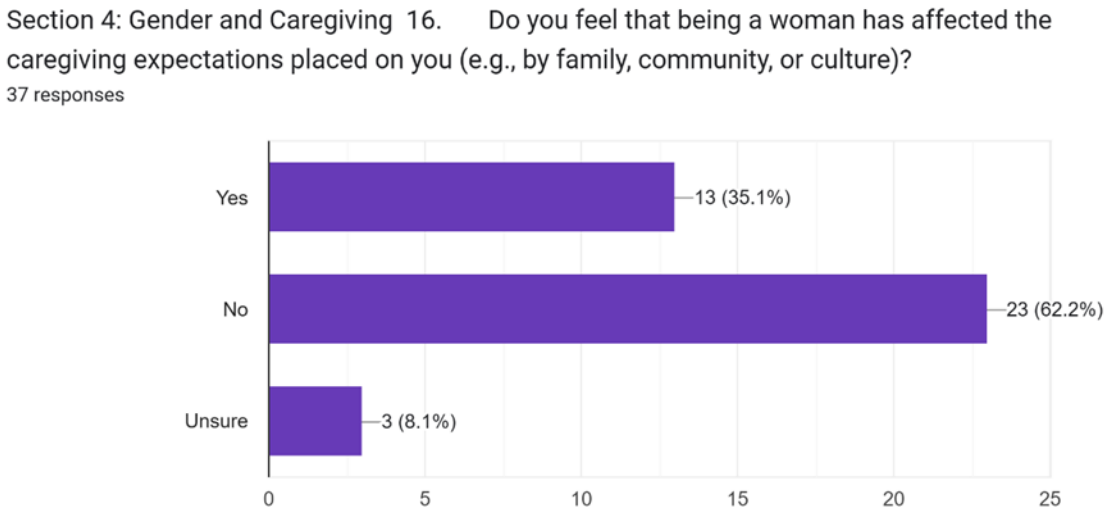


Figure 18: Gender and caregiving expectations

Among those who answered "yes," three main themes emerged from their open-ended responses (see Appendix B for full responses):

- ✓ **Cultural and familial expectations** – Several women described how caregiving was viewed as a woman's "duty" or "responsibility" within their family or community.
  - "It's expected that as a woman, I must take care of everyone."
  - "In our culture, women are seen as natural carers - men don't do that."
- ✓ **Emotional burden and gendered norms** – Participants expressed that women are often expected to provide not only physical care but also emotional and psychological support.
  - "I must always be strong for my family and hide my emotions."
  - "People think women can handle stress better, so they depend on us more."
- ✓ **Limited support and recognition** – Some participants reported that their caregiving work is undervalued or taken for granted because they are women.
  - "People don't see what I do as work - they just say I'm doing what women should do."
  - "If a man was doing this, he'd get more help and respect."

These findings are consistent with previous research showing that gender roles and cultural expectations reinforce women's unpaid caregiving responsibilities, leading to emotional and economic strain (Dalmia & Lawrence, 2022).

(Full qualitative responses to this question are provided in Appendix E.)

Perceptions of Gender Influence on Caregiving Roles

Participants were also asked whether they felt that gender influences who is expected to provide care within their community (Question 17). As shown in Figure 19, half of the respondents (50%) believed that gender does influence caregiving expectations, while 32.4% did not, and 17.6% were unsure. These findings suggest that caregiving is still viewed as a gendered responsibility by many participants, reflecting cultural and social norms that associate caregiving primarily with women.

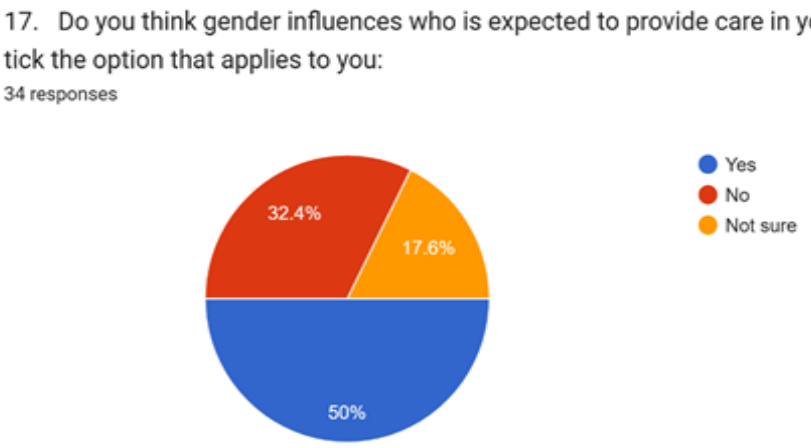


Figure 19: Perceived influence of gender on caregiving expectations

Participants who answered "Yes" to Question 17 ("Do you think gender influences who is expected to provide care in your community?") were asked a follow-up question:

- ✓ "If yes, in what ways do you think gender affects caregiving roles?"

Among the 18 participants who responded, several themes emerged. Most viewed caregiving as a woman's responsibility, rooted in cultural and social expectations that women are more nurturing and family-oriented. Some noted that men are often excluded or discouraged from participating in care, reinforcing traditional gender divisions.

Representative responses included:

- ✓ "Because I am the mother in the family, it is my duty and role to take care of my child."
- ✓ "They think it's a norm for a woman to be a caregiver."
- ✓ "As the wife, I am expected in my culture and society to look after my husband."
- ✓ "Men are not included to be caregivers in our community; they are viewed as being head of the house."

Overall, the findings highlight that caregiving continues to be shaped by gender norms, with women often expected to assume care responsibilities regardless of their personal or professional circumstances.

(See Appendix F for full verbatim responses.)

Impact of Caregiving on Employment and Education

As shown in Figure 20 (Question 18), nearly half of the participants (48.6%) reported that caregiving responsibilities had negatively affected their ability to work or study. A further 16.2% indicated that caregiving somewhat affected their ability to do so, suggesting that over 60% of respondents experienced at least some disruption in their employment or educational activities. Meanwhile, 32.4% reported that caregiving did not affect their ability to work or study.

These findings highlight that the demands of caregiving can significantly constrain carers' participation in the labour market or education. This is consistent with international research

showing that unpaid caregiving often leads to reduced employment opportunities and financial insecurity (Schultz & Eden, 2016; Colombo et al., 2011)

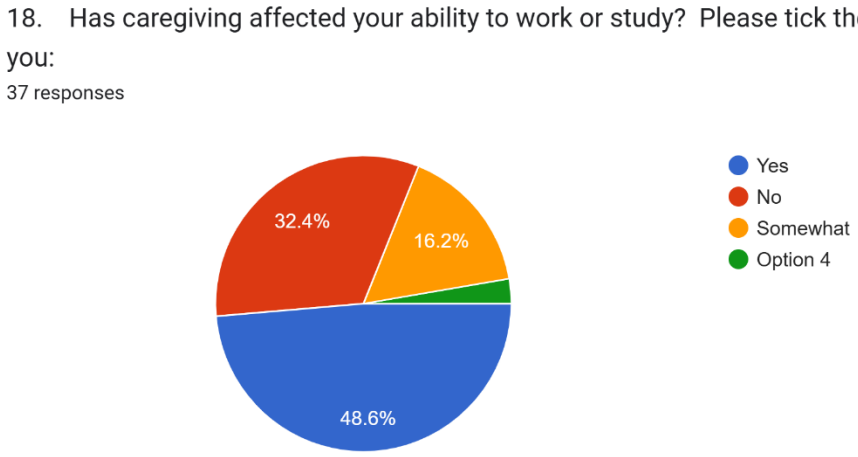


Figure 20: Impact of caregiving on work or study

Insights: How Caregiving Affects Work and Study

Among participants who indicated that caregiving had affected their ability to work or study (25 respondents), several recurring themes were identified. These included reduced employment opportunities, difficulty balancing caregiving with work or education, and the emotional and logistical challenges of full-time care.

- ✓ **Reduced or lost employment opportunities** – Many participants reported being unable to seek or maintain paid work due to their caregiving duties.
  - "Yes, I had an offer for a job, and I had to decline it because there is no one who can look after my child."
  - "I had to stop working because he needed someone to care for him all day."
- ✓ **Difficulty balancing caregiving with work or study** – Several carers described constant disruptions to work or education caused by medical emergencies, hospital visits, or the unpredictability of the person's condition.
  - "I am late at work and not in good standing because I take care of my son."
  - "During the period while I was in high school, I wasn't able to concentrate, so it affected my end-of-year results."
- ✓ **Lack of support and reliance on self-caregiving** – A number of carers explained that they had no one to share the caregiving load with and could not afford to hire help.
  - "I cannot work — who will look after the person I am looking after? I cannot afford someone to look after him."
  - "It's difficult to find full-time employment as I always have to be available for whatever is needed with regards to my son."

These findings underscore the intersection between unpaid caregiving, gender, and economic vulnerability, as women are disproportionately likely to assume full-time care roles at the expense of employment or education (Colombo et al., 2011; Schultz and Eden, 2016).

(See Appendix G for the complete list of verbatim responses.)

Physical Health Impact of Caregiving

When asked how caregiving affected their physical health, responses varied in intensity. As shown in Figure 21, more than one-third of participants (37.8%) reported experiencing a mild physical impact, while 32.4% described a moderate impact. A smaller group (24.3%) indicated that caregiving had no impact on their physical health, and one participant (5.4%) reported a severe impact.

These findings suggest that caregiving responsibilities often place a measurable strain on women's physical well-being, with many experiencing fatigue, stress-related symptoms, and reduced time for self-care. This pattern is consistent with previous research indicating that unpaid carers, especially women, are more likely to experience physical health challenges due to prolonged caregiving demands (Schulz & Sherwood, 2008).

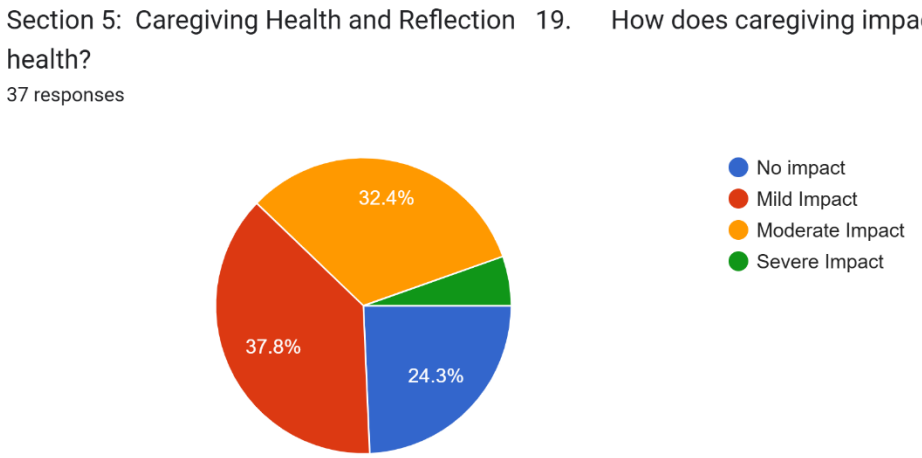


Figure 21: Physical health impact of caregiving

Sources of Strength and Motivation in Caregiving

When participants were asked what gives them strength or motivation as caregivers, 36 respondents shared deeply personal reflections. The responses highlighted several key themes:

- ✓ **Faith and spirituality**: Many caregivers mentioned that their belief in God, church involvement, and prayer are vital sources of strength. As one caregiver expressed, "My faith in God. Especially attending church groups where we talk and pray about things."
- ✓ **Family love and support**: A large proportion cited the support of family members, the love for their child or spouse, and the desire to see them improve as central motivations. For instance, one participant wrote, "He is my child and if I do not care for him, no one else will; I am living for him, that is what motivates me."
- ✓ **Seeing progress and independence**: Caregivers also derived motivation from witnessing positive changes in their care recipients - "To see my patient able to be independent and attending skills projects without my help."
- ✓ **Purpose and compassion**: Several respondents described caregiving as a calling or act of compassion, noting that it gives them a sense of meaning and self-worth: "I at least give hope to someone who is helpless and hopeless."

Overall, these responses show that caregivers' resilience is grounded in faith, family connection, and the sense of purpose derived from caring for others. These intrinsic motivators help sustain them despite emotional, physical, and financial challenges.

(See Appendix H for full participant responses.)

Recommendations and Future Support

Participants highlighted several key areas where caregiver support services could be improved. The most mentioned needs were:

- ✓ Training and education for caregivers (mentioned by most respondents).
- ✓ Counselling and emotional support, including access to mental health services.
- ✓ Financial assistance, such as stipends, grants, or subsidies for caregiving costs.
- ✓ Increased recognition and appreciation for caregivers by the government and community.
- ✓ Improved access to resources and facilities, including ramps, respite care, and better infrastructure for people with disabilities.
- ✓ A smaller number of respondents also emphasized the importance of support groups, self-care programmes, and opportunities for rest or respite.

Overall, the responses indicate a strong desire for comprehensive, ongoing support that addresses caregivers' emotional, financial, and practical needs while also acknowledging their vital contribution to community and family care.

(See Appendix I for full participant responses.)

Training or Guidance Received as a Caregiver

Out of the 36 respondents, 18 participants (50%) reported that they had received some form of training or guidance on caregiving, while the remaining 18 participants (50%) indicated that they had not received any formal or informal instruction (Figure 22). The results show an even split between caregivers who have received training and those who have not. This suggests that access to caregiving training and education is inconsistent, with half of caregivers potentially lacking the skills, knowledge, or confidence needed for effective care. This finding reinforces the need for accessible, community-based caregiver training programmes, as highlighted in participants' recommendations for more structured education, counselling, and support.

Figure 22: Training or received as a caregiver

Of the 23 participants who responded to this follow-up question (Question 22.1: If yes, who provided the training or guidance? Caregivers identified several sources of training and guidance:

- ✓ Epilepsy South Africa (Epilepsy SA) – 4 responses
- ✓ Non-Profit Organisations (NPOs) – 6 responses (including Sakhelwe Home Base Care, Amcare in Alberton, Asiphepheni NPO)
- ✓ Clinics/Health Facilities – 3 responses
- ✓ Workplace/Old Age or Retirement Homes – 3 responses
- ✓ Palliative Care Providers – 1 response
- ✓ Nursing Background or Formal Education – 2 responses
- ✓ None/Not Applicable – 4 responses

Most caregivers who received training obtained it through community-based or non-profit organisations (NPOs) such as Epilepsy SA or home-based care initiatives. A smaller number benefited from formal nursing education or clinic-based instruction. However, the presence of multiple "None" or "N/A" responses further highlights gaps in structured and accessible caregiver training, particularly for informal family caregivers.

Follow-up Interviews: Qualitative Insights

To complement the survey findings, follow-up qualitative interviews were conducted with women caregivers across five Epilepsy South Africa Branches: Mpumalanga, Western Cape, South Cape/Karoo, Gauteng, and Free State & North West. Although 37 women were eligible for follow-up interviews, 35 ultimately participated; two were unable to attend due to family or logistical challenges. In addition, within the Free State & North West Branch, six interviews were initiated, though two had to be discontinued early when participants became too emotionally distressed to continue. Their partial contributions were still acknowledged in the overall analysis, reflecting the sensitivity and emotional depth of the caregiving experience.

The interviews explored caregivers' daily realities, emotional and practical challenges, coping mechanisms, and their perceptions of community and institutional support. Collectively, their narratives reveal the deeply personal, gendered, and often invisible labour of caregiving in South Africa, highlighting both the resilience and the emotional toll inherent in this role. The interviews followed a semi-structured guide comprising ten open-ended questions designed to explore women caregivers' daily routines, emotional and mental wellbeing, spiritual coping, gendered experiences, encounters with stigma, and visions for improved caregiver support. This flexible format enabled participants to share their stories in their own words, while ensuring consistency across all participating branches.

The Daily Realities of Caregiving

Across all branches, women described their days as structured entirely around the needs of the person they care for—usually a child or spouse. Morning routines were particularly demanding: waking the person, assisting with bathing, dressing, medication, and often transporting them to daycare or a special programme. Caregivers spoke of exhaustion and of how their own needs are consistently secondary.

A Gauteng caregiver captured the relentlessness**:**

- ✓ "There are moments that I feel like it's difficult for me because there's no one to help me with my son. He's getting older and bigger."

In the Western Cape, another caregiver described the constant repetition and emotional strain:

- ✓ “You always have to remind him do this, take that, sit down. Every day, it’s the same. Sometimes you just want to be quiet, but you can’t.”

Yet even amid the exhaustion, many expressed gratitude and purpose. A mother from the South Cape/Karoo Branch reflected:

- ✓ “I’m grateful that he’s alive. Yesterday was worse; today is better than yesterday. When I look back, I smile.”

This duality exhaustion and gratitude defined much of the caregiving experience.

Emotional Transformation and Mental Health

Caregiving brought profound emotional and spiritual transformation. Women spoke of learning patience, humility, and endurance, but also of loneliness, depression, and anxiety. The emotional burden was often compounded by the absence of relief or formal support systems.

From the Mpumalanga Branch:

- ✓ “It has changed my personality a lot because I can’t engage with other people except for my son. I no longer feel emotional about situations - I’ve become used to taking care of him.”

In Free State & North West, one caregiver shared how faith became her anchor:

- ✓ “When I feel overwhelmed, I pray a lot. I try to get information from my phone, to hear what others are doing. That helps me not to give up.”

Several caregivers admitted symptoms of burnout and depression. A Western Cape mother described sleeplessness and fatigue:

- ✓ “Sometimes I feel like I have depression. I don’t sleep until two or three in the morning. I think, what if something happens to me - who will take care of him?”

Another from Gauteng added:

- ✓ “Caregiving can lead to chronic stress. You must balance your caregiving duties and your family life so you can do it equally.”

Despite these challenges, women often reframed their suffering through spirituality and purpose, viewing caregiving as a calling or test of faith.

Sources of Strength and Coping

Faith and prayer were repeatedly mentioned as primary sources of resilience. Across provinces, women linked survival and endurance to spiritual connection, religious community, and belief in divine purpose.

A Free State caregiver summarised this feeling:

- ✓ “The church, praying to God - that gives me strength. He gave me the strength.”

Others found comfort in small moments of joy and self-care: a walk, music, time with grandchildren, or laughter shared with the person they care for.

- ✓ **“**My son motivates me. A child with a disability is always positive that makes my day,” said one Western Cape participant.

Several mentioned the value of brief respites: even a few hours at church or at a friend’s house is crucial to emotional balance. Yet formal respite care services were largely absent, forcing many to rely entirely on family or faith.

Gendered Nature of Caregiving

Across all interviews, caregiving was deeply gendered. Most women saw it as an expected extension of motherhood or womanhood. Many described being “naturally” nurturing or viewed by others as “strong women.”

A caregiver in Gauteng reflected:

- ✓ “I’m respected by other women. It gives other women responsibility and obligation to do their work.”

In contrast, others felt this gendered expectation was oppressive that caregiving responsibilities were taken for granted.

One mother from Mpumalanga expressed frustration:

- ✓ “There’s no one to help me. Because I am the mother, it’s my job.”

Women also recognized that gender roles shape how caregiving is valued socially: men’s support was often described as minimal or absent, and women bore both emotional and economic burdens. As one participant put it:

- ✓ “Even if the father is there, it’s me who must take him to the hospital. When things get bad, I am the one who must be strong.”

Stigma, Judgment, and Social Isolation

Nearly all participants had experienced some form of stigma, misunderstanding, or exclusion whether from neighbours, extended family, or the public. Many reported being stared at in public, whispered about, or blamed for their loved one’s condition.

From Mpumalanga:

- ✓ **“**The negative reaction from people - the stares they give you when you’re walking with your child. Sometimes they don’t want to speak to you.”

A mother in the South Cape/Karoo added:

- ✓ “People said my son was going crazy. Even colleagues asked for my number just to gossip. The community can make you take a rope and hang yourself if you are not strong.”

Several women linked stigma to ignorance about epilepsy:

- ✓ “Society doesn’t understand that your life is not your own -it revolves around the person you are caring for.”

Stigma reinforced isolation. Caregivers often avoided social gatherings or public places to protect their children from ridicule or to spare themselves from judgment, leading to feelings of loneliness and exclusion.

Support Systems and Unmet Needs

Support networks were fragile and inconsistent. Most women relied on family, church, and Epilepsy SA programmes as their only sources of assistance. While many praised the care centres and daycare facilities for providing structure, others lamented the absence of long-term or accessible respite options.

A recurring desire was for special schools and training programmes for both caregivers and their dependents.

- ✓ **"**We need special schools and honest feedback - people who help us stay on track," said one Gauteng caregiver.

Others envisioned practical, local support:

- ✓ "I would create a support group where caregivers could learn patience and share experiences."

Financial stress was another major theme. Several participants said they needed financial assistance, transport, or home adaptations such as ramps.

- ✓ "I asked for help to build a ramp, but no one has come to help," one woman explained.

Caregivers are also worried about the future:

- ✓ "What will happen to my child when I am gone?"

These reflections highlight the systemic gaps in social protection, healthcare, and disability inclusion that leave caregivers largely unsupported.

Hopes, Advice, and Visions for Change

When asked what advice they would give to new caregivers, most women emphasized patience, love, and education:

- ✓ "Ask for help from other caregivers who have been doing this for a long time. Take time for yourself. Love what you do -do it with an open heart."

Others urged society to cultivate empathy and inclusion:

- ✓ "People must understand that a disabled child is also a person longing to be accepted."

Caregivers' visions for support systems were modest but powerful: they wanted training, counselling, opportunities for income generation, and community awareness campaigns to reduce stigma. Many also asked for periodic gatherings of caregivers for motivation, storytelling, and rest.

- ✓ "We sometimes need a break - a weekend where we can sit and not think about our children. To be motivated, to hear stories of others who survived."

Cross-Cutting Insights

Caregiving is unpaid, invisible, and feminised, yet central to the functioning of families and communities. Faith, hope, and informal networks sustain caregivers in the absence of structured support. Stigma and misunderstanding continue to isolate families affected by epilepsy. Institutional gaps in healthcare, social welfare, and education leave caregivers vulnerable. Women's voices reflect resilience and leadership, but also reveal exhaustion and unmet needs for recognition, respite, and resources.

As one caregiver concluded poignantly:

- ✓ "This is not for someone who is weak. You hold your last breath for your child. Even when you are tired, you keep going."

The qualitative interviews highlight that caregiving for people with epilepsy and other neurological disorders in South Africa is an act of love, endurance, and sacrifice carried largely by women. While caregivers find meaning and faith in their roles, their testimonies expose the urgent need for targeted policy interventions, community education, accessible support services, and recognition of caregiving as skilled essential work. The voices of these women from Mpumalanga to the Western Cape, from Gauteng to the Free State remind us that behind every person living with epilepsy and other neurological disorders stands a caregiver whose strength sustains them, often at great personal cost.

Together, these accounts illuminate the five cross-cutting themes identified in the study: faith and spirituality, emotional and physical strain, economic insecurity and lack of support, stigma and social exclusion, and resilience through love and identity reinforcing the interconnected nature of women's caregiving experiences across South Africa.

Discussion

The findings of this study confirm that caregiving for individuals with epilepsy and other neurological disorders in South Africa is deeply gendered, economically constrained, and socially undervalued. The integration of survey and interview data provided a holistic understanding of carers' lived realities and quantitative findings established the prevalence of financial strain and emotional stress, while qualitative interviews revealed the personal narratives behind these statistics. The 37 respondents—virtually all women—illustrate the multidimensional nature of caregiving burdens, encompassing financial strain, emotional fatigue, and restricted social participation. These results align closely with national and global research that identifies unpaid caregiving as an essential yet largely invisible component of community health systems (WHO, 2023; Silaule et al., 2023).

The Gendered Nature of Caregiving

The study reinforces that caregiving remains predominantly a female responsibility, shaped by cultural expectations and gender norms. Nearly all survey respondents identified as women, and qualitative responses repeatedly described caregiving as a "mother's duty" or a role "expected of women in the family." These findings echo those of Keikelame and Swartz (2016), who observed similar gendered expectations among caregivers of people with epilepsy in Cape Town. This pattern mirrors broader global findings that unpaid caregiving remains feminized labour, with women performing over 75% of unpaid care work worldwide (WHO, 2021).

Interview narratives across all participating branches reinforced this pattern. Women frequently spoke of caregiving as something "God has chosen me to do," or "what mothers must do," reflecting

both spiritual acceptance and social obligation. One participant from the South Cape/Karoo branch said, “People always tell me I’m strong, but they don’t see how hard it is every day.” Another from Gauteng reflected that “men in my family don’t help they say it’s women’s work.”

Cultural and patriarchal values continue to naturalise women’s unpaid care work, resulting in unequal divisions of labour and limited recognition of their contributions within households and communities. This aligns with global literature indicating that women provide more than three-quarters of unpaid care globally (WHO, 2021), reflecting structural gender inequities.

Economic and Employment Challenges

Financial strain was one of the most prominent findings of this study. Quantitative survey data reinforced this trend, with 64.9% of participants reporting unemployment linked directly to caregiving responsibilities. Over 70% of participants indicated that caregiving negatively affected their financial situation, with respondents describing challenges such as transport costs, loss of employment opportunities, and reliance on social grants. Thematic analysis revealed three recurring issues: increased household expenses, loss of income, and dependence on inadequate social grants.

Interview participants provided vivid accounts of these hardships. In Mpumalanga, one woman said, “I stopped working because there’s no one else to look after him. The money is finished before the middle of the month.” A caregiver in the Western Cape added, “We survive on the disability grant, but it’s not enough for food, medication, and transport.” Others expressed frustration that the Care Dependency Grant applies only to children: “What happens when they turn 18? The need doesn’t stop,” asked a caregiver from the Free State.

These experiences mirror findings from Silaule et al. (2023), who reported that economic stress and lack of institutional support are key predictors of caregiver burden. Similarly, Yakubu and Schutte (2023) highlighted economic deprivation and poor environmental conditions as major stressors in their multidimensional model of caregiver burden.

The high unemployment rate among respondents (64.9%) underscores the intersection between caregiving and poverty. Many caregivers indicated that their responsibilities prevented them from seeking or maintaining employment. Survey data also showed that 73% of respondents reported significant financial strain and 58% relied primarily on social grants or family assistance for survival. This pattern has been observed internationally, where unpaid caregiving often leads to long-term financial insecurity, especially among women in low-income settings (Colombo et al., 2011). Although the South African Social Assistance Act (2004) provides care dependency grants, these mechanisms remain insufficient to offset income loss or provide sustainable livelihoods for adult caregivers.

Access to Support Services

While over half of respondents (58.3%) reported awareness of caregiver support programmes, participation was limited, and services were unevenly distributed. Counselling (58.3%) and training (50%) were the most accessed supports, yet several participants described gaps in access, quality, and continuity. Quantitative results also indicated that although 50% of carers had received some form of training, while 40% reported that available sessions were too short or infrequent, reflecting gaps in continuity. Although 69% of respondents were satisfied with available services, many expressed the need for expanded training, counselling, and financial assistance.

Interview data revealed that some carers had benefited from local Epilepsy SA support groups and day-care programmes, describing them as “a lifeline” and “the only time I can rest.” However, others particularly in rural areas reported that these supports were “too far away” or “only for a few people.” Several participants asked for workshops on epilepsy management, stress relief, and self-

care, noting that they had never received formal training. A respondent from North West remarked, “If we could learn how to handle seizures properly, it would take away the fear.” These findings are consistent with WHO’s Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (2023), which emphasises the integration of community-based caregiver support within national health systems. The limited availability of structured support services in South Africa suggests a gap between policy intent outlined in frameworks such as the White Paper on the Rights of Persons with Disabilities (2016) and implementation.

Psychosocial and Emotional Dimensions

Emotional distress emerged as a significant theme across both survey and qualitative responses. Caregivers described feelings of exhaustion, social isolation, and anxiety about the future of their dependents. The reliance on faith, spirituality, and family support as coping mechanisms was particularly strong.

Interview participants across all five branches echoed these emotional burdens. One woman said, “Sometimes I feel like I am breaking inside, but I keep going because of prayer.” Others described depression and burnout, often worsened by stigma: “People stare when I walk with him; they think epilepsy is a curse,” said a participant from Gauteng. Still, many expressed hope: “Even when I cry, I thank God for giving me strength,” said another caregiver in the South Cape/Karoo region.

These findings echo the work of Keikelame and Swartz (2016), who noted that spirituality often serves as an informal but vital psychosocial resource for caregivers facing chronic stress and stigma.

Unmet Needs and Motivations

When asked to identify their top unmet needs, the most common responses included information, transportation, financial support, and emotional counselling. Survey responses echoed these priorities, identifying financial assistance (81%), emotional counselling (65%), and respite care (54%) as the most urgently needed forms of support. These findings highlight systemic barriers to accessing essential health and social resources, especially for caregivers in rural and peri-urban areas. Despite these challenges, respondents demonstrated strong intrinsic motivation rooted in love, responsibility, and faith.

Interview data confirmed these priorities, with multiple carers mentioning the need for respite: “We never get a break,” one said. Another added, “If there was someone to help even one weekend a month, it would change everything.” Participants also expressed a desire for recognition and dignity: “We are not only caregivers; we are human too.” Despite these hardships, caregivers’ motivation remained grounded in love and faith, as reflected in statements such as, “He may not speak, but his smile keeps me going.” This resilience reflects what Sabo et al. (2020) described as “purpose-driven caregiving,” where emotional commitment provides meaning despite substantial hardship.

Policy Implications

Collectively, these findings point to significant policy and implementation gaps. Although existing frameworks such as the National Mental Health Policy Framework (2023–2030) and National Development Plan 2030 recognise the importance of community-based care, they offer limited provisions for informal caregivers’ psychosocial and financial support.

Interviews reinforced the urgency of policy reform. Many caregivers said they were unaware of any government assistance specifically for adult carers. One participant noted, “Only parents of children get something. What about us who look after adults?” Another said, “We do this for love, but love doesn’t buy food.”

Aligning national strategies with WHO's Intersectoral Global Action Plan (IGAP) could provide a roadmap for integrating caregiver training, respite services, and mental health support into primary care systems. Recognising and compensating unpaid caregiving, particularly for women, is essential to advancing both gender equality and health system sustainability. Taken together, the findings call for policy responses that extend beyond medical support to recognise the social, emotional, and economic dimensions of caregiving. This includes strengthening linkages between Epilepsy SA, local clinics, and social development departments to ensure coordinated care pathways for both persons with epilepsy and their caregivers.

Overall, this study contributes to the growing body of evidence that caregiving for people with epilepsy and other neurological disorders in South Africa is shaped by overlapping vulnerabilities of gender, poverty, and systemic underinvestment. The interviews, drawn from five provincial branches, vividly illustrate the lived realities behind the statistics of women balancing love, exhaustion, faith, and survival in conditions of limited formal support.

The experiences of women caregivers underscore the urgent need for integrated, gender-sensitive policy responses and locally accessible support programmes. By making the invisible labour of caregiving visible, this research strengthens advocacy for more inclusive health and social protection systems. The findings of this study provide empirical evidence supporting the priorities outlined in SAINAP, particularly the need for integrated, community-based, and gender-responsive care systems. By highlighting the lived realities of women caregivers, this research underscores the urgency of implementing SAINAP's proposed actions on caregiver training, social protection, and intersectoral collaboration.

Recommendations

The 2024 Carer and Peer Support Group Training Needs Assessment provided a clear framework for addressing the skill and support gaps among carers. Findings from the current 2025 Carer Survey confirm and deepen these insights, highlighting the urgent need for sustained and structured interventions. The findings of this study highlight the urgent need for comprehensive, gender-sensitive, and community-based interventions to support unpaid caregivers of people with epilepsy and other neurological disorders in South Africa. To build on these foundations, the following recommendations are proposed:

Strengthening Training and Education for Caregivers

Many participants expressed a need for structured training on epilepsy management, first aid, medication adherence, and psychosocial care. Findings from the 2024 Carer and Peer Support Group Training Needs Assessment Survey, which included both carers and social development staff, identified similar priorities for capacity building, particularly in mental health support, communication, and self-care.

Based on this earlier assessment, Epilepsy South Africa developed and will be piloting a Carer Training Module within the Development Hub Training Programme in 2026. It is recommended that this module now be expanded nationally and adapted to reflect the findings of the 2025 Carer Survey, ensuring that training remains both evidence-based and responsive to carers' evolving needs.

Interview participants repeatedly emphasised their desire for "practical skills" and "real guidance" rather than theory. One woman from the South Cape/Karoo Branch said, "If we could be taught how to deal with seizures properly, it would take away the fear." Others requested training in stress

management, emergency response, and self-care. Several also noted that male relatives should be included, as “care shouldn’t only be the women’s burden.”

Partnerships between Epilepsy South Africa, NGOs, and local health departments should continue to strengthen standardised caregiver training programmes, including both practical and emotional support components. Survey data indicates that 40% of caregivers have never received any formal training, which further underscores the urgency of structured educational interventions. Training should also target male family members, challenging gender norms that assign care exclusively to women (Keikelame & Swartz, 2016).

Expand Psychosocial Support and Counselling Services

The emotional toll of caregiving linked to stress, burnout, and social isolation requires formal recognition. Counselling services, peer-support groups, and community-based therapeutic interventions should be integrated into district-level health services. Collaboration with faith-based organisations and community networks can provide additional spaces for emotional and spiritual support.

Interview data strongly reinforced this need. Many women described sleeplessness, depression, and anxiety about the future. A caregiver from Gauteng said, “Sometimes I feel like I am breaking inside, but I keep going because of prayer.” Another from Mpumalanga added, “We need someone to talk to someone who understands.” Carers valued the few peer-support sessions held at Epilepsy SA branches, describing them as “a place to breathe.” Given that 65% of survey respondents reported high emotional distress, scaling psychosocial and peer-based interventions is essential for promoting caregiver wellbeing and retention in care.

Provide Financial and Material Assistance

Economic hardship was a consistent theme in this study, reflecting broader national evidence that unpaid caregiving contributes to household poverty (Silaule et al., 2023; WHO, 2021). While South Africa currently provides the Care Dependency Grant through South African Social Security Agency (SASSA) for caregivers of children under 18 with severe disabilities, this support is limited in scope and does not extend to all unpaid caregivers such as those caring for adults with epilepsy or neurological disorders who do not meet the child-specific criteria.

It is therefore recommended that the Department of Social Development (DSD), in collaboration with SASSA, review and expand social assistance mechanisms to include caregivers who fall outside existing grant eligibility but still face significant economic strain. This could include:

- ✓ Expanding eligibility for a caregiver stipend or targeted top-up to include carers of adults with neurological disorders.
- ✓ Linking caregivers support to broader disability and chronic illness frameworks to ensure caregivers are not excluded due to age or diagnosis.
- ✓ Continued improvements to transport subsidies, assistive devices, and home-based care resources to ease the financial and physical burden on caregivers.

Many interviewees voiced frustration with the current system. One woman from the Free State explained, “I look after my son every day, but because he’s over 18, I get nothing.” Another said, “We do this for love, but love doesn’t buy food.” These accounts underscore the need for a fair, inclusive caregiver grant policy that recognises unpaid labour across the life course. Survey data further supports this, as 73% of participants indicated that caregiving caused significant financial hardship and limited income-generating opportunities.

Improve Access to and Quality of Caregiver Support Services

Although 69% of caregivers reported satisfaction with existing services, access remains uneven, especially in rural areas. Day-care and respite services should be extended to weekends and holidays to allow caregivers to rest and time for self-care. Integration of caregiver support into primary healthcare and community-based rehabilitation programmes would ensure continuity and accessibility.

Interviews highlighted the scarcity of respite opportunities. As one carer from Mpumalanga shared, “Even one weekend a month would help us rest.” Caregivers from the Western Cape described Epilepsy SA day-care centres as “a lifeline” but asked for more consistent availability. Others in rural branches noted travel distances and lack of transport as major barriers. These insights suggest that extending and decentralising support services is vital. Survey findings showing that 56% of caregivers had never accessed respite or day-care support reinforce the urgency of this recommendation.

Increase Public Awareness and Recognition of Caregivers

Social stigma and the invisibility of caregivers remain major barriers to empowerment. National awareness campaigns should highlight the contributions of caregivers to public health and promote shared responsibility across genders. Recognition initiatives such as “Caregiver Appreciation Days”, awards, or inclusion in local health planning forums can help validate caregivers’ roles and contributions.

Interview participants described feeling invisible or judged by their communities. One mother said, “People think my child is cursed.” Another explained, “They praise me for being strong, but they don’t see my tears.” Public awareness initiatives should therefore aim not only to destigmatise epilepsy but also to humanise caregiving as valuable social and health work. Survey results indicated that 60% of carers experienced some form of stigma, underscoring the need for community education and inclusion campaigns.

Policy Alignment and Intersectoral Collaboration

Despite several policy frameworks, implementation remains fragmented. Government should align existing frameworks such as the White Paper on the Rights of Persons with Disabilities (2016), National Mental Health Policy Framework (2023–2030), and the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (2022–2031) to ensure coordinated caregiver support.

In this regard, Epilepsy South Africa has led the development of the South African Intersectoral Action Plan (SAINAP), a national adaptation of the IGAP designed to strengthen interdepartmental collaboration between the health, social development, and education sectors. SAINAP is being finalised for presentation to Cabinet in 2026. It identifies caregivers as essential partners in neurological health and calls for gender-responsive, community-based interventions to support them.

The implementation of SAINAP would therefore serve as a critical mechanism to address the economic, emotional, and social vulnerabilities faced by women caregivers across South Africa. Monitoring and evaluation systems must include indicators on unpaid caregiving, gendered labour, and psychosocial well-being. The inclusion of caregiver well-being indicators in SAINAP’s monitoring framework would ensure accountability and sustained visibility for this workforce.

Promote Research and Data Collection on Caregiving

This study highlights the need for continued research on gender, care, and neurological disorders. Future studies should include longitudinal and qualitative approaches to capture the evolving experiences of caregivers. Community-based participatory research (CBPR) models could empower caregivers to co-design interventions that reflect their realities.

Interview participants expressed willingness to be involved in future initiatives, with one stating, “We want to be part of the solution, not just the story.” Incorporating caregivers into research and programme design can enhance relevance, ownership, and sustainability. Survey feedback also suggested that caregivers are eager for feedback and involvement in programme planning this provides an opportunity for participatory co-design in Epilepsy SA’s upcoming national Carers Workshop.

Implementation Link: From Needs Assessment to Practice

The 2024 Needs Assessment Survey and the 2025 Carer Survey together provide a strong evidence base for action. Building on these findings, Epilepsy South Africa will be refining the Carer Training Module to ensure it is evidence-based and responsive to carers’ needs. These findings will also inform the 2026 National Carers Roadshow, which aims to promote peer learning, advocacy, and capacity building among caregivers nationwide. Both initiatives will contribute directly to the integration of caregiver perspectives into the implementation of the SAINAP. The roadshow combines skill development, psychosocial support, and advocacy training to build long-term caregiver capacity across provinces. Interview participants across branches confirmed that they would “welcome a national carer workshop” that offers both learning and connection. One caregiver summarised it simply: “We need training, but we also need each other.”

These recommendations call for an integrated, rights-based approach to caregiver support, one that values unpaid care as essential social and health infrastructure. Addressing the emotional, financial, and gendered dimensions of care will not only improve caregiver wellbeing but also strengthen outcomes for people living with epilepsy and neurological disorders.

Conclusion

This study set out to explore the roles, experiences, and unmet needs of women caregivers supporting individuals with epilepsy and neurological disorders in South Africa. The findings reveal that caregiving in this context is profoundly gendered, undervalued, and under-supported, despite its indispensable contribution to family and community wellbeing.

Most caregivers surveyed were women, primarily mothers and close relatives, who provide care with minimal financial or institutional assistance. Their daily responsibilities encompass medication management, emotional support, and the coordination of health appointments, often at the expense of their own employment, education, and social lives. As one caregiver from Gauteng put it, “We wake up tired, but we keep going because they need us.” Another from the South Cape/Karoo explained, “I used to have my own life - now my time belongs to him.”

While many caregivers expressed deep motivation rooted in love, faith, and family commitment, they also described significant emotional fatigue, financial strain, and social isolation. One participant in Mpumalanga shared, “Sometimes I feel like crying, but I pray instead.” Others described prayer, church involvement, and peer conversations as vital sources of hope when professional support was unavailable.

These lived experiences mirror findings from previous research (Keikelame & Swartz, 2016; Silaule et al., 2023; Sabo et al., 2020), affirming that caregiving burdens are intensified by systemic inequalities, poverty, and the lack of structured support mechanisms. The study further demonstrates how traditional gender norms continue to assign caregiving to women, reinforcing their economic vulnerability and limiting participation in the formal labour market—an issue consistent with global evidence on unpaid care work (WHO, 2021).

Despite these challenges, the study also highlights caregivers' resilience and agency. Caregivers repeatedly spoke of "strength through love" and the pride they felt when their loved ones showed progress. A woman from the Western Cape said, "When he smiles again after a bad day, I feel like I can do anything." Many derive strength from spirituality, family support, and the visible recovery of their loved ones. These positive elements underscore the potential of community networks and peer-based support models to enhance caregiver wellbeing.

However, the overall picture remains one of policy gaps and fragmented services. Existing frameworks, such as the White Paper on the Rights of Persons with Disabilities (2016) and the National Mental Health Policy Framework (2023–2030), recognise the importance of caregivers but fail to provide concrete, funded mechanisms for their support. Caregivers across provinces described feeling "forgotten by the system," with one noting, "There's training for nurses and doctors, but not for us who are there every day." Aligning these national policies with the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (2022–2031) would ensure that caregiver wellbeing becomes an explicit public health priority.

In this context, the SAINAP developed by Epilepsy South Africa in collaboration with government departments and civil society partners offers a critical opportunity to institutionalise caregiver recognition and support. SAINAP localises the IGAP's global objectives within South Africa's context and is being prepared for presentation to Cabinet in 2026.

Its implementation would strengthen intersectoral coordination, promote gender-sensitive caregiver support, and embed unpaid care within national health and social development strategies. By including caregivers' lived experiences in SAINAP's rollout, South Africa can ensure that national policy is informed by real-world realities rather than assumptions. As one participant said, "Don't plan for us - plan with us."

In conclusion, caregiving for people with epilepsy and neurological disorders in South Africa is a critical but overlooked form of social and health labour. Addressing the financial, emotional, and structural barriers identified in this study is essential for achieving equity, inclusion, and sustainable health outcomes. These women's stories remind us that caregiving is not just an act of duty, but one of courage and endurance. As another caregiver expressed, "We may be tired, but we will never give up." By investing in caregiver training, financial assistance, counselling, and recognition, South Africa can move towards a more compassionate and gender-responsive care system that honours the contributions of women caregivers as indispensable partners in health and community development.

Study Limitations and Future Research

While this study provides valuable insight into the lived experiences of women caregivers of people with epilepsy and other neurological disorders, several limitations should be acknowledged. The sample was relatively small and geographically limited, which may restrict the generalisability of findings across South Africa's diverse social and cultural contexts. In addition, the study relied on self-reported data from online surveys and follow-up interviews, which may be influenced by recall or social desirability bias.

Although five Epilepsy South Africa Branches participated (Western Cape, South Cape/Karoo, Gauteng, Mpumalanga, and Free State & North West), some provinces such as the Eastern Cape and KwaZulu-Natal were not represented due to staffing and logistical constraints. Future studies should therefore aim to include these and other provinces to capture regional variations in caregiving practices, access to services, and social attitudes toward epilepsy and other neurological disorders.

The inclusion of qualitative interviews significantly strengthened the study's depth and authenticity, providing a platform for caregivers' own voices. However, since interviews were conducted only once per participant, the study could not capture how caregiving experiences evolve over time or how interventions (such as training or support groups) influence wellbeing. Longitudinal research, combining follow-up interviews and survey tracking, would be valuable to understand how caregivers' emotional, social, and economic conditions change across the caregiving journey.

Future research should also prioritise participatory and co-designed methodologies such as Community-Based Participatory Research (CBPR) to actively involve caregivers in shaping study questions, interpreting findings, and designing policy recommendations. As one participant powerfully stated, "Don't plan for us-plan with us." Such approaches would ensure that interventions and training programmes genuinely reflect caregivers' lived realities.

Given that this study focused primarily on women, future research should also include male caregivers, whose experiences remain largely undocumented in the South African context. Understanding how men engage in or are excluded from caregiving roles could illuminate gender dynamics that either reinforce or challenge traditional norms.

Finally, further mixed-methods studies should assess the implementation and outcomes of the upcoming Carer Training Module and SAINAP framework, evaluating their effectiveness in improving caregiver knowledge, psychosocial wellbeing, and inclusion in health system planning. Comparative research across provinces and partnerships with universities and government departments could deepen evidence for policy change and guide a coordinated national approach. In summary, this study lays the groundwork for a long-term research agenda on unpaid care, gender, and neurological health in South Africa. Building on these qualitative insights will help ensure that future programmes, policies, and partnerships are informed not just by data, but by the lived experience and wisdom of caregivers themselves.

Bibliography

Adelman, R. D., Tmanova, L. L., Delgado, D., Dion, S., & Lachs, M. S. (2014). Caregiver burden: a clinical review. *JAMA, 311*(10), 1052–1060. https://doi.org/10.1001/jama.2014.304

Arno, P. S., Levine, C., & Memmott, M. M. (2014). The economic value of informal caregiving. *Health Affairs, 33*(6), 952–959.

Austin, J. K., Perkins, S. M., & Johnson, C. S. (2014). Family caregiving and the management of chronic illness: Parental roles in epilepsy care. *Epilepsy & Behavior, 37*, 82–90.

Brodaty, H., & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience, 11*(2), 217–228.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Camfield, C., & Camfield, P. (2018). Helping families cope with epilepsy. *Epilepsia Open, 3*(S2), 51–55. https://doi.org/10.1002/epi4.1225

Colombo, F., Llena-Nozal, A., Mercier, J., & Tjadens, F. (2011). *Help wanted? Providing and paying for long-term care.* Organisation for Economic Co-operation and Development (OECD) Publishing.

Dalmia, S., & Lawrence, A. (2022). Gendered perspectives of informal caregiving: A global review. *Health & Social Care in the Community, 30*(5), e2834–e2846. https://doi.org/10.1111/hsc.13722

de Oliveira, G. N., et al. (2020). The emotional burden and coping of caregivers of people with epilepsy: A cross-sectional study. *Epilepsy & Behavior, 111*, 107279.

Family Caregiver Alliance. (2021). *Caregiver statistics: Demographics.* Family Caregiver Alliance National Center on Caregiving. Retrieved December 15, 2025, from https://www.caregiver.org/resource/caregiver-statistics-demographics/

Gemito, L., Ferreira, R., Pinho, L., & Fonseca, C. (2024). Programmes addressed to informal caregivers' needs: A systematic review on interventions improving caregiver outcomes. *Geriatrics, 9*(3), 71. https://doi.org/10.3390/geriatrics9030071

García-Mochón, L., Peña-Longobardo, L. M., del Río-Lozano, M., Oliva-Moreno, J., Larrañaga-Padilla, I., & García-Calvente, M. d. M. (2019). Determinants of burden and satisfaction in informal caregivers: Two sides of the same coin? The CUIDAR-SE study. *International Journal of Environmental Research and Public Health, 16*(22), 4378. https://doi.org/10.3390/ijerph16224378

Government of South Africa. (2016). *White Paper on the Rights of Persons with Disabilities*.

Johnson, R. B., Onwuegbuzie, A. J., & Turner, L. A. (2007). Toward a definition of mixed methods research*. Journal of Mixed Methods Research, 1*(2), 112–133.

Keikelame, M. J., & Swartz, L. (2016). "Whom will I give him to? The difficulty is mine": Psychosocial difficulties experienced by caregivers of patients with epilepsy in Cape Town, South Africa. *Journal of Health Psychology, 21*(8), 1826–1836.

Lloyd, J., Patterson, T., & Muers, J. (2018). The positive aspects of caregiving in dementia: A critical review of the qualitative literature. *Dementia, 15*(6), 1534–1561.

National Department of Health. (2023). *National Mental Health Policy Framework and Strategic Plan 2023–2030.*

National Planning Commission. (2012). *National Development Plan 2030: Our future—make it work*.

Phillipson, L., Jones, S. C., & Magee, C. (2016). A review of the factors associated with the non-use of respite services by carers of people with dementia: Implications for policy and practice. *Health & Social Care in the Community, 22*(1), 1–12.

Ploeg, J., Markle-Reid, M., Valaitis, R., McAiney, C., Duggleby, W., Bartholomew, A., ... & Sherifali, D. (2020). Web-based interventions to improve mental health, general caregiving outcomes, and general health for informal caregivers of adults with chronic conditions living in the community:

Rapid evidence review. *Journal of Medical Internet Research, 22*(7), e16247. https://doi.org/10.2196/16247

Pinquart, M., & Sörensen, S. (2006). Gender differences in caregiver stressors, social resources, and health: An updated meta-analysis. *The Journals of Gerontology: Series B, 61*(1), P33–P45.

Pinquart, M., & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging, 18*(2), 250–267.

Rigby, H., Gubitz, G., & Phillips, S. (2009). A systematic review of caregiver burden following stroke. *International Journal of Stroke, 4*(4), 285–292.

Republic of South Africa. (2004). *Social Assistance Act* (Act No. 13 of 2004).

Sabo, U. A., Buttner, P., & Scher, G. (2020). Impact of caregiver burden on health-related quality of life and family functioning of carers of children with epilepsy. *South African Journal of Child Health, 14*(2), 71–76.

Silaule, O., Nkosi, N. G., & Adams, F. (2023). Extent of caregiver burden among informal caregivers of persons with severe mental disorders in rural South Africa. *Rural and Remote Health, 23*(2), Article 7509.

Schulz, R., & Eden, J. (Eds.). (2016). *Families caring for an aging America.* Washington, DC: National Academies Press.

Schulz, R., & Sherwood, P. R. (2008). Physical and mental health effects of family caregiving. *American Journal of Nursing, 108*(9 Suppl), 23–27. https://doi.org/10.1097/01

Lantano, I., Dell'Aversana, G., Bacher, G., & Miglioretti, M. (2025). The caregiving penalty: Gender and caregiving effects on career opportunities perceived by Italian employees. *Social Sciences, 14*(9), 547. doi.org

Van Den Berg, B., Fiebig, D. G., & Hall, J. (2020). Well-being losses due to care-giving. *Journal of Health Economics, 70*, 102283.

World Health Organization. (2021). *Epilepsy: A public health imperative – Global report.* Geneva: WHO Press.

World Health Organization. (2022). *Global report on effective access to assistive technology.* Geneva: World Health Organization.

World Health Organization. (2023). *Intersectoral global action plan on epilepsy and other neurological disorders 2022–2031.* Geneva: World Health Organization.

World Health Organization. (2023). *Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022–2031.*

Yakubu, Y. A., & Schutte, D. W. (2023). Predictors of female caregivers' burden: An estimated conceptual model in low-income settings. *The Journal for Transdisciplinary Research in Southern Africa, 19*(1), 1159.

Appendix A: Carer Survey Instrument (Google Form Questionnaire)

This instrument was used to collect quantitative data from 37 women caregivers across five Epilepsy South Africa Branches between August and September 2025.

Survey: The Roles, Needs, and Experiences of Women Caregivers of People with Epilepsy & Neurological Disorders in South Africa

Section 1: Demographic Information

1. What is your gender identity?

Note: This survey is intended for women who provide care to individuals with epilepsy or other neurological disorders.

Non-binary or gender diverse refers to people whose gender identity does not fit within the traditional categories of “man” or “woman.”

Gender Identity	Tick (✓)
Woman	-
Man	-
Non-binary/Gender diverse	-
Prefer not to say	-
Other:	

2. What is your age?

Select the age group that applies to you by ticking the appropriate box below:

Age group	Tick (✓)
18-24	-
25-34	-
35-44	-
45-54	-
55-64	-
65 and above	-

3. Where do you live?

Please tick the option that best describes your area:

Area	Description	Tick (✓)
Urban area	A city or large town with many buildings, roads, and services like hospitals, schools, and shops close together. Examples: Johannesburg, Cape Town, Durban	-
Peri-urban area	A place on the edge of a city or town. It has both town and village features. Some services may be nearby, but not as many as in a city. Examples: Settlements just outside a major town or township areas near urban centres.	-
Rural area	A village or countryside area with fewer people, more open land, and limited access to services like clinics or public transport. Examples: Small villages or farming communities far from cities	-

4. What is your employment status?

Please tick the option that best describes your current situation:

Employment Status	Tick (✓)
Employed full-time	-
Employed part-time	-
Self-employed	-
Unemployed	-
Student	-
Retired	-

5. What is your highest level of education?

Please tick the option that applies to you:

Education Level	Tick (✓)
No formal education	-
Primary education	-
Secondary education	-
Tertiary education	-
Other (please specify)	

6. What is your relationship to the person you care for?

Please tick the option that best describes your relationship:

Relationship Type	Tick (✓)
Parent	-
Spouse/Partner	-
Sibling (Brother/Sister)	-
Extended Family Member (e.g. grandparent, aunt or cousin)	-
Friend/Neighbour	-
Other (please specify)	

7. Does caregiving affect your financial situation (e.g. transport, medical costs, job loss).

Please tick the option that applies to you:

Response Option	Tick (✓)
Yes	-
No	-
Somewhat	-

7.1. If yes or somewhat, please describe how caregiving affects your financial situation:

Section 2: Caregiving Roles and Responsibilities

8. What neurological disorder does the person you care for have?

Please tick all that apply:

Neurological Disorders	Tick (✓)
Epilepsy	-
Headache disorders	-
Neurodegenerative disorders (NDDs)	-
Cerebrovascular diseases (CVDs)	-
Neuroinfectious or neuroimmunological disorders	-
Neuromuscular disorders	-

Neurodevelopmental disorders	-
Traumatic brain and spinal cord injuries	-
Cancers of the nervous system	-
Others (please specify)	

9. How long have you been a caregiver for someone with epilepsy or a neurological disorder?

Please tick the option that applies to you:

Duration of Caregiving	Tick (✓)
Less than 1 year	-
1-3 years	-
4-6 years	-
7-10 years	-
More than 10 years	-

10. How many hours per day do you spend on caregiving duties?

Please tick the option that applies to you:

Hours per Day	Tick (✓)
Less than 2 hours	-
2-4 hours	-
5-8 hours	-
Full-time	-

11. What are your main caregiving responsibilities?

Please check all that apply:

Caregiving Responsibility	Tick (✓)
Assisting with daily activities (bathing, dressing, eating, etc.)	-
Managing medication	-
Providing emotional support	-
Managing finances	-

Transporting to medical appointments	-
Night-time supervision or sleep disruption	-
Advocacy / Coordination of care	-
Helping with mobility (e.g. wheelchair support)	-
Other (please specify)	

Section 3: Access to Support and Resources

12. What types of support do you currently receive?

Please check all that apply:

Support Type	Tick (✓)
Family support	-
Support from friends	-
Government assistance	-
Disability grants	-
Support groups	-
None	-
Other (please specify)	

13. Are you aware of any caregiver support programmes or resources in your area?

Please tick the option that applies to you:

Response Option	Tick (✓)
Yes	-
No	-
Unsure	-

13.1. If yes, which have you accessed?

Support Programme	Tick (✓)
Counselling	-
Financial assistance	-

Training/education	-
Peer support groups	-
Other (please specify)	

13.2. How satisfied are you with the services you've accessed?

Please tick the option that best reflects your experience

Level of satisfaction	Tick (✓)
Very satisfied	-
Neutral	-
Not satisfied	-

14. What are your top three unmet needs as a caregiver?

15. What additional resources would help you in your caregiving role?

Please tick all that apply:

Resources Needed	Tick (✓)
Financial assistance	-
Respite care (temporary relief)	-
Mental health support	-
Counselling or emotional support	-
Training on caregiving and managing neurological disorders	-
Access to medications and medical supplies	-
Peer support groups or caregiver networks	-
Transportation assistance	-
Information about available services and rights	-
Other (please specify)	

Section 4: Gender and Caregiving

16. Do you feel that being a woman has influenced the expectations placed on you as a caregiver (e.g. from family or community)?

Please tick the option that applies to you:

Response Option	Tick (✓)
Yes	-
No	-
Unsure	-

16.1. If yes, please explain

17. Do you think gender influences who is expected to provide care in your community?

Please tick the option that applies to you:

Response Option	Tick (✓)
Yes	-
No	-
Not sure	-

17.1. If yes, in what ways do you think gender affects caregiving roles?

18. Has caregiving affected your ability to work or study?

Please tick the option that applies to you:

Response Option	Tick (✓)
Yes	-
No	-
Somewhat	-

18.1. If yes or somewhat how has caregiving affected your ability to work or study.

Section 5: Caregiving Health & Reflection

19. How does caregiving impact on your health?

Level of Impact	Tick (✓)
No impact	-
Mild impact	-

Moderate impact	-
Severe impact	-

20. What gives your strength or motivation as a carer?

Section 6: Recommendations and Future Support

21. What changes or improvements would you like to see in caregiver support services?

22. Have you ever received any training or guidance on how to be a caregiver?

Please tick the option that applies to you:

Response Option	Tick (✓)
Yes	-
No	-

22.1. If yes, who provided it? (e.g. clinic, NPO, Epilepsy SA, family member etc...)

Appendix B: Semi-structed Interview Guide (10 questions)

This guide was used by trained social workers to conduct follow-up interviews with caregivers. Questions were designed to explore daily routines, emotional and mental wellbeing, spiritual coping, gendered experiences, encounters with stigma, and visions for improved caregiver support.

Interview Questions:

1. Can you walk me through a day in your life as a caregiver? What moments feel most difficult or rewarding?
2. Looking back, how has caregiving changed you personally, emotionally, mentally, or spiritually?
3. Can you share a time when you felt especially proud or defeated in your caregiving role?
4. What has helped you keep going when things felt overwhelming?
5. How do you feel being a woman has shaped how others see your caregiving role in your family or community?
6. Have you ever faced stigma or judgement from others because of the person you care for or because of your role as a caregiver?
7. In what ways do you wish society better understood the experience of caregivers like you?
8. If you could design the ideal support system or program for caregivers, what would it look like?
9. What advice would you give to another woman just starting her caregiving journey?
10. Is there anything else you'd like to share about your caregiving experience that hasn't been asked?

Appendix C: Verbatim Responses on the Financial Impact

Below are the verbatim responses provided by participants (n = 30) to the open-ended survey question:

“If yes or somewhat, please describe how caregiving affects your financial situation.”

Participant ID	Verbatim Response
Participant 1	If it's raining I have to get a taxi and I don't get paid, so no transport fee.
Participant 2	Paying for care – someone to look after my child.
Participant 3	Medical aid, day care facility, self-care needs (hygiene and bedding when wetting the bed etc.), basic human needs.
Participant 4	I have to provide transportation and food with grant money and my partner is not working so he can’t assist me.
Participant 5	Because I’m not working and I rely on the disability grant.
Participant 6	because i have to stay indoor all the time instead of goiing out to look for work
Participant 7	the grant disability is low and i cant cover daily costs
Participant 8	it's difficult finding full time employment since i have to be away from work to attend check-ups, collect medication or be there when my son gets hospitalized
Participant 9	I spend more money
Participant 10	When I must go to the hospital with my child and hire car if the ambulance take to long, I can't get n job because I can't leave her with any one
Participant 11	Petrol and car payment.
Participant 12	funeral and life policies, Accounts, Transportation,
Participant 13	I have to use most of my money to buy him nappies in the end we run short on money for other things.
Participant 14	He needs more than what the grant can cover. and i am unable to work due to my age.
Participant 15	Financially transport and food

Participant 16	there is no transportation for my mother to go to hospital for check up
Participant 17	i dont have money to attend the physiotherapy and i cant work
Participant 18	Transport money, sometimes I need to help financially
Participant 19	They can't walk distant so we
Participant 29	we dont have money for transport to go to the hospital for my father's medication
Participant 21	Petrol, medical aid
Participant 22	by staying at hone with no souce of income is hard because i need money for my baby
Participant 23	I have money to pay for medication and for transport for both of us.
Participant 24	sometimes i run out medical supply and i have to dip out my own money, which i dont have since im not working and im always at hoome taking care of my child.
Participant 25	Many times i do not have money for trasnport cause most of my money goes to my child
Participant 26	It affects me as sometimes I'm compelled to give my uncle the grant of my child to go to the clinic and also my R350 SRD grant as the situation is not well at home, I also have to buy groceries and the other staff.
Participant 27	I spent I lot of money on traveling cause iam far from the hospital.i don't work so it's expensive.
Participant 28	When buying for my ow children i always have to consider my dependents and buy for them as well.
Participant 29	Buying clothes and funeral policies, and other otter items to make his life more comfortable at home as well adult day care fees, toiletries.
Participant 30	N/A
Note: Participant identifiers (P1–P30) are pseudonyms used to maintain confidentiality.	

Appendix D: Verbatim Responses to "Top Three Unmet Needs as a Caregiver"

Participants were asked:
"What are your top three unmet needs (e.g., emotional support, information, transportation, respite care) as a caregiver?"
A total of 37 responses were received. The comments are reproduced verbatim below.

Participant ID	Verbatim Response
Participant 1	Information.
Participant 2	Transportation.
Participant 3	Information, transport, and financial support.
Participant 4	Rest, alone time, self-care.
Participant 5	Information, finance, emotional support.
Participant 6	Night-time assistance since my husband constantly needs the toilet and is physically disabled due to the stroke.
Participant 7	Special schools, financial support, and training.
Participant 8	House, job, and financial assistance.
Participant 9	Social needs - not having time to socialize, emotional support, or time alone.
Participant 10	Financial assistance, good housing, and counselling.
Participant 11	Transport, access to medication, and old-age home.
Participant 12	Emotional support, lack of information, and transportation for check-ups.
Participant 13	Emotional support.
Participant 14	Information, transport, and respite care as a caregiver.
Participant 15	Emotional support, information, and transportation.
Participant 16	Full-time caregiver, clinical care, and finance.
Participant 17	Emotional support and finance.
Participant 18	Need nappies, assistance with transport, information, clothes, and bedding.
Participant 19	Clothes, food, and emotional support.
Participant 20	Emotional support, transportation, and help during financial problems.

Participant 21	Emotional support, transportation, and information.
Participant 22	Transport, financial assistance, and information about the brain tumour.
Participant 23	House and information about his condition.
Participant 24	Support group and facilities that cater for autoimmune recovery.
Participant 25	Transportation, information, and respite care.
Participant 26	Not getting enough medical supply, transport, and wheelchair.
Participant 27	Stigma, transportation to work and from, emotional support.
Participant 28	Money, food, and clothes.
Participant 29	Counselling.
Participant 30	Job, financial assistance, and free transportation
Participant 31	Emotional support and information.
Participant 32	Emotional support, transportation, and financial support
Participant 33	Emotional support, information, and transportation.
Participant 34	None that I can think of at this moment.
Participant 35	Financial support - cost of living is too high, transportation.
Participant 36	Information on available services, emotional support, and rest.
Participant 37	Assistance with daily care, financial aid, and peer support group.

Appendix E: Verbatim Responses on Gender and Caregiving Expectations

(Question: Do you feel that being a woman has affected the caregiving expectations placed on you (e.g., by family, community, or culture)? If yes, please explain)

Participant ID	Verbatim Response
Participant 1	You are expected to be more understanding, caring and to be always available.
Participant 2	I am his mother, i have to take care of him otherwise people will look down on me, no matter what my own challenges are. I need someone who will motivate me as a woman because i am so down.
Participant 3	my family and society i live in would not look down on me if i were to put my husband in a facility or receive extra care help from a formal carer.
Participant 4	because as a women i have to care for my child alone and i dont receive any help from my partner.
Participant 5	because i cant meet other people and engage with them since im a women who needs to care for my mother
Participant 6	As a woman you're expected to always hold it together and take care of your child.
Participant 7	You're expected to always drop everything to cater to your child's needs
Participant 8	Some man are involved but most of the time is the woman, community or culture I think there's no difference
Participant 9	The family and the community prefare women over man and it's tiring
Participant 10	It was expected of me to leave my job to look after my husband. In the end i decided to let him come to the day care and continue working.
Participant 11	People have been telling me that they would never do what i am doing since he is not related to me so there are no expectations.
Participant 12	Yes, in my culture the mother is responsible for all caregiving needs in a household.
Participant 13	because i need to be at home all the time and im expected to do caregiver alone also i cant date
Participant 14	Im doing it voluntary
Participant 15	The whole family in the house of 21 support in looking after my child.

Participant 16	I am the mom and I feel responsible for my son. It is accepted culturally as the mother to look after the child especially with my child's dad being not part of the child's life even when he lives close by.
Participant 17	All of us in the house watch the dependant, no gender roles influence the care of the dependant.

Appendix F: Open-Ended Responses – How Gender Affects Caregiving Roles

(Question 17.1: If yes, in what ways do you think gender affects caregiving roles?)

Participant ID	Verbatim Response
Participant 1	It is the responsibility of me as his mom.
Participant 2	Because I am the mother in the family it is my duty and role to take care of my child.
Participant 3	They think it's a norm for a woman to be a caregiver.
Participant 4	They say it is a woman's job to be a caregiver.
Participant 5	They think that women have to care all the time; they exclude males.
Participant 6	A woman is known for her caring and loving nature, and is expected to have a nurturing motherly side naturally.
Participant 7	In every situation in a child's life, most of the time the mom is involved with everything.
Participant 8	Because of cultural things — women are born to be nurturers.
Participant 9	As the wife I am expected in my culture and society to look after my husband; getting a caregiver is frowned upon.
Participant 10	Mothers must take care of the children while the husband provides.
Participant 11	Men are not included to cater or be caregivers.
Participant 12	Generally, it's the belief that women are the caregivers because they have a more nurturing personality.
Participant 13	Because people always think a caregiver has to be a woman.
Participant 14	Men should take care of male clients as well as females taking care of females.
Participant 15	Being a caregiver is not easy because I can't leave my client with a person I don't trust.
Participant 16	Men are not included to be caregivers in our community; they are viewed as being head of the house.
Participant 17	It's always the mom that does everything.
Participant 18	Culture influences how roles are made up, and with me, I have to look after the child.

Appendix G: – Verbatim Responses - Caregiving Impact on Work and Study

(Question: 18.1. If yes or somewhat how has caregiving affected your ability to work or study.)

Participant ID	Verbatim Response
Participant 1	I have to be there for the patient especially when she has too many attacks.
Participant 2	I am late at work and not at good standing because i take care of my son and influence how i function at work.
Participant 3	Because i have epilepsy adult day care here, it has made things easier but during holidays or when the centre close, it becomes difficult to work.
Participant 4	We work around what needs to be done with my children.
Participant 5	yes i had an offer for a job an i had to decline it because there is no one who can look after my child.
Participant 6	because i cant look for a job and take care of my son alone.
Participant 7	i have to to take care of the person all the time and i cant find time to do anything for myself..
Participant 8	It's difficult to find full time employment as i always have to be available for whatever is needed with regards to my son. Be it being there for monthly checkups, collection of medication and also being there whenever he gets hospitalized
Participant 9	It's difficult to leave my child with because you are most of the time scared that what if my child gets a fit wil the people know what to do
Participant 10	When he has issues with grants or his health i have to take leave off work, unpaid.
Participant 11	Yes, i cannot work, who will look after the person i am looking after; and if i have work i cannot afford someone to look after him.
Participant 12	I had to stop working because he needed someone to care for him all day.
Participant 13	during
Participant 14	Since retired, I don't have me time and look after my health
Participant 15	i cant further my studies because there is no money.
Participant 16	yes because there is no one who can look after my child
Participant 17	I was only person that was available to take care of my mom.

Participant 18	Sometimes the client refuses to be taken care of by someone else they just want me
Participant 19	Because there nobody who will take care of my son.
Participant 20	yes, i cant look for a job since im getting old
Participant 21	My child needs 24 care and i cannot expect others to take this responsibility, hence i do not work and look after my child.
Participant 22	During the period while I, was in high school it affected me, I wasn't able to concentrate so it affected my end of the year results
Participant 23	I don't have people to look after my son if I went to work.
Participant 24	Yes, because we could not leave the house or work without someone looking after her
Participant 25	I could not work. My child needs 24 care and i cannot afford to pay someone, luckily with the adult day care i can work now since my child is safe.

Appendix H: Sources of Strength and Motivation in Caregiving (Open-ended Responses)

(Question 20: “What gives you strength or motivation as a caregiver?”)

Participant ID	Verbatim Response
Participant 1	The fact that I take care of someone who I brought into this world who needs it, even though I am struggling.
Participant 2	My faith in God. Especially attending church groups where we talk and pray about things.
Participant 3	To support my husband knowing he is taken care of.
Participant 4	I get my strength because I get support from family and friends.
Participant 5	To see change and be able to assist others.
Participant 6	I go to church to get my strength and get fresh air.
Participant 7	Being able to wake up, help others to improve their daily life, to be well and taken care of motivates me every day; it encourages me that I am a patient person, I can work with people and it’s what I’ll be studying for in the next coming years.
Participant 8	I believe that a person has to get fair treatment regardless of their disability.
Participant 9	It keeps me aware of noticing small things about a person living with epilepsy.
Participant 10	The support I receive from family and friends, knowing that my son sees that he is loved and cared for, having that one person who says thank you for loving your son wholeheartedly.
Participant 11	To have a friend to talk to whose child also has epilepsy, because we understand one another.
Participant 12	Positive outcomes.
Participant 13	Things that take me out of my comfort zone - I’m being challenged to do more.
Participant 14	The patients feeling difference in them.
Participant 15	It is a pleasure caring for my husband; I vowed in sickness and in health. My strength comes from God.
Participant 16	I get very tired emotionally but God gives me strength.
Participant 17	Family support and counselling.

Participant 18	To see my mother awake and well when I wake in the morning.
Participant 19	It gives me strength because I have to help that person because I'm giving them life and supporting him and also improving his situation.
Participant 20	I at least give hope to someone who is helpless and hopeless.
Participant 21	To be a caregiver is not easy, but I do it because I like to care for people who need my care.
Participant 22	Because I'm doing something that I love - taking care of my child and hoping to see him better by nursing him.
Participant 23	The support I receive from family gives me motivation.
Participant 24	At the end of the day, I want to see my uncle being able to live independently, and also I am doing this caregiving out of love and respect.
Participant 25	I look at my son and know God doesn't make mistakes, because he is blessed.
Participant 26	To see my patient able to be independent and attending skills projects without my help.
Participant 27	I believe in God and the church people support me.
Participant 28	That I will be the best caregiver because I got some research about epilepsy and other neurological disorders.
Participant 29	My child is alive.
Participant 30	When I have all support from my family and when they give me and my baby love.
Participant 31	My dependant is family and I have to care for her.
Participant 32	That I have family support.
Participant 33	Prayer and reading the Bible.
Participant 34	To see the progress of the patient.
Participant 35	The doctors showing me how to take care of my child and giving me hope that he will be fine.
Participant 36	He is my child, and if I do not care for him, no one else will; I am living for him - that is what motivates me.

Appendix I: Recommendations and Future Support

Question 21: *"What changes or improvements would you like to see in caregiver support services (e.g., training, counselling, financial help, more recognition for caregivers)?"*

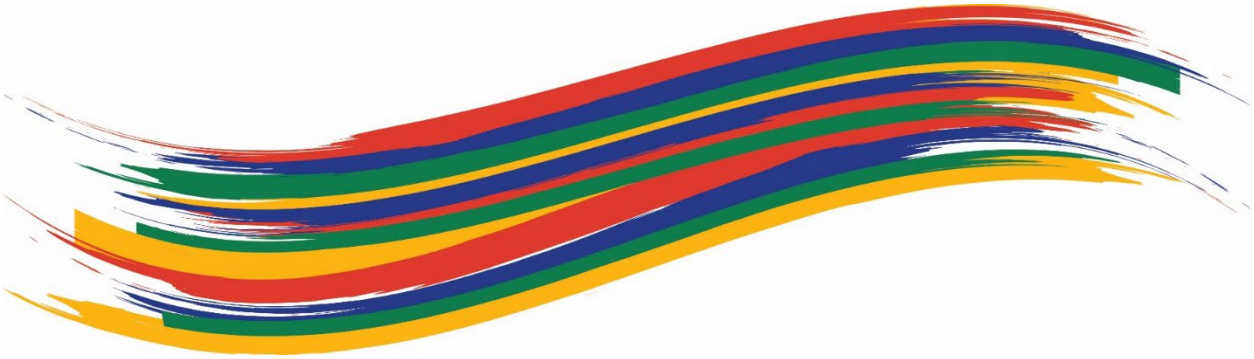
Participant ID	Verbatim Response
Participant 1	Training.
Participant 2	More training, financial help and counseling.
Participant 3	Have day care over weekends as well for carers to be able to rest.
Participant 4	Mental health services and individual therapeutic interventions.
Participant 5	More help from other organizations for holistic care.
Participant 6	More trainings, awareness campaigns and support groups.
Participant 7	More recognition for caregivers and to be offered support, ongoing training, and financial assistance.
Participant 8	To have a community that will offer free training for being a caregiver.
Participant 9	Counselling because caregivers go through a lot emotionally and physically, and it's hard to be open or get enough rest and time to relax.
Participant 10	Government must provide training and financial assistance.
Participant 11	To have more training about caregiving in the safety of our homes.
Participant 12	Access to training, counselling, support groups and some financial help.
Participant 13	Training, counselling, financial help.
Participant 14	Financial and emotional support.
Participant 15	Financial help.
Participant 16	Counselling, financial help, and assistance.
Participant 17	Self-help programs on caring for yourself; educational programs on specific disabilities and how to care for them (e.g., bathing, transferring from wheelchair).
Participant 18	More training, transport for disabled persons, more ramps in the communities, nappies, and access to and from my house gate for the wheelchair.

Participant 19	Have more residential facilities, especially for caregivers who need a place for their children when the caregiver is elderly.
Participant 20	Training.
Participant 21	To have training about the condition so that I can have more information about it.
Participant 22	Training, counselling, and definitely better salaries.
Participant 23	Financial support and training.
Participant 24	Training so that I can have more knowledge on how to care for that person.
Participant 25	Training, counselling, financial help.
Participant 26	Counselling regarding the disease, and financial assistance.
Participant 27	To provide support groups and training for me and my mother.
Participant 28	Training, counselling, financial support, caregiver support groups, and more recognition.
Participant 29	More recognition for caregivers by the health department and give them a decent salary.
Participant 30	Training and counselling.
Participant 31	I would like to see caregivers working in institutions helping others.
Participant 32	Provide more caregiver training and stipends to sustain themselves.
Participant 33	Training on epilepsy, counselling, self-help programmes.
Participant 34	Training and more recognition for caregivers - counselling, training, and financial help.
Participant 35	Have resources available to make surroundings more comfortable such as ramps and recovery rooms; carers need relaxation activities for their wellbeing, and more interventions for dependents' mental health.
Participant 36	More therapeutic and support groups, financial help, and public recognition.
Participant 37	Caregivers need more recognition for the care they give, programmes that make them feel valued, and self-care programmes for their wellbeing.

EDID-GHDI

We acknowledge our presence and work on Indigenous Territories. We respectfully recognize the persistent and unequal effects of colonization on Indigenous peoples and all Canadians.

We gratefully acknowledge funding from the Social Sciences and Humanities Research Council of Canada for this project.



Live Work Well Research Centre
University of Guelph
Attention: EDID-GHDI
501 MacKinnon Building
50 Stone Rd E
Guelph, Ontario, Canada
N1G 2W1
Email: edid-ghdi@uoguelph.ca
Website: www.edid-ghdi.ca

Social Sciences and Humanities Research Council of Canada
Conseil de recherches en sciences humaines du Canada
Canada