



## **BREAKING THE SILENCE:**

*Empowering and Supporting People with Mental Illness and Epilepsy  
and their Carers in Tribal Regions of Odisha*



**Baseline Study Report**

*November 2019*

# FOREWORD

Carers are individuals who provide unpaid care and support to persons living with long-term illness or disability. Carers do this role often at a great expense to their own self yet at a great benefit to the State who do not have to meet the high demand for care.

Whilst caring has been scientifically proven around the world to affect the mental, physical, economic and social wellbeing of those providing care, little effort has been made in low and middle income countries to meet the needs of carers. When interventions focusing on carers have taken place, they have tended to focus on how to strengthen their ability to care as opposed to focusing on meeting the personal needs of the carers themselves.

Carers Worldwide and Carers Worldwide India are par excellence organisations committed towards improving the wellbeing of carers in low and middle income countries. The organisations also encourage carers to advocate for their rights and does this by bringing carers together in to community self-help groups and Associations. Their paramount vision is to create a world in which every carer is recognised, valued, and has their physical, emotional, economic and social needs met. In a world where the demand for caring continues to rise, their vision should be lauded and supported across various sectors.

An integral component of Carers Worldwide and Carers Worldwide India's work is the collecting, analyzing, and sharing of evidence which demonstrates the importance and effectiveness of meeting the needs of carers. This evidence-base can also be used by carers and Associations when advocating for formal recognition and support for their needs.

The study in this report has been conducted in Koraput District of Odisha State through financial support from the Live Love Laugh Foundation. Koraput District is a tribal area and one of the most underdeveloped areas in the State with a low development index. The research has been conducted in collaboration with one of Carers Worldwide's partners, NGO WORD. WORD's vision is for a just and sustainable society in which vulnerable groups can lead a healthy life, and live with dignity without any discrimination. The organisation has extensive experience of working in these marginalised tribal areas and have used this experience to carry out this baseline survey meticulously through well-trained field staff.

The findings of this research will be taken to design individual, tailored intervention plans to support carers and persons living with mental illness within the District. At the end of the project, follow-up data will be collected to compare with the baseline data to understand how effective the project activities have been. Learnings and findings from this evaluation will be shared to encourage future projects to recognise and support carers.

**Dr N Janardhana, Professor at National Institute of Mental Health and Neuro-Sciences (NIMHANS) and Trustee of Carers Worldwide India**

**November 2019**

# ACKNOWLEDGEMENTS

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I am grateful to all the project staff of WORD who interviewed the carers and collected the baseline data. Thanks also go to Mr Natesha N K from Carers Worldwide for co-ordinating and monitoring the data collection and supporting the project staff.

I would like to acknowledge the excellent technical support of Dr Manjula B under the guidance of Prof Janardhana N, from the Department of Psychiatric Social Work, National Institute of Mental Health and Neuro Sciences (NIMHANS), Bangalore.

A special thanks goes to Victoria Nicholson who has analysed the data and produced this rich summary report, presenting a significant body of evidence on carers health, well-being and economic situation, which will assist in the ongoing task of advocating for the recognition and support of unpaid family carers in India.

Without the support of Dr Racheal Raykumari, Executive Secretary, WORD, none of this would have been possible and to her I express my sincere gratitude and thanks.

Finally, I am grateful to the Live Love Laugh Foundation for supporting this study and the broader project "Breaking the Silence: Empowering and Supporting People with Mental Illness and Epilepsy and their Carers in Tribal Regions of Odisha". I would like to thank them for their recognition of the critical role carers play in the rehabilitation and empowerment of persons with mental illness and epilepsy and for their commitment to supporting those carers.

**Dr. Anil K Patil, Founder and Executive of Carers Worldwide and Trustee of Carers Worldwide India**

**November 2019**

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## SUMMARY

This is the report of a study conducted in Odisha state, India, among carers of persons living with mental illness and/or epilepsy. The survey explores wellbeing of carers, as subjectively reported by the survey respondents.

An informal carer is:

... someone who spends a significant proportion of their life providing unpaid support to family or potentially friends. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems (UK Government, 2008).

Developing countries, such as India, do not have adequate social security or support systems which means the role of caring can completely take over the life of carers who, in extreme but not so rare cases, have caring responsibilities all day, every day, without the prospect of respite. When caring is a full-time responsibility, the opportunity to earn a living is lost for the carer, just as much as it is for the person being cared for. The ensuing poverty can be compounded by exhaustion, mental and physical health problems, and a sense of isolation.

Carers may be thought of as an unheard and unseen army of people who voluntarily meet the needs of others at the expense of their own.

The purpose of this study is to establish baseline data in which change can be measured later, and to provide an insight into the types of intervention that would be of greatest benefit to carers within this particular socio-cultural-economic context.

This baseline study concerns the project "Breaking the Silence: Empowering and Supporting People with Mental Illness and Epilepsy and their Carers in Tribal Regions of Odisha. The purpose of this project is to improve the mental health of 600 persons living with mental illness and epilepsy, and their carers, in Koraput District, Odisha, by creating a sustainable system of mental illness prevention and treatment.

This study is designed to arm stakeholders (Carers Worldwide, their local partners, and carers principal among them) with the hard evidence they need to achieve these objectives, and this project sits in a growing Carers Worldwide programme which addresses the needs of carers in low and middle-income countries through an evolving, systematic and evidence-based methodology.

The results of the survey are presented and analysed in full below. However, key findings include: majority of carers are female (71.9%); majority of carers cared for their spouse or their child (71.9%); majority of carers were uneducated (86.3%); 38.7% of carers were not in employment; majority of carers reported having a health issue of their own (52.7%) with 69.6% of those not receiving any treatment or support for their health issue; and the majority of carers expressed concerns about their economic, social, physical, and mental wellbeing (various results).

These findings are consistent with those from other studies. Carers Worldwide's experience and the literature indicate that this project will help participating carers through known interventions. It will also add to the body of knowledge about carers' lives and welfare and further our understanding of effective approaches for supporting carers.

# ABOUT CARERS WORLDWIDE

Carers Worldwide highlights and tackles the issues facing carers. It is the only organisation working exclusively with carers in South Asian countries.

Carers Worldwide is a UK registered charity (1150214) and a UK company limited by guarantee (8083816). Its objective is to promote the relief of people who require care due to physical or mental ill health, disability, old age, frailty, substance misuse or any other cause, in particular (but not without limitation) by:

- Raising the awareness of carers and the general public to the needs of, and difficulties experienced by, individuals as a result of their caring role.
- Relieving financial hardship, illness and distress among carers, and
- Providing relief to cared-for individuals by improving the quality of their care and rehabilitation through the provision of training, support and advice to carers.

In pursuance of this objective Carers Worldwide's purpose is to bring about "sustained positive change for carers in developing countries by addressing issues of recognition, social and economic concerns."

The strategic goal of Carers Worldwide is to serve as a catalyst to:

- Bring about systemic change in the work of governments, charities and other agencies so that they recognise and respond to the needs of carers in the developing world.
- Facilitate the provision of support for individual carers and their families in the developing world, bringing them better health, wellbeing and economic security.

Carers Worldwide achieves its strategic goals by:

- Working in partnership with established charities and other organisations that are skilled in service delivery for those in need and are well networked in their communities in order to create systemic changes in attitudes and support of carers.
- Disseminating the Carers Worldwide holistic model of the support provision necessary for effecting systemic change for carers.

## **ABOUT WORD**

WORD was initiated by a group of grassroot women from Koraput district in 1991 with a purpose of building a collective of women to address the issue of poverty and discrimination in Laxmipur Block. WORD visualizes itself as a People's Initiative for addressing these issues without discriminating on the basis of caste, colour, creed, gender, religion or region and ensuring justice, peace, equality and fraternity. The organisation addresses the most vulnerable population in the district with special emphasis on women and children. The guiding principle of WORD is community empowerment by the people for their own development with gender as the transversal through all its process and projects.

WORD has been always focussing on the most vulnerable sections cross cutting Gender and Disability in all its projects. However, with the support of CBR Forum, Bangalore, PWDs were capacitated for advocate for their rights and formed into Disabled People's Organisations, and during this period 20 DPOs were strengthened. They together formed a Block level Disabled People's Organisation. WORD along with DPOs mobilised various social security schemes for the PWDs like certificates, rail and bus pass, aids and appliances, few medical supports for free operations etc., The DPOs are now converged into the existing Community Based Organisation like women federation, farmers groups, SHGs etc., for inclusive development.

# BACKGROUND TO THE STUDY

## **Odisha at a glance**

The population of India as per the 2011 Census was 1,210,193,422. 2.21% of the population are disabled which is over 26,750,000 people. A person with disability (PWD), according to the 2016 Act means a person with long term physical, mental, intellectual or sensory impairment which, in interaction with barriers, hinders his full and effective participation in society equally with others. Therefore, statistics relating to disability are relevant to this study as mental illness and epilepsy, the conditions of care recipients investigated in the study, are classified as disabilities.

The 2011 Census found a population of 41,974,218. That includes a rural population of 34,970,562. Applying the 2.21% disability percentage, this would mean there are nearly 928,000 people living with disabilities in the state of Odisha with over 770,000 of those living in rural areas.

## **Odisha's Tribal Population: Socio-Economic Status and State Support**

Tribes are social divisions within traditional societies that consist of families linked by blood ties, religion, social and economic factors, and share common culture and dialect. Each tribe possesses certain characteristics and qualities that makes it a unique social, cultural and political entity.

Tribal peoples constitute 8.6% of India's total population, about 104 million people according to the 2011 census (an increase from 68 million people according to the 1991 census). This is the largest population of tribal people in the world. One concentration lives in a belt along the Himalayas stretching through Jammu and Kashmir, Himachal Pradesh, and Uttar Pradesh in the west, to Assam, Meghalaya, Tripura, Arunchal Pradesh, Mizora, Manipur and Nagaland in the northeast. Another concentration lives in the hilly areas of central India (Madhya Pradesh and Odisha).

## **Status of Scheduled Tribes in Odisha**

Odisha has the third largest concentration of tribal population in India. Odisha comprises 9.17% of the total tribal population of the country after Madhya Pradesh (14.6%) and Maharashtra (10.08%). About 44.7% of the state's geographical area, which is known as "Scheduled Areas", extend over 119 out of 314 blocks in 13 districts and a portion of Sorada Tahasil of Ganjam district. Out of 635 tribal communities in India, 62 are found in Odisha and 13 are Particularly Vulnerable Tribal Groups (PVTG). The ethos, ideology, world view and cultural heritage of tribal communities are rich and varied, which ranges from nomadic food gatherers and hunters to skilled and settled agriculturists and horticulturists. Tribal areas of Odisha present in an extremely diverse socio-economic panorama and speak a total of 74 different dialects.

The PVTG in Odisha include Bonda, Chuktia, Bhunjia, Didayi, Dongaria Kondh, Juang, Hill-Kharia, Kutia Kondh, Lanjia Saora, Lodha, Mankirdia, Paudi Bhuyan, Soara and Birhor. These communities are considered a special category in view of their distinct social, cultural and occupational practices and traits.

The PVTG are distinguished from other tribal communities for their relative physical isolation,

stagnant or diminishing population, very low level of literacy, low level of techno-economy, i.e. subsistence level of economy, very low level of literacy associated with pre-agricultural stage of hunting, food gathering and sifting cultivation. They reside in parts of 21 blocks of 12 districts.

### **Disabilities and Tribal Persons – A specific cause for concern**

Such persons living in rural and tribal areas are particularly vulnerable to living with stress, disability and illness more than the general population. Due to the vulnerable nature of persons living in rural communities, more resources and special attention should be given to those PWDs and those who care for them.

### **National Mental Health Programme and Mental Health Act**

Historically, there was a severe lack of awareness of mental illness and a lack of available treatment for persons living with mental illness in India so in 1982 the Government of India launched the National Mental Health Programme (NMHP) with the following objectives:

1. To ensure the availability and accessibility of minimum mental healthcare for all in the foreseeable future, particularly to the most vulnerable and underprivileged sections of the population;
2. To encourage the application of mental health knowledge in general healthcare and in social development; and
3. To promote community participation in the mental health service development and to stimulate efforts towards self-help in the community.

Following the NMHP, the District Mental Health Program (DMHP) was launched under NMHP in the year 1996. The main objective of DMHP is to provide Community Mental Health Services and integrate mental health with General Health Services by decentralizing treatment from Specialized Mental Hospitals to Primary Healthcare Services. The DMHP focuses on:

1. Early detection & treatment of mental illness
2. Providing short-term training to general physicians to enable them to diagnosis and treat common mental illnesses
3. Increasing public awareness of mental illness

In May 2018 India's new mental health legislation, the Mental Healthcare Act 2017, came into effect. It seeks explicitly to comply with the United Nations Convention on the Rights of Persons with Disabilities and grants a legally binding right to mental healthcare for India's 1.3 billion population. Key provisions include:

1. New definitions of 'mental illness' and 'mental health establishment';
2. Revised consideration of 'capacity' in relation to mental healthcare
3. 'Advance directives' to permit persons with mental illness to direct future care;
4. 'Nominated representatives', who need not be family members;
5. The right to mental healthcare and broad social rights for the mentally ill;
6. Establishment of governmental authorities to oversee services;
7. Mental Health Review Boards to review admissions and other matters;
8. Revised rules governing treatment, restraint and research; and
9. De facto decriminalization of suicide

Whilst the legislation makes provisions for all persons living mental illness in India, a key challenge of the legislation relates to availability of resources at the public level.

## **Role of Caregiving**

Providing care or 'caregiving' involves assisting another person to perform activities which are necessary for survival, human functioning or social participation, or performing such activities for a person who is unable to do them. Depending on the extent of assistance required and resources available, caregiving will involve variable amounts of physical work. Caregiving is predominately performed informally. An informal carer is:

... someone who spends a significant proportion of their life providing unpaid support to family or potentially friends. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems (UK Government, 2008).

## **Informal Caregiving – Demand and the Indian Scenario**

Informal caring is the most common form of caring. Whilst certain Acts and Provisions exist, as discussed above for those with Mental Illness, Globally, most governments, donors, multilateral organisations and many international NGOs have paid no attention to the role of caring, its effects and costs to carers, and the benefits it brings to society, with most bodies and organisations only concerning themselves with paid, visible forms of economic contribution made (Eyben and Fontana, 2011). Ignoring unpaid care work is also often a tactical move that enables governments to pass on the costs associated with caring to families and communities as opposed to finding ways to fund caring as a public good (Smith, 2005). When references are made to carers e.g. in the Mental Health Act 2017, India, this still focuses on the carers in relation to the person with the mental illness as opposed to an individual focus on the carers themselves.

In relation to mental illness in India, more than 90% of patients with chronic mental illness live with and are cared for by their families (Kumar, Suresha, Thirthalli, Arunachala, & Gangadhar, 2015). The family caregiver plays multiple roles in care of persons with mental illness, including taking day-to-day care, supervising medications, taking the patient to the hospital and looking after the financial needs.

## **Impact of Caregiving on Caregivers**

Whilst many carers are proud of their role and find it rewarding to care for a loved one (Cavaye, 2016), caring can also have negative effects on the wellbeing of carers (Thrush and Hyder, 2014). A patient's illness, associated behaviours, disabilities and perceived disruptions of the carers' life can cause stress to a caregiver whilst a caregiver's personality, quality of family relationships and degree of social support are considered as the mediating factors (Szmukler et al., 1996).

Challenges of caring are known as 'burden of care'. This burden is a complex construct, which includes not only the physical and, economic impact but also, shame, embarrassment, feelings of guilt and self-blame. The burden may be objective (taking care of daily tasks, etc.) or subjective caregiver's perception of burden (Awad & Voruganti, 2008). Family caregivers might experience time lost from work, unreimbursed medical and other patient-related expenses, limited time for leisure and socializing, elevated symptoms of psychological distress and feelings of stigmatization, poorer quality of life, poorer self-rated health, chronic medical conditions, increased visits to a primary care physician, greater use of psychotropic drugs and increased risk of medical hospitalization (Perlick et al., 2016).

In developing countries, including India, limited research is available on the challenges experienced by carers (Yakubu and Schutte, 2018). From the data that is available, meta-analysis of 51 studies across 33 low-and-middle income countries (LMICs) found a negative impact on the social, mental, physical and financial wellbeing of carers with 64% - 68% of carers reporting financial difficulties and 88% of carers reporting concerns of exhaustion and fatigue. (Thrush and Hyder, 2014). Koyanagi et al. did a cross-sectional analysis of 58 low, middle and high-income countries and found that in all countries, caregiving can lead to significantly worse stress, depression and poor sleep patterns (2018). The same study found that carers had very limited free time in which they could socialize or have any respite.

Although carers in both low and high income countries feel negative effects of caring, it is possible those in lower-income settings face greater challenges with research focusing on carers in low-income settings found that caring causes greater pressure on the financial resources of a lower-income household which creates greater stress to carers in comparison to carers in higher-income settings (Yakubu and Schutte, 2018).

Another challenge is that stigmatization, which is commonly faced by people living with medical conditions, disability and mental illness (Duran and Ergün, 2018), is also acquired by those closely related to such individuals (Goffman, 1963). This is known as 'courtesy stigma' and such stigma can negatively affect the social standing and social life of affected individuals (Goffman, 1963).

The 'caregiver burden' may be seen in all stages of illness. Sometimes, the caregivers have high hopes in the initial phases of illness, which gradually go down. The burden has been reported to be seen with the complete range of symptoms. Some authors have reported more burden with positive symptoms, others with disorganized or disruptive behaviour or the negative symptoms (social withdrawal and lack of activity). In general, it is the poor functioning of the patient due to symptoms, which leads to more severe burden (Smith et al., 2014).

Most caregivers take up the caring role in the absence of any significant knowledge about the illness. The role and demands are incorporated within the regular family responsibilities. The caregivers develop different kinds of coping strategies to deal with the burden of caregiving. A lot of trial and error may be involved in coping. The coping strategies can be broadly grouped into two groups: Emotion focused, and problem focused. The emotion focused strategies aim to diminish the negative emotional impact of the stressor, and include avoidance, denial, fatalism, or looking to religion. The problem focused coping refers to direct actions, which individual undertakes to change the situation. These include problem solving or seeking social support to resolve the stress of caregiving.

Thus, the family caregiver experiences considerable stress and burden, and needs help in coping with it. The caregivers develop different kinds of coping strategies to deal with the burden. An unhealthy coping style is likely to adversely affect the caregiving function (Crews, 2012). Hence, it is important to take care of the needs of the family caregivers.

### **Caregiving Issues in the Context of Providing Care to Children**

The health of a carer is a key factor which can affect the well-being of the child with disabilities for whom they care (Brehaut et al., 2004; Raina et al., 2005). In low-income countries, many carers of children with disabilities contend with poverty, limited public services and a lack of

assistive devices. In these situations, caregiving may require more physical work than in high-income countries and so carry greater risk of physical injury or health problems. There is some evidence that poverty and limited access to health care and equipment may affect the physical health of those who care for children with disabilities (Geere et al., 2013).

### **Caregiving and mental illness**

Close family members or friends are often a source of primary support for a person with mental illness (Perlick et al., 2016). These individuals take on considerable responsibility for the care of an ill person in the community, including coping with fluctuating, often unpredictable, symptoms of depression and mania and high suicide risk (Berk et al., 2013).

Caregivers have to spend more time when their family member is symptomatic as they need to care for their personal hygiene, calm down during emotional outburst and take the brunt of abuse and assaults from their mentally ill family members. Caregivers' involvement in direct and indirect care changes over time, in response to the stage of illness and treatment, and caregivers must be able to adapt to changes in the amount, level and intensity of care demands (Reinhard, Given, Petlick, & Bemis, 2008). Caregivers of people mental illness face different challenges and they are affected by cultural and social attitudes to the illness, and these have important effects on the level of burden experienced. Caregivers do have stress while caring their mentally ill family members, their stress and burdens need to be addressed in the interest of person with mental illness. Caregiving for chronically mentally ill family members disrupts the normal functions of families, and it almost always causes stress in the family (Alliance, 2012). caregiving work is not only stressful because it requires the performance of difficult physical care and medical care like administering medicines, follow-ups, involvement in productive work and encouraging, but also because of (Scharlach, Li, & Dalvi, 2006). The caregivers' needs should be understood and addressed; they have variety of psychosocial needs: Understanding illness, managing the ill family member, dealing with stigma, involving them in to community activities, etc (Sales, 2003).

The nature of the relationship between caregiver and the mentally ill person, interpersonal relation within the family, pre-existing emotional resources of the caregiver, type of the family, coping ability of the caregiver, availability of economic and social support personality of the caregiver, caregiving beliefs and values have been found to be significant related to the caregiving. The caregivers should be acknowledged and looked as resources in the mental health programme (Janardhana, Raghunandan, Naidu, Saraswathi, & Seshan, 2015).

Studies carried out in the specific area of mental illness, shows that burden, physical health problems and psychological distress are commonly experienced among caregivers, both in schizophrenia and bipolar disorder (Aschbrenner, Greenberg, Allen, & Seltzer, 2010; Hoenig & Hamilton, 1966).

The caregivers caring for their patient with mental illness feel stressed, anxious and low, since the illness tends to be chronic and demanding. In the long run, there may occur burnout and emotional exhaustion. The caregivers feel isolated from the society, both due to restriction of their social and leisure activities, as well as the social discrimination and stigma attached to the mental illnesses. Some caregivers may need to look after more than one patient in the family (Kate, Grover, Kulhara, & Nehra, 2013, 2014).

Numerous factors related to caregivers, patients, and illness determine the caregiver burden.

These include characteristics of the person with mental illness, characteristics of caregivers, and relationship between them, time spent by the caregiver with the patient and nature and severity of illness (Creado, Parkar, & Kamath, 2006).

### **Need for addressing the caregiving issues**

The issue of family caregiver has remained neglected a lot, often ignored by the mental health professionals. This key support system can't be taken as granted and ignored by the mental health professionals as the burden outlined above shows they need support (Fave, Fianco, & Sartori, 2015).

It is essential for the mental health professionals and those working with persons with epilepsy to identify the burden in the caregivers of the patients they are treating, so that they are not adversely affected by it. Early identification and suitable interventions would help in keeping this support base intact, healthy and effective. The mental health professionals and those working with persons with epilepsy need to take timely care of the needs of the caregivers and provide necessary support and interventions, as per indication. This would help the caregivers to deal effectively with the burden of caregiving using healthy coping strategies and also improve their caregiving capability (Chadda, 2014)

### **Summary**

Family caregivers of persons with mental illnesses are a key support system in India as well as in most of the non-western world. In the absence of adequate mental health infrastructure, the family caregivers take multiple roles at providing care for persons with mental illnesses. The family caregivers suffer substantial burden as a result of the caregiving role and need help from the mental health professionals. It is very important for the mental health professionals to identify the needs of the family caregivers, the stresses faced by them and introduce suitable interventions, so as to reduce the burden as well as help in developing healthy coping strategies.

# SURVEY RESULTS

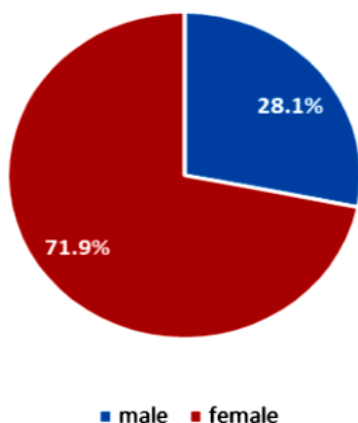
## Results of survey conducted by WORD

256 carers from Laxmipur Block, Koraput District, Odisha participated in the survey. Questions were asked about the carer, the wellbeing of the carer, the health of the carer and cared for person, and knowledge on epilepsy. The results of each question are analysed below.

### Part I - Questions about the Carer

#### Q1. What is the gender of the carer?

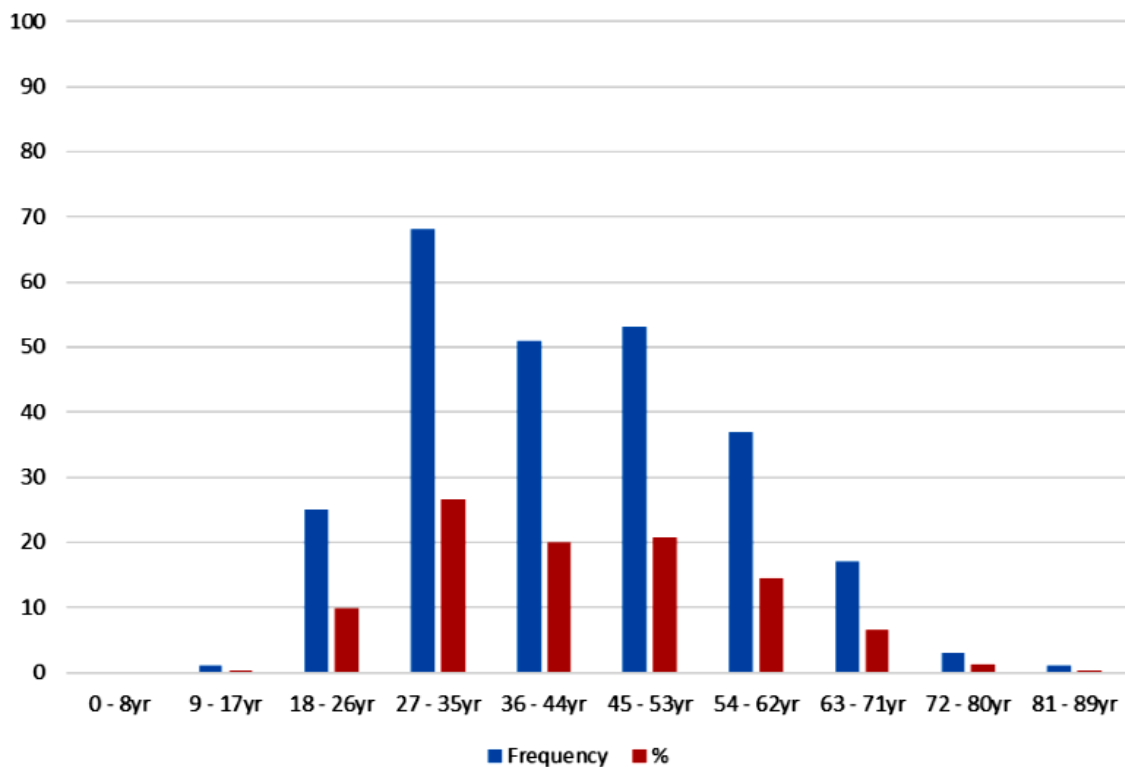
Gender	Frequency (N = 256)	%
male	72	28.1%
female	184	71.9%



Majority of the carers (71.9%) surveyed were female.

#### Q2. What is the age of the carer?

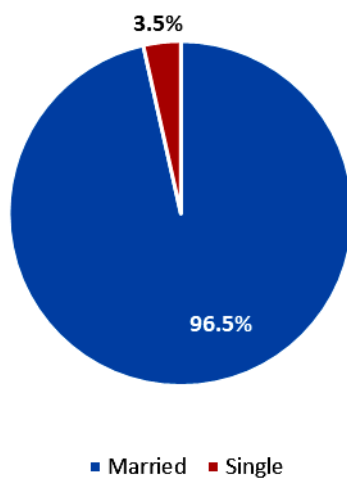
Age	Frequency (N = 256)	%
0 - 8yr	0	0.0%
9 - 17yr	1	0.4%
18 - 26yr	25	9.8%
27 - 35yr	68	26.6%
36 - 44yr	51	19.9%
45 - 53yr	53	20.7%
54 - 62yr	37	14.5%
63 - 71yr	17	6.6%
72 - 80yr	3	1.2%
81 - 89yr	1	0.4%



Majority of the carers (67.5%) surveyed were between 27 to 53 years old. 26.6% of carers surveyed were 27 to 35 years old. 20.7% of carers surveyed were 45 to 53 years old. 19.9% of carers surveyed were 36 to 44 years old.

### Q3. What is the marital status of the carer?

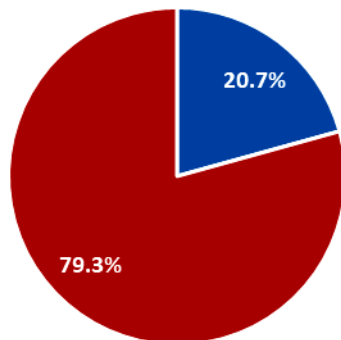
Marital Status	Frequency (N = 256)	%
Married	247	96.5%
Single	9	3.5%



Majority of the carers (96.5%) surveyed were married.

#### Q4. What is the family type of the carer?

Type of Family	Frequency (N = 256)	%
Joint	53	20.7%
Nuclear	203	79.3%

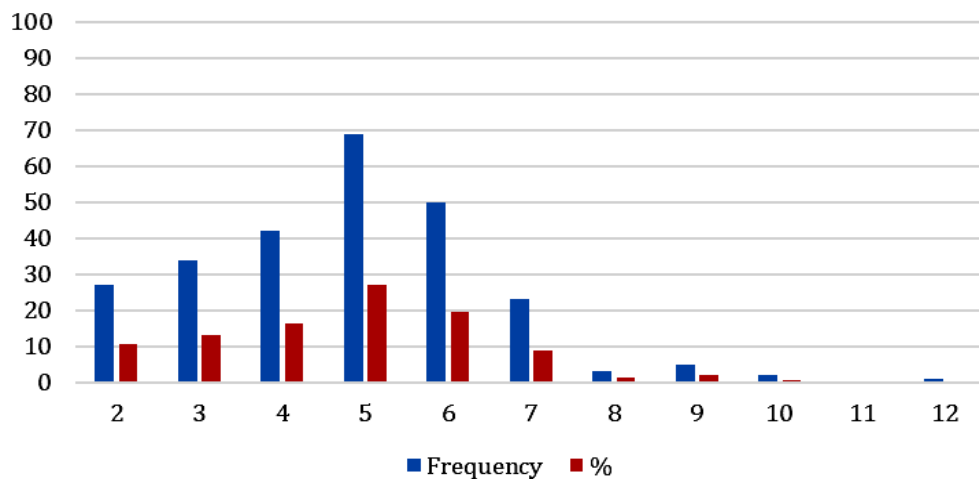


■ Joint ■ Nuclear

Majority of carers (79.3%) surveyed were living within a nuclear (non-extended) family.

#### Q5. How many members live in the household of the carer (including the carer)?

Household Members	Frequency (N=256)	%
2	27	10.5%
3	34	13.3%
4	42	16.4%
5	69	27.0%
6	50	19.5%
7	23	9.0%
8	3	1.2%
9	5	2.0%
10	2	0.8%
11	0	0.0%
12	1	0.4%



Out of all the responses, it was most frequent (27.0%) for carers to live in households with 5 members.

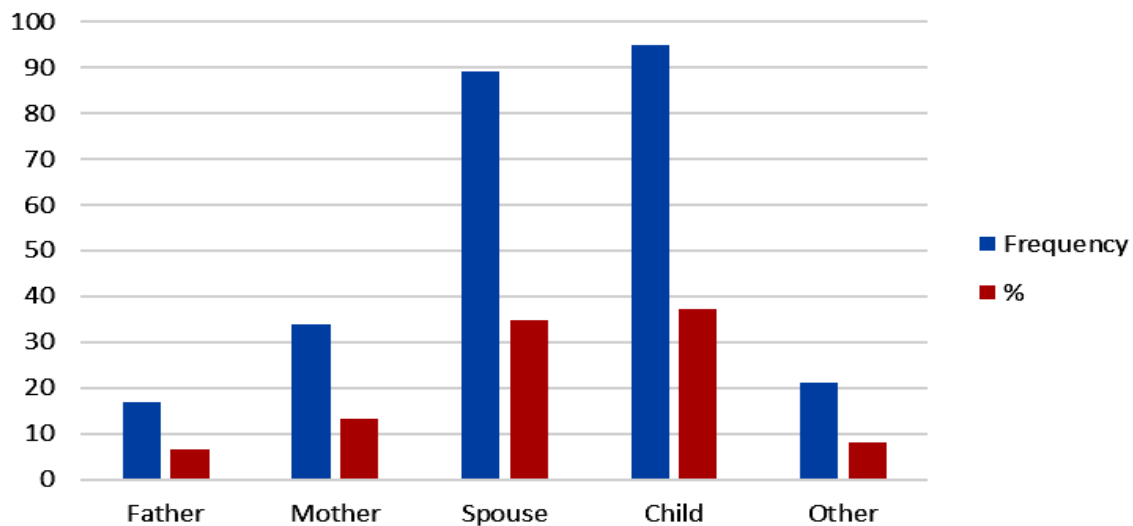
### Q6. How many men, women and children reside in each household?

Variable	Mean &SD (N=256)	Minimum – Maximum
No of household members	4.81 ± 1.726	2-12
1-5	172	
6-10	83	
Above 10	1	
No of men	1.51 ± .797	0-5
0	9	
1-3	249	
Above 4	4	
No of women	1.57 ± .774	0-4
0	4	
1-3	246	
Above 4	6	
No of Children	1.72 ±1.220	0-5
0	51	
1-3	187	
Above 4	18	

The above table shows that, average number of members in the family was 4.81 ranged between 2-12 members. Most of the family members were children (average of 1.71, maximum 4 children), followed by women (average 1.57) and men (1.51).

### Q7. What relation is the person cared for to the carer?

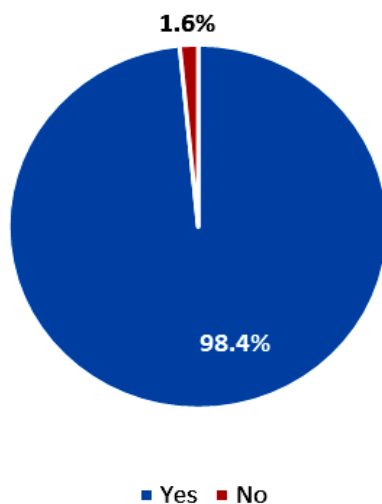
Relationship to Person Cared for	Frequency (N = 256)	%
Father	17	6.6%
Mother	34	13.3%
Spouse	89	34.8%
Child	95	37.1%
Other	21	8.2%



The majority of carers (71.9%) surveyed look after their spouse or their child. 34.8% of carers surveyed care for their spouse whilst 37.1% care for their child.

### Q8. Does the Carer have an ID Card?

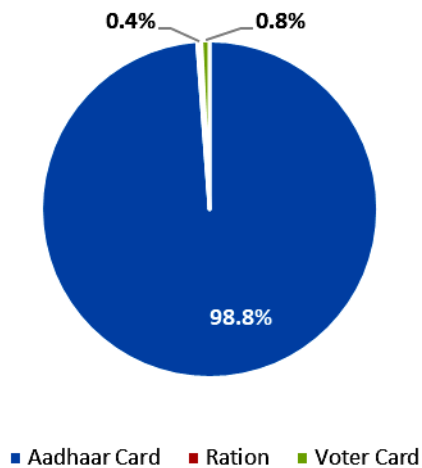
ID Card	Frequency (N=256)	%
Yes	252	98.4%
No	4	1.6%



The majority of carers (98.4%) surveyed have an ID card.

### Q9. What type of ID Card does the carer have?

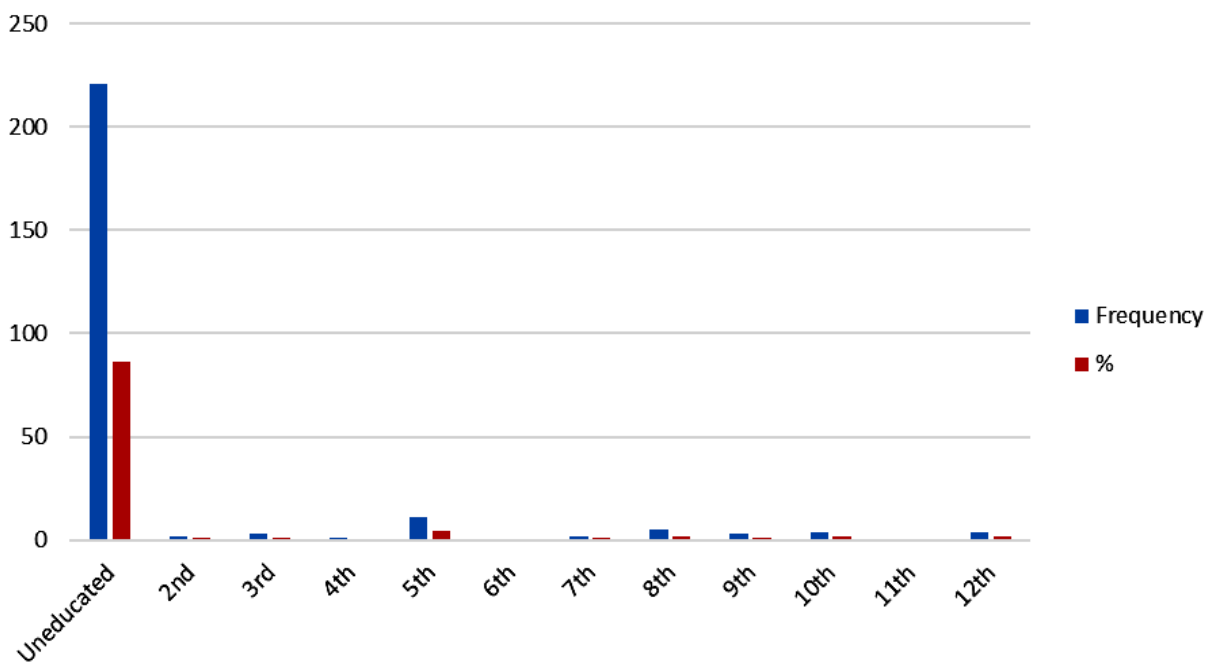
Type of Card	Frequency (N = 252)	%
Aadhaar Card	249	98.8%
Ration	1	0.4%
Voter Card	2	0.8%



Out of the 252 carers who have an ID card, 98.8% of those have the Aadhaar Card.

### Q10. What is the education level of the carer (attained)?

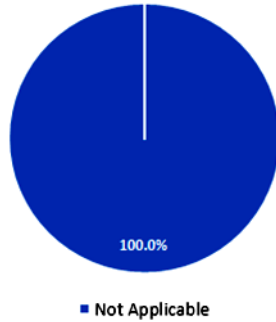
Education Level (Attained)	Frequency (N=256)	%
Uneducated	221	86.3%
2nd	2	0.8%
3rd	3	1.2%
4th	1	0.4%
5th	11	4.3%
6th	0	0.0%
7th	2	0.8%
8th	5	2.0%
9th	3	1.2%
10th	4	1.6%
11th	0	0.0%
12th	4	1.6%



The majority of carers (86.3%) surveyed were uneducated. Only 1.6% of the carers surveyed had completed 12th grade.

**Q11. What is the current education status of the carer?**

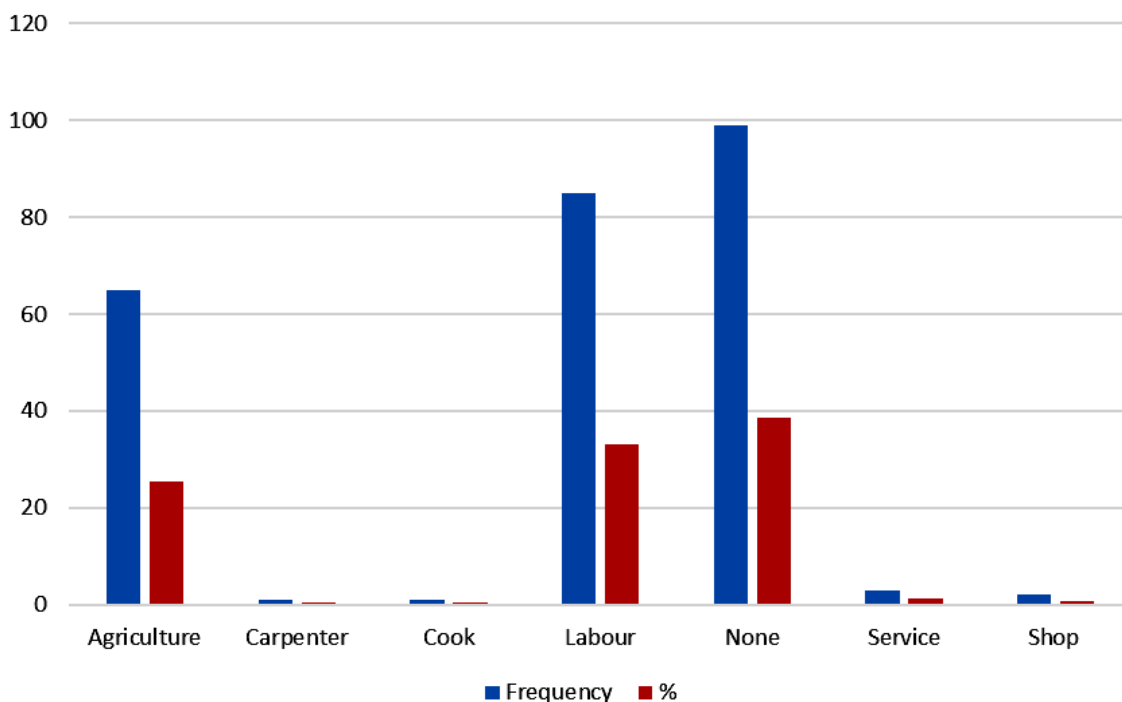
Current Education Status	Frequency (N=256)	%
Not Applicable	256	100.0%



All of the carers (100%) surveyed are not currently in education.

**Q12. What is the current employment of the carer?**

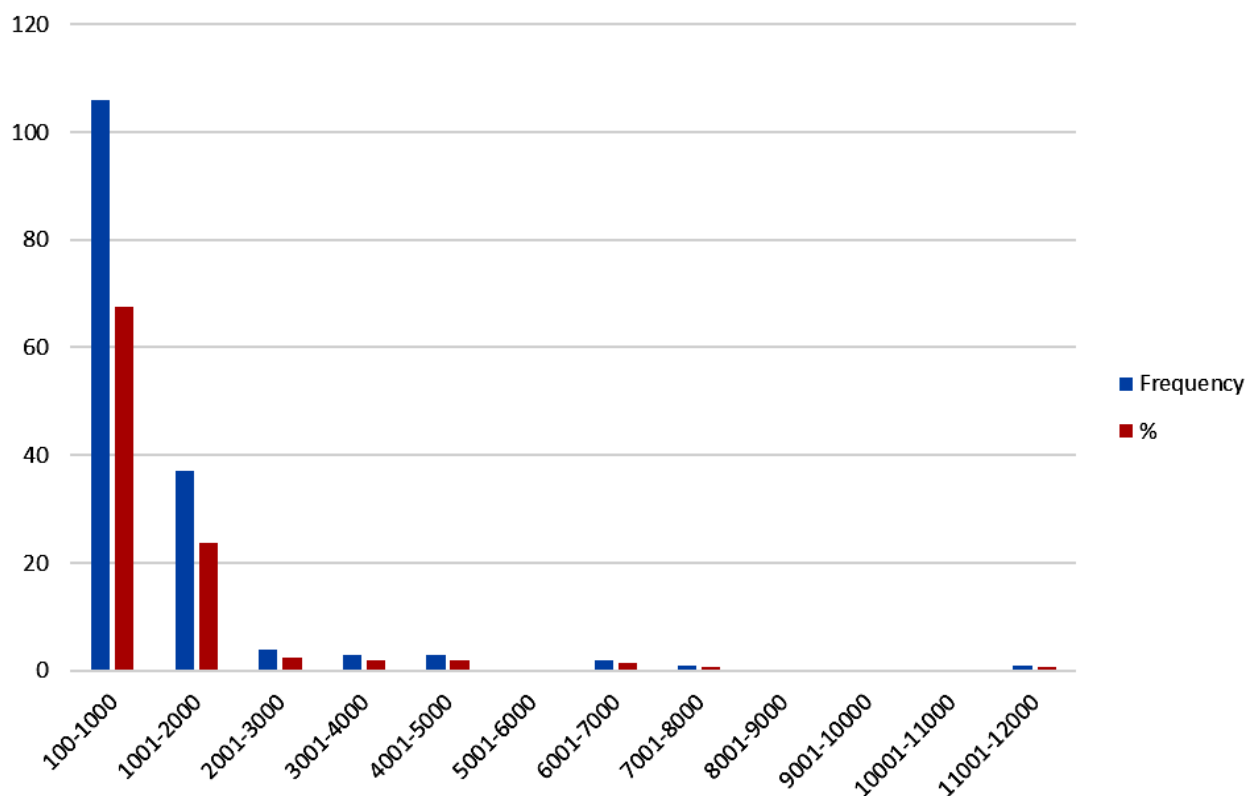
Current Employment	Frequency (N=256)	%
Agriculture	65	25.4%
Carpenter	1	0.4%
Cook	1	0.4%
Labour	85	33.2%
None	99	38.7%
Service	3	1.2%
Shop	2	0.8%



The majority of carers (61.4%) surveyed are employed. 33.2% of carers surveyed are employed as labourers whilst 25.4% of carers surveyed are employed in agriculture. However, a total of 38.7% of carers surveyed were not in any employment.

**Q13. What is the monthly income of the carers who are in employment?**

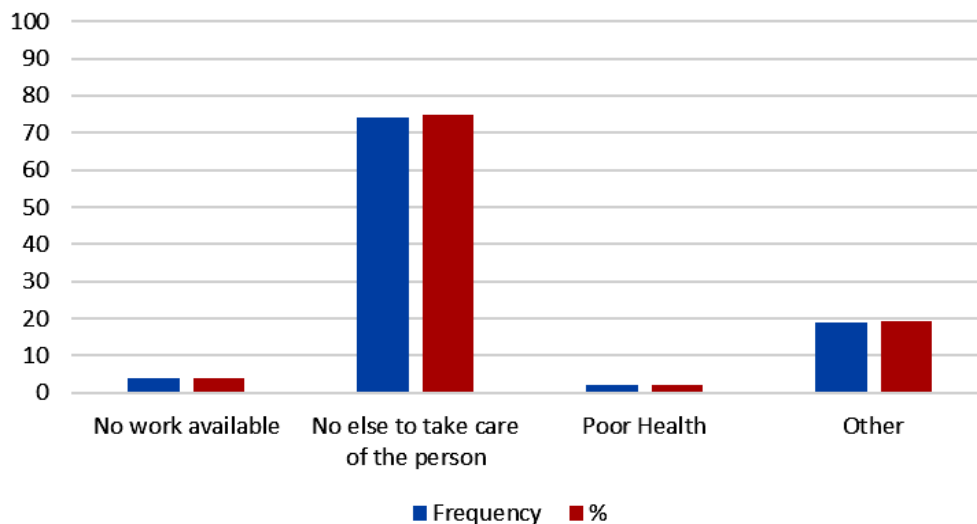
Income (Rs.)	Frequency (N=157)	%
100 - 1000	106	67.5%
1001 - 2000	37	23.6%
2001 - 3000	4	2.5%
3001 - 4000	3	1.9%
4001 - 5000	3	1.9%
5001 - 6000	0	0.0%
6001 - 7000	2	1.3%
7001 - 8000	1	0.6%
8001 - 9000	0	0.0%
9001 - 10000	0	0.0%
10001 - 11000	0	0.0%
11001 - 12000	1	0.6%



The majority of carers (67.5%) surveyed who were earning an income earned between 100 to 1000 rupees per month. 23.6% of the carers earning an income earned between 1001 to 2000 rupees per month.

**Q14. What is the reason for not working for carers who are not in employment?**

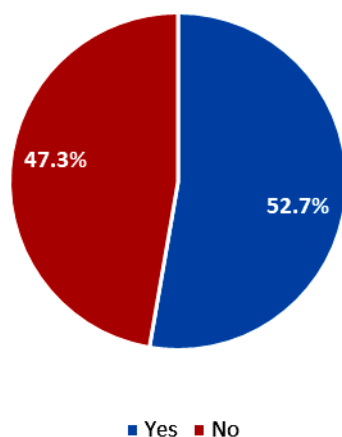
Reason for Not Working	Frequency (N=99)	%
No work available	4	4.0%
No else to take care of the person	74	74.7%
Poor Health	2	2.0%
Other	19	19.2%



*Of the 99 carers surveyed who were not working the majority of those (74.7%) were not in employment as they could not find anyone else to take care of the person they cared for.*

**Q15. Does the carer have any health issues?**

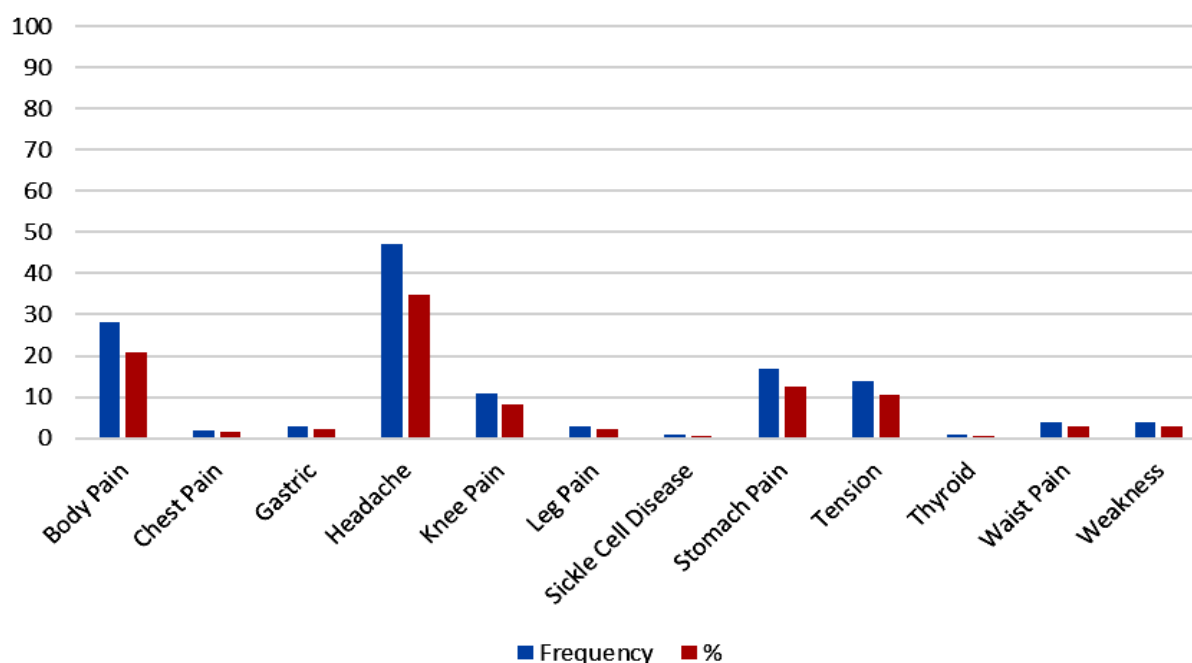
Health Issue	Frequency (N=256)	%
Yes	135	52.7%
No	121	47.3%



*The majority of carers (52.7%) surveyed reported having a health issue.*

### Q16. What health issue does the carer have?

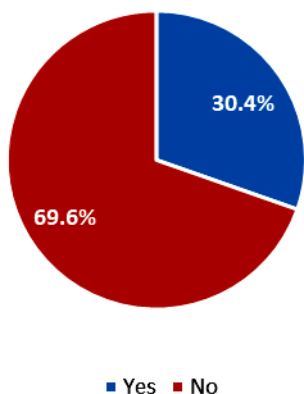
Health Issue	Frequency (N=135)	%
Body Pain	28	20.7%
Chest Pain	2	1.5%
Gastric	3	2.2%
Headache	47	34.8%
Knee Pain	11	8.1%
Leg Pain	3	2.2%
Sickle Cell Disease	1	0.7%
Stomach Pain	17	12.6%
Tension	14	10.4%
Thyroid	1	0.7%
Waist Pain	4	3.0%
Weakness	4	3.0%



Out of the 135 carers who reported having a health issue, the most frequently reported health issue was headache (34.8%) followed by body pain (20.7%).

### Q17. Has the carer received support/treatment for their health issue?

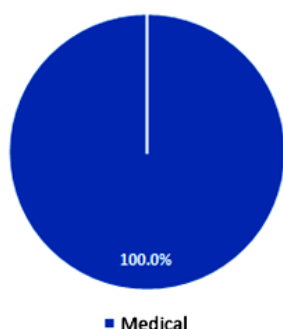
Support/Treatment Received	Frequency (N=135)	%
Yes	41	30.4%
No	94	69.6%



Out of the 135 carers who reported having a health issue, the majority (69.6%) had not received support/treatment for their condition.

### Q18. Has the carer received support/treatment for their health issue?

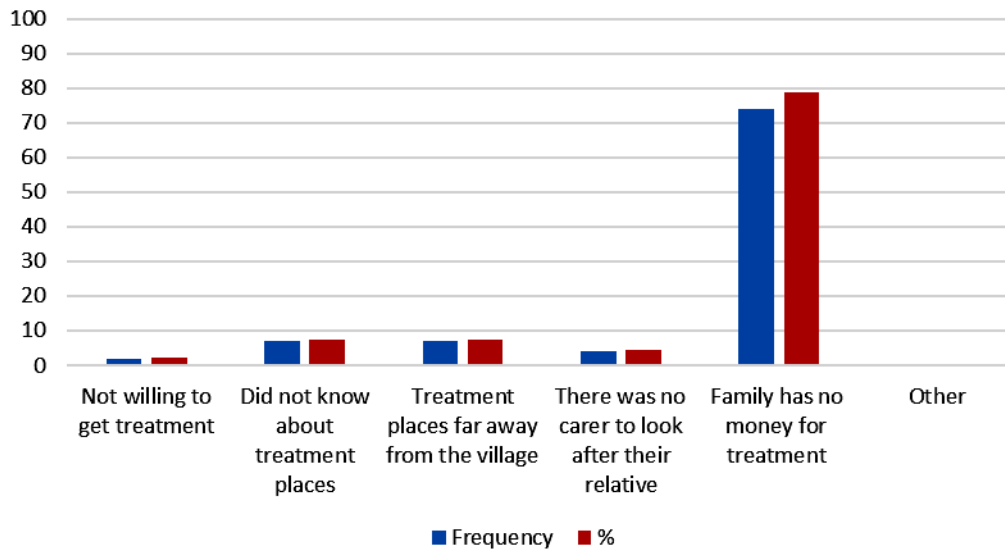
Type of Treatment	Frequency (N=41)	%
Medical	41	100



Out of the 41 carers who did receive support/treatment, all of those (100.0%) received medical treatment.

### Q19. For carers with health issues who did not seek treatment, what was the reason for not seeking treatment?

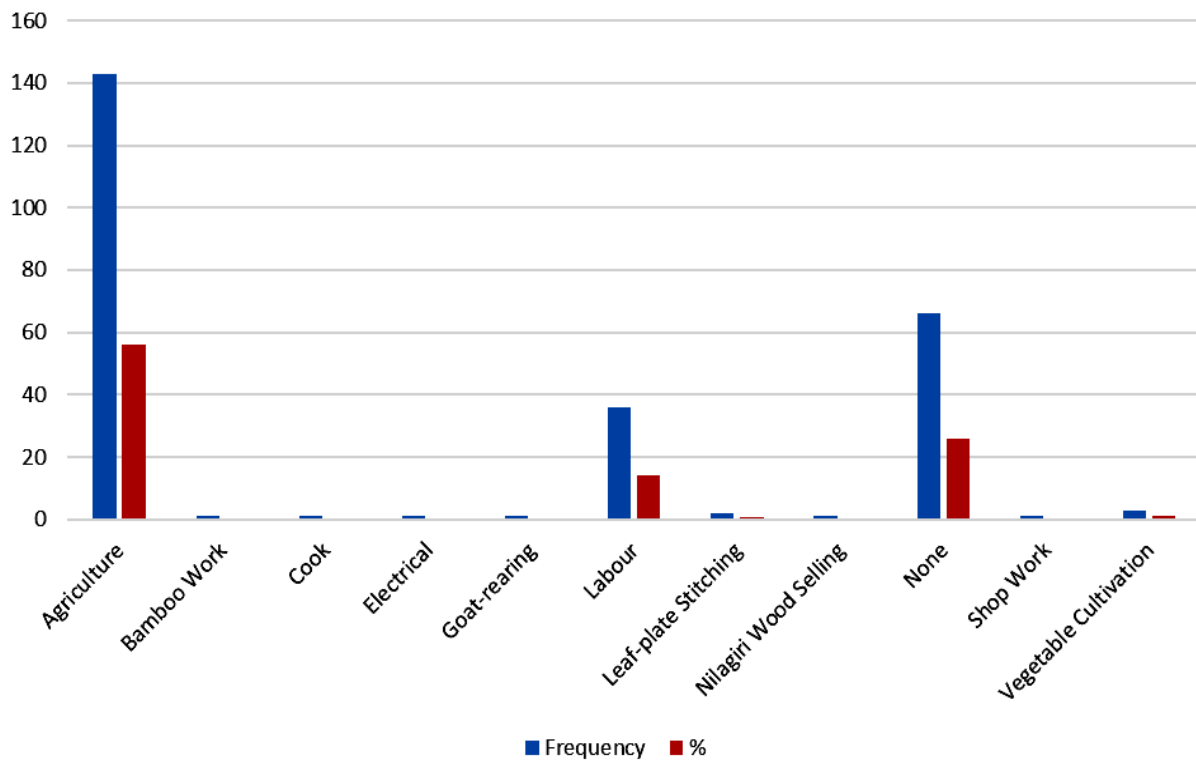
Reason for not receiving treatment	Frequency (N=94)	%
Not willing to get treatment	2	2.1%
Did not know about treatment places	7	7.4%
Treatment places far away from the village	7	7.4%
There was no carer to look after their relative	4	4.3%
Family has no money for treatment	74	78.7%
Other	0	0.0%



*Out of the 94 carers who did not receive treatment for their health issue, the majority (78.7%) did not seek treatment because their family had no money for treatment.*

### Q20. What skills/experience does the carer have?

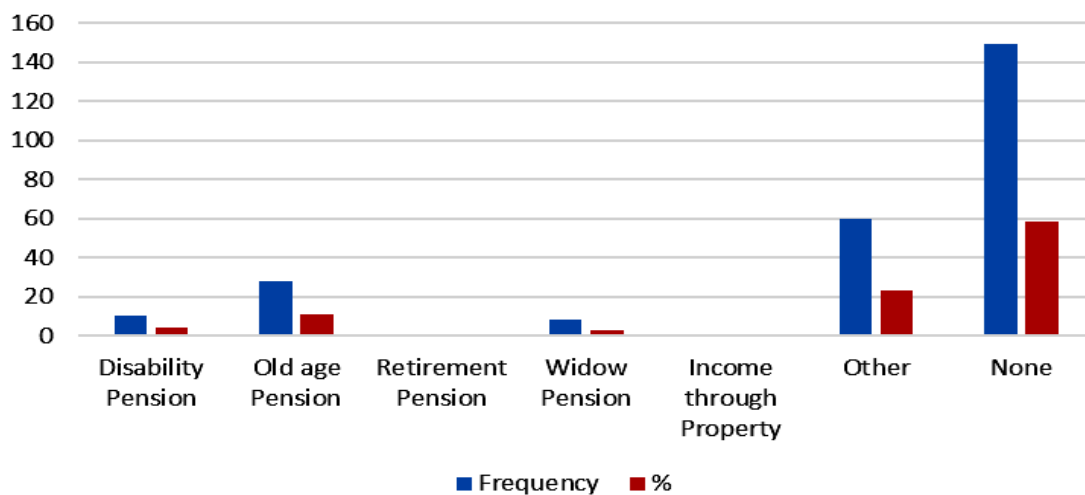
Skill/Experience	Frequency (N=256)	%
Agriculture	143	55.9%
Bamboo Work	1	0.4%
Cook	1	0.4%
Electrical	1	0.4%
Goat-rearing	1	0.4%
Labour	36	14.1%
Leaf-plate Stitching	2	0.8%
Nilagiri Wood Selling	1	0.4%
None	66	25.8%
Shop Work	1	0.4%
Vegetable Cultivation	3	1.2%



The majority of carers (55.9%) of carers surveyed had agricultural skills/experience. A total of 25.8% of carers surveyed reported having no skills/experience

### Q21. What other income does the carer have?

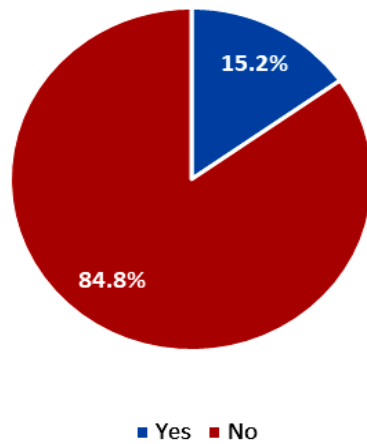
Other Income	Frequency (N=256)	%
Disability Pension	10	3.9%
Old age Pension	28	10.9%
Retirement Pension	1	0.4%
Widow Pension	8	3.1%
Income through Property	0	0.0%
Other	60	23.4%
None	149	58.2%



The majority of carers (58.2%) surveyed had no other income.

### Q22. Is the carer a member of an SHG?

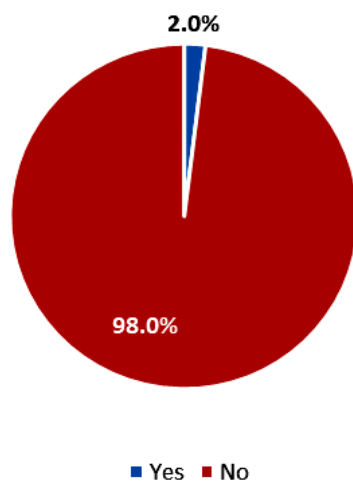
SHG Member	Frequency (N=256)	%
Yes	39	15.2%
No	217	84.8%



The majority of carers (84.8%) surveyed were not a member of a SHG.

### Q23. Is the carer a member of their community?

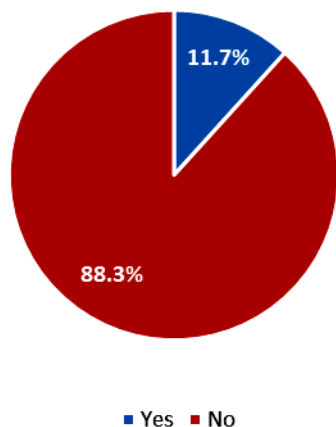
Community Member	Frequency (N=256)	%
Yes	5	2.0%
No	251	98.0%



The majority of carers (98.0%) surveyed were not a member of their community.

### Q24. Has the carer taken a loan?

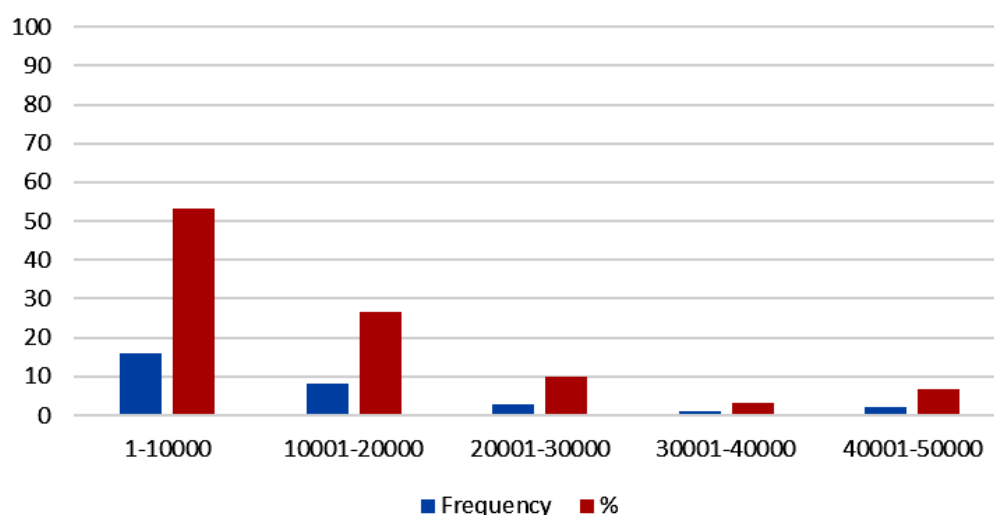
Loan Taken	Frequency (N=256)	%
Yes	30	11.7%
No	226	88.3%



The majority of carers (88.3%) surveyed had not taken a loan.

### Q25. For carers who have taken a loan, what was the value of the loan?

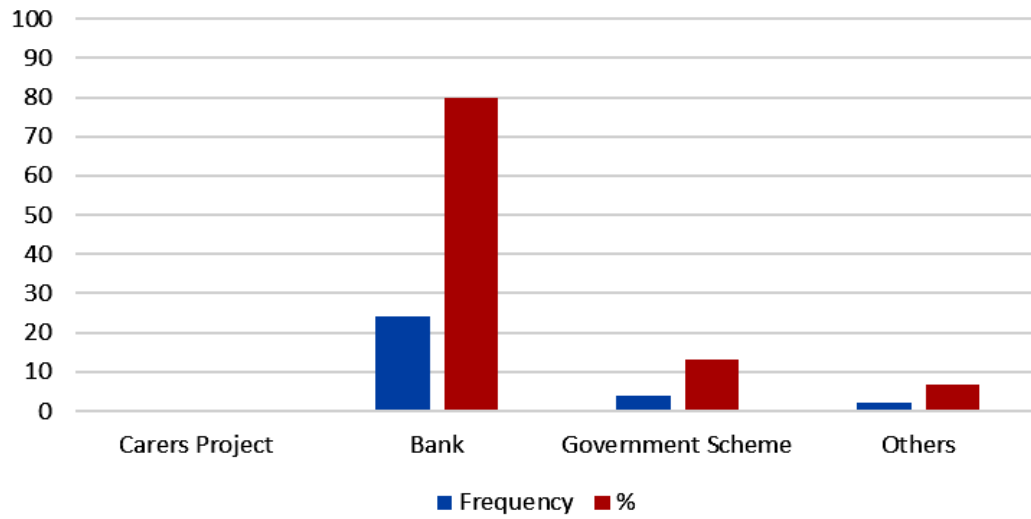
Loan Amount	Frequency (N=30)	%
1-10000	16	53.3%
10001-20000	8	26.7%
20001-30000	3	10.0%
30001-40000	1	3.3%
40001-50000	2	6.7%



Out of the 30 carers who had taken a loan, the majority (53.3%) borrowed under 10,000 rupees.

**Q26. For carers who had taken a loan, what was the source of the loan?**

Source of Loan	Frequency (N=30)	%
Carers Project	0	0.0%
Bank	24	80.0%
Government Scheme	4	13.3%
Others	2	6.7%

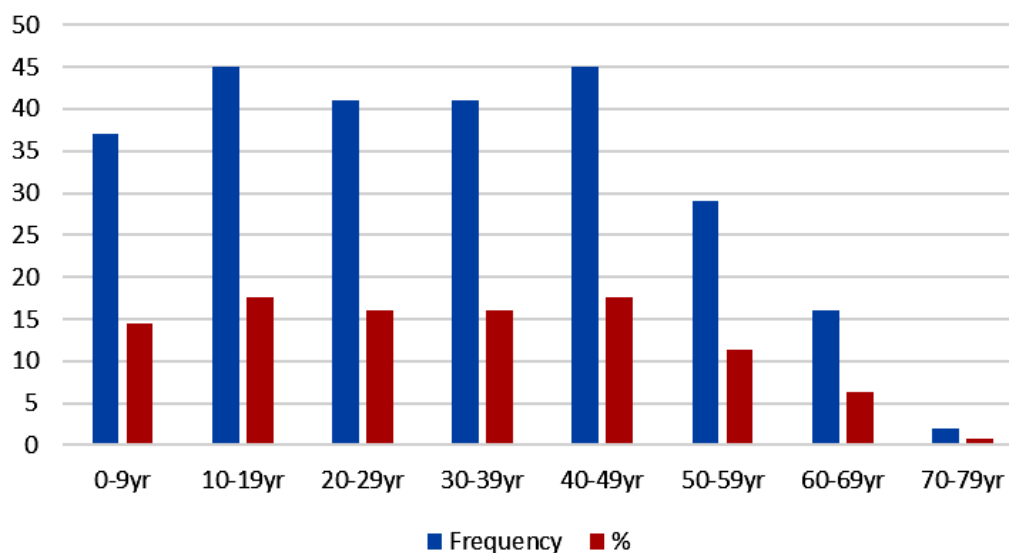


*Out of the 30 carers who had taken a loan, the majority (80.0%) borrowed from a bank.*

## Part II - Questions about the Person Cared for

### Q27. What is the age of the person cared for?

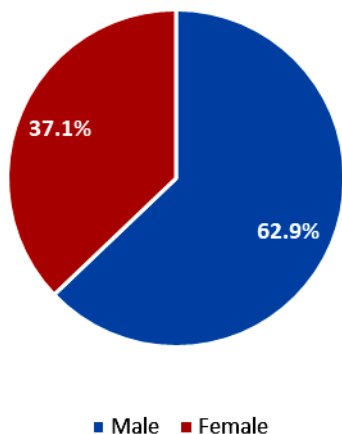
Age of Person Cared for	Frequency (N=256)	%
0-9yr	37	14.5%
10-19yr	45	17.6%
20-29yr	41	16.0%
30-39yr	41	16.0%
40-49yr	45	17.6%
50-59yr	29	11.3%
60-69yr	16	6.3%
70-79yr	2	0.8%



The age of the person cared for was varied. 17.6% were aged 10 to 19 years old. 17.6% were aged 40 to 49 years old. 16.0% were aged 20 to 29 years old. 16.0% were aged 30 to 39 years old. 14.5% were age 0 to 9 years old. 11.3% were aged 50 to 50 years old. 6.3% were aged 60 to 69 years old. 0.8% were aged between 70 to 79 years old.

### Q27. What is the gender of the person cared for?

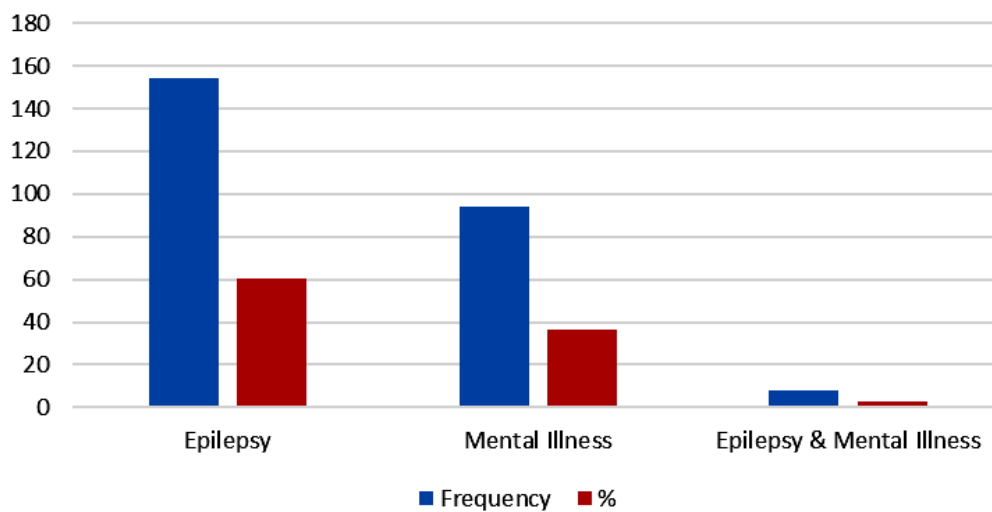
Gender	Frequency (Number = 256)	%
Male	161	62.9%
Female	95	37.1%



The majority of persons cared for (62.9%) in this survey were male.

### Q29. What is the condition of the person cared for?

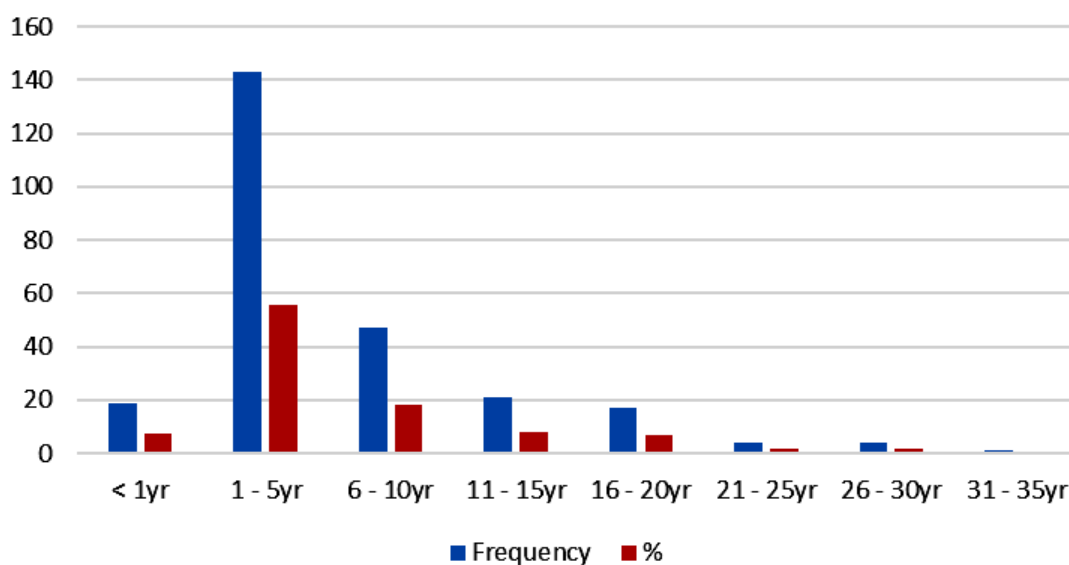
Condition	Frequency (N=256)	%
Epilepsy	154	60.2%
Mental Illness	94	36.7%
Epilepsy & Mental Illness	8	3.1%



The majority of persons cared for (60.2%) in this survey had epilepsy. 36.7% had mental illness. 3.1% had both epilepsy and mental illness.

### Q30. What is the duration of the condition of the person cared for?

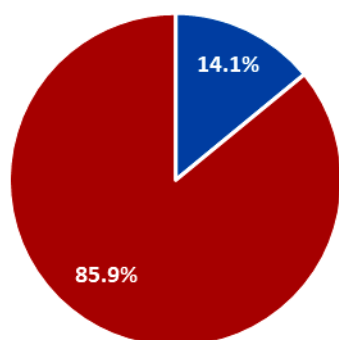
Duration	Frequency (N=256)	%
< 1yr	19	7.4%
1 - 5yr	143	55.9%
6 - 10yr	47	18.4%
11 - 15yr	21	8.2%
16 - 20yr	17	6.6%
21 - 25yr	4	1.6%
26 - 30yr	4	1.6%
31 - 35yr	1	0.4%



The majority of persons cared for (55.9%) in this survey had their condition(s) for between 1 to 5 years. 18.4% had their condition(s) for 6 to 10 years.

### Q31. Is the person cared for earning?

Earning	Frequency (N=256)	%
Yes	36	14.1%
No	220	85.9%

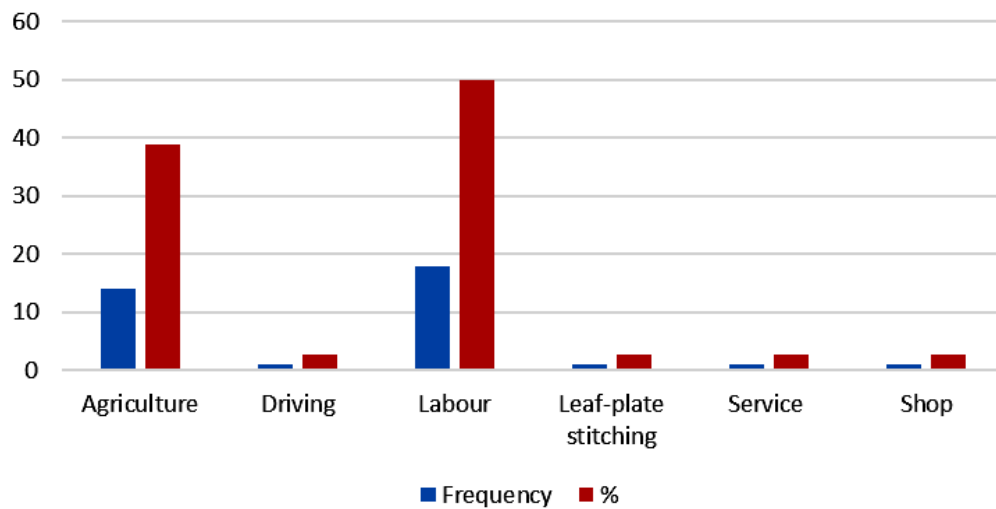


■ Yes ■ No

The majority of persons cared for (85.9%) in this survey are not earning an income.

**Q32. If the person cared for is earning, what type of work do they do?**

Type of Work	Frequency (N=36)	%
Agriculture	14	38.9%
Driving	1	2.8%
Labour	18	50.0%
Leaf-plate stitching	1	2.8%
Service	1	2.8%
Shop	1	2.8%

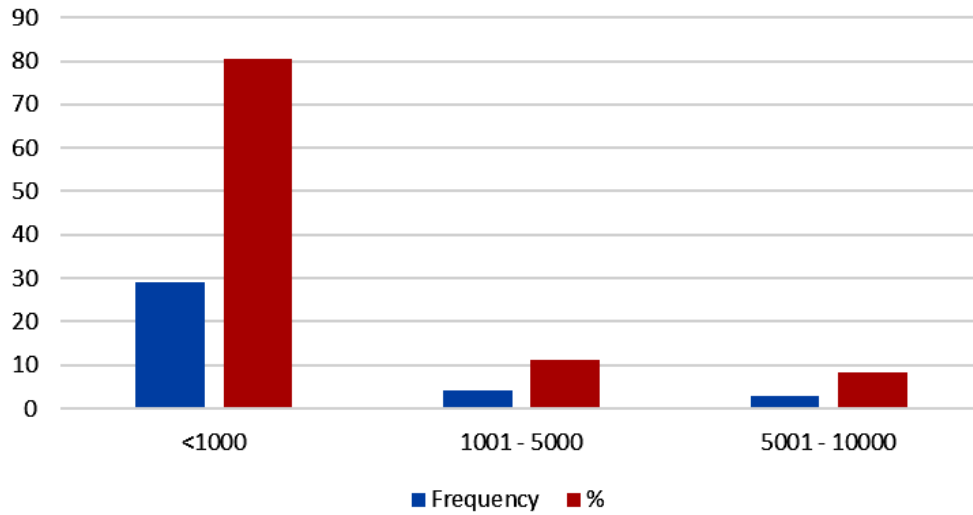


Out of the 36 persons cared for in this survey who are earning an income, 50% of those work as labourers and 38.9% work in agriculture. The remaining work as drivers, leaf-plate stitchers, as service providers or shop workers.

**Q33. If the person cared for is earning, what is their monthly income?**

Income (Rs)	Frequency (N=36)	%
<1000	29	80.6%
1001 - 5000	4	11.1%
5001 - 10000	3	8.3%

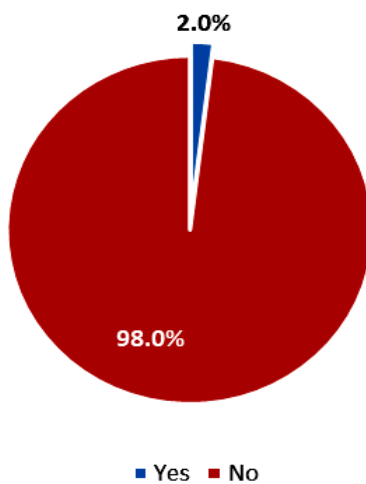
### Income per Month



Out of the 36 persons cared for in this survey who are earning an income, the majority (80.6%) earn less than 1000 rupees per month.

### Q33. Is the person cared for a member of an SHG?

SHG Member	Frequency (N=256)	%
Yes	5	2.0%
No	251	98.0%



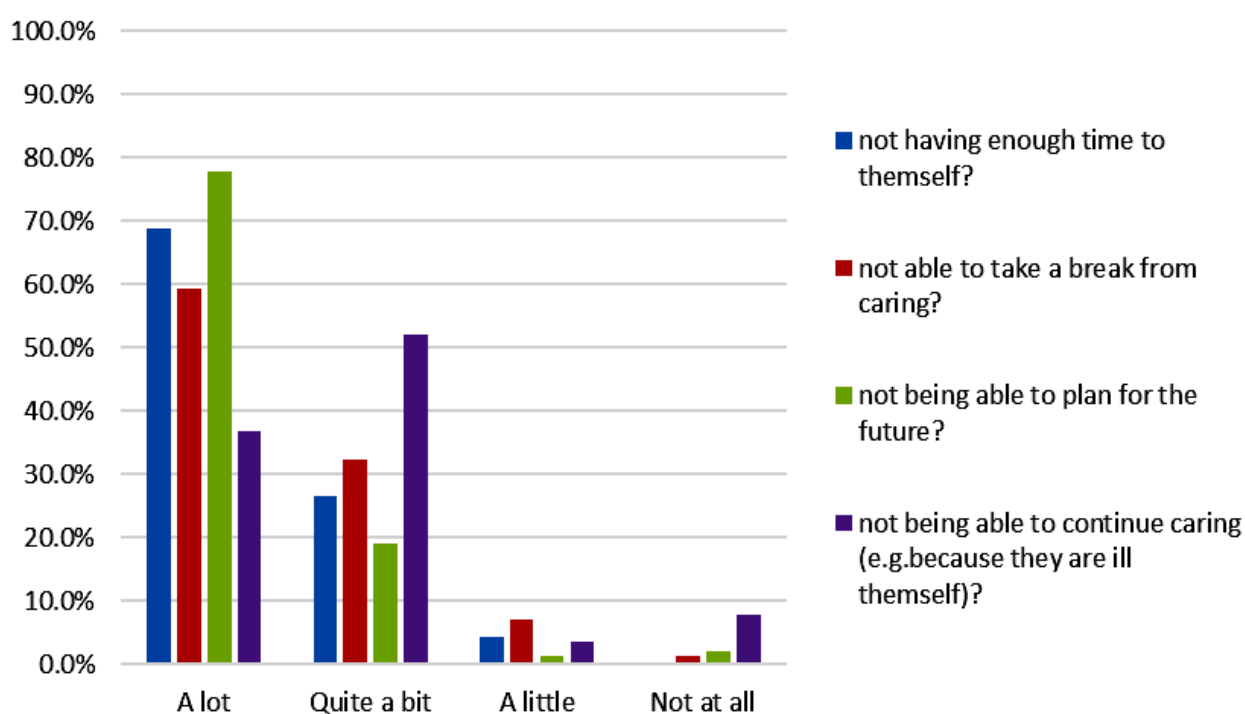
The majority of persons cared for (98.0%) in this survey are not a member of an SHG.

## Part III - Questions about the Wellbeing of the Carer

**Q35. How concerned is the carer about:**

- a. Not having enough time to themselves?
- b. Not being able to take a break from caring?
- c. Not being able to plan for the future?
- d. Not being able to continue caring (e.g. because they are ill themselves)?

How Concerned is the Carer about:	Response	Frequency (N=256)	%
not having enough time to themselves?	A lot	176	68.8%
	Quite a bit	68	26.6%
	A little	11	4.3%
	Not at all	1	0.4%
not able to take a break from caring?	A lot	152	59.4%
	Quite a bit	83	32.4%
	A little	18	7.0%
	Not at all	3	1.2%
not being able to plan for the future?	A lot	199	77.7%
	Quite a bit	49	19.1%
	A little	3	1.2%
	Not at all	5	2.0%
not being able to continue caring (e.g. because they are ill themselves)?	A lot	94	36.7%
	Quite a bit	133	52.0%
	A little	9	3.5%
	Not at all	20	7.8%

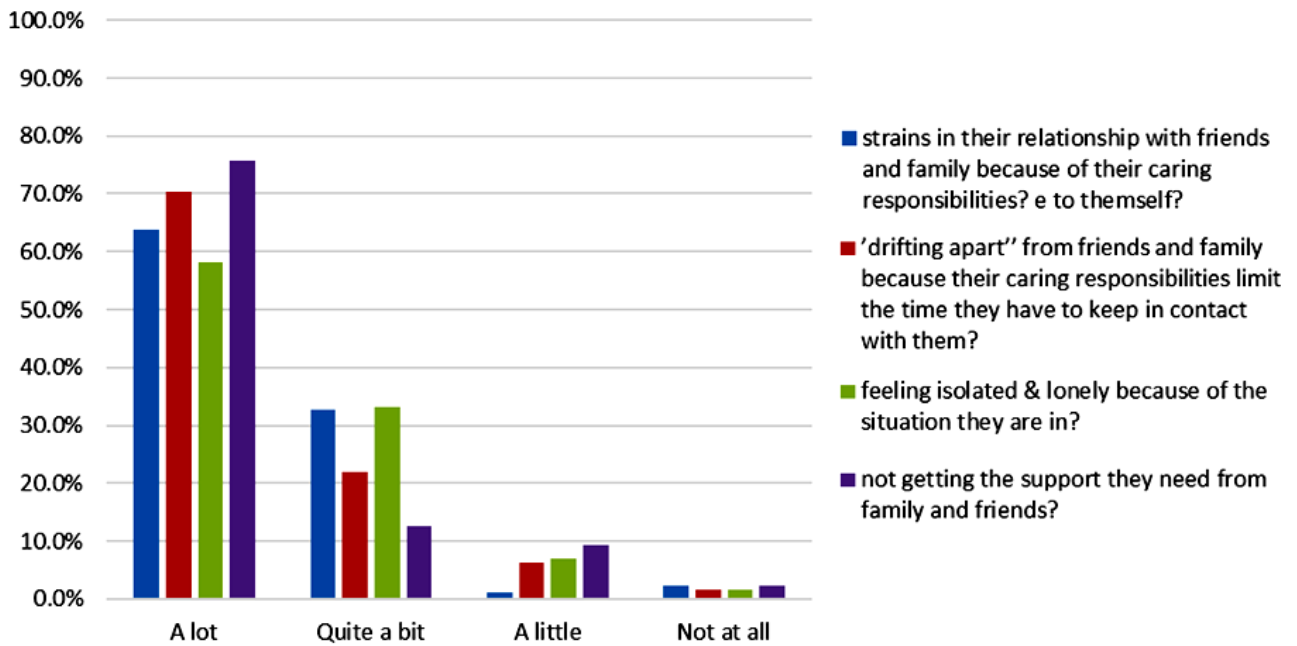


The majority of carers surveyed were concerned (either a lot or quite a bit) about: not having enough time to themselves (95.4%); not being able to take a break from caring (91.8%); not being able to plan for the future (96.8%); not being able to continue caring (e.g. because they are ill themselves?) (88.7%).

**Q36. How concerned is the carer about:**

- a. strains in their relationship with friends and family because of their caring responsibilities?**
- b. 'drifting apart' from friends and family because their caring responsibilities limit the time they have to keep in contact with them?**
- c. feeling isolated & lonely because of the situation they are in?**
- d. not getting the support they need from family and friends?**

<b>How Concerned is the Carer about:</b>	<b>Response</b>	<b>Frequency (N=256)</b>	<b>%</b>
strains in their relationship with friends and family because of their caring responsibilities?	A lot	163	63.7%
	Quite a bit	84	32.8%
	A little	3	1.2%
	Not at all	6	2.3%
'drifting apart' from friends and family because their caring responsibilities limit the time they have to keep in contact with them?	A lot	180	70.3%
	Quite a bit	56	21.9%
	A little	16	6.3%
	Not at all	4	1.6%
feeling isolated & lonely because of the situation they are in?	A lot	149	58.2%
	Quite a bit	85	33.2%
	A little	18	7.0%
	Not at all	4	1.6%
not getting the support they need from family and friends?	A lot	194	75.8%
	Quite a bit	32	12.5%
	A little	24	9.4%
	Not at all	6	2.3%

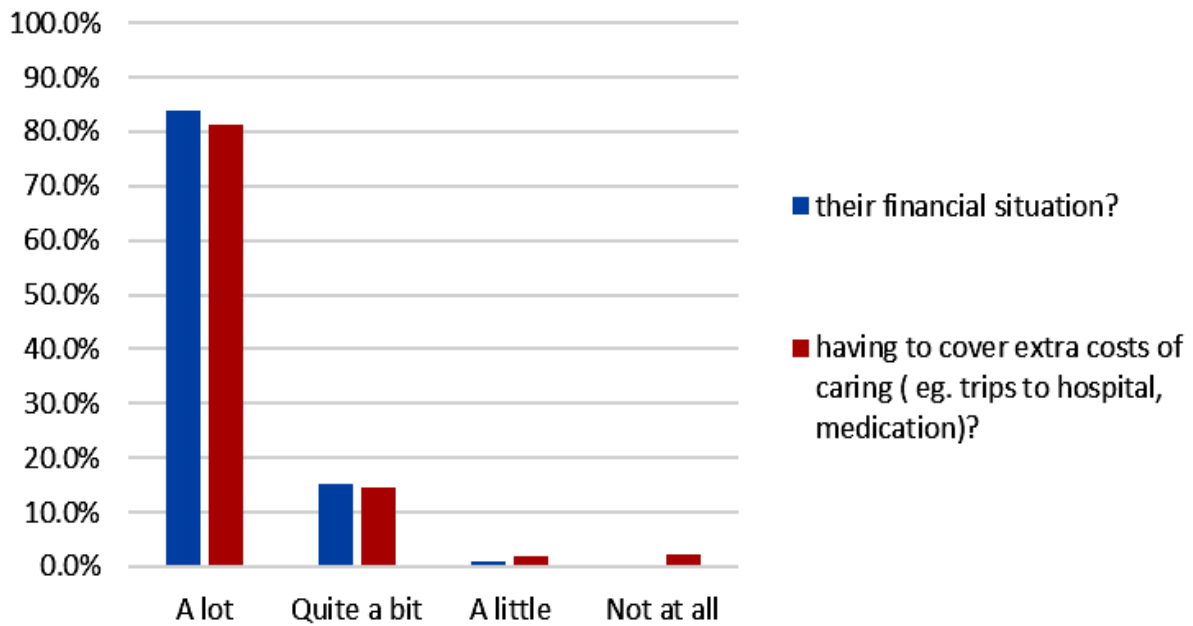


The majority of carers surveyed were concerned (either a lot or quite a bit) about: strains in their relationship with friends and family because of their caring responsibilities (96.5%); 'drifting apart' from friends and family because their caring responsibilities limit the time they have to keep in contact with them (92.2%); feeling isolated & lonely because of the situation they are in (91.4%); not getting the support they need from family and friends (88.3%).

**Q37. How concerned is the carer about:**

- a. Their financial situation?
- b. Having to cover extra costs of caring (e.g. trips to hospital, medication)?

How Concerned is the Carer about:	Response	Frequency (N=256)	%
their financial situation?	A lot	215	84.0%
	Quite a bit	39	15.2%
	A little	2	0.8%
	Not at all	0	0.0%
having to cover extra costs of caring ( eg. trips to hospital, medication)?	A lot	208	81.3%
	Quite a bit	37	14.5%
	A little	5	2.0%
	Not at all	6	2.3%

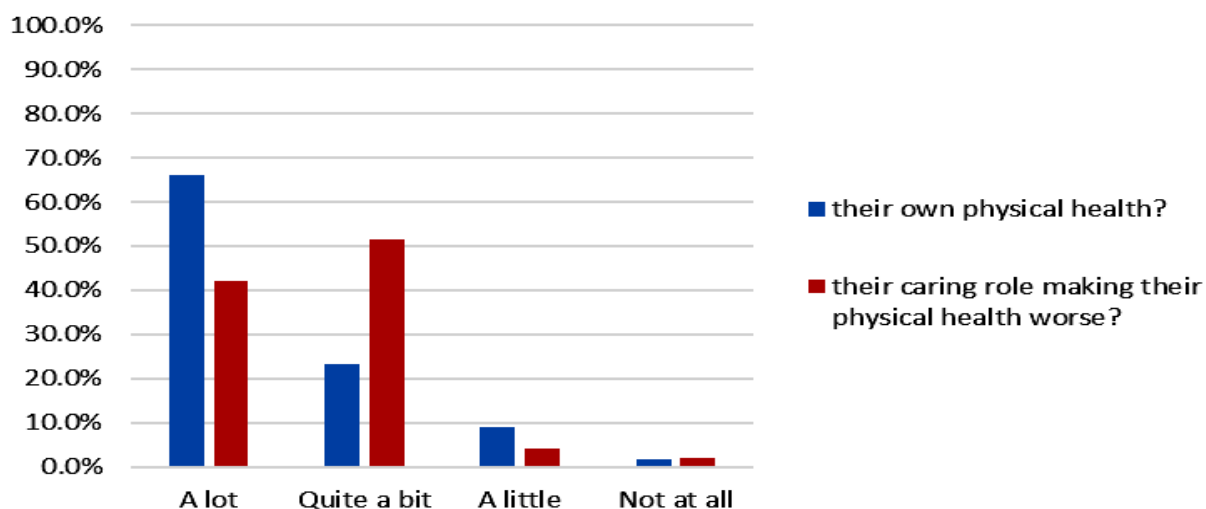


The majority of carers surveyed were concerned (either a lot or quite a bit) about: their financial situation (99.2%); having to cover extra costs of caring (e.g. trips to hospital, medication) (95.8%).

**Q38. How concerned is the carer about:**

- a. Their own physical health?
- b. Their caring role making their physical health worse?

How Concerned is the Carer about:	Response	Frequency (N=256)	%
their own physical health?	A lot	169	66.0%
	Quite a bit	60	23.4%
	A little	23	9.0%
	Not at all	4	1.6%
their caring role making their physical health	A lot	108	42.2%
	Quite a bit	132	51.6%
	A little	11	4.3%
	Not at all	5	2.0%

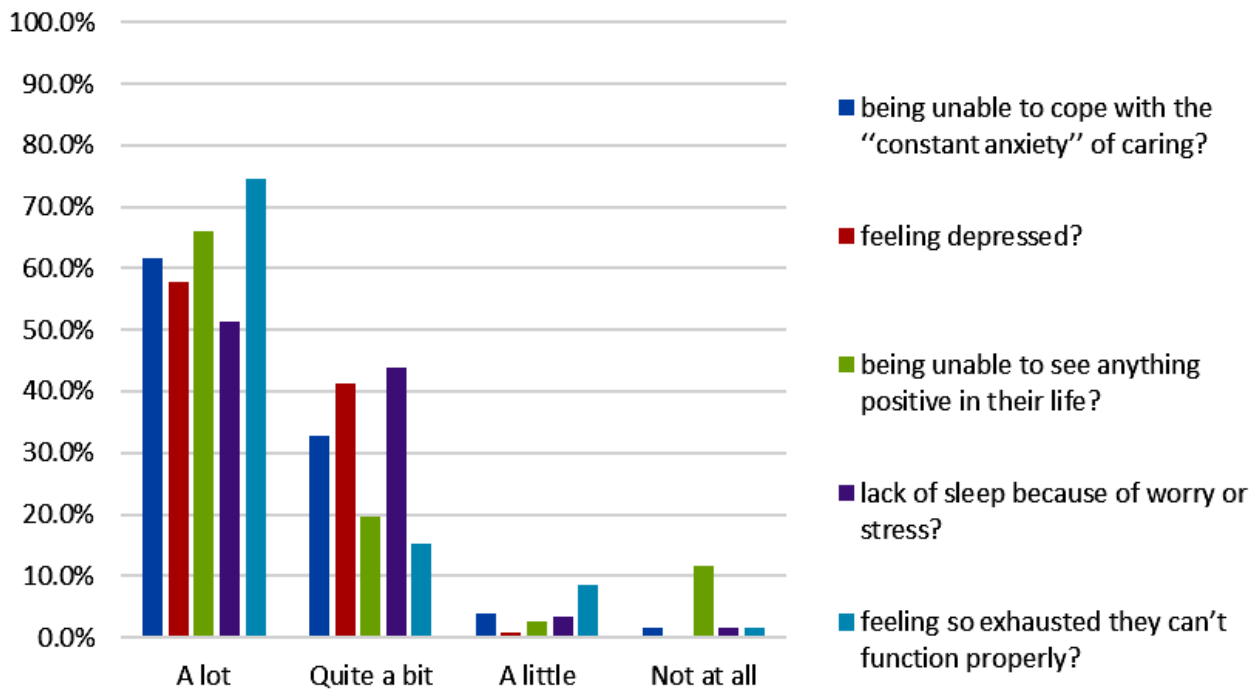


The majority of carers surveyed were concerned (either a lot or quite a bit) about: their physical health (89.4%); their caring role making their physical health worse (93.8%).

**Q39. How concerned is the carer about:**

- Being unable to cope with the “constant anxiety of caring”?
- Feeling depressed?
- Being unable to see anything positive in their life?
- Lack of sleep because of worry or stress?
- Feeling so exhausted they can’t function properly?

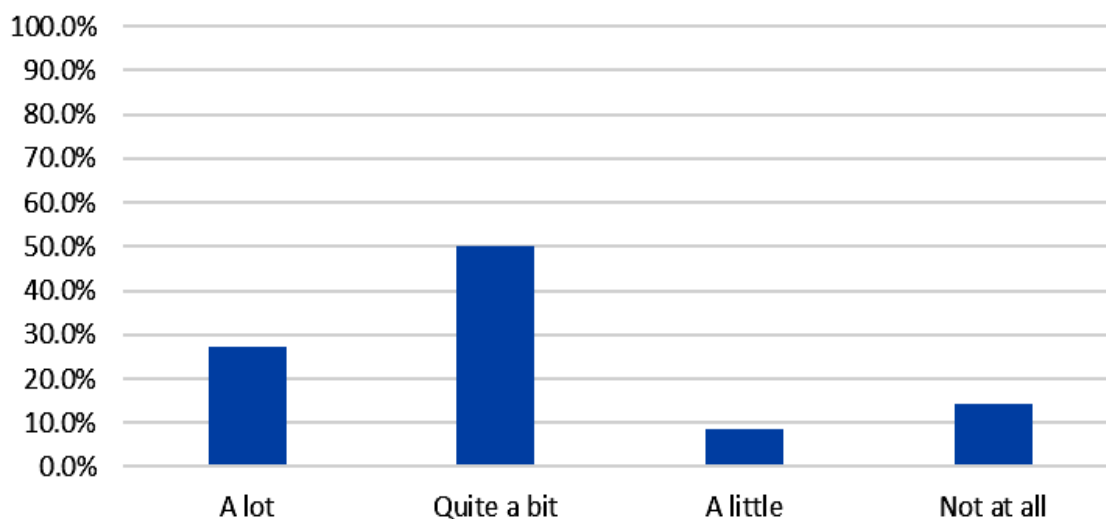
How Concerned is the Carer about:	Response	Frequency (N=256)	%
being unable to cope with the “constant anxiety”	A lot	158	61.7%
	Quite a bit	84	32.8%
	A little	10	3.9%
	Not at all	4	1.6%
feeling depressed?	A lot	148	57.8%
	Quite a bit	106	41.4%
	A little	2	0.8%
	Not at all	0	0.0%
being unable to see anything positive in their life?	A lot	169	66.0%
	Quite a bit	50	19.5%
	A little	7	2.7%
	Not at all	30	11.7%
lack of sleep because of worry or stress?	A lot	131	51.2%
	Quite a bit	112	43.8%
	A little	9	3.5%
	Not at all	4	1.6%
feeling so exhausted they can’t function properly?	A lot	191	74.6%
	Quite a bit	39	15.2%
	A little	22	8.6%
	Not at all	4	1.6%



The majority of carers surveyed were concerned (either a lot or quite a bit) about: being unable to cope with the “constant anxiety of caring” (94.5%); feeling depressed (99.2%); being unable to see anything positive in their life (85.5%); lack of sleep because of worry or stress (95.0%); feeling so exhausted they can't function properly (89.8%).

**Q40. How concerned is the carer about people treating them differently because of the illness or condition of the person they care for?**

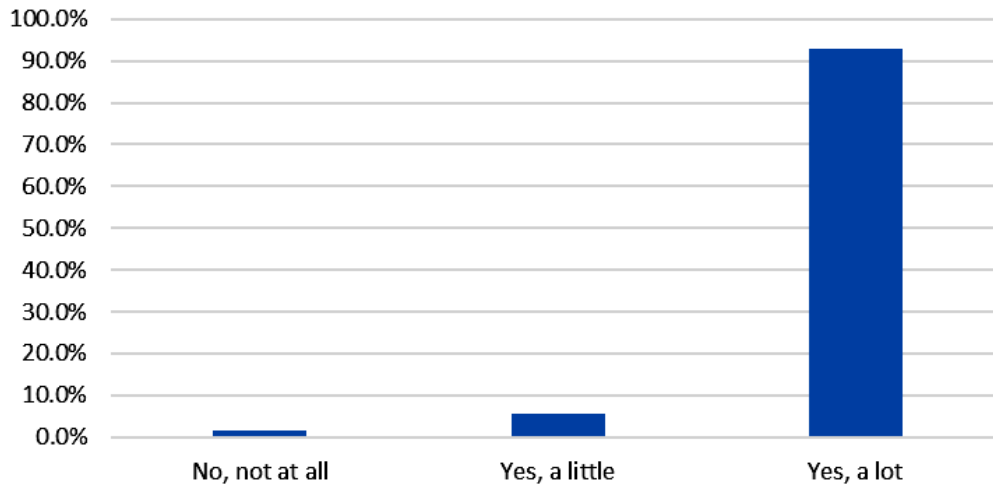
Response	Frequency (N=256)	%
A lot	70	27.3%
Quite a bit	128	50.0%
A little	22	8.6%
Not at all	36	14.1%



The majority of carers surveyed were concerned (either a lot or quite a bit) about people treating them differently because of the illness or condition of the person they care for (77.3%).

**Q41. Would the carer like more support or help in their role as a carer?**

Response	Frequency (N=256)	%
No, not at all	4	1.6%
Yes, a little	14	5.5%
Yes, a lot	238	93.0%



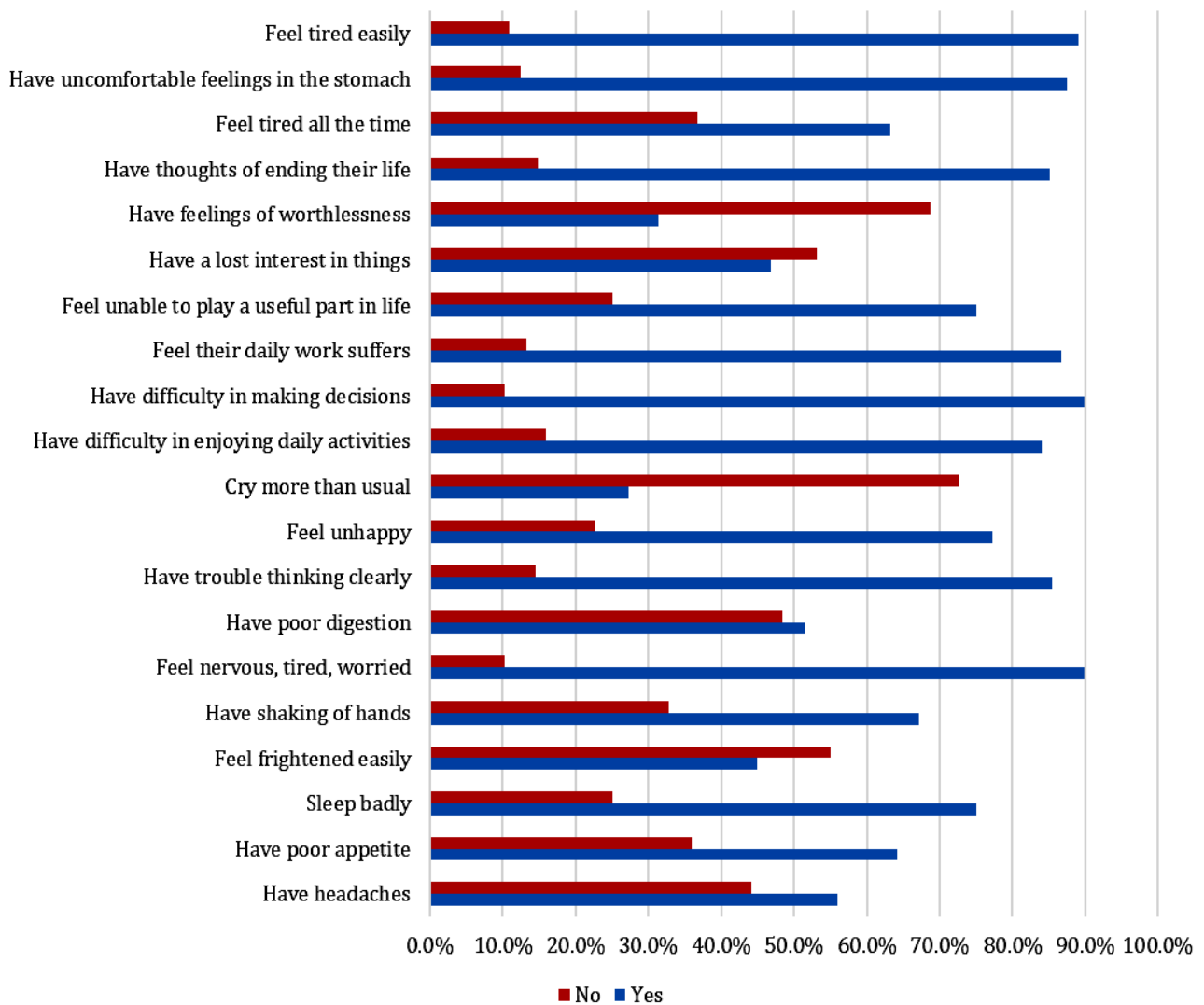
The majority of carers surveyed would like more support or help in their role as a carer, a lot (93.0%). 5.5% would like more support or help, a little (5.5%). 1.6% of carers would not like more support or help in their role as a carer.

## Part IV - Questions about the Health of the Carer

Q42. Does the carer:

- a. Feel tired easily?
- b. Have uncomfortable feelings in the stomach?
- c. Feel tired all the time?
- d. Have thoughts of ending their life?
- e. Have feelings of worthlessness?
- f. Have a lost interest in things?
- g. Feel unable to play a useful part in life?
- h. Feel their daily work suffers?
- i. Have difficulty in making decisions?
- j. Have difficulty in enjoying daily activities?
- k. Cry more than usual?
- l. Feel unhappy?
- m. Have trouble thinking clearly?
- n. Have poor digestion?
- o. Feel nervous, tired, worried?
- p. Have shaking of the hands?
- q. Feel frightened easily?
- r. Sleep badly?
- s. Have poor appetite?
- t. Have headaches?

<b>Does the Carer:</b>	<b>Response</b>	<b>Frequency (N=256)</b>	<b>%</b>
Feel tired easily	Yes	228	89.1%
	No	28	10.9%
Have uncomfortable feelings in the stomach	Yes	224	87.5%
	No	32	12.5%
Feel tired all the time	Yes	162	63.3%
	No	94	36.7%
Have thoughts of ending their life	Yes	218	85.2%
	No	38	14.8%
Have feelings of worthlessness	Yes	80	31.3%
	No	176	68.8%
Have a lost interest in things	Yes	120	46.9%
	No	136	53.1%
Feel unable to play a useful part in life	Yes	192	75.0%
	No	64	25.0%
Feel their daily work suffers	Yes	222	86.7%
	No	34	13.3%
Have difficulty in making decisions	Yes	230	89.8%
	No	26	10.2%
Have difficulty in enjoying daily activities	Yes	215	84.0%
	No	41	16.0%
Cry more than usual	Yes	70	27.3%
	No	186	72.7%
Feel unhappy	Yes	198	77.3%
	No	58	22.7%
Have trouble thinking clearly	Yes	219	85.5%
	No	37	14.5%
Have poor digestion	Yes	132	51.6%
	No	124	48.4%
Feel nervous, tired, worried	Yes	230	89.8%
	No	26	10.2%
Have shaking of hands	Yes	172	67.2%
	No	84	32.8%
Feel frightened easily	Yes	115	44.9%
	No	141	55.1%
Sleep badly	Yes	192	75.0%
	No	64	25.0%
Have poor appetite	Yes	164	64.1%
	No	92	35.9%
Have headaches	Yes	143	55.9%
	No	113	44.1%



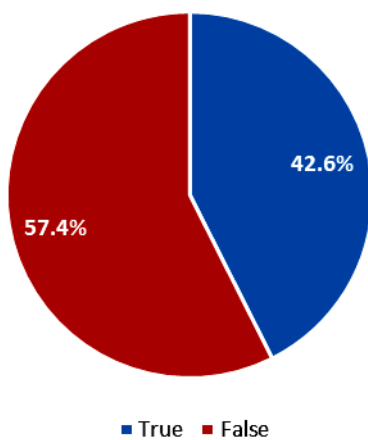
*The carers surveyed reported in the affirmative that they had or felt all of the listed conditions except feelings of worthlessness (31.3%); having a lost interest in things (46.9%); crying more than usual (27.3%); and feeling frightened easily (44.9%). 89.1% of respondents felt tired easily. 87.5% of respondents had uncomfortable feelings in the stomach. 85.2% of carers had thoughts of ending their life. 75% of carers felt unable to play a useful part in life. 86.7% of carers felt their daily work suffers. 89.8% of carers had difficulty in making decisions. 84.0% of carers had difficulty in enjoying daily activities. 77.3% of carers felt unhappy. 85.5% of carers had trouble thinking clearly. 51.6% of carers had poor digestion. 89.8% of carers felt nervous, tired, worried. 67.2% of carers had shaking of the hands. 75.0% of carers slept badly. 64.1% of carers had poor appetite. 55.9% of carers had headaches.*

## Part V - Questions about Epilepsy

This part of the survey asked carers about their knowledge on epilepsy.

### Q43. “Epilepsy and mental illness are often referred to as poverty related disorders”

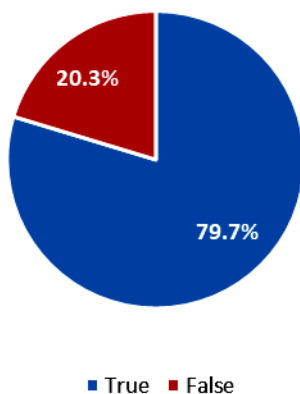
Response	Frequency (N=256)	%
True	109	42.6%
False	147	57.4%



The majority of carers (57.4%) surveyed thought it was false that epilepsy and mental illness are often referred to as poverty related disorders. 42.6% of carers surveyed thought this statement was true.

### Q44. “Epileptic fits can be controlled by taking medication regularly”

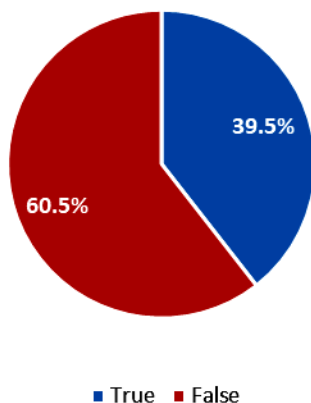
Response	Frequency (N=256)	%
True	204	79.7%
False	52	20.3%



The majority of carers (79.7%) surveyed thought it was true that epileptic fits can be controlled by taking medication regularly. 20.3% of carers thought that it was false that epileptic fits can be controlled by taking medication regularly.

**Q45. “Anti-epileptic drugs can be stopped after two years of ‘fit-free’ period in majority of patients”**

Response	Frequency (N=256)	%
True	101	39.5%
False	155	60.5%



The majority of carers (60.5%) surveyed thought it was false that anti-epileptic drugs can be stopped after two years of ‘fit-free’ period in majority of patients. 39.5% of carers thought it was true that anti-epileptic drugs can be stopped after two years of ‘fit-free’ period in majority of patients.

# SURVEY RESULTS SUMMARY

## Carers

- Majority of the carers (71.9%) surveyed were female.
- Majority of the carers (67.5%) surveyed were between 27 to 53 years old. 26.6% of carers surveyed were 27 to 35 years old. 20.7% of carers surveyed were 45 to 53 years old. 19.9% of carers surveyed were 36 to 44 years old.
- Majority of the carers (96.5%) surveyed were married.
- Majority of carers (79.3%) surveyed were living within a nuclear (non-extended) family.
- Out of all the responses, it was most frequent (27.0%) for carers to live in households with 5 members.
- The majority of carers (71.9%) surveyed look after their spouse or their child. 34.8% of carers surveyed care for their spouse whilst 37.1% care for their child.
- The majority of carers (98.4%) surveyed have an ID card.
- Out of the 252 carers who have an ID card, 98.8% of those have the Aadhaar Card.
- The majority of carers (86.3%) surveyed were uneducated. Only 1.6% of the carers surveyed had completed 12th grade.
- All of the carers (100%) surveyed are not currently in education.
- The majority of carers (61.4%) surveyed are employed. 33.2% of carers surveyed are employed as labourers whilst 25.4% of carers surveyed are employed in agriculture. However, a total of 38.7% of carers surveyed were not in any employment.
- The majority of carers (67.5%) surveyed who were earning an income earned between 100 to 1000 rupees per month. 23.6% of the carers earning an income earned between 1001 to 2000 rupees per month.
- Of the 99 carers surveyed who were not working the majority of those (74.7%) were not in employment as they could not find anyone else to take care of the person they cared for.
- The majority of carers (52.7%) surveyed reported having a health issue.
- Out of the 135 carers who reported having a health issue, the most frequently reported health issue was headache (34.8%) followed by body pain (20.7%).
- Out of the 135 carers who reported having a health issue, the majority (69.6%) had not received support/treatment for their condition.
- Out of the 41 carers who did receive support/treatment, all of those (100.0%) received medical treatment.
- Out of the 94 carers who did not receive treatment for their health issue, the majority (78.7%) did not seek treatment because their family had no money for treatment.
- The majority of carers (55.9%) of carers surveyed had agricultural skills/experience. A total of 25.8% of carers surveyed reported having no skills/experience.
- The majority of carers (58.2%) surveyed had no other income.
- The majority of carers (84.8%) surveyed were not a member of a SHG.

### **Carers (Continued)**

- The majority of carers (88.3%) surveyed had not taken a loan.
- Out of the 30 carers who had taken a loan, the majority (53.3%) borrowed under 10,000 rupees.
- Out of the 30 carers who had taken a loan, the majority (80.0%) borrowed from a bank.

### **Persons Cared for**

- The age of the person cared for was varied. 17.6% were aged 10 to 19 years old. 17.6% were aged 40 to 49 years old. 16.0% were aged 20 to 29 years old. 16.0% were aged 30 to 39 years old. 14.5% were age 0 to 9 years old. 11.3% were aged 50 to 50 years old. 6.3% were aged 60 to 69 years old. 0.8% were aged between 70 to 79 years old.
- The majority of persons cared for (62.9%) in this survey were male.
- The majority of persons cared for (60.2%) in this survey had epilepsy. 36.7% had mental illness. 3.1% had both epilepsy and mental illness.
- The majority of persons cared for (55.9%) in this survey had their condition(s) for between 1 to 5 years. 18.4% had their condition(s) for 6 to 10 years.
- The majority of persons cared for (85.9%) in this survey are not earning an income.
- Out of the 36 persons cared for in this survey who are earning an income, 50% of those work as labourers and 38.9% work in agriculture. The remaining work as drivers, leaf-plate stitchers, as service providers or shop workers.
- Out of the 36 persons cared for in this survey who are earning an income, the majority (80.6%) earn less than 1000 rupees per month.
- The majority of persons cared for (98.0%) in this survey are not a member of an SHG.

### **Wellbeing of Carers**

- The majority of carers surveyed were concerned (either a lot or quite a bit) about: not having enough time to themselves (95.4%); not being able to take a break from caring (91.8%); not being able to plan for the future (96.8%); not being able to continue caring (e.g. because they are ill themselves?) (88.7%).
- The majority of carers surveyed were concerned (either a lot or quite a bit) about: strains in their relationship with friends and family because of their caring responsibilities (96.5%); 'drifting apart' from friends and family because their caring responsibilities limit the time they have to keep in contact with them (92.2%); feeling isolated & lonely because of the situation they are in (91.4%); not getting the support they need from family and friends (88.3%).
- The majority of carers surveyed were concerned (either a lot or quite a bit) about: their financial situation (99.2%); having to cover extra costs of caring (e.g. trips to hospital, medication) (95.8%).
- The majority of carers surveyed were concerned (either a lot or quite a bit) about: their physical health (89.4%); their caring role making their physical health worse (93.8%).

### **Wellbeing of Carers (Continued)**

- The majority of carers surveyed were concerned (either a lot or quite a bit) about: being unable to cope with the “constant anxiety of caring” (94.5%); feeling depressed (99.2%); being unable to see anything positive in their life (85.5%); lack of sleep because of worry or stress (95.0%); feeling so exhausted they can’t function properly (89.8%).
- The majority of carers surveyed were concerned (either a lot or quite a bit) about people treating them differently because of the illness or condition of the person they care for (77.3%).
- The majority of carers surveyed would like more support or help in their role as a carer, a lot (93.0%). 5.5% would like more support or help, a little (5.5%). 1.6% of carers would not like more support or help in their role as a carer.

### **Health of Carers**

- The carers surveyed reported in the affirmative that they had or felt all of the listed conditions except feelings of worthlessness (31.3%); having a lost interest in things (46.9%); crying more than usual (27.3%); and feeling frightened easily (44.9%). 89.1% of respondents felt tired easily. 87.5% of respondents had uncomfortable feelings in the stomach. 85.2% of carers had thoughts of ending their life. 75% of carers felt unable to play a useful part in life. 86.7% of carers felt their daily work suffers. 89.8% of carers had difficulty in making decisions. 84.0% of carers had difficulty in enjoying daily activities. 77.3% of carers felt unhappy. 85.5% of carers had trouble thinking clearly. 51.6% of carers had poor digestion. 89.8% of carers felt nervous, tired, worried. 67.2% of carers had shaking of the hands. 75.0% of carers slept badly. 64.1% of carers had poor appetite. 55.9% of carers had headaches.

### **Questions on Epilepsy**

- The majority of carers (57.4%) surveyed thought it was false that epilepsy and mental illness are often referred to as poverty related disorders. 42.6% of carers surveyed thought this statement was true.
- The majority of carers (79.7%) surveyed thought it was true that epileptic fits can be controlled by taking medication regularly. 20.3% of carers thought that it was false that epileptic fits can be controlled by taking medication regularly.
- The majority of carers (60.5%) surveyed thought it was false that anti-epileptic drugs can be stopped after two years of ‘fit-free’ period in majority of patients. 39.5% of carers thought it was true that anti-epileptic drugs can be stopped after two years of ‘fit-free’ period in majority of patients.

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