

Caring for Carers

Raising Awareness and Identifying Carers in Chamarajanagar District, Karnataka, India



BASELINE SURVEY | JUNE 2021

Margadarshi



Service is Our Motto



FOREWORD



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Carers are persons who devote time to support and meet the needs of family members, friends, and neighbours who live with chronic illness or disabilities. They provide physical care, social care, psychological care and other multidimensional care, as needed. In Asian countries it is expected that family members will care for persons living with disability and chronic illness, with estimates suggesting that 70% of chronically ill persons live with relatives. Carers act as a link between persons living with chronic illness or disabilities and the communities they live in so that those persons can lead as comfortable a life as possible.

Scientific research around the world has highlighted the burden of caring on carers. Despite evidence demonstrating the impact of caring on carers, previous intervention projects have tended to focus on how best to utilize carers as potential resources in care, as opposed to how best to address the needs of carers themselves.

Carers Worldwide (including Carers Worldwide India) is the quintessential organisation dedicated to improving the wellbeing of informal carers in low and middle income countries. The organisation also enables carers to stand up for their rights by bringing carers together in to community self-help groups and Associations. The ultimate vision of the organization is to create a world where each carer is recognised and in which their physical, emotional, economic and social needs are met.

To Carers Worldwide, recognition of carers includes acknowledgement and understanding of how the efforts of carers reduces a country's responsibility to provide care. State and National Agencies, including National Health Policy, needs to identify and support carers, not only because it is a carer's right as an individual to be treated with dignity, but also because of the extent to which carers relieve Governments of caring responsibilities. Carers Associations need to be invited to participate in public decisions which relate to their lives and the lives of the persons they care for.

As part of their work, Carers Worldwide is building a body of evidence that not only focuses on the burden of caring, but also on how interventions that address the specific needs of carers can transform the wellbeing of carers, families and communities as a whole. Carers Worldwide has made research an important part of their model which stems from the conviction that those affected by an issue should have the necessary evidence required to make sustainable change for themselves.

This report presents baseline data collected by Margadarshi, one of Carers Worldwide's NGO partners. Margadarshi exists to support persons living with disabilities in Bengaluru and Chamarajangar District, Karnataka State, India. Its main purpose is to help and support the most vulnerable groups of persons living with disabilities in achieving physical, social, psychological and economic wellbeing. They seek to remove the barriers imposed by disability and to instill self-belief in persons living with disabilities so that they can become responsible for their own development. Margadarshi has reached over 5,000 persons to date through of services including: Early Intervention, Medical Rehabilitation, Residential Support, Educational Support, Livelihood Training, Counseling & camp; Guidance.

By partnering with Carers Worldwide, Margadarshi has started to expand their services to not only address the needs of persons living with disabilities but also to address the needs of their carers. This study, the first of such a study in Chamarajangar District, collects and analyses baseline data on the health and wellbeing of carers. The data was collected by field workers with little research knowledge and demonstrates that research can be accessible by many and should not be exclusively for academics and experts.

This research does not stop with this report. The results of the report are to be used to create individual plans to support carers so that interventions best meet the needs of each carer. During the final evaluation of this project, baseline data will be contrasted with end of project data to measure and demonstrate the quality and effectiveness of those interventions. This evidence can then be used to encourage wider implementation of projects that promote recognition and wellbeing of carers.

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

July 2021

“Carers Worldwide is the quintessential organisation dedicated to improving the wellbeing of informal carers in low and middle income countries.”

Dr N Janardhana

ACKNOWLEDGEMENTS

I am grateful for the opportunity to work with the carers of people with disabilities in Chamarajanagar district, Karnataka State. This report is one of the results of the close collaboration between Carers Worldwide and Margadarshi. A very special thank you goes to the carers, who have graciously given their time and participated in the survey, providing us with a glimpse into their lives and the impact of caring on their own health and wellbeing.

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Finally, I am truly grateful to Margadarshi's Board of Trustees for recognising the vital role carers play in the rehabilitation and empowerment of persons with disabilities and for their commitment to supporting those carers.

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

July 2021

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ABOUT CARERS WORLDWIDE

Caring for a sick or disabled loved one can provide invaluable emotional benefits but at the same time it can take its toll on the physical, mental, social, and economic wellbeing of the person providing care. Whilst the challenges of caring are a global phenomenon, carers in low and middle income countries are particularly hard hit due to inadequate social services, limited support systems and poor healthcare provisions. Our research conducted with carers in South Asia has found that a staggering 92% of carers worry about not having enough money to meet their family's basic needs and 79% of carers experience anxiety and depression.

Founded by Anil Patil, an experienced development practitioner and himself a carer, Carers Worldwide is the only organisation working exclusively and strategically with unpaid family carers in the Global South. We act as a catalyst by promoting recognition of unpaid family carers and drawing attention to their needs. We do this at all levels with families, communities, local, national and international NGOs, service providers, academics, the corporate sector and local and national Governments across India, Nepal and Bangladesh. We also interact with other carer organisations on a global scale to promote a global change for carers.

Our core approach is simple, cost effective and replicable, involving building local partnerships which implement the 'Carers Worldwide Model.' The outcome is holistic transformation of the physical, mental, social and economic wellbeing of carers and their families.

In just nine years our work has changed the lives of over 73,000 carers and their family members in South Asia.

Notable impacts include:

- 80% of carers now earning a living and lifting their families out of poverty
- 97% of carers experiencing improved physical and mental health
- An advocacy network of 631 local carer groups, 8 district Carers Associations and 4 State Level Carer Forums
- 3,113 carers accessing short breaks opportunities
- Being recognised as a Nodal Agency by State Government of Karnataka and as a Domain Expert by Karnataka State Legal Services Authority

This year we are launching a new training and consultancy service available to not for profit and private organisations looking to increase their engagement with and support of carers, at home or in the workplace.

Carers Worldwide is at the forefront of providing solutions to the increasing care challenges faced by our society by promoting better support of family carers. Our strategic vision is to impact the lives of 10 million carers in South Asia by the end of 2030 through direct intervention and policy change

SUMMARY OF RESULTS

Summary of the results of carers profile

Socio demographic profile of the carers:

- Majority of the carers were in the age group of middle adulthood (37.5%) and small proportion (9.37%) of care givers who are elderly
- Almost every carers were female, who were married and hailed from nuclear families
- More than 50% of them didn't attend any formal education, those who had formal education-majority of them studied till primary education
- Majority of the carers were mothers (57.7%) followed by spouse (17.9%) and significant others
- On an average, each household had around four to five members – almost equal distribution of men, women and children

Financial profile:

- Majority of the carers hold identity card and most of them had ration cards/aadhar cards and voters ID
- Majority of the carers were not involved in any income generating work and other small proportion of carers who were working, involved in daily wage work and earning less than 10000 per month
- As far as vocational skills of the carers are concerned, majority (79.96%) of them have reported of not having any skills. 16.68% have conventional vocational skills like basket making, candle making, beedi rolling, dairy farming, tailoring, mat making etc.
- Lack of any other member to take care of the person with chronic illness is cited by majority (80.60%) as the reason for not earning
- Majority of the carers were having income through property followed by social security measures. This reflects the possible financial difficulties the carers go through

Health profile of the carers:

- Majority (97%) of the carers by themselves have health issues which adds to their existing problems of caregiving and related issues
- More than half of the carers experience chronic stress resulting in either mental health issues like constant worries or have mental health disorders like anxiety and depression
- Around 31.68% have both physical ailments, ranging from head-aches and pains to blood pressure, having undergone surgeries etc, and mental health issues like fear and anxiety. However not many of them sought treatment and reasons were not specified for the same.
- Majority (94.9%) of them would have resorted to other methods for addressing their health issue like consulting a faith healer, religious treatment, or conventional methods of treatment generally practiced in rural areas

Social activities:

- More than half the carers were members of any SHGs. However, 97% of them were not community member groups
- Loans:
- More than half of the carers have reported that they have loans to repay which highlights the financial difficulties.
- The loan amount ranges from ₹1000 to above ₹60,000.

- Among those who have revealed about the source of loan, for majority of carers (31.9%), the source of loan was neither from the Carers Project nor from Bank, but from other undisclosed sources

Results of Individuals cared for

- The carers were providing care to individuals from all the age group. Among them majority children/adolescents and young adults.
- Majority of the people who received care were from both Gender, however, more than half of them were Men.
- Almost equal representation of physical and mental illness related disability. 42.92% of the persons requiring care were the ones with physical health conditions like loco-motor problems, speech and hearing impairment, visual impairment, cancer etc. 40.05% had mental health and mental developmental disorders like intellectual developmental disorders.
- Most of them had chronic illnesses, where the duration of illness of ranged between 1-20 years.
- Almost all the persons who were cared for were not earning/ unemployed. This shows the loss of productivity in individuals with health issues.
- None of the persons with chronic illness are members of Self-Help Groups

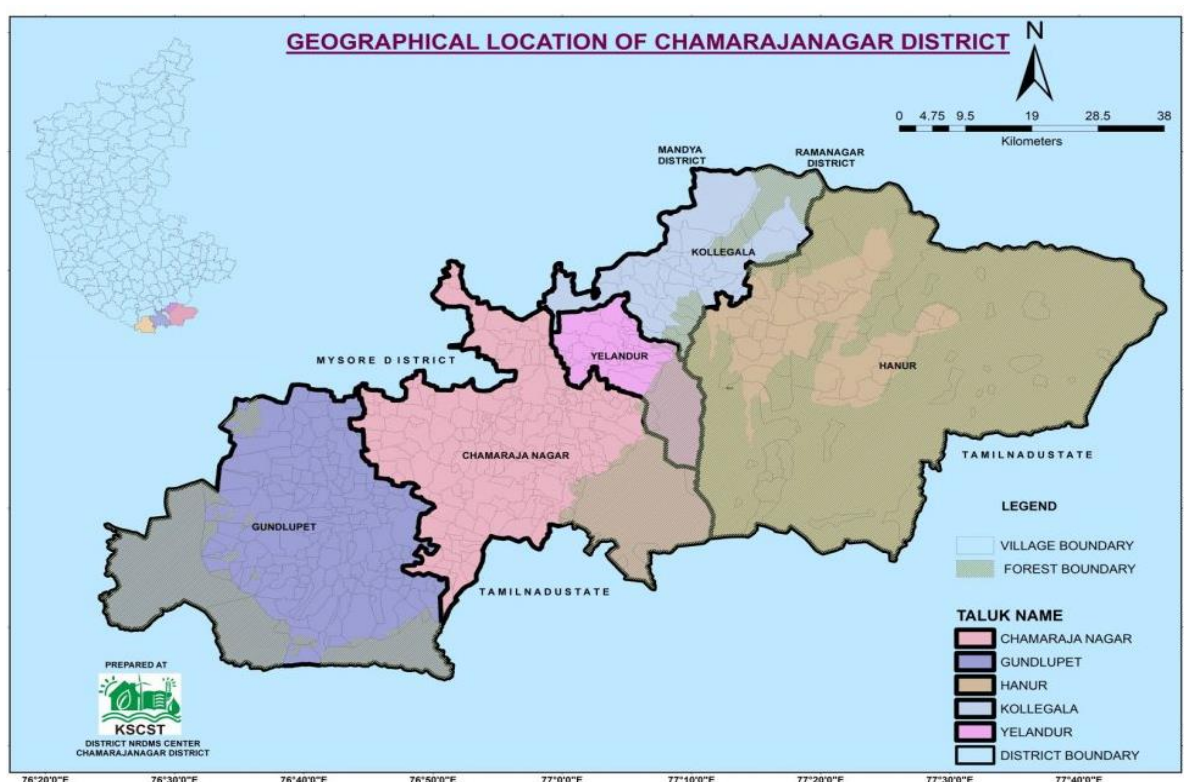
Results from Physical health and subjective wellbeing questionnaire

- Majority of the Carers reported poor importance to their self-care and personal life. More than half of them didn't had break from caring and uncertain about their future. They also reported significant concerns regarding continuation of care.
- They had expressed significant impact on familial and social relationships due to caring responsibilities and sense of loneliness and isolation as their friends and family drifts apart because of the limited contacts they have due to the caring responsibility. To add on to their difficulties, more than half of them receive no support from family and friends.
- In spite of the financial difficulties that the carers have, only 36.5% have expressed a lot of concern about their financial situation. On the contrary, 65.4% are a lot concerned about their having to cover extra costs of caring like visiting the hospital, for medication etc.
- Most of the carers (61.3%) were not concerned about their physical health
- As far as impact of the caregiving on mental health is concerned, most of them reported difficulties in managing their anxiety, low mood and inadequate sleep. More than half of them were unable to see anything positive in their life. The only experience that majority have denied is a feeling of exhaustion. This is indicative of the impact caregiving process can have on the carers.
- Having an ill person in the family makes majority (76.1%) of the carers feel that people are treating them differently.

INTRODUCTION AND BACKGROUND

About the Chamarajanagara District (study area)

Chamarajanagar was earlier known as Arikottara. Chamaraja Wodeyar, the Wodeyar king of Mysooru was born here and hence this place was renamed after him. The geographical area of the district is about 5,101 Km. Being the southernmost district of Karnataka, this district borders the state of Tamil Nadu and Kerala. Most of the district lies in the leeward region of the Nilgiris and consists of mainly semi- arid rain-dependent flatlands along with forested hills. Since 2000, the district has been subject to severe drought conditions and many of the labouring poor migrate to the neighboring Mysore or to plantation belts of Coorg and Kerala in search of seasonal labour. Industrial activities are restricted only to Kollegal belt and with a narrow focus on sericulture development. With the decline of the sericulture industry several settlements such as Mullur, Mudigunda, Mamballi and Hanur have been subject to a process of deindustrialization.



The total population of the district is 1020962 and the literacy rate is 61.1 per cent, which is quite low as compared to the State average of 75.6 per cent. Male literacy at 67.8 per cent is significantly higher than female literacy rate at 54.32 per cent. It consists of 1681 villages and 5 Taluks. People in this district speak Kannada and Tamil. The share of Chamarajanagar district in agriculture and allied activities is 41% in Karnataka. Its GDP contribution to the state is 3.1% (Source: Karnataka Directorate of Economic and Statistics). Close to 85 per cent of the district population is in rural areas. Agriculture is the main occupation, employing 71 per cent of the labour force (as of Census 2001). The remaining is in household industry (four per cent) and other workers at 25 per cent. Maize is the key crop grown in the district, occupying close to 17 per cent of the total cropped area. The district is one of the most industrially backward districts of Karnataka. However, it is rich in mineral resources, especially black granite, which is very high value granite. The district also has very high potential for tourism as it is home to many hill stations and religious places

The district has a total workforce of about 4.74 lakh persons. Of this, 28 per cent are cultivators, 43 percent are agricultural labourers, four per cent are workers in household industry and 25 per cent are other workers (*Source: Census 2001, Census 2011, Karnataka Human Development Report 2005*).

Understanding Disability measures in the state of Karnataka

People with disabilities are subject to multiple deprivations with limited access to basic services, including education, employment, rehabilitation facilities etc. Widespread social stigma plays a major role in hindering their normal social and economic life. To work towards an inclusive, barrier free society by raising awareness and policy actions, there is a need to have comprehensive reliable statistics on people with disability and their socio-economic conditions.

As per the Census 2011, the differently abled population in India is 26.8 million. In percentage terms, this stands at 2.21 %. There has been a marginal increase in the differently-abled population in India, with the figure rising from 21.9 million in 2001 to 26.8 million over the period of 10 years.

The Constitution of India provides ample scope for development of legal instruments to protect the rights of the disabled people. The Ministry of Social Justice & Empowerment, Government of India (MoSJE), through its programmes and policy formulations facilitates empowerment of the persons with disabilities, including persons with visual, hearing, speech, locomotor and mental disabilities. They run a few schemes for disabled persons and released the National Policy for Persons with Disabilities in the year 2006.

Recently, NSO has conducted Survey of Persons with Disabilities conducted in NSS 76th round (July-December 2018). The main objective of the Survey of Persons with Disabilities conducted by NSO in its 76th round was to estimate indicators of incidence and prevalence of disability, cause of disability, age at onset of disability, facilities available to the persons with disability, difficulties faced by persons with disability in accessing/using public building and public transport, arrangement of regular care giver, out-of pocket expenses relating to disability, etc.

In Karnataka it is estimated that nearly 5 to 6% of the population comprises persons with disabilities. Under PWD Act 1995 the state is required to provide for rehabilitation, education economic opportunities, barrier free environment and other supporting services so as to a facilitate the integration of persons with disabilities in the mainstream of society. The Women and Child Development Dept. is the nodal dept. and the office of Commissioner for Persons with Disabilities coordinates and monitors the programmes and schemes for persons with disabilities and take steps to safeguard the rights of persons with disabilities.

Karnataka state policy for persons with disability formed with the objective of ensuring implementation of the legislations related to persons with disabilities. Other objectives are:

- Multi-sectoral coordination amongst concerned agencies for prevention and early detection of disabilities
- Promotion of education as well as enrollment of children with disabilities in schools and to formulate a comprehensive education scheme as enshrined in the Disabilities Act
- Promotion of Self-employment amongst persons with disabilities with special focus on Govt. agencies, which create opportunities for disabled entrepreneurs to provide services within the various Government agencies and Departments
- Effective implementation of various departmental schemes to promote the development of persons with disabilities
- Ensure non-discrimination and monitoring of rehabilitation schemes (schemes under the State Government and the Govt. of India)
- Ensure qualitative services are provided by the voluntary sector in the field of disabilities

Social security measures provided by the state government are Monthly Maintenance Allowance (Min Rs 400, Max Rs. 1000 depending on the percentage of disability); Issuing of Identity Cards; Insurance Scheme for persons with intellectual disabilities; Reservation in Government service; training and employment opportunities; Hostel facilities for trainees; self-employment programme; Rehabilitation services- aids and appliances.

Disability related statistics in Karnataka

Type of disability	Total Persons	Cultivators	Agriculture labor	HHI	Other workers
Total disabled population	503,902	102,038	122,778	19,029	260,057
In Seeing	103,751	19,333	22,978	3,273	58,167
In Hearing	106,291	20,595	23,772	4,152	57,772
In Speech	35,736	8,794	11,027	1,270	14,645
In Movement	104,941	23,208	25,825	3,830	52,078
Intellectual Disability	19,464	4,055	5,653	660	9,096
Mental Illness	4,302	923	1,373	182	1,824
Any Other	110,967	20,888	26,845	4,936	58,298
Multiple disability	18,450	4,242	5,305	726	8,177

Source: [2011 Census: Distribution of Disabled\(India & States/UTs\)](#)

Statistical Profile of Persons with Disability: Karnataka (all figures are given in %)

Variables	Rural			Urban			Rural + Urban		
	Male	Female	Person	Male	Female	Person	Male	Female	Person
Person with Any type of disability	3.0	2.4	2.7	2.0	1.8	1.9	2.6	2.2	2.4
Person with Locomotor Disability	1.9	1.2	1.6	1.3	1.1	1.2	1.7	1.2	1.4
Person with Visual Disability	0.4	0.5	0.4	0.2	0.3	0.3	0.3	0.4	0.4
Person with Hearing Disability	0.4	0.4	0.4	0.3	0.3	0.3	0.3	0.4	0.4
Person with Speech and Language Disability	0.3	0.2	0.2	0.3	0.2	0.2	0.3	0.2	0.2
Person with Intellectual Disability	0.2	0.2	0.2	0.2	0.1	0.1	0.2	0.1	0.2
Person with Mental Illness	0.1	0.1	0.1	0.1	0.0	0.1	0.1	0.1	0.1
Person with Other type of Disability	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Person having disability since birth	29.7	27.3	28.7	30.2	24.7	27.7	29.9	26.5	28.4
Person with disability who are living alone	1.1	7.2	3.8	5.2	8.1	6.5	2.5	7.5	4.7
Persons with disability having certificate of disability	47.1	35.8	42.2	43.5	30.8	37.8	46.0	34.2	40.8

Literacy rate of persons of age 7 years and above with disability	56.9	33.3	46.6	72.0	44.9	59.8	61.6	37.0	50.8
Persons of age 15 years and above with disability having highest level of completed education secondary and above	22.1	9.0	16.4	40.7	19.6	30.9	27.8	12.4	20.9

Source: NSS Report No. 583: Persons with Disabilities in India

Percentage of person with disability who received any assistance in Karnataka

Variables	Rural			Urban			Rural + Urban		
	Male	Female	Person	Male	Female	Person	Male	Female	Person
Aid/help received from Govt.	45.5	40.7	43.4	36.7	30.5	33.9	42.8	37.4	40.4
Aid/help received from organization other than Govt.	1.1	1.2	1.2	1.7	0.8	1.3	1.3	1.1	1.2

Source: NSS Report No. 583: Persons with Disabilities in India

Percentage distribution of persons with disability by arrangement of regular care giver Karnataka

Variables	Rural			Urban			Rural + Urban		
	Male	Female	Person	Male	Female	Person	Male	Female	Person
Where carer is available	68.3	68.2	68.1	67.3	65.6	66.6	68.0	67.4	67.6
Where carer is required but not available	0.1	0.1	0.1	0.1	0.4	0.3	0.1	0.2	0.2
Where no carer is required	31.7	31.8	31.7	32.6	33.9	33.2	32.0	32.5	32.2

Source: NSS Report No. 583: Persons with Disabilities in India

RESEARCH STUDIES ON CARERS AND CHALLENGES OF CARING

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 WHO,2001 (Organization, 2001). Depending on the extent of assistance required and resources available, caregiving will involve variable amounts of physical work.

"Appraisal of caregiving" is understood as a construct existing in the "stress-appraisal-coping" framework, and implies that the experience of caregiving results from an interaction between the relative's illness and factors in the carer's external and internal world. According to the "stress-appraisal-coping" framework, patient's illness, associated behaviors, disabilities and perceived disruptions of the carers' life are appraised as stressors by the carer. The carer's personality, quality of family relationships and degree of social support are considered as the mediating factors(Szmukler et al., 1996). One important aspect of evaluation of caregiving experience in the "stress-appraisal-coping" framework is assessment of both the negative and positive subjective consequences of caregiving.

Many studies from India evaluated the burden experienced by the carers of patients with schizophrenia. However, there is dearth of data in relation to caregiving experience, especially assessment of positive caregiving experience. In India, traditionally the family is very much involved in the care of the mentally ill patients and is involved in all treatment decisions, stays with the patient during the inpatient stay, supervises the medications and provides rehabilitation(Avasthi, 2010). Further, another reason for caring for ill relatives is economic. Most families are unable to pay for fulltime hospital care, and expect that the patient, when well, will contribute to family income. This level of involvement of Indian families is quite different from the Western families(Jagannathan, Thirthalli, Hamza, Nagendra, & Gangadhar, 2014).

Care giving 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 lack assistive devices. In these situations care giving 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).

Carers 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. Carers' involvement in direct and indirect care changes over time, in response to the stage of illness and treatment, and carers must be able to adapt to changes in the amount, level and intensity of care demands (Reinhard, Given, Petlick, & Bemis, 2008). Carers 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. Carers 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 carers' 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 carer and the mentally ill person, interpersonal relation within the family, pre-existing emotional resources of the carer, type of the family, coping ability of the carer, availability of economic and social support personality of the carer, caregiving beliefs and values have been found to be significant related to the caregiving. The carers should be acknowledged and looked as resource in the mental health programme(Janardhana, Raghunandan, Naidu, Saraswathi, & Seshan, 2015)

Caregiving in Indian scenario

Family members are the primary carers of persons with mental illnesses in most of the non-western world. In India, more than 90% of patients with chronic mental illness live with their families(Kumar, Suresha, Thirthalli, Arunachala, & Gangadhar, 2015). The family carer 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. The family carer also has to bear with the behavioral disturbances in the patient(Costa & Ranci, 2010). Thus, the family carer experiences considerable stress and burden, and needs help in coping with it. The carers 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 carers. The family carer has remained a neglected 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(Fave, Fianco, & Sartori, 2015).

In India, as well as in most of the non-western world, and to a lesser extent in other parts of the world, families have been the mainstay of caregiving for persons with mental illnesses(Janardhana et al., 2015). The family carers take care of the day-to-day needs of the patients, monitoring the mental state, identify the early signs of illness, relapse and deterioration, and help the patient in accessing services. The family carer also supervises treatment and provides emotional support to the patient. The family carers bear with the behavioral disturbances of the ill family members and sometimes can also be a target of the patient's abusive or violent behavior. They have to curtail on their social and leisure activities, and sometimes have to take leave from their jobs. In addition, they have to meet the financial needs of the ill member besides meeting the treatment costs. The continuous stress of caregiving may adversely affect the physical and mental health of the carers(Martire, Lustig, Schulz, Miller, & Helgeson, 2004).

Impact of caregiving on carers

Studies carried out in the area of mental illness, shows that burden, physical health problems and psychological distress are commonly experienced among carers, both in Schizophrenia and Bipolar disorder (Aschbrenner, Greenberg, Allen, & Seltzer, 2010; Hoenig & Hamilton, 1966). Burden of care 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 carer's perception of burden (Awad & Voruganti, 2008). Family carers 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).

The carers 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 carers 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 carers may need to look after more than one patient in the family (Kate, Grover, Kulhara, & Nehra, 2013, 2014)

A number of factors related to carers, patients, and illness determine the carer burden. These include characteristics of the person with mental illness, characteristics of carers, and relationship between them, time spent by the carer with the patient and nature and severity of illness(Creado, Parkar, & Kamath, 2006)

The carer burden may be seen in all stages of illness. Sometimes, the carers 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 behavior 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 carers 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 carers 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.

Need for addressing the caregiving issues

It is essential for the mental health professionals to identify the burden in the carers 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 need to take timely care of the needs of the carers and provide necessary support and interventions, as per indication. This would help the carers to deal effectively with the burden of caregiving using healthy coping strategies and also improve their caregiving capability (Chadda, 2014)

Family carers of persons with mental illnesses are a key support system in our country as well as in most of the non-western world. In the absence of adequate mental health infrastructure, the family carers take multiple roles at providing care for persons with mental illnesses. The family carers suffer substantial burden as a result of the care giving 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 carers, the stresses faced by them and introduce suitable interventions, so as to reduce the burden as well as help in developing healthy coping strategies.

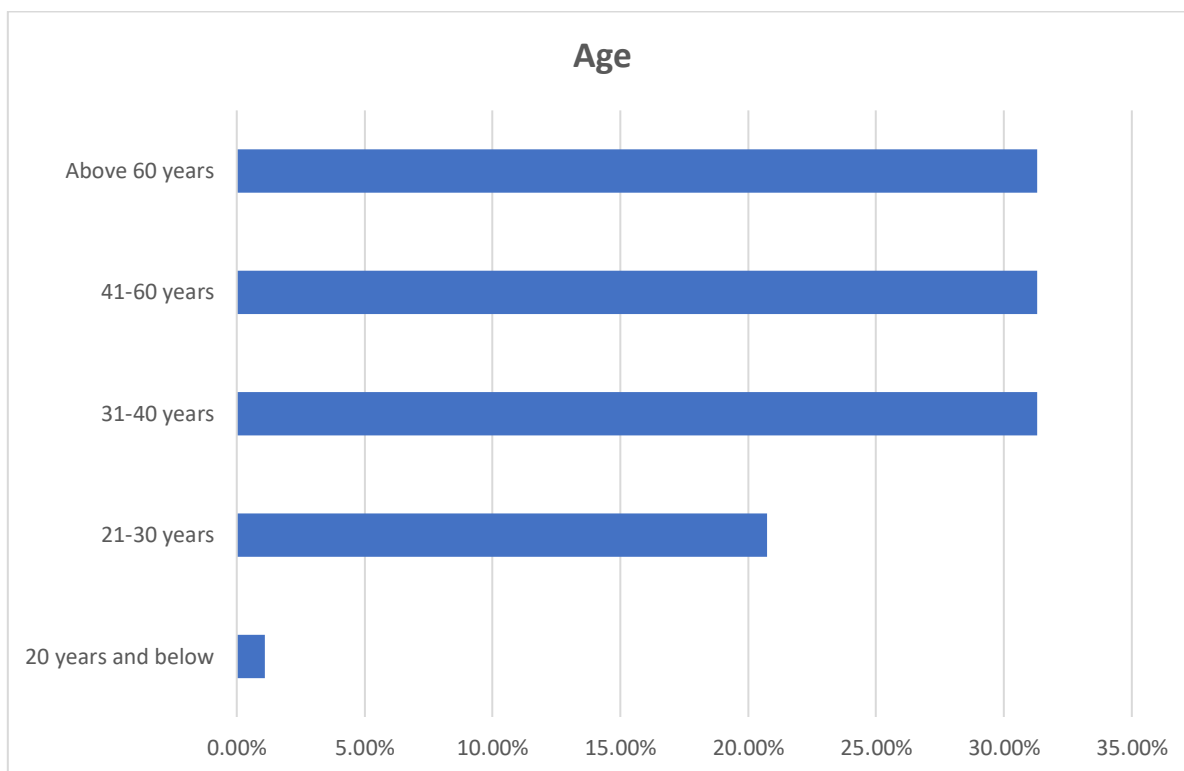
RESULTS OF THE BASELINE SURVEY

Carers Profile

1: Age of the Carers

Majority of the care givers were aged between 41-60 years (37.51%). The mean age of 42.50 (± 12.97) also indicates the same. There is a small proportion (9.37%) of care givers who are elderly.

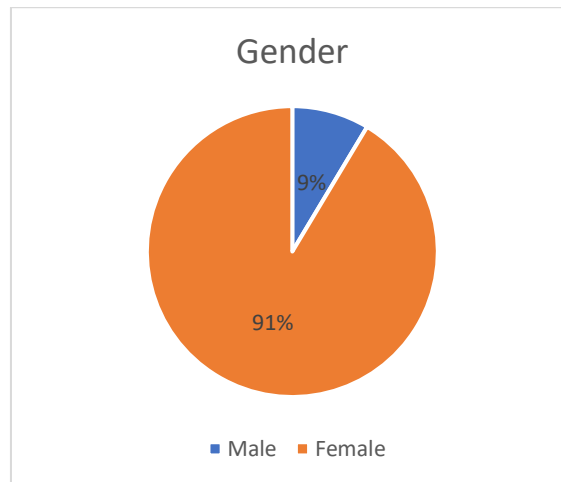
Age	Frequency (N=1013)	Percent
20 years and below	11	1.1
21-30 years	210	20.73
31-40 years	317	31.29
41-60 years	380	37.51
Above 60 years	95	9.37
Mean Age	42.50 (± 12.97)	



2: Gender of the Carers

A large proportion of carers are women (91.4%).

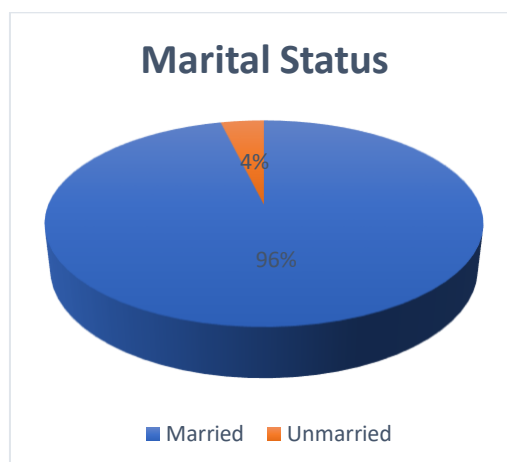
Gender	Frequency (N=1013)	Percent
Male	87	8.6
Female	926	91.4



3: Marital Status of the Carers

Majority (96.2%) of the carers are married.

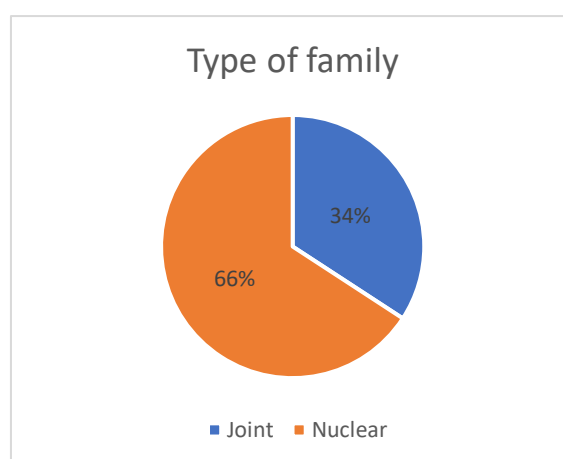
Marital Status	Frequency (N=1013)	Percent
Married	974	96.2
Unmarried	39	3.8



4: Type of Family

Majority of the carers hail from nuclear families.

Family Type	Frequency (N=1013)	Percent
Joint	346	34.2
Nuclear	667	65.8



5: Details of the Household

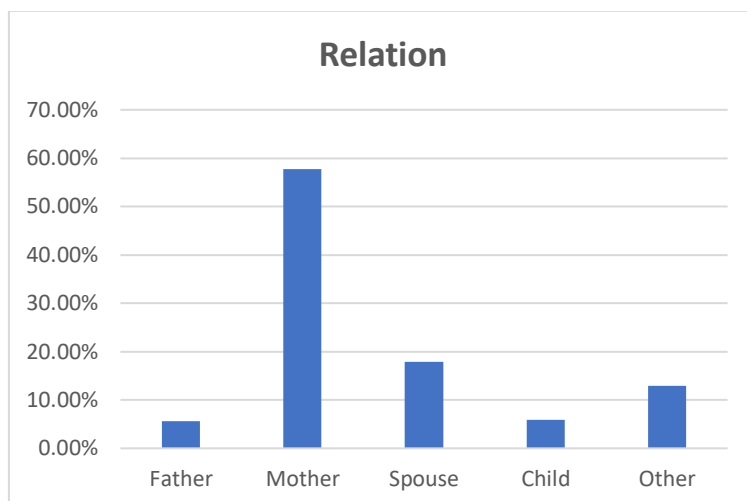
On an average, each household had around four to five members indicated by the mean scores of 4.51 (± 1.64) members. Each of the households had around one to three males and females indicated by the mean scores of 2.27 (± 1.14) and 2.24 (± 1.09) respectively, and one to two children, indicated by the mean score of 1.17 (± 1.63).

Household Details	Mean	SD
Number of household members	4.51	± 1.64
Number of men	2.27	± 1.14
Number of women	2.24	± 1.09
Number of children	1.17	± 1.63

6: Relationship with the Person Cared for

Majority of the carers were mothers (57.7%) followed by spouse (17.9%) and significant others.

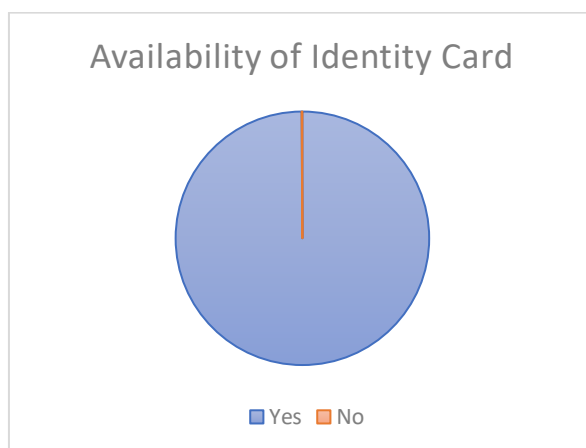
Relation	Frequency (N=1013)	Percent
Father	57	5.6
Mother	584	57.7
Spouse	181	17.9
Child	60	5.9
Other	131	12.9



7: Availability of Identity Card

Almost all carers (99.9%) have identity cards.

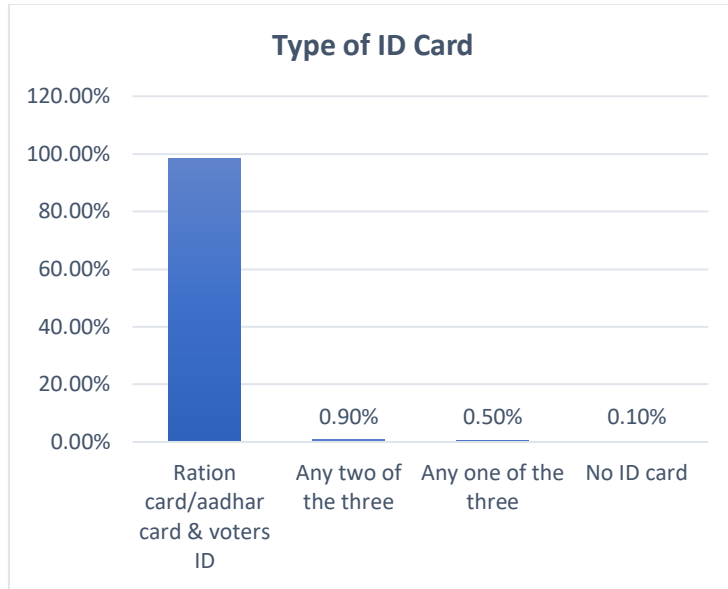
Availability of ID card	Frequency (N=1013)	Percent
Yes	1012	99.9
No	1	0.1



8: Type of Identity Card

98.5% of the carers have ration cards/aadhar cards and voters ID.

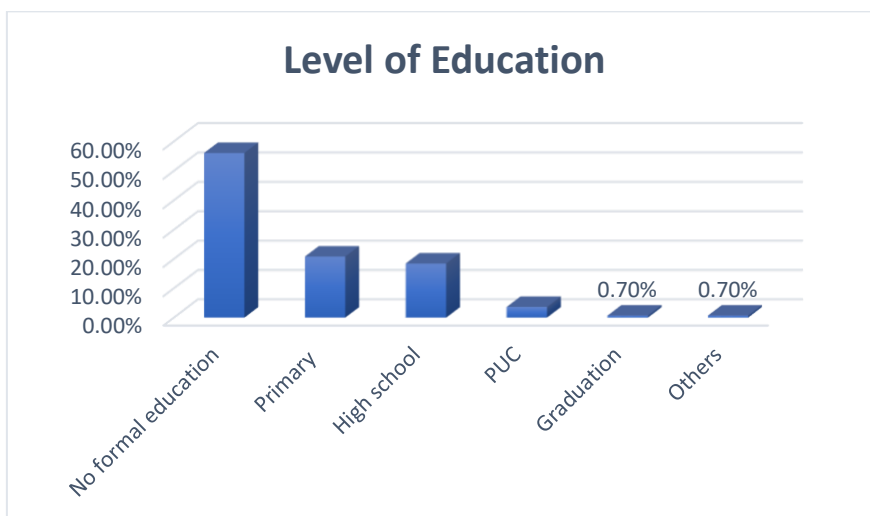
Type of ID Card	Frequency (N=1013)	Percent
Ration /aadhar card & voters ID	998	98.5
Any two of the three	9	0.9
Any one of the three	5	0.5
No ID card	1	0.1



9: Education Level of the Carer

Majority (56.07%) of the carers did not have formal education. Among the few others who were educated, 20.82% have completed their primary level of education and 18.46% have completed their high school. Only 0.70% have completed their graduation.

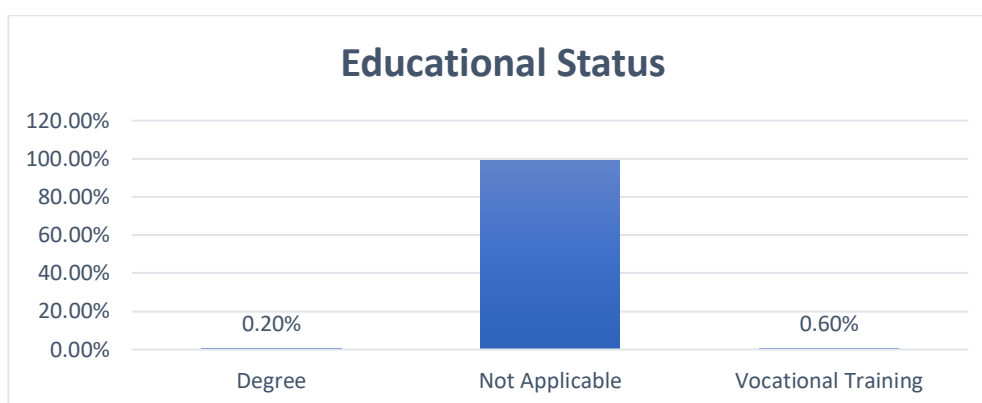
Level of education	Frequency (N=1013)	Percent
No formal education	568	56.07
Primary	211	20.82
High school	187	18.46
PUC	37	3.65
Graduation	7	0.7
Others	3	0.3



10: Present Education Status

Currently, majority of the carers (99.2%) are not undergoing any formal education. Negligible proportion of the carers are undergoing vocational training (0.60%) and are pursuing their graduation (0.2%) along with care-giving.

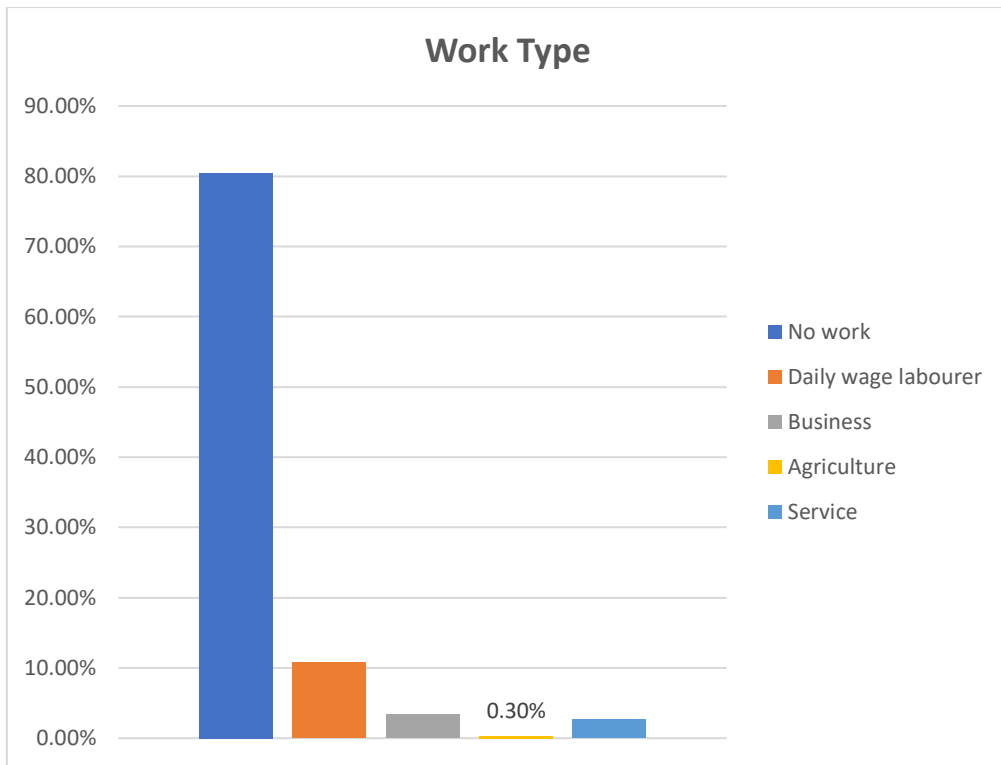
Education Status	Frequency (N=1013)	Percent
Degree	2	0.2
Not Applicable	1005	99.2
Vocational Training	6	0.6



11: Type of Work

With regards to the employment status of the carers, 80.45% of them are not involved in any income generating work. Of the small proportion of carers who are working, 10.76% are involved in daily wage work.

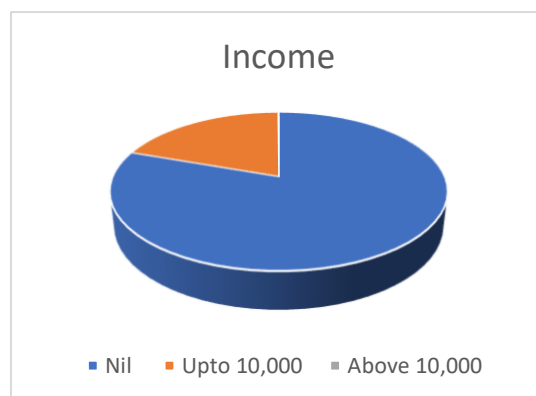
Work type	Frequency (N=1013)	Percent
No work	815	80.45
Daily wage labourer	109	10.76
Business	34	3.36
Agriculture	3	0.3
Service	27	2.66



12: Income per Month

As seen above, as most of the carers are not employed, majority (80%) don't have income. The income of those who are employed is not more than 10,000 per month. This reflects the possible financial difficulties the carers go through.

Income	Frequency (N=1013)	Percent
Nil	814	80.4
Up to 10,000	198	19.5
Above 10,000	1	0.1



13: Reasons for not Earning

Lack of any other member to take care of the person with chronic illness is cited by majority (80.60%) as the reason for not earning.

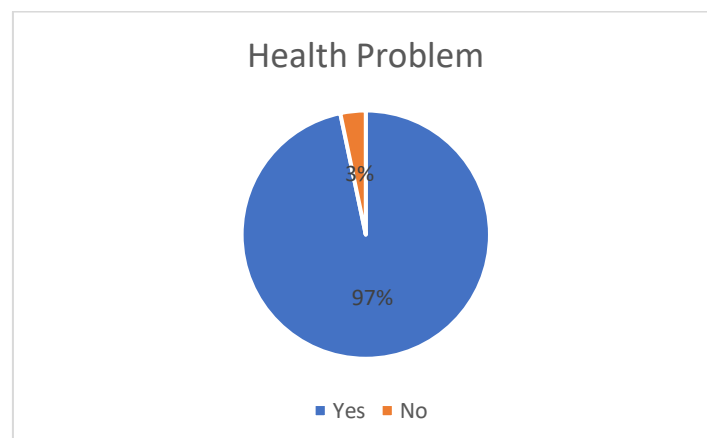
Reasons	Frequency (N=1013)	Percent
No work available	13	1.3
No one else to take care of the person	816	80.6
Poor health	12	1.2
Other	172	17



14: Health Problem of the Carer

Majority (97%) of the carers by themselves have health issues which adds to their existing problems of caregiving and related issues.

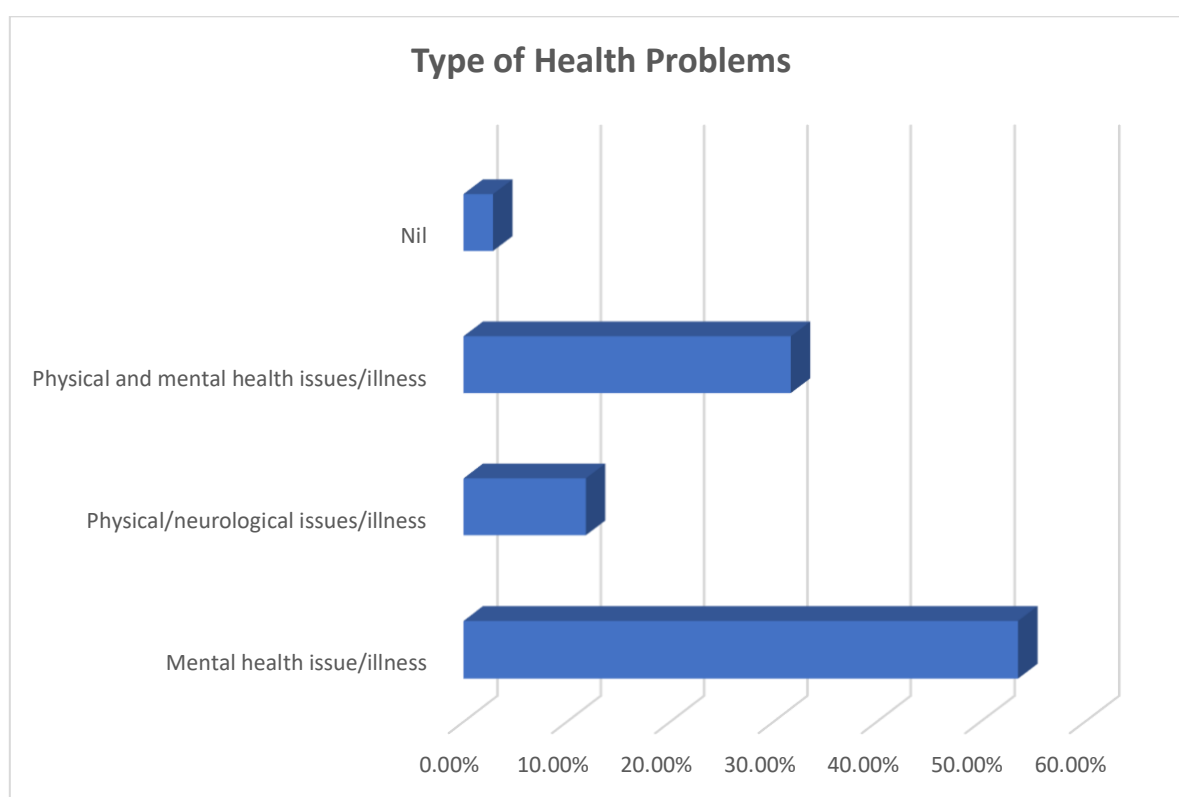
Health Problem	Frequency (N=1013)	Percent
Yes	980	96.7
No	33	3.3



15: Type of Health Problem

Majority (53.60%) of carers experience chronic stress resulting in either mental health issues like constant worries or have mental health disorders like anxiety and depression. Around 31.68% have both physical ailments, ranging from head-aches and pains to blood pressure, having undergone surgeries etc, and mental health issues like fear and anxiety.

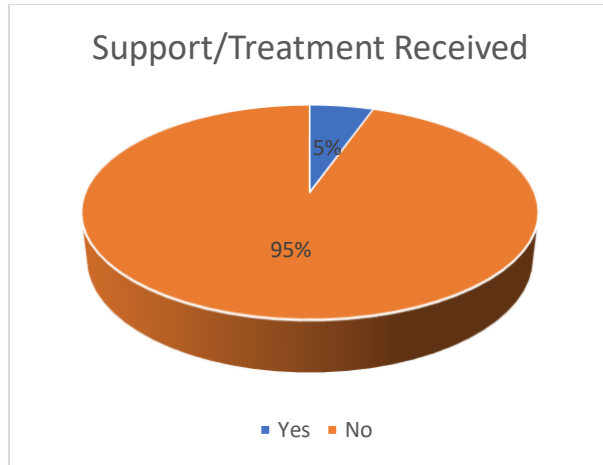
Health Problem	Frequency (N=1013)	Percent
Mental health issue/illness	543	53.60%
Physical/neurological issues/illness	120	11.84%
Physical and mental health issues/illness	321	31.68%
Nil	29	2.86%



16: Support/Treatment Received

Although the carers have health problems, 95% of them have not received any help/treatment for the same.

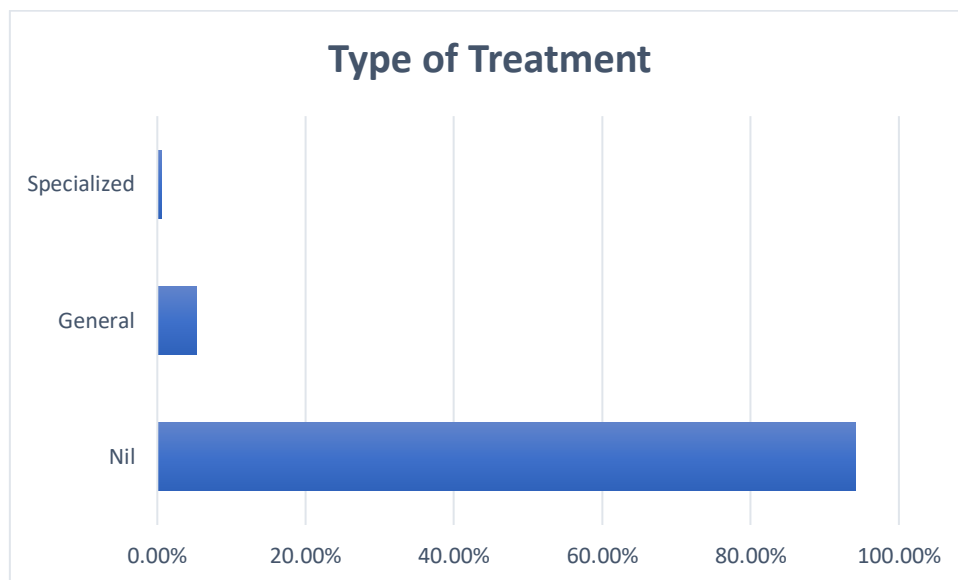
Support	Frequency (N=1013)	Percent
Yes	55	5.4
No	958	94.6



17: Type of Treatment

94.17% of the carers have not received any treatment for their health condition due to reasons explained in the next table and figure. Only 5.23% have received general health care and 0.6% have received specialised health care serviced.

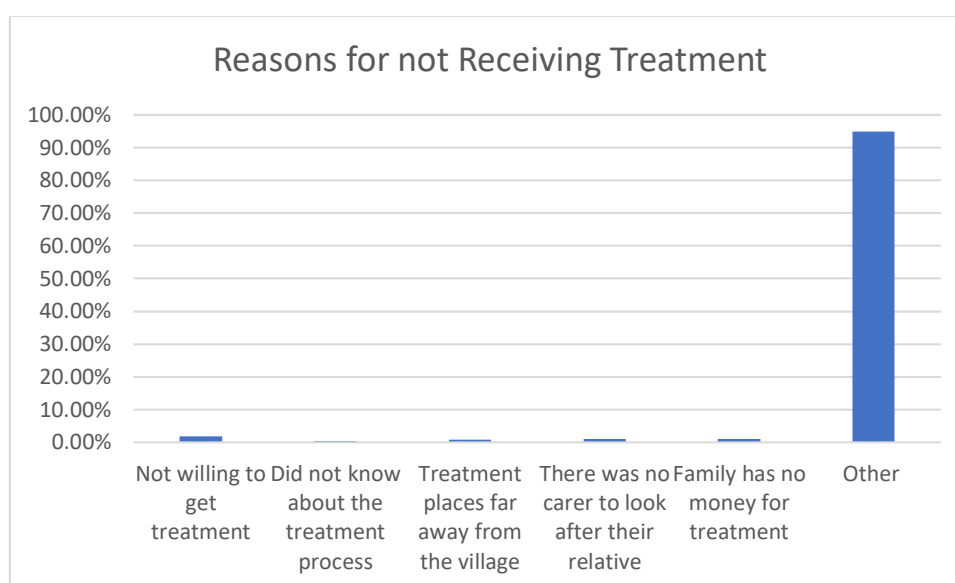
Response	Frequency (N=1013)	Percent
Nil	954	94.17
General	53	5.23
Specialized	6	0.6



18: Reason for not Receiving Treatment

The carers have not received treatment for various reasons. Majority (94.9%) of them would have resorted to other methods for addressing their health issue like consulting a faith healer, religious treatment, or conventional methods of treatment generally practised in rural areas.

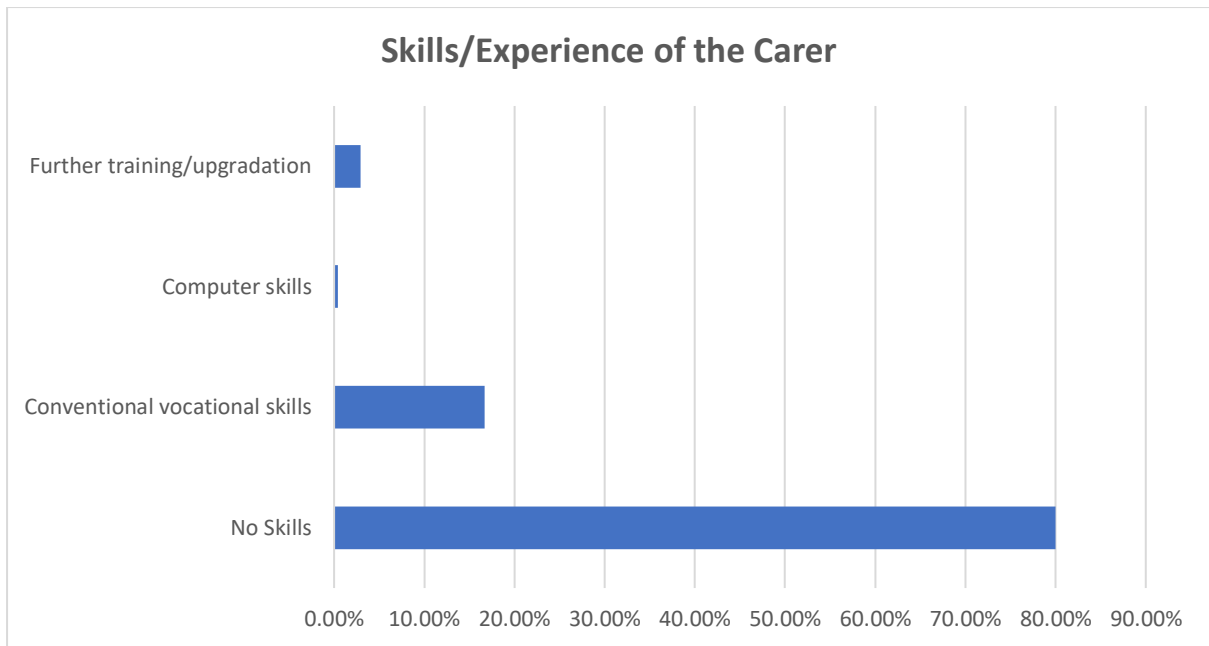
Reasons	Frequency (N=1013)	Percent
Not willing to get treatment	20	1.9
Did not know about the treatment process	3	0.3
Treatment places far away from the village	8	0.8
There was no carer to look after their relative	10	1.0
Family has no money for treatment	11	1.1
Other	961	94.9



19: Skills/Experience of the Carer

As far as vocational skills of the carers are concerned, majority (79.96%) of them have reported of not having any skills. 16.68% have conventional vocational skills like basket making, candle making, beedi rolling, dairy farming, tailoring, mat making etc.

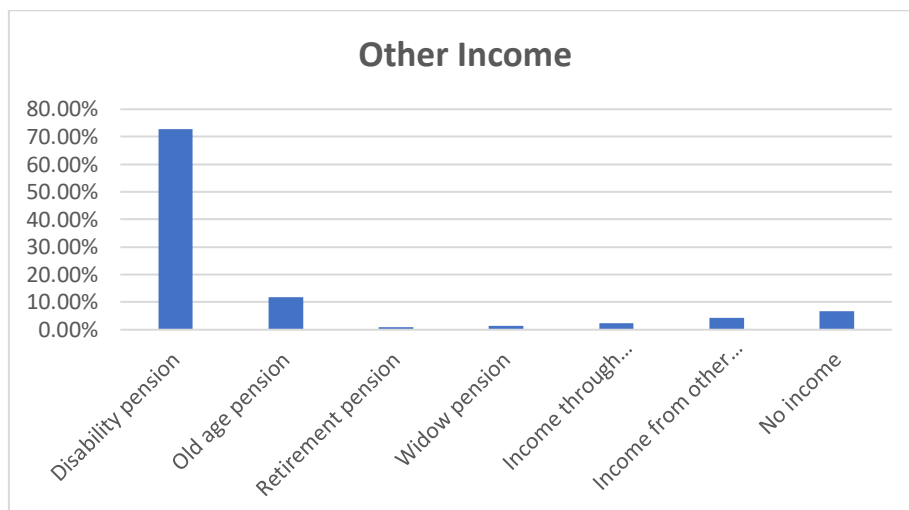
Skills/Experience	Frequency (N=1013)	Percent
No Skills	810	79.96
Conventional vocational skills	169	16.68
Computer skills	4	0.4
Further training/upgradation	30	2.96



20: Other Sources of Income

Apart from the income received through one's job, the other sources of income for majority (72.8%) of the families were from disability pension, that the person with chronic illness received. A small group (11.8%) received old age pension as an alternative source of income. A small group (11.8%) received old age pension as an alternative source of income.

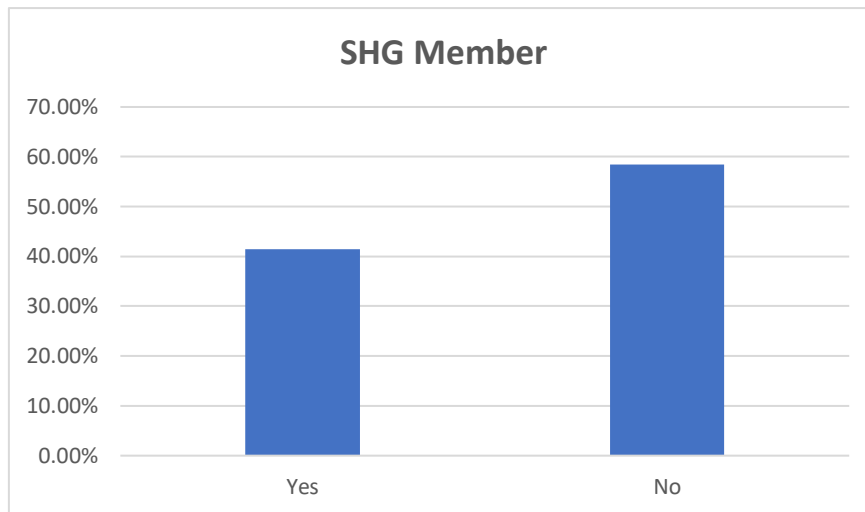
Other Income	Frequency (N=1013)	Percent
Disability pension	737	72.8
Old age pension	120	11.8
Retirement pension	8	.8
Widow pension	14	1.4
Income through property	24	2.4
Income from other sources	43	4.2
No income	67	6.6



21: Self Help Group Member

58.5% of the participants are members of SHG groups.

SHG Member	Frequency (N=1013)	Percent
Yes	420	41.5
No	593	58.5



22: Community Member

97% of the carers are not community members.

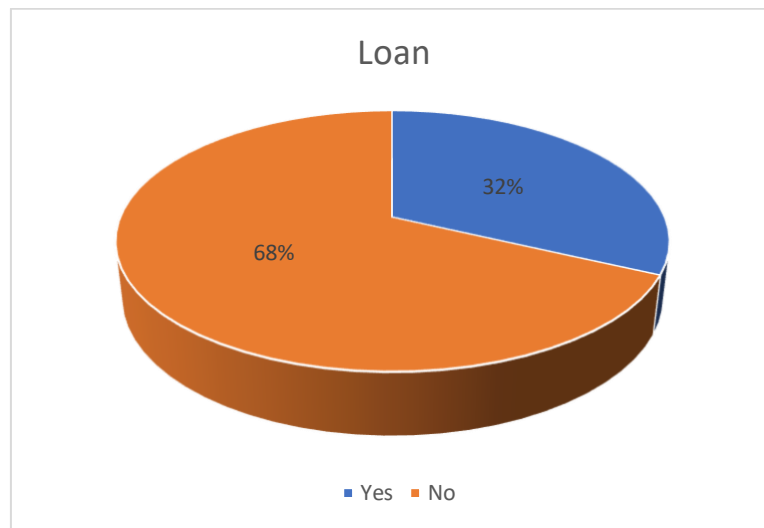
Community Member	Frequency (N=1013)	Percent
Yes	33	3.3
No	980	96.7



23: Loan Taken by the Carer

68% of the carers have reported that they have loans to repay which highlights the financial difficulties.

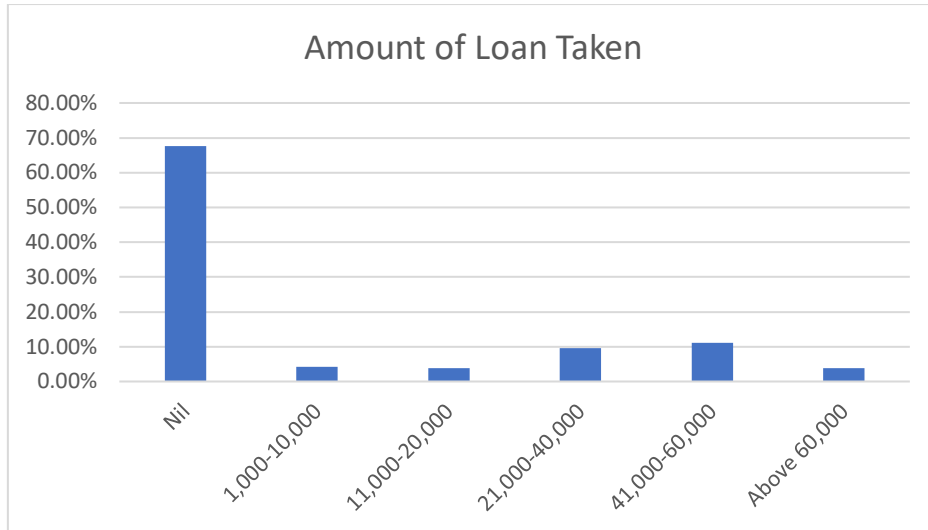
Loan	Frequency (N=1013)	Percent
Yes	324	31.98
No	689	68.02



24: Amount of Loan Taken

The loan amount ranges from ₹1000 to above ₹60,000.

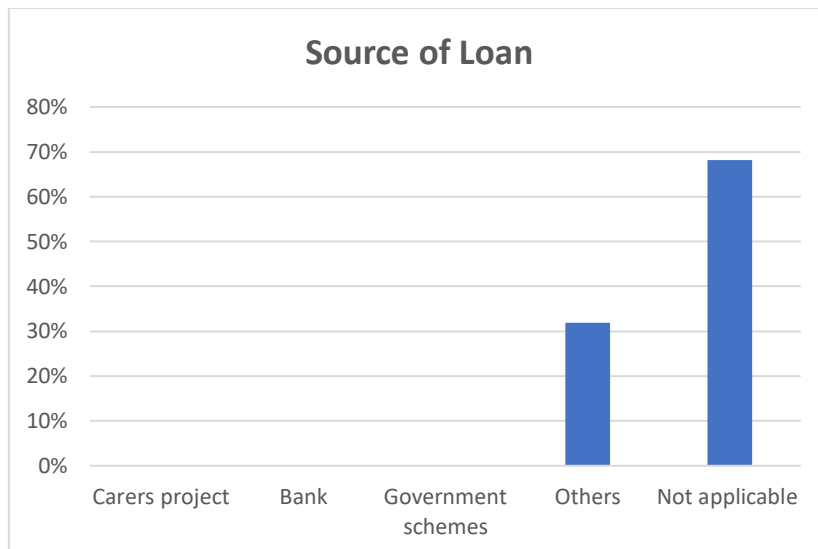
Amount	Frequency (N=1013)	Percent
Nil	685	67.62
1,000-10,000	42	4.14
11,000-20,000	38	3.75
21,000-40,000	98	9.67
41,000-60,000	112	11.05
Above 60,000	38	3.75



25: Source of Loan

Among those who have revealed about the source of loan, for majority of carers (31.9%), the source of loan was neither from the Carers Project nor from Bank, but from other undisclosed sources.

Source of Loan	Frequency (N=1013)	Percent
Carers project	0	0
Bank	0	0
Government schemes	0	0
Others	323	31.9
Not applicable	690	68.1

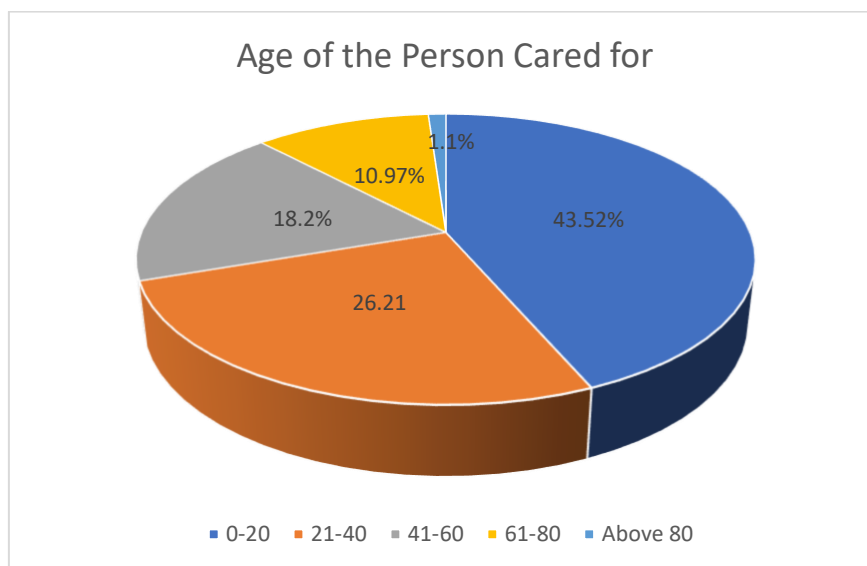


Details of Person Cared For

26: Age of the Person Cared for

The persons who were receiving care belonged to all age groups. The majority (43.52%) of the persons receiving care belonged to the age group of 0-20 year. The next highest representation belonged to the age group of 21-40 years. Persons aged 41 to 60 years comprised 18.2%.

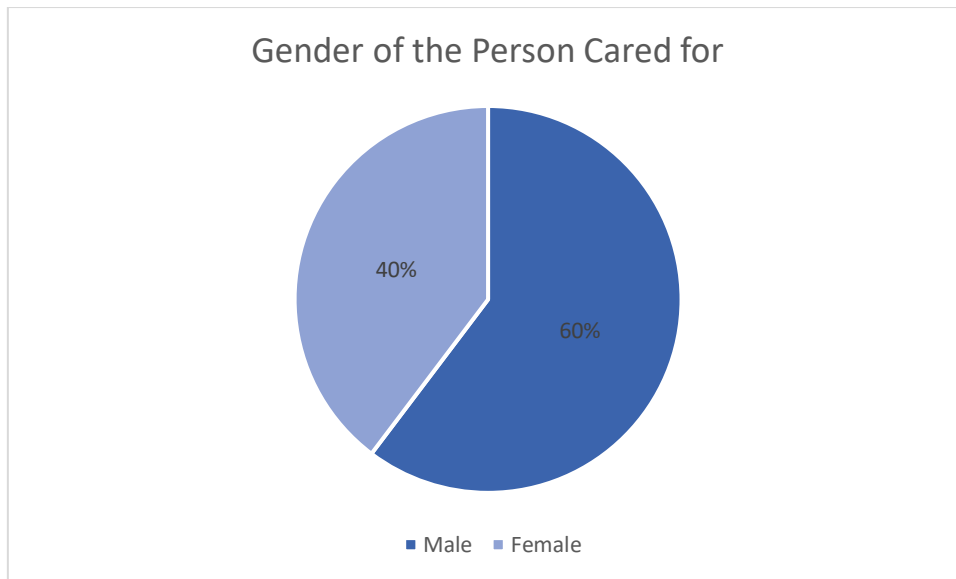
Age	Frequency (N=1011)	Percent
0-20	440	43.52
21-40	265	26.21
41-60	184	18.2
61-80	111	10.97
Above 80	11	1.1



27: Gender of the Person Cared for

Majority (60%) of the persons with chronic illness were males.

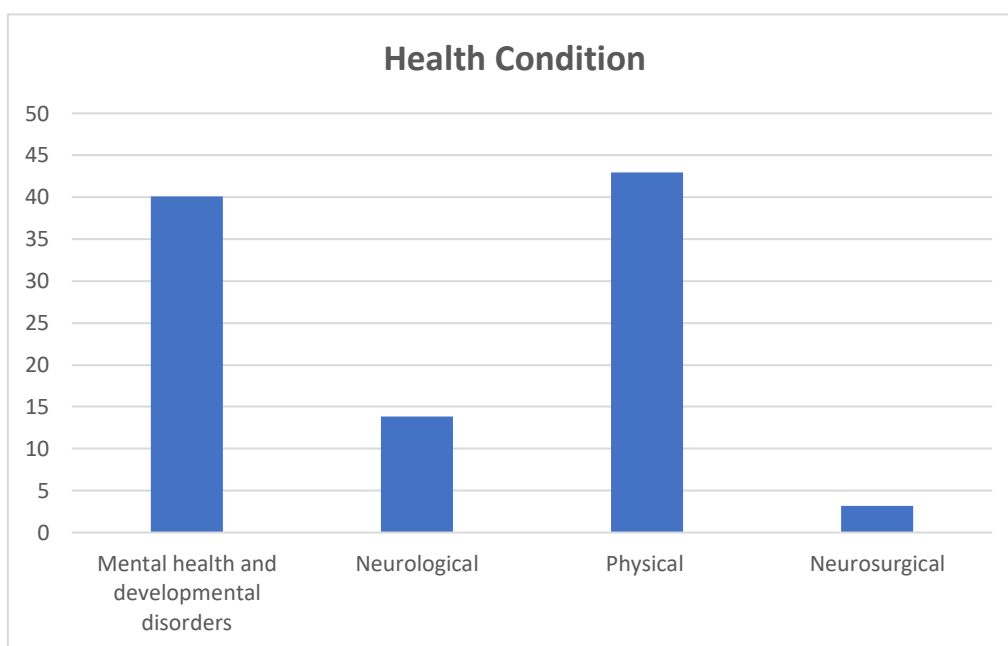
Gender	Frequency (N=1011)	Percent
Male	610	60.3
Female	401	39.7



28: Health Condition

Majority (42.92%) of the persons requiring care are the ones with physical health conditions like locomotor problems, speech and hearing impairment, visual impairment, cancer etc. 40.05% have mental health and mental developmental disorders like intellectual developmental disorders.

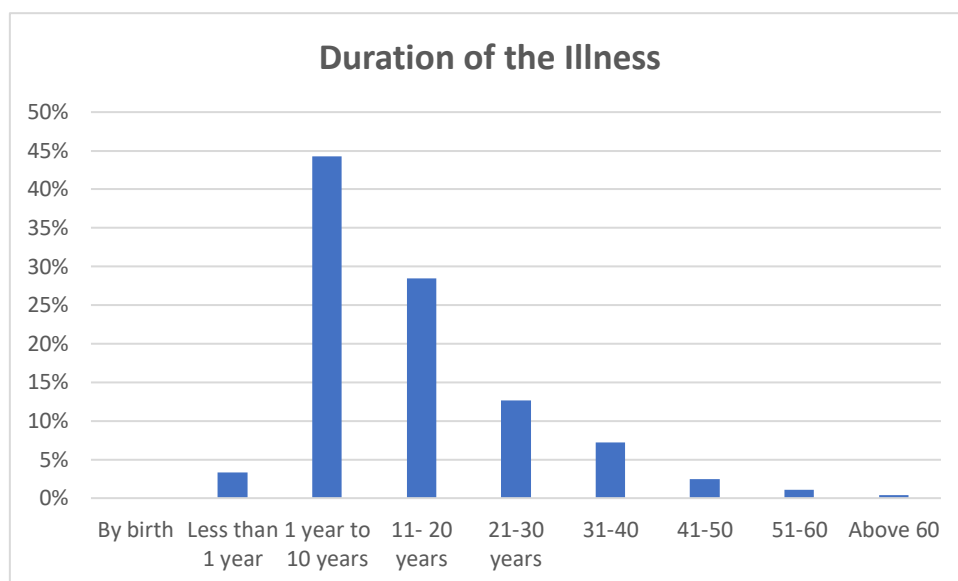
Health Condition	Frequency (N=1011)	Percent
Mental health and developmental disorders	405	40.05
Neurological	140	13.84
Physical	434	42.92
Neurosurgical	32	3.16



29: Duration of the illness

The duration of illness of 44.31% ranged between 1-10 years. 28.48% suffered from illness for around 11-20 years. This indicates the chronicity of the illness.

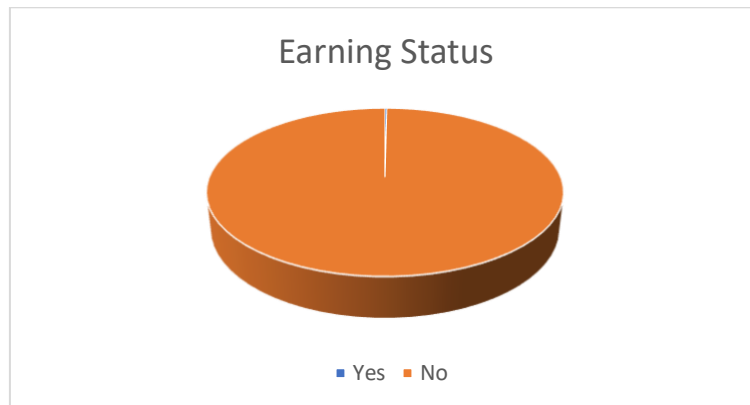
Duration	Frequency (N=1011)	Percent
By birth	0	0
Less than 1 year	34	3.36
1 year to 10 years	448	44.31
11- 20 years	288	28.48
21-30 years	128	12.66
31-40	73	7.22
41-50	25	2.5
51-60	11	1.08
Above 60	4	0.39



30: Earning status

Almost all the persons who were cared for were not earning. This shows the loss of productivity in individuals with health issues.

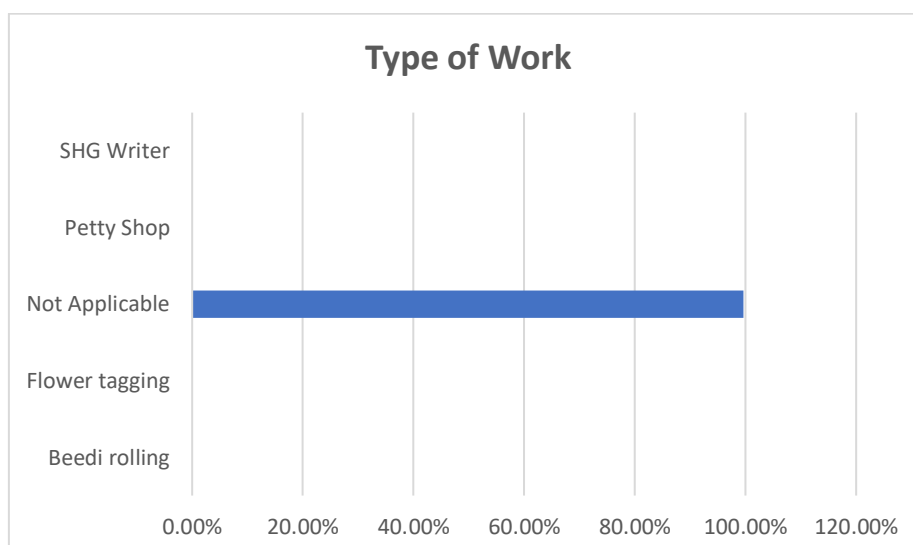
Whether earning?	Frequency (N=1011)	Percent
Yes	2	0.2
No	1009	99.8



31: Type of Work

Majority (99.6%) of the persons with chronic illness are not employed.

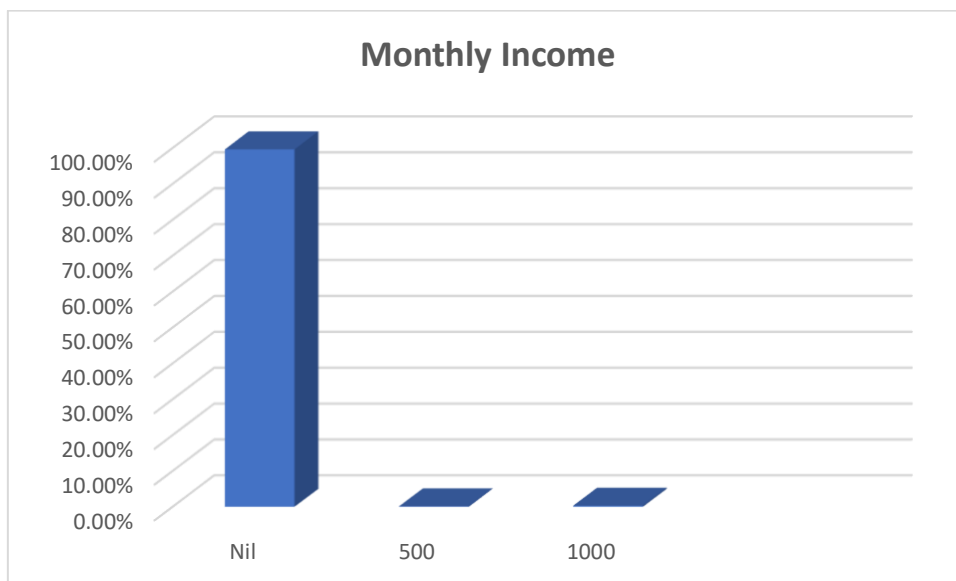
Work	Frequency (N=1011)	Percent
Beedi rolling	1	0.1
Flower tagging	1	0.1
Not Applicable	1007	99.6
Petty Shop	1	0.1
SHG Writer	1	0.1



32: Income Per Month

As majority of the persons cared for do not work, majority of them (99.6%) don't have any earning.

Income in Rupees	Frequency (N=1011)	Percent
Nil	1007	99.6
500	1	0.1
1000	3	0.3



33: SHG Member

None of the persons with chronic illness are members of Self-Help Groups.

Member	Frequency (N=1011)	Percent
Yes	0	0
No	1011	100.0

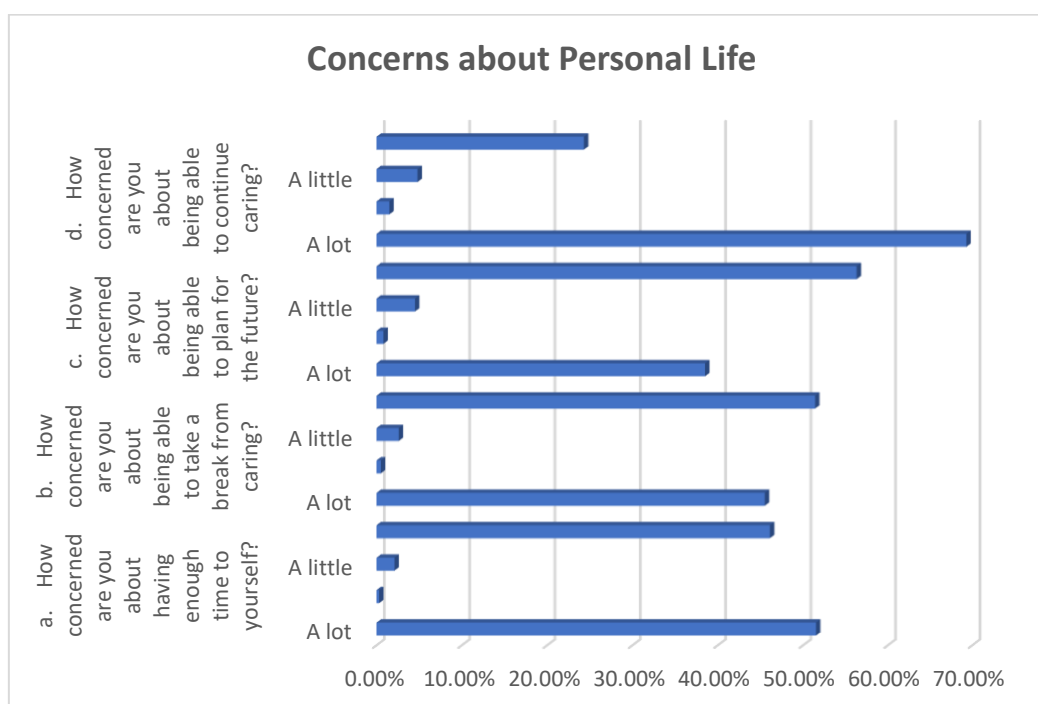


Results of Wellbeing Questionnaire

34: Concerns about Personal Life

Majority (53.9%) of the carers reported that they are concerned about not having enough time for themselves. 51.5% are concerned to a large extent. About 45.5% of the carers are unable to take a break from caring and are a lot concerned about the same. Although most of the carers (56.3%) are not concerned about their future, 69.3% are a lot concerned about continuation of care.

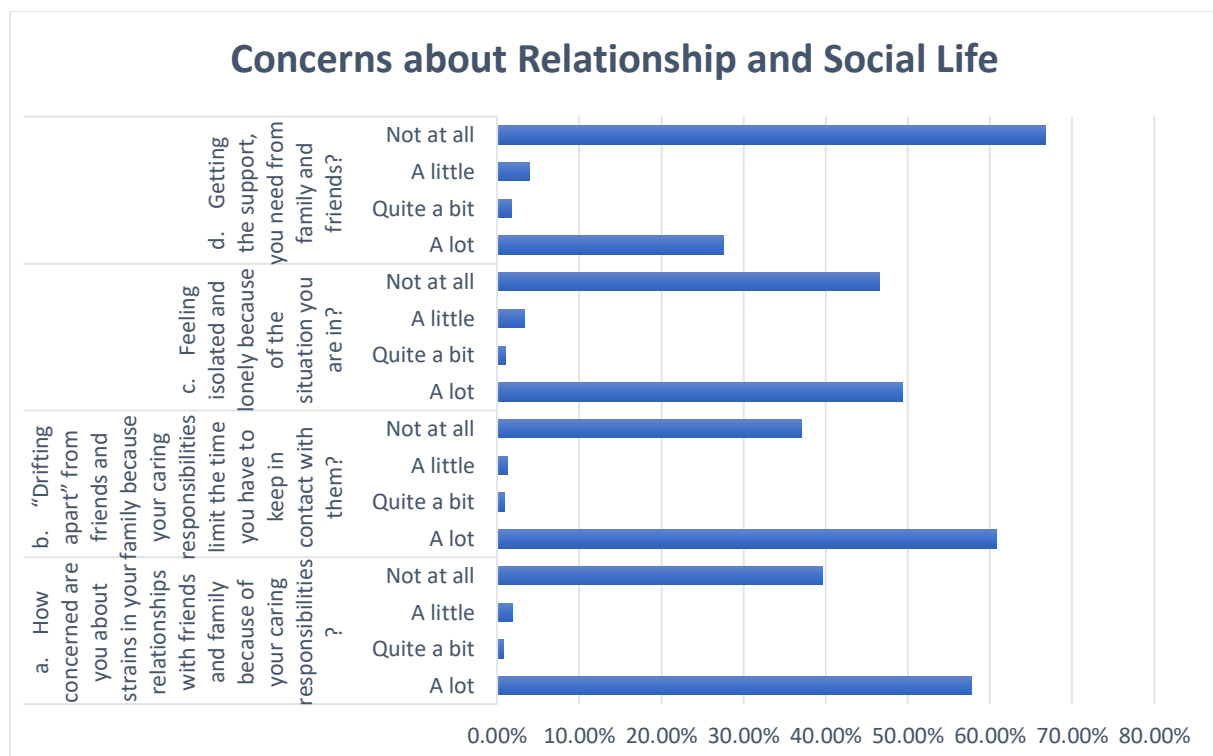
Question	Response	Frequency (N=1011)	Percent
How concerned are you about having enough time to yourself?	A lot	521	51.5
	Quite a bit	3	0.3
	A little	21	2.1
	Not at all	466	46.1
How concerned are you about being able to take a break from caring?	A lot	460	45.5
	Quite a bit	5	.5
	A little	26	2.6
	Not at all	520	51.4
How concerned are you about being able to plan for the future?	A lot	389	38.5
	Quite a bit	8	.8
	A little	45	4.5
	Not at all	569	56.3
How concerned are you about being able to continue caring?	A lot	701	69.3
	Quite a bit	15	1.5
	A little	49	4.8
	Not at all	246	24.3



35: Concerns about Relationships and Social Life

As far as impacts of caring is concerned, 57.8% are concerned that there has been a strain in the relationship with friends and family because of the caring responsibilities. 60.8% have reportedly experienced that the friends and family drifts apart because of the limited contacts they have due to the caring responsibility. Because of the situation that the carers are in, 53.6% of them have reported to be feeling isolated. To add on to their difficulties, majority (66.8%) of them receive no support from family and friends.

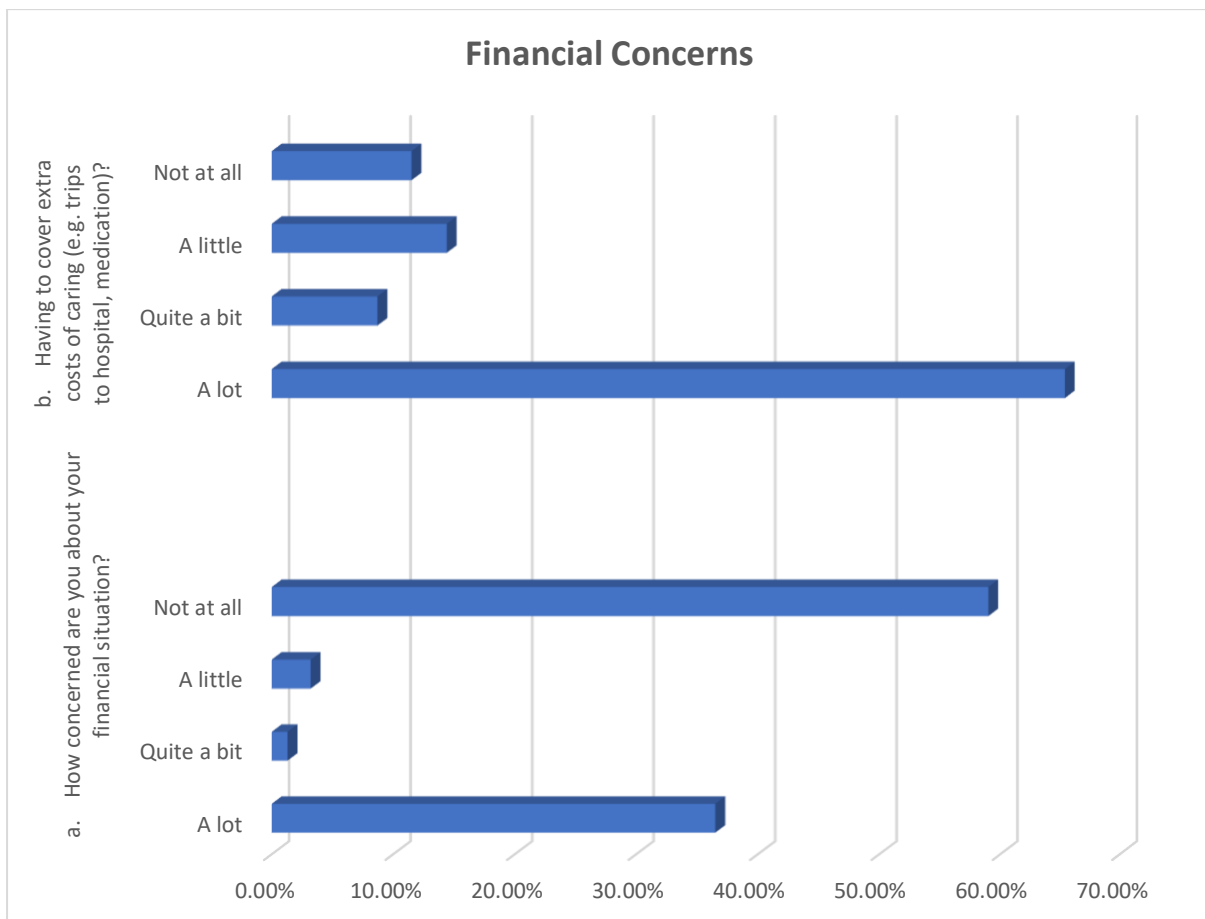
Question	Response	Frequency (N=1011)	Percent
How concerned are you about strains in your relationships with friends and family because of your caring responsibilities?	A lot	584	57.8
	Quite a bit	8	.8
	A little	19	1.9
	Not at all	400	39.6
“Drifting apart” from friends and family because your caring responsibilities limit the time you have to keep in contact with them?	A lot	615	60.8
	Quite a bit	9	.9
	A little	13	1.3
	Not at all	374	37.0
Feeling isolated and lonely because of the situation you are in?	A lot	498	49.3
	Quite a bit	10	1.0
	A little	33	3.3
	Not at all	470	46.5
Getting the support, you need from family and friends?	A lot	278	27.5
	Quite a bit	17	1.7
	A little	40	4.0
	Not at all	676	66.8



36: Concerns about Financial Condition

In spite of the financial difficulties that the carers have, only 36.5% have expressed a lot of concern about their financial situation. 59% have expressed that they don't have any financial concerns at all. On the contrary, 65.4% are a lot concerned about their having to cover extra costs of caring like visiting the hospital, for medication etc.

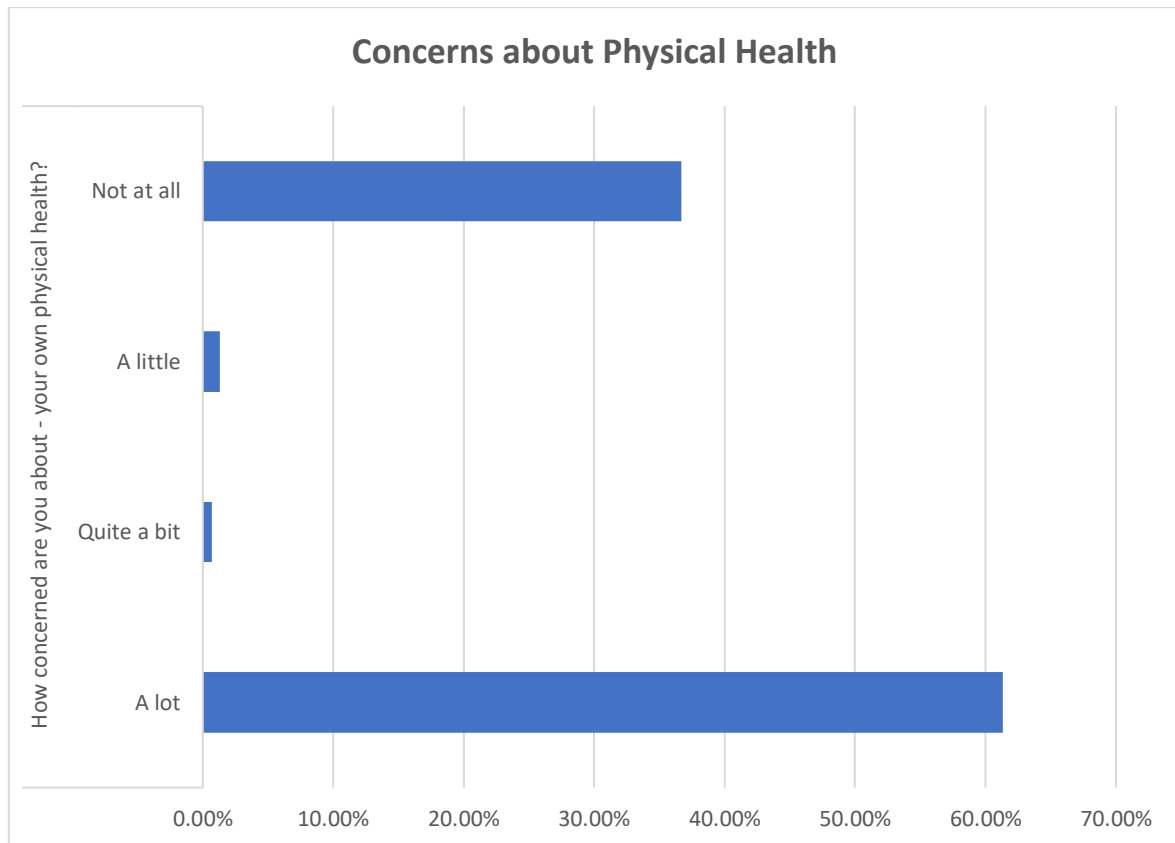
Question	Response	Frequency (N=1011)	Percent
How concerned are you about your financial situation?	A lot	370	36.5
	Quite a bit	13	1.3
	A little	32	3.2
	Not at all	596	59.0
Having to cover extra costs of caring (e.g., trips to hospital, medication)?	A lot	661	65.4
	Quite a bit	88	8.7
	A little	146	14.4
	Not at all	116	11.5



37: Concerns about Physical Health

Most of the carers (61.3%) are a lot concerned about physical health. Only 36.7% are not concerned.

Question	Response	Frequency (N=1011)	Percent
How concerned are you about - your own physical health?	A lot	620	61.3
	Quite a bit	7	0.7
	A little	13	1.3
	Not at all	371	36.7

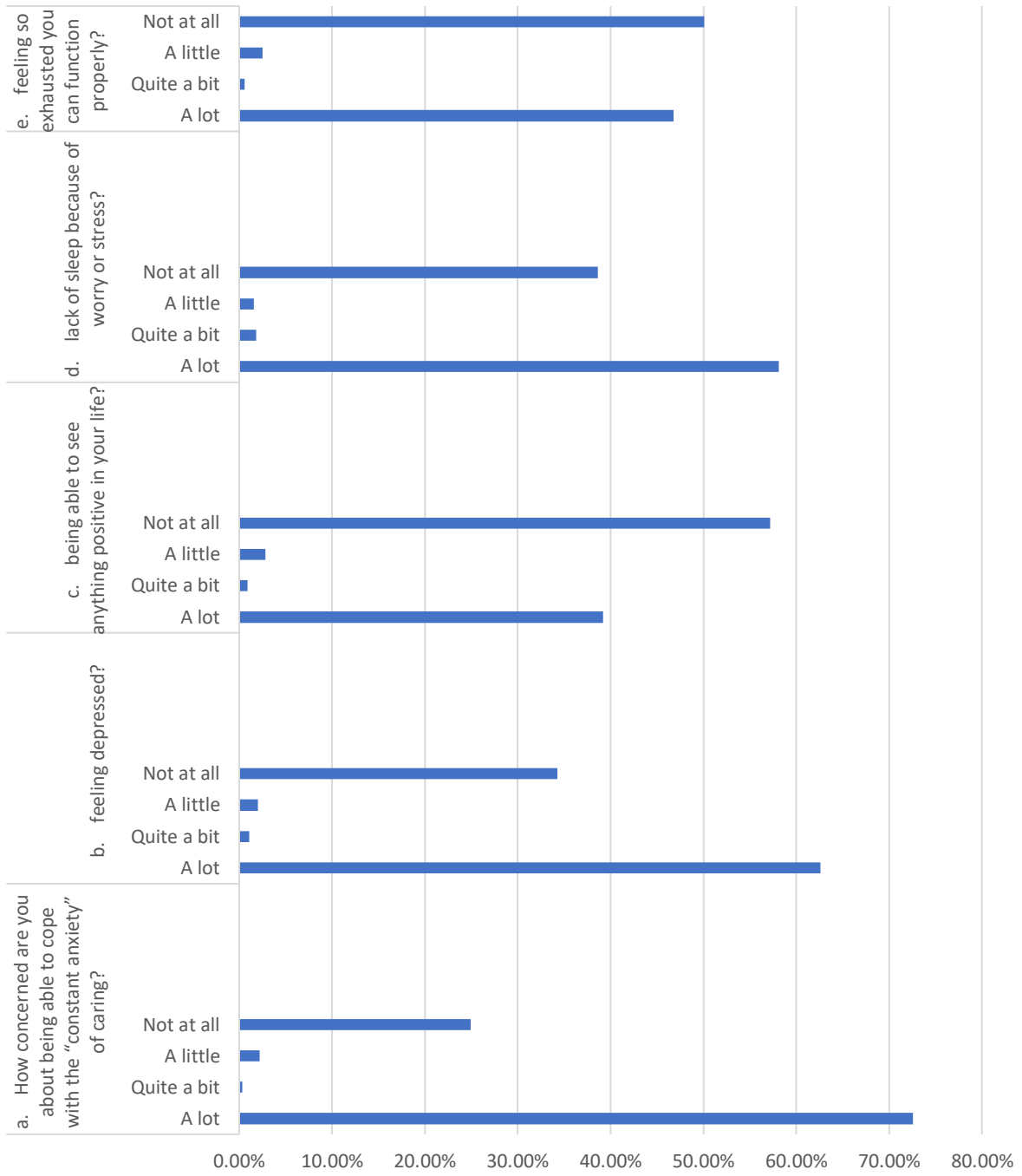


38: Concerns about Mental Health

As far as impact of the caregiving on mental health is concerned, 72.6% have reported to be less confident about managing their anxiety, 62.6% feel depressed and 58.1% have lack of sleep and 57.2% are unable to see anything positive in their life. The only experience that majority have denied is a feeling of exhaustion. This is indicative of the impact caregiving process can have on the carers.

Question	Response	Frequency (N=1011)	Percent
How concerned are you about being able to cope with the “constant anxiety” of caring?	A lot	734	72.6
	Quite a bit	3	.3
	A little	22	2.2
	Not at all	252	24.9
feeling depressed?	A lot	633	62.6
	Quite a bit	11	1.1
	A little	20	2.0
	Not at all	347	34.3
being able to see anything positive in your life?	A lot	396	39.2
	Quite a bit	9	.9
	A little	28	2.8
	Not at all	578	57.2
lack of sleep because of worry or stress?	A lot	587	58.1
	Quite a bit	18	1.8
	A little	16	1.6
	Not at all	390	38.6
feeling so exhausted you can function properly?	A lot	473	46.8
	Quite a bit	6	.6
	A little	25	2.5
	Not at all	507	50.1

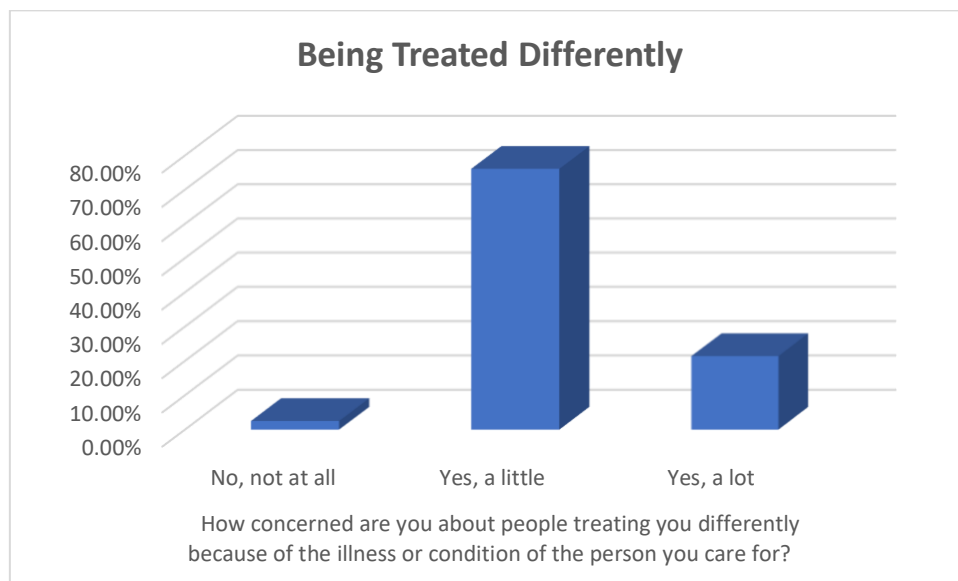
Mental Health Concerns



39: Concerns about Being Treated Differently

Having an ill person in the family makes majority (76.1%) of the carers feel that people are treating them differently.

Question	Response	Frequency (N=1011)	Percent
How concerned are you about people treating you differently because of the illness or condition of the person you care for?	No, not at all	25	2.5
	Yes, a little	769	76.1
	Yes, a lot	217	21.4



CONCLUSION

Caregiving persons with any chronic illness is established to be strenuous to the carer. The survey results also corroborate the difficulties the carer undergoes. The burden severity is higher when the illness is chronic in nature than caring a person with acute conditions. The intensity of the burden depends on the various factors like the nature and prognosis of the illness, the type of illness, the age of onset, the health and financial condition of the carer, the support system etc. These factors also determine the impact caregiving can have on carers and the caregiving process. Therefore, naturally, if there is a tertiary support system along with other support, the well-being of the carers. The quality of caregiving and quality of life of the person who is cared for will be better with added support.

The results of the study are similar to the findings from the census data and National sample survey data of Karnataka state. Most of the carers are from villages and agriculture background. People from Chamarajanagara district are from agricultural background. Unemployment and seasonal migration is one of the major concerns in the district and limited opportunities for work. The present study also reflected lack of income generating activities among the carers.

Karnataka government has launched social security measures for the persons with disability. Monthly pensions are mostly availed services by persons with disability, which is highlighted in the present study, wherein, for most of them monthly pensions are major source of income. There is a need to provide awareness regarding other facilities and need a support mechanism to empower them to avail the same. National sample survey report highlighted the need for availability of carers and in the present study most of them had carers (family members) to support them.

Financial stressors to be addressed through vocational training for persons with disability, rehabilitation services and income generation activities for carers. This highlights the role of Govt and NGOs through multi sectorial approach and decentralization of services.

As highlighted in the study, wellbeing of carers are not been given priority even by carers. This may have long term impact on caregiving and lead to burnout. Hence, activities and programmes to focus on wellbeing of carers too.

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