



## Caring for Carers in Tumkur, Karnataka

Baseline Survey Report  
*November 2021*

**NARENDRA FOUNDATION**



## FOREWORD



**NATIONAL INSTITUTE OF MENTAL HEALTH AND NEUROSCIENCES**  
**(Institute of National Importance)**  
**Department of Psychiatric Social Work, Bengaluru-29**

Carers are persons who provide unpaid care and support to family members, neighbours, and friends who live with chronic illnesses/disabilities. The care provided includes physical care, social care, psychological care and other multidimensional care.

Whilst caring can be rewarding to person providing care, scientific research around the world has highlighted the burden of care. As well as affecting the wellbeing of carers on an individual level, caring can also negatively impact the functioning of families and contributes to the fall of a country's Gross Domestic Product.

Until recently, intervention programmes which have focused on carers have tended to centre around utilizing carers as resources in care that can be used to expand care in the community. Little to no research has been done on developing intervention plans to improve the wellbeing of carers themselves in a targeted manner.

Carers Worldwide (including Carers Worldwide India) is the quintessential organization dedicated to improving the wellbeing of carers in low and middle income countries. The organization enables carers to stand up for their rights by uniting carers together in to self-help groups and Associations, and sharing knowledge with those bodies on best advocacy practices.

The ultimate vision of Carers Worldwide is to create a fair world in which each carer is recognised and acknowledged, and in which the physical, emotional, economic and social needs of carers are met. Carers play an invaluable role in performing caring duties that Governments cannot meet so it is right that Governments ensure measures are in place to support carer wellbeing. National Health Policy, which aims to improve the health of people in their communities, also need to develop programmes for the carers in communities.

Carers Worldwide is committed to implementing measures to support carers which are evidence-based. To do this, they conduct baseline studies at the beginning of projects to understand the individual and collective needs of carers, and then ensure project evaluations are conducted to prove the effectiveness of their interventions. The findings are widely shared to encourage other bodies to support carers.

The study in this report has been conducted by one of Carers Worldwide's partners, the Narendra Foundation. Narendra Foundation is an NGO based in Karnataka which has been operating since 1997. Their vision is a 'a society where people living with disabilities enjoy dignity, rights and opportunities, irrespective of caste, class, religion, age and gender'. After successfully supporting persons with

disabilities for years, Narendra Foundation has recently expanded their reach to support the carers of persons with disabilities by partnering with Carers Worldwide.

This research into the needs of carers in Tumakuru District is greatly welcomed. The study collects baseline data on the health and wellbeing of carers and is performed by field workers with little academic research knowledge which demonstrates that research and evidence-building can be accessible. The findings of this research will shape the project implementation plan which will aim to increase recognition and transform the wellbeing of carers in Tumakuru District.

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

**November 2021**

## **ACKNOWLEDGEMENTS**

I am truly grateful for the opportunity to work with the carers of people with disabilities in Pavagada Taluk, Tumkur district, Karnataka State. This report is the result of the close collaboration between Carers Worldwide and our indispensable partner Narendra Foundation. A very special thank you goes to the carers, who have graciously given up 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 well-being.

This is a unique experimentation and collaboration between the service provider, Narendra Foundation; Department for the Empowerment of Differently Abled and Senior Citizens, Government of Karnataka particularly Tumkur district; and Carers Worldwide. I sincerely thank the project co-ordinator of Narendra Foundation Mr Dona Thimppa and all the 35 Village Rehabilitation Workers (VRWs) and Urban Rehabilitation Worker (URWs), who interviewed the carers and collected the baseline data and Mr Mylarappa, Multi-purpose Rehabilitation Worker (MRWs) who supported VRWs and URW during the baseline survey period. Special thanks also go to Mr Natesha N K for co-ordinating and monitoring the data collection and provided training, guidance and support to the project staff throughout.

I would like to express my sincere thanks to Dr Manjula B for compiling and analysing the data, writing the literature review and preparing this report under the guidance of Professor N Janardhana from the Department of Psychiatric Social Work, National Institute of Mental Health and Neuro Sciences (NIMHANS), Bangalore. Thank you also to Professor Janardhana for writing the Foreword to the report.

A very special gratitude is offered to my colleague Victoria Nicholson for her editorial support and producing the report in its final format.

Without the leadership support of Rajanna K. V, Founder, Narendra Foundation; Mr Ramesh, District Disability Welfare Officer, Tumkur District; Mr Venugoppl, Municipality Office, Pavagada; Mrs Mani, Nodal Officer at CDPO office, Pavagada Taluk; and Mr Mallikarjuna, Planning Officer, Taluk Panchayath Pavagada, none of this would have been possible and to all of them I express my sincere gratitude and thanks.

Finally, I am truly grateful to Narendra Foundation's Board of Trustees for recognising the critical role carers play in the rehabilitation and empowerment of persons with disabilities and for their commitment to supporting those carers. I do hope this report will contribute in building the evidence and engagement with the policy makers at the district and state level.

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

**November 2021**

## CONTENTS

P. 2 – 3	Foreword
P. 4	Acknowledgements
P. 6 - 7	Summary of Results
P. 8 – 14	Introduction and Background
P. 15 - 18	Research Studies on Carers and Challenges of Caring
P. 19 - 43	Results of the Baseline Survey
P. 44	Conclusion
P. 45 - 47	References

## SUMMARY OF RESULTS

### Summary of the results of Carers profile

#### Socio demographic profile of the carers:

- Mean age of the carers was 44.61 years and majority of them (44.2%) belonged to the age group between 41-60 years
- Large number of the carers were female (86.4%)
- Majority of the carers were married (98.1%), and living in a nuclear family (95.7%)
- More than half (54.6%) of the carers didn't attend any formal education and of those who had formal education- majority of them studied till primary school (21.1%)
- Majority of the carers were mothers (64.5%)
- On an average, each household had around four to five members – with almost equal distribution of men and women

#### Financial profile:

- Almost all the carers had either of ration card/aadhar card/voters ID or all of these
- Majority of the carers were not involved in any income generating work whilst a small proportion of carers who engaged in daily wage work were earning less than RS. 10000 per month
- As far as vocational skills of the carers are concerned, majority (73.6%) of them have reported of not having any specialised skills and 17.5% have reported of having 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 (80.7%) as the reason for not earning
- 61.9% of them were depending upon disability pension as a source of livelihood

#### Health profile of the carers:

- 41.5% of the carers had their own health issues, predominately the physical ailments such as headache, body pain, blood pressure and other serious complications
- Despite having health issues, majority of them did not go for any treatment, mainly because of financial constraint (59.3%). Of those who received treatment, it was mostly general treatment (86.2%)

#### Social activities:

- 79.9% of carers and 94.4% carers were not a part of SHGs and community-based groups respectively

#### Loans:

- Large number of carers (87.8%) didn't take any loans to balance their expenses. Those who had opted for loans, had borrowed it from undisclosed informal sources.

### Results of Individuals cared for

- 41.1% of the care recipients belonged to the age group between 0-20 years, followed by which 38.1% were aged between 21-40 years
- Majority of persons who received care were men (58.9%)

- Large number of care recipients (72.7%) had pervasive developmental disorder/neuro-developmental disorders of varied types including loco-motor problems, speech and hearing impairment, visual impairment, intellectual developmental disorders etc.
- Most of the care recipients had long standing health complications
- Almost all the persons who were cared for were not earning/ unemployed
- 95.2% of the care recipients were not a part of Self-Help Groups

#### **Results from Physical health and subjective wellbeing questionnaire**

- Concerns were expressed by carers about their personal lives, in terms of having inadequate time for self, inability to take a break, future worries, and being able to provide continued care
- When it comes to relationships and social life, concern was found in the carers with regard to the strain in the relationship with friends and family because of the caring responsibilities, feeling of drifting apart from friends and family, and feeling isolated.
- 58.3% of carers expressed a concern about their financial situation and 52.1% reported concerns on having to cover extra costs of caring like visiting the hospital, medication etc.
- Most of the carers (62.8%) had at least some concern about their own physical health
- Mental health concerns were reported by the carers pertaining to constant anxiety, feeling constantly sad, inability to stay positive, sleep disturbance due to worry/stress, and feeling exhausted
- Majority of the carers (60.1%) expressed a lot of concern on being treated differently by others for having a dependent family member

## INTRODUCTION AND BACKGROUND

### Tumakuru District and Pavagada Taluk at a Glance

Tumakuru District in Karnataka shares historically culture rich heritage and blessed with innumerable inscriptions and monuments. One unique feature of this district is that one of the taluks, i.e. Pavagada, is not at all connected with it at any point. The taluk is surrounded on all sides by Ananthpur district of Andhrapradesh and is connected with Karnataka at one point by a narrow strip of land on the north-west, and that too, not with the Tumkur district to which it belongs, but with another district of Karnataka, i.e. Chitradurga. This is because of the fact that this taluk once formed part of the Chitradurga district and was separated from it and attached to Tumkur district in 1886.

### TUMAKURU DISTRICT MAP



Tumakuru, commonly known as Tumkur, is a small industrial city about 70 km from Bengaluru. It is also known as the 'Coconut City' due to numerous palm trees found in this town. Tumakuru is located northwest of Bengaluru at an elevation of 2696 feet or 822 meters. It is a part of the Tumkur district with its ten talukas namely, Tumkur, Sira, Turuvakere, Kunigal, Tiptur, Madhugiri, Koratagere, Chikkanayakanahalli, Gubbi and Pavagada, with its district headquarters in Tumkur city.

### Population and percentage share to total Population

Taluks	Geographical Area (sq. kms)	Total Population	Male (No.)	Female (No.)	% Share to total Population	Rank
C.N.Halli	1113	212130	105583	106547	7.91	4
Gubbi	1221	262518	132102	130416	9.79	5
Koratagere	652	167591	84349	83242	6.25	10
Kunigal	981	225783	112803	112980	8.42	7
Madhugiri	1131	267866	134670	133196	10.00	3
<b>Pavagada</b>	<b>1358</b>	<b>245194</b>	<b>123680</b>	<b>121514</b>	<b>9.15</b>	<b>6</b>
Sira	1552	313758	158978	154780	11.71	2
Tiptur	785	222749	111282	111467	8.31	8
Tumakuru	1026	592397	303197	289200	22.11	1
Turuvekere	778	168994	83950	85044	6.30	9

Source: Tumakuru district at a glance-2013-14. Census (2011), Government of Karnataka

### Contribution of Tumakuru district to GDP of Karnataka

Description	INR Crore	Contribution (%)
Total District GDP (Gross Domestic	10,075	3.4
Agriculture and Allied (Agriculture, Animal husbandry, Forestry, Fishing)	2,570	6.1
Industry (Manufacturing, Construction, Mining)	2,494	3
Services (Real estate, hotels, restaurants, banking and legal services)	4,866	2.5

*Source: State and District Domestic Product of Karnataka-2013-14*

### Literacy rate

Literacy rate in Pavagada taluk is 64.32%, last rank in Tumkur district. Rural literacy rate is 64.60%, where in male has 75.05% of literacy rate, women have 54% of literacy rate. In urban areas, total literacy rate is 81.83%, where women have 75.36% and men have 88.33% of literacy rate (*Source: Tumakuru district at a glance-2013-14. Census (2011), Government of Karnataka*).

### Banking sector in Pavagada Taluk

There are 5 Regional Rural Banks, 2 District Cooperative central Bank, 1 primary land development Bank, 20 credit cooperative societies and 1 non cooperative credit society in Pavagada taluk (*Source: Tumkur District at a glance, 2020*)

### Stree Shakthi Self Help Groups and Members in Pavagada Taluk

There are 953 Stree Shakthi self-help groups consists of 14,486 members. Among them, 4190 belongs to SC, 2311 from ST and 7985 from other communities. Among these groups, Rs. 50.9 crore accumulated as savings and 912 SHGs have taken around 11.72 crores as loans from the banks. (*Source: Women and child development officer, Tumakuru - 2013-14.*)

### Understanding Disability

The World Health Organization (WHO) defines 'Disability' as "an umbrella term, covering impairments, activity limitations, and participation restrictions. Impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Thus disability is a complex phenomenon, reflecting an interaction between features of a person's body and features of the society in which he or she lives."

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.

## Disability in India

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.

## Disability welfare measures in the state of Karnataka

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 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

Rights of Persons with Disabilities (RPWD) Act, 2016 covers the following specified disabilities: Blindness, Low-vision, Leprosy Cured persons, Hearing Impairment (deaf and hard of hearing), Locomotor Disability, Dwarfism, Intellectual Disability, Mental Illness, Autism Spectrum Disorder, Cerebral Palsy, Muscular Dystrophy, Chronic Neurological conditions, Specific Learning Disabilities, Multiple Sclerosis, Speech and

Language disability, Thalassemia, Hemophilia, Sickle Cell disease, Multiple Disabilities including deaf-blindness and Acid Attack victims and Parkinson's disease.

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	Avg	Male	Female	Avg	Male	Female	Avg
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	Avg	Male	Female	Avg	Male	Female	Avg
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 carer: Karnataka

Variables	Rural			Urban			Rural + Urban		
	Male	Female	Avg	Male	Female	Avg	Male	Female	Avg
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

### Percentage of total DALYs due to each cause under mental disorders in India, 2017

Condition	Both sexes	Males	Females
<b>Depressive disorders</b>	33.8% (29.5–38.5)	28.9% (25.0–33.3)	38.6% (34.0–43.7)
<b>Major depressive disorder</b>	26.7% (22.6–31.2)	22.7% (19.0–27.0)	30.6% (26.1–35.8)
<b>Dysthymia</b>	7.1% (5.7–8.7)	6.2% (4.9–7.6)	8.0% (6.4–9.7)
<b>Anxiety disorders</b>	19.0% (15.9–22.4)	16.2% (13.5–19.2)	21.7% (18.1–25.5)
<b>Idiopathic developmental intellectual disability</b>	10.8% (6.3–15.9)	11.8% (7.0–17.4)	9.7% (5.6–14.6)
<b>Schizophrenia</b>	9.8% (7.7–12.4)	11.2% (8.8–14.0)	8.5% (6.7–10.8)
<b>Bipolar disorder</b>	6.9% (4.9–9.6)	7.2% (5.1–10.0)	6.6% (4.7–9.1)
<b>Autism spectrum disorders</b>	3.2% (2.7–3.8)	4.8% (4.0–5.7)	1.7% (1.4–2.0)
<b>Attention-deficit hyperactivity disorder</b>	0.3% (0.2–0.5)	0.5% (0.3–0.7)	0.2% (0.1–0.3)
<b>Other mental disorders</b>	8.0% (6.1–10.1)	9.9% (7.5–12.4)	6.3% (4.7–7.9)

*Lancet Psychiatry 2020; 7: 148–61*

### Social security benefits and schemes implemented in the district of Tumakuru

- Scholarship for students
- Reimbursement of education fee to the students for higher education
- Distribution of aids and appliances- talking tap; tricycles; wheel chair, hearing aid, brail watch, walking stick etc.
- 1 lakh rupees loan for self-employment, wherein they get Rs 50000 subsidy
- After the delivery Rs 2000/month child care support money to the visually challenged mothers for 2 years
- Unemployment benefit of Rs 1000/month to persons with disability in the age group of 25-45 years, who have completed 10<sup>th</sup> standard and above
- For any surgical procedure to minimize the disability, Rs 1,00,000 compensation would be provided
- If a person with disability get married to a normal individual, couple gets Rs 50000 in their joint account, which will be kept as FD for 5 years duration
- Scheme to encourage them to take up competitive exams
- Appreciation money for individuals taking part in sports and cultural programmes

*(Source: Information leaflet prepared by disability welfare department, Tumakur district)*

### Mental Health in the State of Karnataka

According to the Karnataka Mental Health Report-2019 (Source: CHD Group - Karnataka Mental Health Report 2018-19, www.chdefforts.org) more than a million people sought mental healthcare in public

health institutions across Karnataka during 2018-19, and depression and general anxiety disorders constituted 34% of the cases.

This reports also revealed that, severe mental health issues (schizophrenia and bipolar disorder) and alcohol and substance abuse constituted 18.4% and 11.2% of the cases, respectively. The rest fell in the category of suicide and diseases involving co-morbid conditions, referral cases, idiopathic ailments, and rare diseases

The report noted that only 0.37% of the State's budget health expenditure was allocated towards mental health, of which 74.4% and 62.4% were utilized by the District Mental Health Programme (DMHP) and Manasadhara, respectively. The DMHP has been implemented in all 30 districts since 2016-17.

Among the common mental disorders, the most were reported from Raichur district (17.7%), followed by Bidar (9.3%), Chickballapur (7.7%), and Bengaluru Urban (7.5%). The lowest number of cases were reported in Vijayapura (0.6%), Yadgir (0.7%) and Kodagu (0.8%).

Over the course of the year, 1,874,330 cases of severe mental disorder were reported across the State's public health institutions. Raichur (13.2%) accounted for the most, followed by Bidar (7.3%) and Ballari (6.1%). Kodagu (0.7%) and Chikkamagaluru (1%) reported the least number of cases. Such cases were higher in Bengaluru Urban (4.1%) than Bengaluru Rural (1.7%).

A majority of alcohol and substance use disorders were reported from Raichur (25.1%), followed by Chickballapur (17.3%) and Bidar (15.7%). Bengaluru Urban (4.2%) reported more cases than Bengaluru Rural (1.3%).

Since 2016-17, DMHP is implemented in all 30 districts as well as in Bruhat Bengaluru Mahanagara Palike (BBMP) i.e. total 31 DMHPs. DMHP also covers 10 talukas under Taluka Mental Health Program (TMHP) wherein 1 psychiatrist and 1 social worker is recruited per taluka. Presently, 216 DMHP staff and 11 TMHP are recruited throughout Karnataka. In 2018-19, 47240 personnel were trained in 30 districts. In 2018-19, there were 1,001,717 consultations in public health institutions across Karnataka.

In the year 2018-19, 29,005 people with suicidal thoughts sought assistance in the state of Karnataka. Majority of the consultations were reported in Hassan district (25.6%) and Haveri district (18.8%). 12.1% of the consultations were reported from Bellary. Bengaluru urban (2.1%) reported more cases than its rural counterpart (0.7%). No consultations for suicidal thoughts were reported in Bijapur district.

## RESEARCH STUDIES ON CARERS AND CHALLENGES OF CARING

Providing care 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, caring will involve variable amounts of physical work.

“Appraisal of caring” is understood as a construct existing in the “stress-appraisal-coping” framework, and implies that the experience of caring 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 caring experience in the “stress-appraisal-coping” framework is assessment of both the negative and positive subjective consequences of caring.

Many studies from India evaluated the burden experienced by the carers of patients with schizophrenia. However, there is dearth of data in relation to caring experience, especially assessment of positive caring 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).

### Caring 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).

### Caring and Mental illness

Mental disorders were the second leading cause of disease burden in terms of years lived with disability (YLDs) and the sixth leading cause of disability-adjusted life-years (DALYs) in the world in 2017, posing a serious challenge to health systems, particularly in low-income and middle-income countries.

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 with 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 for their mentally ill family members, their stress and burdens need to be addressed in the interest of the person with mental illness. Caring for chronically mentally ill family members disrupts the normal functions of families, and it almost always causes stress in the family (Alliance, 2012). Caring 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 a variety of psychosocial needs: Understanding illness, managing the ill family member, dealing with stigma, involving them in community activities, etc (Sales, 2003).

The nature of the relationship between carer and the mentally ill person, interpersonal relations 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, caring beliefs and values have been found to be significantly related to the caring. The carers should be acknowledged and looked upon as a resource in the mental health programme (Janardhana, Raghunandan, Naidu, Saraswathi, & Seshan, 2015).

### Caring 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 the 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 caring 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 caring 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, identifying 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 caring may adversely affect the physical and mental health of the carers (Martire, Lustig, Schulz, Miller, & Helgeson, 2004).

### Impact of caring on carers

Studies carried out in the area of mental illness, show 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 caring. 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 caring.

### **Need for addressing the caring issue**

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 caring using healthy coping strategies and also improve their caring 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.

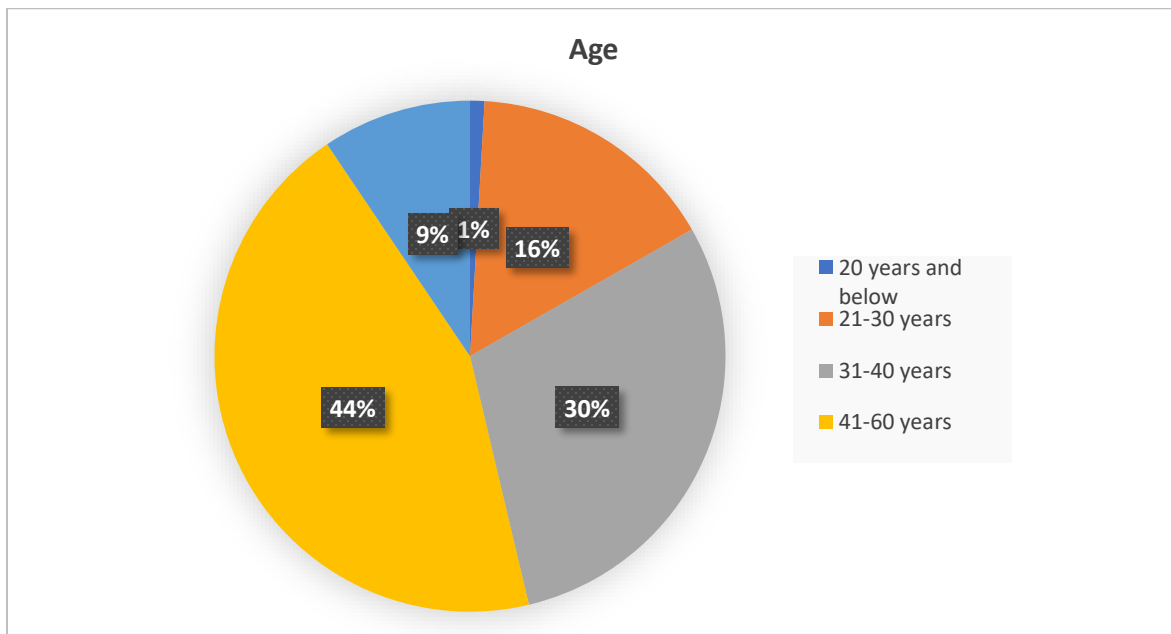
## RESULTS OF THE BASELINE SURVEY

### CARERS PROFILE

#### 1: Age of the Carers

Majority of the care givers were aged between 41-60 years (44.2%). The mean age of 44.61 ( $\pm 12.832$ ) also indicates the same. There is a very small proportion (0.9%) of care givers who were below 20 years of age.

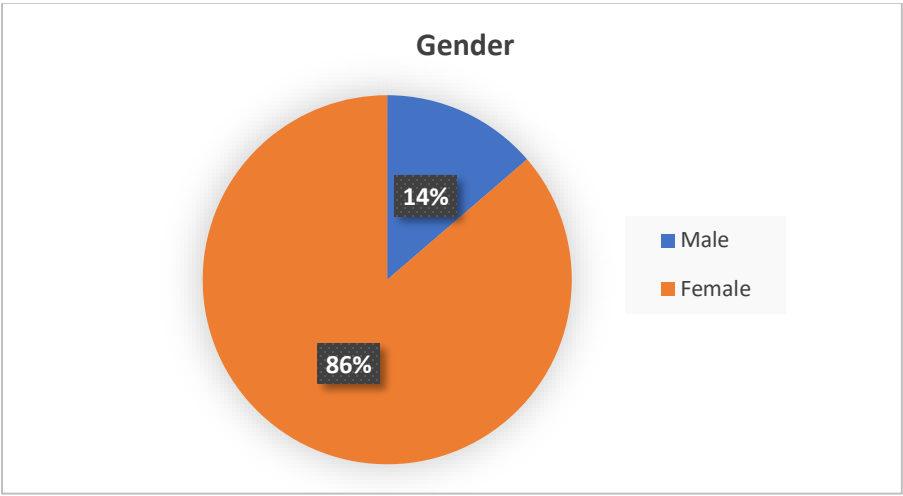
Age	Frequency (N=436)	Percent
20 years and below	4	0.9
21-30 years	69	15.8
31-40 years	129	29.5
41-60 years	193	44.2
Above 60 years	41	9.4
Mean Age	44.61 ( $\pm 12.832$ )	



#### 2: Gender of the Carers

Significantly large proportion of carers were women (86.4%).

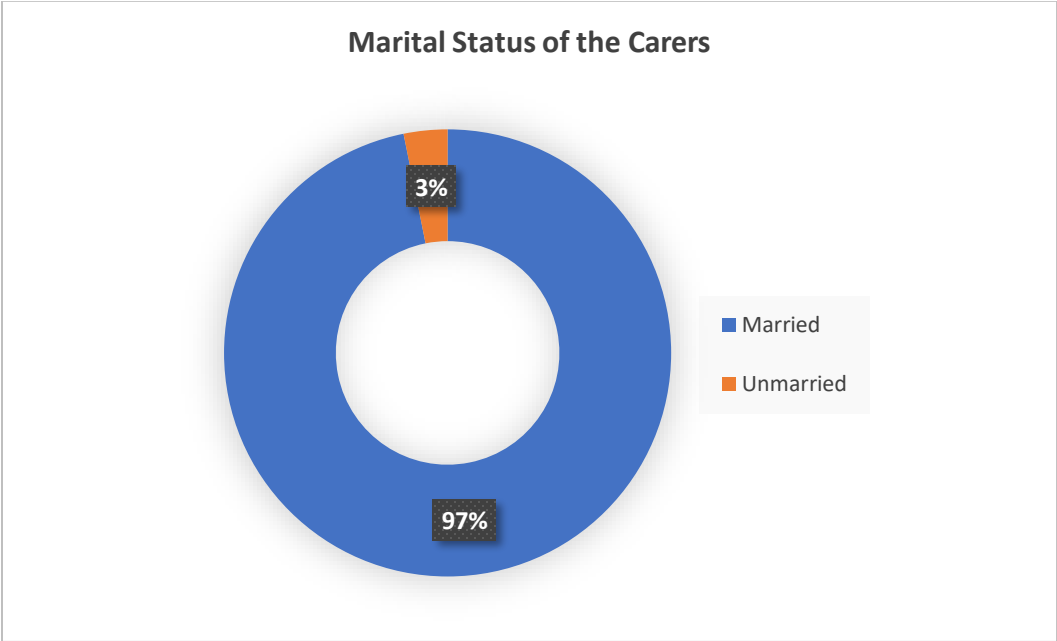
Gender	Frequency (N=436)	Percent
Male	59	13.5
Female	377	86.4



**3: Marital Status of the Carers**

Large number of the carers were married (98.1%).

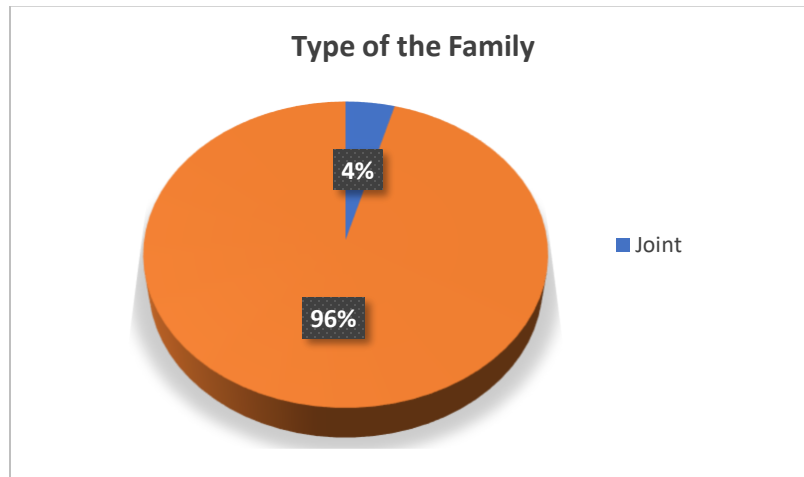
Marital Status	Frequency (N=436)	Percent
Married	428	98.1
Unmarried	8	1.9



**4: Type of Family**

Majority of the carers were hailing from nuclear families (95.7%).

Family Type	Frequency (N=436)	Percent
Joint	19	4.3
Nuclear	417	95.7



### 5: Details of the Household

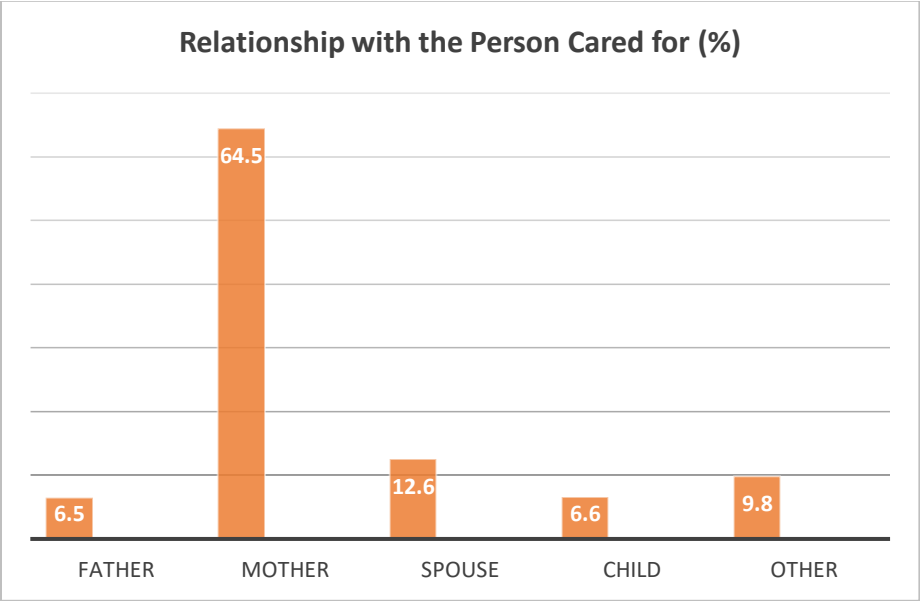
On an average, each household had around four to five members indicated by the mean scores of 4.54 ( $\pm 1.734$ ) members. Each of the households had around one to three males and females indicated by the mean scores of 2.25 ( $\pm 1.100$ ) and 2.28 ( $\pm 1.110$ ) respectively. None of the participants had children as indicated by the mean score .00.

Household Details	Mean	SD
Number of household members	4.54	$\pm 1.734$
Number of men	2.25	$\pm 1.100$
Number of women	2.28	$\pm 1.110$
Number of children	.00	$\pm .000$

### 6: Relationship with the Person Cared for

Majority of the carers were mothers (64.5%) followed by spouse (12.6%) and significant others (9.8%).

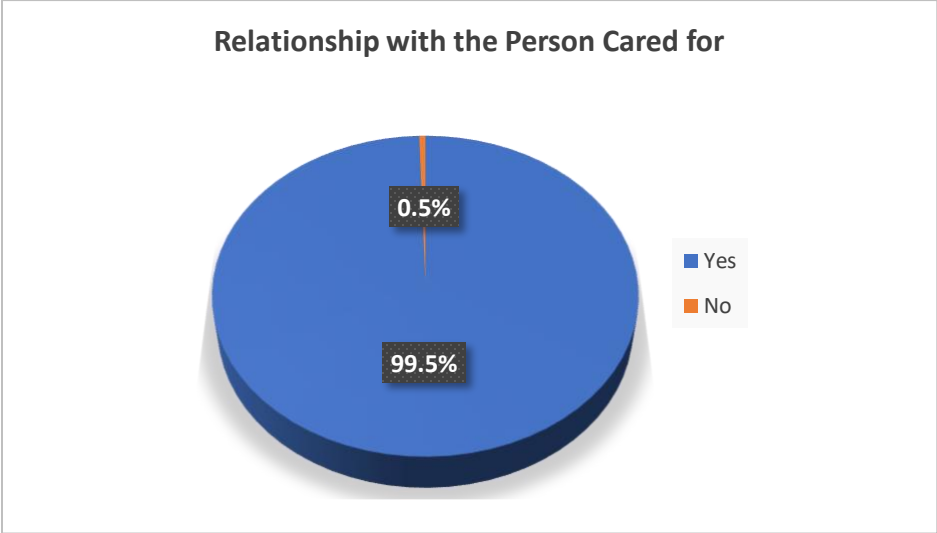
Relation	Frequency (N=436)	Percent
Father	28	6.5
Mother	281	64.5
Spouse	55	12.6
Child	29	6.6
Other	43	9.8



**7: Availability of Identity Card**

Almost all the carers (99.5%) had identity cards.

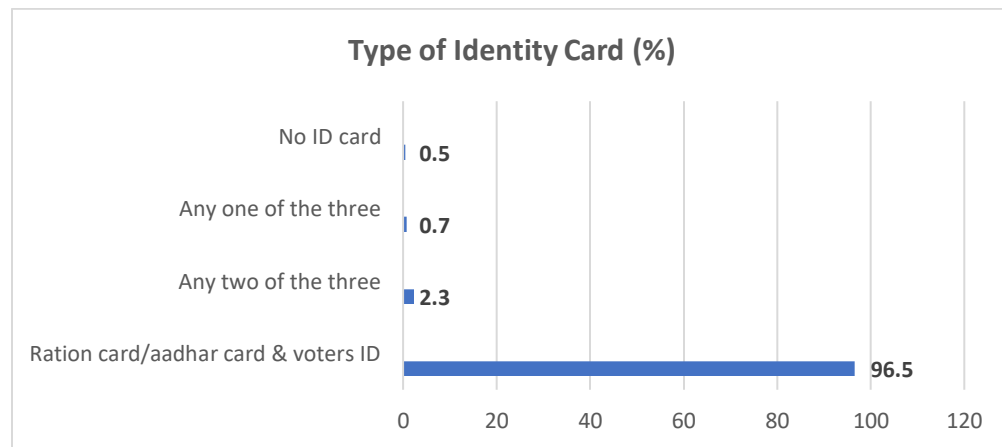
Availability of ID card	Frequency (N=436)	Percent
Yes	434	99.5
No	2	.5



### 8: Type of Identity Card

96.5% of the carers had ration cards/aadhar cards and voters ID as their identity proof.

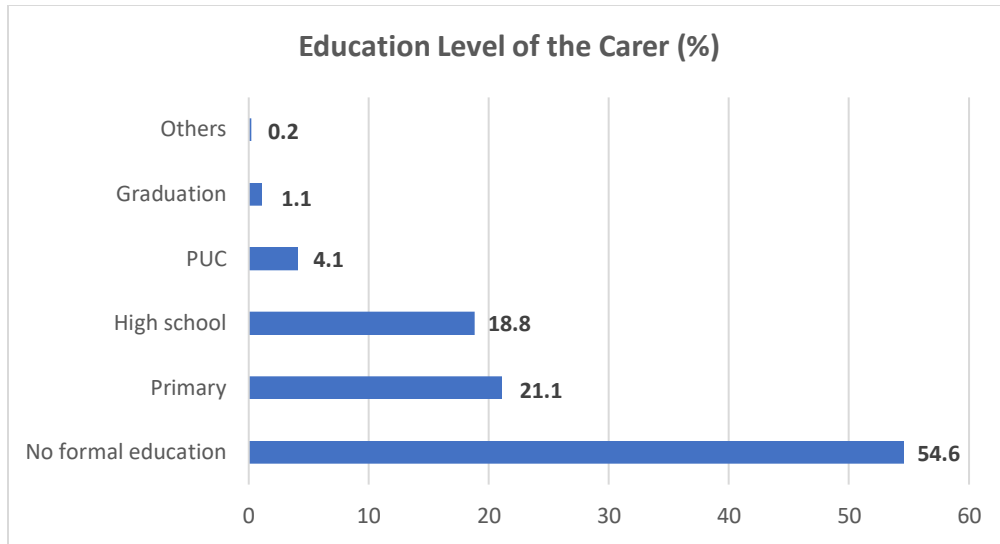
Type of ID Card	Frequency (N=436)	Percent
Ration card/aadhar card & voters ID	421	96.5
Any two of the three	10	2.3
Any one of the three	3	.7
No ID card	2	.5



### 9: Education Level of the Carer

Majority (54.06%) of the carers did not have formal education. Among the few others who were educated, 21.1% have completed their primary level of education and 18.8% have completed their high school.

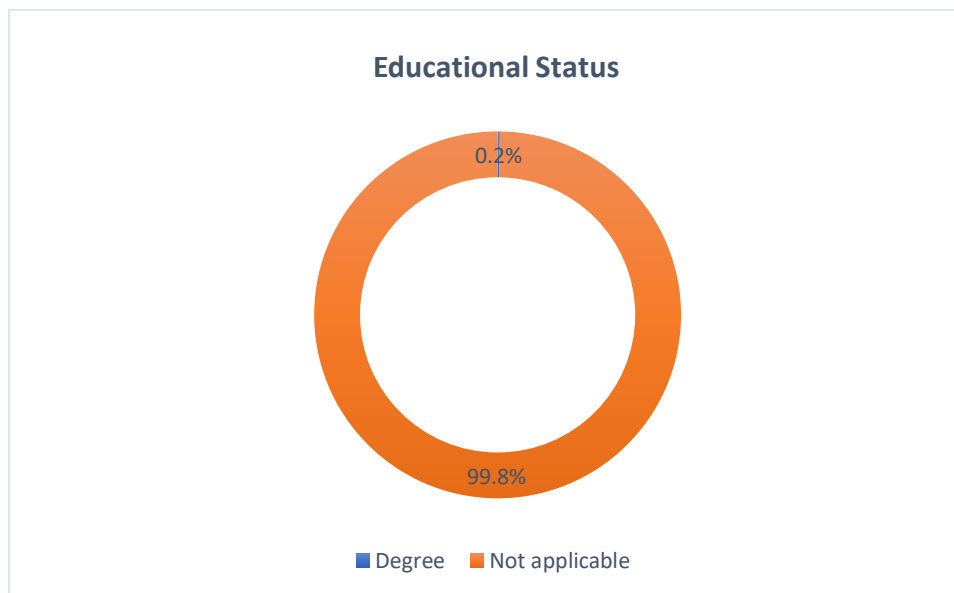
Level of education	Frequency (N=436)	Percent
No formal education	238	54.6
Primary	92	21.1
High school	82	18.8
PUC	18	4.1
Graduation	5	1.1
Others	1	.2



### 10: Present Education Status

Currently, almost all the carers (99.8%) were not undergoing any formal education.

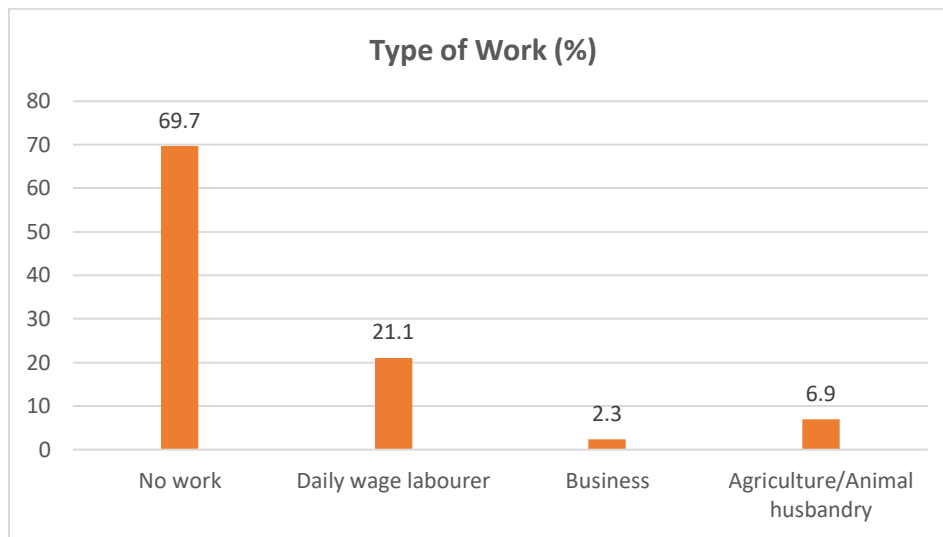
Education Status	Frequency (N=436)	Percent
Degree	1	.2
Not Applicable	435	99.8
Vocational Training	0	.0



### 11: Type of Work

With regards to the employment status of the carers, 69.7% of them are not involved in any income generating work. Of the small proportion of carers who are working, 21.1% were involved in daily wage work, followed agriculture/animal husbandry (6.9%).

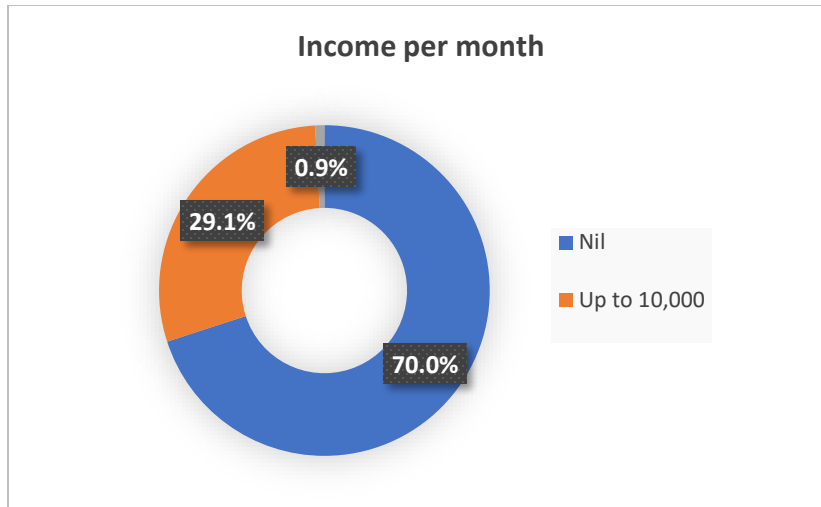
Work type	Frequency (N=436)	Percent
No work	304	69.7
Daily wage labourer	92	21.1
Business	10	2.3
Agriculture/Animal husbandry	30	6.9
Service	0	.0



### 12: Income per Month

As seen in the Table 11 and Figure 10 as most of the carers are not employed, majority (70%) didn't have any 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.

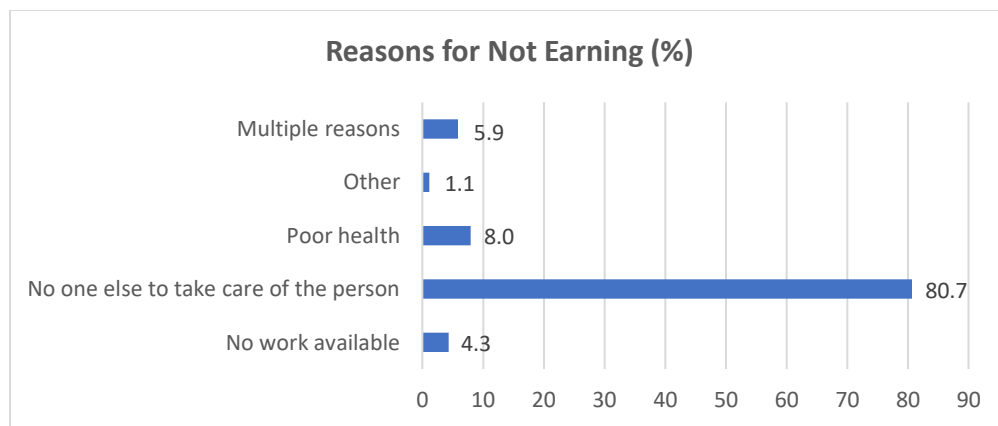
Income	Frequency (N=436)	Percent
Nil	305	70.0
Up to 10,000	127	29.1
Above 10,000	4	.9



### 13: Reasons for not Earning

Lack of any other member to take care of the person with chronic illness is cited by majority (80.7%) as the reason for not earning.

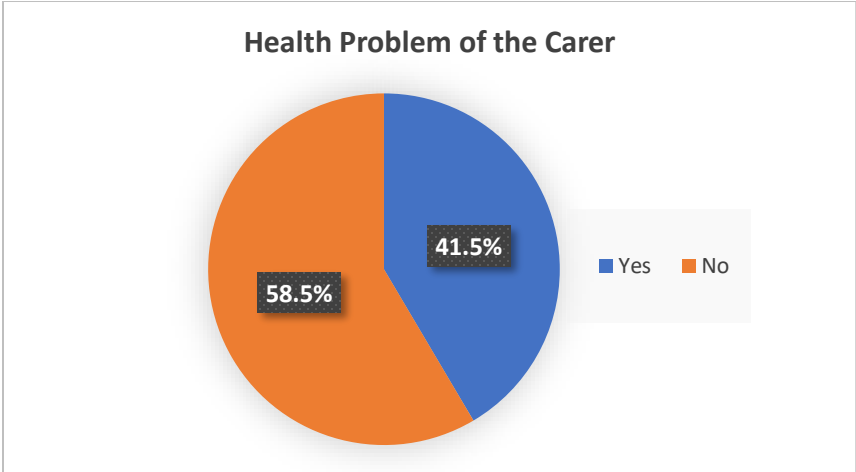
Reasons	Frequency (N=436)	Percent
No work available	19	4.3
No one else to take care of the person	352	80.7
Poor health	34	8.0
Other	5	1.1
Multiple reasons	26	5.9



### 14: Health Problem of the Carer

58.5% didn't reported of having any health issues. On the other hand, 41.5% of the carers said that they are having health issues.

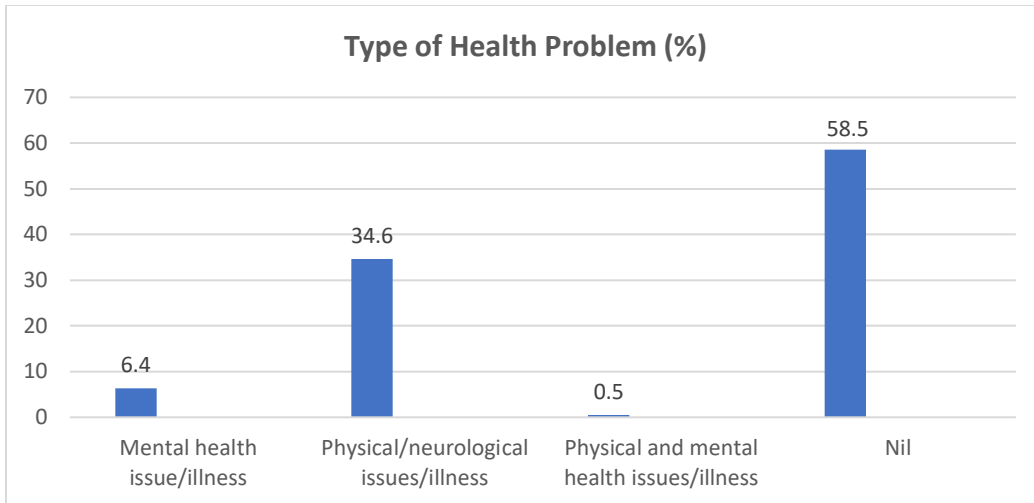
Health Problem	Frequency (N=436)	Percent
Yes	181	41.5
No	255	58.5



**15: Type of Health Problem**

Of those who reported of having health issues, large number of them found to be having physical/neurological issues (34.6%), ranging from head-aches and pains to blood pressure, having undergone surgeries etc.

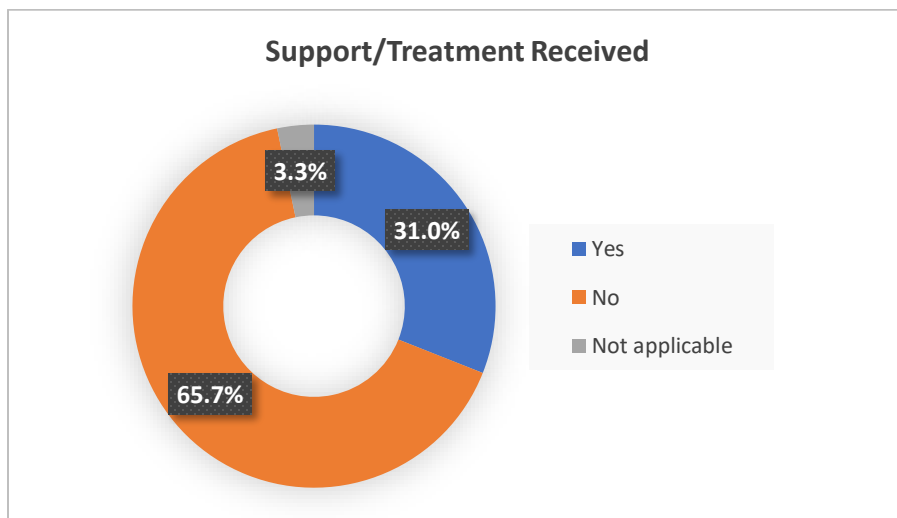
Health Problem	Frequency (N=436)	Percent
Mental health issue/illness	28	6.4
Physical/neurological issues/illness	151	34.6
Physical and mental health issues/illness	2	.5
Nil	255	58.5



### 16: Support/Treatment Received

Despite of having health problems, large number of them (28.2%) did not receive any help/treatment for the same.

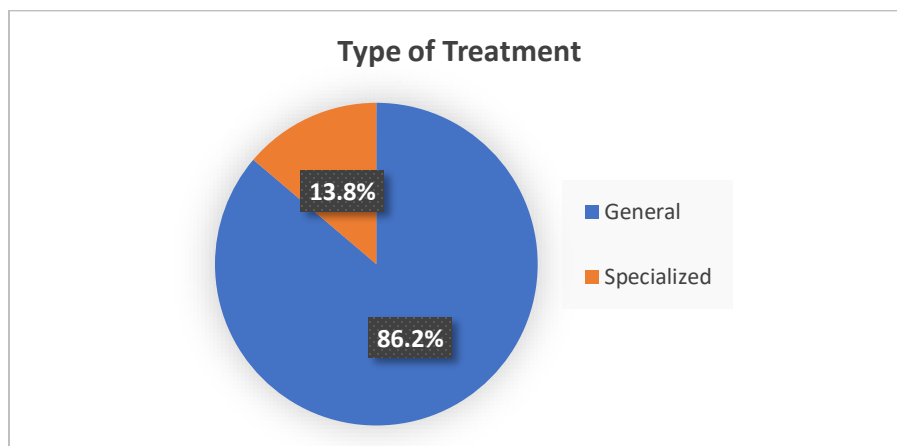
Support	Frequency (N=436)	Percent
Yes	58	13.3
No	123	28.2
Not applicable	255	58.5



### 17: Type of Treatment

Majority of the carers went for general health care treatment (86.2%).

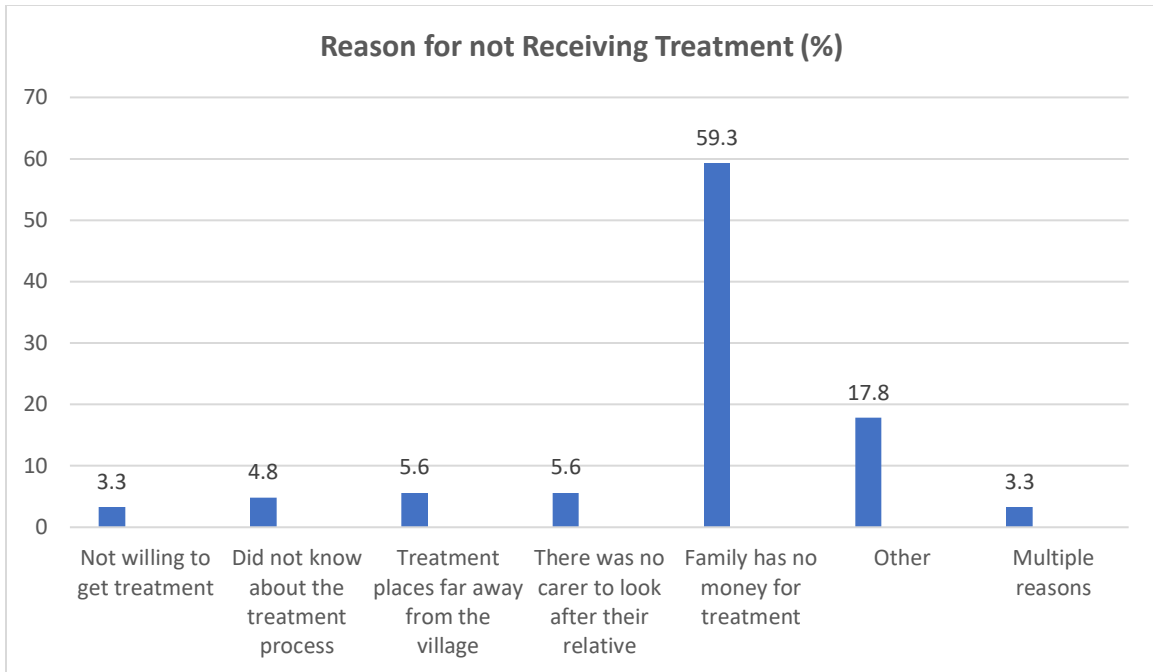
Response	Frequency (N=58)	Percent
General	50	86.2
Specialized	8	13.8



### 18: Reason for not Receiving Treatment

The carers have not received treatment for various reasons. Majority (59.3%) of them didn't go for treatment for their health problems due to financial constraint.

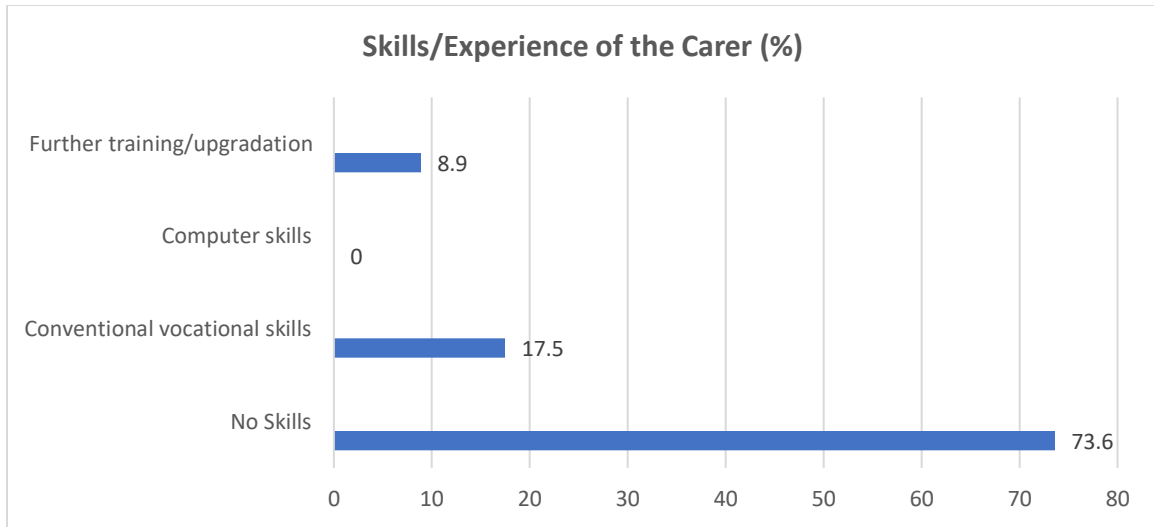
Reasons	Frequency (N=123)	Percent
Not willing to get treatment	4	3.3
Did not know about the treatment process	6	4.8
Treatment places far away from the village	7	5.6
There was no carer to look after their relative	7	5.6
Family has no money for treatment	73	59.3
Other	22	17.8
Multiple reasons	4	3.3



### 19: Skills/Experience of the Carer

As far as vocational skills of the carers are concerned, majority (73.6%) of them have reported of not having any skills. 17.5% have conventional vocational skills like basket making, candle making, beedi rolling, dairy farming, tailoring, mat making etc.

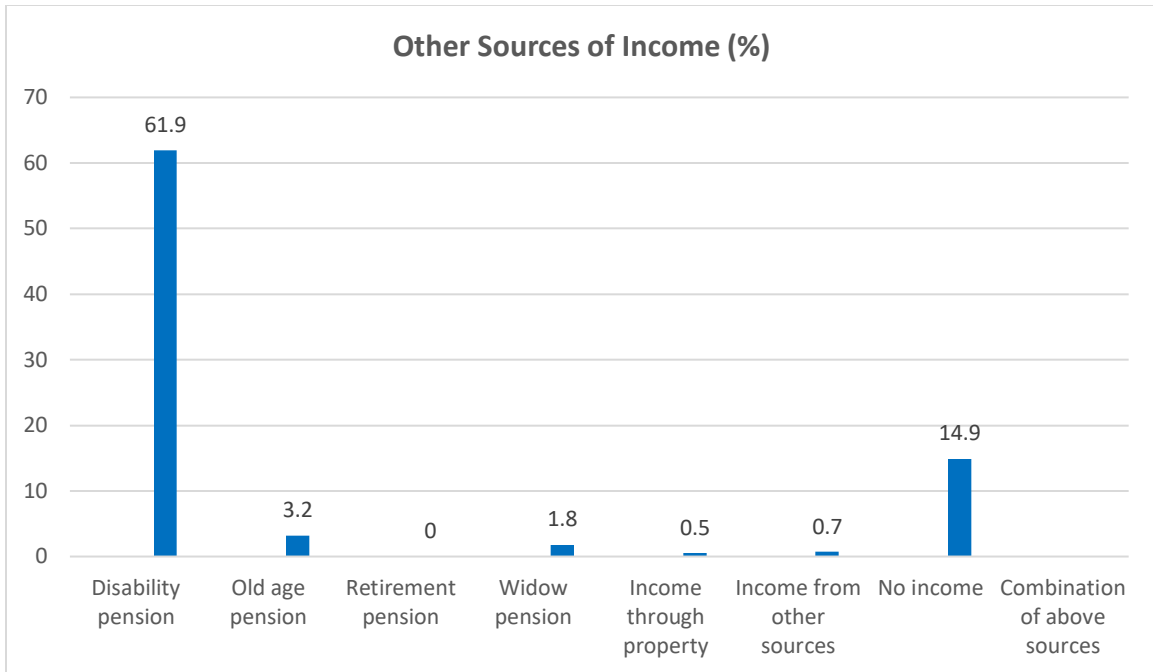
Skills/Experience	Frequency (N=436)	Percent
No Skills	321	73.6
Conventional vocational skills	76	17.5
Computer skills	0	.0
Further training/upgradation	39	8.9



**Table 20: Other Sources of Income**

Apart from the income received through one's job, the other sources of income for majority (61.9%) of the families were from disability pension, that the person with chronic illness received.

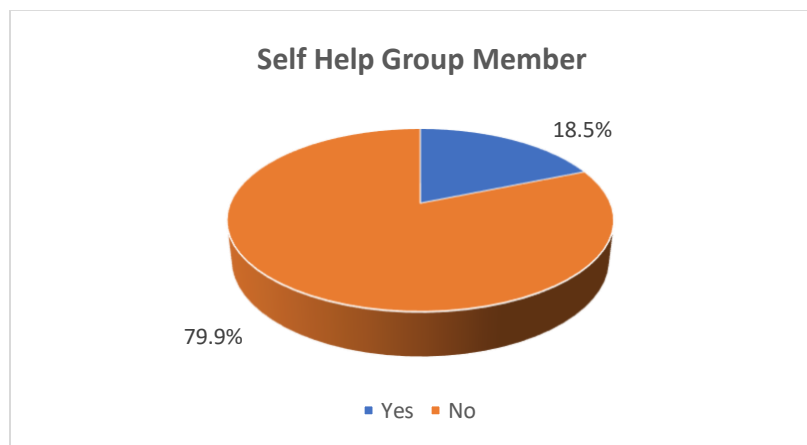
Other Income	Frequency (N=436)	Percent
Disability pension	274	61.9
Old age pension	14	3.2
Retirement pension	0	.0
Widow pension	8	1.8
Income through property	2	.5
Income from other sources	3	.7
No income	66	14.9
Combination of above sources	69	15.6



### 21: Self Help Group Member

Large number of participants were not members of SHG groups (79.9%).

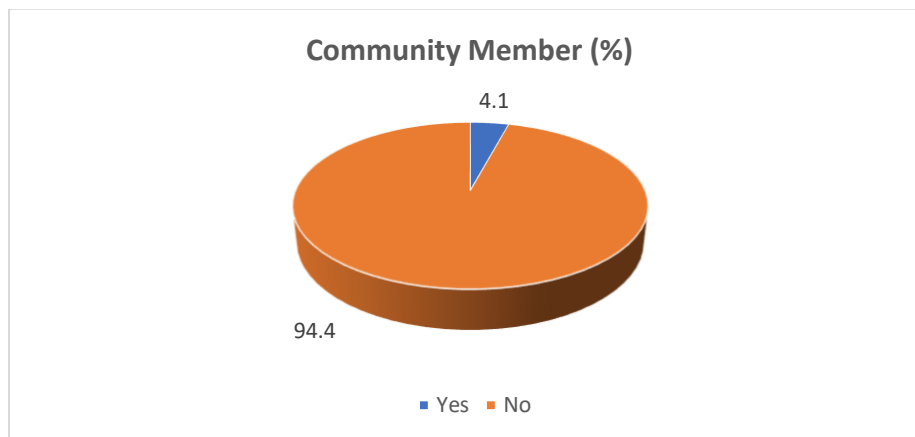
SHG Member	Frequency (N=436)	Percent
Yes	82	18.5
No	354	79.9



### 22: Community Member

94.4% of the carers were not community members.

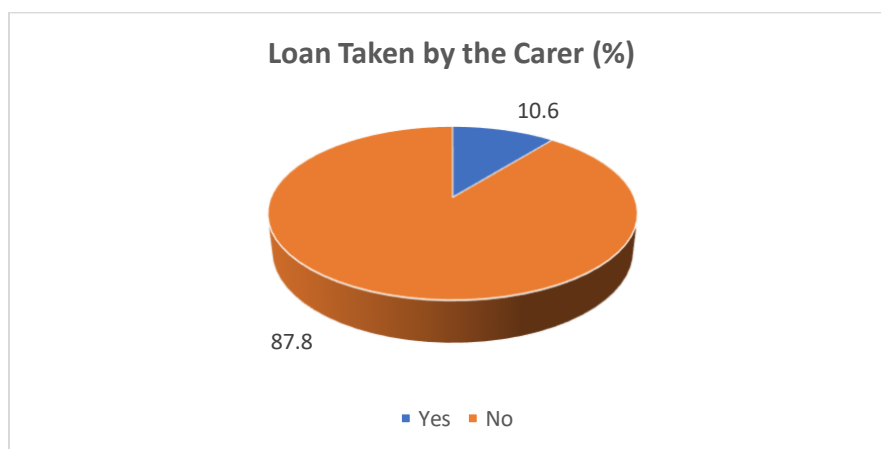
Community Member	Frequency (N=436)	Percent
Yes	18	4.1
No	418	94.4



### 23: Loan Taken by the Carer

87.8% of the carers have reported that they have not taken loans to manage the expenses.

Loan	Frequency (N=436)	Percent
Yes	47	10.6
No	389	87.8

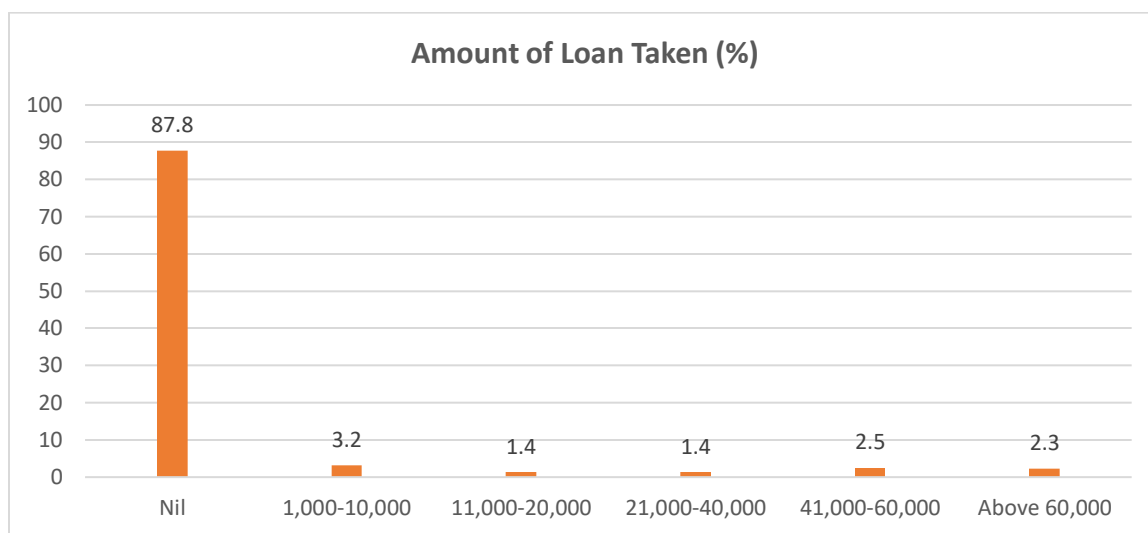


### 24: Amount of Loan Taken

Although majority of them didn't take loan, of those who took the amount ranged from ₹1000 to above ₹60,000.

Amount	Frequency (N=436)	Percent
Nil	389	87.8

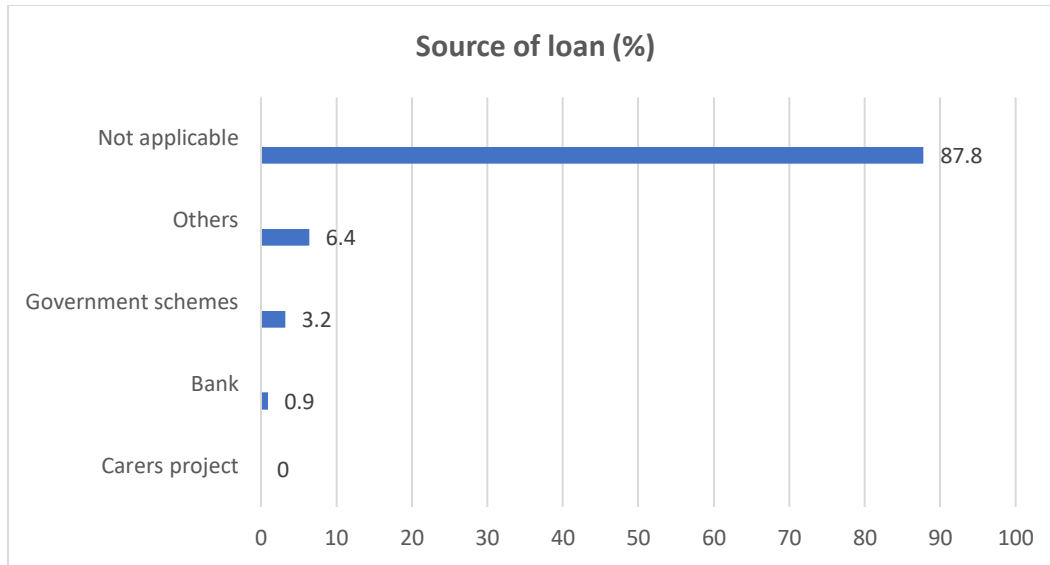
1,000-10,000	14	3.2
11,000-20,000	6	1.4
21,000-40,000	6	1.4
41,000-60,000	11	2.5
Above 60,000	10	2.3



## 25: Source of loan

Among those who have revealed about the source of loan, for majority of carers (6.4%), the source of loan was neither from the Carers Project nor from Bank, but from other undisclosed sources.

Source of Loan	Frequency (N=436)	Percent
Carers project	0	0
Bank	4	.9
Government schemes	14	3.2
Others	28	6.4
Not applicable	389	87.8

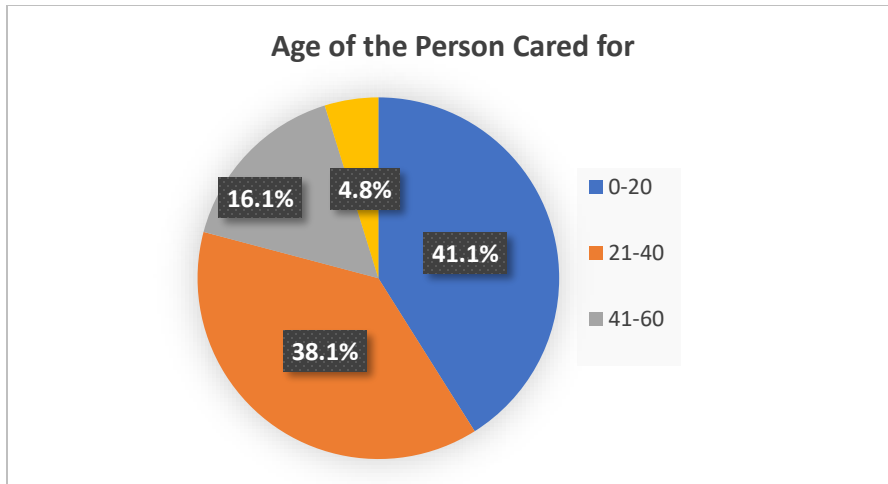


## DETAILS OF PERSON CARED FOR

### 26: Age of the Person Cared for

Majority (41.1%) of the persons receiving care belonged to the age group of 0-20 years, followed by the age group of 21-40 years (38.1%).

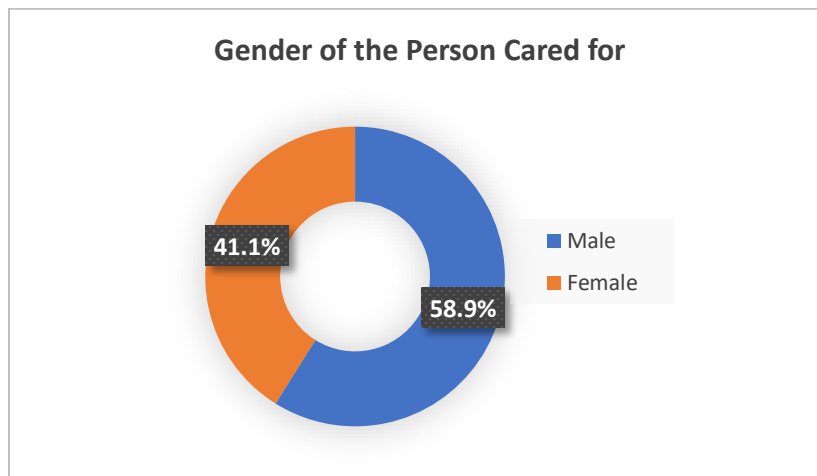
Age	Frequency (N=436)	Percent
0-20	179	41.1
21-40	166	38.1
41-60	70	16.1
61-80	21	4.8
Above 80	0	.0



**27: Gender of the Person Cared for**

Comparing to females (41.1%), majority of the persons with chronic illness were males (58.9%).

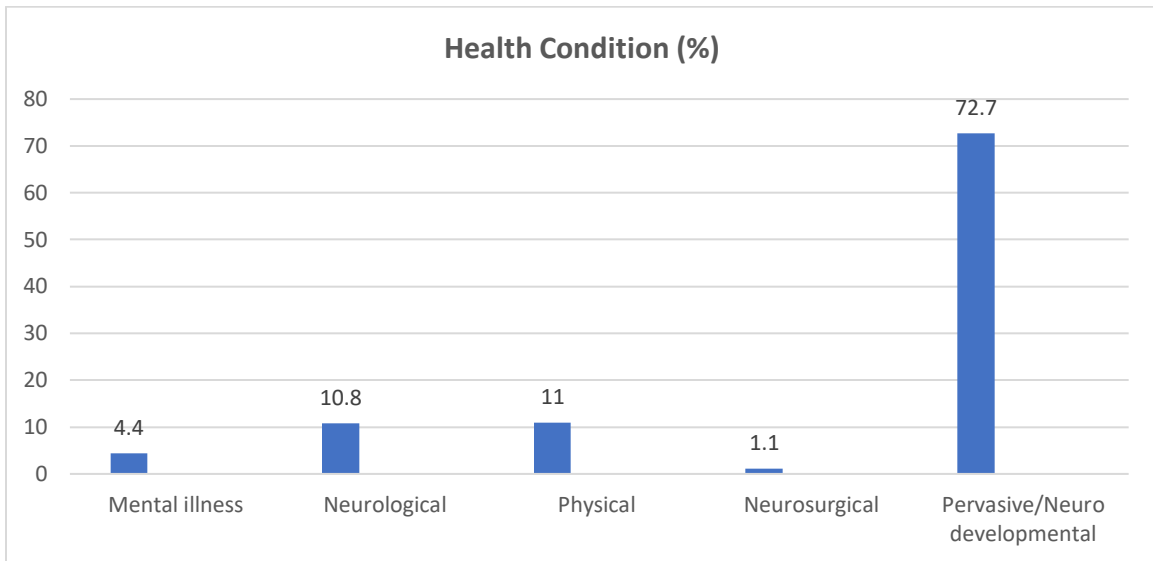
Gender	Frequency (N=436)	Percent
Male	257	58.9
Female	179	41.1



**28: Health Condition**

Large number of the persons (72.7%) requiring care were having pervasive developmental disorders/neuro developmental disorders, such as loco-motor problems, speech and hearing impairment, visual impairment, intellectual developmental disorders etc.

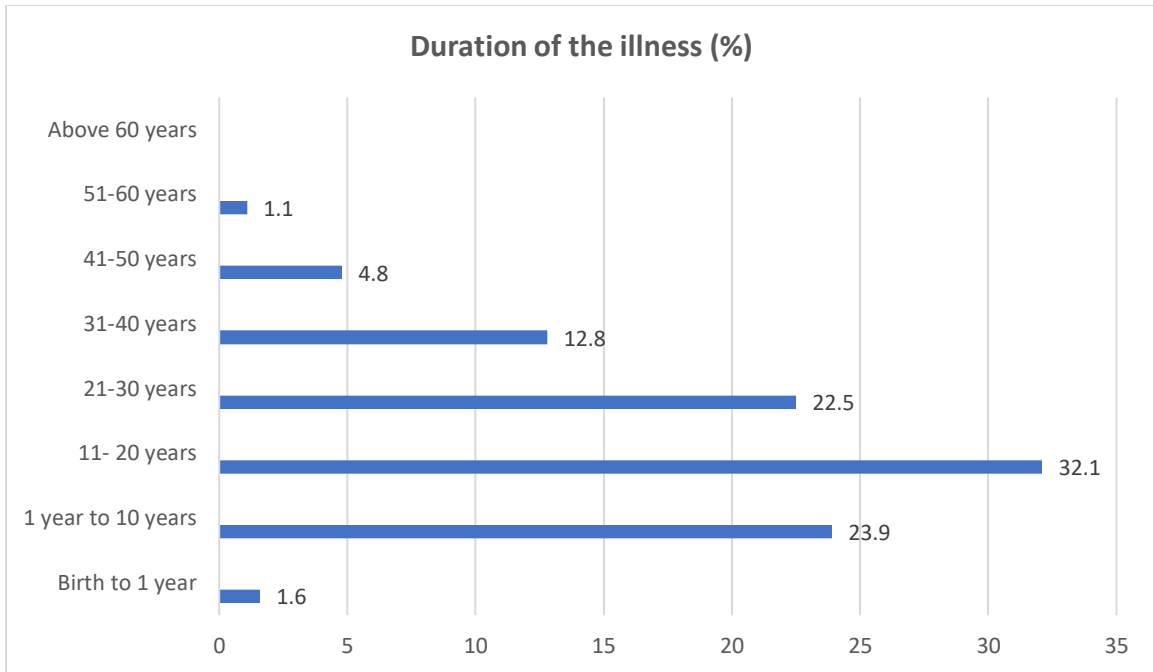
Health Condition	Frequency (N=436)	Percent
Mental illness	19	4.4
Neurological	47	10.8
Physical	48	11.0
Neurosurgical	5	1.1
Pervasive/Neuro developmental	317	72.7



### 29: Duration of the illness

The duration of illness of predominantly falls between 11-20 years (32.1%), followed by 1-10 years (23.9%) and 21-30 years (22.5%). This could be an indication for the chronicity of the condition.

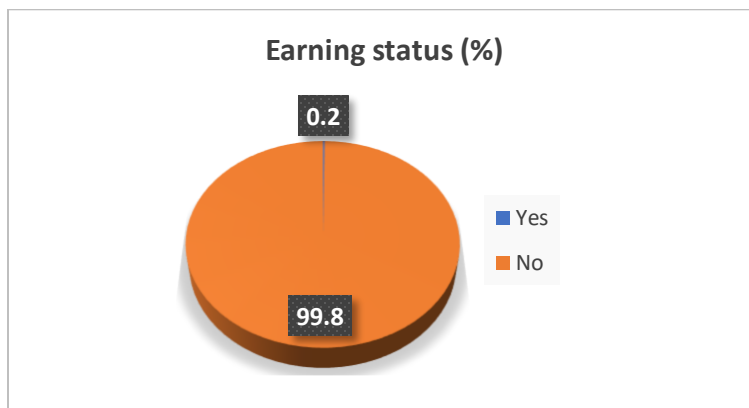
Duration	Frequency (N=436)	Percent
Birth to 1 year	7	1.6
1 year to 10 years	104	23.9
11- 20 years	140	32.1
21-30 years	98	22.5
31-40 years	56	12.8
41-50 years	21	4.8
51-60 years	5	1.1
Above 60 years	5	1.1



### 30: Earning status

Almost all the persons who were cared for were not earning (99.5%). This shows the loss of productivity in individuals with health issues.

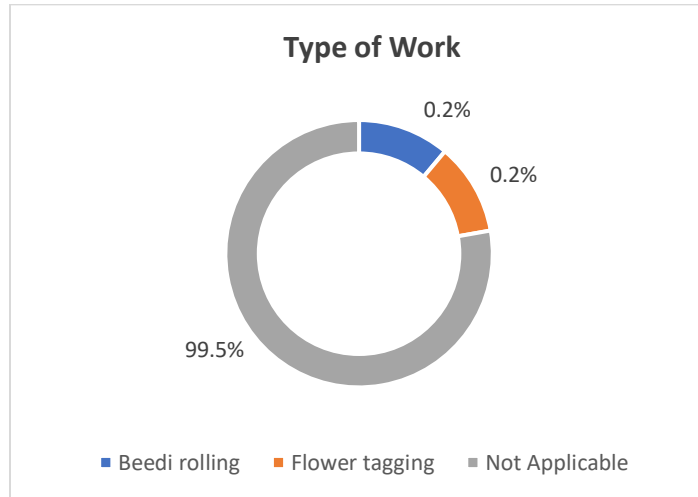
Whether earning?	Frequency (N=436)	Percent
Yes	2	.5
No	434	99.5



### 31: Type of Work

The results above corroborate Table No 30 that majority (99.5%) of the persons with chronic illness are not employed.

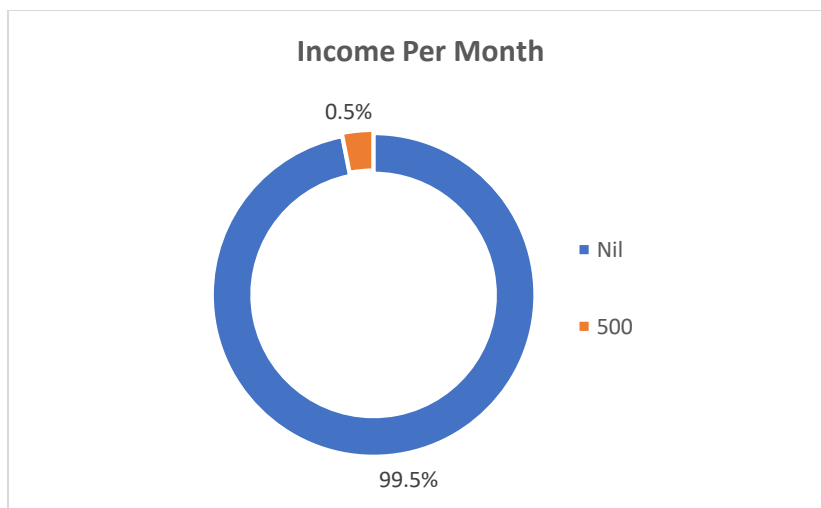
Work	Frequency (N=436)	Percent
Beedi rolling	1	.2
Flower tagging	1	.2
Not Applicable	434	99.5



### 32: Income Per Month

As majority of the persons cared for do not work, majority of them (99.5%) didn't have any earning.

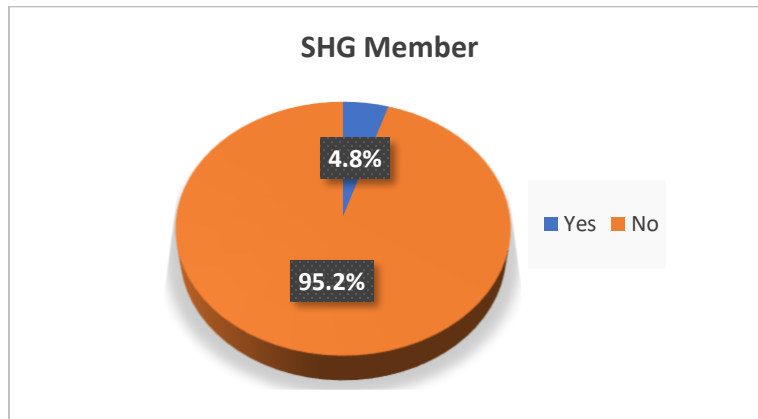
Income in Rupees	Frequency (N=436)	Percent
Nil	434	99.5
500	2	.5



### 33: SHG Member

Huge number (95.2%) of the persons cared for were not SHG members.

Member	Frequency (N=436)	Percent
Yes	21	4.8
No	415	95.2



## RESULTS OF WELL-BEING QUESTIONNAIRE

### 34: Concerns about Personal Life

Majority of the carers reported a little concern about their personal life, in terms of having time for self (62.6%), taking a break from caring (67.2%), future planning (59.4%), and being able to provide continued care (58.3%).

Question	Response	Frequency (N=436)	Percent
How concerned are you about having enough time to yourself?	A lot	1	.2
	Quite a bit	162	37.2
	A little	273	62.6
	Not at all	0	.0
How concerned are you about being able to take a break from caring?	A lot	0	.0
	Quite a bit	143	32.8
	A little	293	67.2
	Not at all	0	.0
How concerned are you about being able to plan for the future?	A lot	0	.0
	Quite a bit	177	40.6
	A little	259	59.4
	Not at all	0	.0
How concerned are you about being able to continue caring?	A lot	0	.0
	Quite a bit	182	41.7
	A little	254	58.3
	Not at all	0	.0

### 35: Concerns about Relationships and Social Life

With regard to the relationship and social life, 55.7% were concerned that there has been a strain in the relationship with friends and family because of the caring responsibilities and felt like drifting apart. Because of the situation, 58% of them have felt like feeling isolated. To a little extent (58.9%) they perceived the support from family and friends.

Question	Response	Frequency (N=436)	Percent
How concerned are you about strains in your relationships with friends and family because of your caring responsibilities?	A lot	0	.0
	Quite a bit	193	44.3
	A little	243	55.7
	Not at all	0	.0
“Drifting apart” from friends and family because your caring responsibilities limit the time you have to keep in contact with them?	A lot	0	.0
	Quite a bit	193	44.3
	A little	243	55.7
	Not at all	0	.0
Feeling isolated and lonely because of the situation you are in?	A lot	0	.0
	Quite a bit	183	42.0
	A little	253	58.0
	Not at all	0	.0
Getting the support, you need from family and friends?	A lot	1	.2
	Quite a bit	177	40.6
	A little	257	58.9
	Not at all	0	.0

### 36: Concerns about Financial Condition

In spite of the financial difficulties, 58.3% have expressed a little concern about their financial situation and having to cover extra costs of caring (52.1%) like visiting the hospital, for medication etc.

Question	Response	Frequency (N=436)	Percent
How concerned are you about your financial situation?	A lot	0	.0
	Quite a bit	182	41.7
	A little	254	58.3
	Not at all	0	.0
Having to cover extra costs of caring (e.g., trips to hospital, medication)?	A lot	2	.5
	Quite a bit	207	47.5
	A little	227	52.1
	Not at all	0	.0

### 37: Concerns about Physical Health

Most of the carers (62.8%) were concerned a bit about their own physical health.

Question	Response	Frequency (N=436)	Percent
How concerned are you about - your own physical health?	A lot	0	.0
	Quite a bit	161	36.9
	A little	274	62.8
	Not at all	0	.0

### 38: Concerns about Mental Health

A bit of mental health concerns was reported by the carers, pertaining to constant anxiety (56.7%), feeling depressed (65.1%), staying positive in life (61.9%), decreased sleep due to the worry/stress (68.8%) and feeling exhausted (63.8%).

Question	Response	Frequency (N=436)	Percent
How concerned are you about being able to cope with the "constant anxiety" of caring?	A lot	0	.0
	Quite a bit	189	43.3
	A little	247	56.7
	Not at all	0	.0
feeling depressed?	A lot	0	.0
	Quite a bit	152	34.9
	A little	284	65.1
	Not at all	0	.0
being able to see anything positive in your life?	A lot	0	.0
	Quite a bit	166	38.1
	A little	270	61.9
	Not at all	0	.0

lack of sleep because of worry or stress?	A lot	0	.0
	Quite a bit	136	31.2
	A little	300	68.8
	Not at all	0	.0
feeling so exhausted you can function properly?	A lot	1	.2
	Quite a bit	157	36.0
	A little	278	63.8
	Not at all	0	.0

### 39: Concerns about Being Treated Differently

Majority of the carers (60.1%), expressed a lot of concerns on being treated differently by others for having a dependent family member who is unwell.

Question	Response	Frequency (N=436)	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	1	.2
	Yes, a little	173	39.7
	Yes, a lot	262	60.1

## CONCLUSION

Being a carer is well-known to be stressful to the carer. Similar results have been found in this present survey. Understanding concerns and issues of carers is very crucial to enhance the wellbeing of both persons with disability and carers. Various factors such as 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. determine the severity of the caring burden. Therefore, naturally, if there is a tertiary support system along with other support, the wellbeing of the carers is often improved. As a result, the quality of caring and quality of life of the person who is cared for will also be higher with added support.

The District Disability Welfare Department of Tumakuru District has been active in implementing social security measures for persons with disability, which was launched by the Karnataka government. Monthly pensions are the most availed service for persons with disability, which is highlighted in the present study, wherein for most of the families, monthly pensions are a major source of income. The Department has also established a helpline to avail disability welfare benefits and an information leaflet has been circulated; however, there is a need to identify the barriers which are still in place to claiming and to establish support mechanisms to enable all those entitled to claim.

The present study highlighted that the wellbeing of carers is not a priority which could ultimately lead to burnout of carers. The national sample survey report highlighted the need for availability of carers and in this present study most of the individuals who required care had family members acting as carers. Hence, activities and programmes to focus on the wellbeing of carers are required too.

Financial stressors identified in this study could be addressed through vocational training for persons with disability, rehabilitation services, and income generation activities for carers. Pavagada Taluk stands last (in Tumkuru district) in regards to accessing loans from the existing banking sectors, and not many carers have registered themselves in SHGs. This highlights the need to empower carers to take actively part in social and economic programmes. It also calls for the involvement of Government and NGOs through a multi-sectorial approach and decentralization of services.

## REFERENCES

- <http://e-krishiuasb.karnataka.gov.in/ItemDetails.aspx?DepID=14&cropID=0&SubDepID=18#>
- <http://www.dwdsc.kar.nic.in/index.asp>
- [http://www.mospi.nic.in/sites/default/files/publication\\_reports/Persons\\_Disabilities\\_31mar21.pdf](http://www.mospi.nic.in/sites/default/files/publication_reports/Persons_Disabilities_31mar21.pdf)
- <https://skillsip.nsdscindia.org/sites/default/files/kps-document/karnataka-sg.pdf>
- [https://des.karnataka.gov.in/storage/pdf-files/CIS/Economic%20Survey%202020-21\\_Eng\\_Final\\_R.pdf](https://des.karnataka.gov.in/storage/pdf-files/CIS/Economic%20Survey%202020-21_Eng_Final_R.pdf)
- [http://www.mospi.nic.in/sites/default/files/publication\\_reports/Persons\\_Disabilities\\_31mar21.pdf](http://www.mospi.nic.in/sites/default/files/publication_reports/Persons_Disabilities_31mar21.pdf)
- [https://des.karnataka.gov.in/storage/pdf-files/CIS/Economic%20Survey%202020-21\\_Eng\\_Final\\_R.pdf](https://des.karnataka.gov.in/storage/pdf-files/CIS/Economic%20Survey%202020-21_Eng_Final_R.pdf)
- <https://www.chdgroup.org/wp-content/uploads/2020/09/Mental-Health-Report-1.pdf>

Alliance, F. C. (2012). Fact sheet: Selected caregiver statistics. *San Francisco, CA*.

Aschbrenner, K. A., Greenberg, J. S., Allen, S. M., & Seltzer, M. M. (2010). Subjective burden and personal gains among older parents of adults with serious mental illness. *Psychiatric Services, 61*(6), 605-611.

Avasthi, A. (2010). Preserve and strengthen family to promote mental health. *Indian journal of psychiatry, 52*(2), 113.

Awad, A. G., & Voruganti, L. N. (2008). The burden of schizophrenia on caregivers. *Pharmacoeconomics, 26*(2), 149-162.

Basu, S. (2000). Dimensions of tribal health in India. *Health and Population Perspectives and Issues, 23*(2), 61-70.

Berk, L., Berk, M., Dodd, S., Kelly, C., Cvetkovski, S., & Jorm, A. F. (2013). Evaluation of the acceptability and usefulness of an information website for caregivers of people with bipolar disorder. *BMC medicine, 11*(1), 162.

Brehaut, J. C., Kohen, D. E., Raina, P., Walter, S. D., Russell, D. J., Swinton, M., . . . Rosenbaum, P. (2004). The health of primary caregivers of children with cerebral palsy: how does it compare with that of other Canadian caregivers? *Pediatrics, 114*(2), e182-e191.

Chadda, R. K. (2014). Caring for the family caregivers of persons with mental illness. *Indian journal of psychiatry, 56*(3), 221.

Costa, G., & Ranci, C. (2010). Disability and Caregiving: A Step Toward Social Vulnerability? *Social Vulnerability in Europe* (pp. 159-185): Springer.

- Creado, D. A., Parkar, S. R., & Kamath, R. M. (2006). A comparison of the level of functioning in chronic schizophrenia with coping and burden in caregivers. *Indian journal of psychiatry*, 48(1), 27.
- Crews, J. E. (2012). Neither prepared nor rehearsed: The role of public health in disability and caregiving. *Multiple Dimensions of Caregiving and Disability* (pp. 83-97): Springer.
- Fave, A. D., Fianco, A., & Sartori, R. D. (2015). Psychological and relational resources in the experience of disability and caregiving. *Positive Psychology in Practice: Promoting Human Flourishing in Work, Health, Education, and Everyday Life, Second Edition*, 613-634.
- Fernandes, W., & Thukral, E. G. (1989). *Development, displacement, and rehabilitation: Issues for a national debate*: Indian Social Institute.
- Geere, J., Gona, J., Omondi, F., Kifalu, M., Newton, C., & Hartley, S. (2013). Caring for children with physical disability in Kenya: potential links between caregiving and carers' physical health. *Child: care, health and development*, 39(3), 381-392.
- Hoenig, J., & Hamilton, M. W. (1966). The schizophrenic patient in the community and his effect on the household. *International Journal of Social Psychiatry*, 12(3), 165-176.
- Jagannathan, A., Thirthalli, J., Hamza, A., Nagendra, H., & Gangadhar, B. (2014). Predictors of family caregiver burden in schizophrenia: Study from an in-patient tertiary care hospital in India. *Asian journal of psychiatry*, 8, 94-98.
- Janardhana, N., Raghunandan, S., Naidu, D. M., Saraswathi, L., & Seshan, V. (2015). Care giving of people with severe mental illness: An Indian experience. *Indian journal of psychological medicine*, 37(2), 184.
- Kate, N., Grover, S., Kulhara, P., & Nehra, R. (2013). Caregiving appraisal in schizophrenia: A study from India. *Social science & medicine*, 98, 135-140.
- Kate, N., Grover, S., Kulhara, P., & Nehra, R. (2014). Relationship of quality of life with coping and burden in primary caregivers of patients with schizophrenia. *International Journal of Social Psychiatry*, 60(2), 107-116.
- Kumar, C. N., Suresha, K. K., Thirthalli, J., Arunachala, U., & Gangadhar, B. N. (2015). Caregiver burden is associated with disability in schizophrenia: Results of a study from a rural setting of south India. *International Journal of Social Psychiatry*, 61(2), 157-163.
- The burden of mental disorders across the states of India: the Global Burden of Disease Study 1990–2017. India State-Level Disease Burden Initiative Mental Disorders Collaborators. *Lancet, Psychiatry*, 2020 <https://www.thelancet.com/action/showPdf?pii=S2215-0366%2819%2930475-4>
- Mahantu, Y. (2011). *Evaluation of a Community Mental Health programme in a tribal area—South India*. SCTIMST.
- Martire, L. M., Lustig, A. P., Schulz, R., Miller, G. E., & Helgeson, V. S. (2004). Is it beneficial to involve a family member? A meta-analysis of psychosocial interventions for chronic illness. *Health psychology*, 23(6), 599.

Mishra, S. K. (2002). Development, Displacement and Rehabilitation of Tribal People: A Case Study of Orissa. *Journal of Social Sciences*, 6(3), 197-208.

Organization, W. H. (2001). *The World Health Report 2001: Mental health: new understanding, new hope*: World Health Organization.

Perlick, D. A., Berk, L., Kaczynski, R., Gonzalez, J., Link, B., Dixon, L., . . . Miklowitz, D. J. (2016). Caregiver burden as a predictor of depression among family and friends who provide care for persons with bipolar disorder. *Bipolar disorders*, 18(2), 183-191.

Raina, P., O'Donnell, M., Rosenbaum, P., Brehaut, J., Walter, S. D., Russell, D., . . . Wood, E. (2005). The health and well-being of caregivers of children with cerebral palsy. *Pediatrics*, 115(6), e626-e636.

Reinhard, S. C., Given, B., Petlick, N. H., & Bemis, A. (2008). Supporting family caregivers in providing care.

Sales, E. (2003). Family burden and quality of life. *Quality of life research*, 12(1), 33-41.

Samal, K. C. (1998). Poverty Alleviation after Post-Liberalisation: Study of a Tribal Block in Orissa. *Economic and Political Weekly*, 1846-1851.

Scharlach, A., Li, W., & Dalvi, T. B. (2006). Family conflict as a mediator of caregiver strain. *Family Relations*, 55(5), 625-635.

Scudder, T., & Colson, E. (1982). From welfare to development: a conceptual framework for the analysis of dislocated people.

Smith, L., Onwumere, J., Craig, T., McManus, S., Bebbington, P., & Kuipers, E. (2014). Mental and physical illness in caregivers: results from an English national survey sample. *The British Journal of Psychiatry*, 205(3), 197-203.

Szmukler, G., Burgess, P., Herrman, H., Bloch, S., Benson, A., & Colusa, S. (1996). Caring for relatives with serious mental illness: the development of the Experience of Caregiving Inventory. *Social psychiatry and psychiatric epidemiology*, 31(3-4), 137-148.

Turner, R. J., Wheaton, B., & Lloyd, D. A. (1995). The epidemiology of social stress. *American Sociological Review*, 104-125.



Carers Worldwide Charity Number (UK): 1150214

Carers Worldwide India: Registered Trust 986 - 2018/2019

Website: [www.carersworldwide.org](http://www.carersworldwide.org)

Facebook: [www.facebook.com/CarersWorldwide](https://www.facebook.com/CarersWorldwide)

Twitter: [www.twitter.com/CarersWorldwide](https://www.twitter.com/CarersWorldwide)

Instagram: [www.instagram.com/CarersWorldwide](https://www.instagram.com/CarersWorldwide)

LinkedIn: [www.linkedin.com/company/carers-worldwide](https://www.linkedin.com/company/carers-worldwide)

**NARENDRA FOUNDATION**

