



A Voice for Carers: Achieving recognition and inclusion of family of the disabled and mentally ill from Adivasi communities of Odisha

Baseline Study Report

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FOREWORD

Carers Worldwide is one of the pioneer organizations understanding the needs of the caregivers, and developed interventions for the development and welfare of the carers not only in India but also throughout the World. Carers Worldwide's vision of supporting carers needs to be appreciated and supported all their initiatives. The role of carers must not only be identified, but also be recognized and their efforts supported with resources, and organizing them to play the role of advocacy force to meet their rightful needs is also important. The state and national bodies need to recognize and identify the needs and concerns of the caregivers and support their initiatives, because carers have relieved the workforce of governments in providing continuous care for the people with chronic illness and disabilities. Carers Worldwide as an organization has recognized the efforts of the caregivers and working for their wellbeing is something to be learned from and replicated to makes the lives of carers better and to create an environment for the carers to live a dignified life with recognition.



A person with illness/condition impacts not only his/her life but also affects the functioning at the family level and their contribution in the community. Thus caregivers act as bridge between chronic the person with chronic illnesses/disabilities and the community by facing the brunt of caring. Research studies throughout the world have proved and recognized the burden of caring, expressed emotions associated with caring, and developed several intervention programmes for the caregivers to modify their expressed emotions, and developing information booklets about the illness has also have helped to reduce the burden of the caregivers. But most of the intervention programmes have looked at caregivers as potential resources, which can be tapped, and expect caregivers to continue to care for their ill family members. Little research has been conducted in developing intervention programmes exclusively for caregivers' wellbeing.

National Health programmes aim at reaching people in the community using a public health approach and initiating community-based approaches, which are based on the premise that the locus of care should remain with the caregivers. Families receive limited support and guidance from professionals and are often looked on as plentiful resources available in the community who are compensating the poorly funded health system in India. If the caregivers are providing sustainable care, it is both ethical and imperative that their wellbeing also needs to be addressed in a systematic manner.

The current study is conducted in Koraput District, of Odisha state, which is one of the backward districts not only in the country but also in the state. Koraput district is far from the state's capital city bordering neighbouring state, and has been neglected from all developments. Koraput is also known for the influence of Maoists, and military battalions have been on duty to check Maoists and protect the civil society. The development index in Koraput district is much lower than any other district in Orissa and in the country, warranting special focus to be given for the development of the district. Available natural resources have been exhaustively utilized for meeting the needs of the people, hence there is an urgent need to develop programmes to preserve natural resources. The efforts of three organizations, SPREAD, Ekta and WORD need to be appreciated, their efforts need to be recognized, supported and appreciated, and they should be invited to share their experiences in the national and international forums. All the field staffs and the coordinators of the three organizations have taken meticulous attention in understanding the research process, and sincerely made efforts in collecting the data, and have maintained individual records of their beneficiaries.

The current study has captured the baseline data/point of departure for the organizations, which would help them to look back and measure their journey, both quantitatively and qualitatively. The methodology adopted and training provided for the field staff in documentation and collecting data has to be appreciated, their efforts need to be recognized, which is the strength of this research. The researchers have shown that the research is not only meant for learned people, but also can be carried out and implemented by field staff

The strengths of this research initiative are many: most importantly, it has been designed within an ongoing, multi-location, multicultural, and multi-regional context, and the involvement of the implementers and the affected community have to be recognized. This action research would definitely help the staff in owning the programme, and to measure their development activity. The research won't stop with generating the report, but the results would help them in designing programmes and strengthening Carers Worldwide's model. In doing so, the research questions, design, methodology and execution have incorporated the experiences of front-line field workers who have a robust understanding of their community, and developed their skills. Another strength of this research is that the research team is able to demystify research skills to the field staff with limited exposure to academic achievements.

Carers Worldwide has included research as one of the important components of their model, which definitely arose from the belief of involving affected people in the research process, thereby empowering them with information about themselves, so that they would advocate for their rights. Carers Worldwide is an initiative of involvement of the partnering organization in collecting data, documenting the processes, analysing the data, feeding back the findings in strengthening the programme. All other organizations need to learn from their research experience and reflect for up-scaling the same in their programmes. The findings of this report should not remain on paper or with the funding organization - this needs to be taken back to people for whom the research was carried out. The findings will also serve the purpose of sensitizing the community and larger society.

Probably for the first time in India, the organization has identified the core components of the caregiver and the need for their well being as a motto of the organization. Caregivers as valuable resources whose experiences can be meaningful to create community awareness and help fight stigma has also emerged as an important finding. The research has highlighted the fact that caregivers need to be supported and nurtured through many programmes for their own well being first and then their ill family members. It is hoped that the authors would continue to take their research activities in understanding care giving being a multi-layered, multidimensional process that changes over time, requiring role adaptations and skill acquisition by the families. Carers Worldwide needs to take this research initiative forward by identifying critical components for interventions in rural areas, validate through further research, and then develop a manual for working with families.

I wish the team success and thank them for giving me the opportunity to be part of the team, and gain more learning for myself. This knowledge will help me in both by academic life and personal life.

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Message from Rangoonwala Foundation (India) Trust:

It is with great interest that I read the much awaited baseline survey report for the project that we support for Carers in the Koraput district of Odisha with Ekta, SPREAD and WORD.

I say interest because, quite a few of the findings, we as development sector workers intuitively knew, but the report brings it forth in a systematic, evidence based, research format.

The report was much awaited because of the importance of a baseline, particularly in the area of work with Carers of people with special needs, which remains highly neglected and unrecognized.

The majority of projects we partner at present in the country, are on different aspects of disability. While all our partnership projects focus on Carers in some way, it is with our three Odisha partners that they form the primary focus of our intervention.

For us, the baseline survey report is very important as it is an indicator for a benchmarking process to track the impact of the intervention as it progresses. It will help us reflect on the objectives and expected outcomes we had set for ourselves as we began work with the partnership a year ago, in hitherto uncharted territory of focusing on the issues of Carers of people with special needs.

It will help us in model creation, strategizing and planning ahead, it will also help us create more understanding on the issues faced by caregivers amongst various stakeholders starting with their immediate family and social circle and right up to the Government, which needs to include them in specific socio-economic development initiatives.

The survey report is more powerful, coming from one of the poorest districts of our country- Koraput, so that we sit up and acknowledge the contributions of these Caregivers in the midst of most challenging circumstances. It is also powerful because of its participatory methodology- coming from local people- the involvement is more, understanding is better and bonding is stronger, which I am sure will lead to more effective advocacy.

Congratulations to one and all who have been part of the process of this survey and in putting its report together, and best wishes for the future, now that we have a Base on which to chart the Roadmap ahead.

Nisreen Ebrahim

CEO

Rangoonwala Foundation (India) Trust

Mumbai, August 2018



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Sincere thanks are due to everyone who has contributed their time, experiences, knowledge, and information to this study. Conducting such a large-scale survey, and then analysing and distilling the results is a huge task. The contribution of each person involved, at whatever level, has been invaluable and has resulted in this impressive report.



In particular, I would like to thank the Carers of Ekta, Society for Promoting Rural Education and Development (SPREAD) and Women's Organisation for Rural Development (WORD) for their time and for sharing their experiences which have added considerably to our understanding of what it is like to be a carer in a low-income setting.

I am grateful to all the project staffs of Ekta, SPREAD and WORD who visited and interviewed the carers and afterwards carefully recorded their data and collated all the information, and to Natesha N K from Carers Worldwide who liaised diligently between the partners and the report author.

I would like to acknowledge the outstanding technical support of Dr N Janardhana and Ms Manjula B from the Department of Psychiatric Social Work, National Institute of Mental Health and Neuro sciences (NIMHANS), Bangalore, who worked very hard on preparing this report. Further, I would like to acknowledge the support received from Simon Godziek, International Development Consultant, in editing the document and producing the report in its final format.

Without the support of Mr Jagannath Mishra, Secretary, Ekta, Mr Bidyut Mohanty, Secretary, SPREAD and Dr Racheal Raykumari, Executive Secretary, WORD, none of this would have been possible and to all of them I express sincere thanks.

Finally, special thanks go to the Rangoonwala Foundation India Trust for making possible this study and the broader project "A Voice for Carers: Achieving recognition and inclusion of family carers of the disabled and mentally ill from Adivasi communities of Odisha". I would like to thank them for their recognition of the significant needs of family carers and for their ongoing support.

Dr Anil K Patil
Founder and Executive Director
Carers Worldwide

July 2018

SUMMARY

This is the report of a study conducted in Odisha state, India, among carers and the people for whom they care, who may have a disability or mental illness, seeking to establish clear and firm empirical evidence about their circumstances. Two aspects distinguish this study: firstly, that it concerns itself with both people giving and receiving care, and, secondly, that it explores wellbeing, as subjectively reported by the survey respondents.

“A caregiver is anyone who cares, unpaid, for a friend or family member who, due to illness, disability, a mental health problem or an addiction, cannot cope without their support” (Angothu & Chaturvedi, 2016).

Dr Anil Patil, Carers Worldwide's Founder and Executive Director, estimates that the pecuniary value of caring given free in the UK (£134 billion) exceeds the total budget of the National Health Service (£124 billion in 2017-8). Aware that carers are often motivated by love or a sense of familial obligation, governments are able to accept this effective subsidy without the need either to recognise nor acknowledge carers and the support they provide.

While the UK has relatively well developed social service and support systems, the same cannot be said of poorer countries, such as India. Caring there can completely take over the life of carers who, in extreme but not so rare cases, have caring responsibilities all day, every day, without the prospect of respite.

When caring is a full-time occupation and more, the opportunity to earn a living is lost for the carer, just as much as it is for the person being cared for. The ensuing poverty can be compounded by exhaustion, psychological and physical health problems, and a keenly-felt sense of isolation.

Carers therefore may be said to be an often unheard and unseen army of people who voluntarily meet the needs of others at the expense of their own.

This study's purpose is to establish baseline data in order to be able to measure change later, and to provide insight into the types of interventions would be of greatest benefit to cares in this socio-cultural-economic context.

This baseline study concerns the project, “A Voice for Carers: Achieving recognition and inclusion of family carers of the disabled and mentally ill from Adivasi communities of Odisha”

This three-year project, funded by the Rangoonwala Foundation India Trust, started in September 2017 and will work with 1,500 carers of people with disabilities and mental illness from marginalised tribal communities in Koraput district, one of the poorest districts in India, in Odisha state. In partnership with three well-established and highly respected local NGOs – Ekta, SPREAD and WORD – the project aims, among other things, to:

- improve carers' physical and mental health, promote social inclusion and increase household income; and
- empower groups of carers to advocate for their needs and rights.

The specific objectives of the project are to enable carers to:

- continue their caregiving responsibilities;
- address their own health and emotional needs;
- find ways to support their family;
- advocate as a group for their rights and needs through the establishment of local and national networks; and
- access the necessary services to enable appropriate assessment and management of their disabled or mentally ill relative's health and therapy needs.

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

Because there are three local partners implementing the project among carers, three discrete groups of carers participated in the study. This report presents the findings for each of the three groups separately, and then synthesises the findings into a meta-analysis to draw out findings from all three together. The body of the report shows the data in full, but the following are the headline findings.

The interviews/data collection were undertaken by development workers from the three local NGOs, and 1,501 carers were consulted for the study. Of these, the great preponderance (83.9% in the three groups) are women: the gender discrepancy is lowest in the group surveyed by SPREAD (78.4%), and highest in WORD's group (88.6%). This is further evidence – of which Carers Worldwide have already amassed a great amount – of the disproportionate caring burden shouldered by women. Similarly, overwhelmingly carers are married (93.5% in the three areas), with the highest percentage (97.2%) in SPREAD's area, which may indicate that group to be more traditional or in a more traditional location than the other two.

Regarding carers' ages, very consistently in all three areas some 80% are between 26 and 60 years. When we combine this with the finding that in two of the three group (those of SPREAD and WORD) carers' children are the most sizeable group being cared for, two stark conclusions become evident: firstly, that the great majority of carers are of working age, and, secondly, that any caring involving physical lifting (for bathing and so on) will inevitably become more difficult as both carer and cared for get older. There is also the great and abiding concern expressed by many carers: what will happen to my charge when I die?

Between the three groups it is interesting to note the variations in type of family: while in Ekta's group, nuclear families account for 92.4%, in SPREAD's the figure is just 53.8% (with the greater concentration of joint families, again pointing to the possibility of it being more traditional).

A striking finding is the average of 85.2% of carers surveyed who had no formal education, and the three groups show consistency in this: Ekta 85.8%, SPREAD 87.4% and WORD 82.4%. These data contrast sharply with those for current educational enrolment, attendance, and retention rates in Odisha, but manifold potential explanations for this exist, and indeed the survey data may be a function of the carers' ages, with vast improvements brought about in more recent times.

Family membership is around five people among all three groups, which may mean that the loss of income of the carer has an impact on other family members, who may not be of working age. The data show that the average of the three groups concerning carers who do not work is 37.4% (Ekta 34.9%, SPREAD 26.8%, and WORD 50.4%), meaning that approaching two-thirds do work. However, the date regarding income is telling: among the Ekta group 66.4%, among the SPREAD group 89.2%, and among the WORD group 99.8% earn less than Rs 1,000 per month.

Regarding the cared for people, there is a fairly even spread in gender (roughly 52% male) and age (the exception being the WORD group in which the 15-25 age group is under-represented). The profiles of the cared for people vary, with people with mental retardation featuring most prominently among Ekta's group, people with locomotor disability in SPREAD's group, and people with mental illness in WORD's group.

The results of the wellbeing survey are also presented below, and the common themes that clearly emerge are the worry and concern they feel, including financial and jobs, their physical and mental health, the need for support, and time taken by the caring role and the children's functional development.

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

ABBREVIATIONS

AW – Asha worker

AWC – Anganwadi centre

AWW – Anganwadi worker

CWD – Child with disability

CP – Cerebral Palsy

Cr – Crore

GDP – Gross Domestic Product

HI – Hearing impairment

ITDA – Integrated Tribal Development Agency

LM – Locomotor disability

MD – Multiple disabilities

MR – Mental retardation

NGO – Non-governmental organisation

NIMHANS – National Institute of Mental Health and Neurosciences

OH – Orthopaedic handicap

PWD – Person with disability

SC – Scheduled Caste

SHG – Self-help group

ST – Scheduled Tribe

TSP – Tribal sub-plan

VI – Visual impairment

WHO – World Health Organisation

ABOUT CARERS WORLDWIDE

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

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

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

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

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

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

Carers Worldwide achieves its strategic goals by:

- Working in partnership with established charities and other organisations that are skilled in service delivery for those in need and are well networked in their communities in order to create systemic changes in attitudes and support of carers.

Disseminating the Carers Worldwide holistic model of the support provision necessary for effecting systemic change for carers.

ABOUT Ekta

Ekta, which means “Unity is Strength”, is a registered non-governmental, non-profitable, and non-political development organization that came into existence on 2nd October, 1994 in the district of Koraput, Odisha, India. Later, it expanded into other districts of Rayagada, Nabarangpur & Khordha of the state. The organization was conceived as an effort of a few young, energetic and local youths belonging from different professions and backgrounds, charged with the vision of working with the most marginalized sections of the community. The thought came that we live in the area which is considered to be one of the most backward, service-deprived and underdeveloped districts of the state, despite having rich availability of natural resources. But the people of the areas are still poor, debarring them from fulfilling their common basic human necessities. Huge amounts have been allocated & spent for the people in the name of development through declaring various provisions, schemes & packages but all these have no or low positive impacts upon the peoples – rather they lead to more vulnerability. Among them, health hazards were one of the most vital challenges people had been facing for a long time. Taking it seriously, since its first program was in creating health awareness on common ailments, the organization has been undertaking various community-based interventions for the community.

In the meantime, Ekta has already completed 23 glorious, challenging, successful and memorable years of journey & added many more feathers in its cap! It has been recognized as one of the reputed & known organizations not only in the district of Koraput but also in the state and beyond in the field of socio-economic and political development & empowerment of Adivasi communities and other marginalized sections. When it first began, the organization was known for creating awareness among the community on various issues through folk medium, but now it has broadened its activities in the spheres of women & child issues, community-based inclusive development of the persons with disabilities, HIV/AIDS prevention, care and support, education for all especially of girl children, women's empowerment, sustainable livelihoods, promoting and strengthening of community-based organizations, promotion of good governance, clean energy & climate change, and disaster preparedness and management among others.

ABOUT SPREAD

SPREAD (Society for Promoting Rural Education and Development) was started by a group of like-minded individuals with a commitment to work for the betterment of the underprivileged of the society. During the early intervention phase in Koraput the team focused on the problems of the displaced tribal population, those who have been deprived of their homes and hearths due to the dam projects, industries and other developmental initiatives. During initial period of intervention, the group realized that in order to give any meaningful intervention to the suffering of the poorest of the poor they need to work with the marginalized tribal and they started working with the tribal of Koraput. During the early intervention stage in Koraput the team tried to understand the problems of displaced tribal who have been deprived of their livelihood due to the loss of their land and common property resources as a result of major hydroelectric projects. The area that the team chooses to work with was the displaced community in the undivided district koraput (Koraput, Malkangiri, Raygada&Nabaranhpur). Slowly Spread started to work in other KBK districts like undivided Kalahandi & Balangir particularly on the issue of right to food & land.

Alongside SPREAD's extensive experience working on community advocacy and empowerment, promoting People's Organisations and engaging with government on health, education and livelihoods activities, they have worked with 356 PWDs directly on CBR concept. Under this programme, among many achievements, SPREAD has formed DPOs, supported PWDs to get the pension entitlements and CWDs into education, and facilitating service provision.

ABOUT WORD

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

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

BACKGROUND TO THE STUDY

Odisha at a glance

As per Census 2011, in India, out of the 121 Crore population, about 2.68 Cr persons are 'disabled', which is 2.21% of the total population. Understanding their socio-demographic profile and their functional status is important to identify needs since two individuals with the same impairment may face different types of difficulties in undertaking certain activities, and so have different needs that require different kinds of interventions. Functional status data is essential for determining the broader social needs of persons with disabilities, such as provision of assistive technology for use in employment or education or broader policy and laws

Economic and Human development indicators – data on Odisha state (2016-17 Economic Survey)

Indicator	Year	Frequency/Percentage
Sex ratio (female per 1000' Male)	2011	979
Literacy rate	2011	72.9
GDP at current market price (2011-12 base)	2016-17	34,188,733
Per capita income (base2011-12)at constant market price	2016-17	61,678
Unemployment rate by Labour Bureau	2013-14	6%
Poverty ratio	2011-12	32.59%
Dropout rate at primary schools	2015-16	2.82 %

The Census 2011 revealed that, among State/UTs, the proportion of disabled persons to the total population is highest in Sikkim (2.98%), followed by **Odisha** (2.96%), Jammu & Kashmir (2.88%), Andhra Pradesh (2.68%), and Maharashtra (2.64%).

Odisha state's share of disabled persons in State/Union Territories in different areas described in the following table

SI No	Area	%age
1	to the total disabled persons in the country	4.64
2	%age of workers in the respective disabled population	34.32
3	%age of literates to total disabled	53.17
4	Number of disabled 1,244,402; total population 41,974,218	2.96
5	State share of disabled children to the all-India disabled children	3.97

Working status of disabled persons in the state of Odisha

Total population	Working Population				Non-working Population	Disabled population
	Cultivation	Agriculture labour	Working Household industries	Others		
427,020	102,195	162,563	21,288	140,974	817,382	1,244,402

Educational level of disabled persons

Education level	Total disabled Population		
	Person	Male	Female
Total	1,244,402	674,775	569,627
Illiterate	582,804	244,014	338,790
Literate	661,598	430,761	230,837
Below primary	170,523	107,236	63,287
Below middle	199,661	126,360	73,301
Below metric/secondary	111,184	74,172	37,012
Below graduate	108,451	75,376	33,075
Graduate and above	36,450	26,290	10,160

Disabled population by marital status, age and sex

Age Group	Marital Status						Never Married		
	Currently Married			Widowed					
	Person	Male	Female	Person	Male	Female	Person	Male	Female
Total	586,322	357,326	228,996	160,647	41,620	119,027	482,396	270,570	211,826
0-14	1,842	719	1,123	145	39	106	230,450	127,191	103,259
15-59	393,199	228,243	164,956	30,557	7,829	22,728	243,105	138,672	104,433
60+	189,478	127,371	62,107	129,439	33,616	95,823	6,695	3,424	3,271
Age not stated	1,803	993	810	506	136	370	2,146	1,283	863

Odisha's tribal population: socio-economic status and state support

A **tribe** is a social division in a traditional society consisting of families linked by social, economic, religious, or blood ties, with a common culture and dialect. A tribe possesses certain qualities and characteristics that make it a unique cultural, social, and political entity.

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

Status of scheduled tribes in Odisha

Odisha has the third largest concentration of tribal population in the country. Odisha comprises 9.17% of the total tribal population of our country after Madhya Pradesh (14.6%) and Maharashtra (10.08%). About 44.7% of the state's geographical area, which is known as Scheduled Areas, extend over 119 out of 314 blocks in 13 districts and a portion of Sorada Tahasil of Ganjam district.

- Out of 635 tribal communities in India, 62 are found in Odisha and 13 are Particularly Vulnerable Tribal Groups (PVTG).
- The ethos, ideology, world view and cultural heritage of tribal communities are rich and varied, which ranges from nomadic food gatherers and hunters to skilled and settled agriculturists and horticulturists.
- Tribal areas of Odisha present in an extremely diverse socio-economic panorama. Tribals speak as many as 74 dialects.
- The PVTG in Odisha include Bonda, Chuktia, Bhunjia, Didayi, Dongaria Kondh, Juang, Hill-Kharia, Kutia Kondh, Lanjia Saora, Lodha, Mankirdia, Paudi Bhuyan, Soara and Birhor. These communities are considered a special category in view of their distinct social, cultural and occupational practices and traits.

- The PVTG are distinguished from other tribal communities for their relative physical isolation, stagnant or diminishing population, very low level of literacy, low level of techno-economy, i.e. subsistence level of economy, very low level of literacy associated with pre-agricultural stage of hunting, food gathering and sifting cultivation. They reside in parts of 21 blocks of 12 districts.
- The ST population of Odisha increased from about 42.24 lakh in 1961 to 95.91 lakh in 2011. However, their proportion in the total population decreased from 24.07 % in 1961 to 22.85 % in 2011. Mayurbhanj district has the highest ST population (14.80 lakh) as well as highest proportion of ST population (58.7 %) in the State

Tribal development programmes implemented in the state of Odisha (Economic survey data 2016)include:

- Specific initiatives taken by the state government to address the problem of regional disparities and accelerating development process, such as Revised Long-Term Action Plan, programmes funded by Backward Regions Grant Fund and Programmes of Western Odisha Development Council.
- High priority was given to the issue of education for girls and SC&ST communities through Girls' Schools, Residential Schools, Sevashrams, Training Institutes, Educational Complex for Primitive Tribal Groups (PTG)
- Quality Urban Education for ST & SC pupils: ANWESHA programme is being implemented in 17 tribal dominated districts wherein ST and SC pupils are admitted to Class I in best private schools located in their districts. The entire cost of the education for the pupils, including tuition fees, uniform, books and study materials, transportation to schools and post-school tutoring is borne by the State Government.
- Integrated Tribal Development Agencies (ITDA) were set up during the 5th five-year plan as nodal tribal development agencies for plan formulation, programme implementation and operationalization of various development programmes in TSP areas. As many as 119 blocks of Odisha state having 50 % or more ST Population have been covered by 22 ITDAs
- ST and SC Development Department has been implementing Skill Development Training Programmes and Placement Linked Employability Training with an objective of developing employability and entrepreneurship skills among ST and SC youths

Evidence-based understanding on mental health, caregiving issues and concerns among tribal population

General mental health concerns and caregiving

Indigenous peoples are the most potent example of our human diversity of culture, language, and spirit; yet they are often disadvantaged and marginalised. Exposure to "social stress" was highlighted as having differential consequences on mental health across age, gender, marital and occupational status(;), but empirical measurements related to displacement-induced social stress are not yet readily available. Overall, direct and secondary effects of involuntary dislocation in the absence of preventive health measures include psychosomatic diseases, diseases of poor hygiene (such as diarrhoea and dysentery), and outbreaks of parasitic and vector-borne diseases (such as malaria and schistosomiasis) caused by unsafe and insufficient water supplies and inadequate sanitary waste systems.

Tribal people have always been taking care of the ill people in their community, taking them to a temple or a mantravadi or other places and also support them at home. Hopes of recovery from the illness tend to fade after several visits to different places and they begin to accept that this illness or wrath cannot be cured which leads to neglecting the person with mental illness but not to the extent of ill-treating the person().

Displacement and its impact on tribes in the state of Odisha

Floods and cyclones in the coastal belt and drought in the western part is the general feature of Odisha. In the western part of Odisha, particularly the districts of Kalahandi, Bolangir, Sambalpur, severe droughts occur very frequently which lead to poverty, hunger, out-migration, outbreak of serious diseases and etc ().

A study was conducted in 2002 in the state of Odisha on Development, Displacement and Rehabilitation of Tribal People (). The major findings of the study are as follows.

- Out of the total 41,706 families displaced by dam projects, 6,211 families are scheduled tribe, i.e. around 15% of the total families displaced are tribal. Koraput district, where tribal population is 58% has 18 large schemes, occupying 500,000 acres or 7.42% of their area. According to one estimate, the schemes have deprived 6% of the population of the district, mostly tribal, of their livelihood. Thus at least 10% of the tribals in these districts have been affected. The land taken over includes 400,000 acres of forests on which the tribal have depended for their sustenance though they didn't have a legal title to it
- Displacement in the projects follows either from acquisition of private lands or from earmarking and assignment of the Government and community land for use of the project. In either case, there is a disruption of the socio-economic and cultural life.
- The Upper Indravati Hydroelectric Project is a multipurpose river dam project in Odisha. It is located on the trijunction of Koraput, Nawarangpur and Kalahandi districts. Due to the construction of this dam, 5,448 families (total population of about 17,000) have been displaced from their home. A total of 97 villages (44 from undivided Koraput and 53 from Kalahandi) have been affected, with 65 villages fully submerged. Out of these villages, 31 villages from Koraput and 34 from Kalahandi. Moreover, the Project acquired 32,530,87 acres of land i.e. 17,137,97 acres from Kalahandi and 15,388,90 acres from undivided Koraput district (RRU, 1995).
- In the tribal districts of Kalahandi, Nawarangpur and Koraput, the forests are an important source of food, fuel, fodder and other household items of daily use. Earlier the people bartered the product, which is not possible in the new settlements. Collection of forest products used to be a regular feature. Except during the rainy season, women used to regularly visit the forest for collection of fuel wood, seasonal fruits, roots and green leaves. Most of the product collected was domestically consumed while the surplus was sold.

Research studies on caregivers, caregiving process, general concerns and issues

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. 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 behaviours, disabilities and perceived disruptions of the carers' life are appraised as stressors by the caregiver. The caregiver's personality, quality of family relationships and degree of social support are considered as the mediating factors(). 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 caregivers 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(). Further, another reason for caring for ill relatives is economic. Most families are unable to pay for full-time 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 Western families().

Caregiving issues in the context of providing care to children

The health of a carer is a key factor which can affect the well-being of the child with disabilities for whom they care(;). In low-income countries, many carers of children with disabilities contend with poverty, limited public services and lack assistive devices. In these situations, caregiving may require more physical work than in high-income countries and so carry greater risk of physical injury or health problems. There is some evidence that poverty and limited access to health care and equipment may affect the physical health of those who care for children with disabilities().

Caregiving and mental illness

Close family members or friends are often a source of primary support for a person with mental illness (). 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 ().

Caregivers have to spend more time when their family member is symptomatic as they need to care for their personal hygiene, calm down during emotional outburst and take the brunt of abuse and assaults from their mentally ill family members. Caregivers' involvement in direct and indirect care changes over time, in response to the stage of illness and treatment, and caregivers must be able to adapt to changes in the amount, level and intensity of care demands (). Caregivers of people mental illness face different challenges and they are affected by cultural and social attitudes to the illness, and these have important effects on the level of burden experienced. Caregivers do have stress while caring their mentally ill family members, their stress and burdens need to be addressed in the interest of person with mental illness. Caregiving for chronically mentally ill family members disrupts the normal functions of families, and it almost always causes stress in the family(). 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 (). The caregivers' needs should be understood and addressed; they have variety of psychosocial needs: Understanding illness, managing the ill family member, dealing with stigma, involving them in to community activities, etc (Sales, 2003)

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

Caregiving - the Indian scenario

Family members are the primary caregivers 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 caregiver plays multiple roles in care of persons with mental illness, including taking day-to-day care, supervising medications, taking the patient to the hospital and looking after the financial needs. The family caregiver also has to bear with the behavioural disturbances in the patient (Costa & Ranci, 2010). Thus, the family caregiver experiences considerable stress and burden, and needs help in coping with it. The caregivers develop different kinds of coping strategies to deal with the burden. An unhealthy coping style is likely to adversely affect the caregiving function (Crews, 2012). Hence, it is important to take care of the needs of the family caregivers. The family caregiver 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 caregivers 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 caregiver also supervises treatment and provides emotional support to the patient. The family caregivers bear with the behavioural disturbances of the ill family members and sometimes can also be a target of the patient's abusive or violent behaviour. 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 caregivers (Martire, Lustig, Schulz, Miller, & Helgeson, 2004).

Impact of caregiving on caregivers

Studies carried out in the area of mental illness, shows that burden, physical health problems and psychological distress are commonly experienced among caregivers, both in schizophrenia and bipolar disorder (Aschbrenner, Greenberg, Allen, & Seltzer, 2010; Hoenig & Hamilton, 1966). 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 caregiver's perception of burden (Awad & Voruganti, 2008). Family caregivers might experience time lost from work, unreimbursed medical and other patient-related expenses, limited time for leisure and socializing, elevated symptoms of psychological distress and feelings of stigmatization, poorer quality of life, poorer self-rated health, chronic medical conditions, increased visits to a primary care physician, greater use of psychotropic drugs and increased risk of medical hospitalization (Perlick et al., 2016).

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

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

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

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

Need for addressing the caregiving issues

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

Family caregivers 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 caregivers take multiple roles at providing care for persons with mental illnesses. The family caregivers suffer substantial burden as a result of the caregiving role and need help from the mental health professionals. It is very important for the mental health professionals to identify the needs of the family caregivers, the stresses faced by them and introduce suitable interventions, so as to reduce the burden as well as help in developing healthy coping strategies.

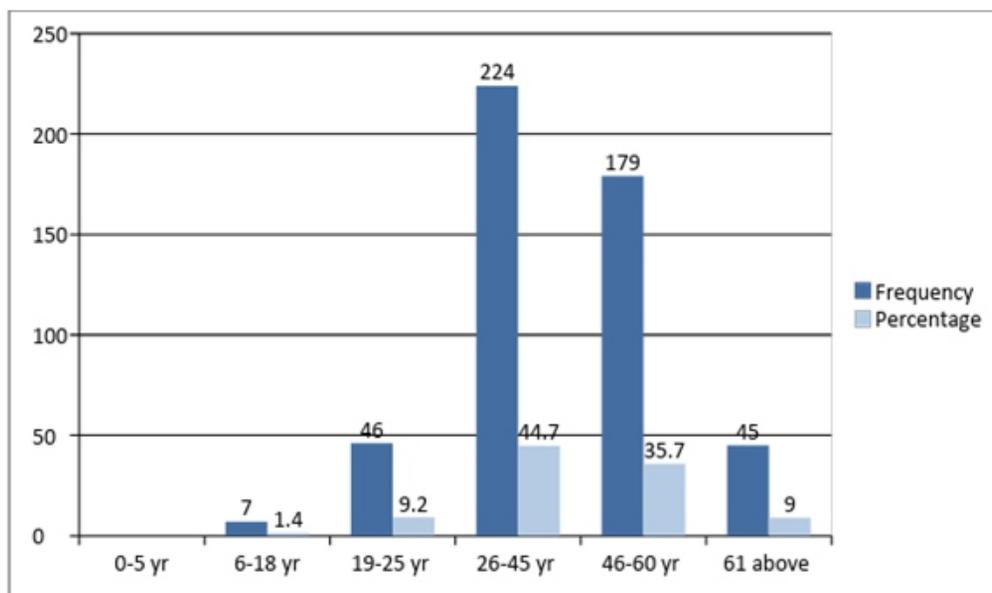
SURVEY RESULTS

Results of survey conducted by Ekta

Caregiver profile

Age

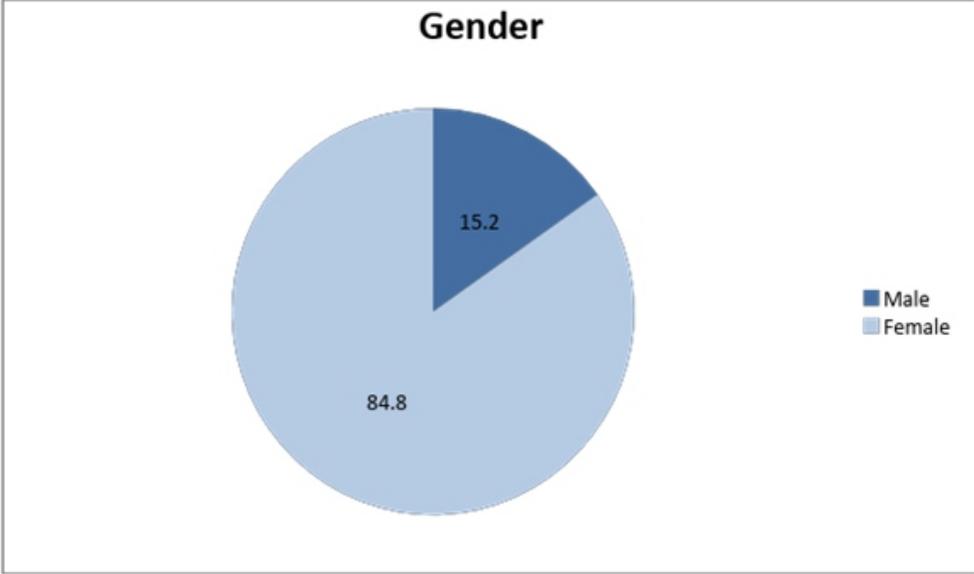
Age Group	Frequency (N=501)	%age
0-5	0	0
6-18	7	1.4
19-25	46	9.2
26-45	224	44.7
46-60	179	35.7
61 +	45	9.0



Majority of the caregivers were in the age group of middle and late adulthood. It was also observed that aged caregivers were also represented.

Gender

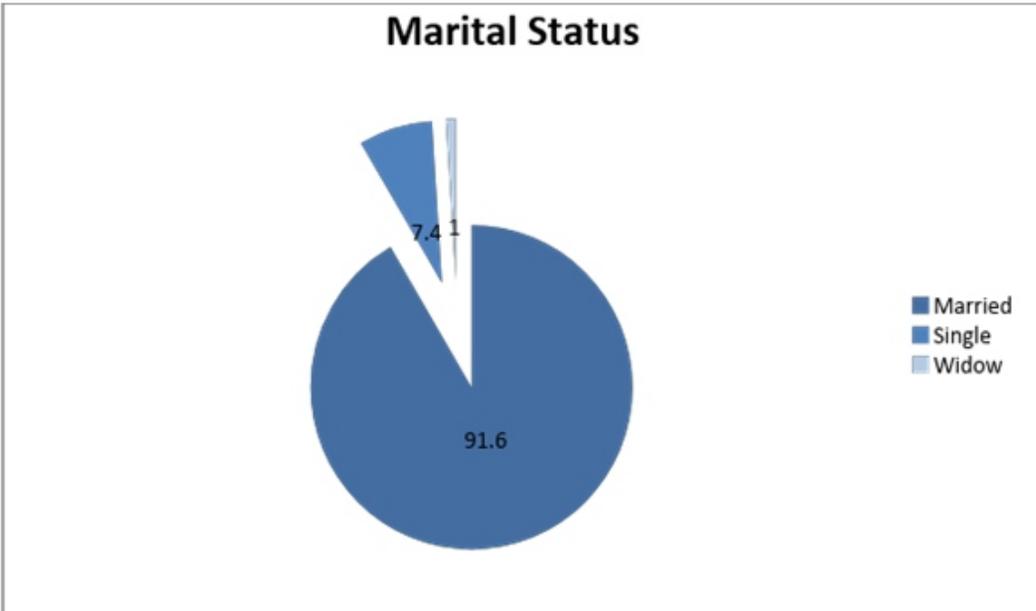
Gender	Frequency (N=501)	%age
Male	76	15.2
Female	425	84.8



Majority of the caregivers are women.

Marital status

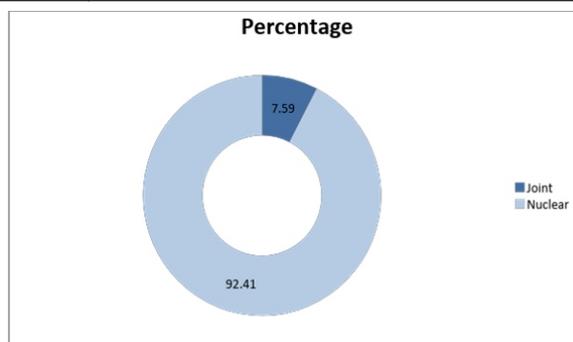
Variable	Frequency (N=501)	%age
Married	459	91.6
Single	37	7.4
Widow	5	1.0



Majority of the caregivers were married and very few of them were single and widows.

Type of family

Variable	Frequency (N=501)	%age
Joint	38	7.59
Nuclear	463	92.41



Majority of the caregivers hails from nuclear families.

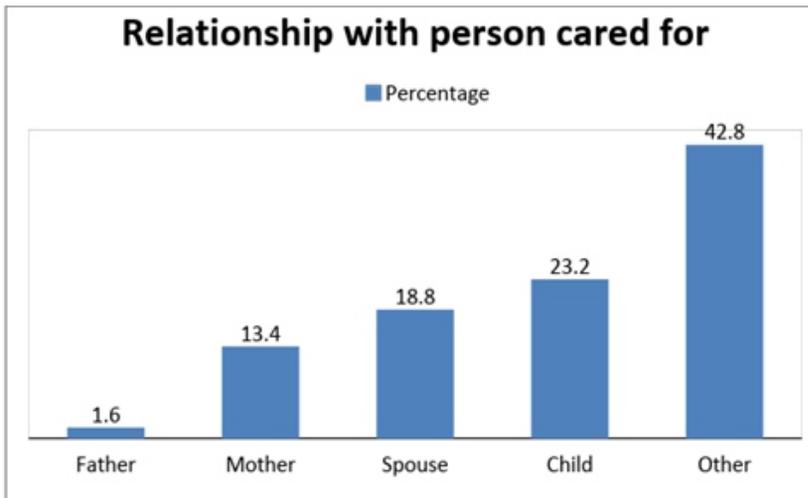
Details of family members

Variable	Mean & SD	Minimum – Maximum
No of household members	4.70 ±2.020	2-16
No of men	1.92 ± 1.130	0-8
No of women	2.12 ±1.133	0-6
No of Children	1.07 ± 1.452	0-9

The average number of family members is 4.70, no of male in the family is 1.92, number of women in the family is 2.12 and number of children is 1.07.

Relationship with the person cared for

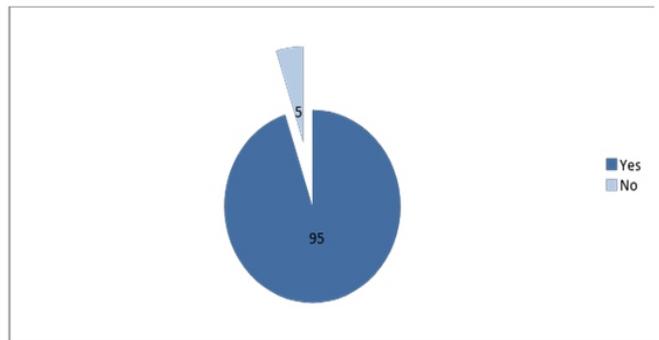
Variable	Frequency (N=501)	%age
Father	8	1.6
Mother	67	13.4
Spouse	94	18.8
Child	116	23.2
Other	216	42.8



The above table shows that majority of the caregivers were other significant family members (42.8%) and offspring (children) 23.8% followed by spouse 18.8% and parents 15%. (both father and mother)

Identity card

Variable	Frequency (N=501)	%age
Yes	476	95
No	25	5

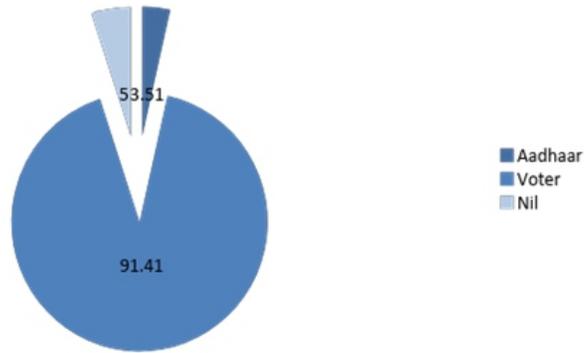


Majority of the caregivers (95%) reported that they have identity cards and very few reported they don't have any ID cards.

Type of ID card

Variable	Frequency (N=501)	%age
Voter	18	3.51
Aadhaar	458	91.41
Nil	25	5

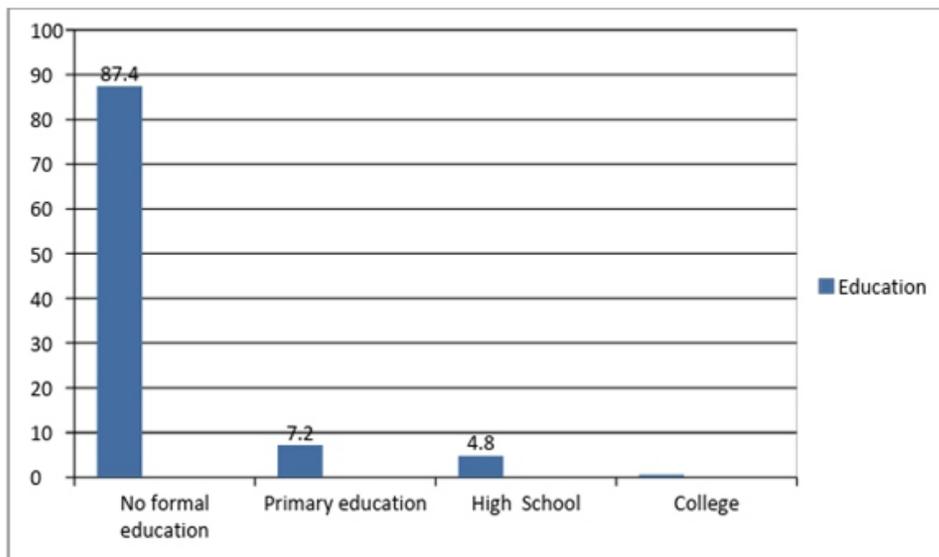
Type of ID card



Among the people who had ID cards, majority of them had Aadhaar card (91.41%) as their identify card and remaining people had voter ID (3.51%).

Education level

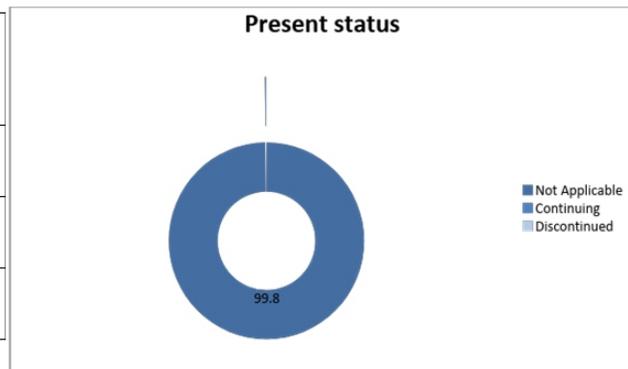
Variable	Frequency (N=501)	%age
No formal education	430	85.8
Primary education	27	5.4
High School	29	5.8
PUC/ITI	9	1.8
Graduation	6	1.2



It is observed that majority of the caregivers didn't attend formal education (85.8%), small number of caregivers had primary (5.4) and high school education (5.8). very few attended college (3%).

Present education status

Variable	Frequency (N=501)	%age
Not Applicable	498	99.4
Continuing	2	.4
Vocational Education	1	.2



Most of the caregivers didn't attend schooling and few completed their studies. Only 3 caregivers were continuing their studies and undergoing vocational training.

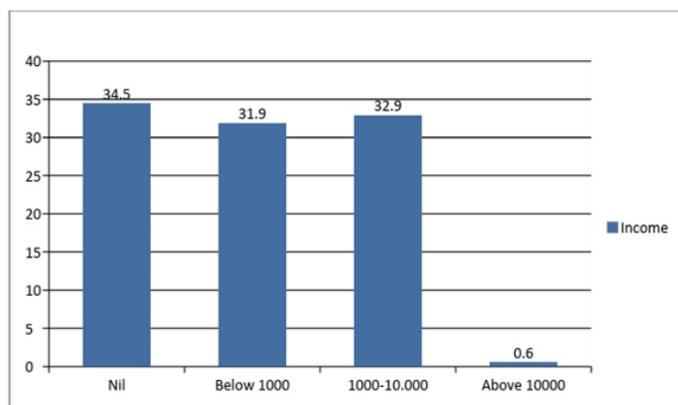
Type of work

Variable	Frequency (N=501)	%age
No/Nil	175	34.9
Farmer/agriculture	106	21.2
Daily labour	169	33.7
Agriculture and daily labour	16	3.19
AWW cook	6	1.2
AWC helper	5	1.0
Asha worker	1	.2
Shop/private job	11	2.2
Business	4	.8
Peon	3	.6
Disabled	2	.4
Retired	1	.2
Teacher	1	.2
Govt employee	1	.2

Majority of the caregivers were not working (34.9%). Among caregivers who were working are mainly involved in daily labour (33.7%), agriculture (21.2%) and both daily labour and agriculture (3.19%). Remaining were working as cook, Asha worker, has shops/ private jobs, business, teacher and govt employee. Among them one was disabled and one was retired from work.

Income per month

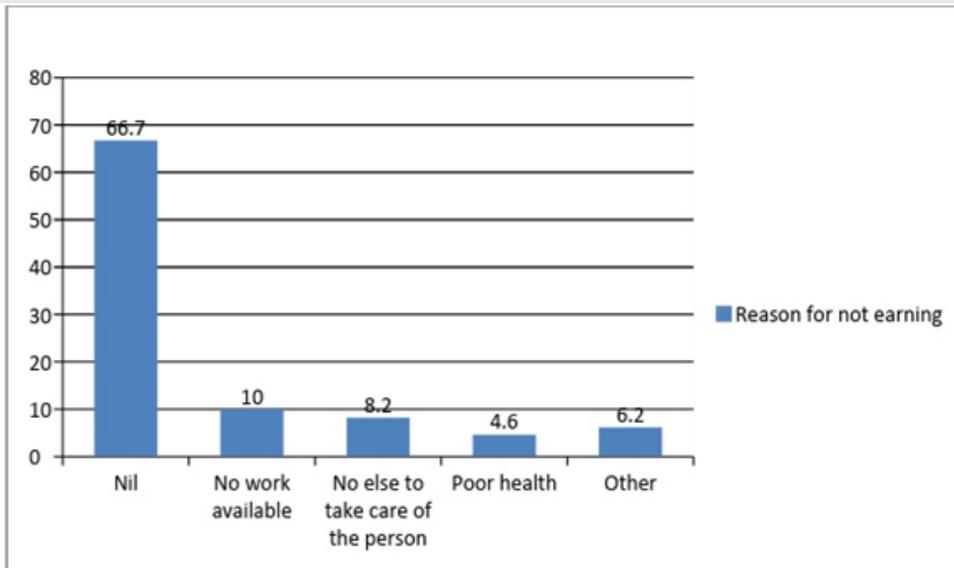
Variable	Frequency (N=501)	%age
Nil	173	34.5
Below 1000	160	31.9
1000-10.000	165	32.9
Above 10000	3	.6



Majority of the caregivers were not earning any income (34.5%). Around 31% of the caregiver's income was below 1,000 rupees and 32.9% of their income was in between 1000-10000. Fewer people were earning above 10,000.

Reason for not earning

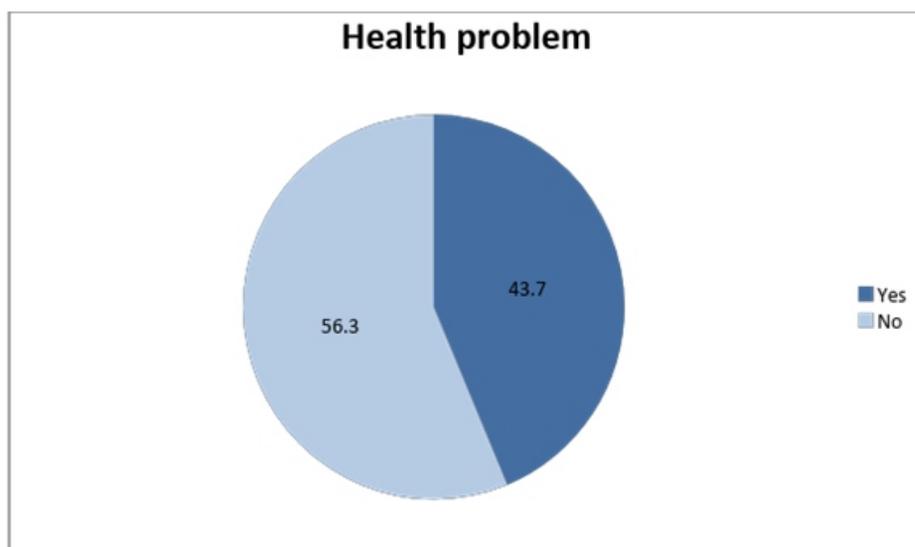
Variable	Frequency (N=501)	%age
Nil	334	66.7
No work available	50	10.0
No else to take care of the person	41	8.2
Poor health	23	4.6
Other	31	6.2



Majority of the participants reported that there were no reasons for not earning (66.7%). Others were not earning because of non-availability of work (10%), no one else to take care of the disabled person (8.2%), health reasons (4.6%) and other reasons (6.2%).

Health problem of the carer

Variable	Frequency (N=501)	%age
Yes	219	43.7
No	282	56.3



Among the caregivers less than half of them reported health problems (44.5%), remaining didn't report any health problem (56.3)

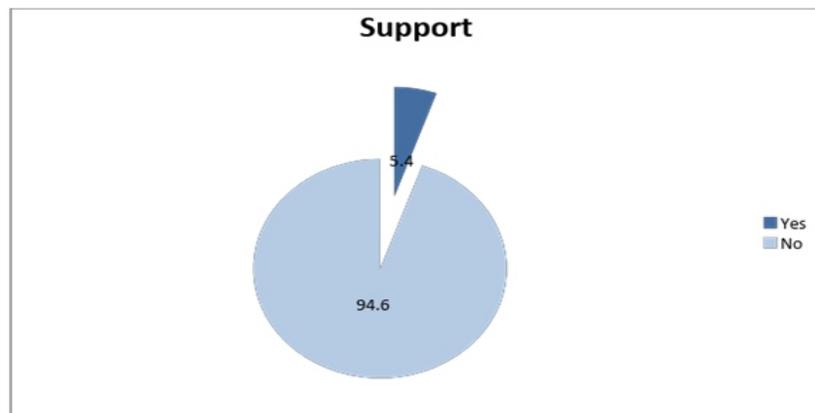
Type of health problem

Variable	Frequency (N=501)	%age
Nil	282	56.3
Depression	148	29.54
Depression and anxiety	26	5.2
Back pain and body pain	31	6.2
Asthma	1	.2
Locomotor	2	.4
BP	5	1.0
TB	1	.2
Vision problem	2	.4
Depression with body/back pain	3	0.6

Majority of them didn't report any health problems among them (56.3%). Remaining who reported health problems had depression (29.54%), depression and anxiety (5.2%), somatic complaints (6.2%), asthma (0.2%), locomotor problem (.4%), high blood pressure (1%), tuberculosis (.2%), vision problem (.4%), and depression with somatic complaints (0.6%).

Support/treatment received for health problems

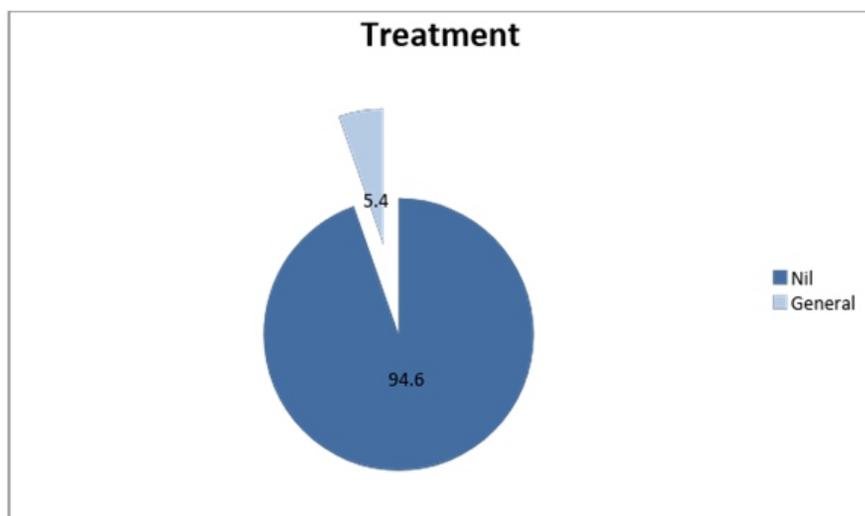
Variable	Frequency (N=501)	%age
Yes	27	5.4
No	474	94.6



Majority of them did not seek help for their health problem (94.6%), very few received help (5.4%)

Type of treatment received

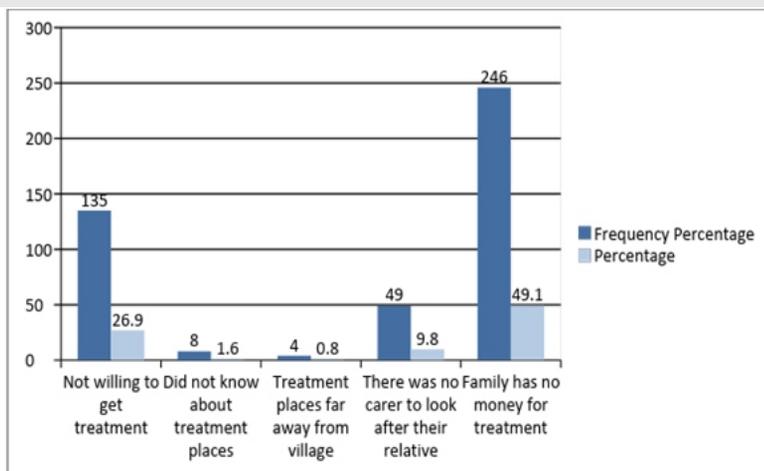
Variable	Frequency (N=501)	%age
Nil	474	94.6
General	27	5.4



Majority of them did not seek help for their health problem (94.6%, remaining received general health care (5.4%).

Reason for not receiving treatment

Variable	Frequency (N=501)	%age
Not willing to get treatment	135	26.9
Did not know about treatment places	8	1.6
Treatment places far away from village	4	0.8
There was no carer to look after their relative	49	9.8
Family has no money for treatment	246	49.1
Other	29	5.8
Multiple reasons	30	5.99



With regard to factors associated with not receiving treatment are financial difficulties (49.1%), unwillingness to receive treatment (26.9%), not aware about the places to take treatment (1.6%), accessibility in terms of long distance (0.8%), non-availability of other people to take care of their relative (9.8%), and remaining reasons were multiple factors and miscellaneous factors (11.8%).

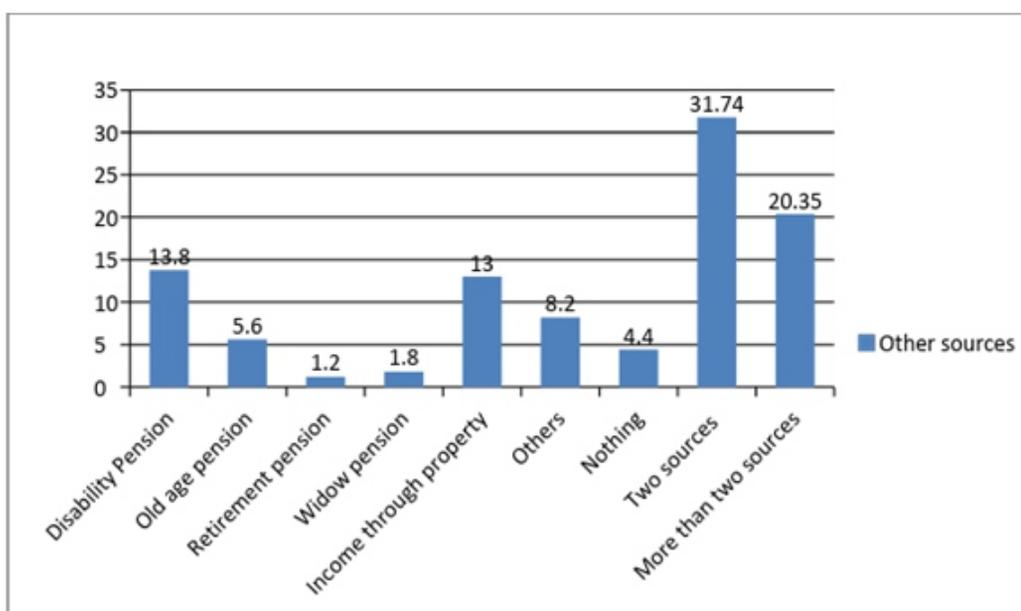
Skills of the carer

Variable	Frequency (N=501)	%age
No	114	22.8
Agriculture	216	43.1
Tailoring	20	4.0
Leaf plate making	3	0.6
Business	28	5.6
Shops/grocery shop	44	8.8
Poultry	10	2.0
Teaching	5	1.0
Looking for job and training	11	2.2
Driving	1	0.2
Potter	5	1
Blacksmith	3	0.6
Knitting	2	0.4
Electronic	1	0.2
Daily wage	9	1.8
Social service	2	0.4
Old age and cannot work	1	0.2
Multi skills	26	5.19

Regarding skills among the caregivers 22.8% of them reported that they do not have any vocational skills. Majority of them were skilled in agriculture (43.1%). Few of them had their own shops (8.8%), business (5.6%) and tailoring work (4%). Few were looking for job and training and remaining were skilled in poultry, pottery, driving, Blacksmith, crafts, electronic and multi skills.

Other sources of income

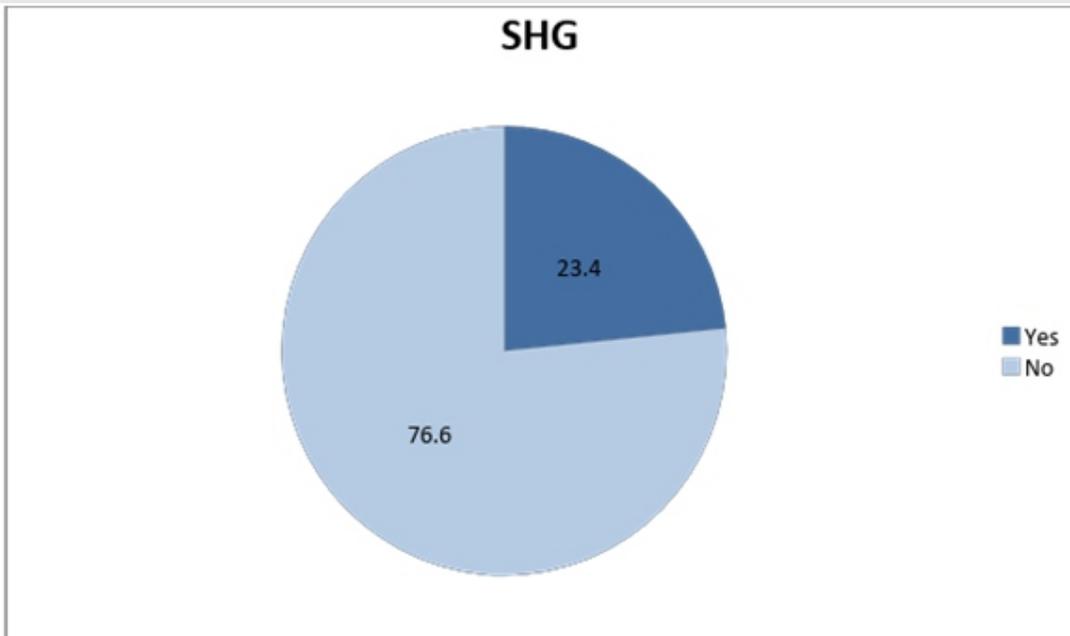
Variable	Frequency (N=501)	%age
Disability pension	69	13.8
Old age pension	28	5.6
Retirement pension	6	1.2
Widow pension	9	1.8
Income through property	65	13.0
Others	41	8.2
Nothing	22	4.4
Two sources	159	31.74
More than two sources	102	20.35



Majority of them were having income from two (31.4%) and more than two sources (20.35%). Social security benefits in terms of disability pension (13.8%), old age pension (5.6%), retirement pension (1.2%), widow pension (1.8%) were one of the main sources of income. Few of them were having income through their property (13%) and other sources (8.2%). Very few said they do not have income (4.4%).

SHG member

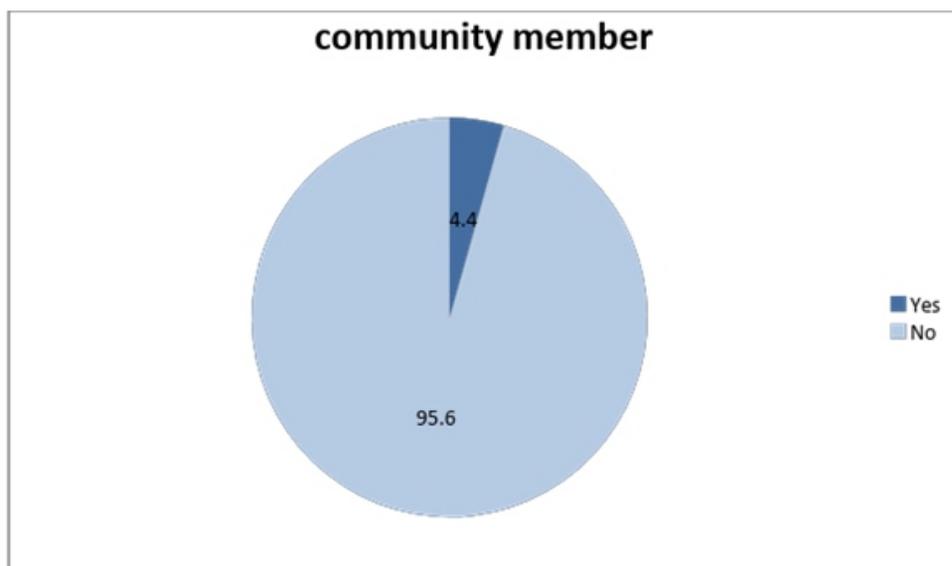
Variable	Frequency (N=501)	%age
Yes	117	23.4
No	384	76.6



Majority of the caregivers are not members of SHGs (76.6%), remaining were (23.4%) members of NGOs.

Community member

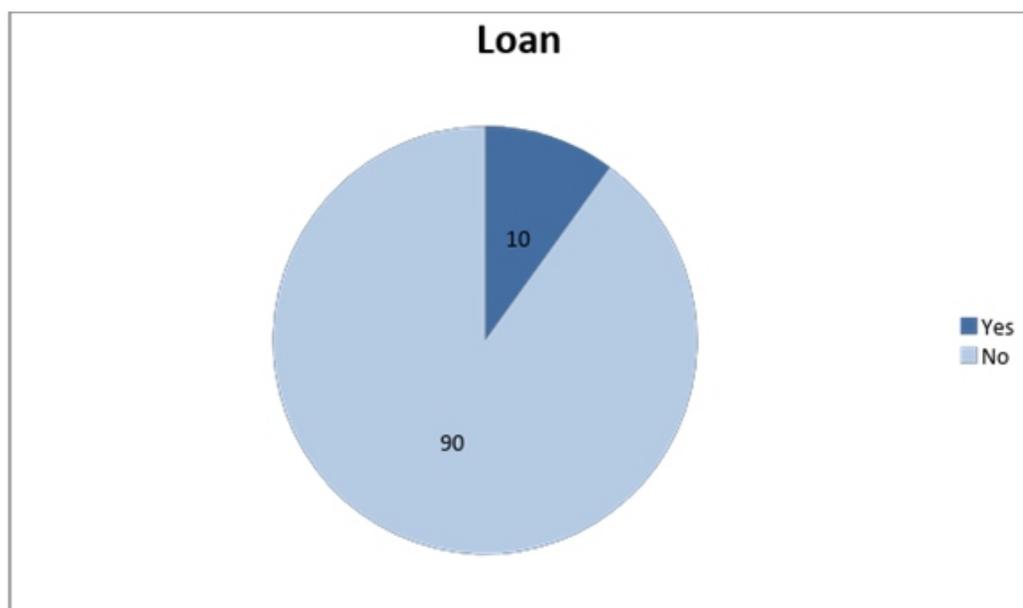
Variable	Frequency (N=501)	%age
Yes	22	4.4
No	479	95.6



Majority of the caregivers are not part of community membership (95.6%), remaining were (4.4%) members of community.

Loan

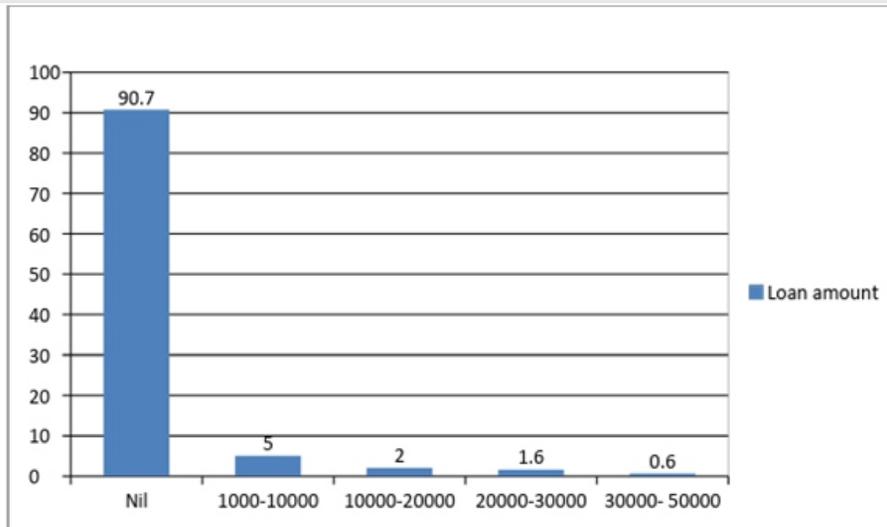
Variable	Frequency (N=501)	%age
Yes	60	12.2
No	441	87.8



Majority of the caregivers (87.8%) reported that they have not taken any loans, remaining 12.2% of them had taken loans.

Amount of loan taken

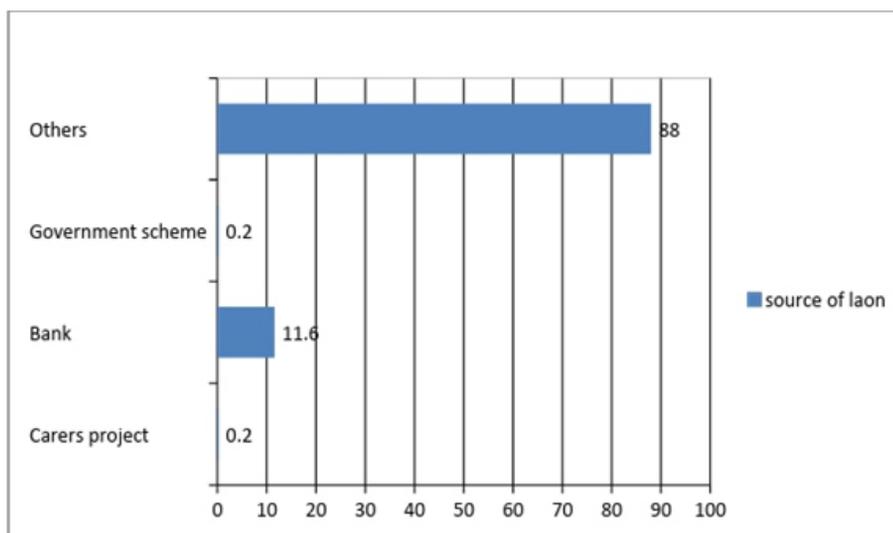
Variable	Frequency (N=501)	%age
Nil	441	87.8
1000-10000	14	2.79
10000-20000	27	5.4
20000-30000	11	2.2
30000- 50000	8	1.6



Majority of the caregivers (87.8%) reported that they have not taken any loan. Among those who have taken loan, majority took loan amount in between 1000-10000 (5.4%) and below 10000 (2.79%). Very few had taken loan of more than 20000 (3.8%) and maximum amount was 50000.

Source of loan

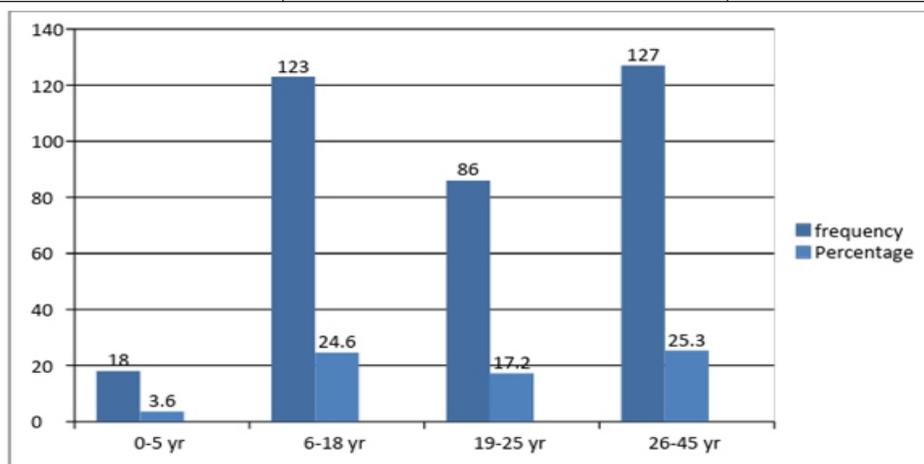
Variable	Frequency (N=501)	%age
Carers project	1	.2
Bank	58	11.6
Government scheme	1	.2
Not applicable	441	88.0



Among the caregivers those who have taken loan, majority of them taken from banks (11.6%), remaining from carer's project and Government scheme(0.4%).

Details of person cared for Age

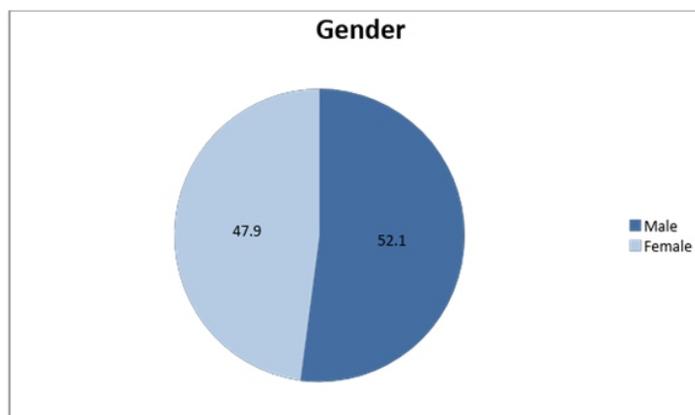
Age Group	Frequency (N=501)	%age
0-5	18	3.6
6-18	123	24.6
19-25	86	17.2
26-45	127	25.3
46-60	82	16.4
61 +	65	13.0



People who were receiving care had representation from all the age groups. Majority of them were children and adolescents (24%) and young adults (25.3%). They were also in the age group of late adulthood (16.4%) and old age (13%). Very few were young children (3.6%).

Gender

Variable	Frequency (N=501)	%age
Male	261	52.1
Female	240	47.9



The people who were receiving care were from both the gender and almost equal representation. Male were 52.1% and female were 47.9%.

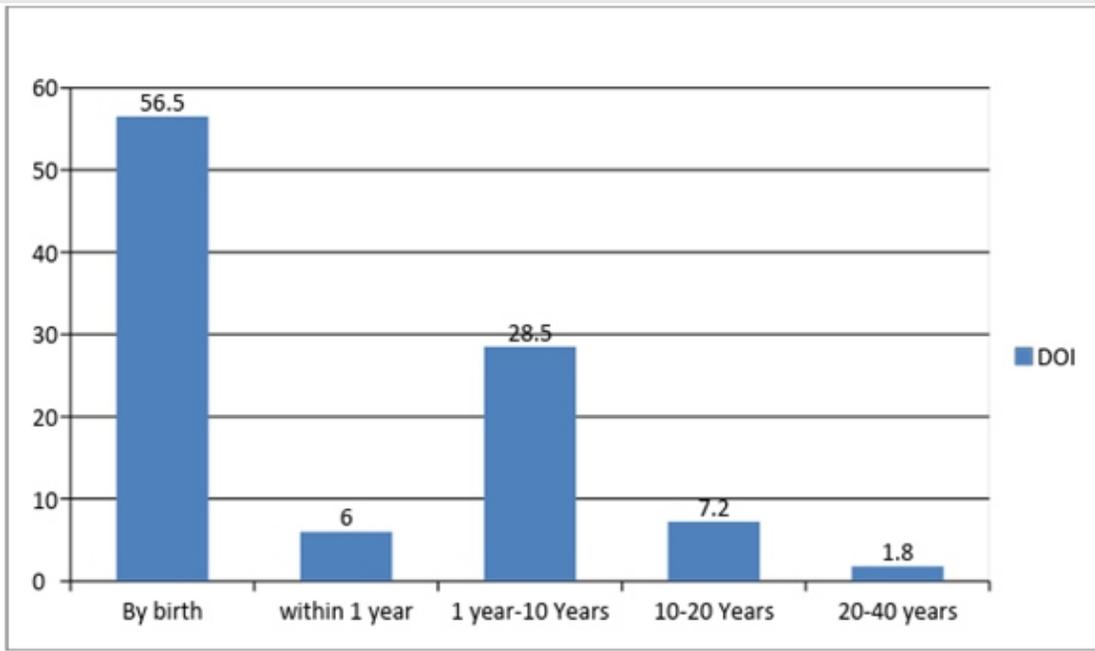
Health/disability condition

Variable	Frequency (N=501)	%age
MR	143	28.5
CP	47	9.4
LM	120	24.0
MD	28	5.6
Paralysis	72	14.4
MI	33	6.6
OH	15	3.0
VI	25	5.0
Epilepsy	8	1.6
Leprosy	5	1.0
HI	4	.8
Polio	1	.2

With regard to disability/health condition of the people who were receiving care, majority of the were mentally retarded (28.5%), followed by locomotor disability (24%), paralysis (14.4%), cerebral palsy (9.4%), mental illness (6.6%), multiple disability (5.6%), visually impaired (5%), OH (3%), epilepsy (1.6%), leprosy (1%), hearing impairment (0.8%)and polio (0.2%).

Duration of illness

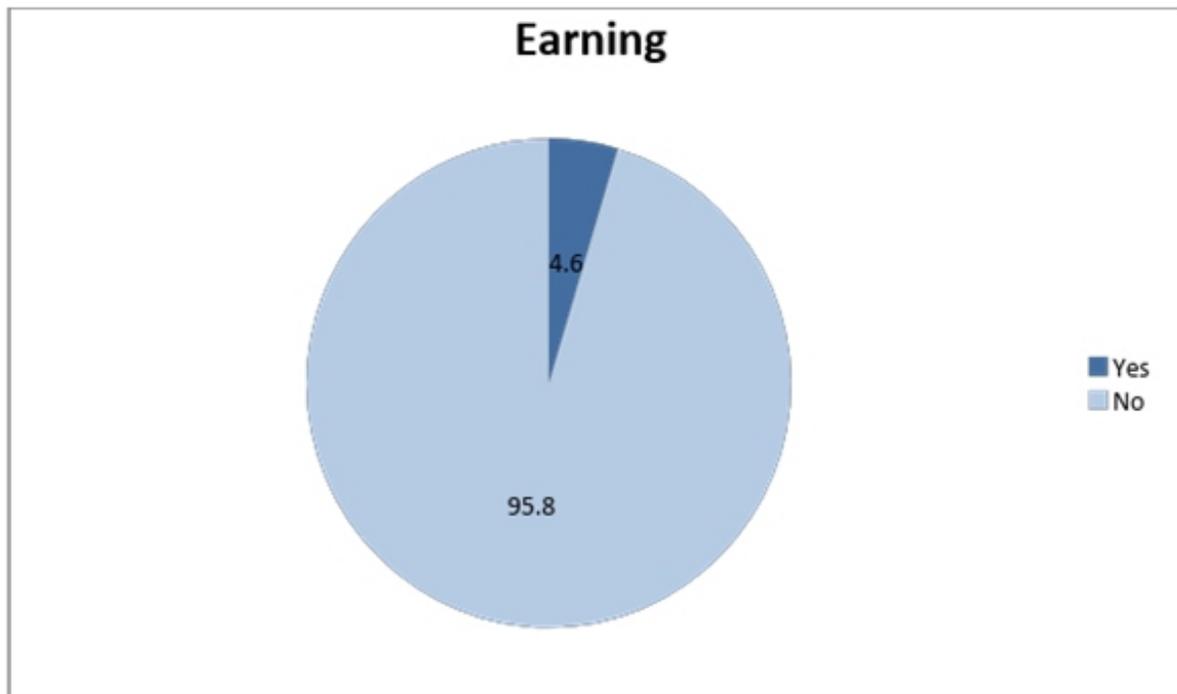
Variable	Frequency (N=501)	%age
By birth	283	56.5
Less than 1 year	30	6.0
1 year-10 years	143	28.5
10-20 years	36	7.2
20-65 years	9	1.8



Majority of them having disability/health issues from their birth (56.5%), followed by having problem for past 10 years (28.5%). Few of them were having problems from 10-20 years (7.2%). Few were having problems less than a year (6%) and very few having illness for longer duration, more than 20 years (1.8%).

Is person looked after earning?

Variable	Frequency (N=501)	%age
Yes	21	4.6
No	480	95.8



It was reported that majority of the caregivers were not earning (95.8%) and very few were earning (4.6%).

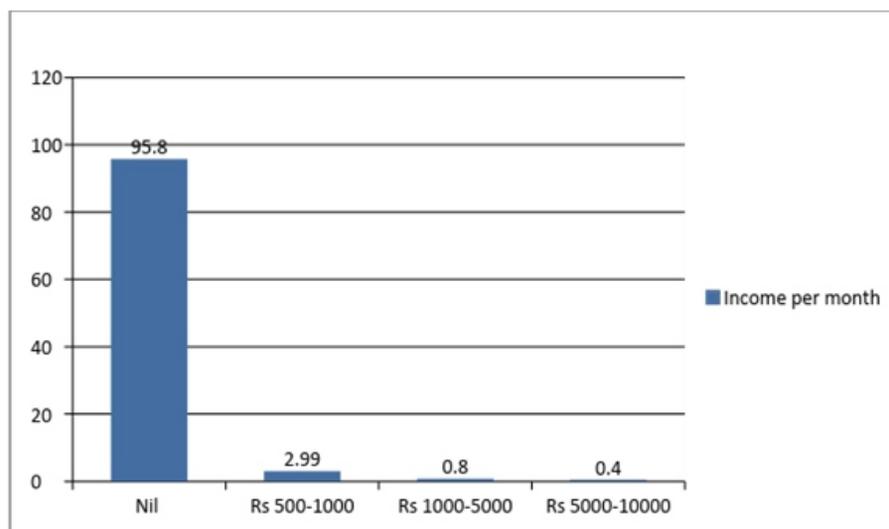
Type of work

Variable	Frequency (N=501)	%age
Not applicable	480	95.8
Farmer	4	0.8
Labour	13	2.6
Pension	1	0.2
Business	1	0.2
Shop	2	0.4

Among the people who were receiving care working (4.8%), few of them working as laborers (2.6%), remaining were farmers (0.8%), hasbusiness (0.2%) and shop (0.4%), and one person depended on pension.

Income per month

Variable	Frequency (N=501)	%age
Nil	480	95.8
500-1000	15	2.99
1000-5000	4	0.8



Majority of the people who were receiving care were not having any income (95.8%). Among who were having income majority of them were earning below 1000 and very few earning below 5000 (0.8%) and between 5000-1000 (0.4%).

SHG member

Variable	Frequency (N=501)	%age
Yes	15	3.0
No	486	97.0

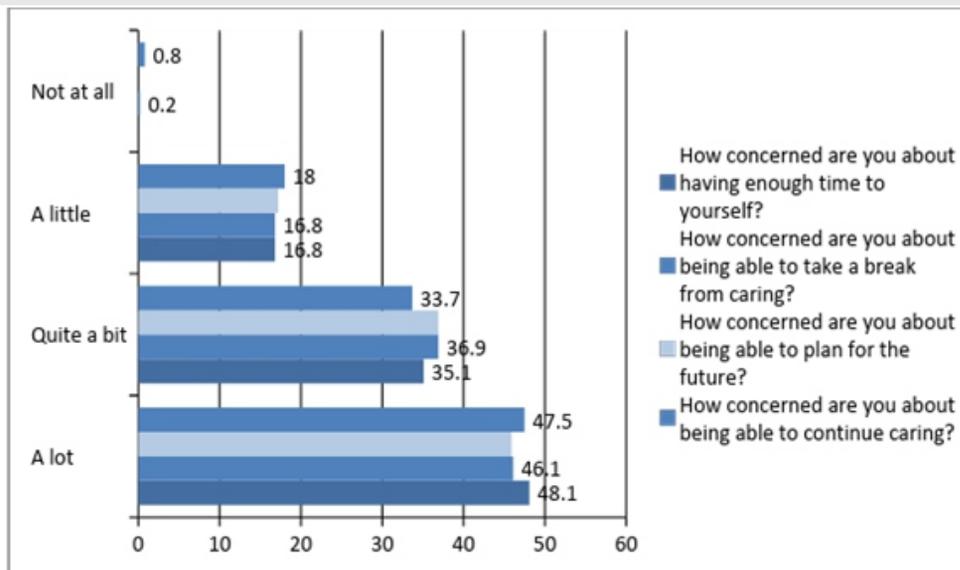


Majority of the people who were receiving care were not members of SHGs (97%) very few were members (3%) of a NGO

Results of wellbeing questionnaire

Concerns about personal life

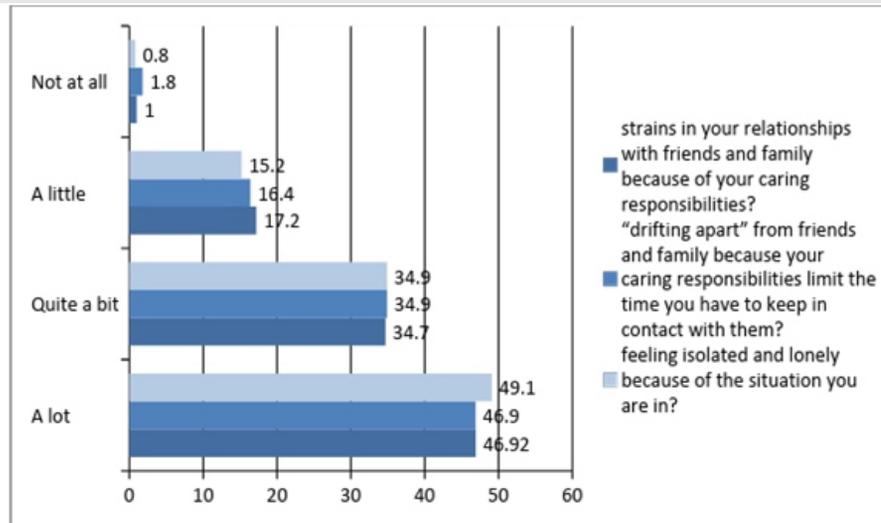
Question	Responses	Frequency	%age
How concerned are you about having enough time to yourself?	A lot	241	48.1
	Quite a bit	176	35.1
	A little	84	16.8
	Not at all	0	0
How concerned are you about being able to take a break from caring?	A lot	231	46.1
	Quite a bit	185	36.9
	A little	84	16.8
	Not at all	1	.2
How concerned are you about being able to plan for the future?	A lot	230	45.9
	Quite a bit	185	36.9
	A little	86	17.2
	Not at all	0	0
How concerned are you about being able to continue caring?	A lot	238	47.5
	Quite a bit	169	33.7
	A little	90	18.0
	Not at all	4	.8



Majority of them reported that they do not have enough time for themselves (83.2%- combining both a lot and quite a bit). None of them reported not being concerned about having time for themselves. Regarding taking break for themselves majority of them reported difficulties (83%- combining both a lot and quite a bit). Majority of them reported that as they are involved actively in the caregiving they are not able to plan for their future (82.8% combining both a lot and quite a bit). Majority of them (81.2%- combining both a lot and quite a bit) are also concerned about being able to continue their caring responsibilities. It shows that caregivers have not given priority for their own care and taking time out.

Concerns about relationships and social life

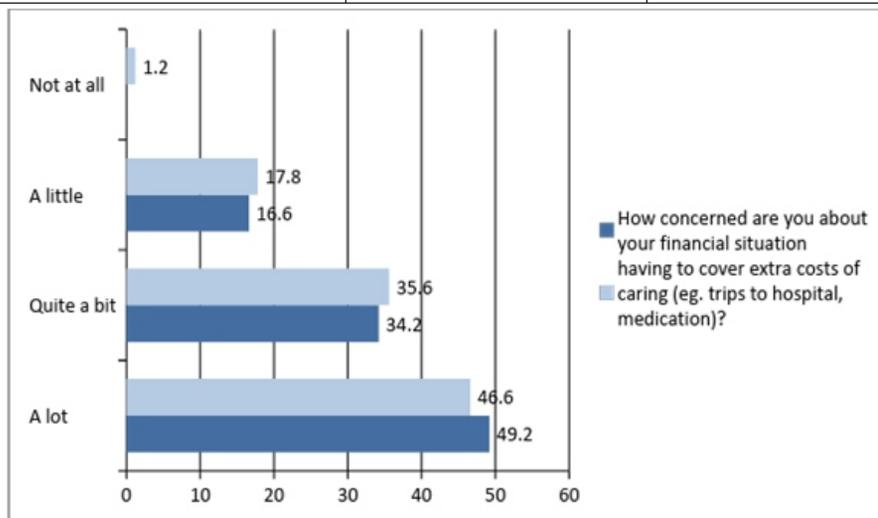
Question	Responses	frequency	%age
How concerned are you about strains in your relationships with friends and family because of your caring responsibilities?	A lot Quite a bit A little Not at all	236 174 86 5	46.92 34.7 17.2 1.0
"drifting apart" from friends and family because your caring responsibilities limit the time you have to keep in contact with them?	A lot Quite a bit A little Not at all	235 175 82 9	46.9 34.9 16.4 1.8
feeling isolated and lonely because of the situation you are in?	A lot Quite a bit A little Not at all	246 175 76 4	49.1 34.9 15.2 .8
getting the support you need from family and friends?	A lot Quite a bit A little Not at all	235 178 82 6	46.9 35.5 16.4 1.2



With regard to impact of caregiving on their personal, familial and social relationships, majority of them reported strains (91.62 combining both a lot and quite a bit) in their relationship due to caring responsibilities and only 1% of them reported that they didn't feel strains on their relationship with family and friends. Majority of them also reported that they are not keeping time for their friends and family and limiting their contact in view of caring tasks.

Concerns about financial condition

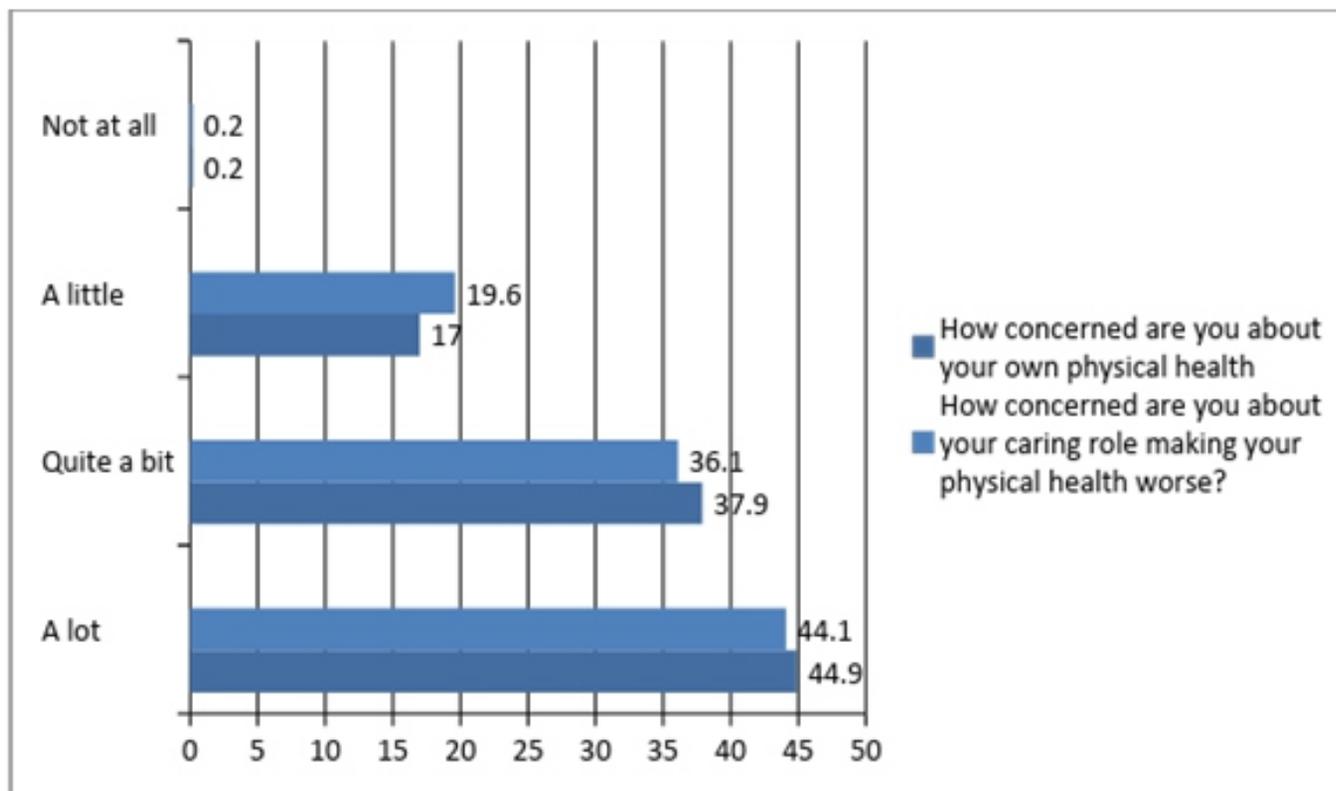
Question	Responses	frequency	%age
How concerned are you about your financial situation?	A lot Quite a bit A little Not at all	247 171 83 0	49.2 34.2 16.6 0
having to cover extra costs of caring (e.g. trips to hospital, medication)?	A lot Quite a bit A little Not at all	234 178 89 0	46.6 35.6 17.8 0



The concerns regarding the financial situation are significant among caregivers as majority of them reported they are concerned a lot (49.2%) and quite a bit too (34.2%). No-one reported that they are not concerned about financial situation. They are concerns regarding other extra costs related to travel for treatment purpose, medication. Majority of them reported they are concerned about these expenses (82.2%, combining both a lot and quite a bit). It is also observed that everyone reported concerns on extra costs.

Concerns about physical health

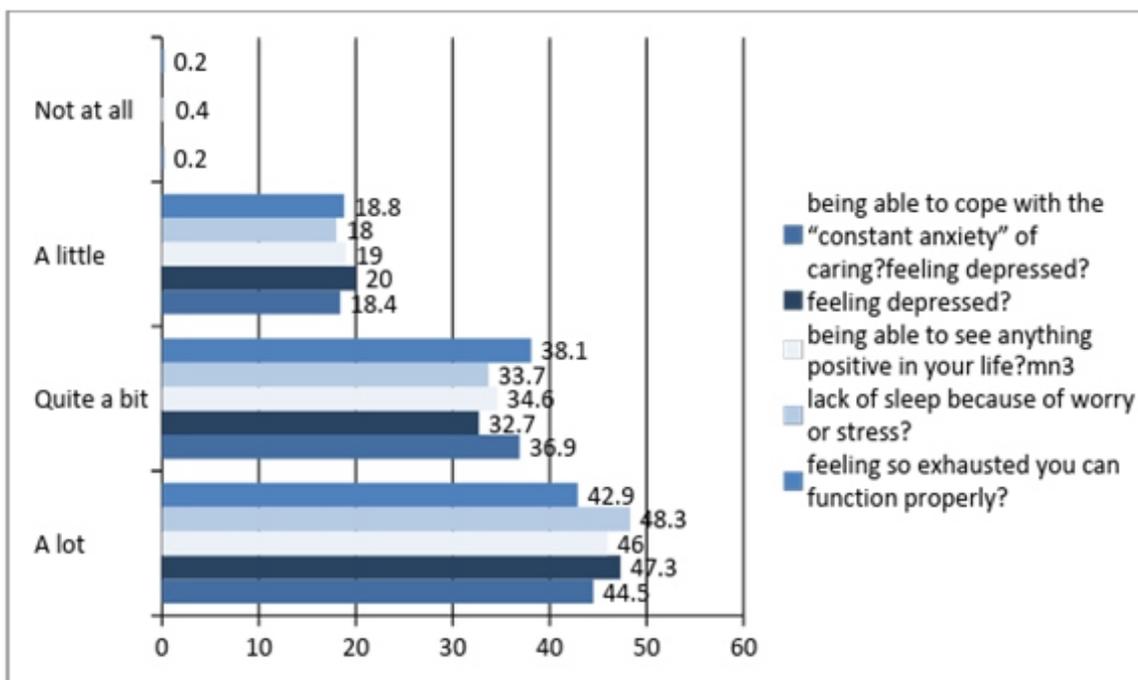
Question	Responses	frequency	%age
How concerned are you about - your own physical health?	A lot	225	44.9
	Quite a bit	190	37.9
	A little	85	17.0
	Not at all	1	.2
your caring role making your physical health worse?	A lot	221	44.1
	Quite a bit	181	36.1
	A little	98	19.6
	Not at all	1	.2



Regarding physical health of caregivers, majority of the respondents reported that they are concerned about their physical health (82.8% - combining both a lot and quite a bit) and caregiving role is worsening their physical health condition (80.2% - combining both a lot and quite a bit).

Concerns about mental health

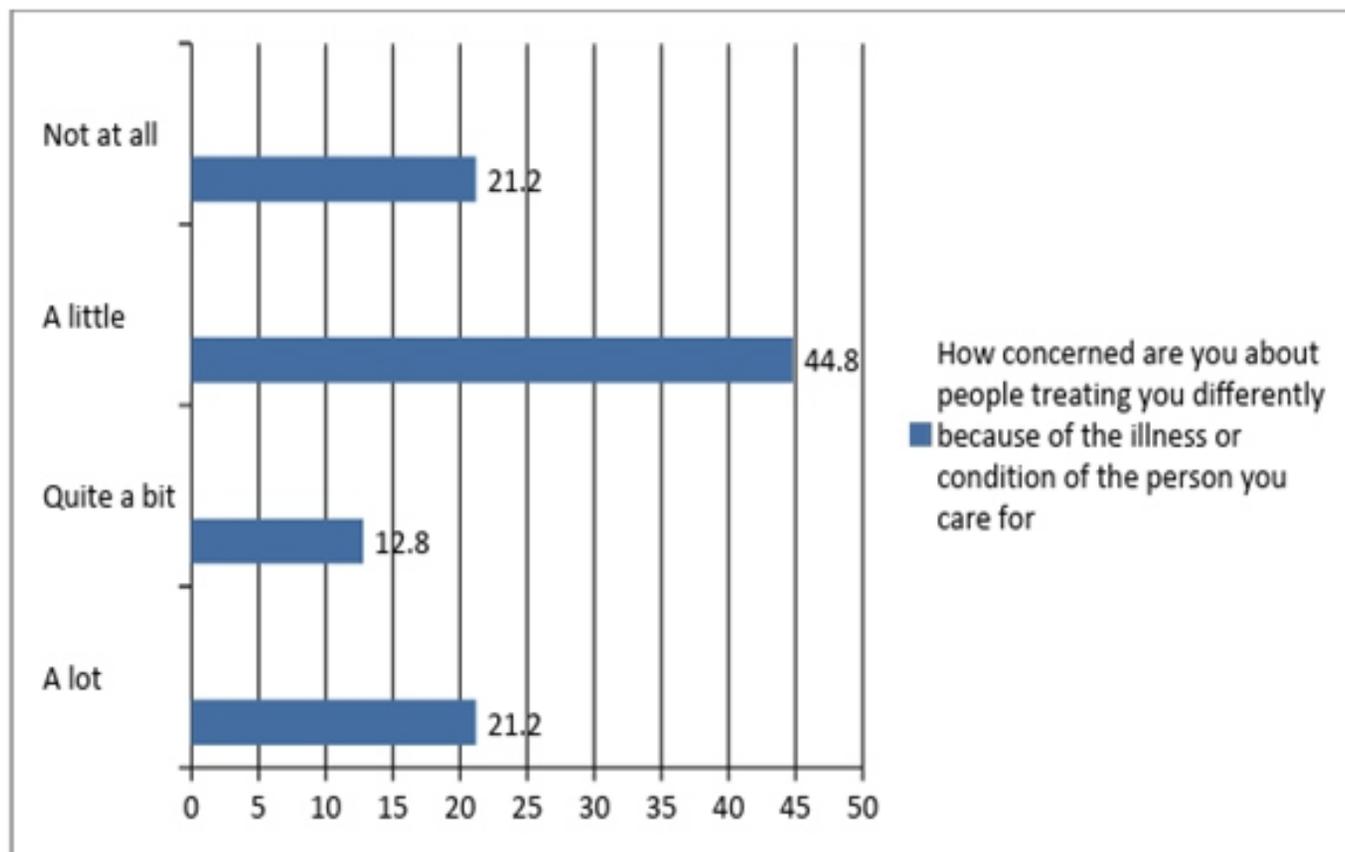
Question	Responses	frequency	%age
How concerned are you about being able to cope with the "constant anxiety" of caring?	A lot Quite a bit A little Not at all	223 185 92 1	44.5 36.9 18.4 .2
feeling depressed?	A lot Quite a bit A little Not at all	237 164 100	47.3 32.7 20.0
being able to see anything positive in your life?	A lot Quite a bit A little Not at all	231 173 95 2	46.0 34.6 19.0 .4
lack of sleep because of worry or stress?	A lot Quite a bit A little Not at all	242 169 90	48.3 33.7 18.0
feeling so exhausted you can function properly?	A lot Quite a bit A little Not at all	215 191 94 1	42.9 38.1 18.8 .2



With regard to mental health aspects such as coping, worries, depression and exhaustion among caregivers, majority of them are constantly anxious about caring (81.4% - combining both a lot and quite a bit), feeling depressed (80%), unable to see positives in their life (80.6%), lack of adequate sleep because of stress(82%) and feelings of exhaustion and cannot function properly (81%). Very few people reported nil concerns about this mental health aspects.

Concerns about being treated differently

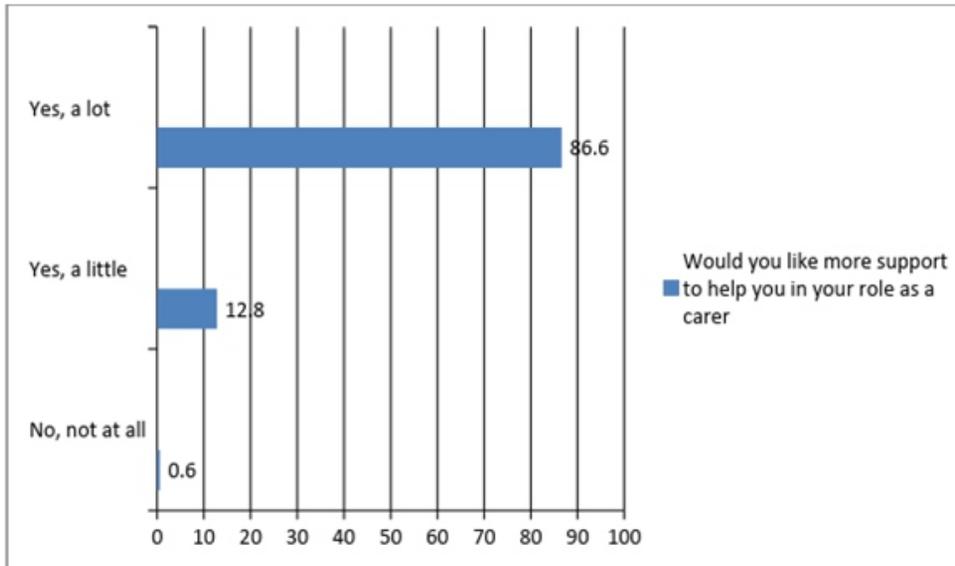
Questions	Response	Frequency	%age
How concerned are you about people treating you differently because of the illness or condition of the person you care for?	A lot	107	21.2
	Quite a bit	64	12.8
	A little	224	44.8
	Not at all	106	21.2



Regarding concerns on stigma due to the condition/illness of their family members who they care for, it was observed that majority of them concerned very little about being treated differently (44.8%). It is also observed that equal number of people concerned a lot (21.1%) and not at all (21.2) concerned about being discriminated against.

Desire for further support

Questions	Response	Frequency	%age
Would you like more support to help you in your role as a carer?	No, not at all	4	.6
	Yes, a little	66	13.2
	Yes, a lot	431	86.2



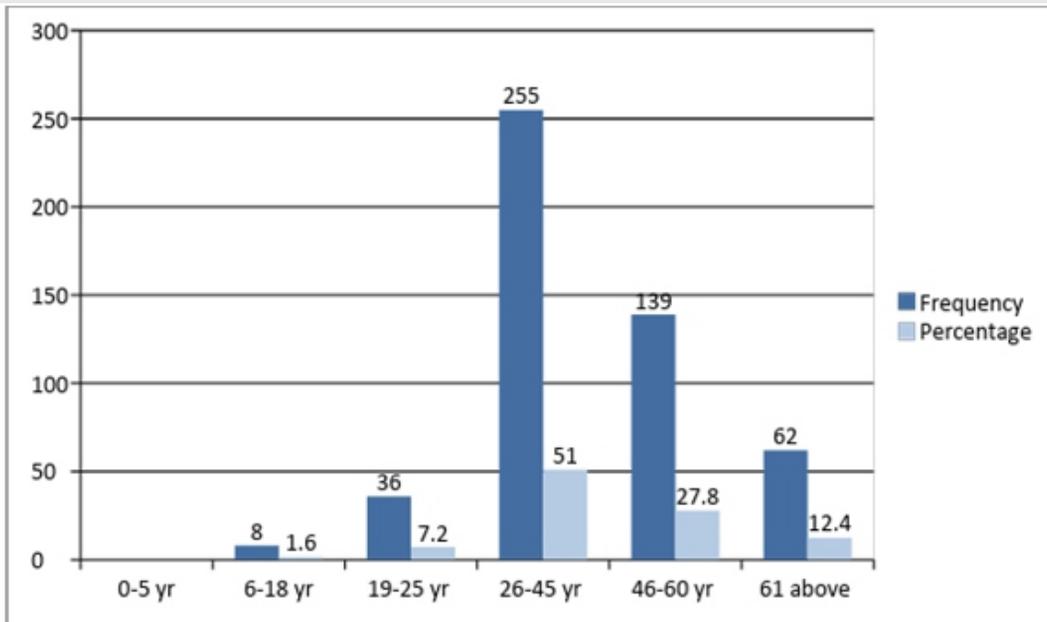
With regard to seeking more help to carry out the carer role, majority of them reported that they need a lot of help (86.6%).

Results of the survey conducted by SPREAD

Caregiver's profile

Distribution of age

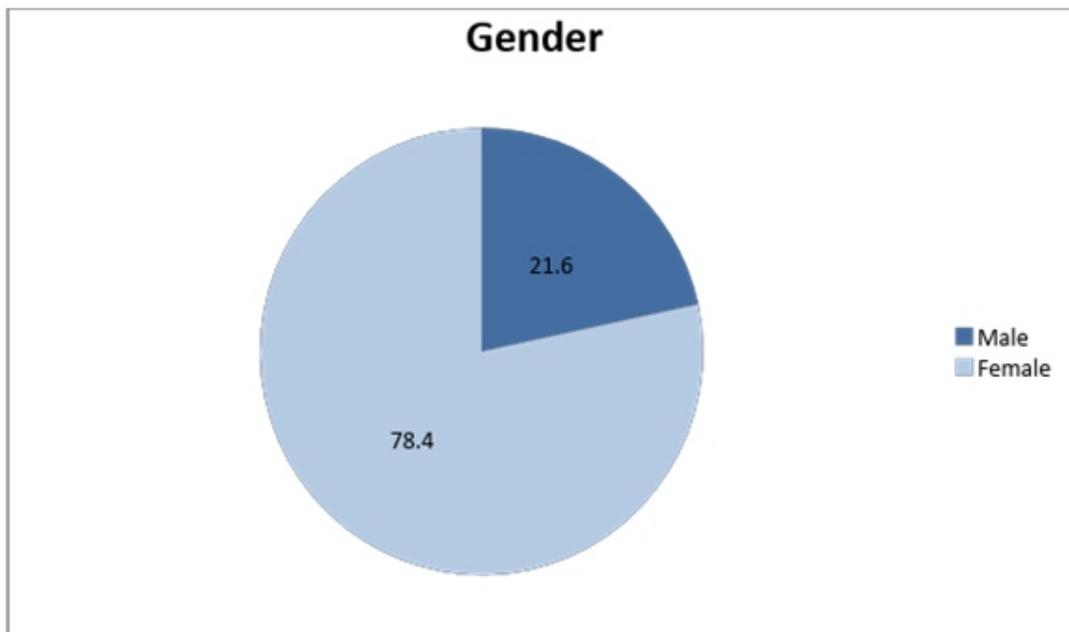
Age Group	Frequency (N=500)	%age
0-5	0	0
6-18	8	1.6
19-25	36	7.2
26-45	255	51.0
46-60	139	27.8
61 +	62	12.4



Almost half of the caregivers fall under the age group of 26-45 years, followed by 27.8 % in the age group of 61 and above and 7.2 % in the age group of 19-25 % respectively. Very less that is 1.6 % caregivers are children or adolescents 6-18 years).

Gender

Variable	Frequency (N=500)	%age
Male	108	21.6
Female	392	78.4



More than three-quarters of caregivers are female, and the remaining one-quarter are males, that is, 78.4 % and 21.6 % respectively.

Marital status

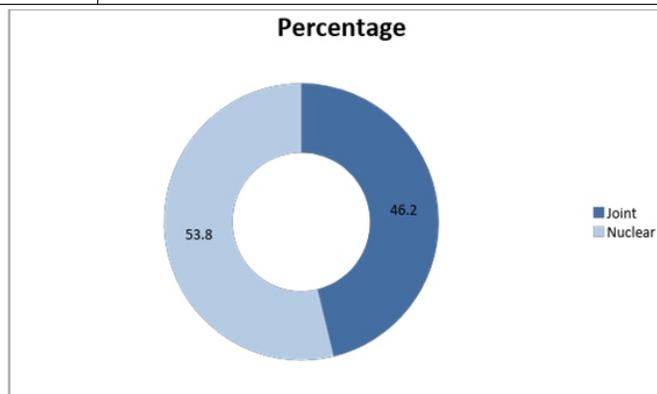
Variable	Frequency (N=500)	%age
Married	486	97.2
Single	14	2.8
Widow	0	0



Almost 97.2 % of the caregivers are married and rest of the 2.8 % are single.

Type of family

Variable	Frequency (N=500)	%age
Joint	231	46.2
Nuclear	269	53.8



More than half of the caregivers are from nuclear family, and the remaining ones from joint family that is 53.8 % and 46.2% respectively.

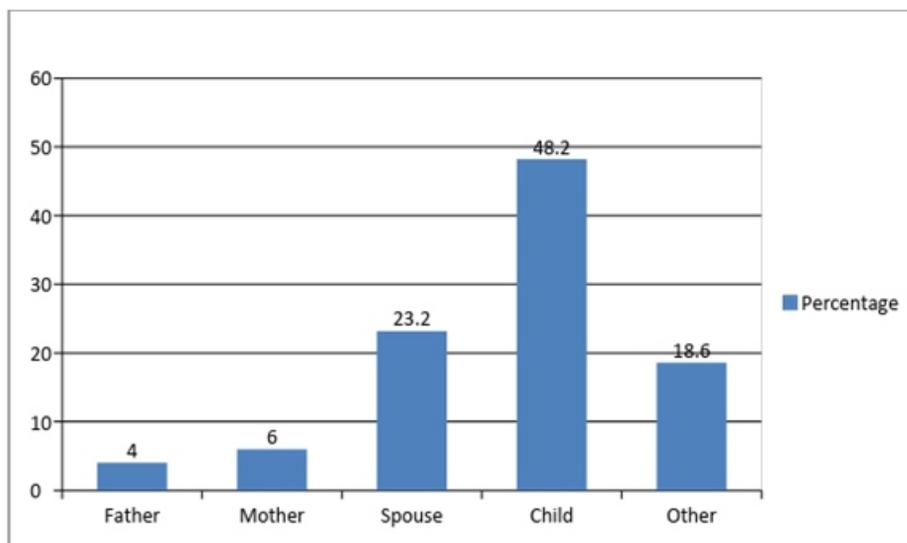
Details of family members

Variable	Mean & SD	Minimum – Maximum
No of household members	5.04 ± 1.948	2-12
No of men	2.54 ± 1.342	0-8
No of women	2.53 ± 1.223	0-8
No of Children	1.34 ± 1.470	0-7

The average household members in the family are 5.04. Average number of men is 2.54, average number of women in the family is 2.53 and children are 1.34. It is observed that there were equal number of men and women in the family.

Relationship with the person cared for

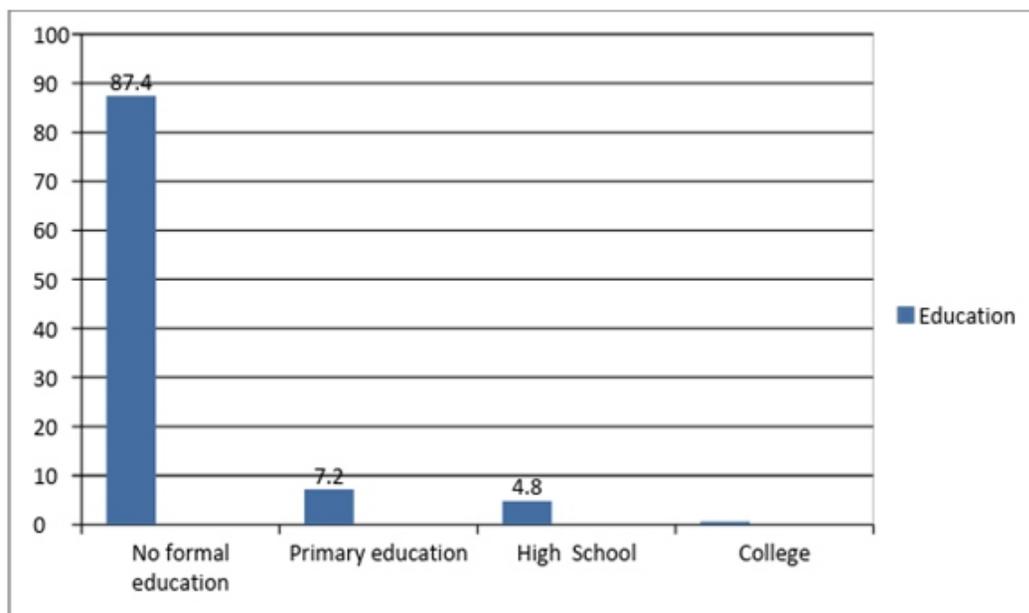
Variable	Frequency (N=500)	%age
Father	20	4.0
Mother	30	6.0
Spouse	116	23.2
Child	241	48.2
Other	93	18.6



Almost 48% of the caregivers are the children in relationship to the person cared for, followed by 23.2 % spouse and 18.6% as others. In some of the cases parents are also caregivers, that is, 4 % mother and 6 % father.

Education level

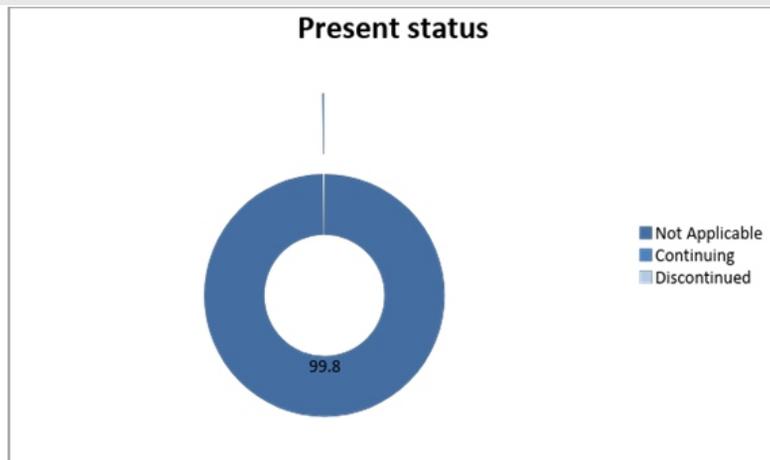
Variable	Frequency (N=500)	%age
No formal education	437	87.4
Primary education	36	7.2
High school	24	4.8
College	3	.6



87.4 % of the caregivers have not received any formal education, followed by 7.2 % with primary education and 4.8 % of caregivers with high school. The caregivers who have attended college are only 0.6 %.

Present education status

Variable	Frequency (N=500)	%age
Not applicable	499	99.8
Continuing	1	.2
Discontinued	0	0

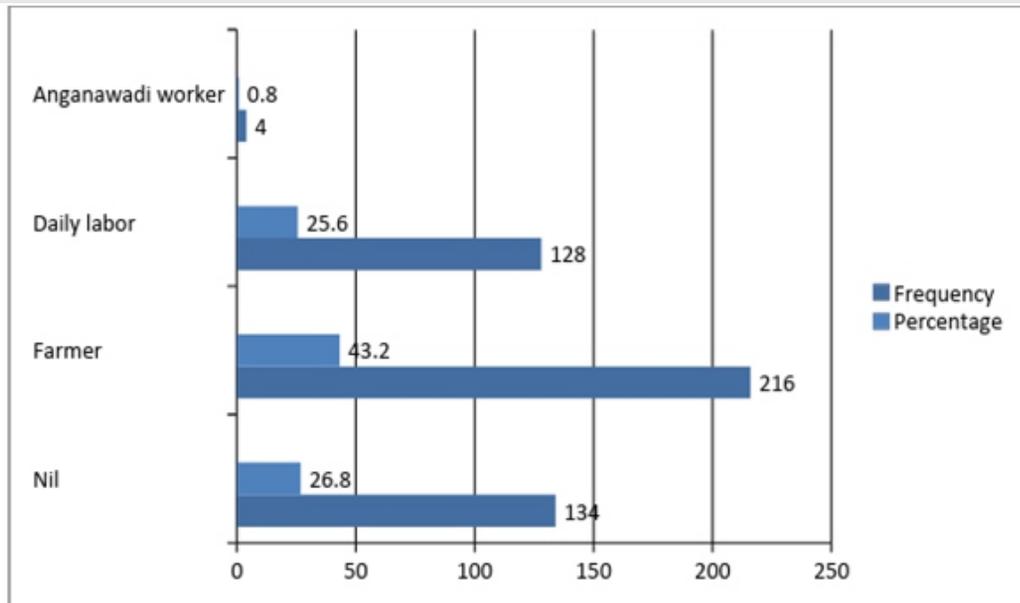


Since most of the caregivers have not received any formal education, only 0.3% of them are continuing the education and it does not apply for the rest 99.8 % of the caregivers.

Type of work

Variable	Frequency (N=500)	%age
No/Nil	134	26.8
Farmer/agriculture	216	43.2
Daily labour	128	25.6
Anganawadi worker	4	.8
Anganawadi helper	2	.4
School cook	3	.6
Asha worker	1	.2
Business	7	1.4
Driver	1	.2
Maid	1	.2
Cycle repair	1	.2
Blacksmith	1	.2
Tailor	1	.2

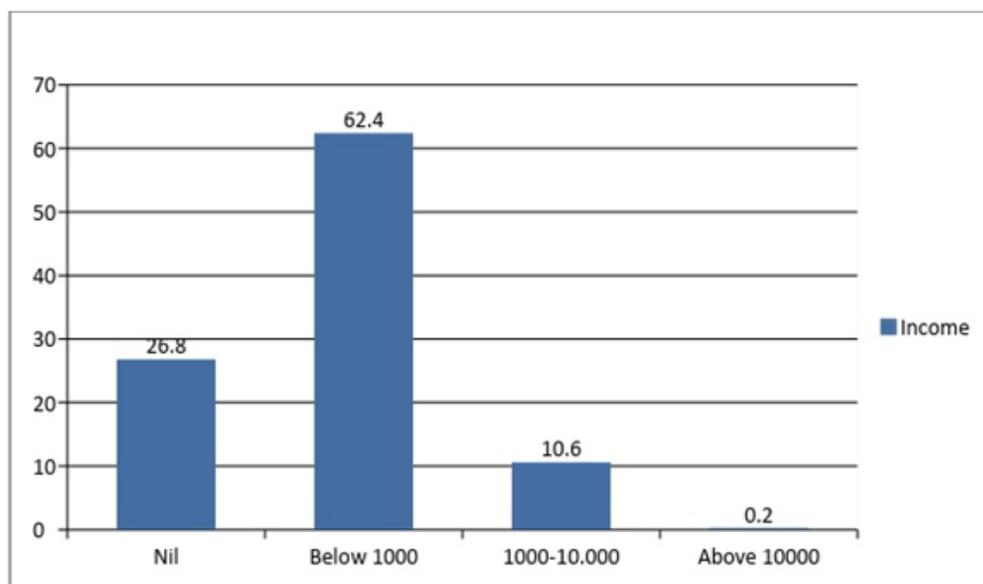
Majority (43.2%) of the caregivers are farmers, 25% are daily labourers, and 26.8 % not employed. The remaining caregivers are either anganwadi workers, anganwadi helpers , school cook, ashaworker or maidsetc.



Income per month

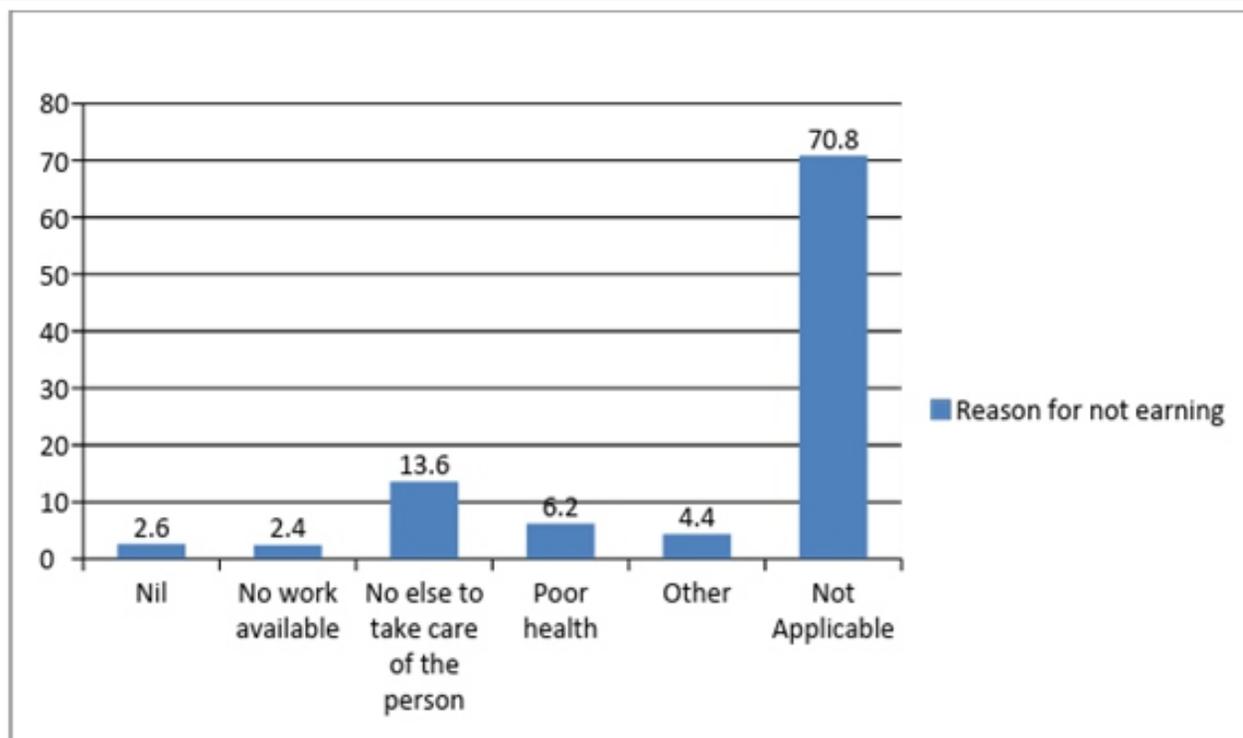
Variable	Frequency (N=500)	%age
Nil	134	26.8
Below 1000	312	62.4
1000-10.000	53	10.6
Above 10000	1	.2

Since most of the caregivers are not employed so they are not earning. Among the ones who are earning, 62.4 % are earning below Rs 1000 per month and 10.6 % are earning up to Rs 10000, and only 0.2 % of the caregivers are earning above Rs 10000 per month.



Reason for not earning

Variable	Frequency (N=500)	%age
Nil	13	2.6
No work available	12	2.4
Nobody else to take care of the person	68	13.6
Poor health	31	6.2
Other	22	4.4
Not Applicable	354	70.8

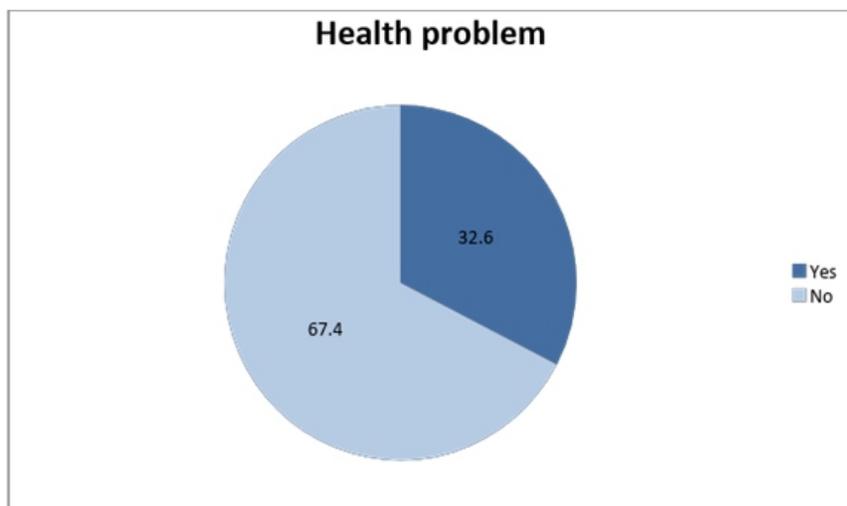


Most of the caregivers are not earning/working and they have their own reasons for that. 13.6 % of the caregivers are not working and earning because there is no one to take care of the other person, 6.2% of them have poor health, 4.4 % have other reasons, and 2.4 % says that there is no work available for them.

Health problem of the caregiver

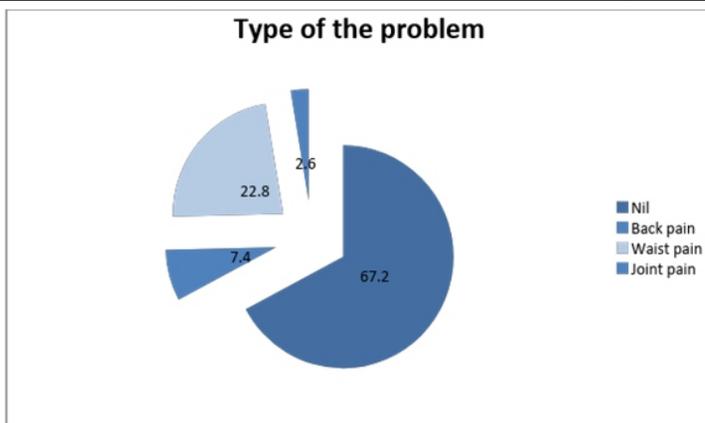
Variable	Frequency (N=500)	%age
Yes	163	32.6
No	337	67.4

Almost one-third of the caregivers have health concerns, i.e. 32 %, and the remaining 67.4% don't have any health concerns.



Type of problem

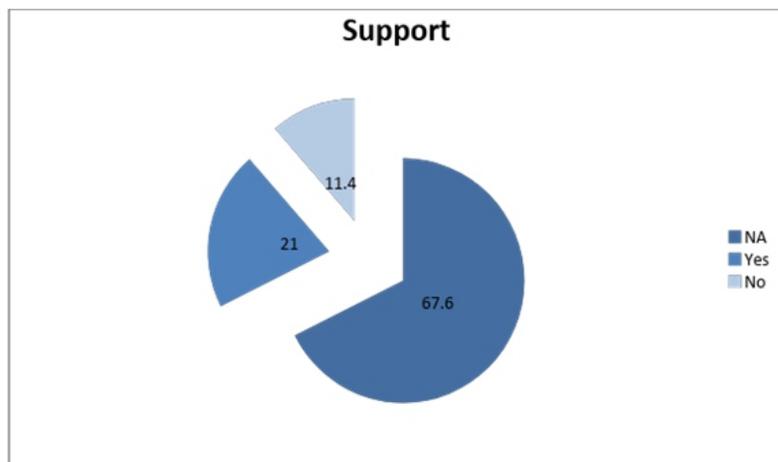
Variable	Frequency (N=500)	%age
Nil	336	67.2
Back pain	37	7.4
Waist pain	114	22.8
Joint pain	13	2.6



As described in the previous table out of 37 % caregiver who expressed physical health concerns, 22.8% caregivers report waist pain, 7.4% report back pain, and 2.6 % report joint pain.

Support/treatment received

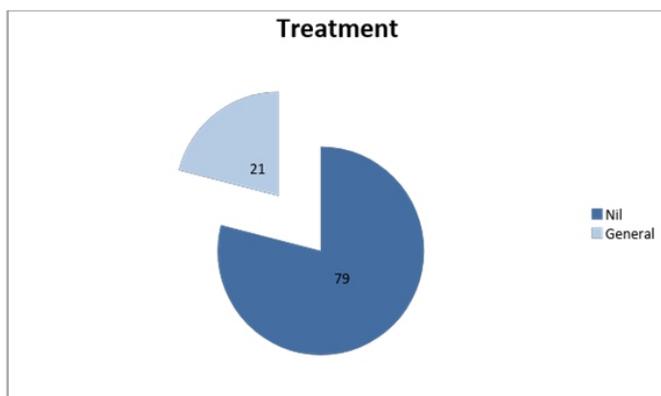
Variable	Frequency (N=500)	%age
NA	338	67.6
Yes	105	21
No	57	11.4



For the physical health concerns only 21 % of the caregivers have received treatment and 11.4 % have not received any treatment.

Type of treatment

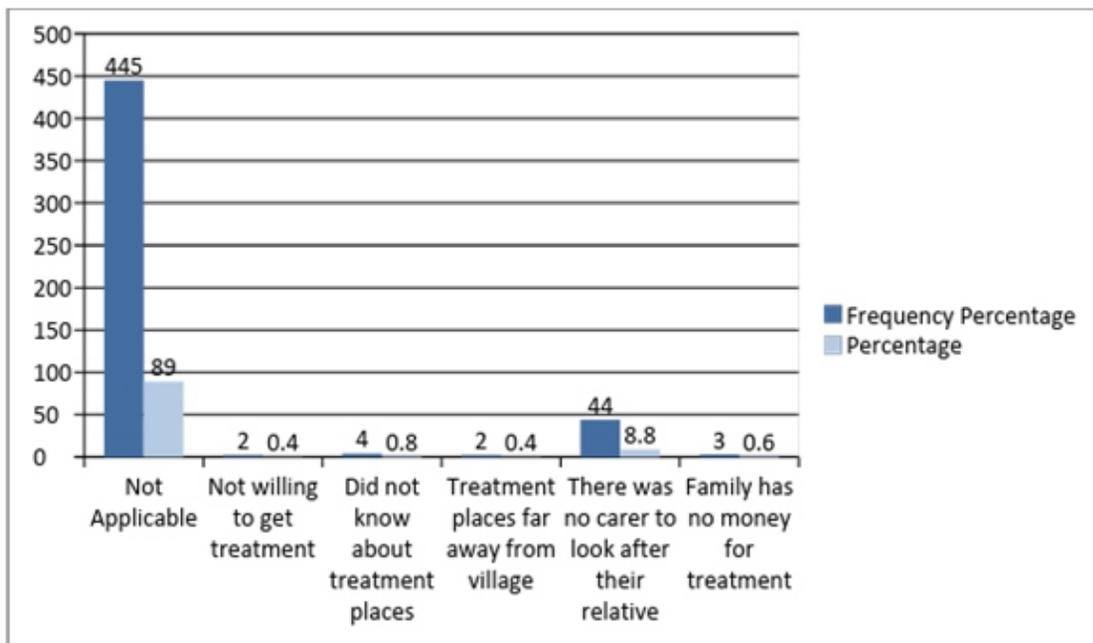
Variable	Frequency (N=500)	%age
Nil	395	79
General	105	21



Among the caregivers who have physical health concerns, 21 % of them have received general treatment.

Reason for not receiving treatment

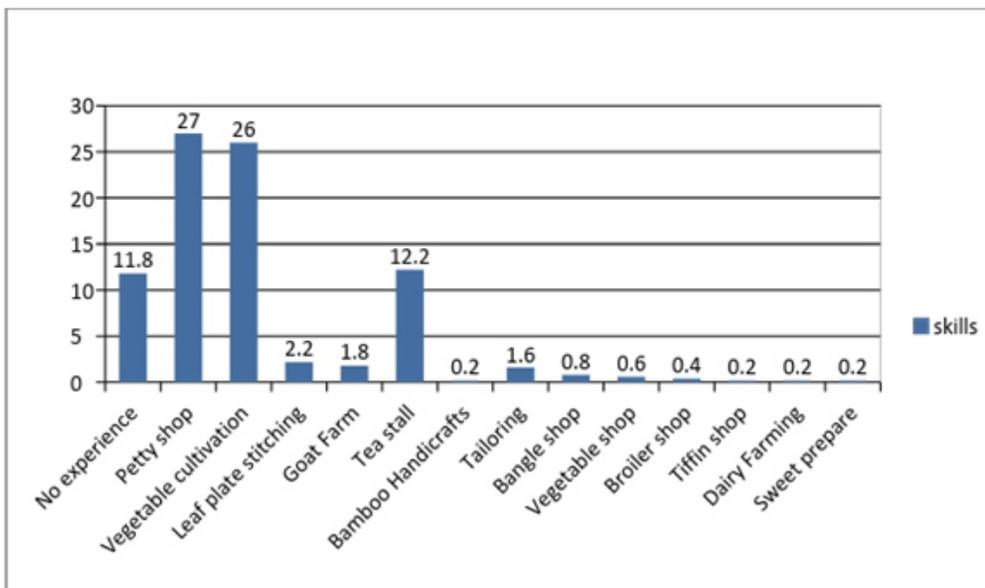
Variable	Frequency (N=500)	%age
Not Applicable	445	89.0
Not willing to get treatment	2	.4
Did not know about treatment places	4	.8
Treatment places far away from village	2	.4
There was no carer to look after their relative	44	8.8
Family has no money for treatment	3	.6



The caregivers who have physical health concerns have not received the treatment for various reasons. 8.8% of them did not receive treatment since there was no one to look after their relative, 0.8 % of them were not aware about the treatment places, 0.6 % of them did not had money and 0.4 % of them were staying away from the treatment places.

Skill of the caregiver

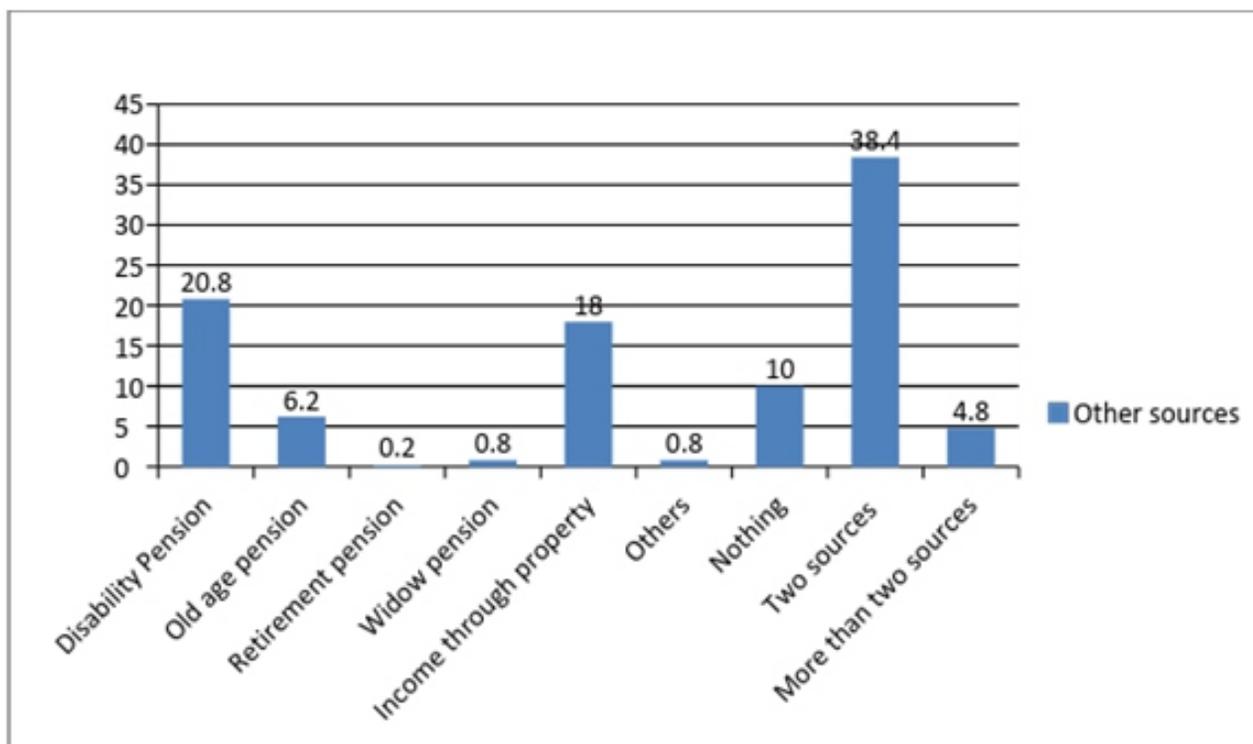
Variable	Frequency (N=500)	%age
No experience	59	11.8
Petty shop	135	27.0
Vegetable cultivation	130	26.0
Leaf plate stitching	75	2.2
Goat Farm	70	1.8
Tea stall	11	12.2
Bamboo handicrafts	9	.2
Tailoring	8	1.6
Bangle shop	4	.8
Vegetable shop	3	.6
Broiler shop	2	.4
Tiffin shop	1	.2
Dairy farming	1	.2
Sweet prepare	1	.2



If we look into the skills of the caregivers, 27 % of them have petty shop and 26 % of them know to do vegetable cultivation. The other skills include tea stall, tailoring, leaf plate stitching that is 12.2 %, 1.6% and 2.2% respectively.

Other sources of income

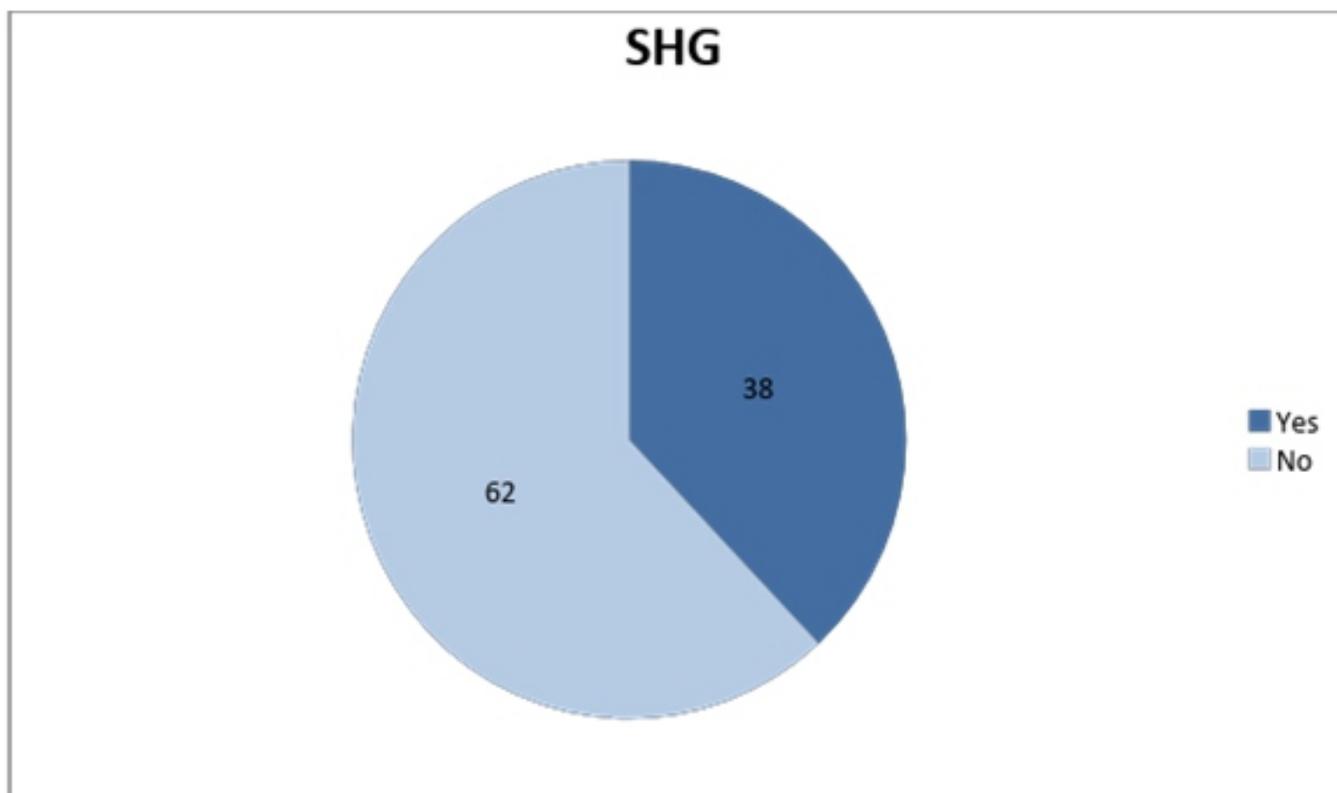
Variable	Frequency (N=500)	%age
Disability pension	104	20.8
Old age pension	31	6.2
Retirement pension	1	.2
Widow pension	4	.8
Income through property	90	18
Others	4	.8
Nothing	50	10
Two sources	192	38.4
More than two sources	24	4.8



Most of the caregivers also have other sources of income. 38.4 % of them have two sources of income, 20.8 % of them have disability pension, 18 % of them have property and 6.2% are getting old age pension. The remaining child caregivers have widow pension, retirement pension etc.

SHG member

Variable	Frequency (N=500)	%age
Yes	190	38
No	310	62

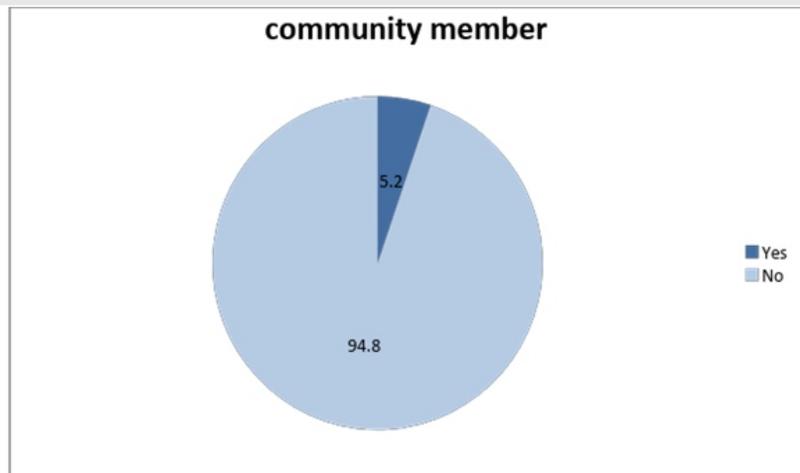


More than half the caregivers are SHG members(62 %).

Community member

Variable	Frequency (N=500)	%age
Yes	26	5.2
No	474	94.8

Only 5.2 % of the caregivers are community members.



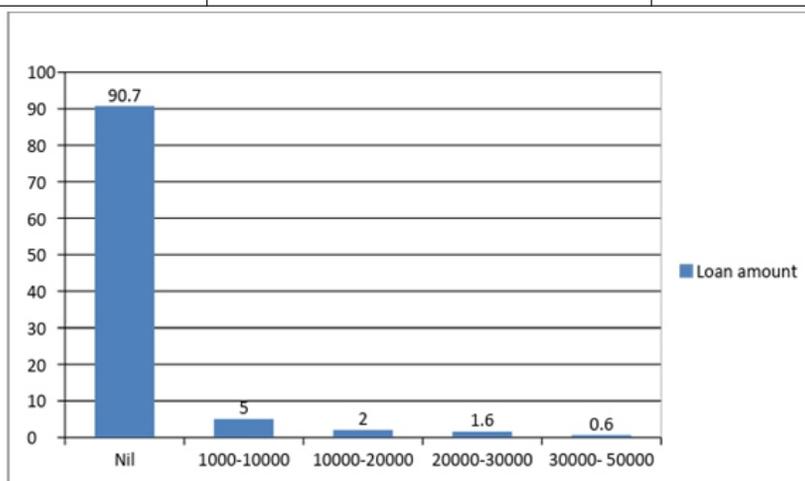
Loan

Variable	Frequency (N=500)	%age
Yes	50	10
No	450	90

Only 10 % of the caregivers have taken loan for personal reasons and the remaining 90% have not.

Loan amount

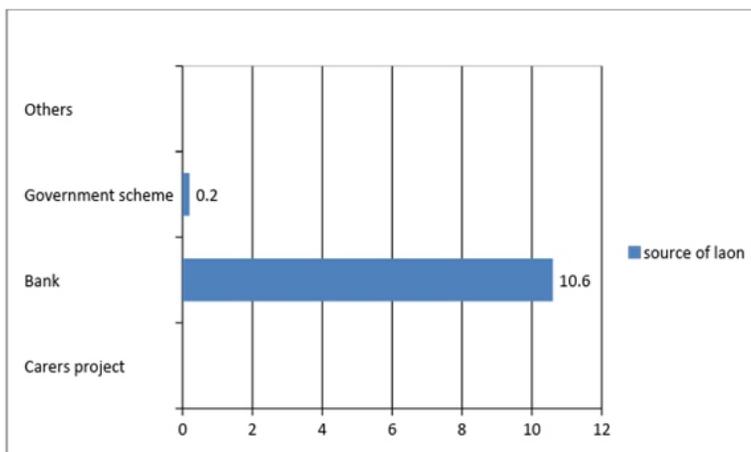
Variable	Frequency (N=500)	%age
Nil	454	90.7
1000-10000	25	5.0
10000-20000	10	2.0
20000-30000	8	1.6
30000- 50000	3	.6



Out of the caregivers who have taken loan, 5% have taken loan up to 10,000, 2% have taken loan up to 20,000, 1.6 % have taken loan up to 30,000. The maximum amount of loan taken is up to Rs 50,000 that is taken by only 0.6 % of the caregivers.

Source of loan

Variable	Frequency (N=500)	%age
Carers project	0	0
Bank	53	10.6
Government scheme	1	.2
Others	0	0
Not applicable	446	89.2

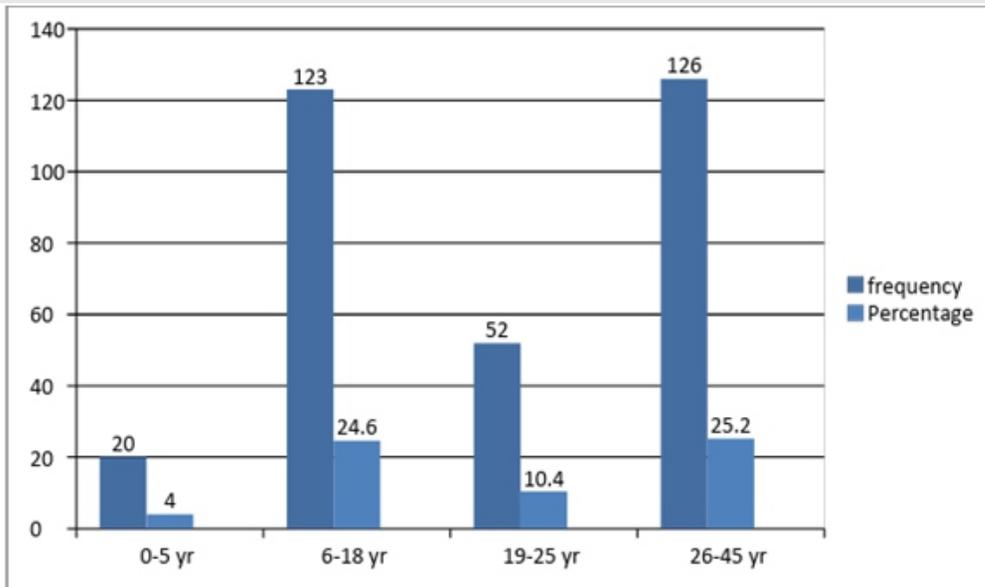


There are different sources of loan from where caregivers have taken loan. 10.6 % of them have taken it from bank and the remaining 0.2 % has utilized the government scheme.

Details of person cared for

Age

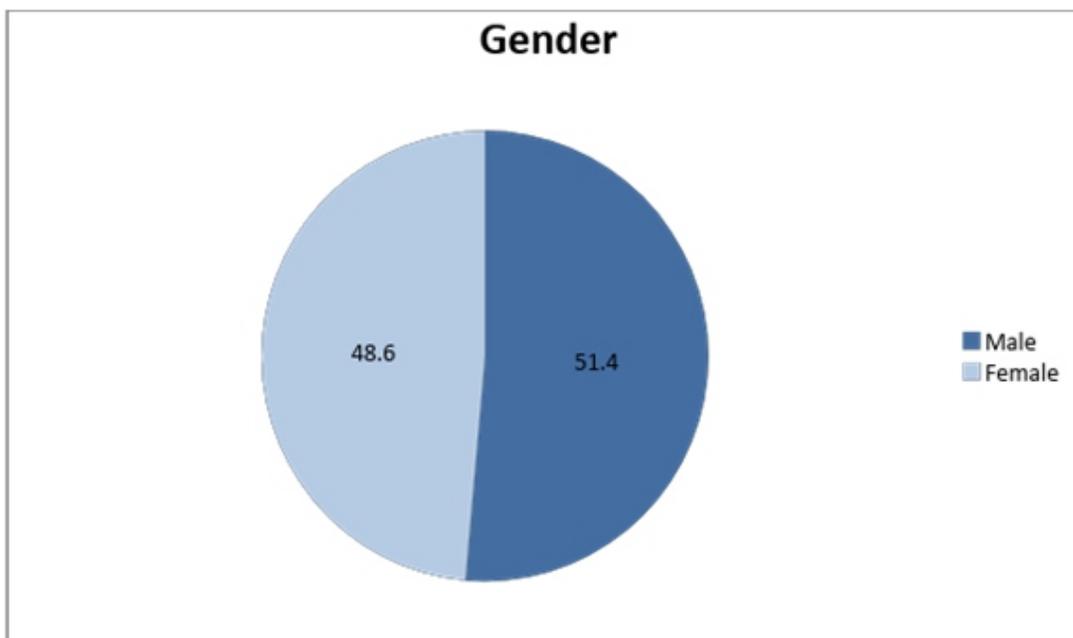
Age Group	Frequency (N=500)	%age
0-5	20	4.0
6-18	123	24.6
19-25	52	10.4
26-45	126	25.2
46-60	78	15.6
61 +	101	20.2



Almost 25% of the person who is cared for fall under the age group of 26-45 years, followed by 24.6 % 6-18 years, 20 % of them above 61 years, and 15 % 46-60 years.

Gender

Variable	Frequency (N=500)	%age
Male	257	51.4
Female	243	48.6



There is only slight difference in the gender proportion of the person who are cared for. 51% of them are males and 48.6% of them are female.

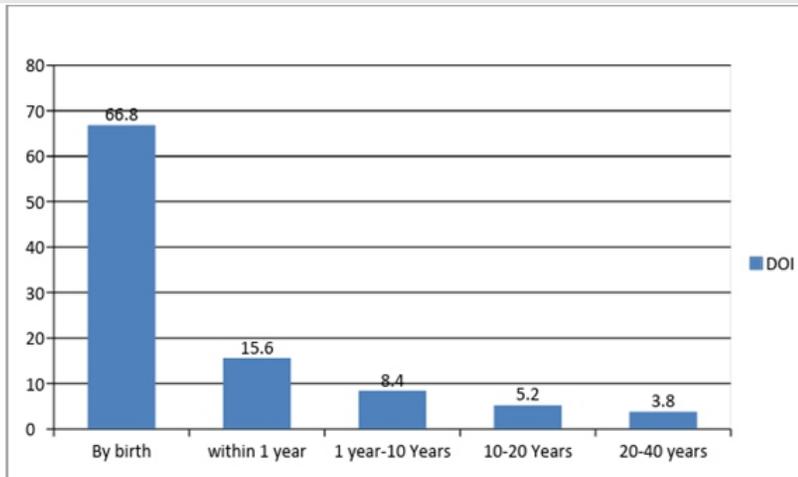
Health/disability condition

Variable	Frequency (N=500)	%age
Locomotor	118	23.6
Multiple disability	108	21.6
Visually challenged	69	13.8
Mental retardation	67	13.4
Paralysis	60	12.0
Epilepsy	28	5.6
Mental illness	21	4.2
Cerebral palsy	16	3.2
Accident	5	1
Old age	5	1
Leprosy	2	.4
Hearing impairment	1	.2

Almost 25% have locomotor disability and multiple disabilities, i.e. 23.6% and 21% respectively. Other disabilities are visually challenged, mental retardation, and paralysis, that is, 13.8%, 13.4 % and 12 % respectively.

Duration of illness

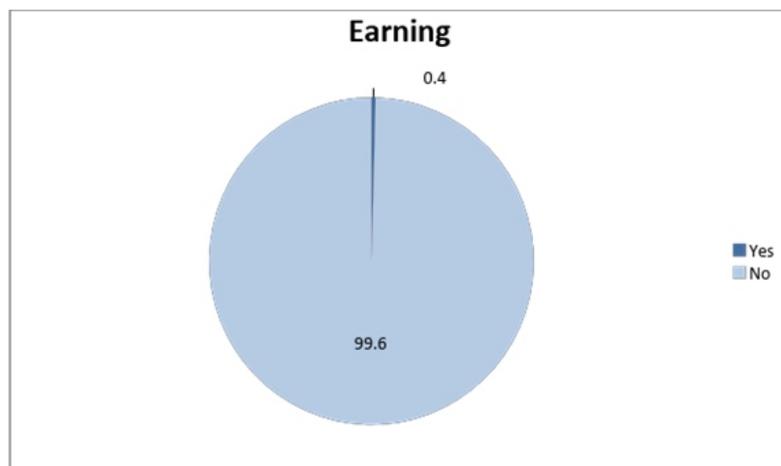
Variable	Frequency (N=500)	%age
By birth	334	66.8
within 1 year	78	15.6
1 year-10 Years	42	8.4
10-20 Years	26	5.2
20-40 years	19	3.8



Not only type but duration of illness is important. 66.8 % have illness by birth, followed by 15% who have developed it one year back, 8.4 % have the illness from past 1-10 years , 5.2 % have it from past 10-20 years and only 3.8 % have it from past 20-40 years.

Is person looked after earning?

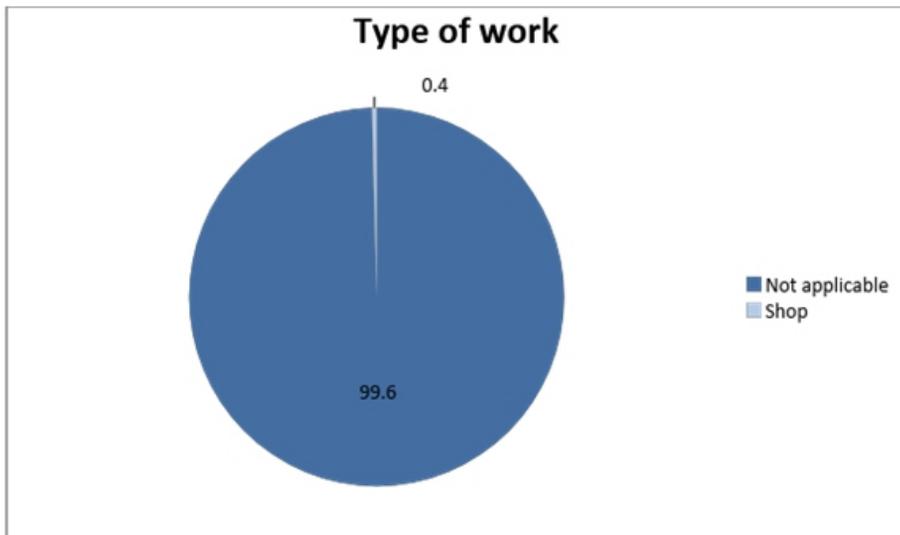
Variable	Frequency (N=500)	%age
Yes	2	.4
No	498	99.6



It is reported that majority of them are not earning, that is, 99.6 % with the remaining 0.4 %earning.

Type of work

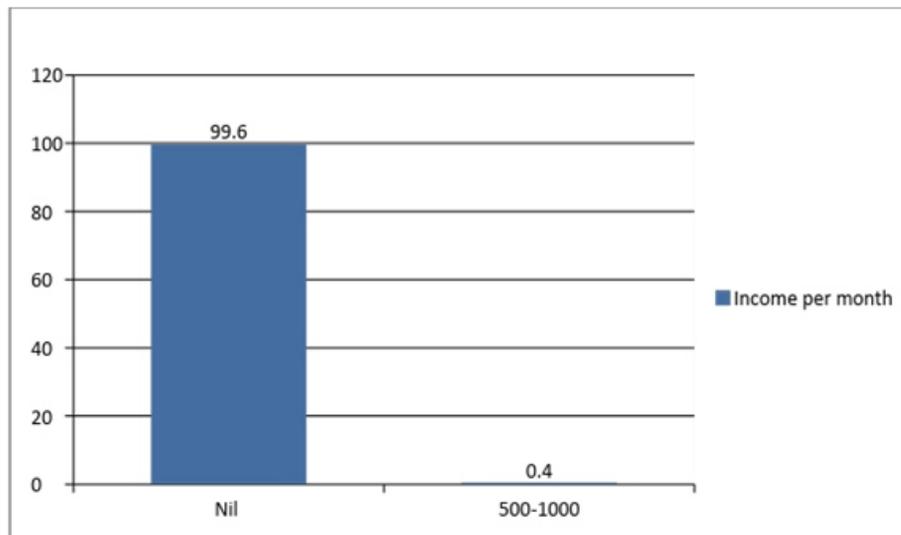
Variable	Frequency (N=500)	%age
Not applicable	498	99.6
Shop	2	.4



Out of the individuals who are earning, 0.4 % of them are working in shop.
Income per month

Variable	Frequency (N=500)	%age
Nil	498	99.6
500-1000	2	.4

Only 0.4 %age of the caregivers are earning, which is Rs 500-1000 per month.



SHG member

Variable	Frequency (N=500)	%age
Yes	2	.4
No	498	99.6

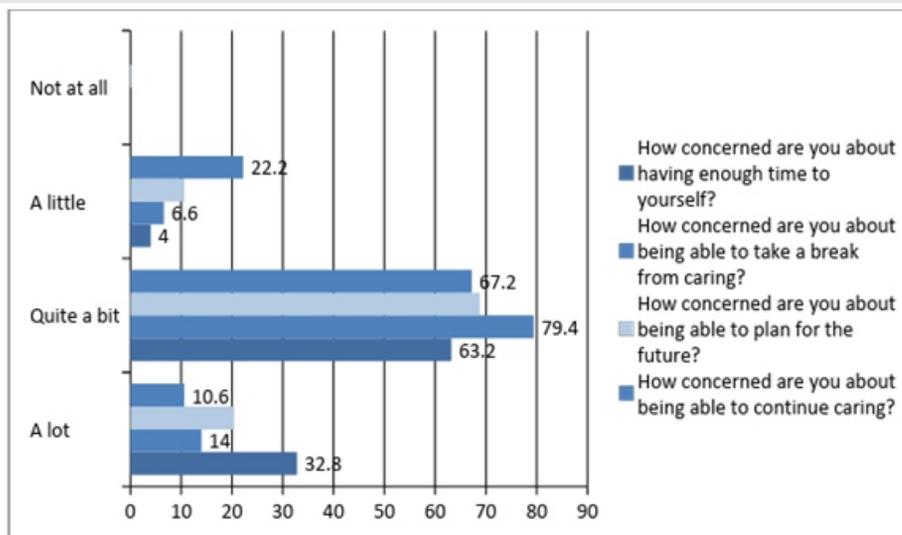


Only 0.4 % of the caregivers are SHG members and the rest of 99.6 % of them are not having SHG membership.

Results of wellbeing questionnaire

Concerns about personal life

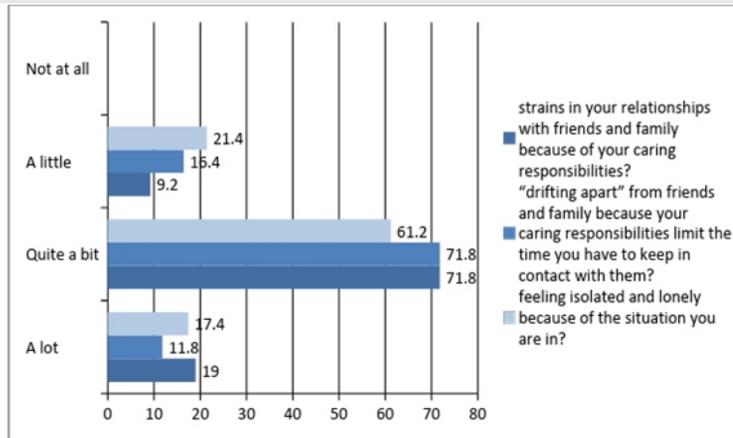
Question	Responses	Frequency	%age
How concerned are you about having enough time to yourself?	A lot	164	32.8
	Quite a bit	316	63.2
	A little	20	4.0
	Not at all	0	0
How concerned are you about being able to take a break from caring?	A lot	70	14.0
	Quite a bit	397	79.4
	A little	33	6.6
	Not at all	0	0
How concerned are you about being able to plan for the future?	A lot	102	20.4
	Quite a bit	344	68.8
	A little	53	10.6
	Not at all	1	.2
How concerned are you about being able to continue caring?	A lot	53	10.6
	Quite a bit	336	67.2
	A little	111	22.2
	Not at all	0	0



Majority of them reported that they do not have enough time for themselves (96%- combining both a lot and quite a bit). None of them reported not being concerned about having time for them. Regarding taking break for themselves majority of them reported difficulties (93.8%- combining both a lot and quite a bit). Majority of them reported that as they are involved actively in the caregiving they are not able to plan for their future (89.2% - combining both a lot and quite a bit). Majority of them (77.8%- combining both a lot and quite a bit) are also concerned about being able to continue their caring responsibilities. It shows that caregivers have not given priority for their own self-care and taking time out.

Concerns about relationships and social life

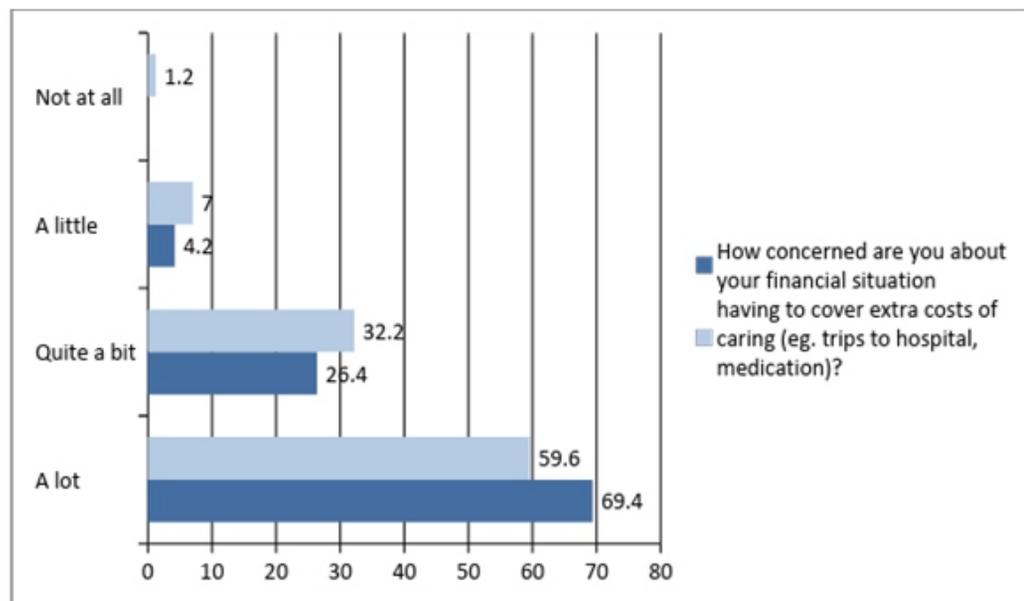
Question	Responses	Frequency	%age
How concerned are you about - strains in your relationships with friends and family because of your caring responsibilities?	A lot Quite a bit A little Not at all	95 359 46 0	19.0 71.8 9.2 0
“drifting apart” from friends and family because your caring responsibilities limit the time you have to keep in contact with them?	A lot Quite a bit A little Not at all	59 359 82 0	11.8 71.8 16.4 0
feeling isolated and lonely because of the situation you are in?	A lot Quite a bit A little Not at all	87 306 107 0	17.4 61.2 21.4 0
getting the support you need from family and friends?	A lot Quite a bit A little Not at all	52 303 145 0	10.4 60.6 29.0 0



With regard to impact of caregiving on their personal, familial and social relationships, majority of them reported strains (90.8% - combining both a lot and quite a bit) in their relationship due to caring responsibilities. Majority of them also reported that they are not keeping time for their friends and family and limiting their contact in view of caring tasks (83.6%). Majority of them reported that they feel a lot of being isolated and lonely because of their situation (78.6%).

Concerns about financial condition

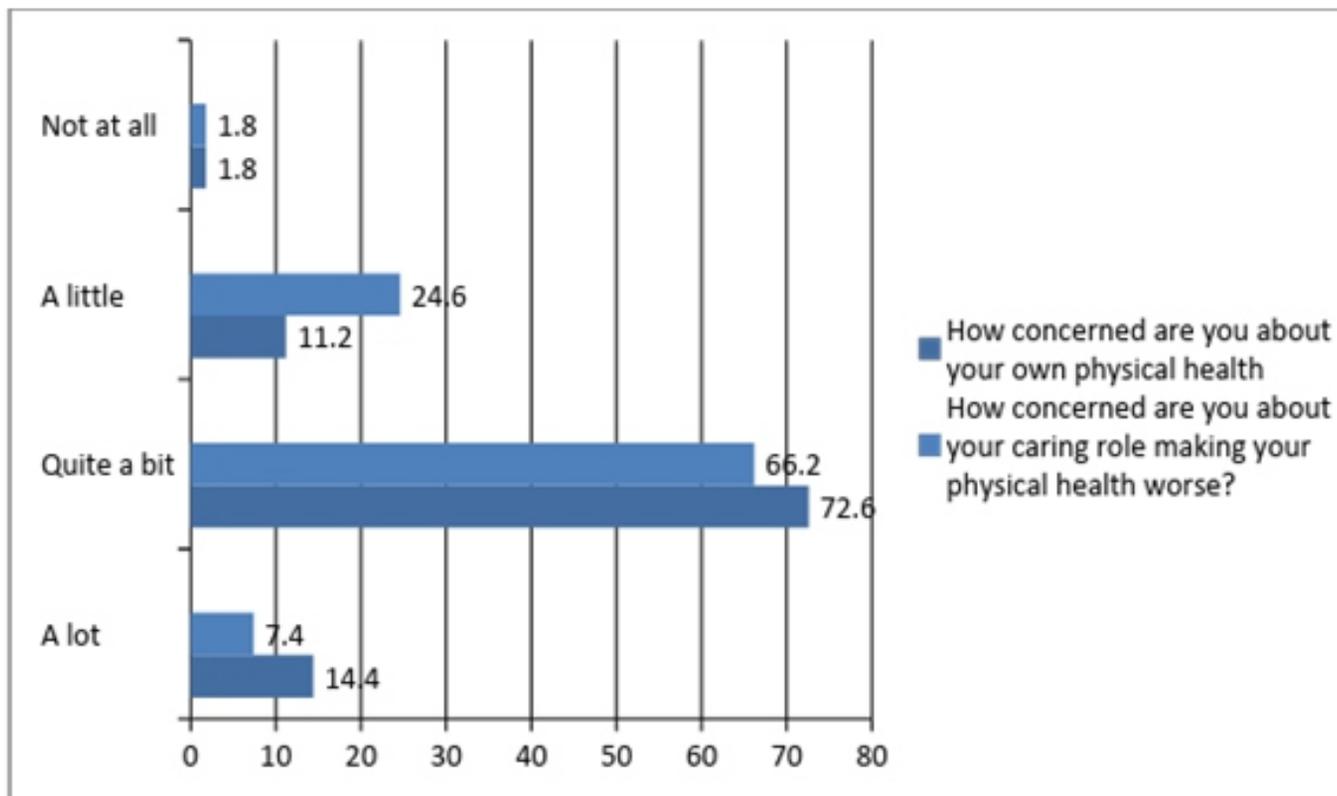
Question	Responses	Frequency	%age
How concerned are you about your financial situation?	A lot Quite a bit A little Not at all	347 132 21 0	69.4 26.4 4.2 0
having to cover extra costs of caring (e.g. trips to hospital, medication)?	A lot Quite a bit A little Not at all	298 161 35 6	59.6 32.2 7.0 1.2



The concerns regarding the financial situation are significant among caregivers as majority of them reported they are concerned a lot (95.8%). No one reported that they are not concerned about financial situation. They are concerns regarding other extra costs related to travel for treatment purpose, medication. Majority of them reported they are concerned about these expenses (81.8%) - combining both a lot and quite a bit). It is also observed that everyone reported concerns on extra costs.

Concerns about physical health

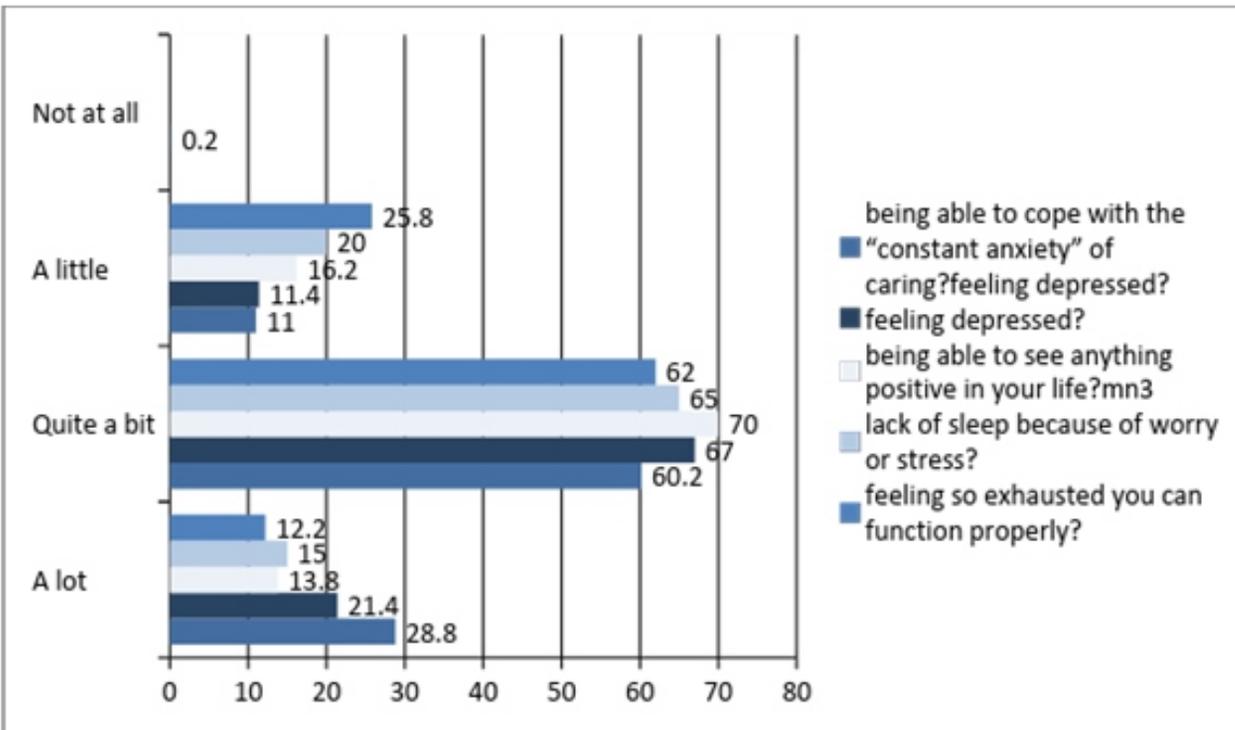
Question	Responses	Frequency	%age
How concerned are you about - your own physical health?	A lot	72	14.4
	Quite a bit	363	72.6
	A little	56	11.2
	Not at all	9	1.8
your caring role making your physical health worse?	A lot	37	7.4
	Quite a bit	331	66.2
	A little	123	24.6
	Not at all	9	1.8



Regarding physical health of caregivers, majority of the respondents reported that they are concerned about their physical health (87% - combining both a lot and quite a bit) and caregiving role is worsening their physical health condition (73.6% - combining both a lot and quite a bit).

Concerns about mental health

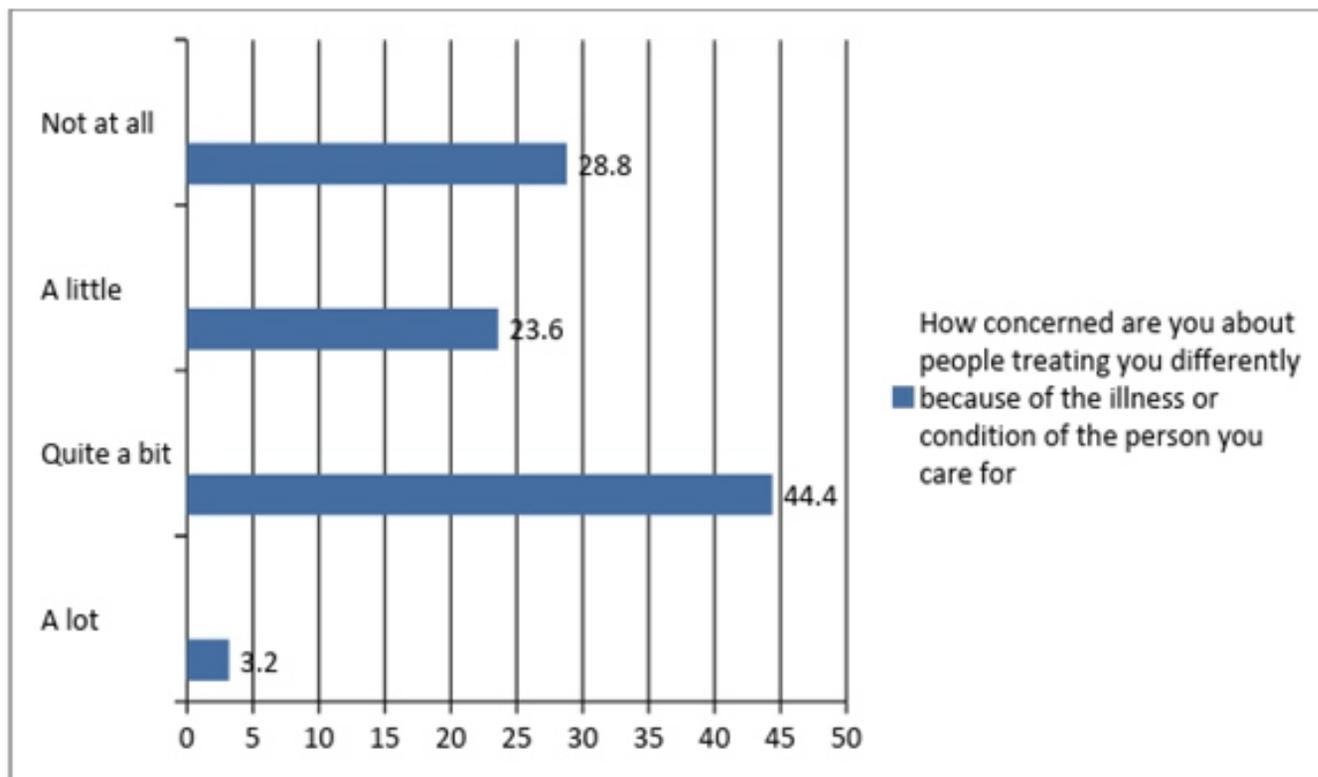
Question	Responses	Frequency	%age
How concerned are you about being able to cope with the “constant anxiety” of caring?	A lot Quite a bit A little Not at all	144 301 55 0	28.8 60.2 11.0 0.0
feeling depressed?	A lot Quite a bit A little Not at all	107 335 57 1	21.4 67.0 11.4 .2
being able to see anything positive in your life?	A lot Quite a bit A little Not at all	69 350 81 0	13.8 70.0 16.2 0.0
lack of sleep because of worry or stress?	A lot Quite a bit A little Not at all	75 325 100 0	15.0 65.0 20.0 0.0
feeling so exhausted you can function properly?	A lot Quite a bit A little Not at all	61 310 129 0	12.2 62.0 25.8 0.0



With regard to mental health aspects such as coping, worries, depression and exhaustion among caregivers, majority of them are constantly anxious about caring (89% - combining both a lot and quite a bit), feeling depressed (88.4%), unable to see positives in their life (83.8%), lack of adequate sleep due to stress (80%) and feelings of exhaustion and cannot function properly (73.2% - combining a lot and quite a bit). No one reported nil concerns about these mental health aspects.

Concerns about being treated differently

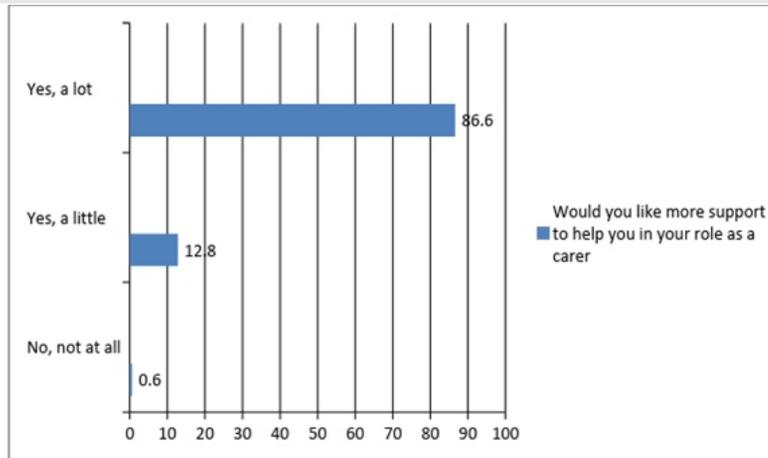
Question	Response	Frequency	%age
How concerned are you about people treating you differently because of the illness or condition of the person you care for?	A lot	16	3.2
	Quite a bit	222	44.4
	A little	118	23.6
	Not at all	144	28.8



Regarding concerns on stigma due to the condition/illness of their family members who they care for, it was observed that majority of them concerned about being treated differently (71.2% - combining a lot, quite a bit and a little). Fewer people are not concerned about being discriminated against (28.8%).

Desire for further support

Question	Response	Frequency	%age
Would you like more support to help you in your role as a carer?	No, not at all	3	.6
	Yes, a little	64	12.8
	Yes, a lot	433	86.6



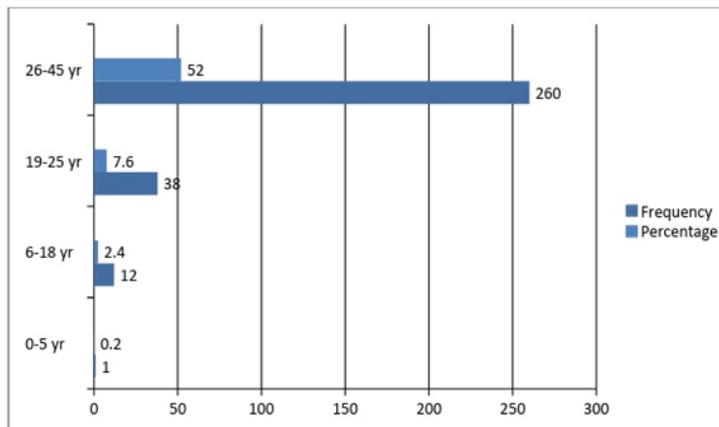
With regard to seeking more help to carry out the carer role, majority of them reported that they need a lot of help (86.2%).

Results of survey conducted by WORD

Caregiver profile

Age

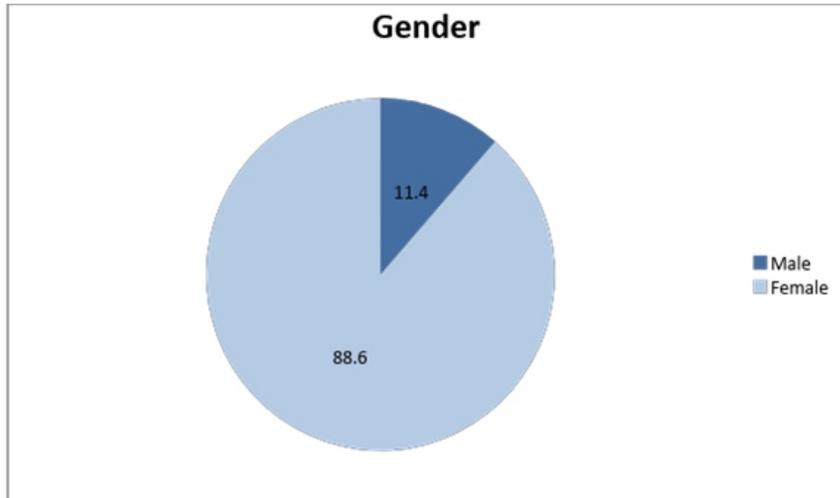
Age group	Frequency (N=500)	%age
0-5	1	.2
6-18	12	2.4
19-25	38	7.6
26-45	260	52.0
46-60	137	27.4
61 +	52	10.4



52 % fall under the age group of 26-45 years, and 27 % of the caregiver fall under the age-group of 46-60 years. Some of the caregivers are aged and some are adolescent, who comprises 10 % and 2.4 % of the population.

Gender

Variable	Frequency (N=500)	%age
Male	57	11.4
Female	443	88.6



Majority of the caregivers are female with a %age of 88.6, and the remaining 11.4 % are males.

Marital status

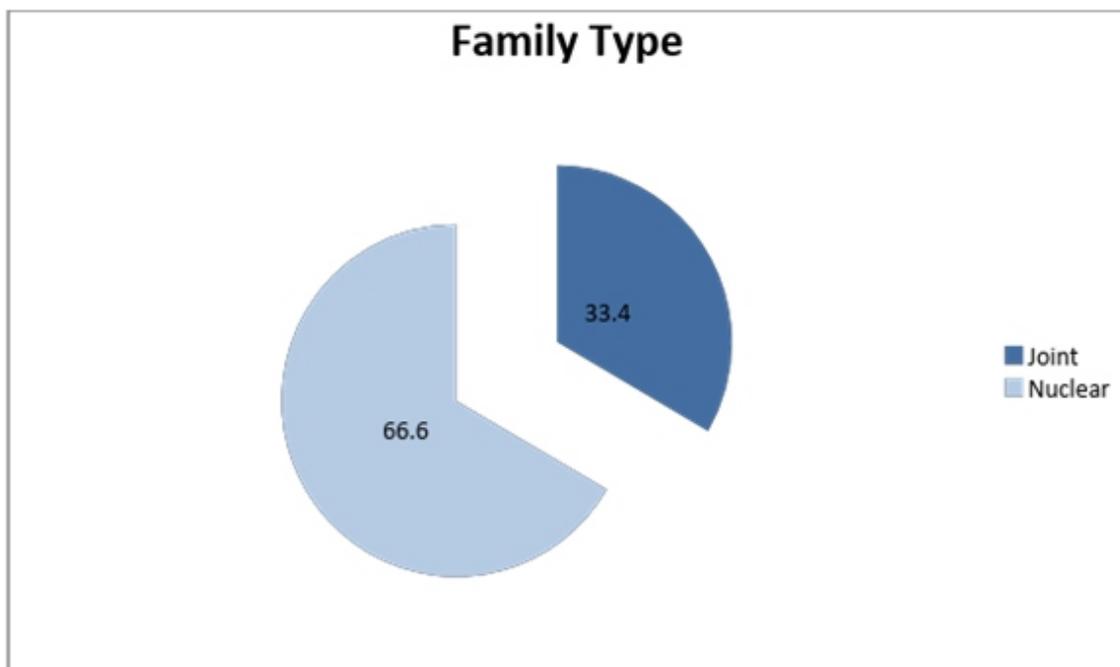
Variable	Frequency (N=500)	%age
Married	459	91.8
Single	40	8.0
Widow	1	2



91.8% of the caregivers are married, followed by 8 % unmarried, and 2 % widows.

Type of family

Variable	Frequency (N=500)	%age
Joint	167	33.4
Nuclear	333	66.6



More than half of the caregivers belong to a nuclear family (66.6%) and the remaining are from nuclear family (33.4%).

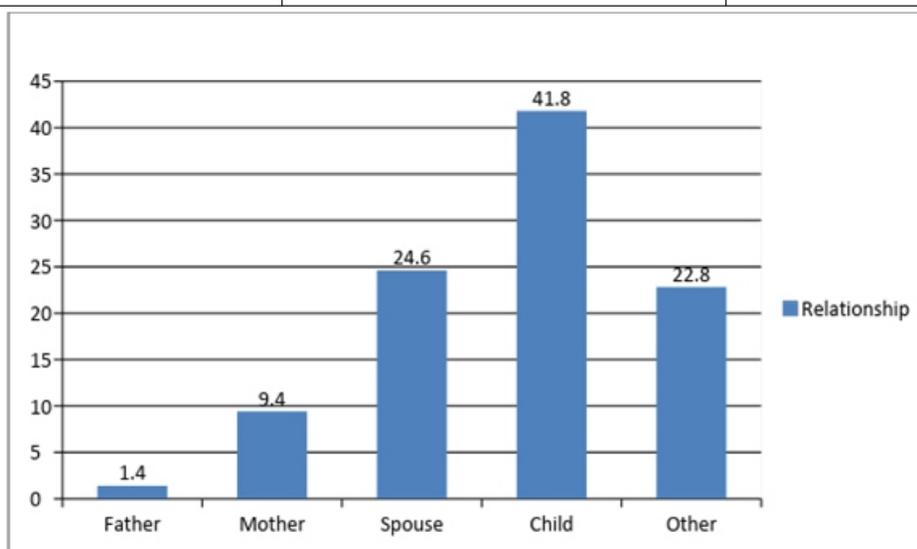
Details of family members

Variable	Mean & SD	Minimum – Maximum
No of household members	5.04 ±1.948	2-12
No of men	2.54±1.342	0-8
No of women	2.53±1.223	0-8
No of children	1.34±1.470	0-7

The average number of household members in the family is 5.04, men are 2.54, women are 2.53 and children are 1.34. there were equal number of men and women in the family.

Relationship with the person cared for

Variable	Frequency (N=500)	%age
Father	7	1.4
Mother	47	9.4
Spouse	123	24.6
Child	209	41.8
Other	114	22.8

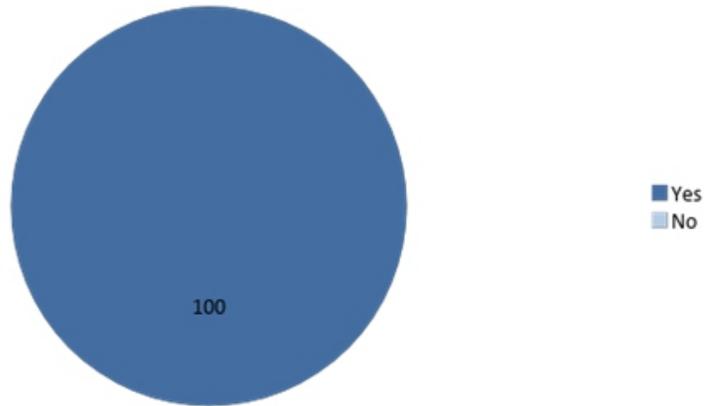


Majority of the caregivers are children (41.8%), whereas spouse and others are equally distributed, that is, 24.6 % and 22% respectively. There are also parents who are looking after the person with illness, in which 1.4 % are fathers and 9.4% are mothers.

Identity card

Variable	Frequency (N=500)	%age
Yes	500	100
No	0	0

Identity card

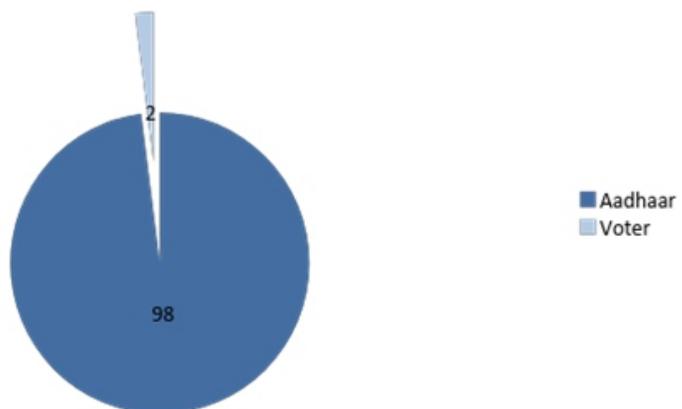


All of the caregivers have an identity card.

Type of ID card

Variable	Frequency (N=500)	%age
Aadhaar	490	98
Voter	10	2

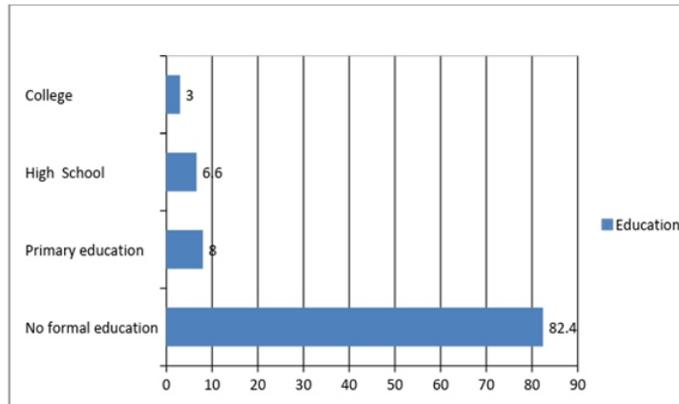
ID type



Almost all(98%) of the respondents have Aadhaar card which they can show as their ID and the remaining 2% have only voter ID.

Education level

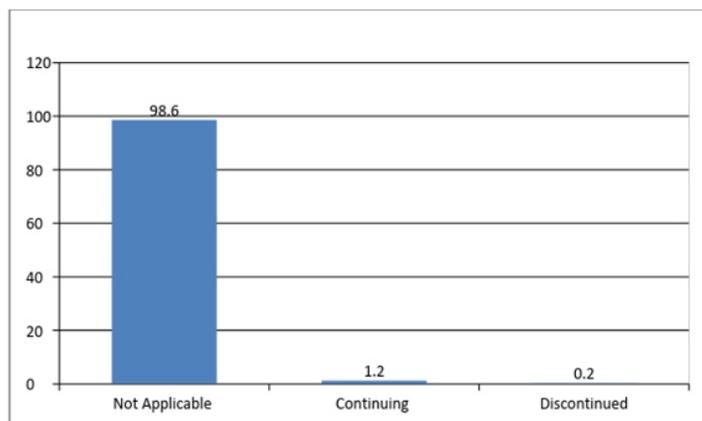
Variable	Frequency (N=500)	%age
No formal education	412	82.4
Primary education	40	8.0
High school	33	6.6
College	15	3



Majority of the caregivers, i.e. 82.4%, have not received any formal education, followed by 8% of caregivers who has completed their primary education, 6. % high school and only 3% have attended college.

Present education status

Variable	Frequency (N=500)	%age
Not Applicable	493	98.6
Continuing	6	1.2
Discontinued	1	.2



Presently very few of the caregivers, i.e. 1.2 %, are continuing education, whereas it's not applicable for the remaining 98.6 % of the caregivers since they have not received any formal education.

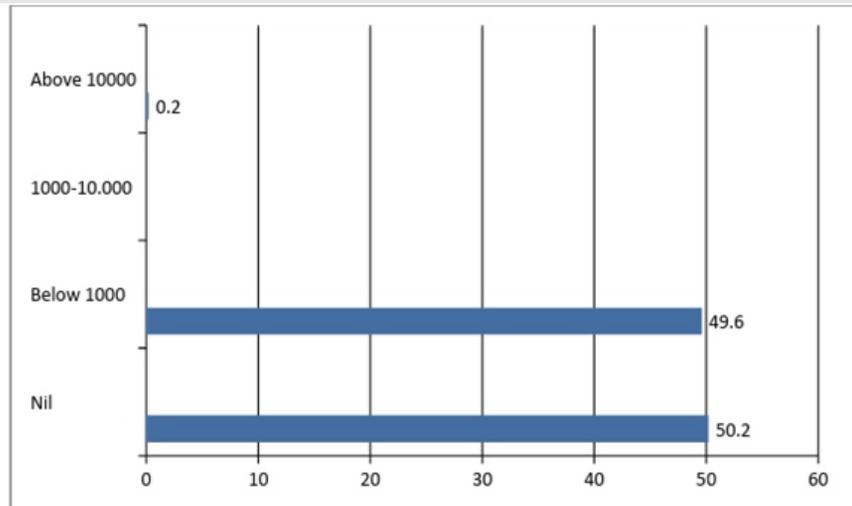
Type of work

Variable	Frequency (N=500)	%age
No/Nil	251	50.4
Farmer/agriculture	57	11.4
Daily labour	161	32.3
Anganwadi worker	2	1.2
Anganwadi helper	6	.6
School cook	3	1.4
Asha worker	7	1.4
Business	7	.6
Bamboo work	3	.2
Hotel	1	.2
Potter	1	.2
Teacher	1	.2

Half of the caregivers, i.e. 50.4%, are not working, followed by 32.2% working in daily labour, and 11.4% are farmers. The rest of the caregivers are anganwadi workers (1.2%) and helpers (.6%).

Income per month

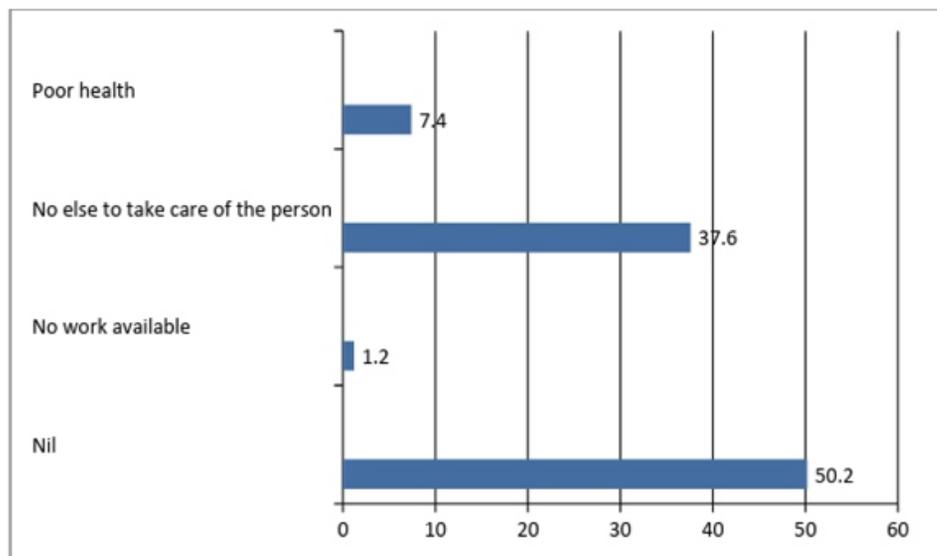
Variable	Frequency (N=500)	%age
Nil	251	50.2
Below 1000	248	49.6
1000-10.000	0	0
Above 10000	1	.2



Half of the caregivers (50.2%) were earning below Rs 1000 per month and only 0.2 % were getting above Rs 10000 per month.

Reason for not earning

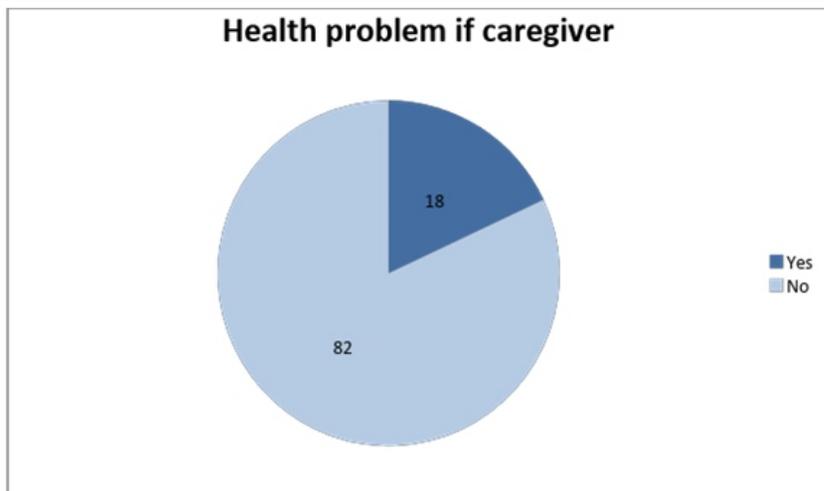
Variable	Frequency (N=500)	%age
Nil	251	50.2
No work available	6	1.2
No else to take care of the person	188	37.6
Poor health	37	7.4
Other	16	3.2
Not Applicable	1	.2



Almost 50.2 % of the caregivers are not working; the reason is different for everyone. 37.6 % of them are not working because there is no one else to take care of the other person, 7.4 % have poor health, 3.2 % have other reasons and 1.2 % says that there is no work available.

Health problem of the caregivers

Variable	Frequency (N=500)	%age
Yes	90	18
No	410	82



Health problem of caregiver is important and a concern, 18 % of the caregivers have health concerns and the rest of them don't have any health issues.

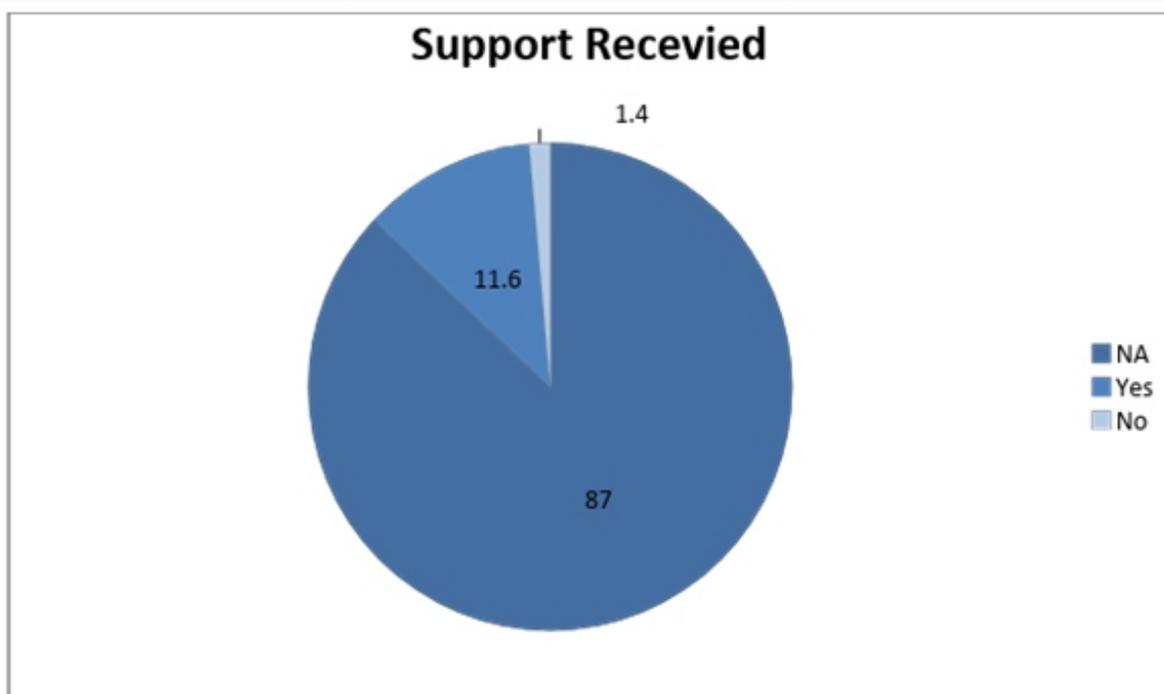
Type of the problem

Variable	Frequency (N=500)	%age
Nil	410	82.0
Back pain	6	1.2
Waist pain	11	2.2
Depression	17	3.4
Body pain	21	4.2
Headache	13	2.6
Weakness	12	2.4
Old age	7	1.4
Disabled	3	.6

The caregivers who have physical health concerns, 4.2% of them have body pain, 2.2% of them have waist pain, and 1.2% have back pain. Not only physical health concerns, 3.4 % caregivers have depression and 2.4 % report weakness, and 1.4% of them are aged.

Support/treatment received

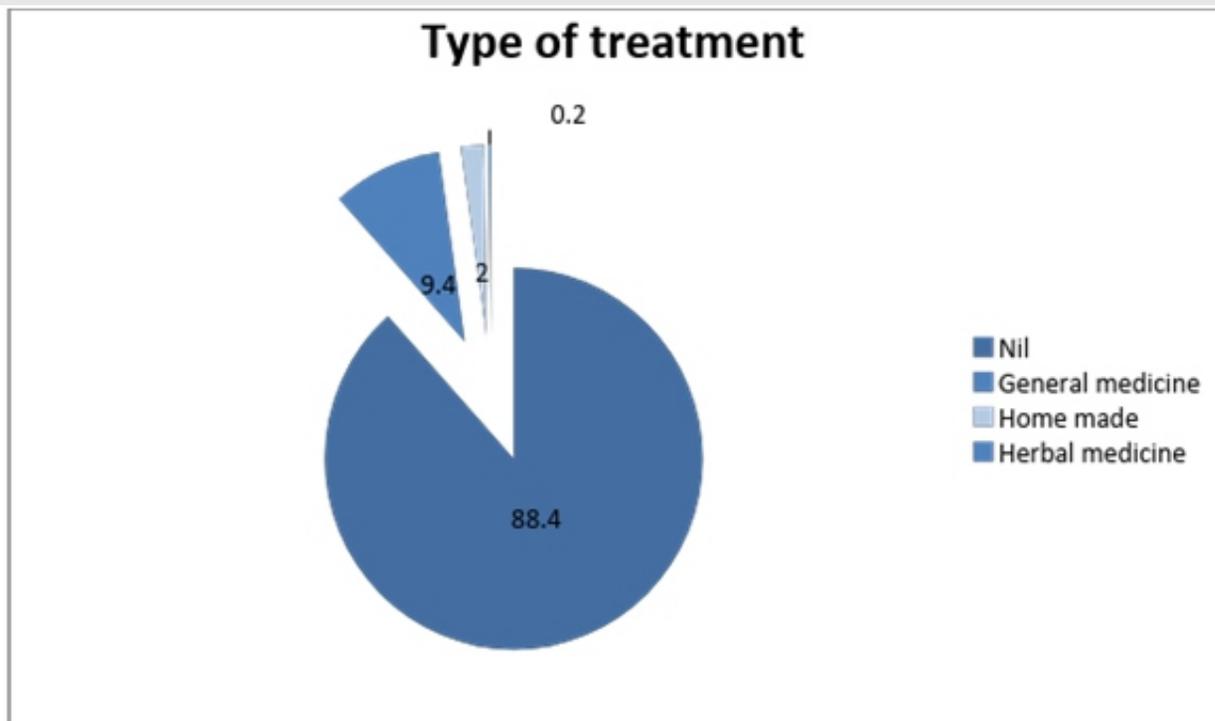
Variable	Frequency (N=500)	%age
NA	435	87.0
Yes	58	11.6
No	7	1.4



For the health concerns, 11.6 % caregivers have support and receiving treatment and the remaining 1.4 % of them are not receiving any.

Type of treatment

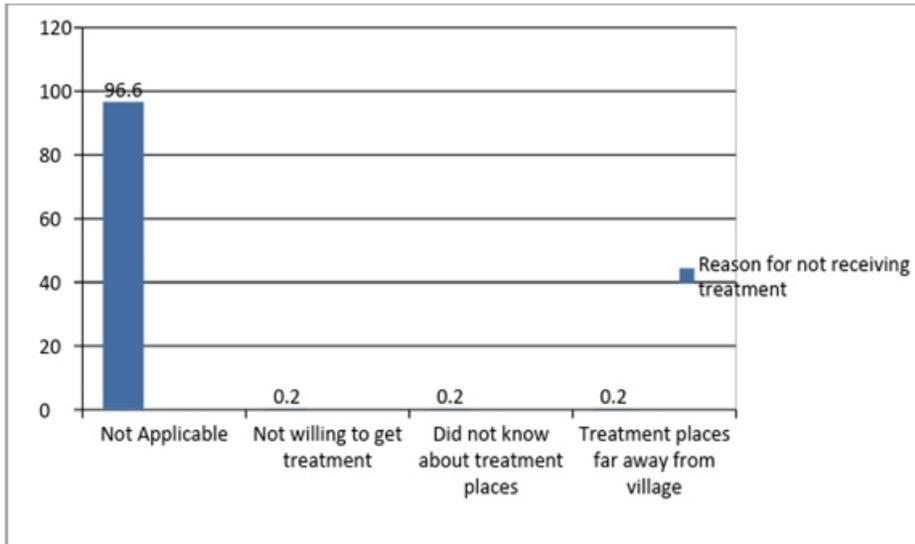
Variable	Frequency (N=500)	%age
Nil	442	88.4
General medicine	47	9.4
Home made	10	2.0
Herbal medicine	1	.2



Out of the treatment which the caregivers are receiving, 9.4% of them are receiving general medicine, 2% are receiving homemade treatment, and only 0.2 % were receiving only herbal medicines.

Reason for not receiving treatment

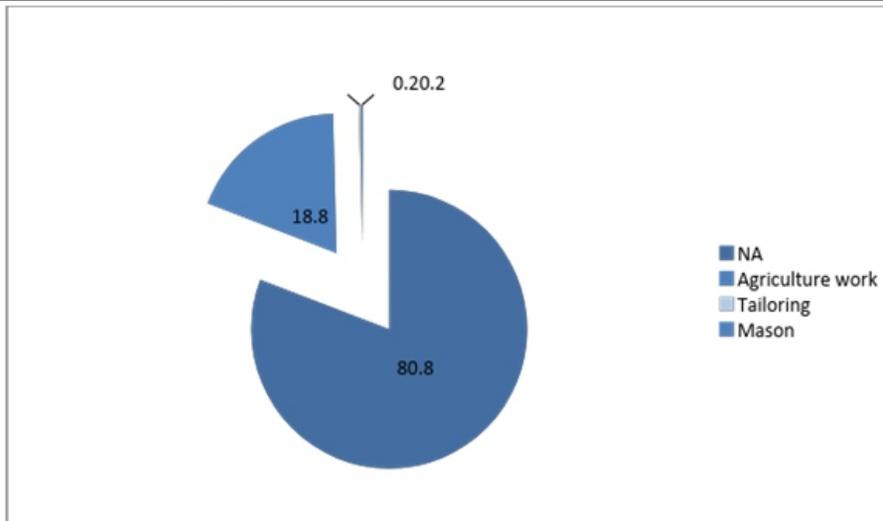
Variable	Frequency (N=500)	%age
Not Applicable	483	96.6
Not willing to get treatment	1	.2
Did not know about treatment places	1	.2
Treatment places far away from village	1	.2
There was no carer to look after their relative	14	2.8
Family has no money for treatment	0	0
Other	0	0



There are various reasons for which caregivers have not received treatment. 2.8 % of the caregivers did not receive the treatment because; there was no carer to look after their relative, the remaining 0.2 % did not above treatment places, 0.2 % were not willing to get treatment, and for 0.2% treatment place was far away from home.

Skill of the caregiver

Variable	Frequency (N=500)	%age
No	404	80.8
Agriculture work	94	18.8
Tailoring	1	.2
Mason	1	.2



The predominant skills of the caregivers are agriculture work (18.8%) and the remaining 0.2% are skilled in tailoring and masonry.

Other income

Variable	Frequency (N=500)	%age
Disability pension	129	25.8
Old age pension	98	19.6
Retirement pension	6	1.2
Widow pension	23	4.6
Income through property	1	.2
Others	24	4.8
Nothing	191	38.2
Two sources	25	5
More than two sources	3	.6

The predominant source of income for the caregivers is disability pension and old age pension, that is, 25.8 % and 19.6 % respectively. Among that also 38.2% caregivers were not having any other source of income. It was also reported that, 1.2% have retirement pension and 4.6% have widow pension.

SHG member

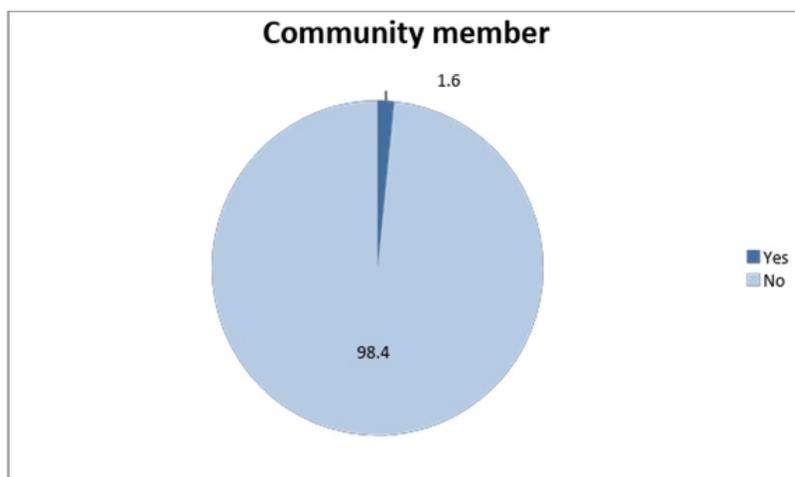
Variable	Frequency (N=500)	%age
Yes	82	16.4
No	418	83.6



Only 16.4% of the caregivers are SHG members and the remaining 83.6% don't have SHG membership.

Community member

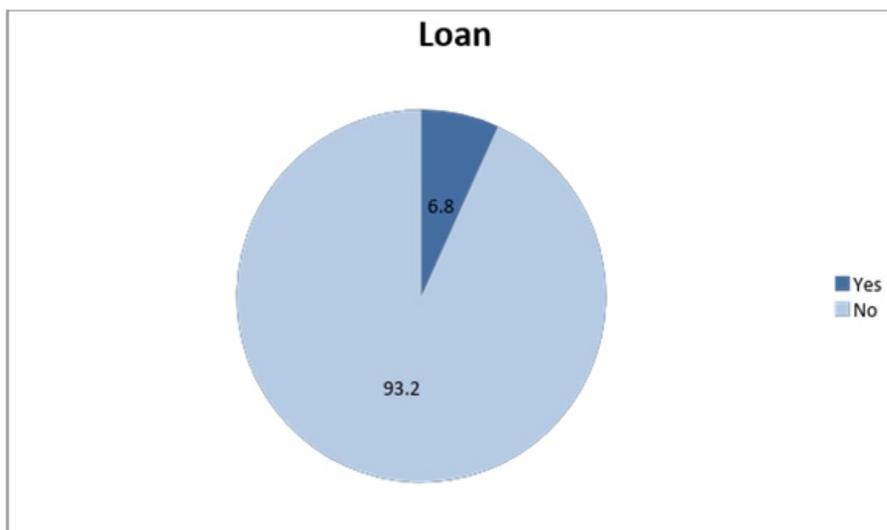
Variable	Frequency (N=500)	%age
Yes	8	1.6
No	492	98.4



Among the caregivers, 1.6 % of them are community members and the remaining 98.4 % are not community members.

Loan

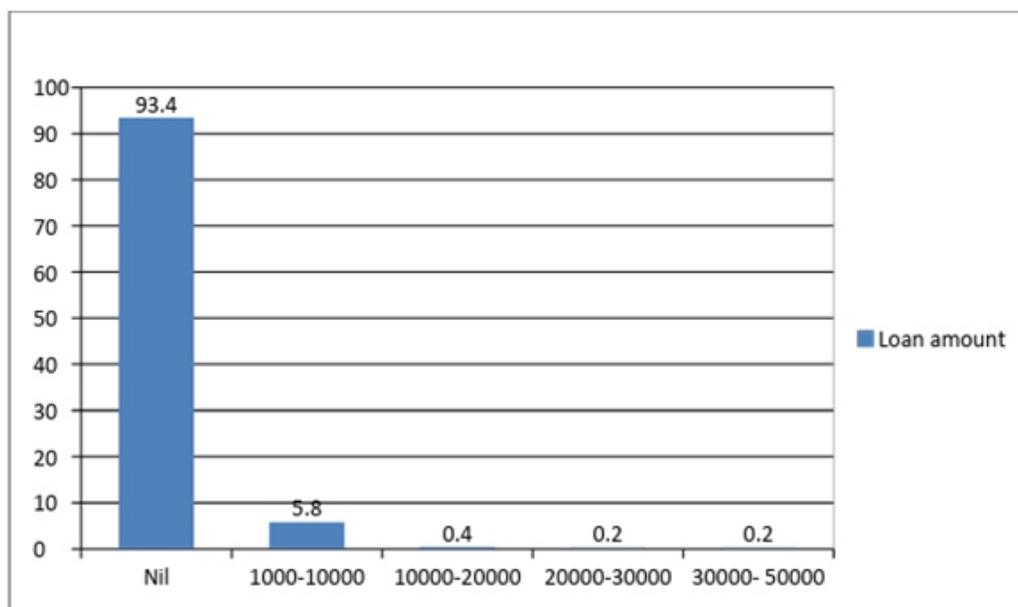
Variable	Frequency (N=500)	%age
Yes	34	6.8
No	466	93.2



Most of the caregivers have taken loan for personal reasons.

Loan amount

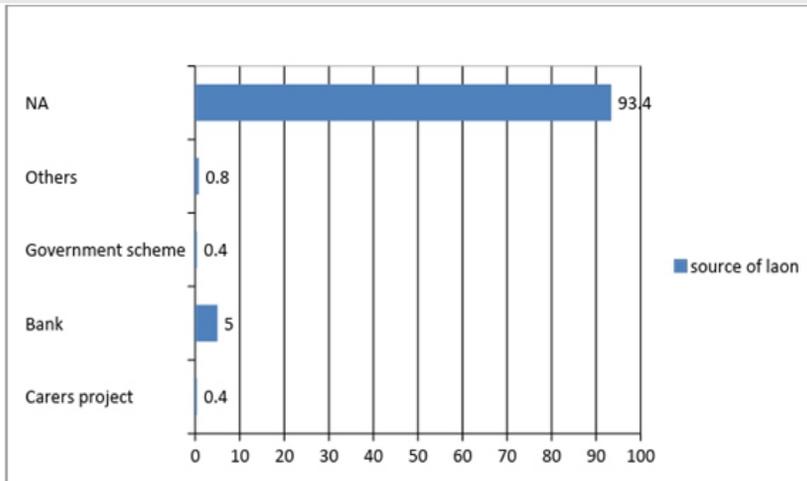
Variable	Frequency (N=500)	%age
Nil	467	93.4
1000-10000	29	5.8
10000-20000	2	.4
20000-30000	1	.2
30000- 50000	1	.2



5.8% of the caregivers have taken loans up to Rs 10,000, and 0.4% of them have taken loan up to Rs 20,000.

Source of loan

Variable	Frequency (N=500)	%age
Carers project	2	0.4
Bank	25	5
Government scheme	2	0.4
Others	4	0.8
Not applicable	467	93.4

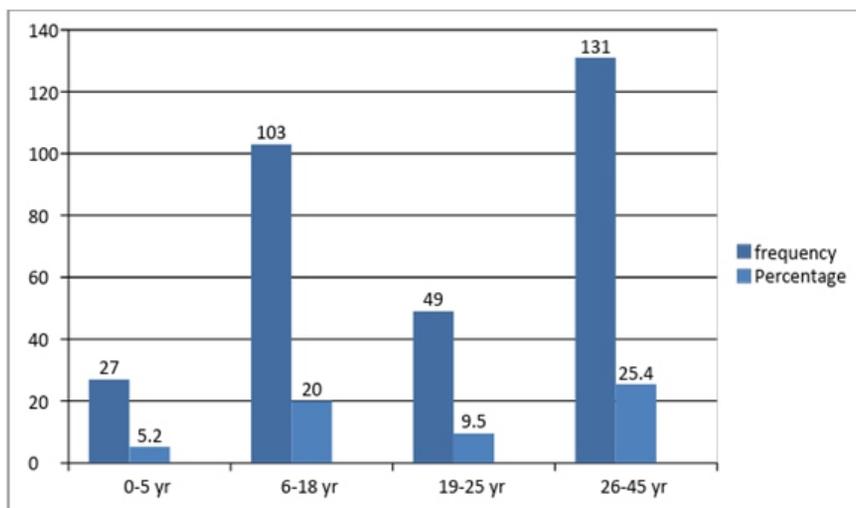


Caregivers have taken loans from various sources; predominantly from bank (5%). 0.8% have taken loans from other sources, and remaining 0.4 % has taken loan from carers' projects and government schemes.

Details of person cared for

Age

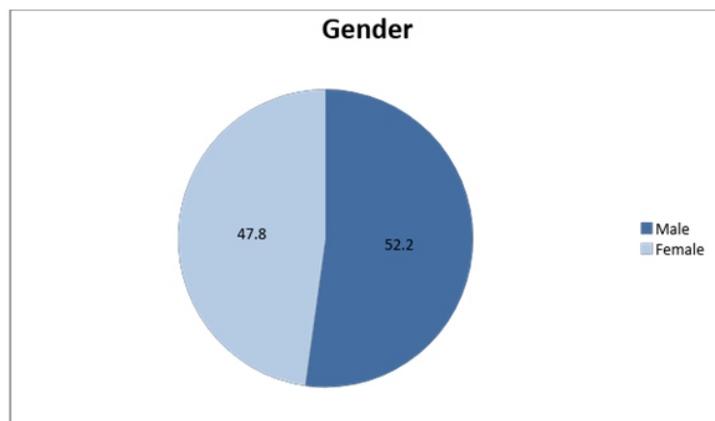
Age Group	Frequency (N=500)	%age
0-5	27	5.2
6-18	103	20.0
19-25	49	9.5
26-45	131	25.4
46-60	123	23.9
61 +	82	15.9



Among the person cared for, more than one-fourth of them fall in the age group of 26-45 and 46-60 years, i.e. 25.4 % and 23.9 respectively. Almost 20% are adolescent and fall in the age group of 6-18 years, 15.9% are 61 and above, and very few are children (5.2%).

Gender

Variable	Frequency (N=500)	%age
Male	261	52.2
Female	239	47.8



The gender proportion is almost equally distributed in this population. 52.2% of them are males and 47.8% of them are females.

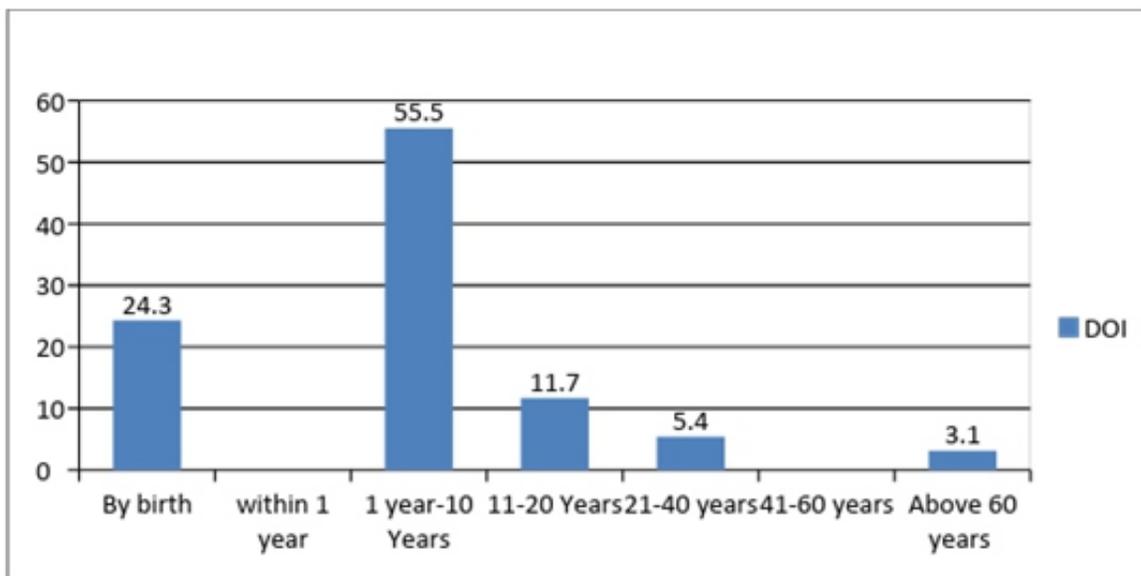
Health/disability condition

Variable	Frequency(N=500)	%age
Mental retardation	56	11.2
Handicapped	75	15.0
Locomotor	3	.6
Epilepsy	45	9.0
Visually challenged	40	8.0
Paralysis	58	11.6
Mental illness	117	23.4
Hearing impairment	1	.2
Leprosy	6	1.2
Severe illness	10	2.0
Chronic illness	4	.8
MD	5	1.0
MH	12	2.4
OH	1	.2
Old age	5	1.0
Multiple disability	30	6.0
Body pain	28	5.6
Unable to walk	1	.2
Tumour	3	.6
Autism	56	11.2

The disability is different for everyone. The predominant disability was mental illness, followed by handicap, paralysis and mental retardation, autism, i.e. 23.6%, 15%, 11.6% and 11.2% respectively.

Duration of illness

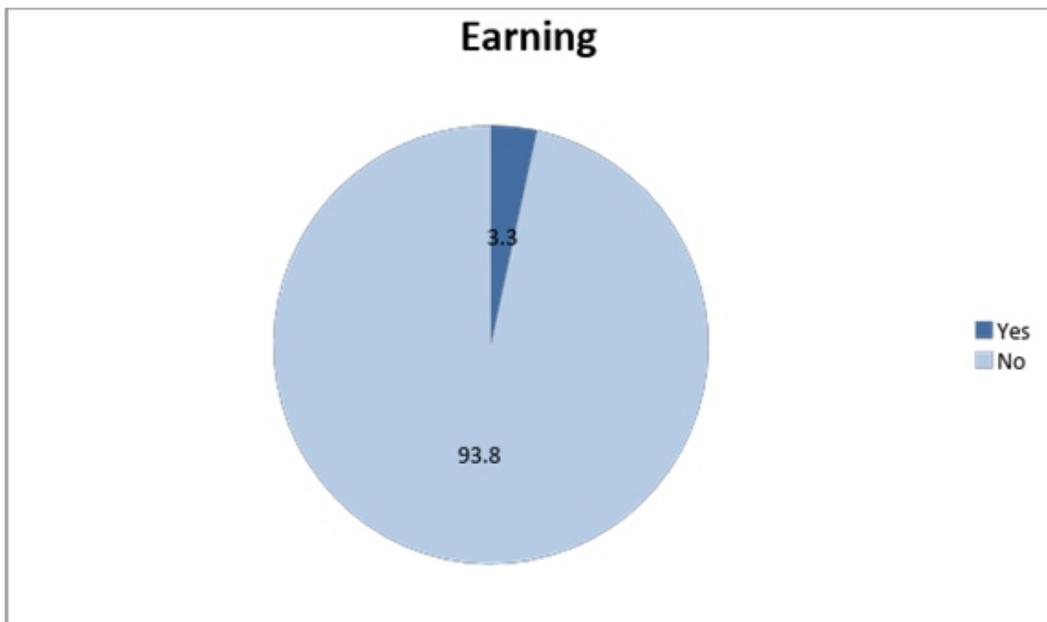
Variable	Frequency (N=500)	%age
By birth	125	24.3
within 1 year	0	0
1 year-10 years	286	55.5
11-20 years	60	11.7
21-40 years	28	5.4
41-60 years	0	0
Above 60 years	16	3.1



55.5% have illness for the past 10 years, almost on- fourth of them have illness by birth, mostly characterized by developmental delay. Rest of them have illness from past 20 and 40 years, that is, 11.7 % and 5.4 % respectively.

Is person looked after earning?

Variable	Frequency (N=500)	%age
Yes	17	3.3
No	483	93.8



Among individuals with the disability, only 3.3% are employed and earning, and the rest are not.

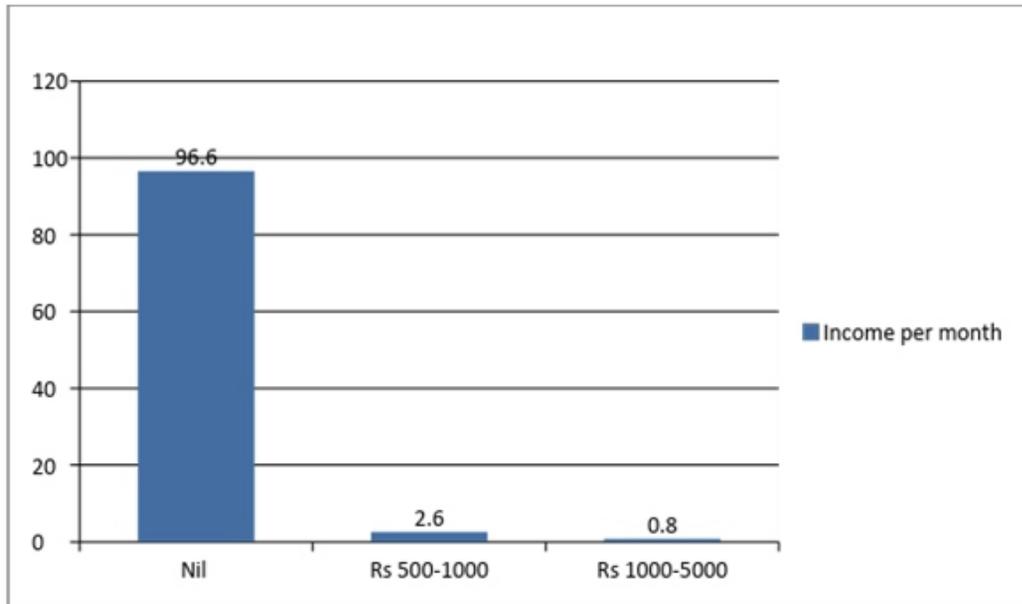
Type of work

Variable	Frequency (N=500)	%age
Not applicable	483	96.6
Farmer	2	.4
Daily labour	11	2.2
AWW	1	.2
Cook	2	.4
Electric work	1	.2

Out of the individuals who are employed and earning 2.2 % are daily labourers, 0.4% are farmers, 0.2 % are cook and doing electric work respectively.

Income per month

Variable	Frequency (N=500)	%age
Nil	483	96.6
500-1000	13	2.6
1000-5000	4	.8



Among the individuals who are employed, 2.6% are earning up to Rs 1000 per month and the rest are earning up to Rs 5000 per month.

SHG member

Variable	Frequency (N=500)	%age
Yes	9	1.8
No	491	98.2

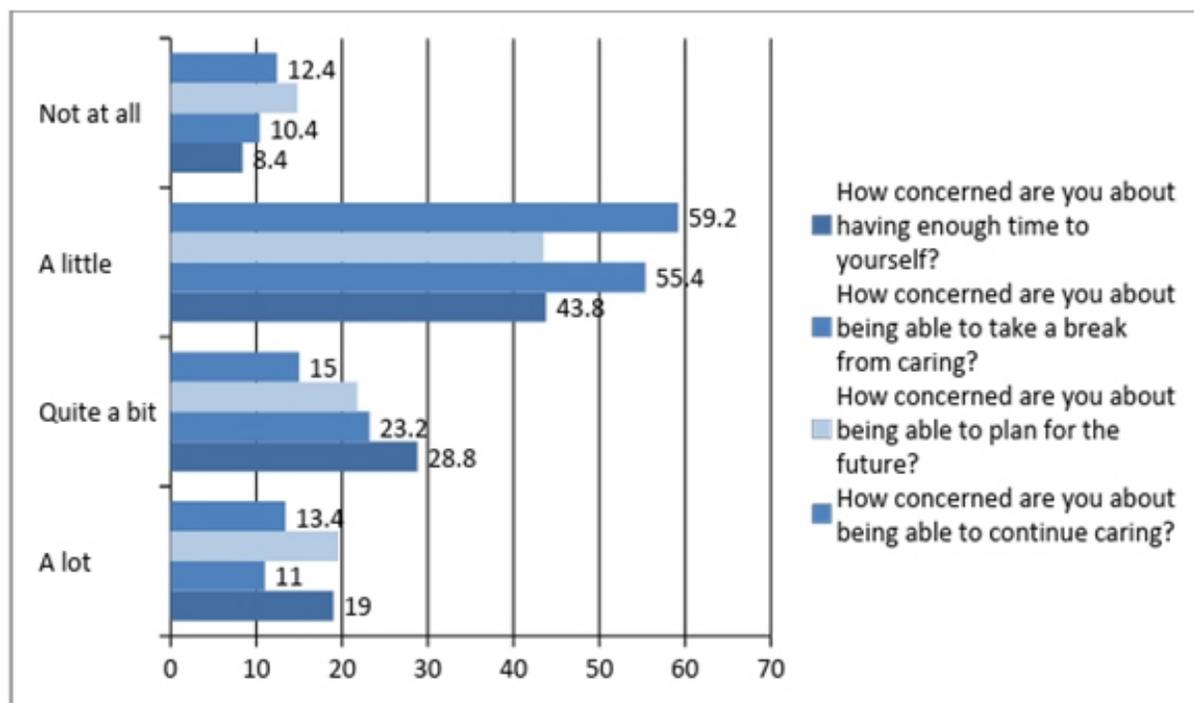


Only 1.8 % of the persons cared for have SHG membership and the remaining 98.2% don't have it.

Results of wellbeing questionnaire

Concerns about personal life

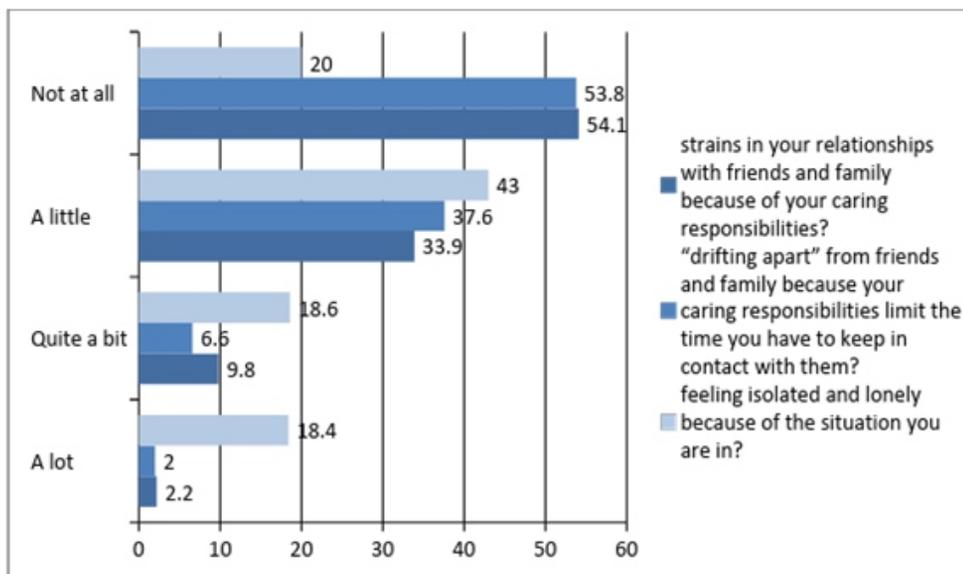
Question	Responses	Frequency	%age
How concerned are you about having enough time to yourself?	A lot	95	19.0
	Quite a bit	144	28.8
	A little	219	43.8
	Not at all	42	8.4
How concerned are you about having enough time to yourself?	A lot	55	11.0
	Quite a bit	116	23.2
	A little	277	55.4
	Not at all	52	10.4
How concerned are you about being able to plan for the future?	A lot	98	19.6
	Quite a bit	110	21.8
	A little	218	43.5
	Not at all	74	14.8
How concerned are you about being able to continue caring?	A lot	67	13.4
	Quite a bit	75	15.0
	A little	296	59.2
	Not at all	62	12.4



Majority of them reported that they do not have enough time for themselves (91.6%- combining both a lot, quite a bit and little). None of them reported not being concerned about having time for them. Regarding taking break for themselves, majority of them reported difficulties (89.6%- combining a lot, quite a bit and a little). Majority of them reported that as they are involved actively in the caregiving they are not able to plan for their future (89.2% - combining both a lot and quite a bit). Majority of them (83.2%- combining a lot, quite a bit and a little) are also concerned about being able to continue their caring responsibilities. It shows that caregivers have not given priority for their own self-care and taking time out.

Concerns about relationships and social life

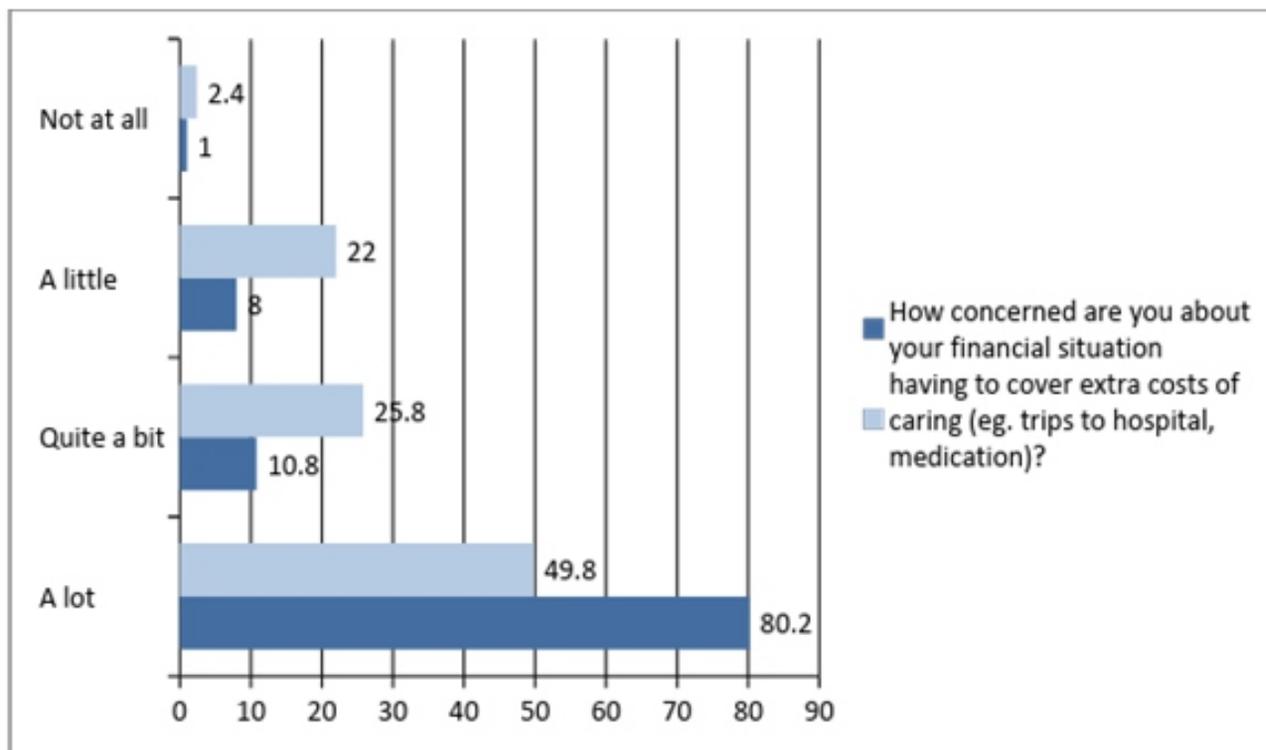
Question	Responses	Frequency	%age
How concerned are you about strains in your relationships with friends and family because of your caring responsibilities?	A lot	12	2.2
	Quite a bit	49	9.8
	A little	169	33.9
	Not at all	270	54.1
“drifting apart” from friends and family because your caring responsibilities limit the time you have to keep in contact with them?	A lot	10	2.0
	Quite a bit	33	6.6
	A little	188	37.6
	Not at all	269	53.8
feeling isolated and lonely because of the situation you are in?	A lot	92	18.4
	Quite a bit	93	18.6
	A little	215	43.0
	Not at all	100	20.0
getting the support you need from family and friends?	A lot	30	6.0
	Quite a bit	91	18.2
	A little	214	42.8
	Not at all	165	33.0



With regard to impact of caregiving on their personal, familial and social relationships, majority of them didn't report strains (54.1%) in their relationship due to caring responsibilities and remaining reported they have strains in their relationship. Majority of them didn't report unable to keep time for their friends and family and not limiting their contact in view of caring tasks (53.8%) and rest of them reported that they do not have time for family and friends. Majority of them reported that they feel a lot of being isolated and lonely because of their situation (80% - combining both a lot, quite a bit and a little).

Concerns about financial condition

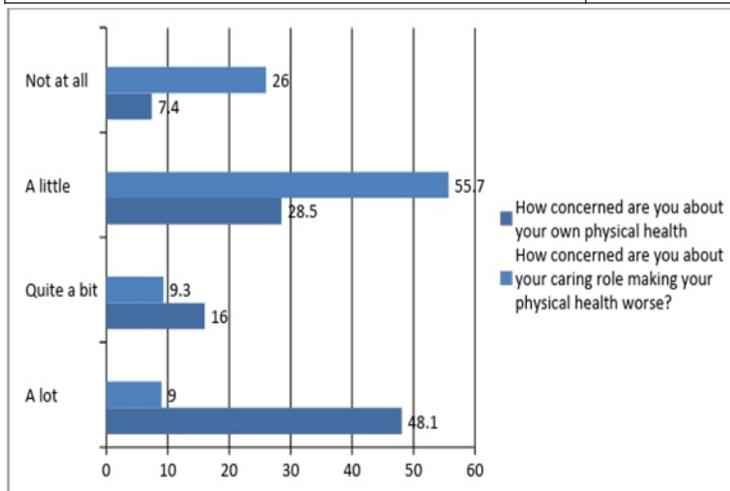
Question	Responses	Frequency	%age
How concerned are you about your financial situation?	A lot	401	80.2
	Quite a bit	54	10.8
	A little	40	8.0
	Not at all	5	1.0
having to cover extra costs of caring (e.g. trips to hospital, medication)?	A lot	249	49.8
	Quite a bit	129	25.8
	A little	110	22.0
	Not at all	12	2.4



The concerns regarding the financial situation are significant among caregivers as majority of them reported they are concerned a lot (95.8%). They are concerns regarding other extra costs related to travel for treatment purpose, medication. Majority of them reported they are concerned about these expenses (75.6%) - combining both a lot and quite a bit). Very few caregivers reported that they are not concerned about extra costs (2.4%).

Concerns about physical health

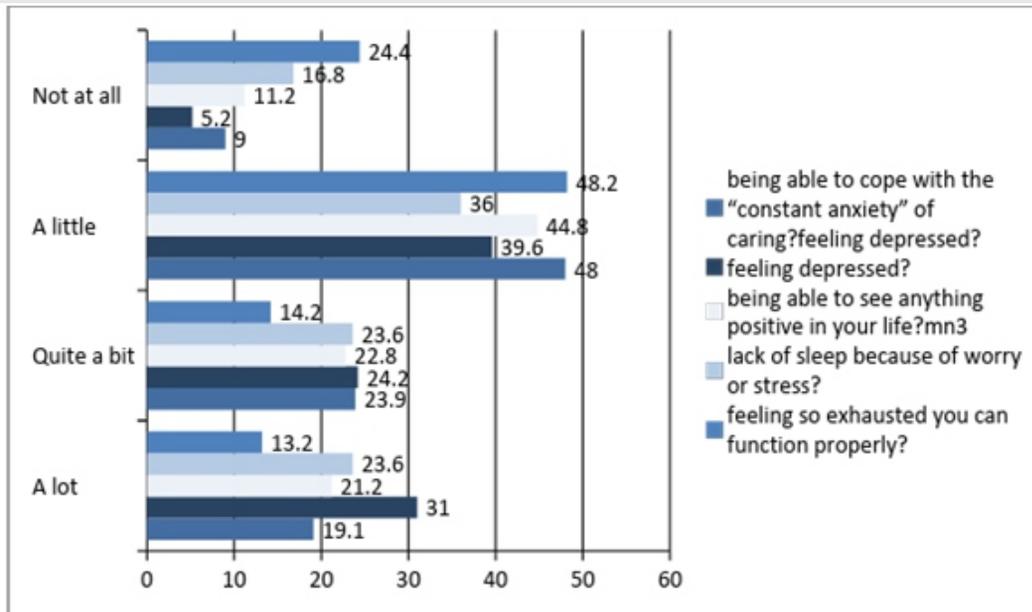
Question	Responses	Frequency	%age
How concerned are you about - your own physical health?	A lot	240	48.1
	Quite a bit	81	16.0
	A little	142	28.5
	Not at all	37	7.4
your caring role making your physical health worse?	A lot	48	9
	Quite a bit	46	9.3
	A little	277	55.7
	Not at all	129	26.0



Regarding physical health of caregivers, majority of the respondents reported that they are concerned about their physical health (92.6% - combining both a lot, quite a bit and a little) and caregiving role is worsening their physical health condition (94.6%-combining both a lot, quite a bit and a little).

Concerns about mental health

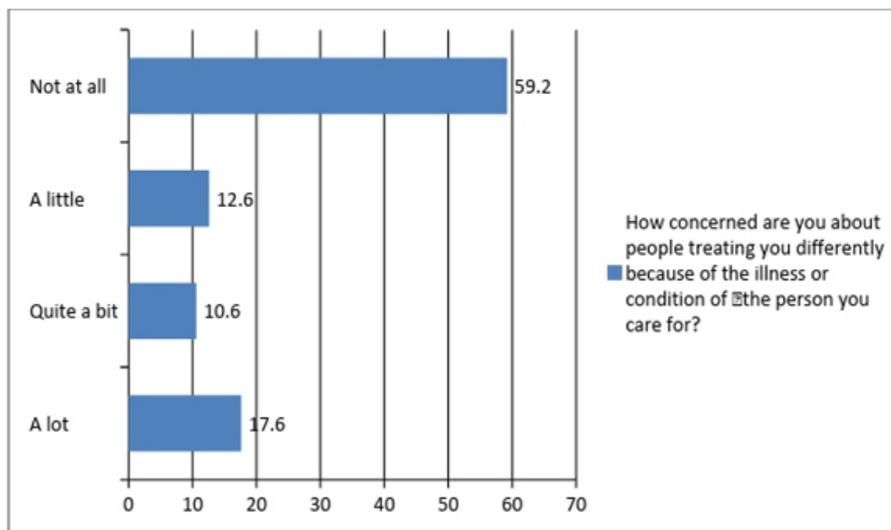
Question	Responses	Frequency	%age
How concerned are you about being able to cope with the "constant anxiety" of caring? feeling depressed?	A lot	97	19.1
	Quite a bit	119	23.9
	A little	239	48.0
	Not at all	45	9.0
being able to see anything positive in your life?	A lot	155	31
	Quite a bit	121	24.2
	A little	198	39.6
	Not at all	26	5.2
lack of sleep because of worry or stress?	A lot	106	21.2
	Quite a bit	114	22.8
	A little	224	44.8
	Not at all	56	11.2
feeling so exhausted you can function properly?	A lot	118	23.6
	Quite a bit	118	23.6
	A little	180	36.0
	Not at all	84	16.8
feeling so exhausted you can function properly?	A lot	66	13.2
	Quite a bit	71	14.2
	A little	241	48.2
	Not at all	122	24.4



With regard to mental health aspects such as coping, worries, depression and exhaustion among caregivers, majority of them are constantly anxious about caring (91% - combining both a lot, quite a bit and a little), feeling depressed (94.8%), unable to see positives in their life (88.8% - combining a lot and quite a bit and a little), lack of adequate sleep due to stress (75.6% - combining a lot and quite a bit and a little) and feelings of exhaustion and cannot function properly (75.6% - combining a lot and quite a bit and a little). No one reported nil concerns about these mental health aspects.

Concerns about being treated differently

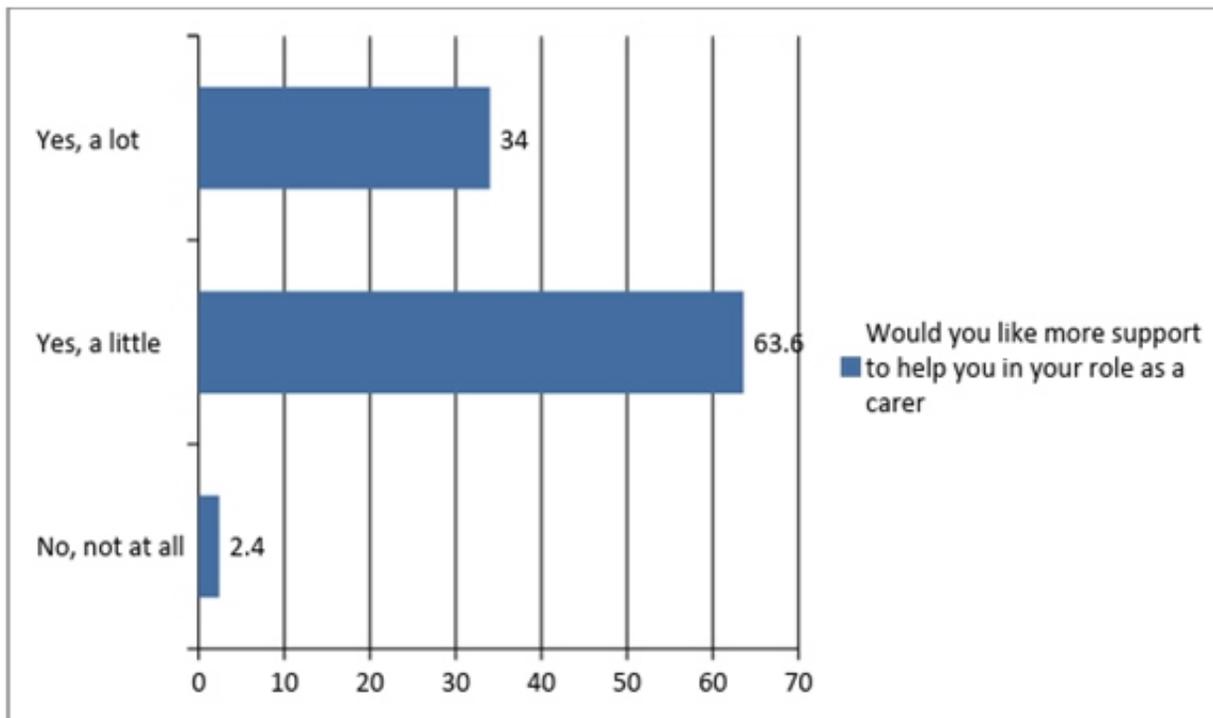
Question	Responses	Frequency	%age
How concerned are you about people treating you differently because of the illness or condition of the person you care for?	A lot	88	17.6
	Quite a bit	53	10.6
	A little	63	12.6
	Not at all	296	59.2



Regarding concerns on stigma due to the condition/illness of their family members who they care for, it was observed that majority of them are not concerned about being treated differently (59.2%) Fewer people are not concerned about being discriminated (40.8%).

Desire for further support

Question	Responses	Frequency	%age
Would you like more support to help you in your role as a carer?	No, not at all	12	2.4
	Yes, a little	318	63.6
	Yes, a lot	170	34.0



With regard to seeking more help to carry out the carer role, majority of them reported that they need a lot of help (97.6%). Rest of them reported they do not require additional help in their caring process.

Overall study summary

(compilation of results from 3 NGOs) Carers

- Majority of the caregivers were in the age group of middle and late adulthood. It was also observed that aged caregivers were also represented
- Majority of the caregivers were female
- Most of the caregivers were married
- Majority of them hail from nuclear families
- Majority of the caregivers hold identity cards and reported to have more Aadhaar cards than voter Ids
- Majority of the caregivers had not attended formal education.
- Majority of the caregivers were employed and involved in daily labour, agriculture and other work. It was also observed that significant number of caregivers was not employed. They acquired skills mainly in agriculture job.
- Those who were employed were earning less than Rs.10000 per month.
- Majority of the caregivers were having income through social security measures and multiple sources.
- There were no clear reasons for not working, and notable reasons were non-availability of other people to take care of the dependent in the family and health issues
- Majority of the caregiver reported health problems, however not many of them sought treatment because of accessibility and financial issues.
- Majority of the caregivers were not members of any SHGs or community member groups.
- Majority of them have not sought loans, whoever sought the amount was lesser than 50000

Individuals cared for

- The caregivers were providing care to all age groups, and the majority of them were children/adolescents and young adults.
- Majority of the people who received care were from both genders – more female.
- The health conditions and disability had representation from all forms of disabilities ranging from developmental disabilities, mental illness, speech and hearing impairments, and multiple disabilities.
- Majority of the individuals had problems from their birth and had duration of condition for more than 10 years.
- Majority of the caregivers were not earning and not employed.
- Majority of the individuals who were receiving care were not members of SHGs and community members

Subjective wellbeing questionnaire

- Majority of them reported that they do not have enough time for themselves and poor importance to their self-care. With regard to the impact of caregiving on their personal, familial and social relationships, majority of them reported strains in their relationship due to caring responsibilities; not keeping time for their friends and family and limiting their contact in view of caring tasks feel a lot of being isolated and lonely because of their situation
- The concerns regarding the financial situation are significant among caregivers and also worried about extra costs related to travel for treatment purpose, medication.
- Regarding physical health of caregivers, majority of the respondents reported that they are concerned about their physical health and caregiving role is worsening their physical health condition
- With regard to mental health aspects they were constantly worried about constantly anxious about caring and there were issues in terms of coping, worries, stress and sleep issues
- Significant number of caregivers reported that they are treated differently and concerned about the same.
- With regard to seeking more help to carry out the carer role, majority of them reported that they need a lot of help

It is also observed that though there were development projects from state Government and special provisions for tribal population, very few have availed the benefits and there is need to empower them to access the services and utilise them.

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