



Self-help Group
for Cerebral
Palsy, Nepal

Caring for Carers of Children with Cerebral Palsy in Nepal

Baseline Study Report



LOTTERY FUNDED

October 2017

Caring for Carers of Children with Cerebral Palsy in Nepal

Baseline Study Report

Project Lead: Dr. Anil K. Patil, Carers Worldwide

Care for Carers Programme Manager: Luni Shakya, SGCP Nepal

Data Collectors: The data collectors were all Development Workers of SGCP. Ms. Rija Shrestha, Ms. Anjana Lamichhane, Ms. Shriya Shrestha, Ms. Rajita Dongol, Ms. Prabina Shrestha

Report Author: Mary Ann Waddell

Foreword

As a critical friend of Carers Worldwide, I am very pleased to write a foreword to this report. The difficult circumstances experienced by carers who are looking after chronically sick or disabled children and adults in both high and low income settings globally is slowly but surely rising up national and international agendas. Carers Worldwide, although a young organisation, has already contributed substantially to this increased awareness and their work on developing a holistic, multi-pronged approach to intervention to support carers in low income settings is already rightly attracting widespread attention from donors and policymakers.

This report describes the preliminary work done in Nepal to explore the situation for carers there. It is a carefully and systematically undertaken piece of work, focussing specifically on carers of children with cerebral palsy. Although of course we should be cautious about generalising from this particular group to others, it gives us stark and valuable insights into the challenges families face when there is a disabled child in the household, which are likely to be similar for those caring for children or adults with other disabilities in contexts of poverty. We can see that the carers face a range of pressures, both at the personal level (affecting their health and wellbeing), in relation to the family and household economics and in their community roles and relationships. It is very clear that not all their needs or those of the children they care for are currently met adequately.

The 2015 Sustainable Development Goals suggest that we should aspire that no one is left behind, and yet we have here an example of a severely neglected and excluded group, who need affirmative and inclusive action across different sectors in order for them not to be left behind. The study aims to provide evidence to support the development of a project to improve the lives of the carers of children with cerebral palsy in Nepal. It certainly provides this in abundance and will serve as both a vital baseline against which to measure progress, as well as a compelling advocacy tool to argue for funds and support at a variety of levels (local, national and international) for such important work.

Aspects of the survey that are particularly striking are the very high percentage of carers who are women (97%), 94% being mothers, as well as the proportion of respondents who say that they themselves have a health problem (69%). We cannot be certain that these health conditions are directly linked to their caring role, but other studies suggest that carers do have increased levels of both physical and mental illnesses. Another stark finding is that just over half of the carers have little or no education (none 26%, 2-5 years 12%) and this must surely impact on the resources

they can harness to ameliorate the pressures of having a disabled child in the family. The majority of carers report that they are not earning, and thus we can see clear evidence of the commonly cited idea that disability and poverty are often interrelated. Additionally it is obvious from the data that carers have a number of social, psychological and emotional concerns including worrying about the future, feeling isolated and needing more support. Overall the data reveals a range of impacts that the caring role has on the carer as well as on the household, and a number of practical solutions and helpful ideas are generated by asking the participants directly about what would relieve their difficulties. Their suggestions directly support the model of support that Carers Worldwide has been implementing in other settings in South Asia.

Having visited one of Carers Worldwide's project sites in South India and seen both the need for specific carer support and the impact that the programme is already having there, I am sure that a similar programme, which responds to the needs identified by the carers in this baseline study, would be well received and highly appreciated. Collecting the evidence before and during the intervention is a very important part of the process and this report does this clearly and compellingly.

Dr. Mary Wickenden
Senior Research Fellow in Disability and Development
Institute for Global Health, University College London

Acknowledgements

We would like to thank the carers of the Self-help Group for Cerebral Palsy Nepal for their time and for sharing their experiences which add to our understanding of what it is like to be a carer in a low-income setting and provide a good baseline which will help the designing and evaluation of this project.

We are grateful to the data collectors of the Self-help Group for Cerebral Palsy Nepal who visited and interviewed the carers and afterwards carefully recorded and collated all the information. We would also like to thank the SGCP Home Visitors for introducing the families to the Care for Carers team.

Mary Ann Waddell worked tirelessly on preparing this report, supported by Ruth Patil.

Without the support of Mr Bimal Lal Shrestha, Chief Executive Officer of SGCP Nepal, none of this would have been possible and to him we express sincere thanks.

Finally, our special thanks to the Big Lottery fund for funding this study.

Dr. Anil K. Patil
Founder and Executive Director, Carers Worldwide

Abbreviation

SGCP	Self-help Group for Cerebral Palsy, Nepal
------	---

Contents

	Page
Foreword	1
Acknowledgement	3
Abbreviation	3
Summary	6
Background to this study and the project	10
Background to this study	10
Project description	11
Carers Worldwide	13
The Self-help Group for Cerebral Palsy, Nepal	14
Review of the literature	15
Baseline study result	23
Profile of the carers	24
Carer gender	24
Carer age	25
Carer marital status	26
Carer type of family	27
Number of household members	28
Number of men in the household	29
Number of women in the household	30
Number of children in the household	31
Relationship to the cared for person	32
Carers' relationship with their spouses	33
Carers' relationship with the rest of the family	34
Carers' relationship with neighbours	35
Citizenship of carers	36
Carers' district of residence	36
Carers caring for additional others	37
Carer household type of accommodation	38
Living space	39
Carers' health	40
The types of health problem carers have	41
Support or treatment received	42
The type of support or treatment carers were receiving for their health	43

Reasons why carers do not receive treatment for their own health	44
Carers' education	45
Carers' current education status	46
Carers' earnings	47
Carers' type of work	48
Carers' income	49
Reasons for carers not working	50
The number of family members working	51
Households in which other family members who are earning are supporting the primary carer	52
Skills carers are interested in for possible alternative work	54
Other income within the household	55
Carers as members of self-help groups	56
Carers as members of other community groups	57
Whether the carer or the person they are looking after is in receipt of any loan or grant	58
The amount of the loan	59
The source of the loan	60
What the loan is for	61
Profile of the cared for people	62
Gender of the cared for people	62
Ages of the cared for people	63
Conditions the cared for people have	64
How long they have had their condition	64
Employment of the cared for people	66
Membership of self-help groups by the cared for people	67
Carer wellbeing	68
Carers' concerns about their personal lives	68
Carers' concerns about their relationships	70
Carers' concerns about their financial situation	72
Carers' concerns about their physical health	73
Carers' concerns about their mental health	74
Summary of carers' wellbeing	76
Carers' thoughts regarding what the most pressing issues were for them and their suggestions regarding what they felt would help them	78
References	82
Appendix	
Baseline data survey instrument	86

Summary

This report describes a study which explores the welfare of carers of young people with neurological conditions in Nepal. The findings will be used to design and evaluate a project which aims to improve the wellbeing of this group of carers.

“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).

Many family members become carers out of love but in countries where social welfare systems are not well developed they will often also have no choice. Carers’ work, in effect, subsidises states which would otherwise have to provide personal and domestic support for citizens who are chronically ill or have disabilities. Carers’ contributions are often going unrecognised by governments.

Carers provide physical and psychological care, day and night; they arrange and accompany their relatives to medical appointments, do the domestic tasks, manage the household finances and navigate discrimination.

“Through their effort, patience, knowledge, understanding, companionship, determination and compassion these carers transformed the lives of the people for whom they were caring.”
(Patil, 2012)

The responsibility of caring can be rewarding but in many cases it leads to psychological distress, a poorer quality of life and physical problems. (Manigandan et al., 2000; Mirza et al., 2009; Thrush and Hyder, 2014; Singh, Sharma and Singh, 2015).

Awareness of carers’ need for support is under-recognised. (Thrush & Hyder, 2014., Janardhana et al., 2015; Ganjiwale et al., 2016). In 2012 Patil consulted carers in India and South Africa. He described the findings as “shocking in terms of the extent of need and the individual experiences and situations discovered.” He also found that carers would welcome help and a willingness among government and non-government organisations to support carers.

This project, funded by the Big Lottery Fund, will enable the Self-help Group for Cerebral Palsy Nepal (SGCP) to improve its capacity to assist the carers of its young clients with neurological conditions through a partnership with Carers Worldwide

who will provide expertise on carer support. This baseline study explores the participating carers' welfare at the outset, contributing towards development of the project objectives and evaluation of its outcomes. The 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.

A review of the literature confirmed that carers of people with cerebral palsy experience a similar raft of difficulties, physical, psychological, financial and social to other carers (Pousada et al., 2013). The literature also identifies a number of interventions which appear to be helpful. Functional enablement of the cared for people reduces stress on carers and frees some of their time, but home rehabilitation has to be programmed realistically around other household demands.

Communication improves carer coping when it is sensitive to carers' access to information sources and well matched to their educational and social backgrounds. Where carers understand the permanence, but also the functional possibilities, for their relatives they may adjust their expectations and move forward with productive strategies. Financial hardship is significant with reduced employment opportunities and extra medical costs and carers are often unaware of the few grants, insurances and concessions which are available. Carers' resilience is affected by personal psychological coping strategies; it follows that psychological intervention programmes should facilitate carer coping. It is not only primary carers but the whole family which is affected, indicating a need for family-centred approaches. Mobilisation of support from the community, statutory and informal, including carer-to-carer groups, brings emotional and practical benefits. Access to services for this often marginalised group is crucial. Community-based services, for example, which are available on the doorstep and shaped and provided largely by members of carers' own communities can feel geographically and financially accessible and socially relevant. Finally, services will only improve if underpinned by awareness among policymakers which is achieved mainly through advocacy and research: the literature indicates a need for carers to be involved in more than participant roles.

For this study the participating carers were interviewed by staff from SGCP about their circumstances, about their cared for relatives and how the caring role impacts on their wellbeing.

The majority of carers were women and mostly mothers to the cared for people. Only one carer, a 17 year old, was below the age of 20. Just over a quarter were also caring for other family members. 80% lived in households with 5 or fewer members and 69% of households had 2 or more children.

69% of carers said they had a health problem. Just under half were receiving treatment, a quarter were not and just over a quarter did not say whether or not

they were. Only 1% said that they could not go for treatment specifically because of their caring role. 3% said they could not afford the treatment, which may or may not relate to the presence in the family of a person with a disability.

26% of carers had had no schooling and 29% had had 11 or more years of education. This suggests that the project is reaching a good cross-section of social groups. It also means that a range of media and communication styles will be needed to communicate with participants.

The majority of carers were of working age, 97% being between 17 and 60. Yet at least 63% were not earning and a very high proportion of those in work were earning poverty wages. 82% of carers were being financially helped by other family members. 14% of households were borrowing money for treatment for their cared-for child and 2% were borrowing for expenses for the child. There were various reasons why some carers were not working but very significantly 47% said they could not find anyone to cover their caring duties. Those who wished to work were missing out not only financially but also on the other benefits of work such as socialisation, respite and possible occupational satisfaction. This group may also be restricted if carer activities, such as self-help groups, require them to leave the house.

Regarding the cared for people. 45% were female which is a gender ratio of 1.2 male to female. The gender ratio of males to females with cerebral palsy internationally is 1.3 (Thapa, 2016) which indicates that this study is reaching both genders. The cared for people were mainly young, with only 9% being 21 or over. The lengths of time people had had their conditions was significantly below their ages. Given that most of these conditions would have been acquired at birth or in infancy one would expect these two profiles to be similar. It may be something to do with the way the question was asked. Sometimes it takes a while before neurological disabilities become clearly evident, but it is difficult to see how this would account for such a marked difference. The reasons for this discrepancy may be important to explore as recognition of the uptake of the carer role has implications for help-seeking.

The survey explored how carers felt about their wellbeing. They were asked to rate the extent to which specific aspects of their personal lives, such as family relationships, their financial situation and their physical and mental health were affected by their caring role. The results show that they were struggling with all of these. Over half were significantly worried about the future. Securing a future for a person with a disability needs at least other family or statutory support to be in place and these were very lacking for this group of carers. Carers were also asked to identify the issues or needs which presented them with the most difficulty and for their ideas and suggestions about what might help. The issues they identified were

time, financial pressures, their physical and mental health, and handling their children. Other concerns were around employment, lack of support from the family and isolation. A surprise was the lack of mention of difficulties around the cared for relatives' behaviour as it has been identified as significant with cerebral palsy. Finally, the carers suggestions about what would help them most were day care/hostel, employment, schooling for the children and improvement in the children. Others were outside help, government and non-government, therapy for the children, sponsorship and support for the carers. But the suggestion for day care or a hostel stood out.

Approaching the questions in different ways has revealed a richer picture. For example, when asked if they had health problems 69% of the carers said yes. But when they were asked to identify the problems no mental health conditions were offered among the answers to select from. Later when asked specifically about anxiety and depression 76% and 71% respectively were concerned a lot or quite a bit about them. With the open questions nobody mentioned exhaustion but when asked specifically about it 77% said it concerned them a lot or quite a bit. The data about incomes does not indicate clearly the financial wellbeing of individual carers as it is tied in in a complex manner with overall household incomes and expenditures. Yet asking carers specifically about their finances and their biggest worries brought finances clearly into focus as one of the most pressing concerns. Asking carers open questions about what they felt would help brought out the suggestions of day care and schooling for the children which would not have otherwise been identified.

This study gives a coherent picture of the most pressing concerns for this group around the caring role, these being financial and jobs, their physical and mental health, the need for support, 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.

Background to this study and the project

Background to this study

This study was undertaken by Carers Worldwide and the Self-help Group for Cerebral Palsy, Nepal and was funded by the Big Lottery Fund.

The study explores the domestic, social and financial context in which the carers for adults and children with neurological conditions in Nepal are working, and their health and social welfare needs.

The Self-help Group for Cerebral Palsy, Nepal (SGCP) supports children and adults with neurological conditions in Nepal. Considering that it might improve the service it provides to the carers for its clients SGCP approached Carers Worldwide, whose expertise is in carer support, to see if together they could develop a project which would address their carers' needs.

This study adds to a picture of the lives and needs of carers in Nepal created through a consultative process between participating carers and the project partners. It contributes towards the identification of project goals and serves as a baseline against which the project final outcomes will be evaluated.

In addition the findings will add to the pool of data, knowledge and experience with which Carers Worldwide continually builds a robust, evolving and evidence-based approach to understanding and addressing the needs of carers.

The study will also contribute towards raising awareness of the needs of carers in society and among social policymakers and help to inform the wider community of researchers and programmers.

Objectives

This study assesses the lives of carers of children and adults with neurological conditions in participating communities in Nepal in order to:

- Understand the domestic, social and financial context in which the participating carers are operating.
- Identify carer needs and how those needs might be met through this project.
- Provide a baseline against which the project outcomes will be evaluated.

Project description

The overall goal of the project is that the joint work of Self-Help Group for Cerebral Palsy, Nepal and Carers Worldwide will lead to an environment in which:

The carers of children and adults with cerebral palsy and other neurological conditions in Nepal will experience greater recognition, increased social inclusion, improved health and increased household financial security.

The project is funded by the Big Lottery Fund

Improving the physical, emotional, economic and social wellbeing of carers of people with disabilities and long-term health conditions is Carers Worldwide's vision and purpose.

Working with 5 local partners in India and Nepal, Carers Worldwide has worked with over 5,000 carers over the last 4 years with encouraging results. For example, within one year of starting a project in India 55% of carers started earning an income for the first time since taking on their caring responsibilities. A project in Nepal reduced the number of carers experiencing physical ill-health from 69% to 33% and those experiencing mental ill-health from 77% down to 33%. 55% of carers were able to access respite for the first time, 285 child carers were re-enrolled in school and 41% of participating carers said they had developed the confidence to advocate for their needs with government officials.

Hearing of Carers Worldwide SGCP approached Carers Worldwide to explore a possible partnership which might enable them to support their carers more effectively.

The needs and wishes of carers were identified through consultation involving Carers Worldwide and SGCP carers, field staff and managers. This consultation process led to identification of the overall goal and the following proposed outcomes and activities:

Outcomes

- Carers will enjoy improved physical and mental health
- The household incomes of carers and their families will increase
- Carers will experience improved emotional support
- Carers will be better able to advocate for their rights and for the services they and their families require

The outcomes and activities chosen are based on the experience of previous Carers Worldwide projects and the core humanitarian principles of participation, relevant actions based on response to communication with the community, and capacity building in order that the community will be able to carry the work forward after the end of the project (CHS Alliance, Groupe URD & Sphere Project, 2014).

Activities

- A baseline assessment of carers
- Capacity building of local partner staff to implement all aspects of the project
 - Training for partner staff to run local carer groups
 - Training for partner staff and doctors on carers' physical and mental health needs
 - Training for staff and other local organisations on the specific needs of carers at times of disaster
- Assessment of carer livelihood needs and training, provision of equipment and access to finance and markets
- Training of staff and carers to run community caring centres

By these means carers will be able to run their own peer-support groups which will enable them to support each other and form carer associations through which they will be able to advocate for their rights and the services they need. With the support for income generation and formation of day care centres for their relatives carers will be able to earn income alongside their caring responsibilities. The carers will feel able to access health care and counselling services for themselves. Arising from the experience of the Nepal earthquake in 2015, which showed how carer groups played a crucial role in post disaster recovery, carers will be trained in disaster preparedness.

The project will run from November 2016 to October 2019.

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.

The Self-help Group for Cerebral Palsy, Nepal

Self-help Group for Cerebral Palsy, Nepal is dedicated to assisting children and adults with cerebral palsy and other neurological conditions to live with dignity and as independently as possible.

The Self-help Group for Cerebral Palsy, Nepal (SGCP), based in the Kathmandu valley, was established in 1986. It is a non-government, non-profit organisation, registered with the Nepal government and affiliated with the Social Welfare Council.



SGCP provides specialist medical and therapeutic expertise for people with cerebral palsy and other neurological conditions while ensuring also holistic care by referral to other medical centres for related and general health matters such as hearing, sight, heart health and similar. SGCP keeps abreast of developments in its specialist field through maintaining links with experts in Europe. SGCP gives academic, life-skills and vocational education to its children in specialist settings and where possible supports them through mainstream education. Parents are given social and psychological support and the technical skills to help them manage the special needs of their children, such as therapeutic rehabilitation skills, and are helped to develop income generating activities which fit around their carer roles. Parents are also involved in the running of some of SGCP's activities.

SGCP provides these services in a main centre, satellite residential and day care centres and a home visiting outreach programme.

Review of the literature

What is cerebral palsy?

Cerebral palsy affects the coordination of movement. It is a lifelong condition caused by damage to the brain before, during or soon after birth. It can be mild, moderate or severe. The muscles may be stiff or limp and be either difficult to move at all or continually moving and uncontrollable. One, two, or all four limbs, the trunk, mouth and swallowing muscles may be involved. Different activities such as walking, purposeful use of the hands, speech and swallowing will be difficult or almost impossible depending on which muscles are involved in each individual. If speech is affected and indistinct individuals may be wrongly perceived to have learning difficulties. Where the mouth and swallowing muscles are involved people have difficulty taking in and swallowing food which makes mealtimes difficult and distressing for them and their carers and sometimes leads to malnutrition. (Adams et al., 2011; NINDS; Scope).

It may not only be muscles which are affected. Up to half of people with cerebral palsy have intellectual impairment, up to a third have epilepsy and some have behavioural difficulties. Visual and hearing impairment occur more frequently in people with cerebral palsy than in the rest of the population. Children with cerebral palsy have more sleep disturbance than their typically developing peers; this can lead to sleep deprivation and an increased risk of depression in their carer. (Wayte et al., 2012; Adiga et al, 2014; NINDS; Scope).

Cerebral palsy is not a progressive condition but some of its effects can cause complications or progressive worsening. For example, the stiff muscles may cause contractures in which joints become fixed in bent positions and therefore less useful. Swallowing impairment can lead to food going into the lungs instead of the stomach and cause chest infections. There is no cure but therapy and good management can help individuals to capitalise meaningfully on what function they do have, perhaps learning to walk with an aid or to be able to go to school, albeit in a wheelchair, instead of allowing inactivity and complications to set in. (NINDS; Scope).

The care needs of people with cerebral palsy and the impact on their carers

Depending upon how an individual is affected they may need to be lifted and carried, have their position continually adjusted, be helped with feeding, toileting (day and night), communication, with washing and dressing and maybe more. They may need

to be taken for medical and therapy appointments and have daily therapy at home.

Some carers will be coping with behavioural difficulties and epileptic fits. The carers have to navigate the healthcare, education and welfare systems. The domestic tasks of the household, food preparation, shopping, cleaning and laundry are likely to fall to the carers. For those at least more than mildly affected this may place a considerable daily demand on carers, long-term and unalleviated. Of course, carers sometimes also feel benefits. Women, for example, sometimes feel that they develop skills and a degree of self-confidence and the role can confer positive identity on child carers. (Skovdal, 2011; Yousafzai, Farrukh & Khan, 2011).

Pousada et al., (2013) studied the impact of caring for a child with cerebral palsy through a systematic review of the literature covering low and high income countries. They found that the effects of caring for the child related not only to the particular features of the child's disability but also to personal characteristics of the carer and social variables of the family.

There is a significant tendency for parents of children with cerebral palsy to have increased levels of anxiety and depression, a poorer quality of life and increased physical problems such as chronic diseases and pain. Many studies did not find a correlation between the severity of the child's motor disability and the carer's wellbeing. By contrast all studies examining children's disturbed behaviour found association with carer stress, but the directionality of this correlation is not established. Two studies regarding the children's cognitive functioning found it to be a predictor of carer stress. A carer's own personal resources affect how well they cope, with several studies finding a relationship between a carer's self-efficacy and stress levels. Some studies cited looked at family adaptation to having a child with cerebral palsy. The findings are complex but indicate that the mother's wellbeing as principal carer is affected by the gender roles taken and it emerged that a family's adaptation changes over time. Mothers and fathers tend to have different approaches. Mothers tend to focus on the child, use emotional disclosure and seek support from social and health professionals. Fathers tend to use more cognitive and action orientated strategies and focus more on the family as a whole. Social support from beyond the immediate family has been found to be an important factor mediating carer wellbeing. (Pousada et al., 2013).

A carer's wellbeing is affected by the features of their child's disability, their personal resilience characteristics, gender, family relationships and external social support. Few features are reliably predictive of carer stress, for example the level of physical disability may or may not affect an individual carer. Therefore assessment of carer wellbeing needs to explore the child's disability, the carer's personal characteristics,

family relationships, social support and changes over time, but most of all be led by the carer's own account of how they are feeling. It follows that carers could be helped by support with management of their child's disability, their personal coping strategies, the family and social inclusion, with each individual having a personally tailored package.

The need for carer support

The majority of carers are women, often mothers, but men also and children. Usually carers support a family member but they may care for multiple family members simultaneously or at different times both within the home and in neighbouring homes; indeed they may be caring for non-related neighbours. (Sahoo & Saur, 2009; Skovdal, 2011; Pousada et al., 2013; Cordier, 2014; Janardhana et al., 2015).

Generally carers will take on the role out of love and voluntarily but in low-resourced settings they may have little choice because state domiciliary care for people with long-term conditions is often not available and because care is viewed as a family responsibility. In traditional extended families the caregiving role might be shared but the social fabric is changing with increasing nuclearisation of families in low and middle income countries intensifying the demands on carers. (Sahoo & Saur, 2009; Skovdal, 2011; Thrush & Hyder, 2014; Angothu & Chaturvedi, 2016). Families, and even carers themselves, often do not recognise the importance of their contribution. Where responsibility is not shifted towards government the perception that this is a plentiful resource is perpetuated. Within families and governments the invaluable contribution and needs of carers are going unrecognised and are being overlooked. (Patil, 2012; Janardhana et al., 2015; Ganjiwale et al., 2016).

There is also a lack of understanding of what constitutes assistance for carers. Community organisations supporting people with long-term conditions sometimes claim that they are helping carers when they are actually working through the carers to meet the needs of the cared for people. In fact they may even perceive carers as a problem when they do not comply with advice.

“... community development workers are all too quick to label carers as non-cooperative if they do not follow our advice... is it carers who are the problem or is it our inability to understand the various issues that are affecting a carer's involvement?”
(Patil, 2012)

Recognition of the need to support carers is emerging. In 2012 Patil undertook a study to explore the situation in India and South Africa. He found that there was no organisation focusing on the needs of carers. Yet he found that carers would

welcome support from organisations and governments, that organisations would be grateful for advice on how to support carers, and a general belief that it is possible. (Patil, 2012).

Effective approaches to support for carers

Minimising the discomforts of cerebral palsy for a child and enabling them as much as possible in daily living skills can reduce the distress and workload for carers. Carers often ask for assistance with activities of daily living for their dependents (Sen & Goldbart, 2005). Carers can be taught how to help their children around positioning and carrying, communication, everyday activities and play thereby making significant improvement for the children and their carers. Every child must be approached as an individual as every case of cerebral palsy is different (LSHTM).

“ From following some of the methods taught my child has experienced some development... and as a result I feel more positive and happier.”
(LSHTM)

If parents are to benefit from their children’s rehabilitation they must feel able to implement the home therapy programmes. Looking after a person with disabilities can be time-consuming with, for example, feeding, toileting and dressing in addition to household tasks. Service providers need to listen to the carers’ assessments of their priority needs and shape the home therapy programmes around the other demands of their daily routines. Possibly, for example, training several family members to share the therapy routines. Unrealistic expectations force carers into non-compliance, leaving them exhausted and with a sense of failure and guilt and the advisors feeling resentment that the carers do not actually care. Where the balance is right parents will be able to participate despite the investment required. (Sen & Goldbart, 2005; Burkhard, 2013; Cordier, 2014; LSHTM).

“ If I had done everything that all the doctors and all the therapists asked me to do, we would not get past breakfast, and then it would be time to go to bed! So, I had to pick and choose what I was going to do, but then, I always felt inadequate, because I’d go back to the therapist, and [they’d ask] “Why haven’t you done [your child’s] exercises?”
(Burkhard, 2013)

Trust in the advisors and professionals and good communication have been found to improve carer coping. There may be low levels of knowledge about disability, its causes and how to manage it. Carers may not have the education to understand technical terminology, or poorer people whose lives in slums are constantly under threat by authorities may be suspicious of outsiders. Not understanding advice is another reason for unintentional non-compliance. Good, well-communicated advice

has been found to be an important factor in parental coping. In particular where parents are able to take on board the realities and permanence of some disabilities they may be able to adjust their expectations and move on with better adapted plans. Communication needs to take into account how carers learn, through, for example written or non-written material and their pace of learning (Maloni et al., 2010; Zuurmond et al., 2015; Ganjiwale et al., 2016; Ribeiro et al., 2016).

“I feel anger at the way they speak! They don’t explain anything properly... We end up not knowing what to do or what to think.”
(Ribeiro et al., 2016)

Carers can benefit from support with financial income. The tasks of caring may leave no time for paid work, even within the home, and it is often impossible to find others to share the role to enable a primary carer to work outside the home. Hospital visits and medicines are costly. State benefits, concessions and health insurances are not available in many low and middle income countries. Where they are available they can help “a great deal” (Thrush & Hyder, 2014) but many carers are unaware of them. (Sen & Goldbart, 2005; Kuppusamy, Narayan & Nair, 2012).

“All primary caregivers expressed their need for financial support.”
(Sen & Goldbart, 2005)

Research has identified that personal psychological outlooks affect resilience. This applies to both the personal characteristic of self-esteem and to cognitive coping strategies. For example, problem solving and support seeking have been found to be associated with greater carer wellbeing, whereas the strategies of denial and avoidance thinking can leave carers feeling more fearful and burdened. The pattern is complex. Religion is often helpful, the benefit possibly deriving more from its cognitive aspects than from the use of rituals. Hope may be regarded not as denial but as a positive strategy, and realism be distinguished from learned helplessness. These findings suggest that psychological interventions to help boost carers’ self-esteem and develop positive cognitive coping strategies could contribute towards better wellbeing for them. Sharing of problems with others seems to also help, indicating peer-support as another way of helping. (Rammohan, Rao & Subbakrishna, 2002; Raina et al., 2005; Chadda, 2014; Nguyen, Pertini & Kettler, 2015; Ganjiwale et al., 2016; Ribeiro et al., 2016).

“I hope to see him well, cured! Any doubts I hide at the back of my mind. Without hope of seeing him recover I would sink, stop, not be able to do anything.”
(Ribeiro et al., 2016)

The quality of life for whole families may be affected across physical, emotional, cognitive and social functioning, daily activities and family relationships. Mothers

and fathers tend to adopt different approaches to coping. Yet focus on family is neglected in programming. (Gathwala & Gupta, 2004; Yousafzai, Farrukh & Khan, 2011; Pousada et al., 2013; Zuurmond et al., 2015). While most of the caring is left to mothers men also act as primary carers or share the role. As caring is generally seen as a woman's place men may fear discrimination if they identify themselves publically by, for example, attending carer groups. Services can recognise the need to support men, and where necessary in a discreet way. (Navalkar, 2004; Institute of Development Studies, 2016; Janardhana et al., 2015; Southern Africa HIV/AIDS Information Dissemination Service). Children may receive less attention if there is a sibling with a disability in the household. They may share the carer role appropriately or possibly be drawn in to their detriment even sometimes foregoing school. (Sahoo & Saur, 2009).

“An increasing body of research highlights the importance of services that... also meet the wider needs of the family, based on a good understanding of the experience of families that have a child with a disability.”
(Zuurmond et al., 2015)

In their literature review on caring for children with cerebral palsy Pousada et al. (2013) found many studies identifying social support as an important factor contributing towards carer wellbeing. Thrush & Hyder (2014) found the most commonly mentioned avenues of support were family, friends, neighbours, formal healthcare services, churches and paid helpers. Although the perceived benefits felt from family and friends were variable. Through organised carer-to-carer meetings parents come to know they are not alone, to find encouragement, support, practical advice and information about resources. (Maloni et al., 2010; Yousafzai, Farrukh & Khan, 2011). Groups may, in addition to peer support, include structured information and advice from professionals, or carers may meet with other stakeholders such as local administrators, community leaders and disabled people's organisations. (Palit & Chatterjee, 2006 ; Cordier, 2014).

“The [parent-to-parent] meeting affected Phalla's mother profoundly. It changed her behaviour towards Phalla...”
(Cordier, 2014)

“Carers reported that many of their concerns were alleviated by the acceptance and support they now had from their communities as a result of the project. While some were not completely resolved carers at least felt that by sharing the issue with neighbours they had decreased their level of worry.”
(Cordier, 2014)

Access to services is key. It seems from an analysis by Thapa (2016) (using retrospective data) that a large proportion of people with disabilities in Nepal never

see a doctor or visit a health centre for their disability. It appeared that treatment for cerebral palsy was sought proportionately more for boys than for girls and more by people of better socioeconomic wellbeing. Sinha & Sharma (2017) looked at the use of physiotherapy for children with cerebral palsy in the Punjab. It seems that some parents did not utilise physiotherapy because they did not believe their child could improve and yet others used physiotherapy in the mistaken expectation of the child attaining normal movement. Zuurmond et al. (2015) report families endlessly visiting traditional healers in search of a cure. There is no cure for cerebral palsy but good management can improve the children's lives considerably. Inappropriate information is leading carers to sometimes invest emotionally and financially in services which may not be helpful to them. Sinha & Sharma (2017) speculated that other factors for non-exposure to physiotherapy were likely to be religious beliefs, competition with ayurvedic and other medical systems, interpersonal and family relationships, attitudes of service providers and economic.

Carers typically have very limited access to support in low and middle income countries, particularly in rural and underdeveloped areas. Community based services can bring practical assistance and even the realisation that the situation can be improved. Recognising this, a community based training programme for parents of children with cerebral palsy has been developed. It's primary focus is to improve the wellbeing of the children rather than the carers but it has been found to improve carers' quality of life by 30% and increase their confidence in caregiving from 36% to 89%. The programme methodology is based on research and the experiences of key disability and other organisations. It trains carers to manage their children's condition, in, for example, activities of daily living, and develop their own support groups. The programme utilises a high degree of parent and family participation and trains carers to be carer trainers. (Cordier, 2014 ; LSHTM; ICED).

*"I understand more about the condition [cerebral palsy] by participating in the training and as a result of this my child has been developing. Now I feel less physical and mental pain."
(LSHTM)*

Carers should benefit if governments and society as a whole recognise the invaluable contribution they make and their needs. The two principal means for promoting recognition are research and advocacy. The World Health Organisation (2013) in its mental health action plan, supports and calls for carer contributions towards policymaking. Semrau et al. (2016) looked at the involvement of carers in mental health system strengthening through involvement in advocacy and in research in low and middle income countries. They observed a recent increase in carer involvement and signs that it can be effective. However they found that carer involvement in research is often confined to the participant role rather than a consultative role.

They also found that often carer involvement in system strengthening is evaluated in terms of satisfaction at the community level, such as the effectiveness of self-help groups, and a lack of attention to identifying what models are effective and of their impact at the systems level.

Summary

Carers help their children with many aspects of daily living, day and night, in addition to giving balanced attention to the rest of the family, managing household tasks and where possible contributing towards the family income. They have to negotiate the healthcare, welfare and education systems. The caring role is one of love and rewards but it also often brings poorer physical and mental health, a poorer quality of life and financial hardship.

Research shows that carers' ability to cope is affected not only by the features of their individual child's condition but also by their understanding of the condition, their own personal psychological coping strategies, the family dynamics, support from the community and access to health and welfare services. While each carer focuses on their own loved one, their collective contribution to society is going largely unrecognised and unsupported by governments who benefit. It is necessary and possible for carers to receive and be partners in giving and shaping support at the individual, family, community and systems levels.



Baseline study results

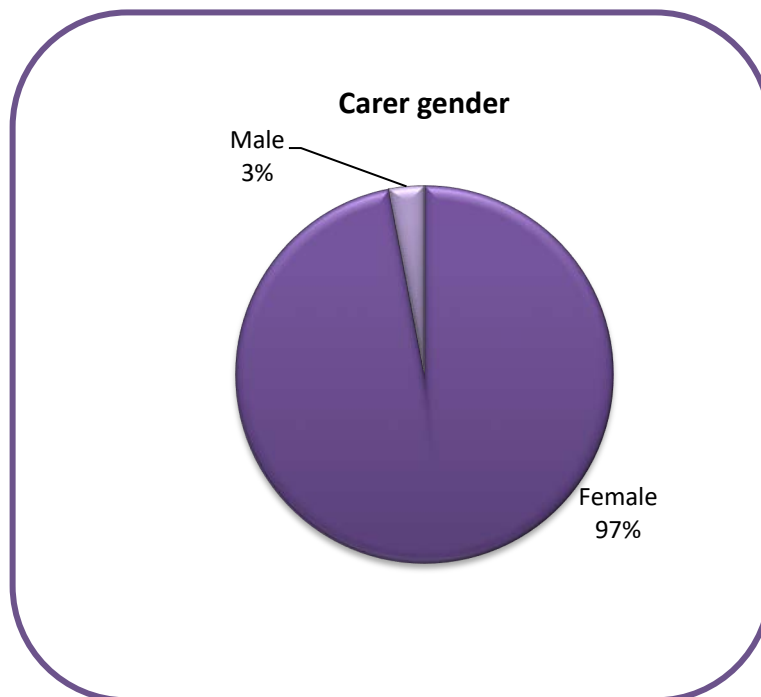
334 carers of clients of the SGCP participated. They were interviewed by SGCP staff about their circumstances, about their cared for relatives, how they were finding the experience of caring for their relatives and their own wellbeing. They were also asked what the most pressing issues were for them in relation to their caring role and for their ideas regarding what might help them in their role as carers. The interview questions are given in the appendix.

With some questions a few participant answers were missing or obviously erroneous which means that the numbers do not always tally exactly. The level of error is generally in the region of 0-1% and has been taken to not significantly affect the balance of the results. The countable figures have been reported.

Profile of the carers

Carer gender

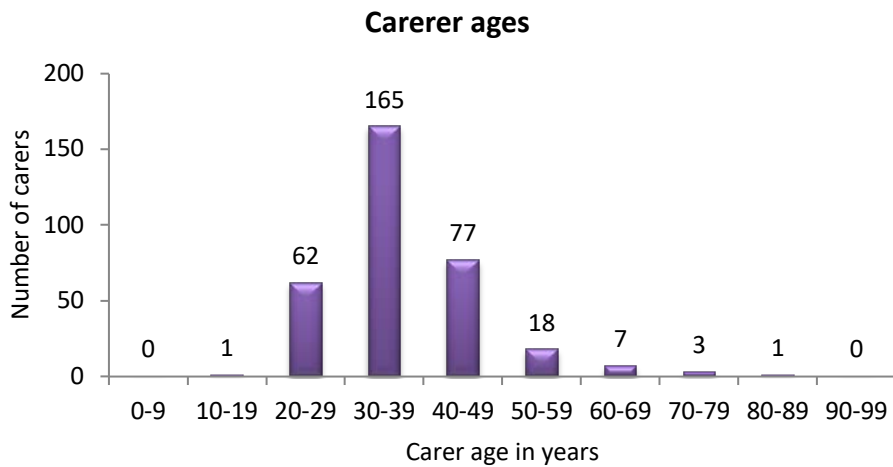
Carer gender		
	Number	%
Female	323	97
Male	11	3



The majority of the carers, 97%, were female, 3% were male.

Carer age

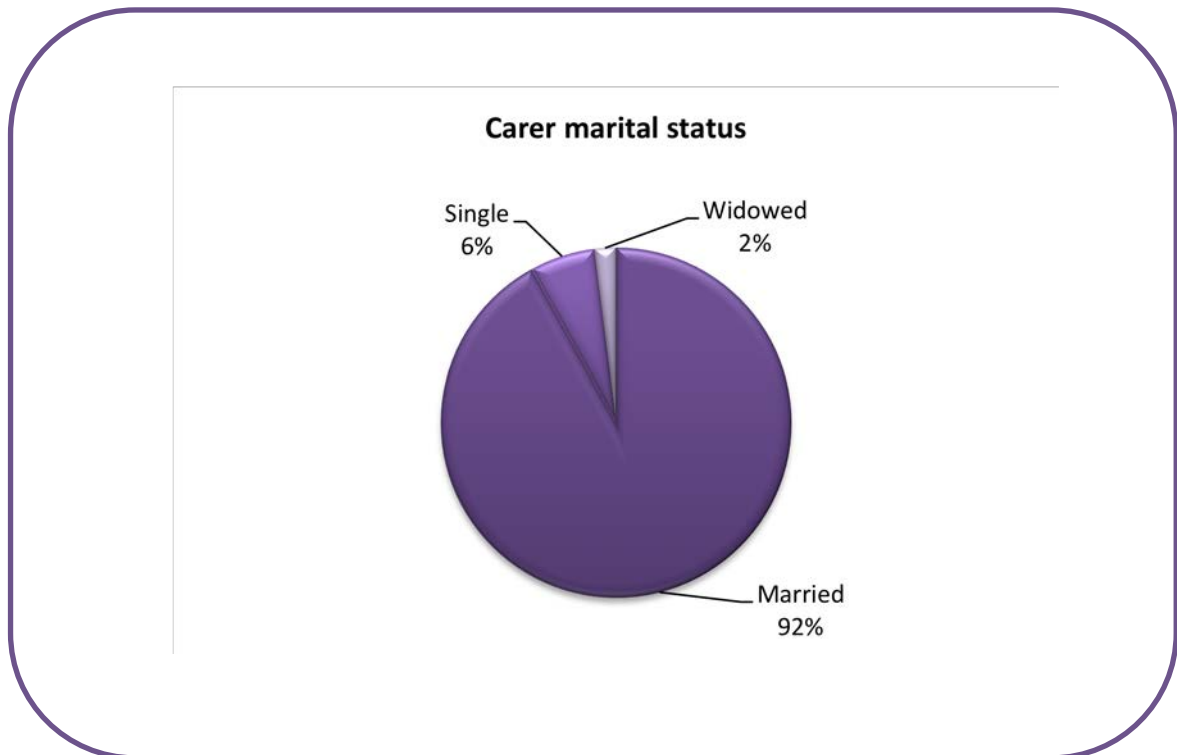
Carer ages	
	Number
0-9	0
10-19	1
20-29	62
30-39	165
40-49	77
50-59	18
60-69	7
70-79	3
80-89	1
90-99	0



Only one carer was under 20 years of age, a 17 year old. The majority were between 20 and 60. 11 were older, with 1 in their 80s.

Carer marital status

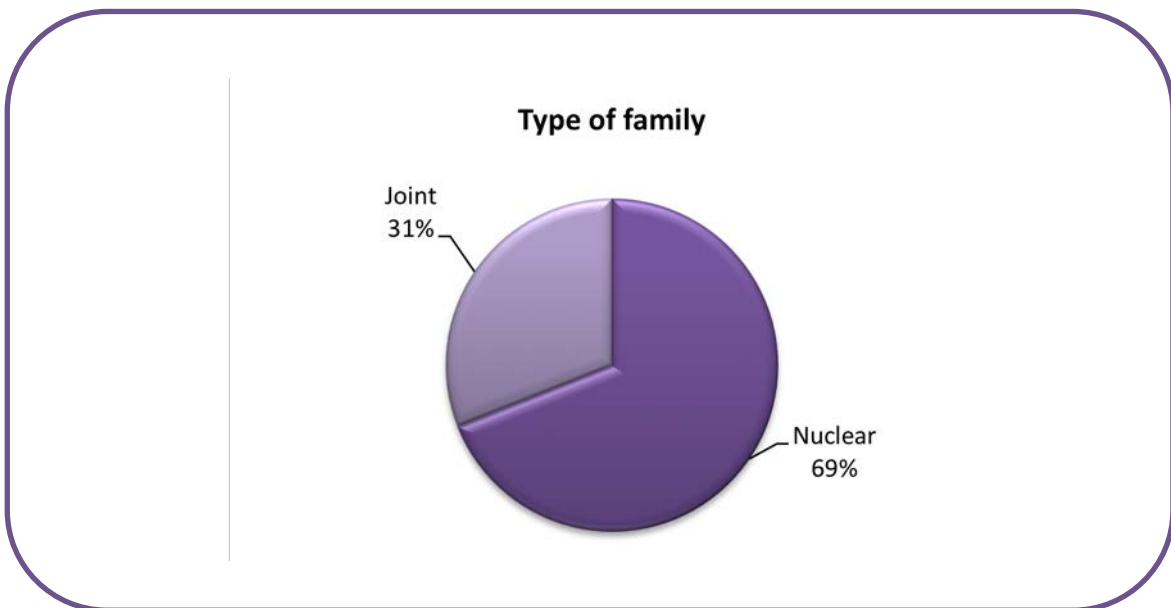
Carer marital status		
	Number	%
Married	307	92
Single	21	6
Widowed	6	2



92% of the carers were married, 6% were single and 2% widowed.

Carer type of family

Type of family		
	Number	%
Nuclear	232	69
Joint	102	31



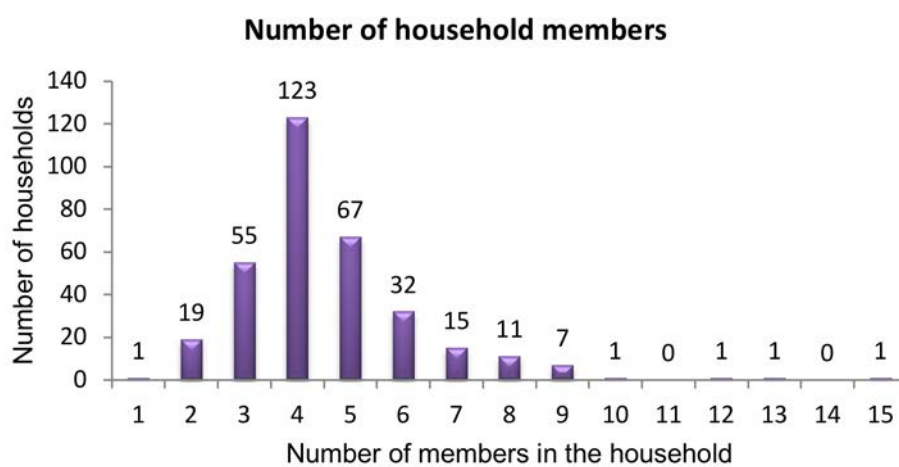
69% of families were nuclear and 31% joint with extended family members in the household.

It is important to notice this particular statistic. It is easy to assume the presence of extended families in Asian households in which the caring role can be shared. The SGCP group reflects a known trend towards nuclearisation of families (Thrush & Hyder, 2014) which intensifies the caring role of the one or few people in the household. In this particular group the number of nuclear families was almost 70%. Data was collected on the number of other adults in the households. 76% (253) had 2 or more men and 77% (256) had more than one woman. Yet 47% of the carers said they could not go to work because there was nobody else to cover.

Number of household members

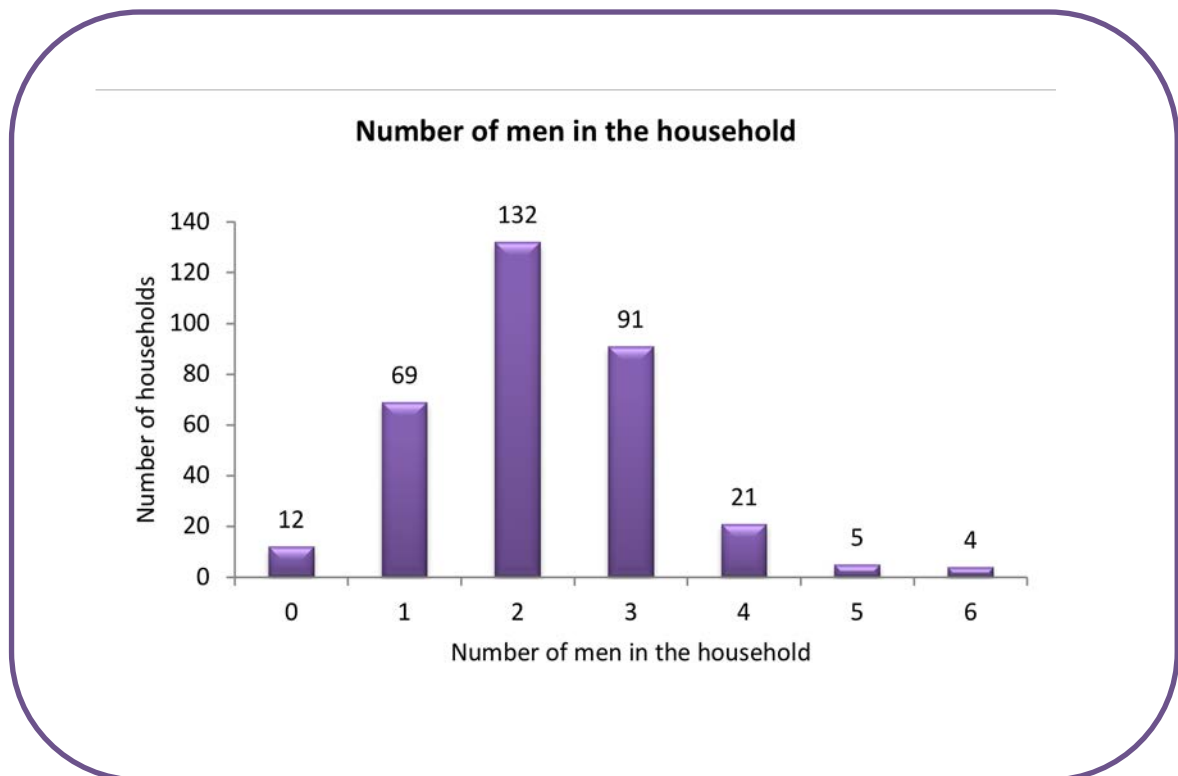
Number of household members	
	Number
1	1
2	19
3	55
4	123
5	67
6	32
7	15
8	11
9	7
10	1
11	0
12	1
13	1
14	0
15	1

The majority of households have 5 or fewer members.
Only 67 (20%) have more than 5 members.



Number of men in the household

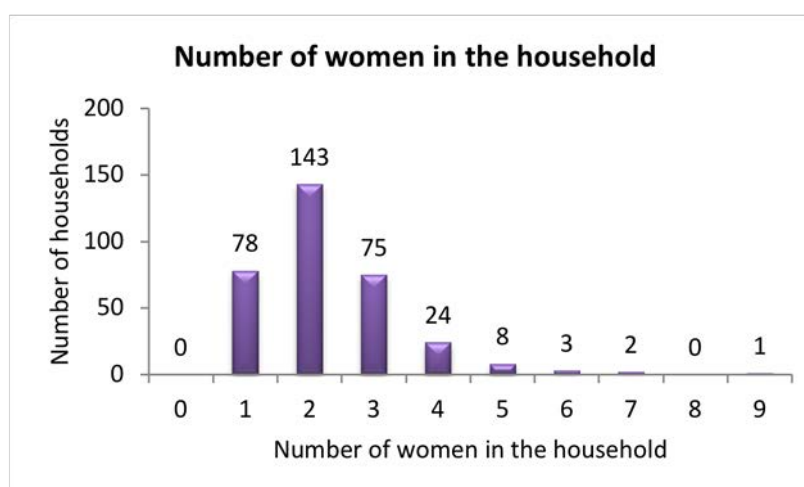
Number of men in the household	
	Number
0	12
1	69
2	132
3	91
4	21
5	5
6	4



132 (40%) of the households had 2 men, 69 (21%) had 1 man, 12 (4%) had no men. Approximately 36% of households had 3 or more men.

Number of women in the household

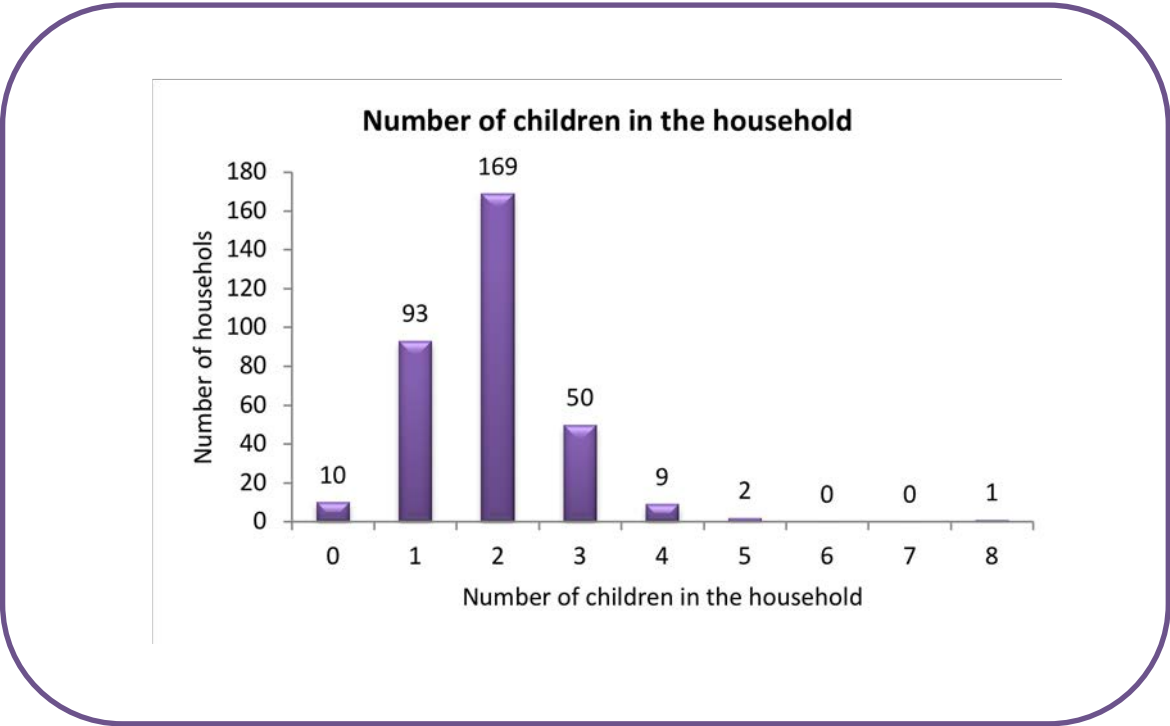
Number of women in the household	
	Number
0	0
1	78
2	143
3	75
4	24
5	8
6	3
7	2
8	0
9	1



143 (43%) of households had 2 women. 78 (23%) had 1 and no households were without a woman in the house. 113 (34%) of households had 3 or more women.

Number of children in the household

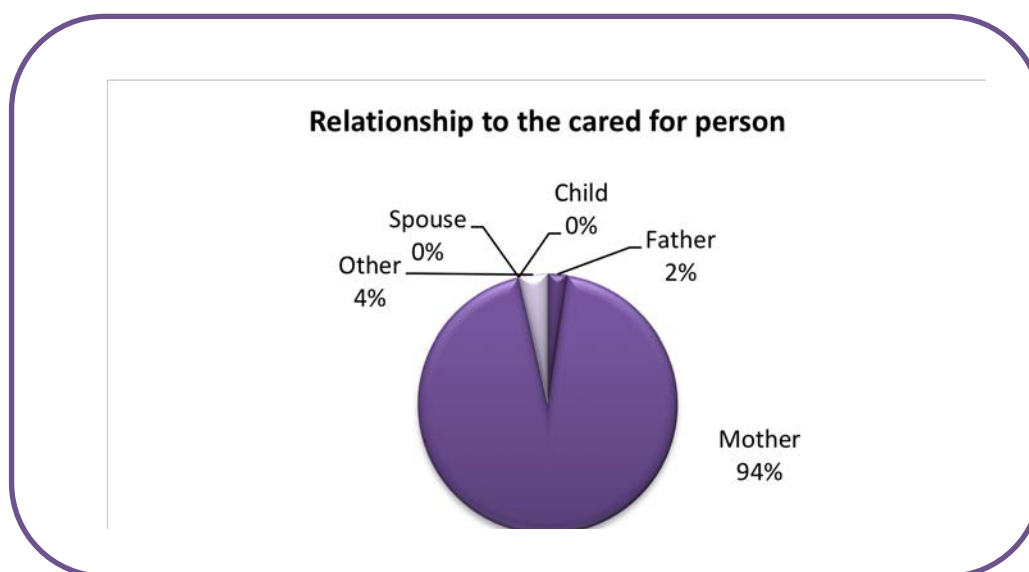
Number of children in the family	
	Number
0	10
1	93
2	169
3	50
4	9
5	2
6	0
7	0
8	1



The largest number, 169 (51%) had 2 children. 93 households (28%) had only 1 child and 10 households (3%) had no children. 231 (69%) families had 2 or more children, and were almost certainly households in which the cared for person has a sibling.

Relationship to the cared for person

Relationship to the cared for person		
	Number	%
Father	8	2
Mother	314	94
Spouse	0	0
Child	0	0
Other	12	4

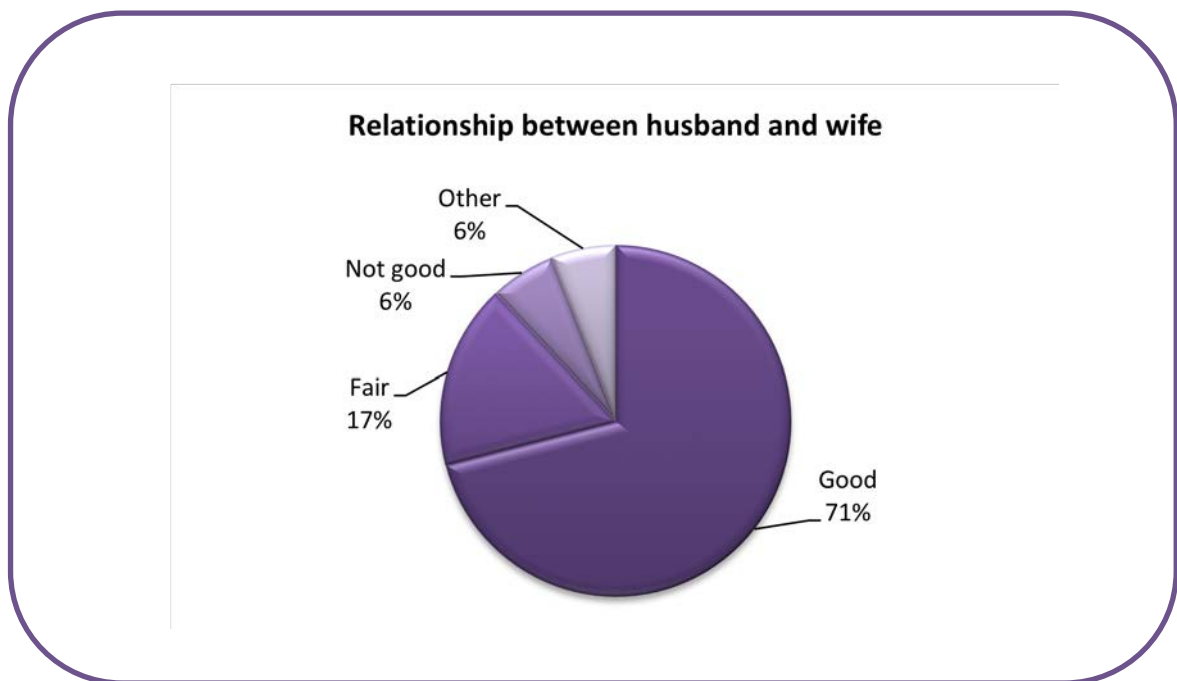


94% of the primary carer participants were mothers of the cared for people. 2% were fathers and 4% had some other relationship to the cared for person.

The majority of the carers were women (97%) and mothers (94%) of the cared for people. One would not expect many children to be primary carers where the disabilities arise at birth or in infancy: only one primary carer, a 17 year old, was under the age of 20, but some siblings may have been co-caring, as would some of the other women and men. The literature reminds us that male carers may not come forward to identify themselves and that men may have different support needs as carers. (Institute of Development Studies, 2016).

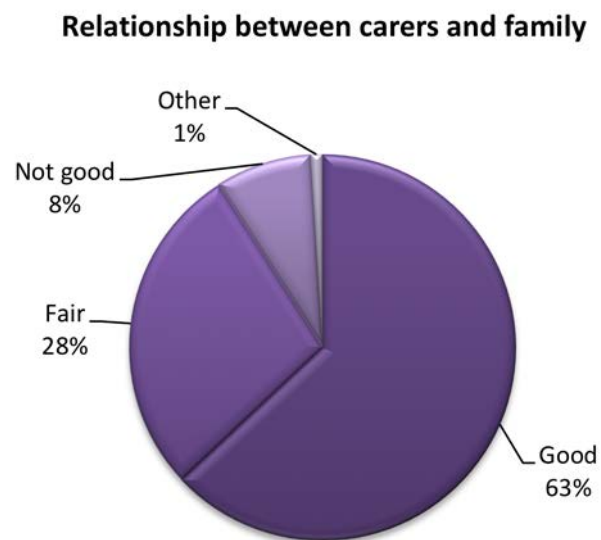
Carers' relationships with their spouses

Relationship between husband and wife		
	Number	%
Good	238	71
Fair	56	17
Not good	21	6
Other	19	6



Carers' relationships with the rest of the family

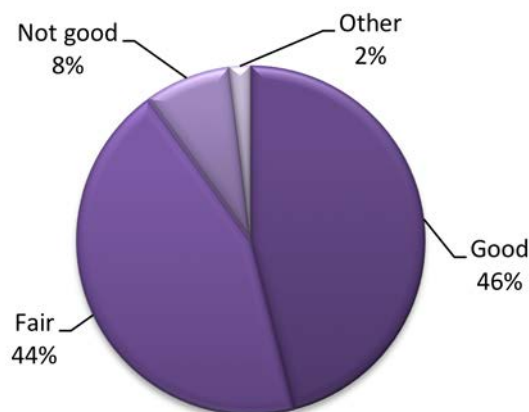
Relationship between carer and family		
	Number	%
Good	210	63
Fair	93	28
Not good	27	8
Other	4	1



Carers' relationships with neighbours

Relationship between carer and neighbours		
	Number	%
Good	155	46
Fair	147	44
Not good	25	8
Other	7	2

Relationship between carer and neighbours



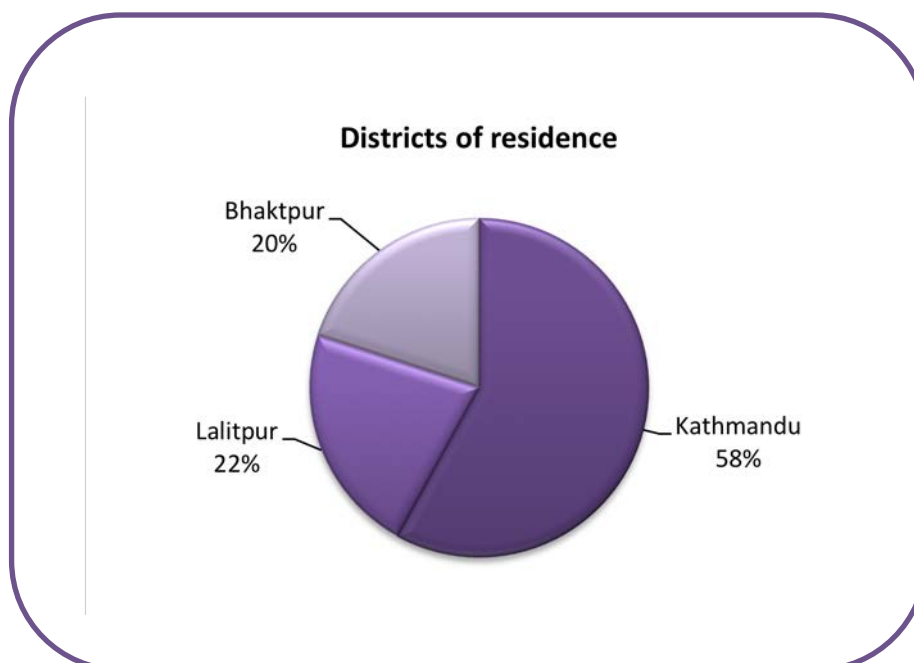
Carer relationships with those close to them were for the most part good-to-fair, 88% between husband and wife, 91% with the rest of the family and 90% with the neighbours. While this is reassuring it is possible that the others may have been having significant difficulties on account of relationships within the family and in the community immediately around them.

Citizenship of carers

96% of the carers have identity cards and citizenship. Citizenship helps individuals apply for state services such as a birth certificate, a disability card or to apply for a job. It facilitates application for state support such as financial benefits but in itself does not confer an automatic right.

Carers' district of residence

Districts of residence		
	Number	%
Kathmandu	195	58
Lalitpur	74	22
Bhaktpur	65	20



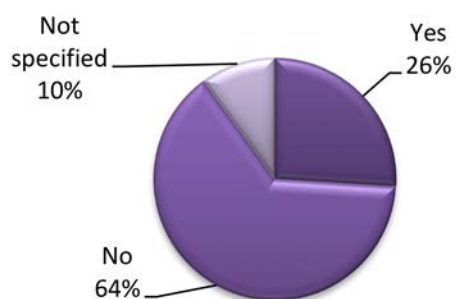
58% of participants lived in the Kathmandu valley, 22% in the district of Lalitpur and 20% in the district of Bhaktpur.

Carers caring for additional others

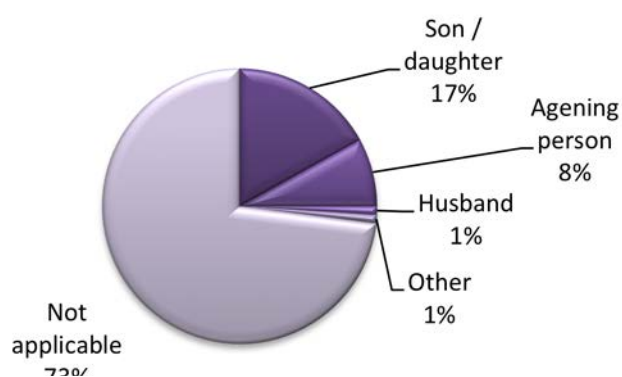
Caring for other family members		
	Number	%
Yes	88	26
No	212	64
Not specified	34	10

Other family members cared for		
	Number	%
Son / daughter	57	17
Ageing person	26	8
Husband	4	1
Other	2	1
Not applicable	245	73

Caring for other family members



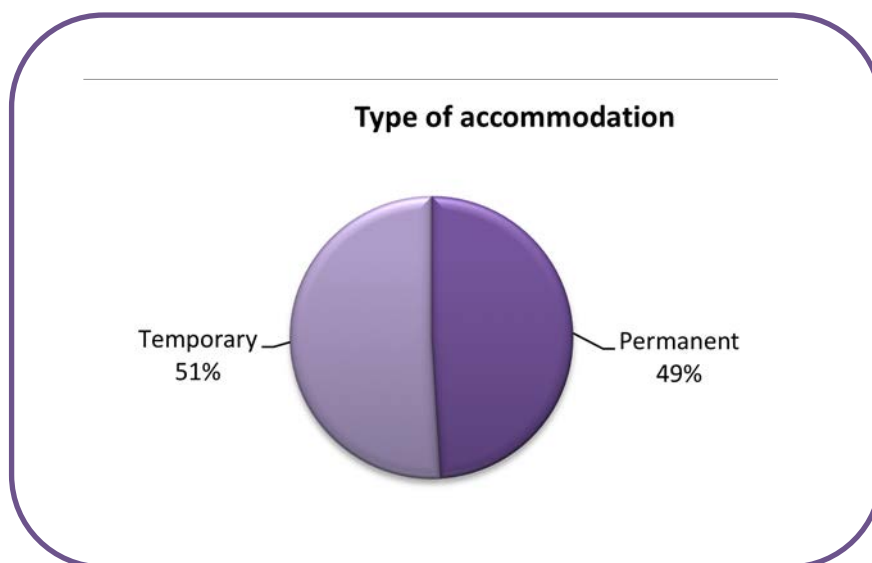
Other family members cared for



Just over a quarter of participating carers looked after another family member. 17% looked after another son or daughter, 8% looked after an ageing person, 1% looked after a husband and 1% looked after members of the household with some other relationship to themselves.

Carer household type of accommodation

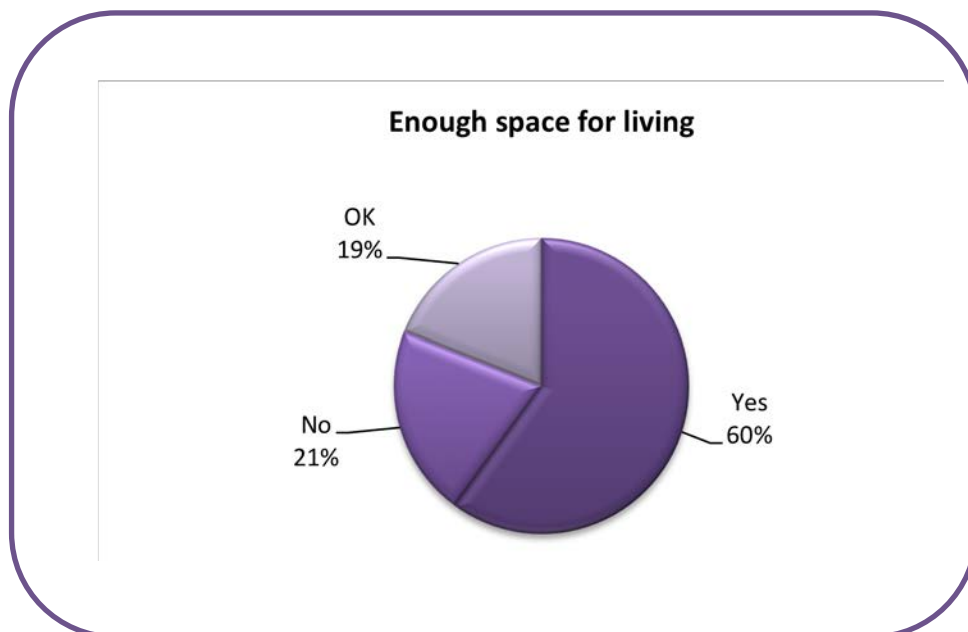
Type of accommodation		
	Number	%
Permanent	165	49
Temporary	169	51



49% of carers were living in permanent residences and 51% were living in temporary accommodation.

Living space

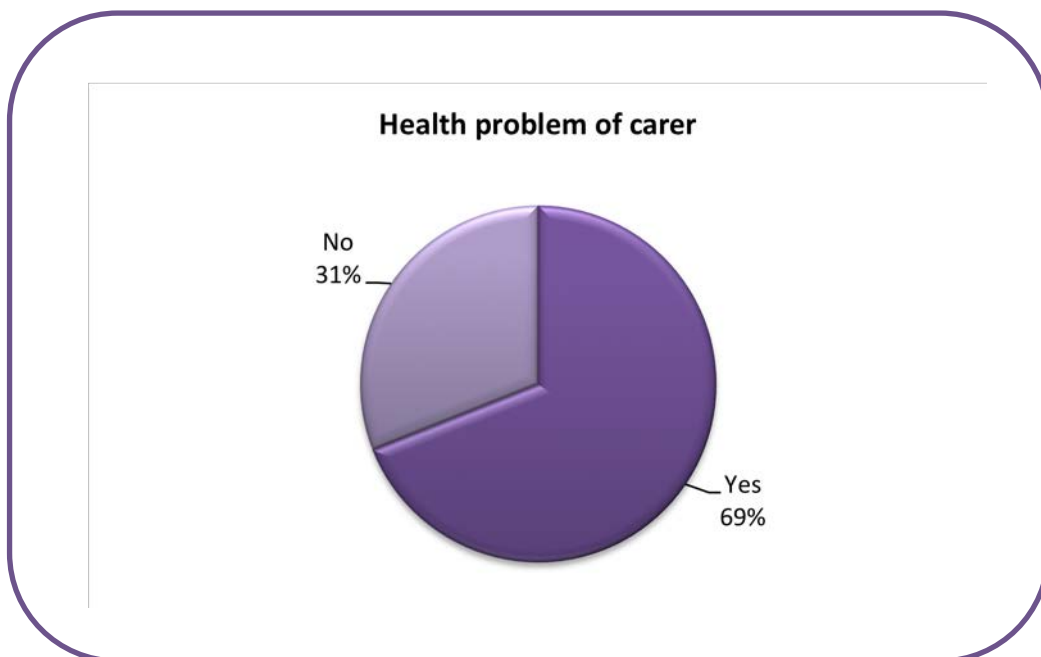
Enough space for living		
	Number	%
Yes	201	60
No	70	21
OK	62	19



60% of participant carers felt that they had enough space for living, 19% felt that the space they had was adequate but 21% felt that they did not have enough space for living.

Carers' health

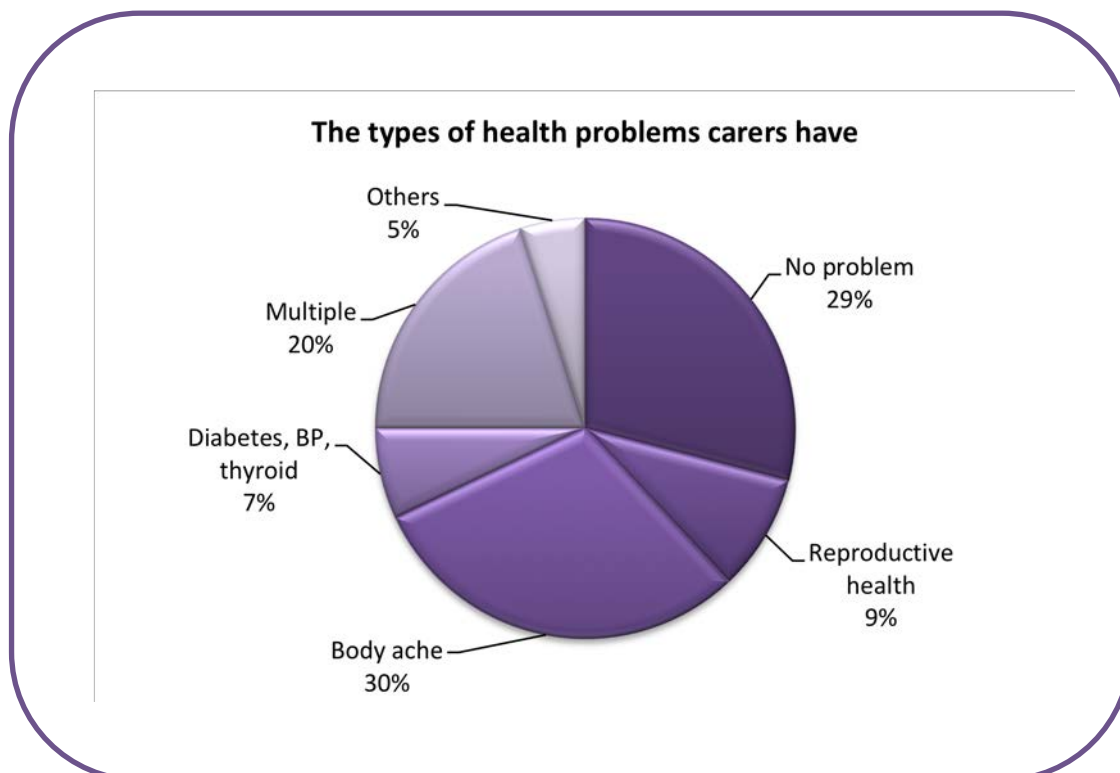
Health problem of carer		
	Number	%
Yes	230	69
No	102	31
Not specified	2	



The carers were asked if they had a current health problem, physical or mental health, or any disability. 69% of participating carers said they did and 31% said they did not.

The types of health problems carers have

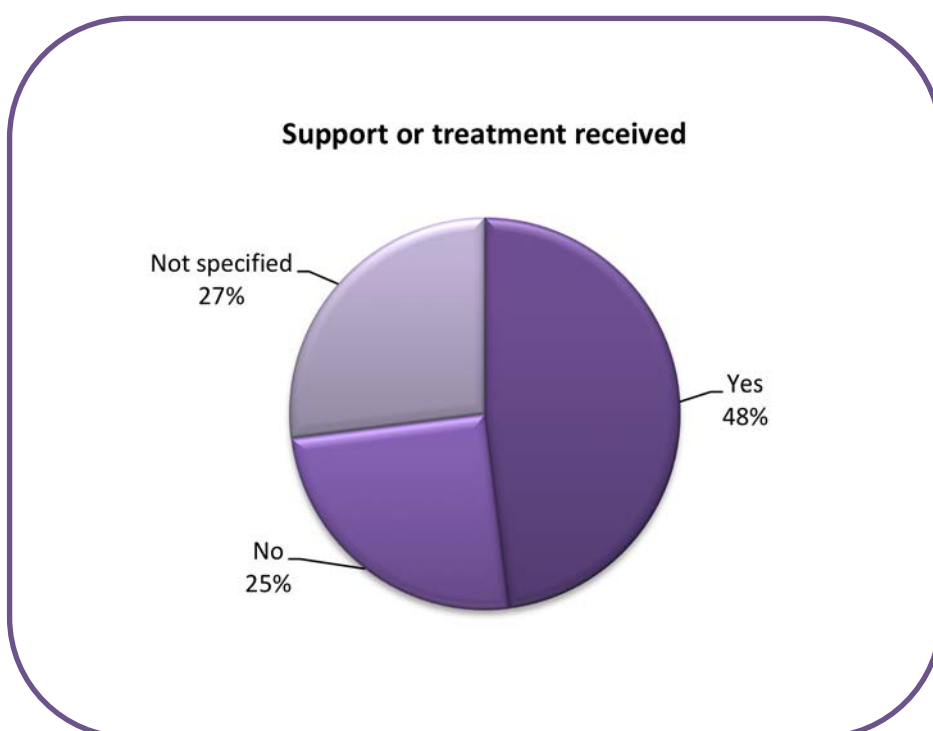
Carer type of health problem		
	Number	%
No problem	97	29
Reproductive health	31	9
Body ache	99	30
Diabetes, BP, thyroid	23	7
Multiple	67	20
Others	17	5



30% of the carers said their body aches, 7% said they have diabetes and/or high blood pressure and /or thyroid problems. 20% said they had multiple health problems and 5% had unspecified health problems.

Support or treatment received

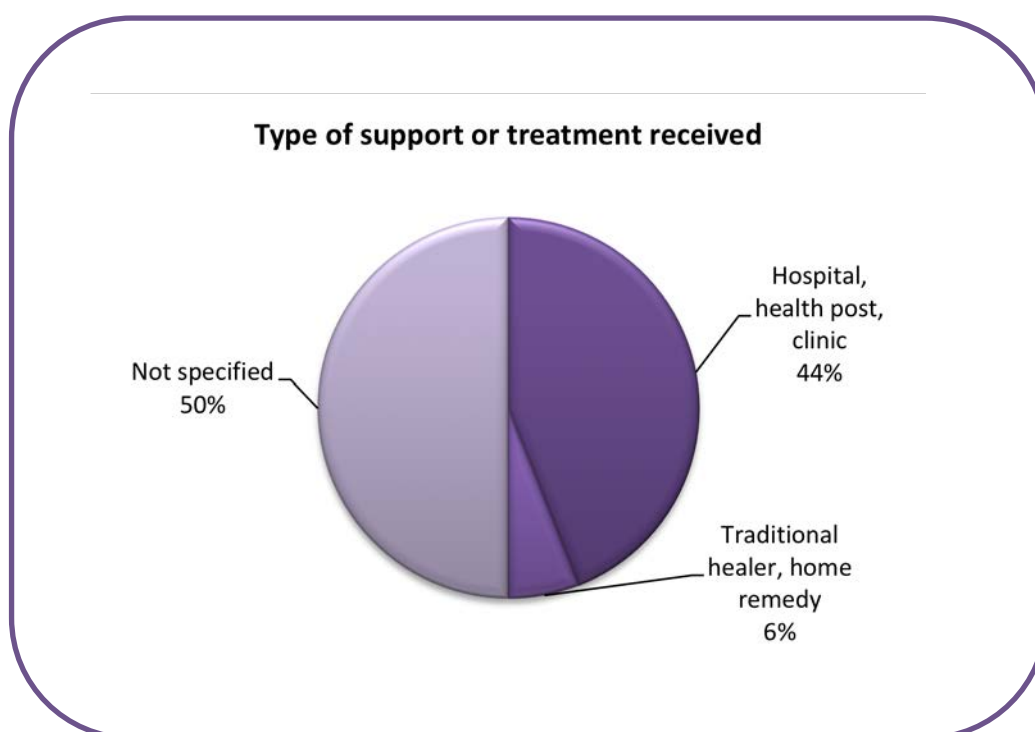
Support or treatment received		
	Number	%
Yes	161	48
No	83	25
Not specified	90	27



48% of the carers said they were receiving support or treatment for their health problems, 25% said they were not receiving support or treatment and 27% did not specify whether they were.

The type of support or treatment carers were receiving for their health

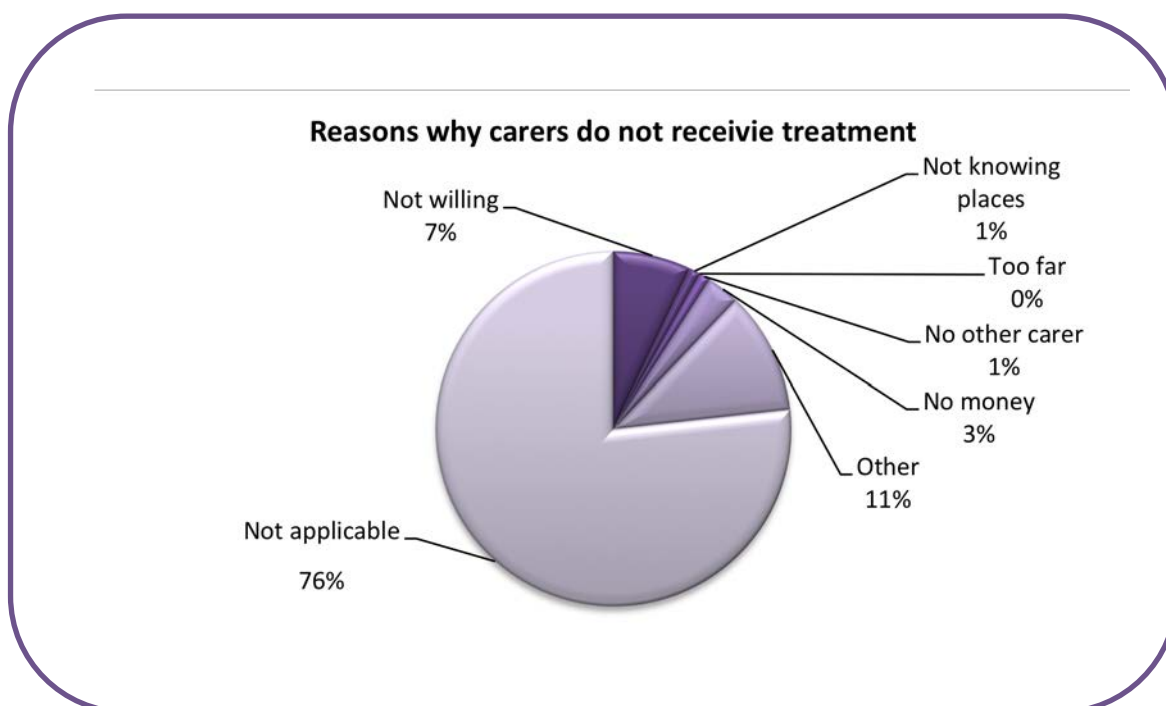
Type of support or treatment received		
	Number	%
Hospital, health post, clinic	146	44
Traditional healer, home remedy	21	6
Not specified	167	50



44% of carers said they received treatment for their own health conditions in hospitals, health posts or clinics. 6% said they go to traditional healers or use home remedies and 50% of carers did not say where or how they receive treatment for their health.

Reasons why carers do not receive treatment for their own health

Carers' reasons for not receiving treatment		
	Number	%
Not willing to get treatment	25	7
Did not know about treatment places	2	1
Treatment places far away from village	0	0
There was no carer to look after their relative	3	1
Family has no money for treatment	11	3
Other	38	11
Not applicable	255	76



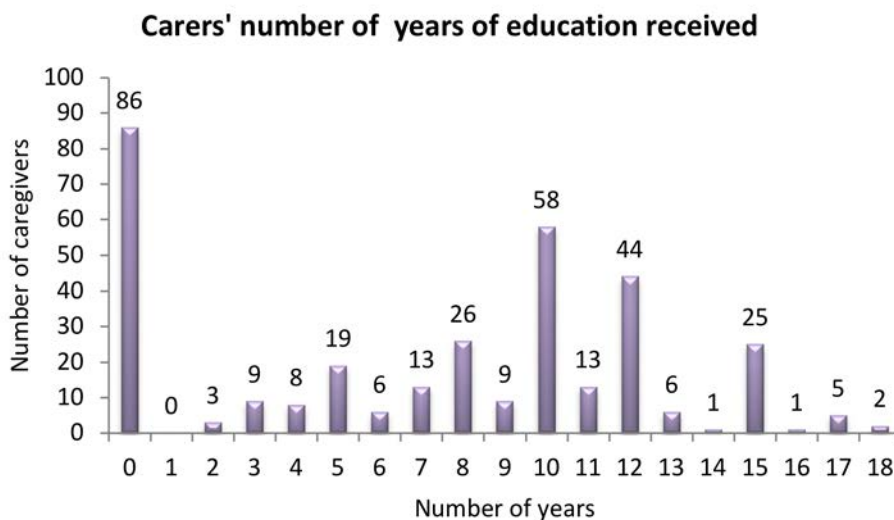
7% of carers said they were not willing to get treatment for their own health conditions, 1% said they did not know where to seek help, 3% said they did not have enough money. Only 1% said it was because there was nobody else to look after their relative. 11% said there are other reasons why they had not sought treatment for themselves.

Carers' education

Carers' number of years of education received	
Years of	Number
0	86
1	0
2	3
3	9
4	8
5	19
6	6
7	13
8	26
9	9
10	58
11	13
12	44
13	6
14	1
15	25
16	1
17	5
18	2

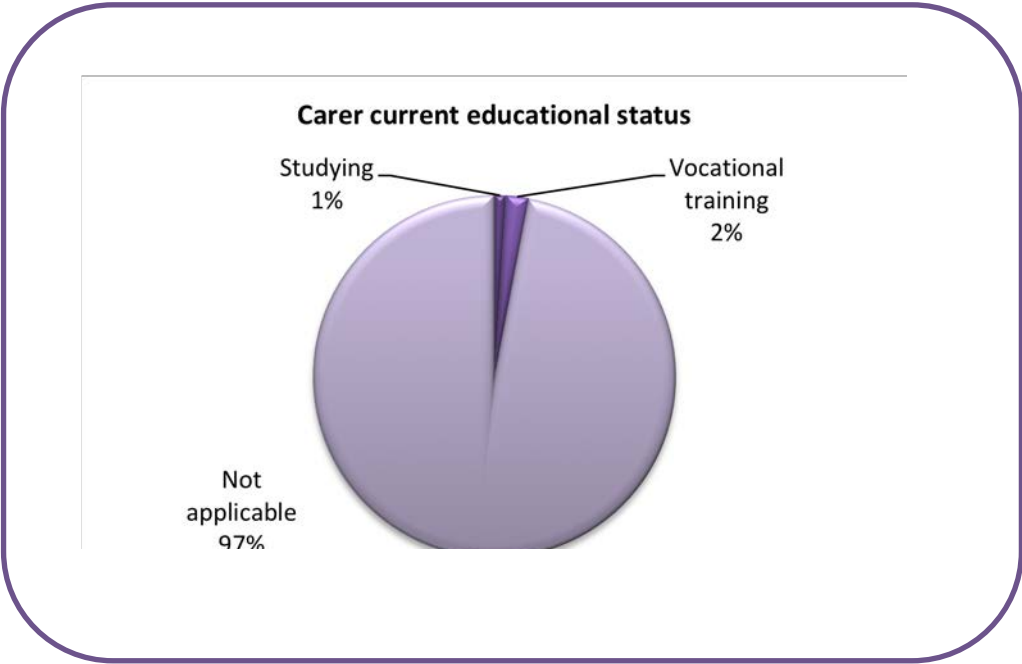
86 (26%) carers had had no formal education. 39 (12%) had between 2-5 years, 112 (34%) had 6-10 years and 97 (29%) had 11 or more years of education.

Good communication has been found to be an important factor in carer coping (Ganjiwale et al., 2016; Ribeiro et al., 2016). For the project this wide variation in carer educational backgrounds means that material will need to be available in different media such as written and non-written and some will need to be free from technical language.



Carer current education status

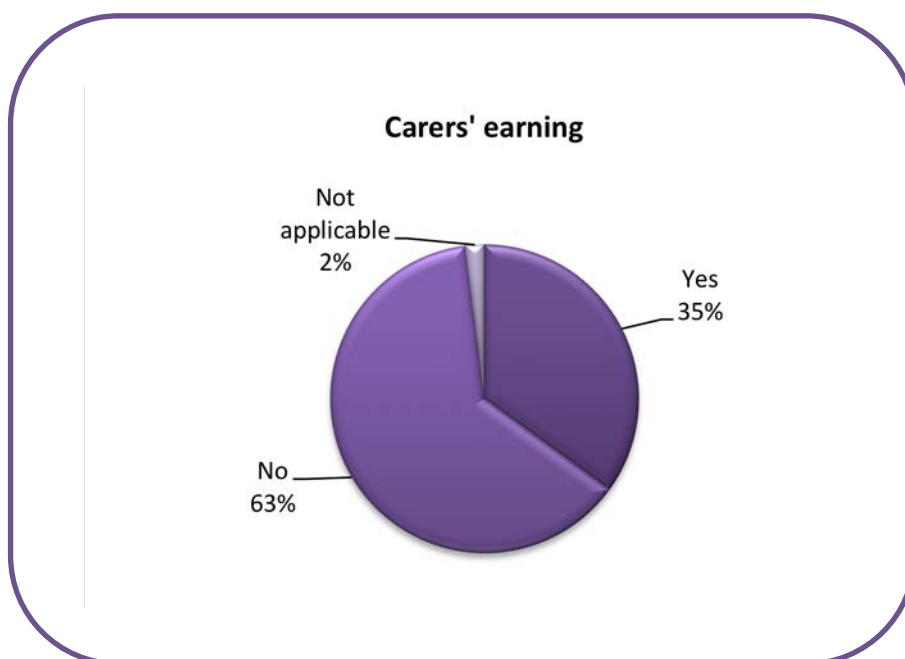
Carer current education status		
	Number	%
Studying	3	1
Vocational training	6	2
Not applicable	325	97



97% of carers said that current education did not apply to them. 3% were in education, 2% in vocational training and 1% were studying.

Carers' earnings

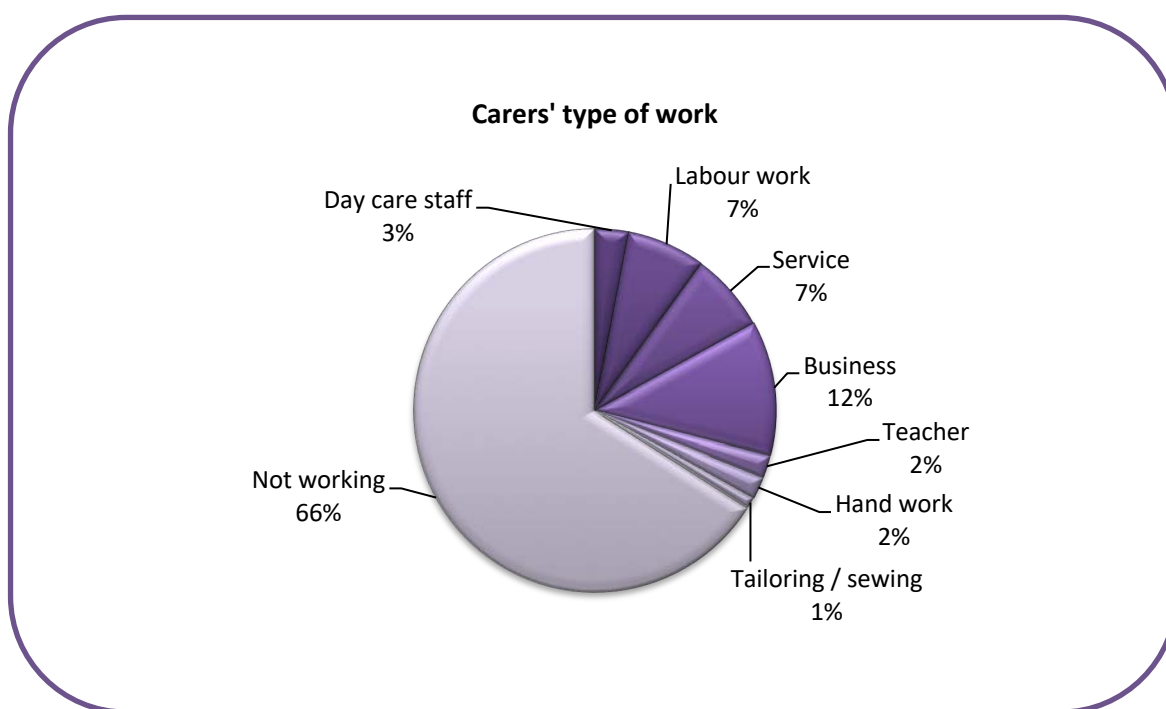
Carers' earning		
	Number	%
Yes	117	35
No	210	63
Not applicable	7	2



35% of participating carers said that they were earning, 63% said they were not earning and 2% said the question was not applicable to them.

Carers' type of work

Carers' type of work		
	Number	%
Day care staff	9	3
Labour work	23	7
Service	24	7
Business	40	12
Teacher	8	2
Hand work	7	2
Tailoring / sewing	4	1
Not working	219	66



12% of carers were in business, 7% in service, 7% labouring, 3% were day care staff, 1% were tailors, 2% were teachers and 2% were doing hand work. We do not know how many carers were working away from the home but it is unlikely that labouring, service, day care or teaching are done at home. The other professions may be done at home or away from home.

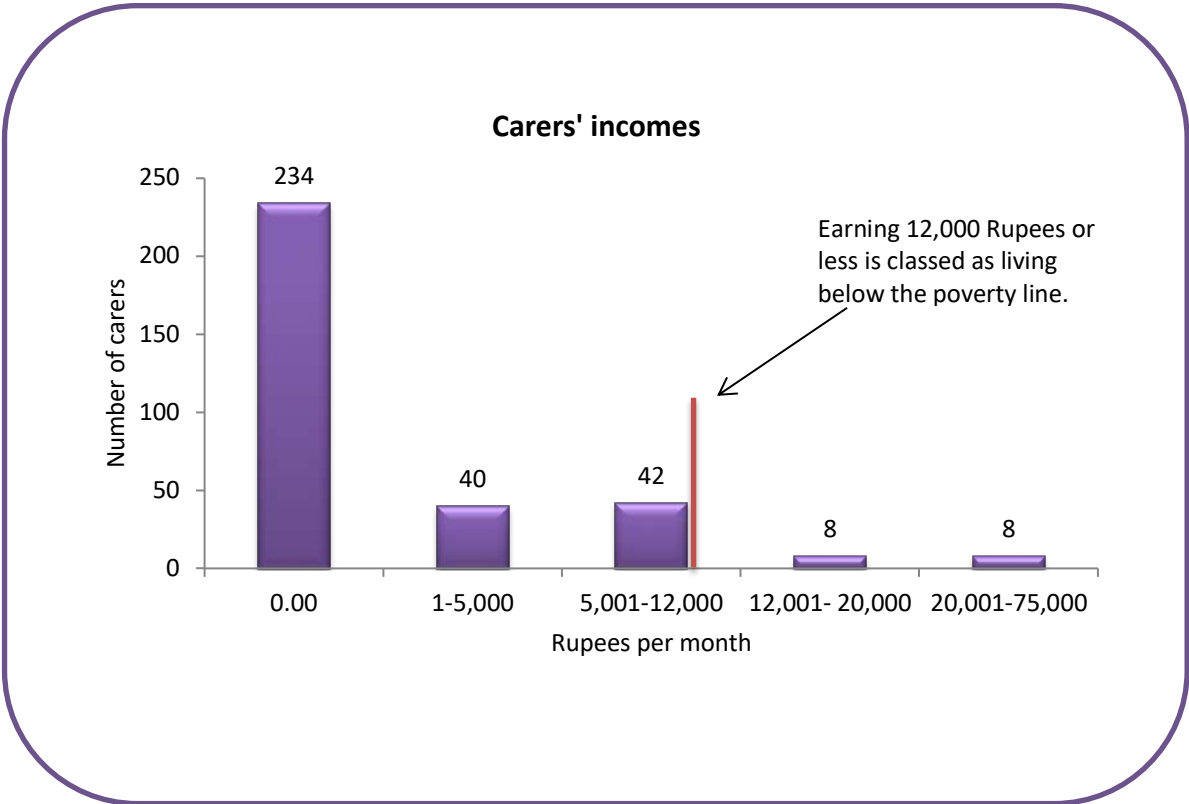
Carers' incomes

Carers' incomes Rupees per month		
	Number	%
0.00	234	70
1-5,000	40	12
5,001-12,000	42	13
12,001- 20,000	8	2
20,001-75,000	8	2

234 (70%) of carers said they were not earning.

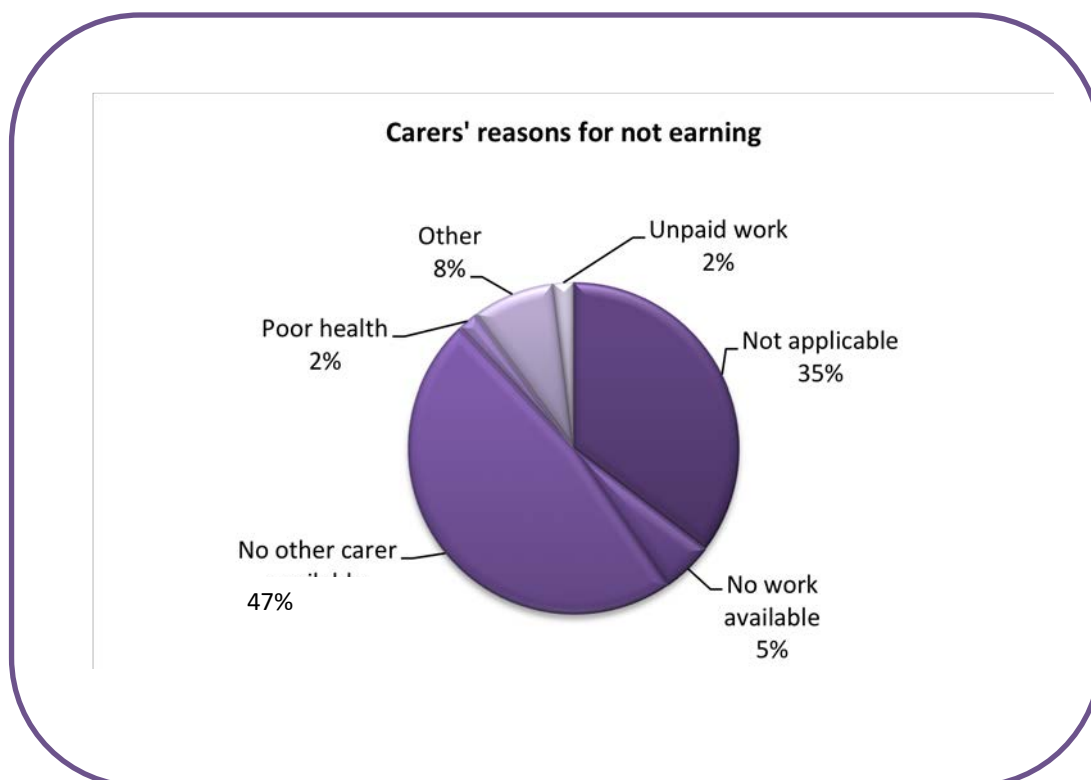
82 (25%) said they were earning 1-12,000 Rupees per month.

Only 16 (5% of the whole group) were earning more than 12,000 Rupees per month.



Reasons for carers not working

Reasons for carers not working		
	Number	%
Not applicable	117	35
No work available	18	5
Nobody else to take care of the relative	157	47
Own poor health	6	2
Other	28	8
Doing unpaid work (eg. volunteer, social work)	8	2

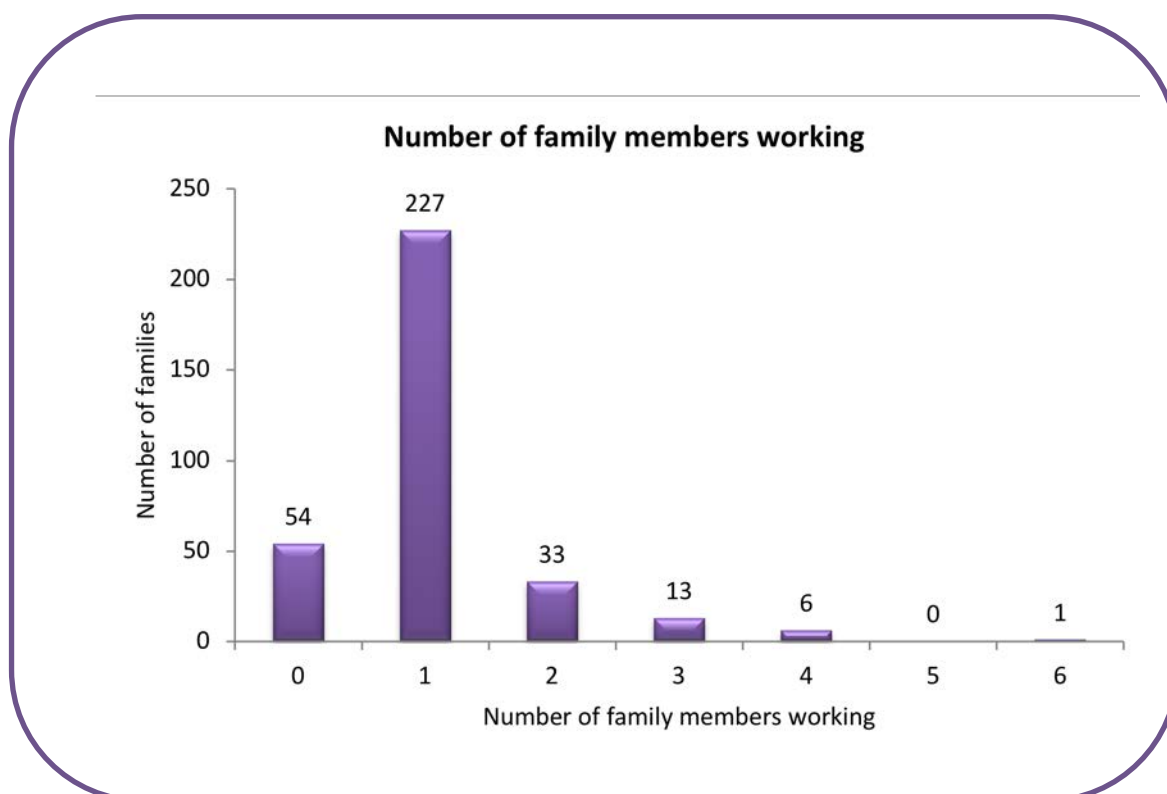


117 (35%) of carers said that the question of not earning was not applicable to them; 115 said they were not working. 47% said they were unable to work because nobody else was available to look after their relative. 2% said their health was preventing them from working, 2% were doing unpaid work, 5% said that work was not available and 8% said there were other reasons why they were not working.

The number of family members working

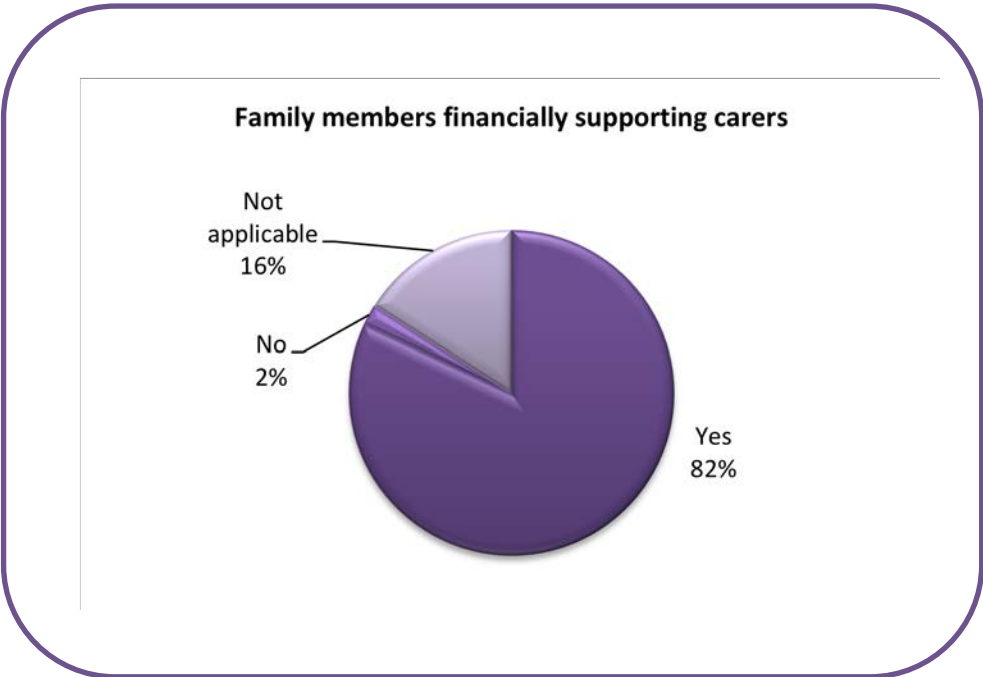
Family members working	
	Number
0	54
1	227
2	33
3	13
4	6
5	0
6	1

Carers were asked how many members of the household were working. 54(16%) said there was nobody in the house working. 227(68%) had one person working, 33 (10%) had 2 people working and 20 (6%) of households had 3 or more people working.



Households in which other family members who are earning are supporting the primary carer

Family members supporting carers		
	Number	%
Yes	273	82
No	8	2
Not applicable	52	16



82% of carers were being financially supported by other family members, 2% are not and 16% did not describe their situation.

There were three questions about carers working and income. The numbers of carers who said they were not working or not earning or giving reasons for not earning do not quite match. 210 said they were not working and 8 said they were doing voluntary work (210 + 8 =218) yet 234 said they had no income. 209 (157+18+6+28) gave reasons why they could not work, although individuals may have more than one reason for not being able to work. However it is clear that a very high proportion of carers, between 210 and 234 (63% - 70%), were not earning and that a very high proportion of those in work were earning below poverty wages of 12,000 Rupees per month.

The majority of carers were of working age; 97% (323) being between 17 and 60, yet it appears that 63% - 70% were not earning. It is noteworthy that 46% of carers (155) had 10 years or more education, the equivalent of complete secondary schooling, so should have good earning potential.

Various reasons are given for carer unemployment. 5% could not find work, 2% had poor health, 2% were doing voluntary work and 8% had other reasons. But very significantly 47% said they could not work because of not being able to find another carer. There may be some in this group who might find it difficult to get out to meetings such as carer support groups.

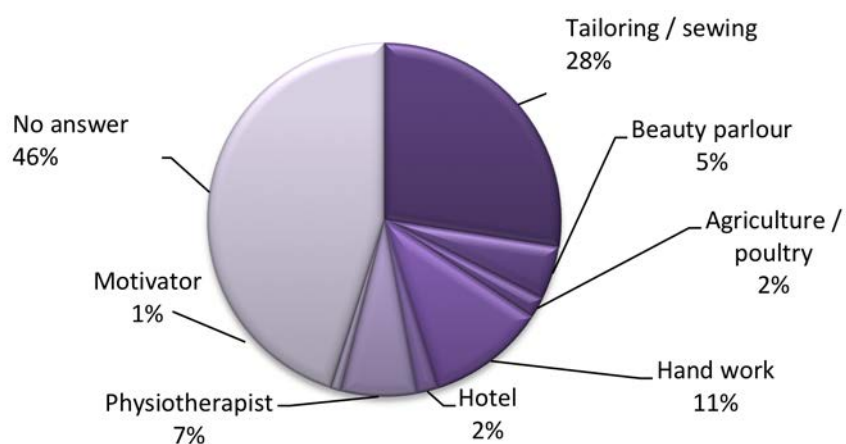
Some carers were not able to earn at all and some appeared to be earning below their capacity. 82% of them were being financially supported by family members. This represents personal and family financial losses. In addition, carers were missing out on other benefits of work such as socialisation, respite from caring and possible occupational satisfaction.

From a government economic perspective the would-be contributions of carers are lost from the Gross Domestic Product, especially those of the potential higher earners; for example 0.6% in Australia in 2005 or at least 1.73% in Spain in 2008. But balancing the overall costs and benefits of releasing carers' hours to the labour market by, for example, providing either domiciliary and/or residential care is complex. (Carers Australia, 2005; Oliva-Moreno, Peña-Longobardo, Vilaplana-Prieto, 2015).

Skills carers are interested in for possible alternative work

Skill of the carer		
	Number	%
Tailoring / sewing	95	28
Beauty parlour	15	5
Agriculture / poultry	7	2
Hand work (candle, soap, doll, chips, pickle, mat etc)	35	11
Hotel	6	2
Physiotherapist	22	7
Motivator	1	1
No answer	152	46

Alternative skills carers are interested in

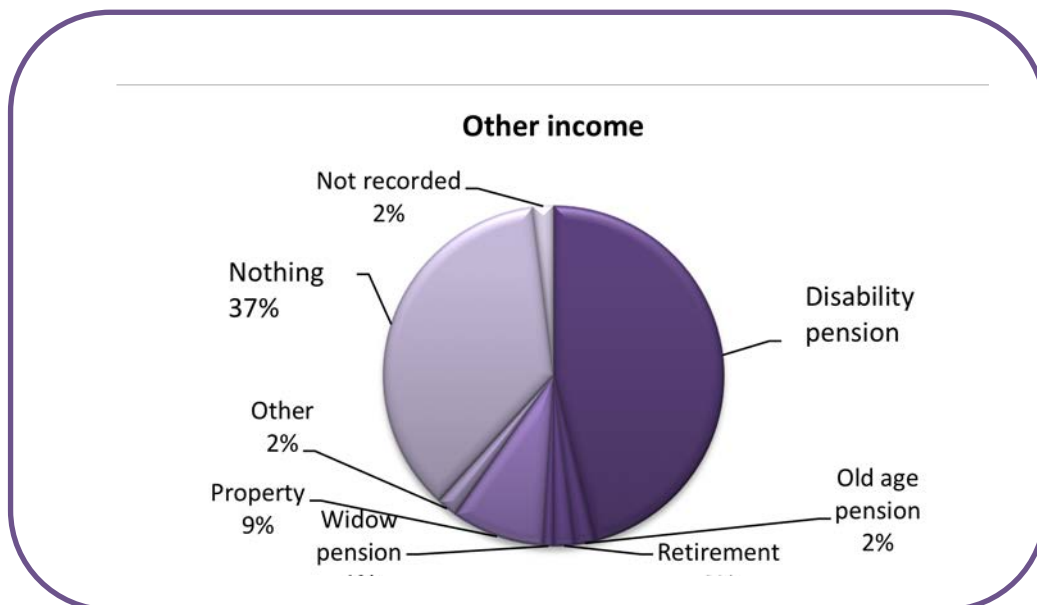


Carers were asked whether there was a particular skill they felt could help them take up a livelihood activity, or whether there was any training they were interested to undertake.

45% did not answer. 27% mentioned tailoring or sewing, 5% beauty parlour work, 2% agriculture, 11% hand work (such as making candles, soap, dolls, chips, pickle, mats or similar), 2% mentioned hotel work, 7% were interested in physiotherapy and 1% said motivator.

Other income within the households

Other income		
	Number	%
Disability pension	158	47
Old age pension	5	2
Retirement pension	5	2
Widow pension	1	1
Income through property	30	9
Other income	7	2
Nothing	123	37
Not recorded	5	2



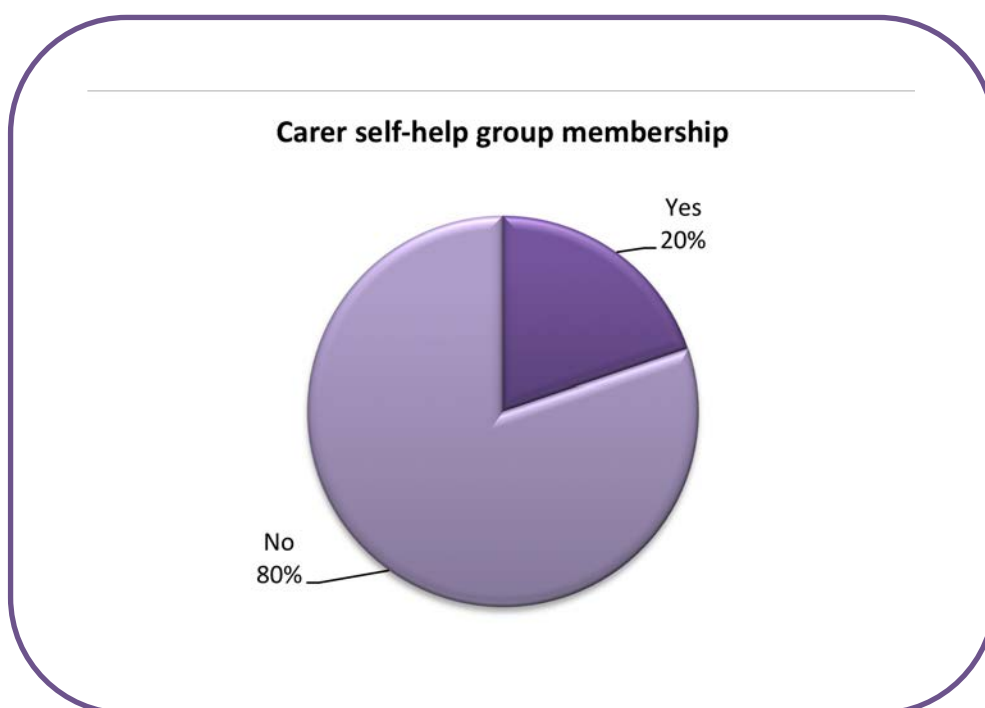
Carers were asked whether there was any other income source for the household.

36% said they had no other source of income and 2% did not record answers. 46% said there was a disability pension, 2% an old age pension, 2% a retirement pension and 1% a widow's pension. 9% were receiving income from property and 2% from other sources.

Just under half of the households were receiving disability pensions and 36% had no other income. It is possible that some households may be missing out on entitlements. The literature tells us that sometimes carers are unaware of their entitlements. (Sen & Goldbart, 2005; Kuppusamy, Narayan & Nair, 2012). This group's need for financial support emerges from later questions in the survey.

Carers as members of self-help groups

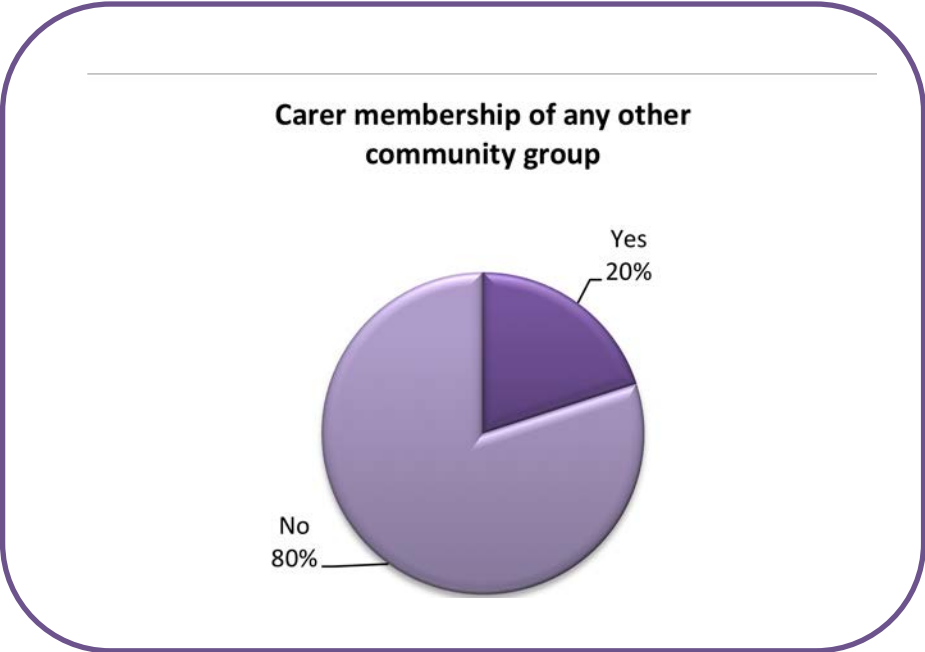
Carer self-help group membership		
	Number	%
Yes	65	20
No	269	81



Carers were asked whether they were members of any community self-help group. 20% said that they were and 80% said they were not.

Carers as members of other community groups

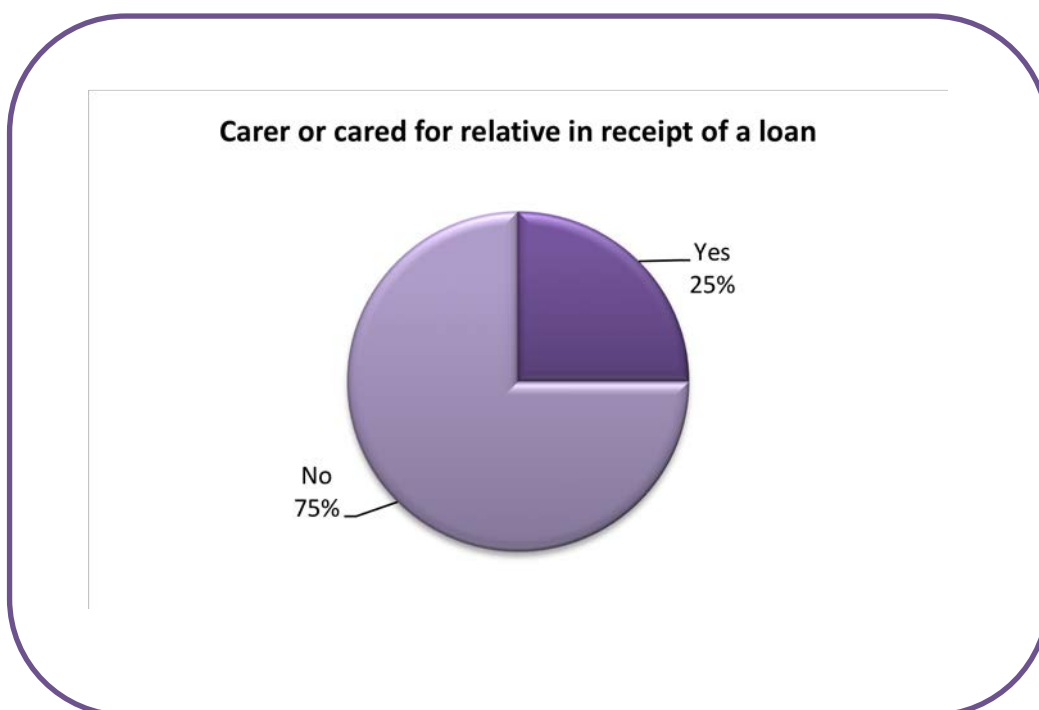
Carer is a member of any other community group		
	Number	%
Yes	67	20
No	266	80



Carers were asked whether they were members of any other community group. 20% said that they were and 80% said that they were not.

Whether the carer or the person they are looking after is in receipt of any loan or grant

In receipt of a loan		
	Number	%
Yes	83	25
No	251	75



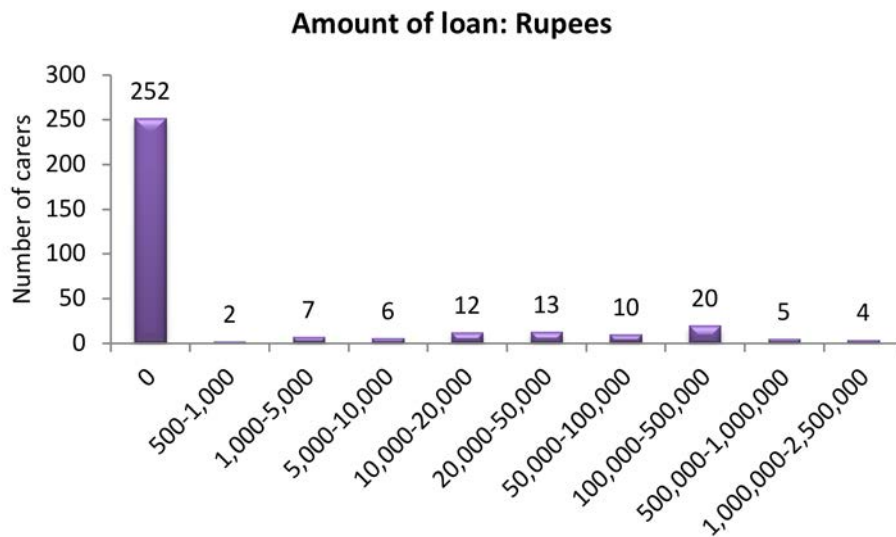
Carers were asked whether they, or the person they are looking after, were in receipt of a loan or grant. 25% said they were and 75% said they were not.

The amount of the loan

Amount of the loan Rupees	
	Number
0	252
500-1,000	2
1,000-5,000	7
5,000-10,000	6
10,000-20,000	12
20,000-50,000	13
50,000-100,000	10
100,000-500,000	20
500,000-1,000,000	5
1,000,000-2,500,000	4

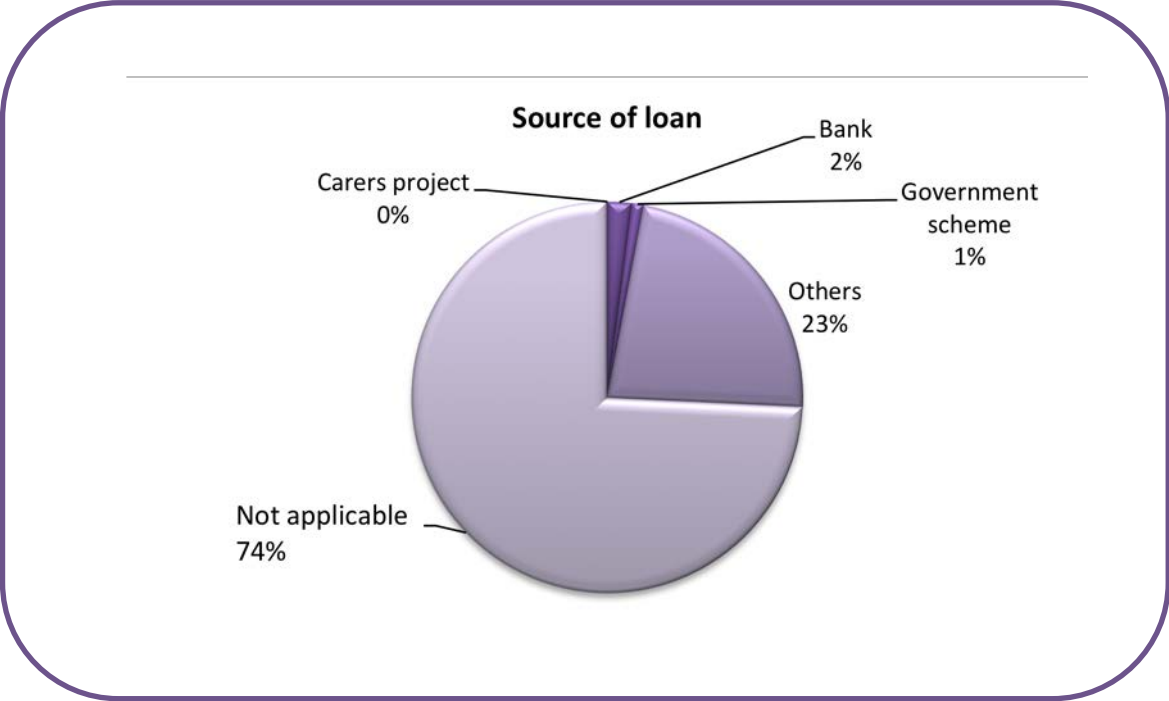
252 (75%) of carers were not receiving a loan for themselves or their looked after relative.

13 loans were between 1,000 and 10,000 Rupees. 55 of the loans were between 10,000 and 500,000 Rupees and 9 of the loans were between 500,000 and 2,500,000 Rupees.



The source of the loans

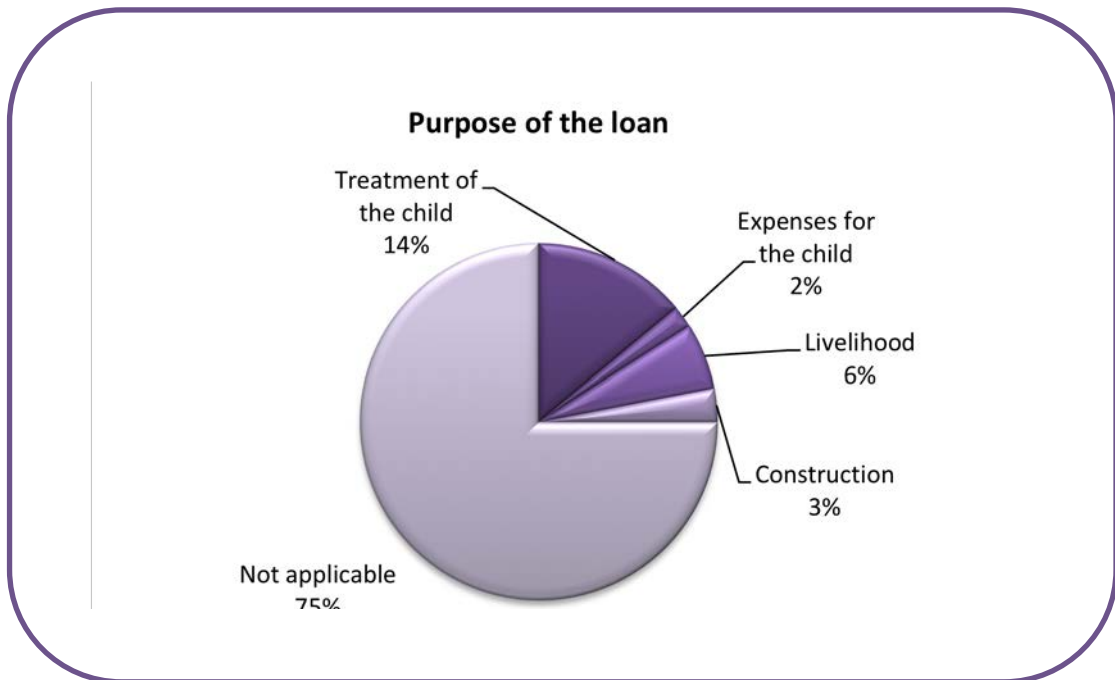
Source of loan		
	Number	%
Carers project	0	0
Bank	6	2
Government scheme	1	1
Others	76	23
Not applicable	251	75



2% of the loans come from the bank, 1% from government schemes, 23% from other sources. No loans came from carers' projects.

What the loan is for

Purpose of loan		
	Number	%
Treatment of the child	46	14
Expenses for the child	7	2
Livelihood	21	6
Construction	9	3
Not applicable	250	75



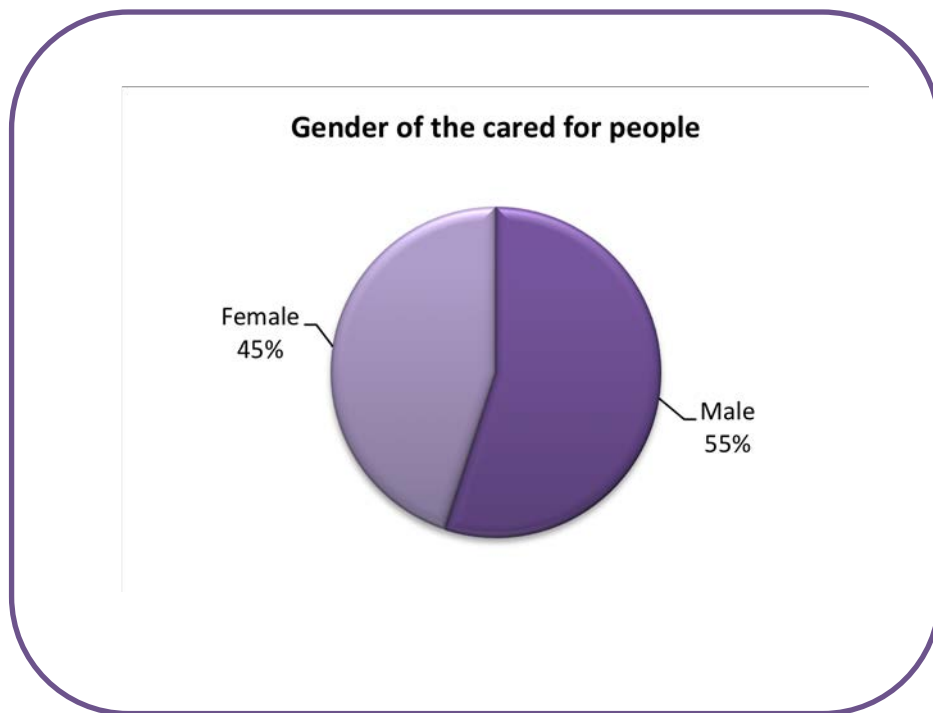
14% of carers were using loans for treatment for their looked after child and 2% for other expenses associated with the child. 6% were using the loan to assist with their livelihoods and 3% towards construction projects.

16% of the loans were directly for the cared for person. No loans came from carers' projects (but the Carers Worldwide / SGCP project had not started this aspect of its activities at the time of baseline data collection).

Profile of the cared for people

Gender of the cared for people

Gender of the cared for person		
	Number	%
Male	183	55
Female	151	45



55% of the cared for people were male and 45% female.

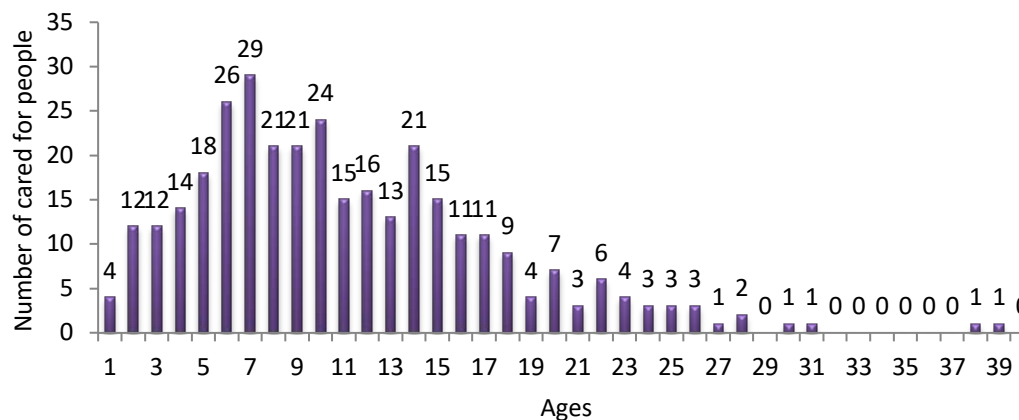
Ages of the cared for people

Cared for person age			
Age in years	Number of people	Age in years	Number of people
1	4	21	3
2	12	22	6
3	12	23	4
4	14	24	3
5	18	25	3
6	26	26	3
7	29	27	1
8	21	28	2
9	21	29	0
10	24	30	1
11	15	31	1
12	16	32	0
13	13	33	0
14	21	34	0
15	15	35	0
16	11	36	0
17	11	37	0
18	9	38	1
19	4	39	1
20	7	40	0

The cared for people ranged in age from 1 year to 39 years.

4 (1%) were around 1 year old
 38 (11%) were 1 -4
 115 (34%) were 5 - 9
 139 (42%) were 10-19
 32 (10%) were 20-29
 4 (1%) were 30 or over

Ages of the cared for people



Conditions the cared for people have

122 (37%) of the cared for people had been diagnosed as having cerebral palsy. It is likely that others described in the survey as “spastic tetraplegic, hemiplegic” or similar also had cerebral palsy. 11 (3%) had been described as having microcephaly, 4 (1%) with autism and 13 (4%) with Down’s syndrome. Others were described as having difficulties with movement or speech or learning difficulties. It appears that all, or almost all, had neurological conditions, most of which will have stemmed from the time of birth or early childhood. In only a few cases is the severity of the condition described.

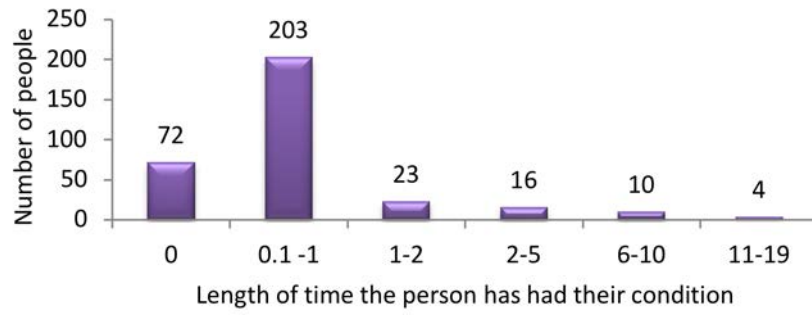
How long they have had their condition

How long the cared for person has had this condition	
Number of years	Number of people
0	72
0.1 -1	203
1-2	23
2-5	16
6-10	10
11-19	4

Most of the conditions diagnosed or described will have stemmed from birth or early childhood. Therefore one would expect the profile of the length of time people had had their condition to be not too dissimilar to the age profile of the group. Yet the lengths of time carers ascribed their relatives to having had their conditions were by-and-large significantly below their ages.

This may be something to do with the way the question was asked. Sometimes it takes a while before neurological disabilities become clearly evident, but it is difficult to see how this would account for such a marked difference.

The number of years each cared for person had had their condition



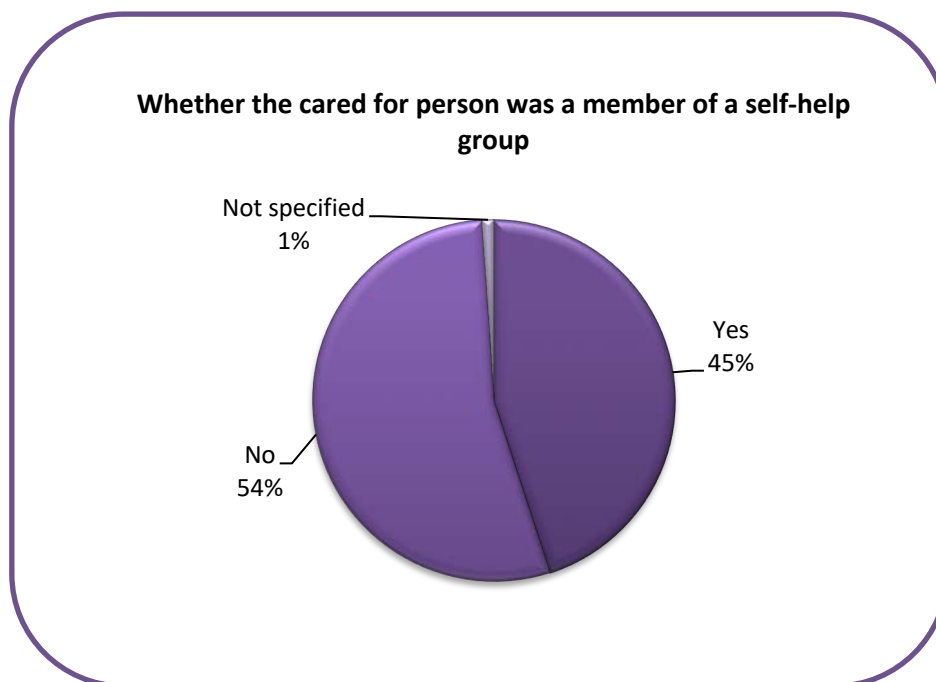
Employment of the cared for people

Only one of the 344 cared for people was in employment, working in a shop. (Their income was not specified).

If working age is taken to be 17 years and upwards then there were 50 people in this group of working age, of whom only 1 was working. The overall level of disability in this group would be high (those with mild disabilities do not attend SGCP) and in addition there is a lack of resources to help them into work.

Membership of self-help groups by the cared for people

Whether the cared for person is a member of a self-help group		
	Number	%
Yes	149	45
No	180	54
Not specified	4	1



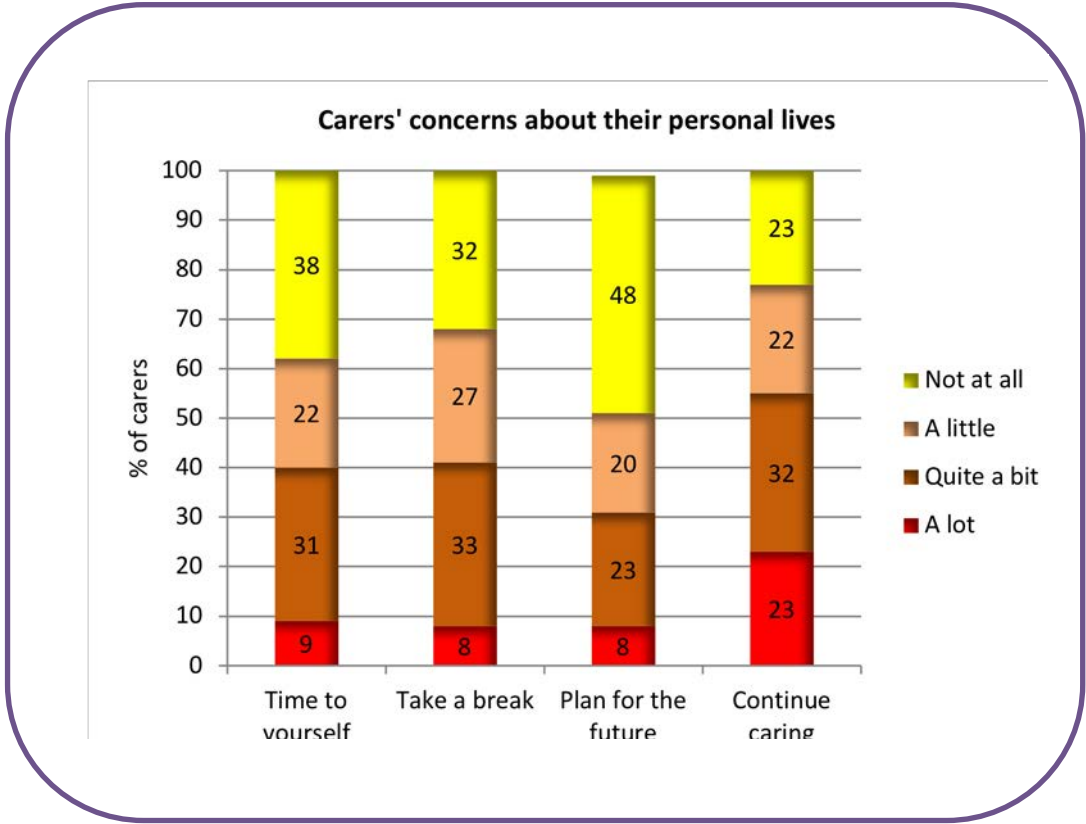
45% of the cared for people were members of a self-help group and 54% were not.

This seems high, given that most of the cared-for are children. It may be that the parents were counting their membership of SGCP as their children's membership of a self-help group.

Carer wellbeing

Carers' concerns about their personal lives

Carers' concerns about their personal life			
		Number	%
How concerned are you about: Having enough time to yourself?	A lot	29	9
	Quite a bit	103	31
	A little	74	22
	Not at all	128	38
Being able to take a break from caring?	A lot	27	8
	Quite a bit	111	33
	A little	90	27
	Not at all	106	32
Being able to plan for the future?	A lot	28	8
	Quite a bit	77	23
	A little	68	20
	Not at all	161	48
Being able to continue caring?	A lot	77	23
	Quite a bit	108	32
	A little	74	22
	Not at all	75	23



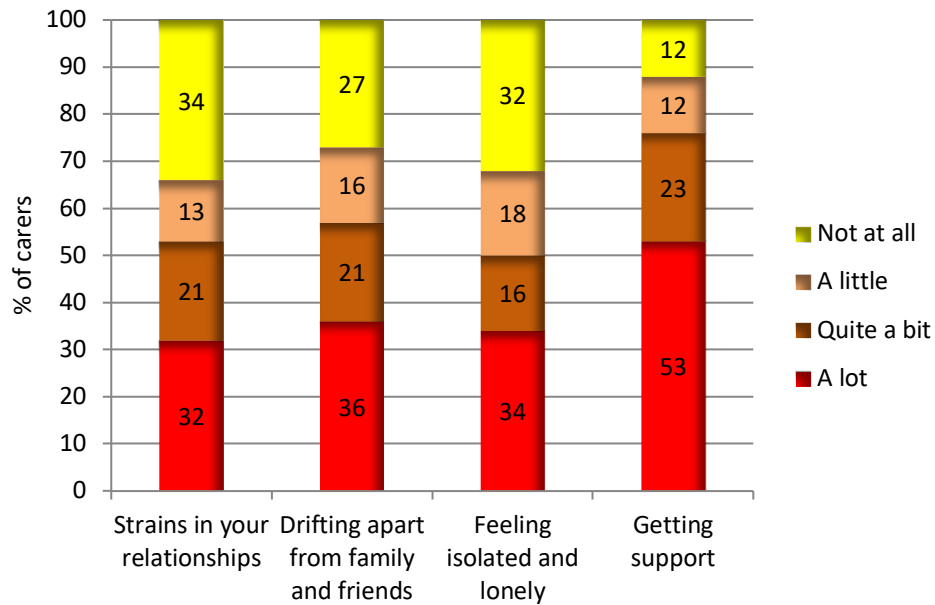
Taking “a lot” and “quite a bit” together 55% of the carers in this category were concerned about being able to continue with their caring role into the future. Fewer, but still 31%, were worried about being able to plan for the future. 40% of carers were struggling at least quite a bit to get time for themselves and 41% were struggling to be able to take a break, with 9% and 8% respectively finding it very difficult to find time for themselves or take a break.

The issue of being able to put something in place for the future is a critical one. What will happen to those individuals being cared for if they no longer have the support of their primary carer?

Carers' concerns about their relationships

Carers' concerns about their relationships			
		Number	%
How concerned are you about: Strains in your relationships with friends and family because of your caring responsibilities?	A lot	108	32
	Quite a bit	70	21
	A little	44	13
	Not at all	112	34
"Drifting apart" from friends and family because your caring responsibilities limit the time you have to keep in contact with them?	A lot	121	36
	Quite a bit	70	21
	A little	54	16
	Not at all	89	27
Feeling isolated and lonely because of the situation you are in?	A lot	114	34
	Quite a bit	53	16
	A little	59	18
	Not at all	108	32
Getting the support you need from family and friends?	A lot	176	53
	Quite a bit	77	23
	A little	41	12
	Not at all	40	12

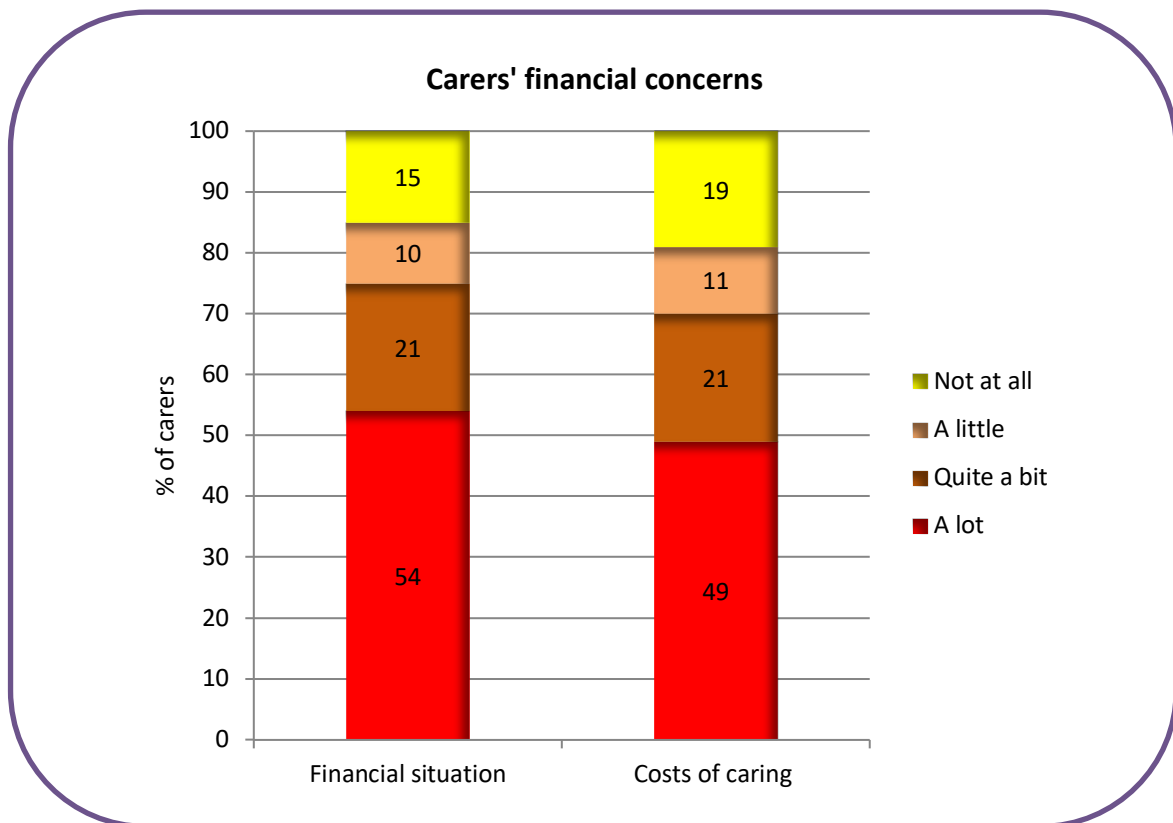
Carers' concerns about their relationships



In terms of their relationships the carers' greatest concern was getting support from family and friends (76% combining concerned a lot and quite a bit). At least half the carers were also concerned (a lot or quite a bit) about the other aspects of their relationships, strains in their relationships with family and friends, drifting apart from family and friends and feeling isolated and lonely as a result of their caring responsibilities.

Carers' concerns about their financial situation

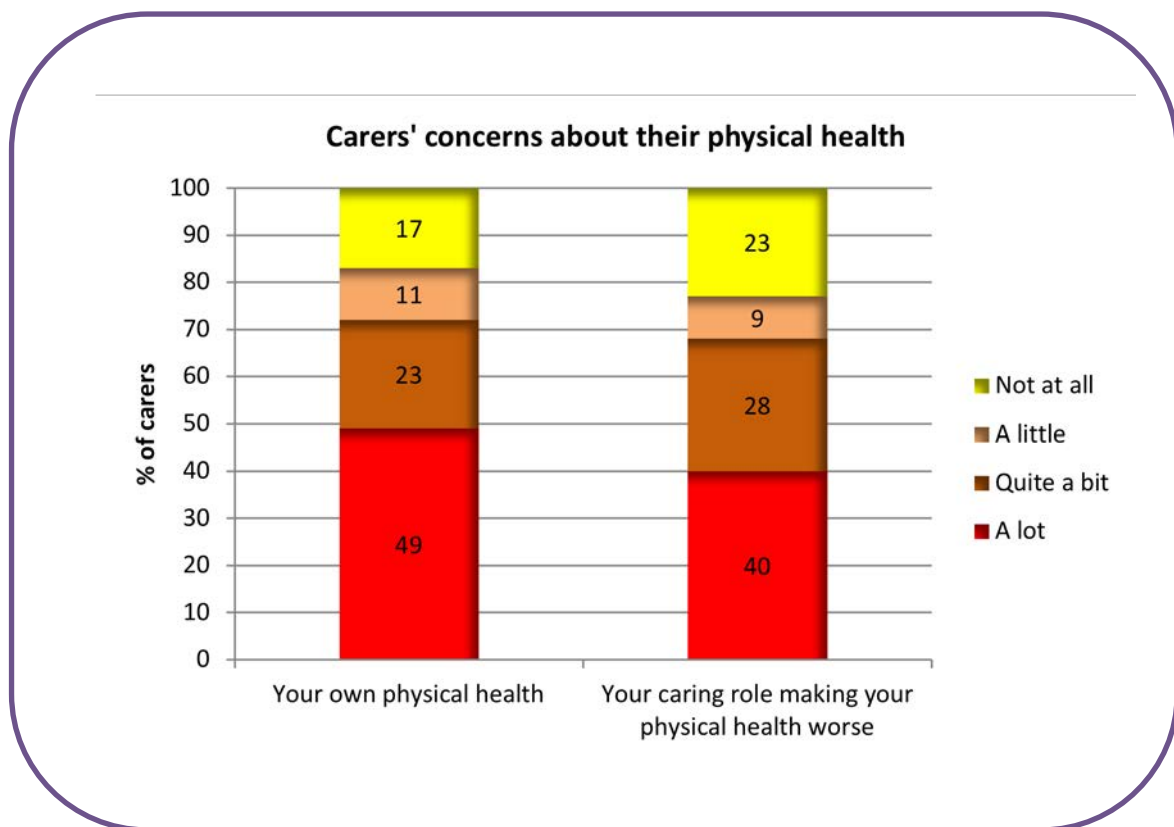
Carers' concerns about their finances			
		Number	%
How concerned are you about: Your financial situation?	A lot	180	54
	Quite a bit	69	21
	A little	34	10
	Not at all	51	15
Having to cover extra costs of caring (eg. trips to hospital, medication)?	A lot	162	49
	Quite a bit	70	21
	A little	38	11
	Not at all	64	19



Finances were causing the carers significant concern. 75% were concerned a lot or quite a bit about their overall financial situation. When the costs of the caring are separated out they emerge as significant, with 70% of carers worried a lot or quite a bit about them.

Carers' concerns about their physical health

Carers' concerns about their physical health			
		Number	%
How concerned are you about: Your own physical health?	A lot	165	49
	Quite a bit	78	23
	A little	36	11
	Not at all	55	17
Your caring role making your physical health worse?	A lot	135	40
	Quite a bit	93	28
	A little	30	9
	Not at all	76	23

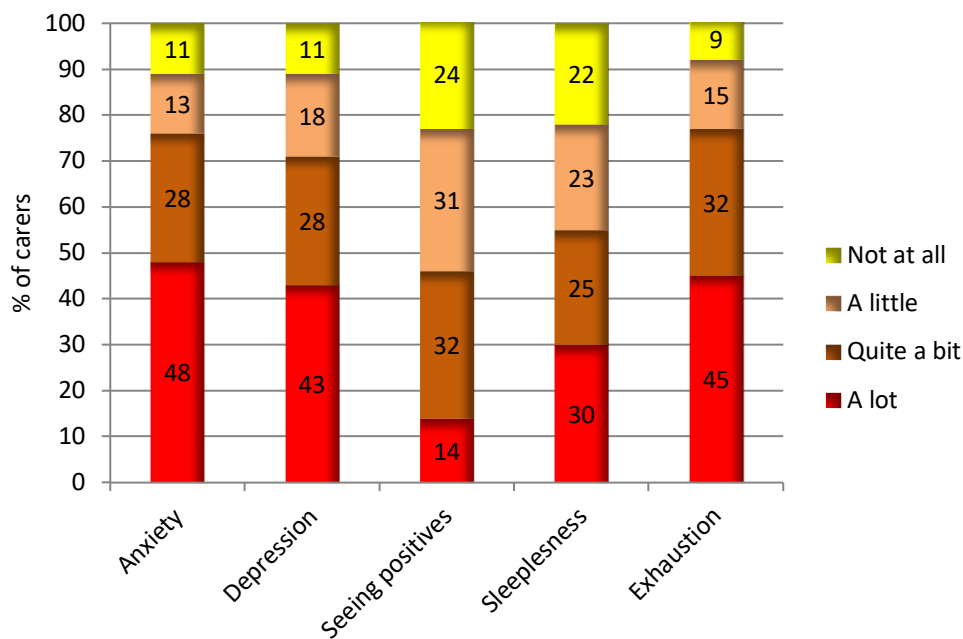


72% of carers were worried a lot or quite a bit about their physical health, with 68% of them feeling that their caring role was impacting upon their physical health.

Carers' concerns about their mental health

Carers' concerns about their mental health			
		Number	%
How concerned are you about: Being able to cope with the "constant anxiety" of caring?	A lot	159	48
	Quite a bit	93	28
	A little	44	13
	Not at all	38	11
Feeling depressed?	A lot	145	43
	Quite a bit	93	28
	A little	61	18
	Not at all	35	11
Being able to see anything positive in your life?	A lot	45	14
	Quite a bit	106	32
	A little	102	31
	Not at all	81	24
Lack of sleep because of worry or stress?	A lot	99	30
	Quite a bit	84	25
	A little	77	23
	Not at all	73	22
Feeling so exhausted you cannot function properly?	A lot	149	45
	Quite a bit	106	32
	A little	49	15
	Not at all	29	9

Carers' concerns about their mental health



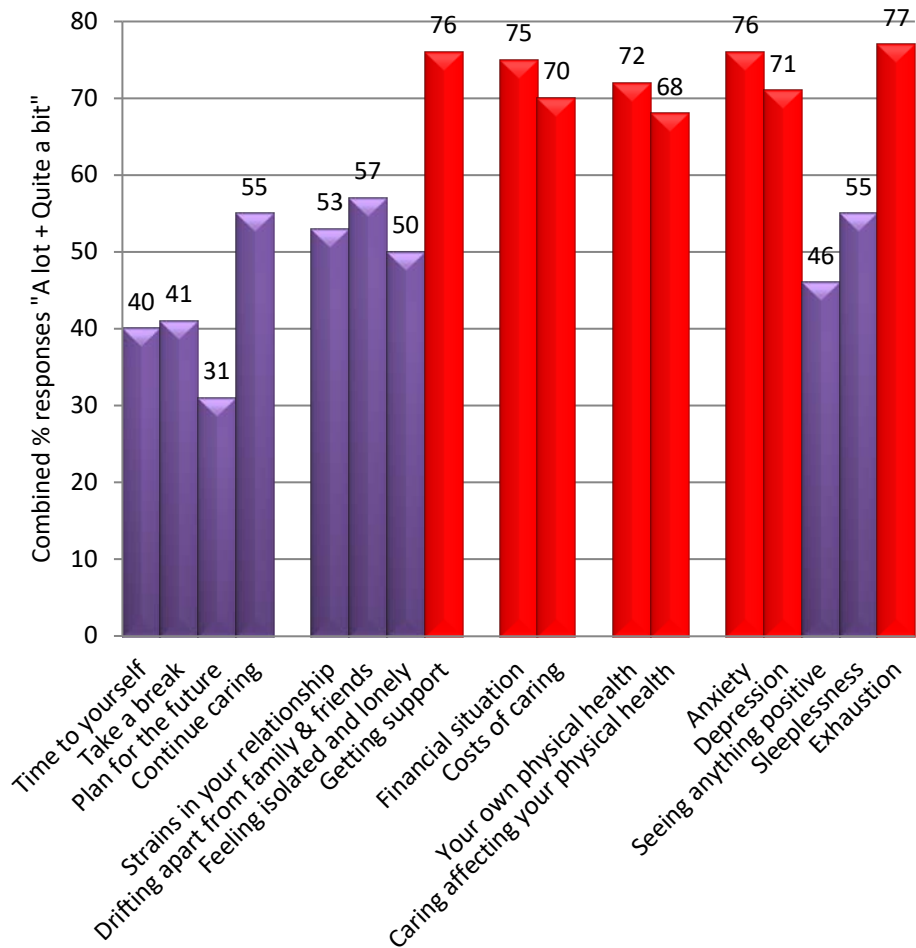
With respect to their mental health 76% of carers were concerned a lot or quite a bit about feeling anxiety. Their other most significant concern was exhaustion (77% concerned a lot or quite a bit). 71% were struggling a lot or quite a bit with depression. Just under half, 46%, were struggling a lot or quite a bit to see positives in their lives. 55% were experiencing chronic lack of sleep.

Summary of carers' wellbeing

Carers' overall wellbeing	
Carers concerns about:	Combined % of concerned a lot or quite bit
Time to yourself	40
Take a break	41
Plan for the future	31
Continue caring	55
Strains in your relationship	53
Drifting apart from family & friends	57
Feeling isolated and lonely	50
Getting support	76
Financial situation	75
Costs of caring	70
Your own physical health	72
Your caring role making your physical health worse	68
Anxiety	76
Depression	71
Seeing anything positive	46
Sleeplessness	55
Exhaustion	77

Carers' overall wellbeing

(Combining carer responses of concerned "A lot + Quite a bit" in all five welfare domains)

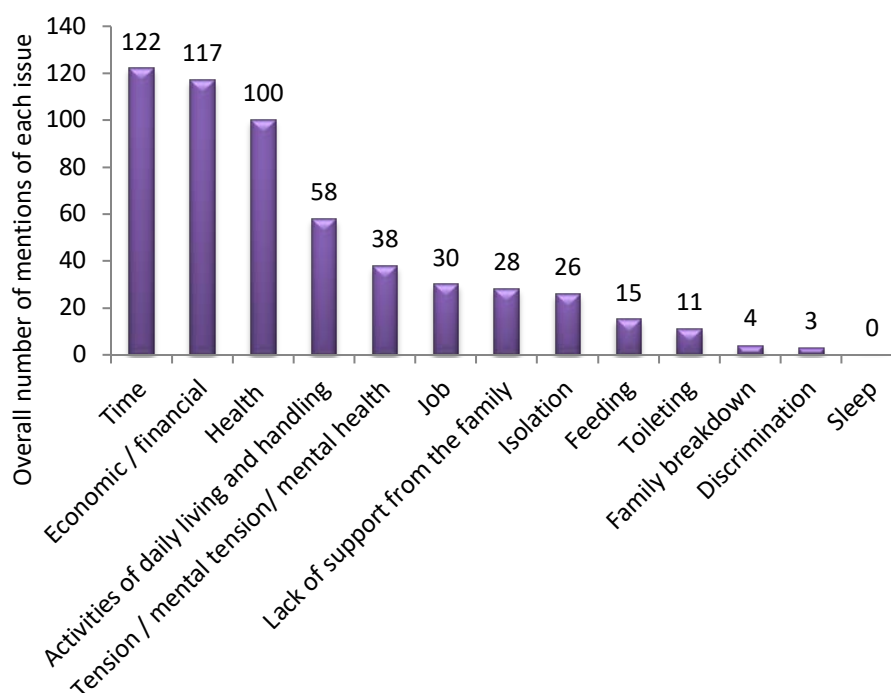


Adding the number of carers who were concerned a lot or quite a bit about each welfare factor shows that getting the support they feel they needed from family and friends, their financial situation, physical health, anxiety, depression and exhaustion were the issues of most concern.

Carers' thoughts regarding what the most pressing issues were for them and their suggestions regarding what they felt would help them.

Each carer was asked to list the three issues or needs which presented them with the most difficulty in relation to their caring role and to explain how they affected their life and the lives of their family. They were also asked for ideas and suggestions which might relieve their difficulties.

Carers' list of the issues and needs which present them with the most problems in their caring role



The three most pressing issues carers identified were time (122 mentions), financial (117) and their health (100). If handling, toileting and feeding are combined with activities of daily living they constitute another major group (of 84 mentions). If financial and job are combined they make 147 mentions and become the most significant single factor, but it may be that some carers would like a job for other reasons such as to have a break or for the

socialisation work offers. One mention was for a job for the cared for relative; it is likely that other mentions referred to carers' thoughts of working themselves. Nonetheless it seems clear that for this group of carers time, finances, their health and managing their children's condition were the most pressing issues. This appears to correlate broadly with participants' answers to their wellbeing questions in which they identified financial concerns, their physical and mental health and getting support as of, in general, more concern than their social situation or other aspects of social relationships. Asking carers to freely identify their most pressing issues brought out their need for support with time management and activities of daily living, which would not have come out from the wellbeing questions.

With respect to time, most just mentioned time management but some identified this as being time for themselves, for gainful employment, to help the child with disability or to spend with the siblings or other family members. One mentioned having time for other activities in order to alleviate depression. Carers who mentioned economics and finances, apart from one who mentioned high treatment costs, did not explain further what the economic pressures were.

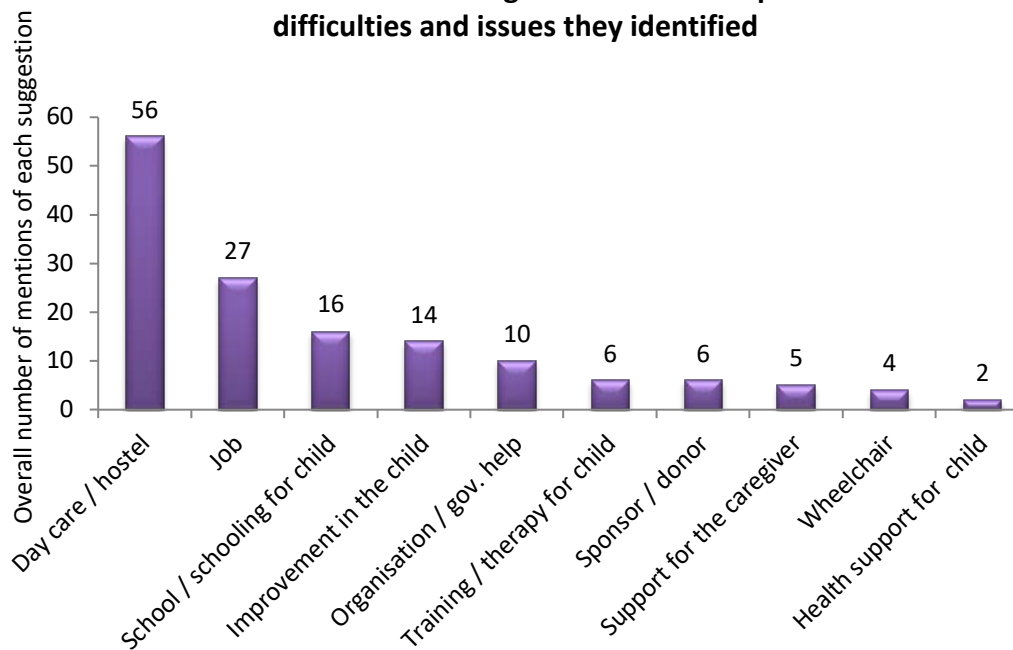
Regarding health, most respondents simply mentioned health, not specifying whether they were referring to the physical or emotional demands of caring impacting on their health and/or whether they did not have the time, financial resources or freedom to go out and seek help for their own health. Those who mentioned tension and mental health by and large did not expand upon this but a few mentioned tension about their child's future or health and a couple mentioned depression. Nobody identified exhaustion as a pressing issue, yet 77% of them identified it in the wellbeing questions as a matter of a lot of concern or quite a bit of concern.

It is very possible that with skills training in managing activities of daily living for their children's disabilities some carers would find a level of contingent reduction in the time taken by their caring role. It might also ease tensions. In, for example, two studies, by Adams et al. (2011) and IECD (2017), advice on feeding techniques markedly reduced the tensions of mealtimes, (which with cerebral palsy can be one of the more distressing activities for carers and children alike).

Lack of family support, isolation, family breakdown and discrimination attributed by the carers as consequences of having the cared for children within the household (41 mentions when combined) create a picture of carers feeling unsupported and possibly family struggling around the extra needs of the cared for children.

It is interesting to note that nobody mentioned lack of sleep or the children's behaviour. When asked specifically about sleeplessness in the welfare questions 55% of participants said they were concerned a lot or quite a bit about it and the literature indicates disturbed sleep to be a very significant factor in carer wellbeing (Mobarak et al, 2000; Wayte et al., 2012; Adiga et al, 2014; Thrush & Hyder, 2014). All studies Pousada et al.'s literature review (2013) which addressed the children's behaviour found an association between disturbed behaviour and carer stress, though the directionality of the relationship was not established. It may be that these were among the factors cares had in mind when mentioning tension.

Carers' list of ideas of the things which would help relieve the difficulties and issues they identified



With respect to carers' suggestions of what would help them most, the stand-out feature was for day care and/or a hostel. One may speculate that this perhaps relates to the most significant identified pressing issues which were time management and financial worries (probably being free to work). The second highest wish was for a job, which is consistent with carers' comments about the issues which concern them most. The need for schooling for the child did not come out of the carer welfare questions or feature among the pressing issues.

As with carers identifying time management and the need for assistance with daily living when asked about pressing issues, asking questions in a different way has brought out different factors of significance for the carers.

It is hard to see with most of the carers' wishes how they might achieve them without outside help. Their needs span across the community, health, education and social welfare sectors.

References

- Adams, M., Khan, N., Begum, S., Wirz, S., Hesketh, T., Pring, T., 2011.** Feeding difficulties in children with cerebral palsy: low-cost caregiver training in Dhaka, Bangladesh. *Child: Care, Health and Development*, 38(6), pp.878-888.
- Adiga, D., Gupta, A., Khanna, M., Taly, A., Thennarasu, K., 2014.** Sleep disorders in children with cerebral palsy and its correlation with sleep disturbance in primary caregivers and other associated factors. *Annals of Indian Academy of Neurology*, 17(4), pp.473-476.
- Angothu, H., Chaturvedi, S., 2016.** Civic and legal advances in the rights of caregivers for persons with severe mental illness related disability. *Indian Journal of Social Psychiatry*, 32, pp.28-34.
- Burkhard, A., 2013.** A different life: caring for an adolescent or young adult with severe cerebral palsy. *Journal of Paediatric Nursing*, 28, pp.357-363.
- Carers Australia, 2005.** *The economic value of informal care*. Carers Australia.
- Chadda, R., 2014.** Caring for the family caregivers of persons with mental illness. *Indian Journal of Psychiatry*, 56(3), pp.221-227.
- CHS Alliance, Groupe URD & Sphere Project, 2014.** *Core Humanitarian Standard*. CHS Alliance, Groupe URD & Sphere Project. Available at <https://corehumanitarianstandard.org/files/files/Core%20Humanitarian%20Standard%20-%20English.pdf> [Accessed 13th July, 2017]
- Cordier, S., 2014.** Caring for people with intellectual disabilities in poor rural communities in Cambodia: experience from ADD International. *Gender and Development*. 22(3) pp.549-561.
- Ganjiwale, D., Ganjiwale, J., Sharma, B., Mishra, B., 2016.** Quality of life and coping strategies of caregivers of children with physical and mental disabilities. *Journal of Family Medicine and Primary Care*, 5(2), pp.343-348.
- Gathwala, G., Gupta, S., 2004.** Family burden in mentally handicapped children. *Indian Journal of Community Medicine*, 29(4), pp.188-189
- Institute of Development studies, 2016.** *The global importance of including mental health carers in policy*. Brighton: Institute of Development Studies.
- (ICED) International Centre for Evidence in Disability, 2017 probable year.** *Evaluating the impact of a community-based parent training programme for children with cerebral palsy in Ghana*. International Centre for Evidence in Disability, London School of Hygiene and Tropical Medicine. Available at <http://disabilitycentre.lshtm.ac.uk/files/2014/07/Ghanacountry-reportfinal.pdf> [Accessed 17th May, 2017].
- Janardhana, N., Raghunandan, S., Naidu, D., Seshn, V., 2015.** Care giving for people with severe mental illness : An Indian experience. *Indian Journal of Psychological Medicine*, 37(2), pp.184-194.
- Kuppusamy, B., Narayan, J., & Nair, D., 2012.** Awareness among family members of children with intellectual disability on relevant legislations in India. *Disability, CBR and Inclusive Development*, 23(1), pp.92-99.

(LSHTM) London School of Hygiene and Tropical Medicine. *Getting to know cerebral palsy. Working with parent groups – a training resource for facilitators, parents, caregivers, and persons with cerebral palsy.* London: London School of Hygiene and Tropical Medicine. Available at <http://disabilitycentre.lshtm.ac.uk/files/2013/06/Getting-to-know-cerebral-palsy-v1-lowres.pdf> [Accessed 17th May, 2017]

Maloni, P., Despres E., Habbous, J., Primmer, A., Slatten, J., Gibson, B., Landry M., 2010. Perceptions of disability among mothers of children with disability in Bangladesh: Implications for rehabilitation service delivery. *Disability and Rehabilitation*, 32(10), pp.845-854.

Manigandan, C., Saravanan, B., Macaden, A., Gopalan, L., Tharion, G., Bhattacharji, S., 2000. Psychological wellbeing among carers of people with spinal cord injury: a preliminary investigation from South India. *Spinal Cord*, 38, pp. 559-562.

Mirza, I., Tareen, A., Davidson, L.L., Rahman, A., 2009. Community management of intellectual disabilities in Pakistan: a mixed methods study. *Journal of Intellectual Disability Research*, 53 (6), pp. 559-570.

Mobarak, R., Khan, N., Munir, S., Zaman, S., McConachie, H., 2000. Predictors of stress in mothers of children with cerebral palsy in Bangladesh. *Journal of Paediatric Psychology*, 25(6), pp.427-433.

(NINDS) National Institute of Neurological Disorders and Stroke.

<https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Hope-Through-Research/Cerebral-Palsy-Hope-Through-Research> [Accessed 15th June,2017] – need to import

Navalkar, P., 2004. Fathers' perception of their role in parenting a child with cerebral palsy: implications for counselling. *International Journal for the Advancement of Counselling*, 26(4), pp.375- 382.

Nguyen, S., Pertini, M., Kettler, L., 2015. Parental cognitive appraisals and coping behaviours following child's epilepsy diagnosis: A qualitative study. *Clinical Child Psychology and Psychiatry*. (20)1, pp.20-38.

Oliva-Moreno, J., Peña-Longobardo, L., Vilaplana-Prieto, C., 2015. An estimation of the value of informal care provided to dependent people in Spain. *Applied Health Economics and Health Policy*, 2015(2), pp.223-231.

Palit, A., Chatterjee, A., 2006. Parent-to-parent counselling – a gateway for developing positive mental health for the parents of children that have cerebral palsy with multiple disabilities. *International Journal of Rehabilitation Research*, 29(4), pp.281-288.

Patil, A., 2012. *Report on consultation on the needs of carers in India and South Africa.* Carers Worldwide. Available at <http://www.carersworldwide.org/wp-content/uploads/2016/03/Carers-Worldwide-Consultation-Report-for-publications-page.pdf>[Accessed 18th May, 2017].

Pousada, M., Guillamón, N., Hernández-Encuentra, E., Munoz, E., Redolar, D., Boixados, M., Gómez-Zúñiga, B., 2013. Impact of caring for a child with cerebral palsy on the quality of life of parents: A systematic review of the literature. *Journal of Developmental and Physical Disabilities*, 25, pp.545-577.

Raina, P., O'Donnell, M., Rosenbaum, P., Brehaut, J., Walter, S., Russell, D., Swinton, M., Zhu, B., Wood, E., 2005. The health and well-being of caregivers of children with cerebral palsy. *Paediatrics*, 115(6), pp.e626-636.

Rammohan, A., Rao, K., Subbakrishna, D., 2002. Religious coping and psychological wellbeing in carers of relatives with schizophrenia. *Acta Psychiatrica Scandinavica*, 105, pp.356-362.

Ribeiro, M., Vandenberghe, L., Prudente, C., da Silva Carvalho Vila, V., Porto, C., 2016. Cerebral palsy: how the child's age and severity of impairment affect the mother's stress and coping strategies. *Ciencia and Saude Coletiva*, 21(10), pp.3203-3212.

Sahoo, R., Saur, D., 2009. Do young carers deserve justice? Young caring in the context of illness. *Psychology and Developing Societies*, 21 (1), pp.133-150.

Scope <https://www.scope.org.uk/support/families/diagnosis/cerebral-palsy>
<http://www.nhs.uk/conditions/Cerebral-palsy/Pages/Introduction.aspx#symptoms>
[Accessed 15th June,2017]

Semrau, M., Lempp, H., Keynejad, R., Evans-Lacko, S., Mugisha, J., Raja, S., Lamichhane, J., Alem, A., Thornicroft G., Hanlon, C., 2016. Service user and caregiver involvement in mental health system strengthening in low- and middle-income countries: systematic review. *BMC Health Services Research*, 16 (79).

Sen, R., Goldbart, J., 2005. Partnership in action: introducing family-based intervention for children with disability in urban slums of Kolkata, India. *International Journal of Disability, Development and Education*. 52(4), pp.275-311.

Singh, N., Sharma, V., Singh, R., 2015. Caregiving burden and hope among caregivers of patients with epilepsy. *Indian Journal of Positive Psychology*, 6(3), pp.299-302.

Sinha, A., Sharma, R., 2017. Factors influencing utilization of physiotherapy service among children with cerebral palsy in Jalandhar district of Punjab. *Journal of Neurosciences in Rural Practice*, 8(2), pp. 209-215.

Skovdal, M., 2011. Examining the trajectories of children providing care for adults in rural Kenya: implications for service delivery. *Children and Youth Services Review*, 33, pp.1262-1269.

Southern Africa HIV/AIDS Information Dissemination Service (SAfAIDS), year not given, *Involving men in community home based care for HIV and AIDS toolkit: information manual*. Southern Africa HIV/AIDS Information Dissemination Service. Available at http://www.jsieurope.org/docs/involving_men_manual.pdf [Accessed 7th July, 2017].

Thapa, R., 2016. Retrospective descriptive study of cerebral palsy in Nepal. *Journal of Autism and Developmental Disorders*, 46, pp.2285-2291. Available at [https://link-springer-com.libproxy.ucl.ac.uk/article/10.1007/s10803-016-2757-x](https://link.springer-com.libproxy.ucl.ac.uk/article/10.1007/s10803-016-2757-x) [Accessed 18th May, 2017].

Thrush, A., Hyder, A., 2014. The neglected burden of caregiving in low- and middle-income countries. *Disability and Health Journal*, 7, pp.262-272.

Wayte, S., McCaughey, E., Holley, S., Annaz, D., Hill, C., 2012. Sleep problems in children with cerebral palsy and their relationship with maternal sleep and depression. *Acta Paediatrica*, 101, pp.618-623.

World Health Organisation (2013) *Mental health action plan, 2013 – 2020* Geneva, World Health Organisation.

Yousafzai, A., Farrukh, Z., Khan, K., 2011. A source of strength and empowerment? An exploration of the influence of disabled children on the lives of their mothers in Karachi, Pakistan. *Disability and Rehabilitation*. 33(12), pp.989-998.

Zuurmond, M., Mahmud, I., Polack, S., Evans, J., 2015. Understanding the lives of caregivers of children with cerebral palsy in rural Bangladesh: use of mixed methods. *Disability, CBR and Inclusive Development*, 26(2), pp.5-21.

Appendix

Baseline data survey instrument



LOTTERY FUNDED

Profile of the carers

Individual Code and Year	(eg. 0001 / 2014)	
Name of Carer		
Gender	Male <input type="checkbox"/>	Female <input type="checkbox"/>
Age		
Marital status		
Type of family	Joint <input type="checkbox"/>	Nuclear <input type="checkbox"/>
Total number of people living in the house	Please give details including adult/child, male/female	
Main person they are caring for	Name	Relationship
	Age	Father Mother Spouse
	Gender	Child
	Condition	
	Since when?	Other
Relationship between husband and wife	Good <input type="checkbox"/> Fair <input type="checkbox"/> Not good <input type="checkbox"/> Other <input type="checkbox"/>	
Relationship between carers and family	Good <input type="checkbox"/> Fair <input type="checkbox"/> Not good <input type="checkbox"/> Other <input type="checkbox"/>	
Relationship between carers and neighbours	Good <input type="checkbox"/> Fair <input type="checkbox"/> Not good <input type="checkbox"/> Other <input type="checkbox"/>	
Do they have an identity card?	Yes <input type="checkbox"/> No <input type="checkbox"/>	
	If yes, which card?	
District of residence	Kathmandu <input type="checkbox"/>	Lalitpur <input type="checkbox"/> Bhaktpur <input type="checkbox"/>
Are they caring for any other family members?	If yes, please give details:	

Eg. another person who is elderly, chronically ill, disabled, etc.	
Household type of living	Permanent <input type="checkbox"/> Temporary <input type="checkbox"/>
Enough space for living	Yes <input type="checkbox"/> No <input type="checkbox"/> OK <input type="checkbox"/>
Postal address inc. village name	
Phone number	
Is the carer currently having any health problem or disability?	Eg. physical problems like back pain or mental health issues like depression or anxiety, etc. Yes <input type="checkbox"/> No <input type="checkbox"/>
If yes, please explain what the problems/disabilities are	Reproductive health <input type="checkbox"/> Body ache <input type="checkbox"/> Diabetes, BP, Thyroid <input type="checkbox"/> Multiple <input type="checkbox"/> Others <input type="checkbox"/> Not applicable <input type="checkbox"/>
If yes, are they receiving any treatment/support?	Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable <input type="checkbox"/>
What treatment and where?	Hospital / health post /clinic <input type="checkbox"/> Traditional healer / home remedy <input type="checkbox"/> Not applicable <input type="checkbox"/>
If they are not receiving treatment for a problem, why not?	Not willing to get treatment <input type="checkbox"/> Did not know about the treatment places <input type="checkbox"/> Treatment places are far away from village <input type="checkbox"/> There was no other carer to look after their relative <input type="checkbox"/> Family has no money to pay for treatment <input type="checkbox"/> Other <input type="text"/>
Education level of carer (Studied up to)	
Present education status of carer	Studying <input type="checkbox"/> Vocational Training <input type="checkbox"/> Not applicable <input type="checkbox"/>
Is the carer earning?	Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable <input type="checkbox"/>
If yes, type of work and amount earned per month?	Type of work <input type="checkbox"/> Day care staff <input type="checkbox"/> Labour work <input type="checkbox"/> Service <input type="checkbox"/> Average Income per month <input type="text"/> Not applicable <input type="checkbox"/>

	Business <input type="checkbox"/> Teacher <input type="checkbox"/> Hand work <input type="checkbox"/> Tailoring / sewing <input type="checkbox"/>		
If the carer is not earning, why not?	Not applicable <input type="checkbox"/> No work available <input type="checkbox"/> No one else to look after the cared for relative <input type="checkbox"/> Unable to work because of the carer's own poor health <input type="checkbox"/> Other <input type="text"/>		
The number of family members working			
Other family members financially supporting the carer	Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable <input type="checkbox"/>		
Is there a particular skill or experience that could help the carer to take up a livelihood activity? Or is there any training they are interested to undertake?	Tailoring / sewing <input type="checkbox"/> Beauty parlour <input type="checkbox"/> Agriculture / poultry <input type="checkbox"/> Hand work (candle, soap, doll, chips, pickle) <input type="checkbox"/> Hotel <input type="checkbox"/> Physiotherapist <input type="checkbox"/> Motivator <input type="checkbox"/> Other <input type="checkbox"/>		
Any other income to the household?	Disability pension <input type="checkbox"/> Old age pension <input type="checkbox"/> Retirement pension <input type="checkbox"/> Widow pension <input type="checkbox"/> Income through property <input type="checkbox"/> Others <input type="checkbox"/> mention Nothing <input type="checkbox"/>		
Is the carer a member of any community Self Help Group (SHG)?	Yes <input type="checkbox"/> No <input type="checkbox"/>		
Is the carer a member of any other community groups?	Yes <input type="checkbox"/> No <input type="checkbox"/> Mention.....		
Was the carer or the person they are looking after given a loan/grant?	Yes <input type="checkbox"/> No <input type="checkbox"/>		
If yes, what is the amount?	Amount Not applicable <input type="checkbox"/>		
Source of loan	Carers Project <input type="checkbox"/> Bank <input type="checkbox"/> Government scheme <input type="checkbox"/> Others <input type="checkbox"/> mention..... Not applicable <input type="checkbox"/>		

What the loan is for	Treatment of the child	<input type="checkbox"/>
	Expenses of the child	<input type="checkbox"/>
	Livelihood	<input type="checkbox"/>
	Construction	<input type="checkbox"/>
	Not applicable	<input type="checkbox"/>

Profile of the cared for people

Gender	Male <input type="checkbox"/>	Female <input type="checkbox"/>
Age		
Conditions the cared for person has		
How long they have had the condition		
Whether earning	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Type of work	Shop <input type="checkbox"/>	Not applicable <input type="checkbox"/>
Income per month		
Membership of a self-help group	Yes <input type="checkbox"/>	No <input type="checkbox"/>

Carer wellbeing

How concerned are you about:	A lot	Quite a bit	A little	Not at all
- not having enough time to yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- not being able to take a break from caring?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- not being able to plan for the future?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- not being able to continue caring (eg. because you are ill yourself)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How concerned are you about:	A lot	Quite a bit	A little	Not at all
- strains in your relationships with friends and family because of your caring responsibilities?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- "drifting apart" from friends and family because your caring responsibilities limit the time you have to keep in contact with them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- feeling isolated and lonely because of the situation you are in?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- not getting the support you need from family and friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How concerned are you about:	A lot	Quite a bit	A little	Not at all
- your financial situation?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- having to cover extra costs of caring (eg. trips to hospital, medication)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How concerned are you about:	A lot	Quite a bit	A little	Not at all
- your own physical health?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- your caring role making your physical health worse?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How concerned are you about:	A lot	Quite a bit	A little	Not at all
- being unable to cope with the “constant anxiety” of caring?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- feeling depressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- being unable to see anything positive in your life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- lack of sleep because of worry or stress?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- feeling so exhausted you can’t function properly?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Ask the carer to list 3 issues/needs that present them with the most difficulty in relation to their caring role and how it affects their life and the life of their family.	1. 2. 3.
Does the carer have any ideas how to relieve the issues/needs they have identified ?	1. 2. 3.
Data collection date	DD <input type="checkbox"/> MM <input type="checkbox"/> YYYY <input type="checkbox"/>

Data collection location (ie camp, home, clinic, SHGs, etc)			
Data collected by	Name	Position	Signature

Acknowledgements:

Adapted from BasicNeeds data collection tool

Additional questions from the Caring Well-being and Support Questionnaire, Quirk et al, 2012



Carers Worldwide

30, Lodgefield
Welwyn Garden City
Hertfordshire
United Kingdom
AL17 1SD

Email: info@carersworldwide.org
Website: www.carersworldwide.org

UK Charity no: 1150214
UK Company no: 08083816