Upscaling and expanding the support of impoverished family carers of persons with disabilities in Bangladesh to further their social and economic inclusion

Baseline Report

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Dedicated to the memory of Maya Rani and Shima Rani, who are featured in the photo on the front cover along with their husband and father Monotosh.

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FOREWORD

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

A disability or long-term health condition impacts not only the life of the person affected but also the functioning at the family level and their contribution in the community. The carers of people with disabilities or long-term conditions shoulder extra work and increased responsibilities. The long-term strain leads to reduced quality of life of a carer in comparison to others. But their efforts are uncounted and barely recognised by both primary and secondary support systems. Carers act as a bridge between the person with chronic illnesses/disabilities and the community. Research studies throughout the world have proved and recognised the burden of caring, expressed emotions associated with caring, and developed several intervention programmes for carers to modify their expressed emotions, and develop information booklets, all of which has helped to reduce the impact of caring on carers. But most of the intervention programmes have looked at carers as potential resources, which can be tapped, and expect carers to continue to care for their family members without any support for themselves. Little research has been conducted in developing intervention programmes exclusively for carers' wellbeing. The situation for every carer is unique in terms of the needs of the individual they are looking after and their family contexts.

With this above backdrop Carers Worldwide has developed a five-faceted approach for improving carer wellbeing suitable for low-and middle-income countries. Carers are enrolled into self-help groups which reduce their social isolation, bring mutual support and access to shared problem solving. The other interventions are improved access to healthcare, employment and respite and empowerment of carers to advocate for themselves. Carers Worldwide has technical expertise in carer support but did not have a presence in Bangladesh. To this end they partnered with the Centre for Disability in Development (CDD). CDD has been working with people with disabilities in Bangladesh for over twenty years; it brings to the partnership trusted relationships with communities, government and non-government organisations and civic agencies across the country.

The project described in the report is addressing the needs of 1008 carers in Savar, Dhaka and acting as a pilot for assessing and adjusting the Carers Worldwide model for upscaling across Bangladesh. Using public health and community-based approaches, based on the premise that the locus of care should remain with the carer, 833 carers were interviewed by CDD personnel with a structured questionnaire in their natural settings. They were asked about the people they care for, about their own physical and mental health, financial and social wellbeing, how caring is impacting on their lives and what suggestions they had to improve their situation. Initial observation indicated that families receive very limited/no support and guidance from professionals and are often looked on as plentiful resources available in the community who are compensating the poorly funded health system. If carers are providing sustainable care, it is both ethical and imperative that their wellbeing also needs to be addressed in a systematic manner.

This is a pioneering project in Bangladesh. Through this baseline survey, Carers Worldwide and CDD have identified the core components of the carer and the need for their wellbeing. Carers as valuable resources, whose experiences can be meaningful to create community awareness, fight stigma and self-help has emerged as an important finding. The survey has highlighted the fact that carers need to be supported and nurtured through many programmes for their own wellbeing, alongside those for their disabled family member.

The efforts of CDD need to be appreciated, recognised, supported and if there is provision, they should be invited to share their experiences in the national and international forums along with the carer. All the field staff and the coordinators of CDD have taken meticulous attention in understanding the project goal, process, collecting the data and maintaining individual records of the project participants.

It is hoped that by adding to the evidence base on carers' needs, this survey will assist Carers Worldwide and CDD in scaling up carer inclusion in Bangladesh, and also in attracting the attention of other NGOs, INGOs and government agencies. Caregiving is a dynamic, multi-layered, multidimensional lifelong process, which requires role adaptations and skill acquisition by the families. These survey results demonstrate the depth of need amongst carers and indicate that support provided by Carers Worldwide and their partnering with CDD should be long-term. Along with the planned need based interventional programmes, it also indicates areas for additional research activities such as adaptation to other geographic areas in Bangladesh, impact measurement and validation of the Carers Worldwide model. An additional support could be development of training manuals for staff and carers in order to assist understanding, internalisation and sustainability.

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

Dr. Apurba Saha
Assistant Professor, Department of Social Work, Tezpur University, Assam, India

ACKNOWLEDGMENTS

I am truly grateful for the opportunity to work with the unpaid family carers of people with disabilities and mental disorders. This report is the result of the close collaboration between Carers Worldwide and our indispensable partner Centre for Disability in Development (CDD). A very special thank you goes to the carers and their loved ones, who have graciously given up their time and participated in the survey, providing us with a glimpse into their lives and the impact of caring on their own health and well-being. This has helped us to design the project and will be useful to policy makers, programmers and researchers in other countries.

Heartfelt gratitude and sincere thank you to the senior co-ordinator of CDD, Mr Md. Moinul Islam and all the 6 Community Facilitator, who interviewed the carers and collected the baseline data and Mr.SK Abdul Latif supervisor of community caring centre and health camp, Mr Md. Rabiul Alam Bakul, livelihoods co-ordinator who supported the staff during the baseline survey period and compiling the data.

A very special gratitude to all the stakeholders in particular Savar Carers Association Executive Members, Volunteers and local Union Parishad for their immense support to this work in identifying and referring the families in need of our intervention.

I would like to express my sincere thanks to Ms Camille Bou for analysing the data, writing the literature review and preparing this report. A very special thank you is offered to Ruth Patil for her proofreading, editorial support and producing the report in its final format.

A very special gratitude is offered to Dr. Apurba Saha, Assistant Professor, Department of Social Work, Tezpur University, Assam, India for writing the Foreword to the report.

Without the leadership support of Mr A H M Noman Khan, Executive Director, CDD, and Mr Nazmul Bari, Director, CDD, none of this would have been possible and to both of them I express my sincere gratitude and thanks.

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

Finally, I would like to express my sincere gratitude to CareTech Foundation and Rangoonwala Foundation for their funding support. Without their generous support this work would have been impossible.

Dr Anil K Patil
Founder and Executive Director, Carers Worldwide

October 2022

ABOUT THE STAKEHOLDERS

Project funders	The Caretech Foundation The Rangoonwala Foundation
The grantee	Carers Worldwide
Implementing partner	Centre for Disability in Development
Project dates	August 2021 – July 2024

About Carers Worldwide

Carers Worldwide highlights the vital role played by carers of people living with chronic illnesses and disabilities in low-and-middle-income countries. It advocates for their inclusion in mainstream development programmes and the development of carer-specific services.

Looking into the lives of carers of people with long-term illnesses and disabilities in South Africa and India, Anil Patil developed an understanding of how caring impacts the physical and mental health of carers, their emotional wellbeing and economic security, and realised that their needs are almost entirely unrecognised and unmet in low-and-middle-income countries. He responded by looking for a way of improving carers' lives.

The journey began with founding Carers Worldwide, which has gone on to implement projects to improve the lives of carers in India and Nepal. The Carers Worldwide Commonwealth Foundation funded project in India lifted 74% of its families out of poverty, enabled 54% of its carers into employment, improved reliable incomes for 55% of its participants, reduced anxiety, or depression in 52% of its carers and reduced those experiencing significant health worries by 39% (Carers Worldwide, 2018). With each project, Carers Worldwide rigorously examines their impact and methodologies.

These projects are not only helping thousands of carers already but are also creating an evidence-based understanding of the needs of carers in low-and-middle-income countries and how those needs can be met cost-effectively. Carers Worldwide has developed a fivefold model to meet carers' needs which it is implementing and evaluating by partnering with established organisations working with people with disabilities and long-term conditions. The model has five elements:

1. Carer self-help groups are the heart of the model. The groups bring carers mutual support and develop their skills to sustain themselves independently for the long-term.

2. Carers access to healthcare is facilitated.

3. Systems for respite are put in place.

4. Carers are helped into employment which is compatible with their caring duties.

5. Carers are given the skills and confidence to advocate for their rights thereby contributing to systemic change for carers.

CARERS' SUPPORT GROUPS
Reducing loneliness and isolation, creating social networks and supporting emotional wellbeing

HEALTH SERVICES
Creating access to physical and mental health services including locally available counseling services

ADVOCACY
Strengthening the collective voice of carers at community, regional and national level to achieve changes in policy and practice

RESPITE AND SHORT BREAKS
Offering a break from caring responsibilities and developing alternative, health quality care options

EMPLOYMENT, TRAINING AND EDUCATION
Facilitating access to employment, training or education opportunities tailored to exist alongside caring responsibilities

About the Centre for Disability in Development

The Centre for Disability in Development works on disability inclusive development in Bangladesh. It does this by simultaneously educating the community in how to be more inclusive, whilst also enabling people with a disability to participate in society by providing them with essential support.

The Centre for Disability in Development is a not-for-profit organisation established in 1996. It exists to ensure that people with disabilities are included in mainstream development activities in Bangladesh, with the aim of helping them enjoy equal opportunities and full participation in all spheres of life.

The organisation sees a twin-track approach as essential to achieving this aim. The first approach is to support individuals with disabilities to be able to engage in daily life activities across access to health, to education, livelihoods, and socialisation. They do this by giving people with disabilities the confidence, skills, and equipment they need for participation. The second of the twin-tracks is to dissolve the societal barriers which hold people with disabilities down. Working at all levels of society, from individual citizens, through community and to government the Centre for Disability in Development provides education on disability experiences, barriers, rights, and solutions. Its expertise is often sought by the government of Bangladesh. The Centre for Disability in Development works in partnership with a network of over 350 organisations nationally and internationally.

The founder and executive director A.H.M Noman Khan had the prestigious honour of being awarded the international Ramon Magsaysay Award in recognition of his pioneering leadership and dedication to building a society that is truly inclusive and barrier-free.

The organisation’s experience, extensive network, and trusted status enable it to offer this project an understanding of disability in Bangladesh, a deep reach into communities across the country, and connections with policymakers and programme implementers from local government to the highest reaches nationally and ongoing implementation for upscaling and sustainability.

About the funders

CareTech Foundation

Established in 2017, the CareTech Charitable Foundation is an independent grant-making corporate foundation registered with the Charity Commission. Funded and founded by CareTech Holdings PLC, the Foundation has an independent Board of trustees responsible for delivering its Charitable Objects. They deliver meaningful impact to communities in the UK and overseas by supporting and championing the social care sector, care workers and those living in care through our four grant streams.

Rangoonwala Foundation

The Rangoonwala Foundation is a charitable endowment of its founder the late philanthropist, social worker, patron and industrialist Mohamed Aly Rangoonwala.

The grant from the CareTech Foundation and Rangoonwala Foundation is for a three year project, being implemented on the outskirts of Dhaka by our partner The Centre for Disability in Development. Working with just over 1,000 carers of disabled children and adults, the project is further expanding the charity’s previous work in the area.

LITERATURE REVIEW: THE CARING EXPERIENCE IN BANGLADESH

To further provide country context to this programme evaluation, and identify data gaps, a rapid literature review on the experiences of caregivers in Bangladesh was conducted, focusing on the impacts of disability and illness on caregivers, their support needs and the availability or lack of this support, and the barriers in accessing support. A search for the key terms disability, mental health, caregiver, impact, burden, needs, and support was conducted on four databases: Medline OVID, Embase OVID, Global Health and Google Scholar covering grey literature and academic literature. Given that Google Scholar was likely to return thousands of results, many of which were likely to be irrelevant, a search limit of 40 results pages (or 400 articles – each results page returns 10 articles) was set to find relevant articles.

Studies were included if they:

1. Were qualitative, quantitative, mixed-methods, or literature reviews published between 2000 and 2022
2. Were conducted in Bangladesh, in whole or in part alongside other South Asian countries
3. Were available within the access provided by the university and were written in English
4. Included the concept of caregiver for an individual who was elderly and frail, and/or with an intellectual, developmental, and/or physical disability and/or mental health problem as central to the study

Database	**Search strategy**		**Hits**
Medline Ovid, Embase Ovid, Global Health	**1**	caregiver* OR carer*	280048
	2	disability OR intellectual disability* OR physical disability* OR mental health*	1327644
	3	burden* OR impact* OR need* OR support*	20836736
	4	Bangladesh	58979
	5	1 AND 2 AND 3 AND 4	79
	6	Limit 5 to English AND from 2000-onwards	**73**
Google Scholar	**1**	caregiver* OR carer* AND disability OR intellectual disability* OR physical disability* OR mental health* AND Bangladesh AND caregiver burden* OR burden* OR impact* OR need* OR support*; Limit 4 to English AND from 2000-onwards	17800
	2	Extracting the most up to date papers (up to page 40, or up to 400 articles)	**87**
	Total hits		**160**
	After removal of duplicates		127
	After title and abstract screening		94
	After full text screening (final number of papers)		**42**

Table 1. Search strategy and hits

The search was conducted throughout July 2022 and identified 160 articles. Once duplicates were removed, 127 articles remained. The titles and abstracts of these articles were screened, resulting in 94 potentially relevant articles. Following a thorough screening and selection process, 42 articles were included in the final synthesis. Out of these 42 articles, 26 related to the impact of caregiving on the carer, and 16 were about carers' needs, interaction with services and barriers in accessing services. See Table 1 for more details.

The impact of disability and illness on caregivers in Bangladesh

The 26 studies on the impact of caregiving concerned caregivers of family members with cerebral palsy (n=9), mental health problems (n=2), autism spectrum disorder (n=3), neurodevelopmental disorders (n=1), intellectual disability (n=3), and other physical disabilities (n=7) (the last study included care-recipients with palliative care needs). Studies in the majority were about carers who were parents caring for children with illnesses or disabilities. Overall, caregiver burden impacted carers and their families in different, interrelated areas of life, including mental and physical health, social networks and support, and finances, and the impact of caregiver burden was also mediated by socio-economic status and socio-cultural norms in Bangladesh.

Mental and Physical Health. The impacts of caring demands on carers' mental and physical health were frequently reported. The impact of caring demands on carers' health (especially mental health) were often strong predictors of care-recipients' Health-Related Quality of Life (Power et al., 2020). High caregiver burden was correlated with poor Quality-of-Life (Banerjee R. et al., 2022). Similarly, care-recipients often had comorbid conditions, and these increased the caregiver burden faced by carers (Mullick et al., 2005) and care-recipients' disability types influences carers' ability to adapt to stress (Shahrier M.A. et al., 2016).

A study by Power at al. (2021) found that compared to their non-carer peers, carers of adolescents with cerebral palsy were at higher risk of depression and stress, but not anxiety. Mothers caring for children with autism spectrum disorder (ASD) were at higher risk of being diagnosed by major depressive disorder (Naheed et al., 2020), and reported physical and psychological tension (Khanam, 2018). Parents of children with an intellectual disability were more likely to suffer from higher levels of depression than parents of children without an intellectual disability (M. A. Islam et al., 2022). Parents reported feeling shame, dishonour, sadness, stress and anxiety over their ability to financially afford their care-recipient's care costs and their future (Khanam, 2018). Caregivers faced sleeping difficulties, lack or appetite, and pleasure in life (Doherty et al., 2020, p.).

Caregivers of children with cerebral palsy in rural settings faced high levels of worry and anxiety due to the lack of social support in caregiving, concern for the child's future, lack of knowledge about the care-recipient's illness, physical exhaustion, and high-levels of stigma (Zuurmond et al., 2015). Caregivers had higher prevalence of musculoskeletal disorders (poor posture, persistent repetitive hand movements, back and hand pain) and faced physical and mental exhaustion during the manual handling of care-recipients with disabilities (Habib et al., 2014; Rahman et al., 2017).

Social support. Another prominent theme in the literature about the impact of caring on the caregiver was social support from carers' entourage: friends, family, neighbours, and professionals. Caring responsibilities and the illness or disability of the care-recipient impacted carers' ability to integrate into the community, form strong social networks, and build social capital in both urban (Aminul, 2020; Rahman, 2015) and rural settings (Jahan I. et al., 2022). Yet evidence also suggests that parents of children with an intellectual disability have higher levels of marital satisfaction than parents of children without intellectual disability (M. A. Islam et al., 2022).

Parents of children with intellectual disabilities tended to have smaller social support networks than parents of children without, and were overall less satisfied with their social networks, making it difficult to seek help, confide private matters and discuss important decisions; they reported higher levels of loneliness and isolation than parents of children without, interacting with their family and friends mostly by telephone, letter or email rather than in person, and overall interacting less with their neighbours (M. A. Islam et al., 2022). Mothers caring for children with ASD were at higher risk of being diagnosed with major depressive disorder if they faced ASD-related stigma from their neighbours, had no childcare support at home, and expressed low-level of satisfaction with the quality of providers when they had sought care for their children with ASD (Naheed et al., 2020). Mothers of children with cerebral palsy often reported feeling isolated from society, not being able to join functions, with little access to transport options and shopping infrastructures (Akter, 2021).

Seeking and accessing social support was hindered by stigma and social judgement associated with the care-recipient's illness within the family, community, educational and healthcare institutions (Tushar et al., 2020). Parents of children with ASD felt hesitation to communicate with neighbours, join social activities, and were often not included or invited in the social activities organised by the community (Khanam, 2018). This was also true for caregivers in rural settings, who reported feeling isolated, stigmatised, and lacking support; studies conducting focus groups with other caregivers allowed them to realise they were not alone in their struggle and that others had caring responsibilities for children with disabilities too (Zuurmond et al., 2015).

The importance of socio-economic status and socio-cultural norms. Caregiver characteristics, household and caring context played a role in mediating the impacts of caring.

Households with people with disabilities and illnesses were at higher risk of poverty (Rahman, 2015; Tamang, 2018), facing high direct costs (healthcare, assistive technologies, transport, accommodations at school and work) and indirect costs (limited ability to partake in the labour market, lower earnings from employment), with unmet direct costs leading to further future indirect costs (Banks et al., 2022). Families with caregiving responsibilities in rural settings were more vulnerable than those living in urban settings, and were at higher risk of psychiatric morbidity in part due to higher rates of poverty and limited resources (Mobarak et al., 2000; Zuurmond et al., 2015). The health-related quality of life of mothers caring for children with cerebral palsy was significantly associated with family income, household composition (number of children and whether they lived with their husbands), and the age of the children (Ahmed et al., 2021). The quality-of-life of mothers of children with ASD was positively associated with Caregivers of psychiatric patients reported differing levels of stress, with the majority claiming average coping levels; income was associated with stress levels and coping status, suggesting that caregivers who are not offered support and who must solely rely on their own coping strategies may be building unsustainable resilience (Tasmin et al., 2020).

The quality-of-life of carers was positively associated with household income and the care-recipients' ability to integrate and partake in community life such as work, school, and social interactions (Milićević, 2022; Naheed et al., 2020). The age and sex of the carer, occupation of the carer, employment status of the care-recipient, relationship between the carer and care-recipient, caregiving duration and hours, the mental health of the care-recipient, the deafness of the care-recipient, and household crowding and poverty, were aggravating factors and predictors of caregiver burden, depression, anxiety, and stress (Banerjee R. et al., 2022; Begum, 2014; Power R. et al., 2021; Rahman, 2015). Evidence suggests a significant association between female caregivers' living area, poverty status, and stress levels (Akter, 2021), with female caregivers and less educated caregivers facing higher parenting stress for children with neurodevelopmental disorders (Haque et al., 2021).

The community's lack of understanding of illness and disability, and the social negligence of communities towards illness and disability had profound effects on care-recipients' recovery and development and carers' suffering (Khanam, 2018). The experience and spread of stigma was exacerbated by misogyny, poverty, the inability to partake in the labour market due to caring responsibilities and misinformation (Pseudo-Scientific Misinformation, Religious-Cultural and Superstition) (Tushar et al., 2020). There were stark gender differences in the provision of caregiving, with women often expected to take on care responsibilities (Tamang, 2018; Tasmin et al., 2020), facing higher caregiver burden and psychological stress (Begum, 2014; Rahman, 2015; Shahar et al., 2021), and even stigmatised, blamed, and discriminated against for the disability of their children (Malek, 2022); one study found that mother's age and education was a significant predictor of children with cerebral palsy's health-related quality-of-life, but not fathers (Power et al., 2020).

Caregivers' needs, interaction with services, and barriers in accessing support

The literature yielded 16 hits relating to caregivers' support needs, their interaction with services, and barriers in accessing support.

Evidence suggests that very little caregiver services and support are currently being offered in Bangladesh. For example, a significant proportion of caregivers of individuals with schizophrenia were living with psychiatric disorders (the most common being depression, anxiety, and pain disorder) for which they were not receiving treatment (Jalal Uddin M.M., 2015). Caregivers reported lacking knowledge about their care-recipients' illness and how to manage them; yet providing such information has benefits for both the carer and care-recipient. Mothers of children with cerebral palsy who faced child behaviour problems were at high risk of stress and psychiatric morbidity, suggesting a need for practical help and advice on managing common behaviour problems as components of interventions for caregivers of cerebral palsy (Mobarak et al., 2000). The provision of general information about cerebral palsy and the available types of services predicted Health-Related Quality of Life domains related to interactions and relationships with parents (Milićević, 2022). Caregiver preparedness to help care-recipients with traumatic brain injury was associated with care-recipients' quality of life (M. N. Islam et al., 2022).

Caregivers also reported lacking peer support and information. The focus groups participants in one study conducted in rural Bangladesh mentioned that they were not aware of other children with disabilities within their own village, and that coming together to form a parent support group provided an invaluable opportunity to talk about their experience with other parents (M. N. Islam et al., 2022). Families of children with disabilities mentioned needing family cohesion and integration of the care-recipient into the community, as well as emotional support to tackle isolation and stigma (Ahmed N. et al., 2018; Nuri et al., 2019). Education and peer support around caregiving for an individual with a disability could foster this cohesion, provide this emotional support through peers, help carers gain knowledge about their care-recipients' disability (e.g., the biomedical causes of the disability and an understanding of treatment options and trajectories), break down carer's negative perceptions of disability (e.g., that the disability was caused by them or traditional beliefs such as ghosts or curses), encourage carers to seek out different education and medical services for their care-recipient, and create realistic expectations of the outcomes of care-recipients' treatment (e.g., allowing the care-recipient to achieve a level of independence vs. “curing” them) (Maloni et al., 2010; Nuri et al., 2019).

Care-recipients’ access to services played a key role in supporting caregivers. However, these services were not always available or accessible. Assistive technology service provision was poor and of limited range, with users having little knowledge about their rights to these services and the availability of these services (Karki et al., 2021). Rehabilitation services for people with disabilities had severe shortages and uneven distribution of services and workforce, often lacked primary and secondary health facilities, were often privately supplied as such in the majority required out-of-pocket payments (limiting uptake), and were overall found to be not integrated into the mainstream health services, financing mechanisms, information systems, and health policies in Bangladesh (Al Imam et al., 2021a; Nuri et al., 2019). Families who were able to access government support for their children with disabilities through disability allowances and a one-stop rehabilitation service had both positive and negative views; the latter of were driven by long wait times, in part due to the important shortage of rehabilitation professionals (Rahaman et al., 2017). Moreover, barriers in access remained for these families such as the inaccessible infrastructure (e.g., facilities, transportation, time) and stigma (Ehsan et al., 2018; Nuri et al., 2022).

The barriers in accessing services were not spread equally across and within families. Parental education was significantly related to rehabilitation service uptake among children with cerebral palsy, with children of illiterate mothers and fathers having lower chances of receiving rehabilitation services (Islam, 2019). A significant negative association between monthly family income and rehabilitation service uptake was observed (Al Imam et al., 2021b; Chandra, 2021; Ehsan et al., 2018). Family income was also related to parents’ hopes for their children with disabilities futures, with richer families seemingly less worried about their children as they believed they could manage care costs throughout their lives (Ehsan et al., 2018). Some studies suggested that male care-recipients had better access to healthcare services and were often prioritised in the division of family resources, especially in families living below the poverty line or in rural areas (Power et al., 2020). Some disability services were not adequately tailored to care-recipients who were women, providing little education and support surrounding their sexual and reproductive health (Power R. et al., 2020). Yet stroke family caregivers of patients in a rehabilitation centre faced low to moderate stress, suggesting strong benefits when caregivers manage to access services and support for their care-recipient (Ahmed, 2018).

The integration of care-recipients with disabilities within the home and home accessibility is also important. A house with inaccessible bathroom, kitchens and stairs reduces one’s ability to self-care and increases dependence on caregivers for simple household tasks such as cooking meals and looking after children (Ahmed N. et al., 2018). The home adaptation level predicted Health-Related Quality of Life domains related to interactions and relationships with parents (Milićević, 2022).

PROJECT DESIGN AND EVALUATION

Project purpose

In 2018, a baseline study was conducted to identify carers of people with disabilities and long-term conditions in a pilot population in Dhaka, Bangladesh. The aims of this study were to understand how caring impacted their health, social and economic welfare and to enrol them into the project of support offered by Carers Worldwide. The baseline study report presented the demographic, caring situation, and health statistics of the recruited carer population. This report evaluates the support offered to them and presents the findings of the evaluation. It also provides baseline statistics of a new group of carers (Carer Group 2) enrolled in the model of support.

The aims of this report are twofold: 1) To evaluate the model of support provided to the pilot population of carers of people with disabilities and long-term conditions in Bangladesh, 2) To provide baseline statistics of the new group of carers.

The current report presents the post-intervention findings of the project. It also presents the baseline statistics of a new group of carers enrolled in the project.

Project and survey design

This project is the result of a close partnership between Carers Worldwide and the CDD. Carers Worldwide has expertise in carer support, with long-standing projects established in India and Nepal, but not Bangladesh. CDD, having worked for more than twenty years in Bangladesh with people with disabilities, has established relationships with communities throughout the country and with policymakers.

The project design drew from Carers Worldwide's project design and management experience in Nepal and India, CDD's contextual and policy knowledge of Bangladesh, and extensive consultations with carers, their relatives with disabilities and mental illness, their families, and local community government and non-governmental stakeholders. This led to the construction of a baseline survey used to collect information on the carers participating in the project.

While the baseline survey differed from the evaluation survey, the surveys broadly contained the following sections:

A) **Demographic questions**, which collected information about the carer such as gender, age, contact details (etc.).
B) **Caring relationship and Cared for Individual**, which collected information about the care-recipient such as their illness, age, and gender, the carer's relationship with the care-recipient, the duration of care (etc.).
C) **Education, Employment, and Household Income**, which collected information about the carer's educational and employment status, their annual income, their household's income, the sources of that income, household possessions, materials with which their home was built (etc.).
D) **Carer Wellbeing**, which collected information about the disability status of the carer, their perceived mental and physical wellbeing, perceived loneliness and isolation, respite and control over daily life, feeling valued as a carer, and whether they had access to support.

E) **Advocacy and Confidence in Advocacy**, which collected carers' trust and confidence in their public officials in supporting them and advocating for their needs.
F) **Final Thoughts**, where carers were asked to share the three most pressing issues they were facing currently and their ideas for resolving such issues.

Because the survey used at baseline (Time 1) differed from the survey used post-project (Time 2), for the sake of the evaluation several assumptions were made in the matching of the questions asked, which covered similar topics but were asked and coded in a different manner. The matching details can be found in Table 2. Two questions in the original survey were unable to be matched: 1) "How concerned are you about strains in your relationships with friends and family because of your caring"? and 2) "Would you like more support to help you in your role as a carer"?

Question survey 1	**Matched Question survey 2**
How concerned are you about not having enough time for yourself? A lot Quite a bit A little Not at all	I do not have enough time to myself because of my caring responsibilities Strongly Agree Agree Disagree Strongly Disagree
How concerned are you about not being able to take a break from caring? A lot Quite a bit A little Not at all	I am unable to take a break from caring Strongly Agree Agree Disagree Strongly Disagree
How concerned are you about not being able to plan for the future? A lot Quite a bit A little Not at all	I am unable to plan for the future because of my caring responsibilities Strongly Agree Agree Disagree Strongly Disagree
How concerned are you about not being able to continue caring (e.g., because you are ill yourself)? A lot Quite a bit A little Not at all	I worry that one day I will have to stop caring due to my physical health deteriorating Strongly Agree Agree Disagree Strongly Disagree
How concerned are you about "drifting apart" from friends and family because your caring responsibilities limit the time you have to keep in contact with them? A lot Quite a bit A little Not at all	I am drifting apart from friends and family because of my caring responsibilities Strongly Agree Agree Disagree Strongly Disagree
How concerned are you about feeling isolated and lonely because of the situation you are in?	I feel lonely Strongly Agree Agree

A lot Quite a bit A little Not at all	Disagree Strongly Disagree
How concerned are you about not getting the support you need from family and friends? A lot Quite a bit A little Not at all	I have friends or family members I can discuss the challenges of caring with Strongly Agree Agree Disagree Strongly Disagree
How concerned are you about your financial situation? A lot Quite a bit A little Not at all	I constantly worry about the financial stability of my household Strongly Agree Agree Disagree Strongly Disagree
How concerned are you about having to cover extra costs of caring (e.g., trips to hospital, medication)? A lot Quite a bit A little Not at all	I have enough money to cover the extra costs of caring (e.g., trips to the hospital) Strongly Agree Agree Disagree Strongly Disagree
How concerned are you about your own physical health? A lot Quite a bit A little Not at all	I am concerned about my own physical health Strongly Agree Agree Disagree Strongly Disagree
How concerned are you about your caring role making your physical health worse? A lot Quite a bit A little Not at all	I am concerned about my caring role making my physical health worse Strongly Agree Agree Disagree Strongly Disagree
How concerned are you about being unable to cope with the “constant anxiety” of caring? A lot Quite a bit A little Not at all	My caring role makes me feel anxious Strongly Agree Agree Disagree Strongly Disagree
How concerned are you about feeling depressed? A lot Quite a bit A little Not at all	I feel depressed due to caring Strongly Agree Agree Disagree Strongly Disagree

How concerned are you about being unable to see anything positive in your life? A lot Quite a bit A little Not at all	I have had thoughts of ending my life due to my caring role Strongly Agree Agree Disagree Strongly Disagree
How concerned are you about lack of sleep because of worry or stress? A lot Quite a bit A little Not at all	I struggle to sleep because of the worry of caring Strongly Agree Agree Disagree Strongly Disagree
How concerned are you about feeling so exhausted you can't function properly? A lot Quite a bit A little Not at all	I am physically exhausted by caring Strongly Agree Agree Disagree Strongly Disagree
How concerned are you about people treating you differently? A lot Quite a bit A little Not at all	I feel excluded or stigmatised by others due to caring for a sick or disabled loved one Strongly Agree Agree Disagree Strongly Disagree

Table 2. Matched questions from Survey 1 to Survey 2

Evaluation method

The following section presents the findings of the evaluation of the Carers Worldwide model of support for Carer Group 1 (n=504). Carer Group 1 consists of carers enrolled in the pilot (n=288) in October 2018, and a further 216 carers enrolled following the successful pilot until January 2019. Data was collected 2 years and 10 months following Carer Group 1's enrolment into the project (from October 2021 to January 2022) to evaluate the support offered.

Two statistical tests were used to evaluate the differences in the survey responses for each individual partaking in the project: 1) The chi^2 test of statistical independence was conducted on the matched survey questions to understand how carers' responses to the questions changed after their enrolment in the project (see Table 3 in Results); 2) Each response to the survey questions were given a score, which were aggregated to give each respondent a score at time 1 and time 2. The mean difference between survey responses for each participant were then calculated (Figure 1 in Results).

Results

Carer Group 1 enrolled 504 carers into the project. At Time 2, it was found that 175 carers dropped out of the project, presenting an approximate attrition rate of participation of ~34.7% and a Time 2 sample size for Carer Group 1 of 329 carers. This was, for the majority of cases, due to the COVID-19 pandemic- 138 carers migrated away from Dhaka for health, employment and financial reasons. Other reasons for attrition included the death of the care-recipient, carer, or both (11 cases), and not being found at the time by the surveyors at the time of the interview (13 cases). Finally, thirteen (n=13) carers who dropped out of the programme were replaced by other carers on the waitlist for the programme- they were not included in the analysis, giving a sample size of 491 at Time 1 in the analysis. Despite this significant attrition, the evidence suggests a positive and statistically significant impact of the project on the enrolled carers' lives, as measured by the survey.

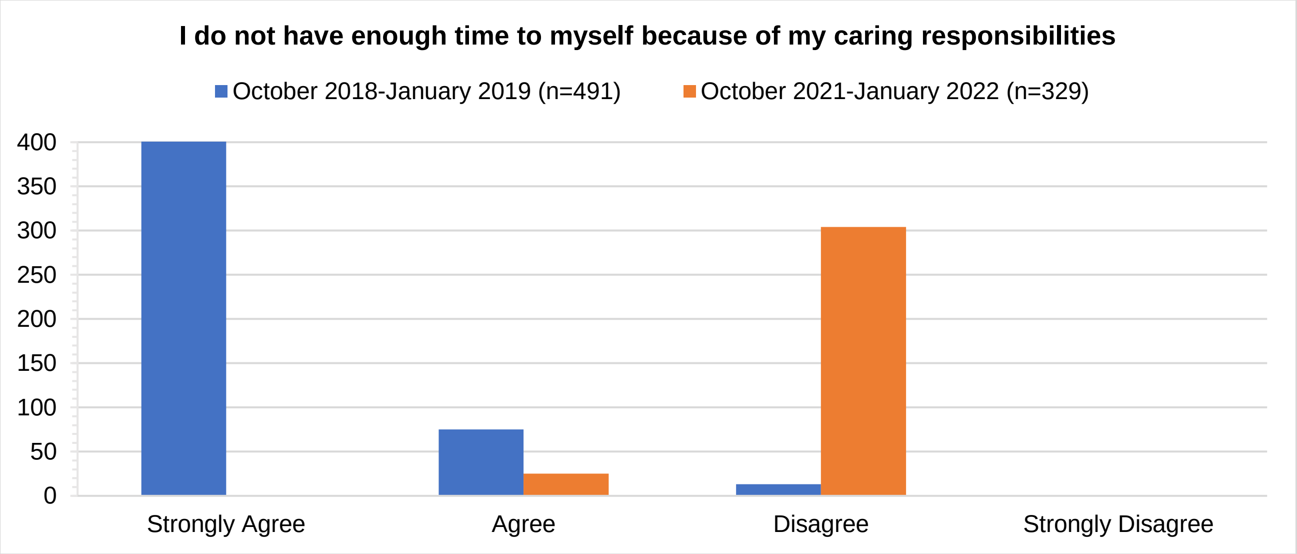
Measure	**October 2018-January 2019 Time 1 (n=491)**	**October 2021-January 2022 Time 2 (n=329)**	**Test**
I do not have enough time to myself because of my caring responsibilities			689.1131 <0.001
Strongly Agree	401(81.84%)	0	
Agree	75 (15.31%)	25 (7.60%)	
Disagree	13 (2.65%)	304 (92.40%)	
Strongly Disagree	1 (0.20%)	0	
Missing	1	0	
I am unable to take a break from caring			501.4887 <0.001
Strongly Agree	377 (77.10%)	0	
Agree	99 (20.25%)	329 (100.00%)	
Disagree	13 (2.66%)	0	
Strongly Disagree	0	0	
Missing	2	162	
I am unable to plan for the future because of my caring responsibilities			711.9013 <0.001
Strongly Agree	410 (84.19%)	0	
Agree	67 (13.76%)	25 (7.60%)	
Disagree	7 (1.44%)	304 (92.40)	
Strongly Disagree	3 (0.62%)	0	
Missing	3	162	
I am concerned about my own physical health			8.9962 0.029
Strongly Agree	425 (86.91%)	304 (92.40%)	
Agree	56 (11.45%)	25 (7.60%)	
Disagree	6 (1.23%)	0	
Strongly Disagree	2 (0.41%)	0	
Missing	2	162	
I worry that one day I will have to stop caring due to my physical health deteriorating			689.8348 <0.001
Strongly Agree	447 (91.41%)	0	
Agree	34 (6.95%)	329 (100.00%)	
Disagree	8 (1.64%)	0	
Strongly Disagree	0	0	
Missing	2	162	
I am concerned about my caring role making my physical health worse			672.9845 <0.001
Strongly Agree	435 (88.96%)	0	
Agree	39 (7.98%)	329 (100.00%)	

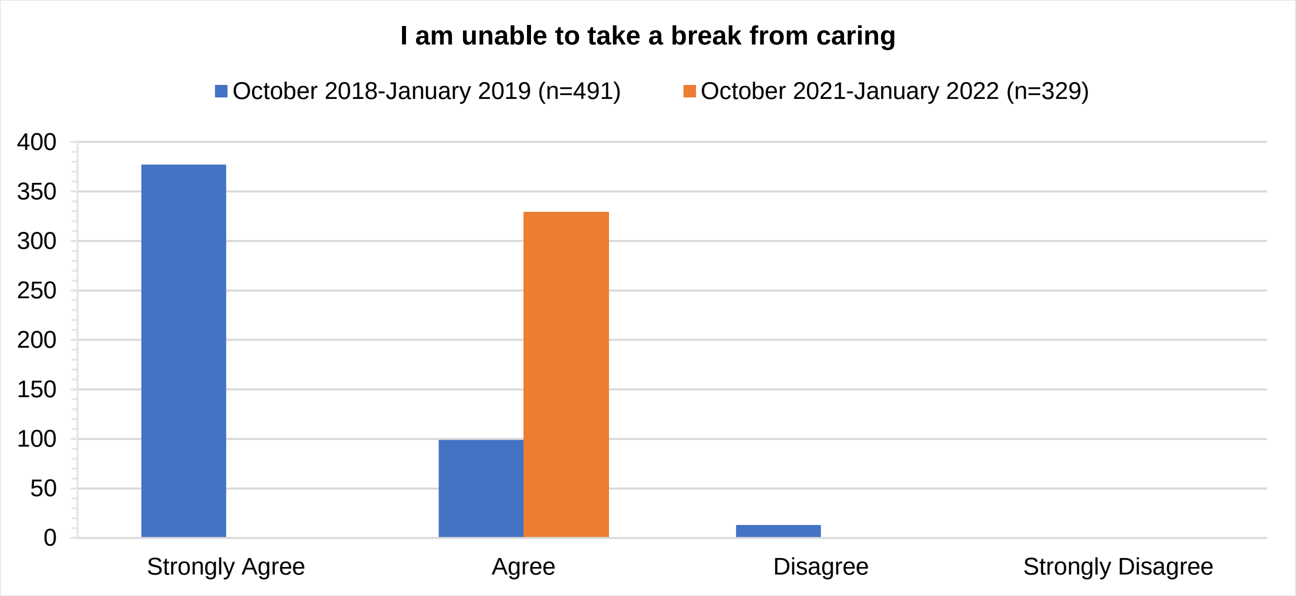
Disagree	15 (3.07%)	0	
Strongly Disagree	0	0	
Missing	2	162	
I am physically exhausted by caring			740.6837 <0.001
Strongly Agree	444 (91.17%)	1 (0.30%)	
Agree	41 (8.42%)	24 (7.29%)	
Disagree	2 (0.41%)	304 (92.40%)	
Strongly Disagree	0	0	
Missing	4	162	
I am drifting apart from friends and family because of my caring responsibilities			681.6001 <0.001
Strongly Agree	321 (65.91%)	3 (0.91%)	
Agree	153 (31.42%)	19 (5.78%)	
Disagree	13 (2.67%)	304 (92.40%)	
Strongly Disagree	0	3 (0.91%)	
Missing	4	162	
I feel lonely			730.5493 <0.001
Strongly Agree	419 (85.69%)	0	
Agree	65 (13.29%)	25 (7.60%)	
Disagree	3 (0.61%)	304 (92.40%)	
Strongly Disagree	2 (0.41%)	0	
Missing	2	162	
I feel excluded or stigmatised by others due to caring for a sick or disabled loved one			501.4887 <0.001
Strongly Agree	382 (78.12%)	0	
Agree	99 (20.25%)	329 (100.00%)	
Disagree	8 (1.64%)	0	
Strongly Disagree	0	0	
Missing	2	162	
I have a friend or family member I can discuss the challenges of caring with			37.0986 <0.001
Strongly Agree	372 (76.23%)	304 (92.40%)	
Agree	108 (22.13%)	25 (7.60%)	
Disagree	8 (1.64%)	0	
Strongly Disagree	0	0	
Missing	3	162	
I feel depressed due to caring			683.3678 <0.001
Strongly Agree	405 (82.99%)	7 (2.13%)	
Agree	71 (14.55%)	17 (5.17%)	
Disagree	12 (2.46%)	305 (92.71%)	
Strongly Disagree	0	0	
Missing	3	162	
My caring role makes me feel anxious			674.6613 <0.001
Strongly Agree	385 (78.89%)	6 (1.82%)	
Agree	88 (18.03%)	18 (5.47%)	
Disagree	14 (2.87%)	305 (92.71%)	
Strongly Disagree	1 (0.20%)	0	
Missing	3	162	

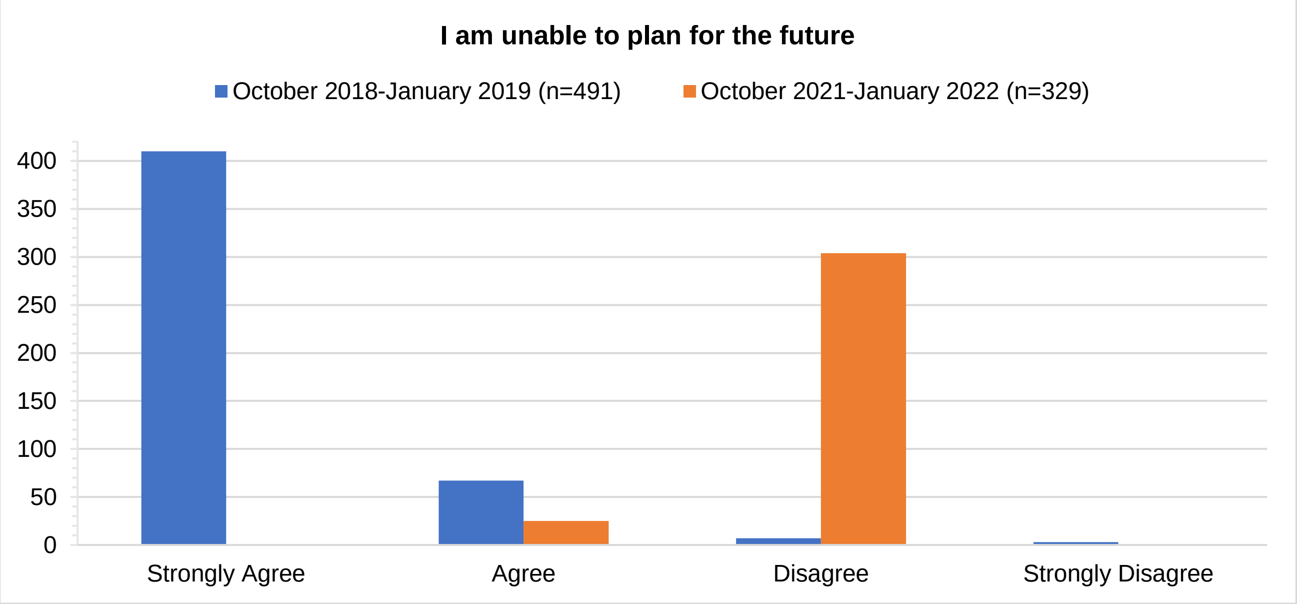
I struggle to sleep because of the worry of caring			719.7278 <0.001
Strongly Agree	433 (88.55%)	2 (0.61%)	
Agree	50 (10.22%)	23 (6.99%)	
Disagree	6	304 (92.40%)	
Strongly Disagree	0	0	
Missing	2	162	
I have had thoughts of ending my life due to my caring role			720.5383 <0.001
Strongly Agree	378 (77.62%)	0	
Agree	100 (20.53%)	25 (7.60%)	
Disagree	6 (1.23%)	0	
Strongly Disagree	3 (0.62%)	304 (92.40%)	
Missing	4	162	
I have enough money to cover the extra costs of caring (e.g., trips to the hospital)			727.2350 <0.001
Strongly Agree	444 (90.98%)	1 (0.30%)	
Agree	38 (7.79%)	24 (7.29%)	
Disagree	6 (1.23%)	304 (92.40%)	
Strongly Disagree	0	0	
Missing	3	162	
I constantly worry about the financial stability of my household			766.9873 <0.001
Strongly Agree	473 (96.53%)	0	
Agree	13 (2.65%)	25 (7.60%)	
Disagree	4 (0.82%)	304 (92.40%)	
Strongly Disagree	0	0	
Missing	1	162	
Total score (t-test)			-73.21
Mean (Std. dev)	8.35 (3.78)	26.20 (2.81)	<0.001
Median	7	27	
P74	9	27	
P25	6	27	
Max value	32	27	
Min value	1	13	

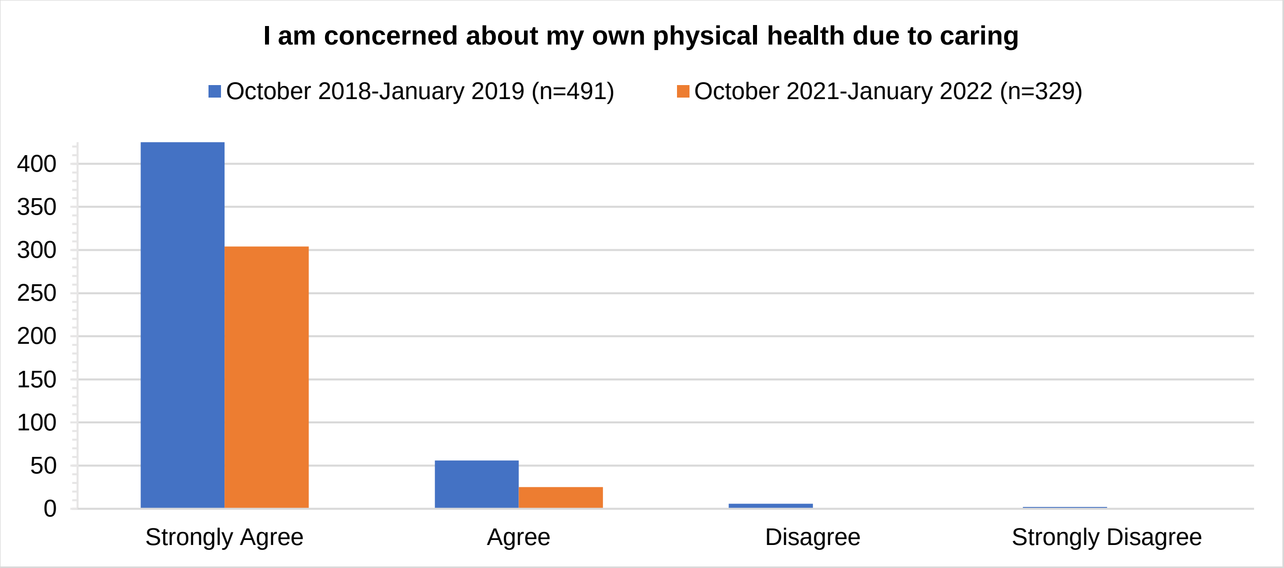
Table 3. Distribution differences pre-and-post project. Missing values are not counted in the analysis.

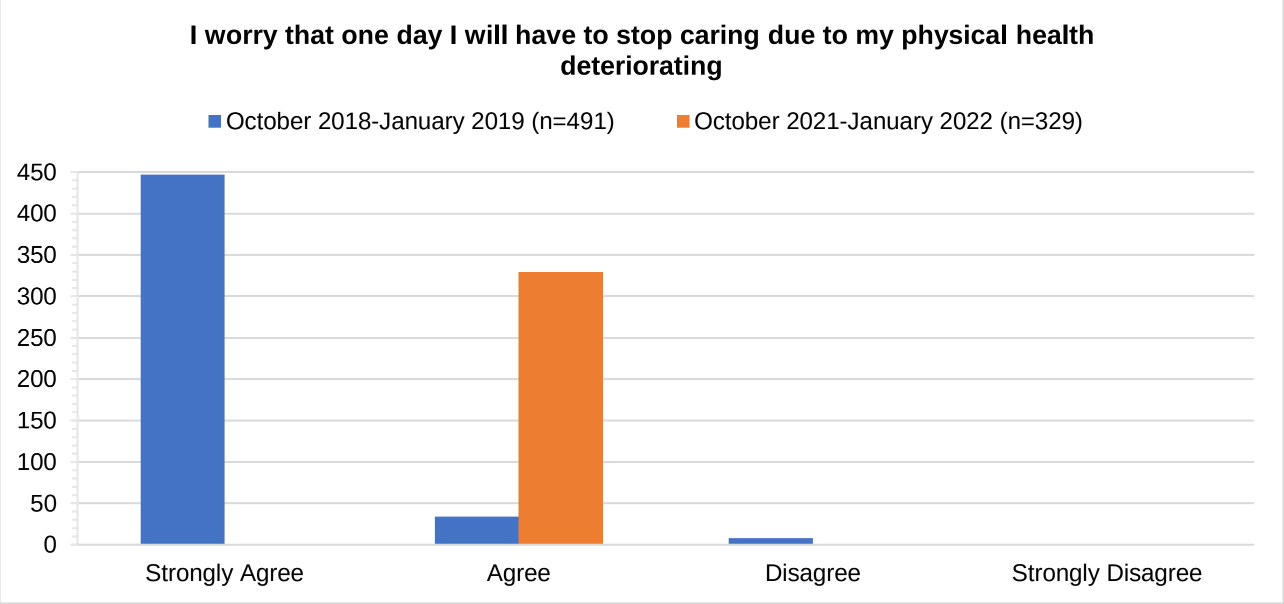
The following sets of graphs presents the number of carers answering the survey questions before and after the project.

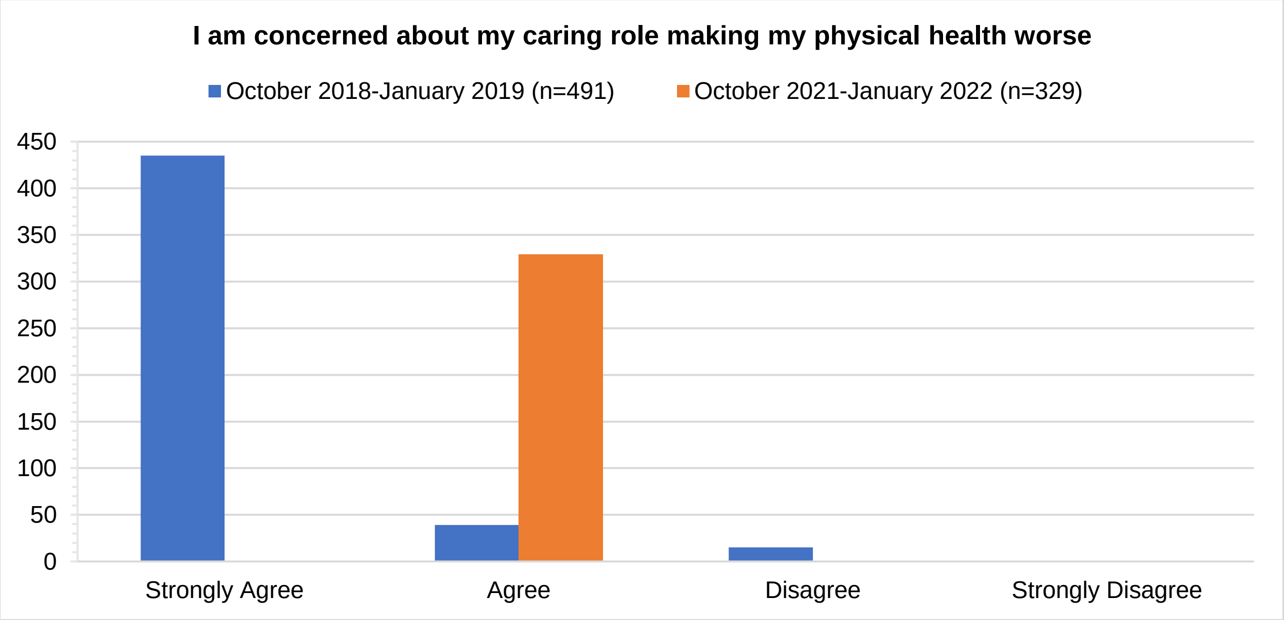

I do not have enough time to myself because of my caring responsibilities
October 2018-January 2019 (n=491)
October 2021-January 2022 (n=329)
400
350
300
250
200
150
100
50
0
Strongly Agree
Agree
Disagree
Strongly Disagree

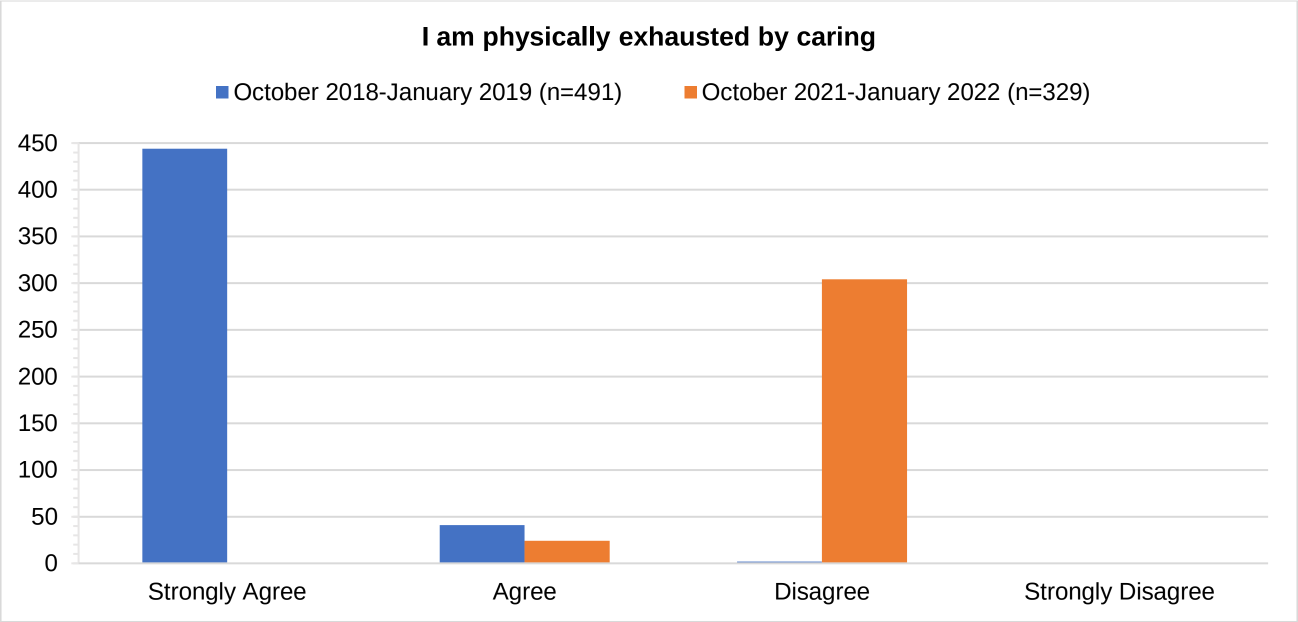

I am unable to take a break from caring
October 2018-January 2019 (n=491)
October 2021-January 2022 (n=329)
400
350
300
250
200
150
100
50
0
Strongly Agree
Agree
Disagree
Strongly Disagree

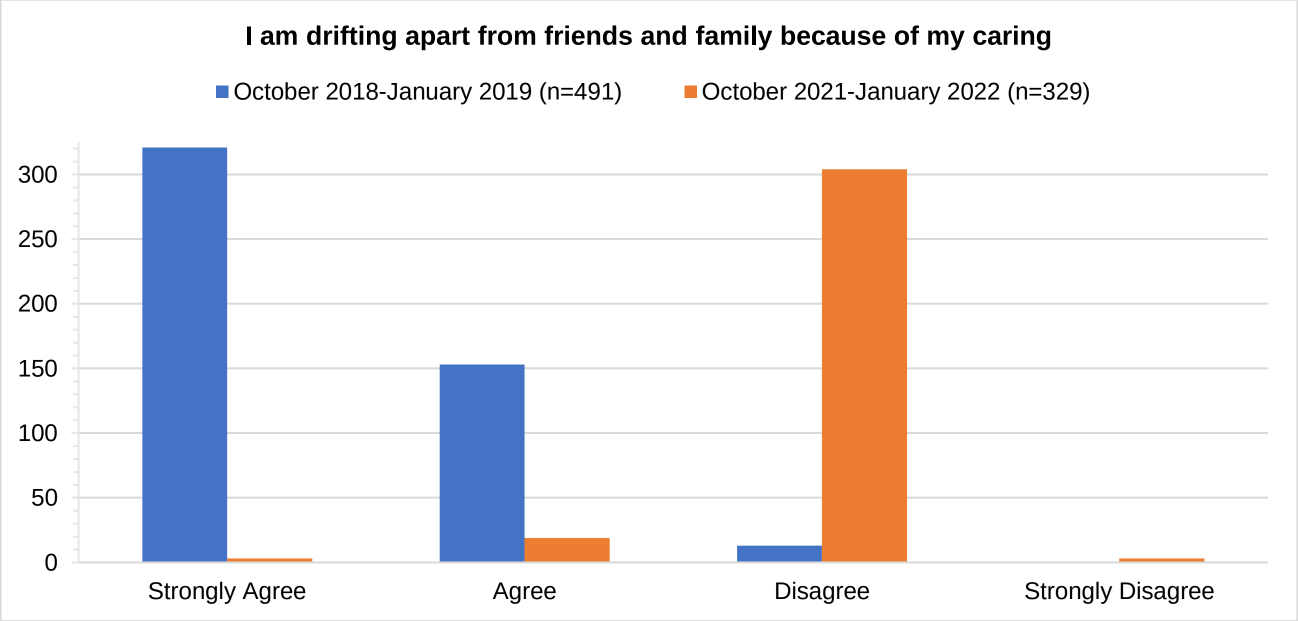

I am unable to plan for the future
October 2018-January 2019 (n=491)
October 2021-January 2022 (n=329)
400
350
300
250
200
150
100
50
0
Strongly Agree
Agree
Disagree
Strongly Disagree

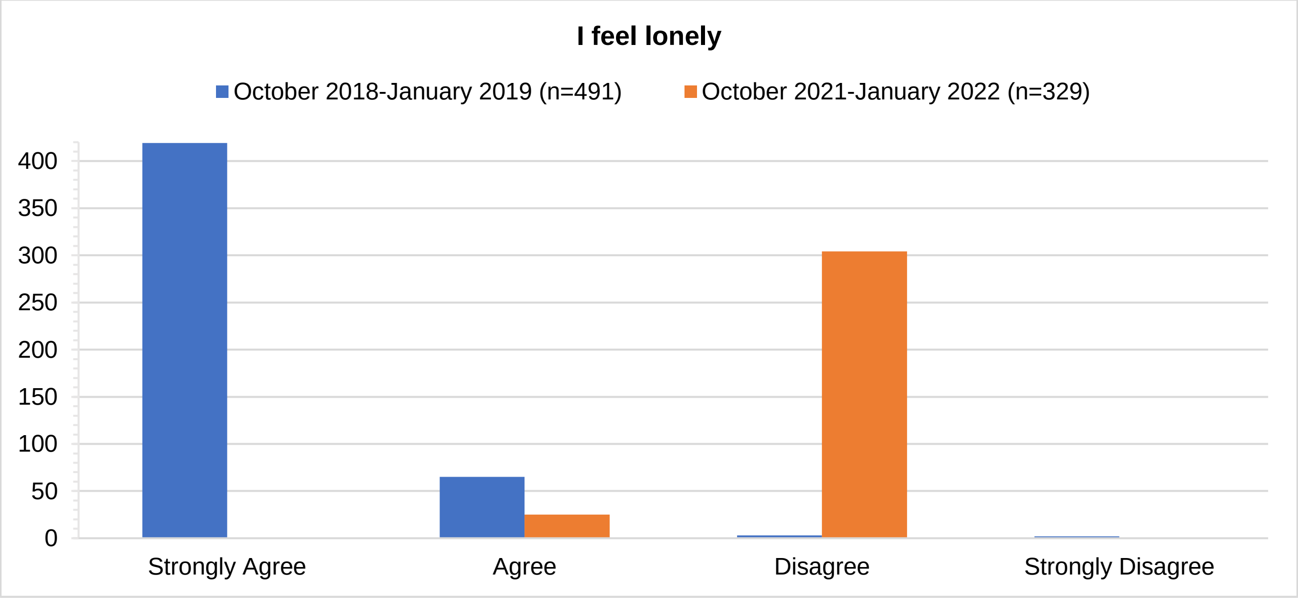

I am concerned about my own physical health due to caring
October 2018-January 2019 (n=491)
October 2021-January 2022 (n=329)
400
350
300
250
200
150
100
50
0
Strongly Agree
Agree
Disagree
Strongly Disagree

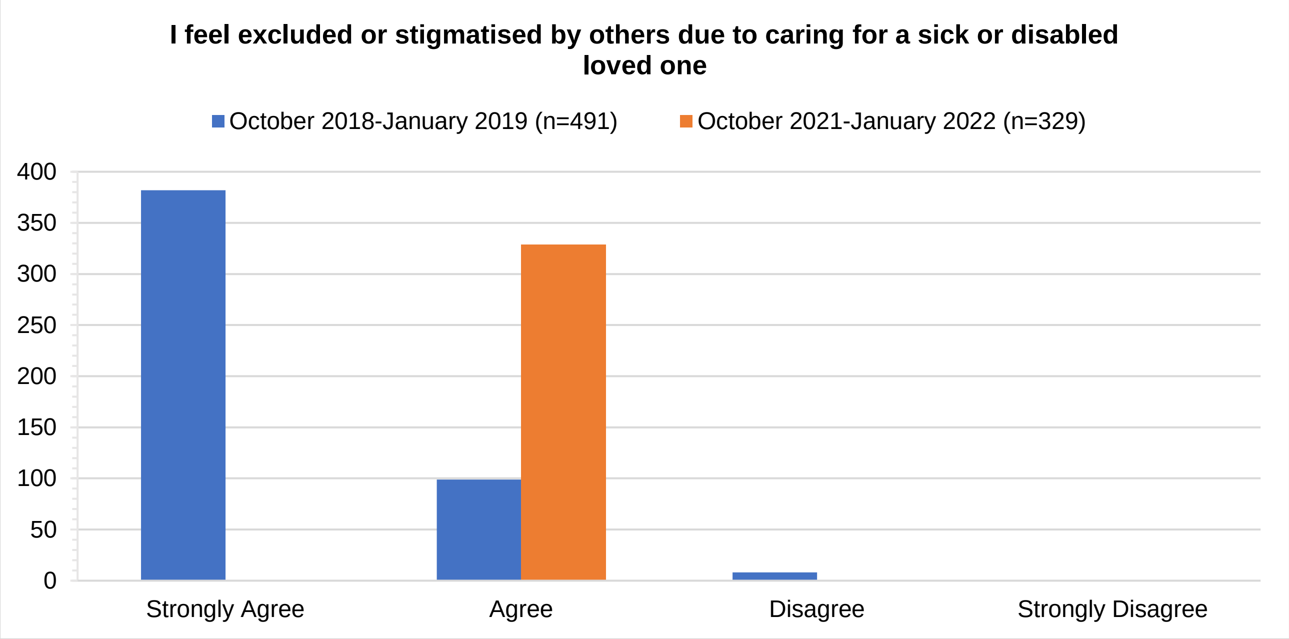

I worry that one day I will have to stop caring due to my physical health deteriorating
October 2018-January 2019 (n=491)
October 2021-January 2022 (n=329)
450
400
350
300
250
200
150
100
50
0
Strongly Agree
Agree
Disagree
Strongly Disagree

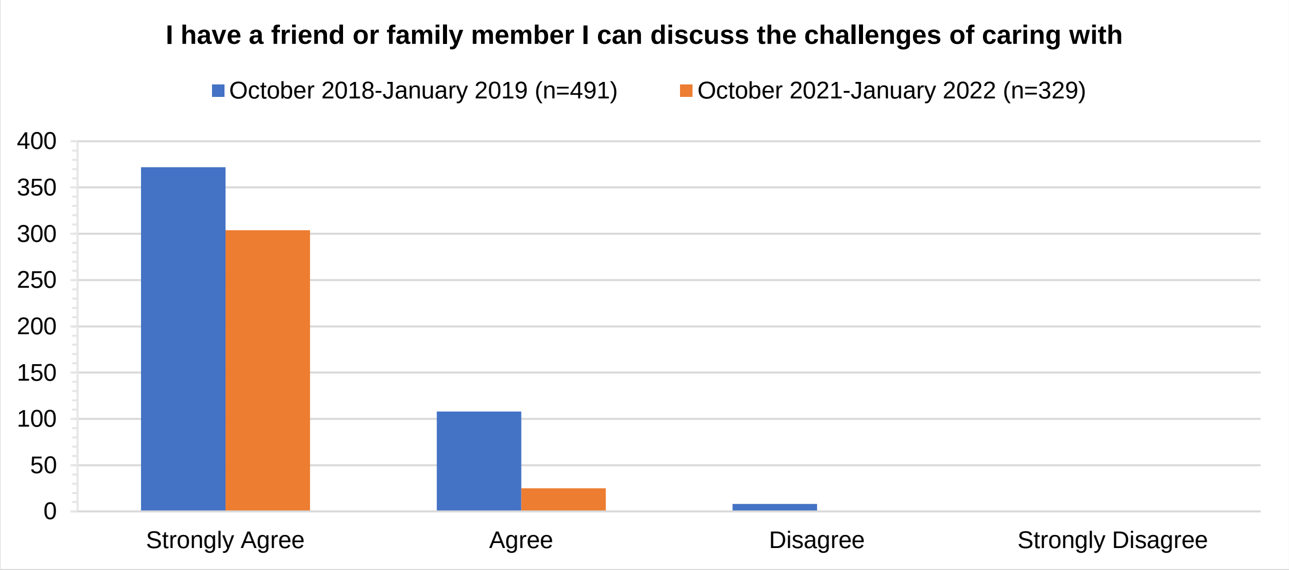

I am concerned about my caring role making my physical health worse
October 2018-January 2019 (n=491)
October 2021-January 2022 (n=329)
450
400
350
300
250
200
150
100
50
0
Strongly Agree
Agree
Disagree
Strongly Disagree

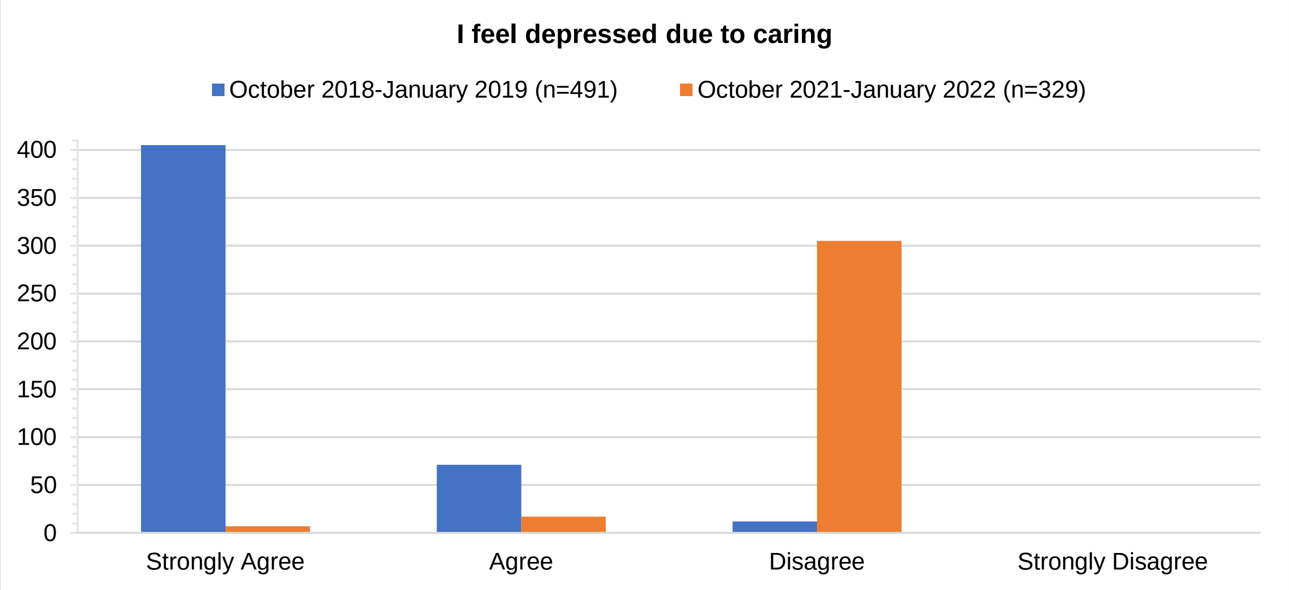

I am physically exhausted by caring
October 2018-January 2019 (n=491)
October 2021-January 2022 (n=329)
450
400
350
300
250
200
150
100
50
0
Strongly Agree
Agree
Disagree
Strongly Disagree

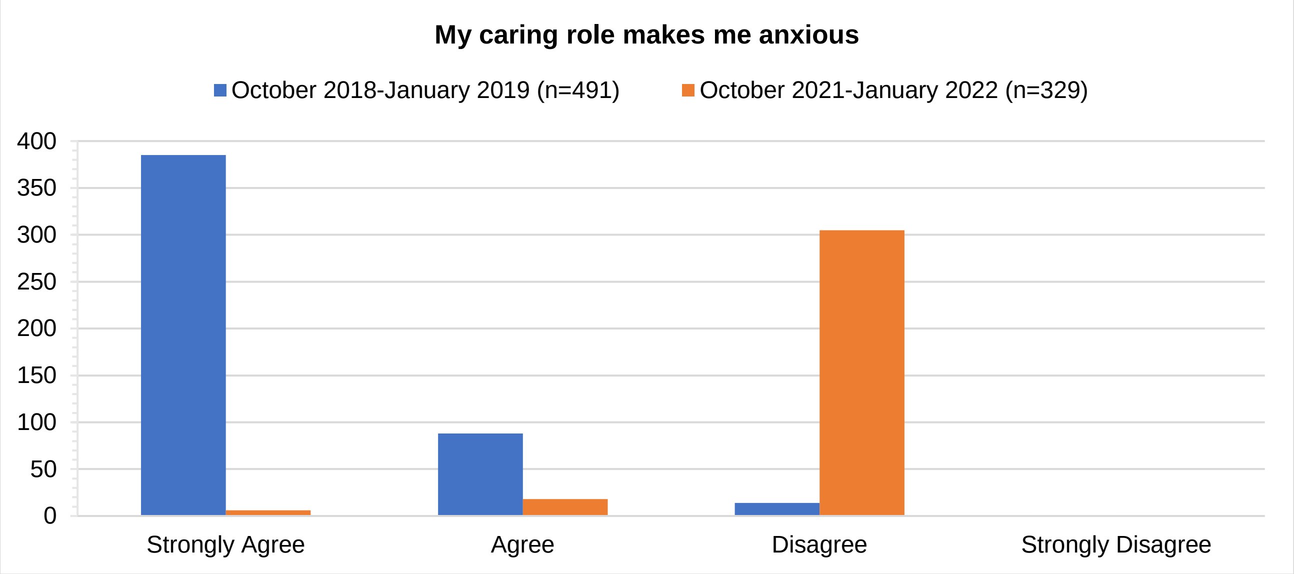

I am drifting apart from friends and family because of my caring
October 2018-January 2019 (n=491)
October 2021-January 2022 (n=329)
300
250
200
150
100
50
0
Strongly Agree
Agree
Disagree
Strongly Disagree

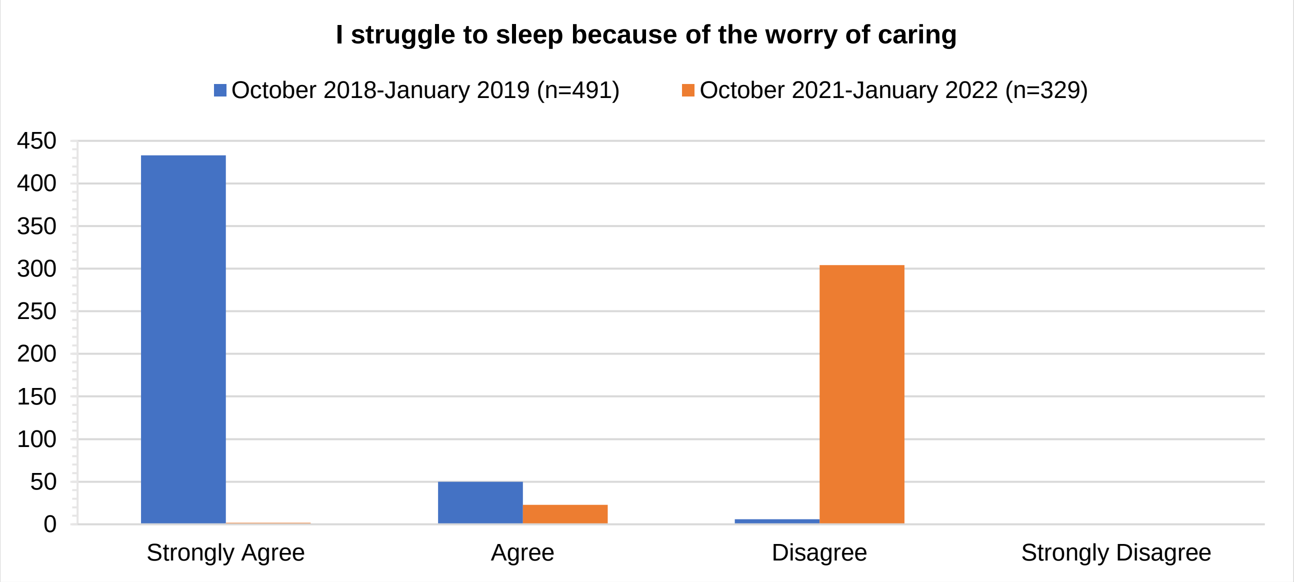

I feel lonely
October 2018-January 2019 (n=491)
October 2021-January 2022 (n=329)
400
350
300
250
200
150
100
50
0
Strongly Agree
Agree
Disagree
Strongly Disagree

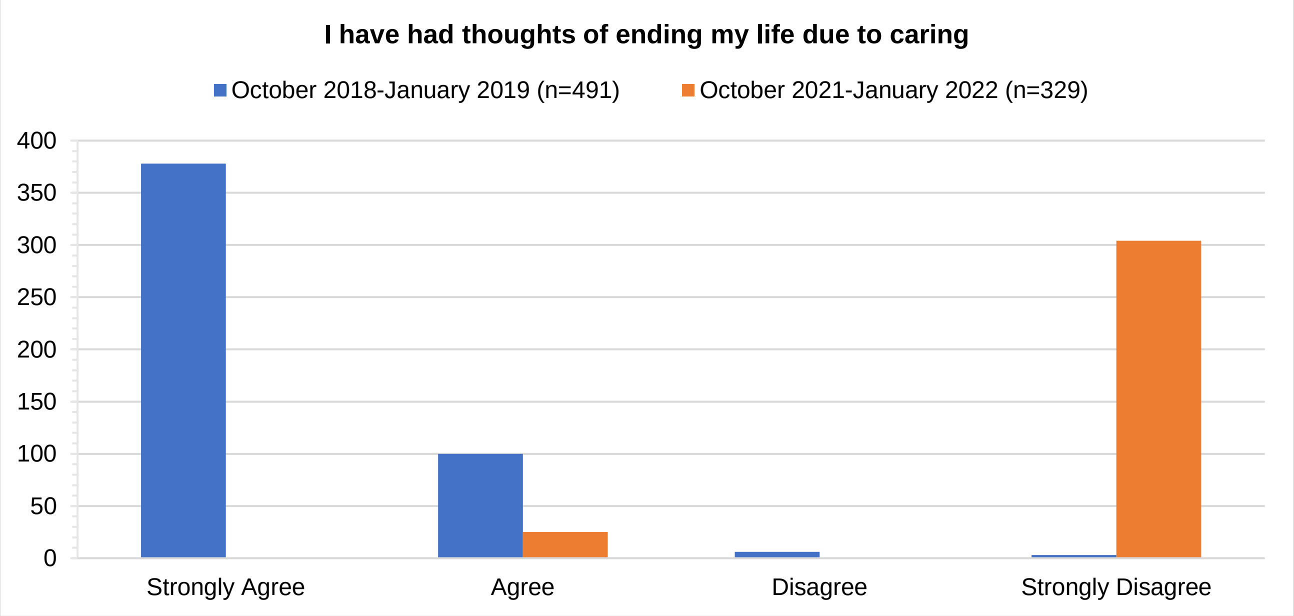

I feel excluded or stigmatised by others due to caring for a sick or disabled loved one
October 2018-January 2019 (n=491)
October 2021-January 2022 (n=329)
400
350
300
250
200
150
100
50
0
Strongly Agree
Agree
Disagree
Strongly Disagree

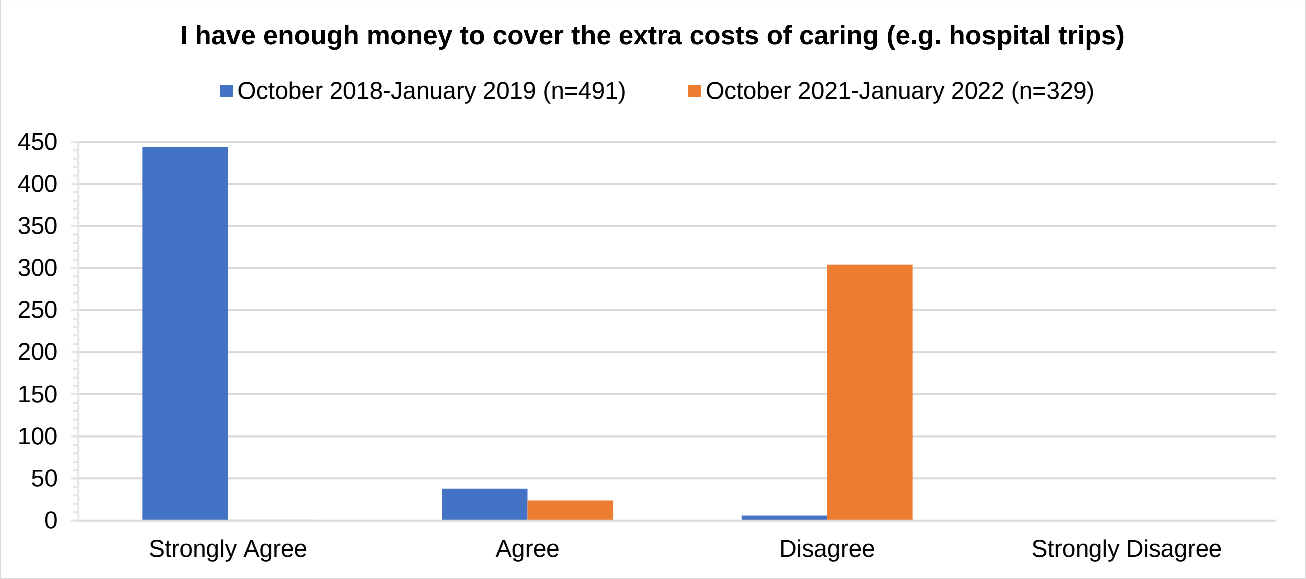

I have a friend or family member I can discuss the challenges of caring with
October 2018-January 2019 (n=491)
October 2021-January 2022 (n=329)
400
350
300
250
200
150
100
50
0
Strongly Agree
Agree
Disagree
Strongly Disagree

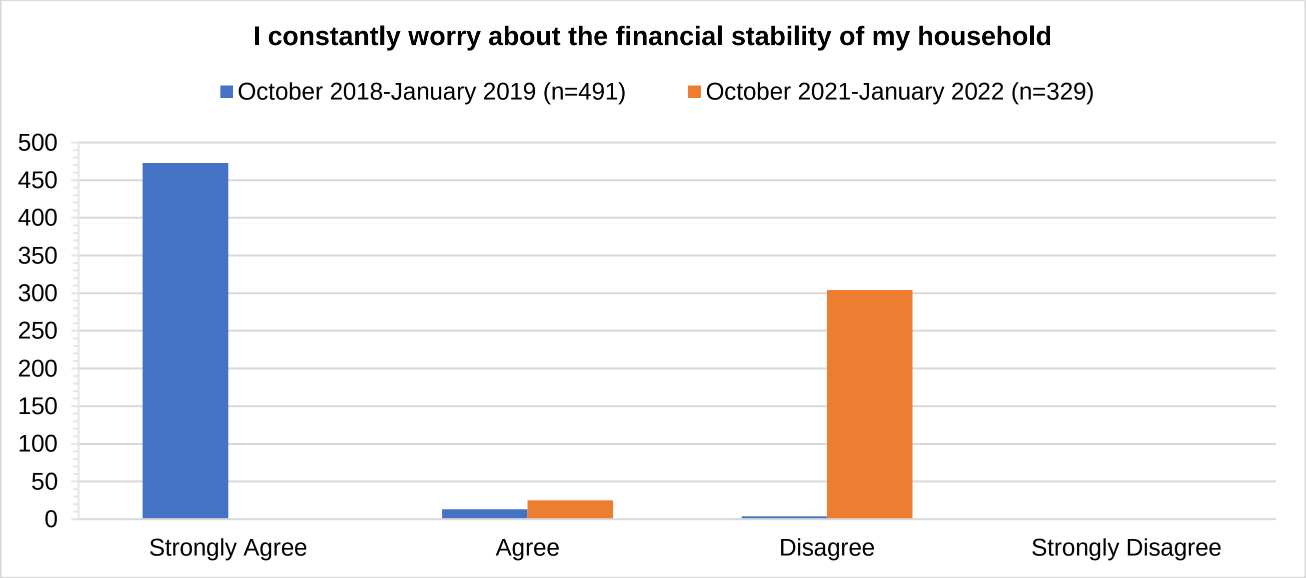

I feel depressed due to caring
October 2018-January 2019 (n=491)
October 2021-January 2022 (n=329)
400
350
300
250
200
150
100
50
0
Strongly Agree
Agree
Disagree
Strongly Disagree


My caring role makes me anxious
October 2018-January 2019 (n=491)
October 2021-January 2022 (n=329)
400
350
300
250
200
150
100
50
0
Strongly Agree
Agree
Disagree
Strongly Disagree


I struggle to sleep because of the worry of caring
October 2018-January 2019 (n=491)
October 2021-January 2022 (n=329)
450
400
350
300
250
200
150
100
50
0
Strongly Agree
Agree
Disagree
Strongly Disagree


I have had thoughts of ending my life due to caring
October 2018-January 2019 (n=491)
October 2021-January 2022 (n=329)
400
350
300
250
200
150
100
50
0
Strongly Agree
Agree
Disagree
Strongly Disagree





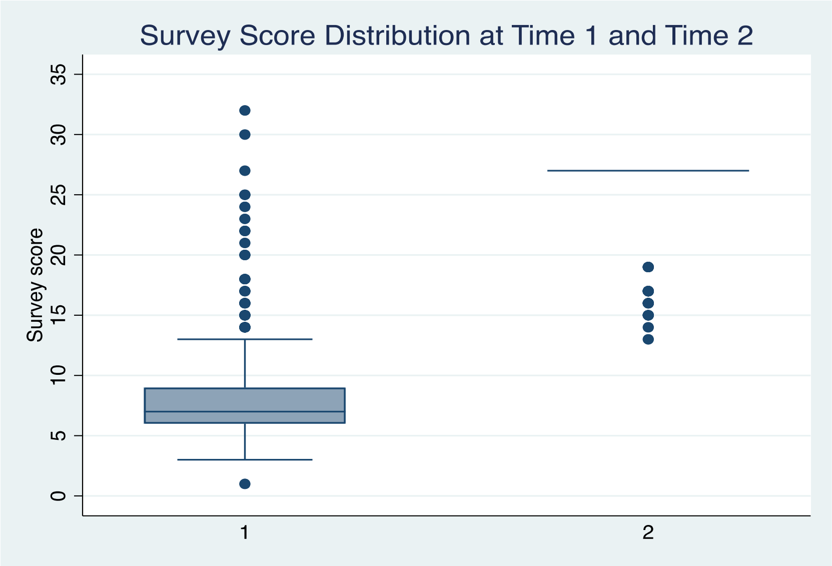


Figure 1. Survey Score Distribution at Time 1 and Time 2

BASELINE SURVEY RESULTS FOR CARER GROUP 2

Summary

The following section presents the baseline survey results of a second group of carers (n=506; hereafter referred to as “Carer Group 2”) recruited in the expansion of the Carers Worldwide support model. The data was collected with the second survey (i.e., the one which was also used at Time 2 for Carer Group 1).

Carer characteristics

Gender. Of the 506 carers in the sample, 475 were female (93.87%) and 31 were male (6.13%), suggesting a gender bias in the adoption of caring responsibilities.

Age. The majority of carers in the sample were of working age (between the ages of 15-64), with the mean age= 38.88933, std error=0.6074577. Table 4 and Figure 2 presents the age distribution of the carers.

Age category	Frequency	Percentage
0-14	9	1.78
15-24	49	9.68
25-34	134	26.48
35-44	150	29.64
45-54	81	16.01
55-64	57	11.26
65-74	19	3.75
75-90	7	1.38
Total	**506**	**100.00**

Table 4. Distribution of carers’ age

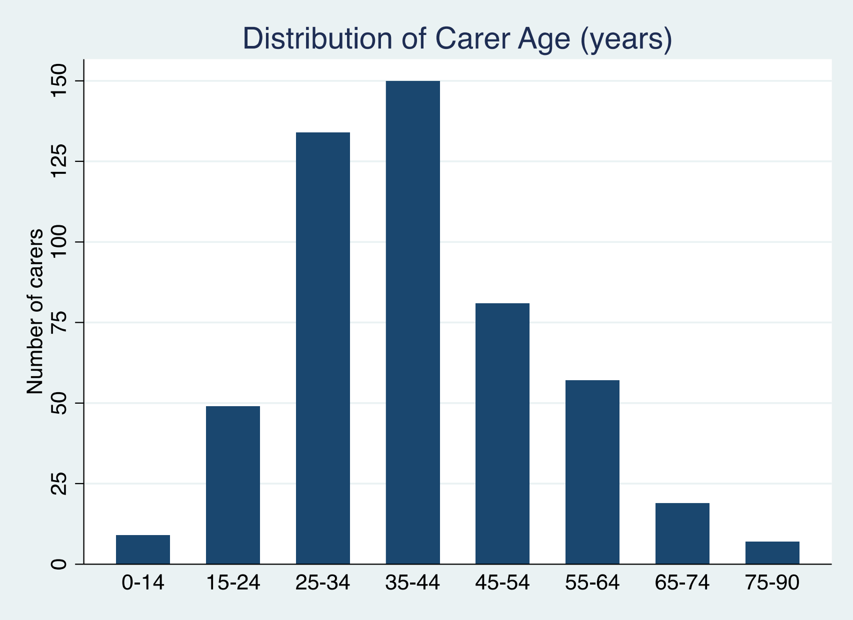


Figure 2. Distribution of carer age in years.

Marital status. Most carers were married (n=443, 87.55%), followed by widowed (n=33, 6.52%), single (n=23, 4.55%), divorced (n=7, 1.38%).

Do you have an identity card? Most carers (n=486, 96.05%) possessed a form of legal identification (e.g., national identity card, passport, driver's license). Only 20 carers did not (3.95%). Of those 20 carers, 14 were above the age of 18, 19 were female and 1 was male.

Carer education, employment, and income

Highest level of education attained. Most carers were educated at the primary education level (n=164, 32.41%), followed by no education (n=160, 31.62%), junior secondary education to secondary education/SSC (n=141, 27.87%), HSC (n=22, 4.35%), and university level or Bachelor and Master-level (n=19, 3.75%). Figure X presents the carer distribution in highest educational level attained.

Present education status. 85.57% of carers (n=433) were not studying because they were not of school age. Fifty-seven (11.26%) of carers stated they were not studying but were of school age. Finally, 16 carers (3.16%) were currently studying (including vocational training); they were between the ages of 11-47.

Interestingly, of the 433 carers who stated they were not studying because they were not of school age, 4 were between the ages of 13-17 and therefore were old enough to attend Junior Secondary to Higher Secondary school; 49 were between the ages of 18-25, and therefore were old enough to attend post-secondary education.

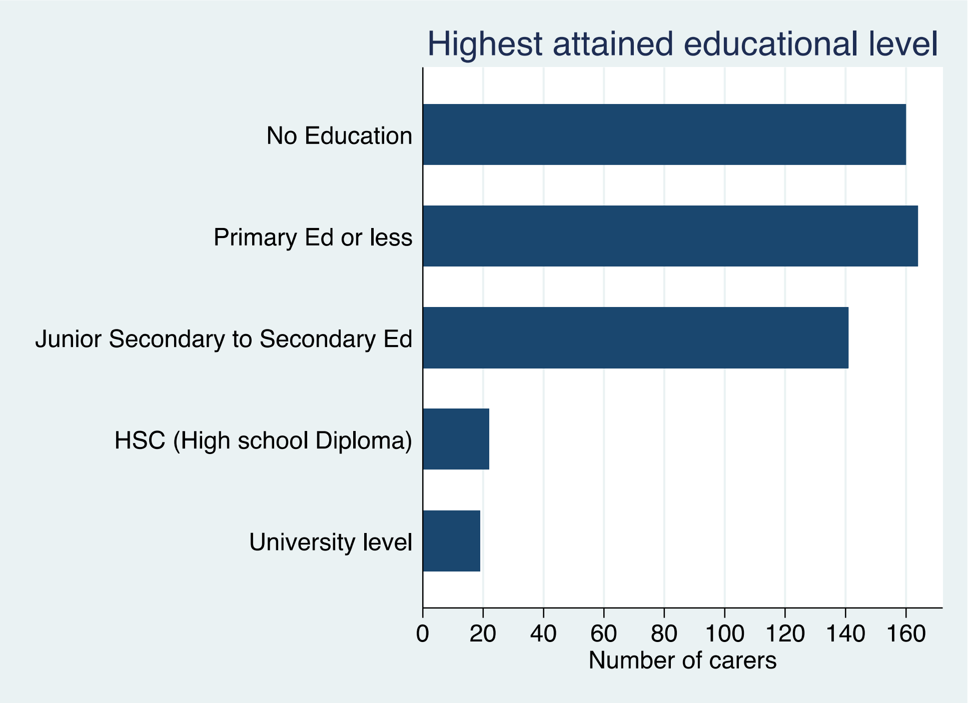


Figure 3. Distribution of carers per highest educational level attained

Paid employment status and change in employment status due to caring. Most carers (n=467, 92.29%) were not currently in paid employment, with a minority (n=16, 3.16%) having regular work and 23 having non-regular paid employment (4.55%). Of the 467 carers stating they were not in employment, 85% (n=396) claimed this was due to caring responsibilities (see Figure X). 9 out of 23 carers who had irregular paid employment claimed that this was due to caring responsibilities (~39%). While the majority of carers (n=409, 80.83%) were not in paid employment before starting their provision of care, 30 carers (5.93%) stated they had to completely or partly give up paid work in order to become a carer. 67 (13.24%) of carers were still performing the same amount of work despite their caring responsibilities.

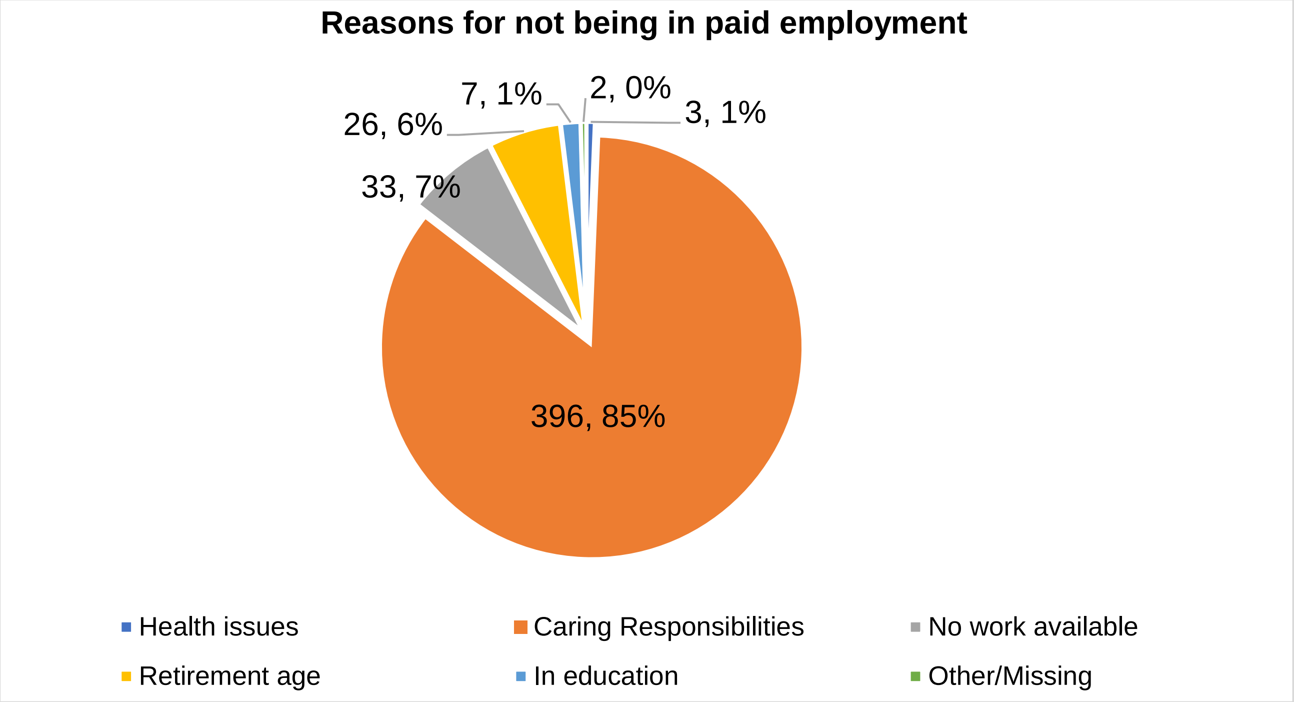


Figure 4. Non-employed carers' reasons for not being in paid employment

Annual income. Of those in some form of paid employment, their individual annual income ranged from ৳5,000 to ৳1,44,000 (equivalent to ~£43 to ~£1,237).

Household and Caring Situation

Number of people in the household. The mean number of people in the households of carers (including themselves) was ~4.46 (.067; CI: 4.33-4.60). Thus, most households in the sample (n=152, 30.04%) had 4 individuals, followed by 5 (n=117, 23.12%), and 3 (n=102, 20.16%).

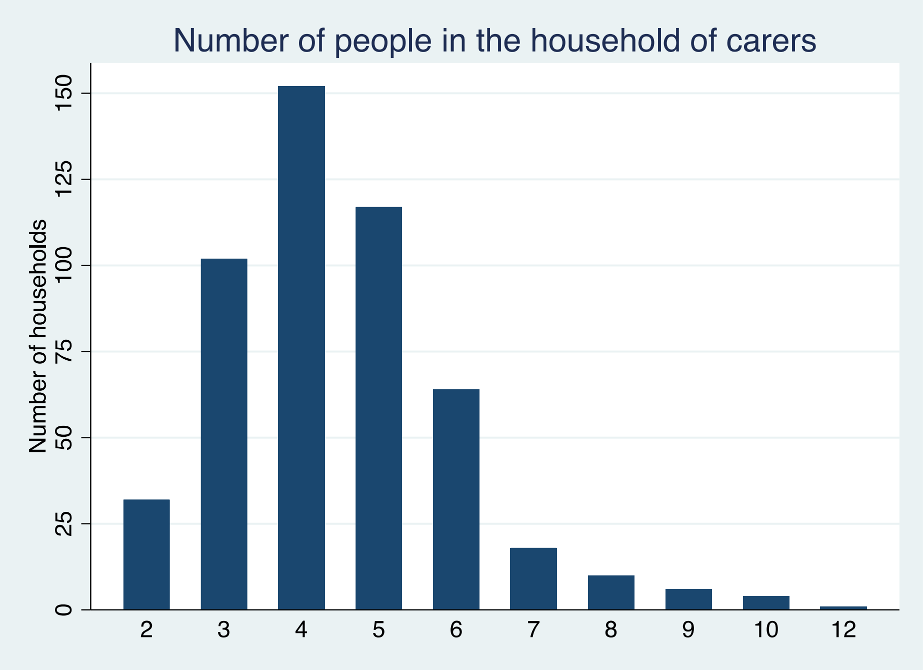


Figure 5. Number of people in the household of carers

Who they cared for and for how long. Most carers (n=277, 54.74%) in the sample cared for a daughter or a son, 94 carers (18.58%) cared for a spouse or partner, 27 carers (5.34%) cared for a granddaughter or grandson. Those carers who answered “Other” (n=51, 10.08%) cared for brothers and sisters (including in-laws). The mean length of caring was approximately 184 months (6.42; CI: 170.98-196.20), or close to 15 years, and all carers (n=506, 100%) stated they cared 7 days a week. When asked how many hours they had cared for in the previous week, most carers (n=312, 61.66%) said they had cared for 54 hours; the mean time spent caring was approximately 55 (0.22; CI: 54.25-55.12).

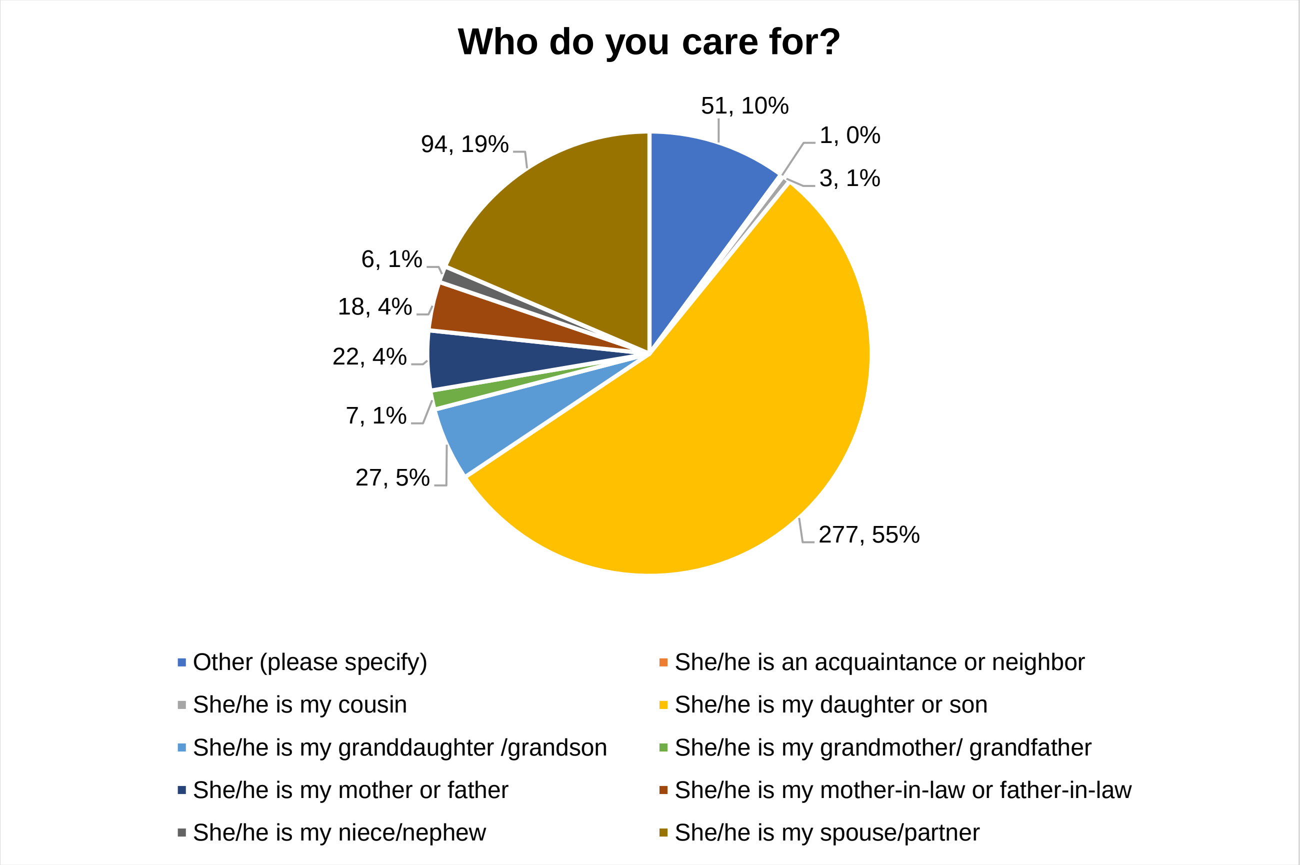


Figure 6. Relationship with the care-recipient

Support for caring role. In most cases (n=489, 98.64%), the carer was providing care alone, with no help from other people. The minority of carers who did receive help from other people (n=17, 3.36%) often did so from family members including mothers, fathers, brothers, sisters, daughters, grandmothers, spouse, and in-laws. Most carers (n=474, 93.86%) were not a part of a help or support group, with only 32 carers (6.32%) currently accessing this type of support.

Household income and income sources. Figure 7 presents the distribution of annual household income. Most families (n=152, 30.04%) earned between ৳84,001 to ৳120,000 (equivalent to ~£724.31 to ~£1,035). Alternative sources of income from paid employment included disability pension (n=137), old age pension (n=16), retirement pension (n=3), widow pension (n=2), property income (n=11), loans from banks, government schemes or other sources (n=78) and other forms of income such as agriculture (n=11), begging (n=2), help from family or people (n=5).

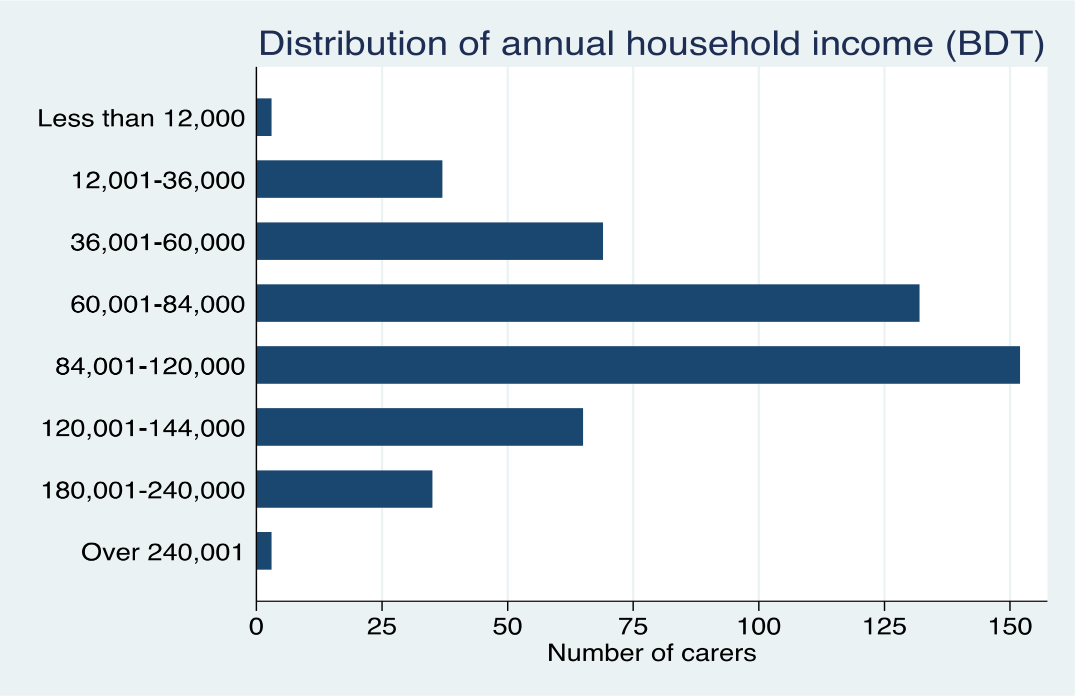


Figure 7. Distribution of carers per highest educational level attained

Household possessions and income quintiles. The baseline survey collected information on the household possessions and household materials of carers to understand the relative wealth of the project participants with regards to the general population of Bangladesh. Tables 5 and 6 depict the families' household possessions and materials; 183 carers stated that their households had all four possessions. Using the Metrics for Management Equity Tool (Tables 7 and 8), which separated participants into 5 wealth quintiles (Quintiles 1 being the poorest and Quintile 5 being the richest), the baseline survey showed that compared to the urban population of Bangladesh, the carers enrolled in the project were concentrated around quintiles 2-4, suggesting an average level wealth within the participants relative to the rest of the urban population. Relative to the national wealth of Bangladesh, the carers enrolled in the project were concentrated around quintiles 4-5, a logical result given that the study setting was Dhaka.

Household possessions	**Yes**	**No**
Televisions	335	171
Fridge	320	186
Almirah or wardrobe	252	254
Electric fan	496	10

Table 5. Household possessions of carers

Household Materials	**Cement**	**Earth/Sand**	**Other (tin, iron steel)**
Floor	358	121	27
Roof	107	21	378
Exterior walls	217	30	259

Table 6. Household materials of carers

Urban Quintile	Number of carers	Percent	Cumulative
Quintile 1	35	6.92	6.92
Quintile 2	148	29.25	36.17
Quintile 3	155	30.63	66.80
Quintile 4	112	22.13	88.93
Quintile 5	56	11.07	100.00
Total	506	100.00	

Table 7. Wealth distribution of the carers in the sample relative to urban wealth

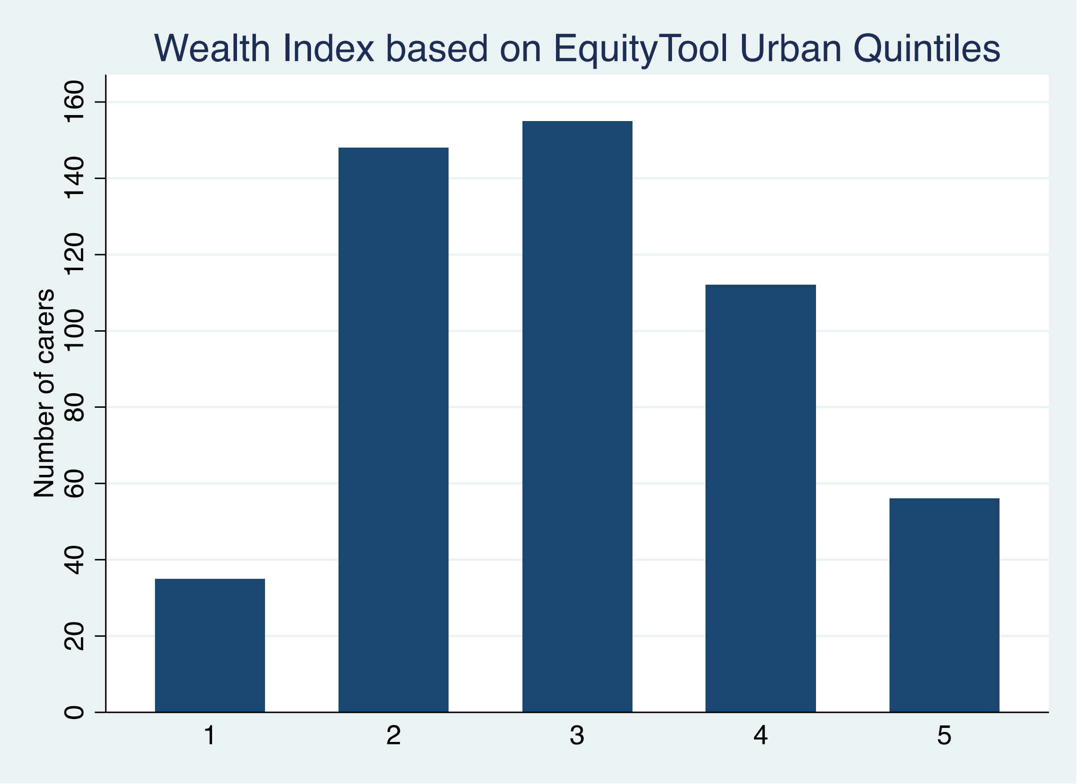


Figure 8. Wealth distribution of the carers in the sample relative to urban wealth

National Quintile	Number of carers	Percent	Cumulative
Quintile 1	0	0	0
Quintile 2	28	5.53	5.53
Quintile 3	52	10.28	15.81
Quintile 4	206	40.71	56.52
Quintile 5	220	43.48	100.00
Total	506	100.00	

Table 8. Wealth distribution of the carers in the sample relative to national wealth

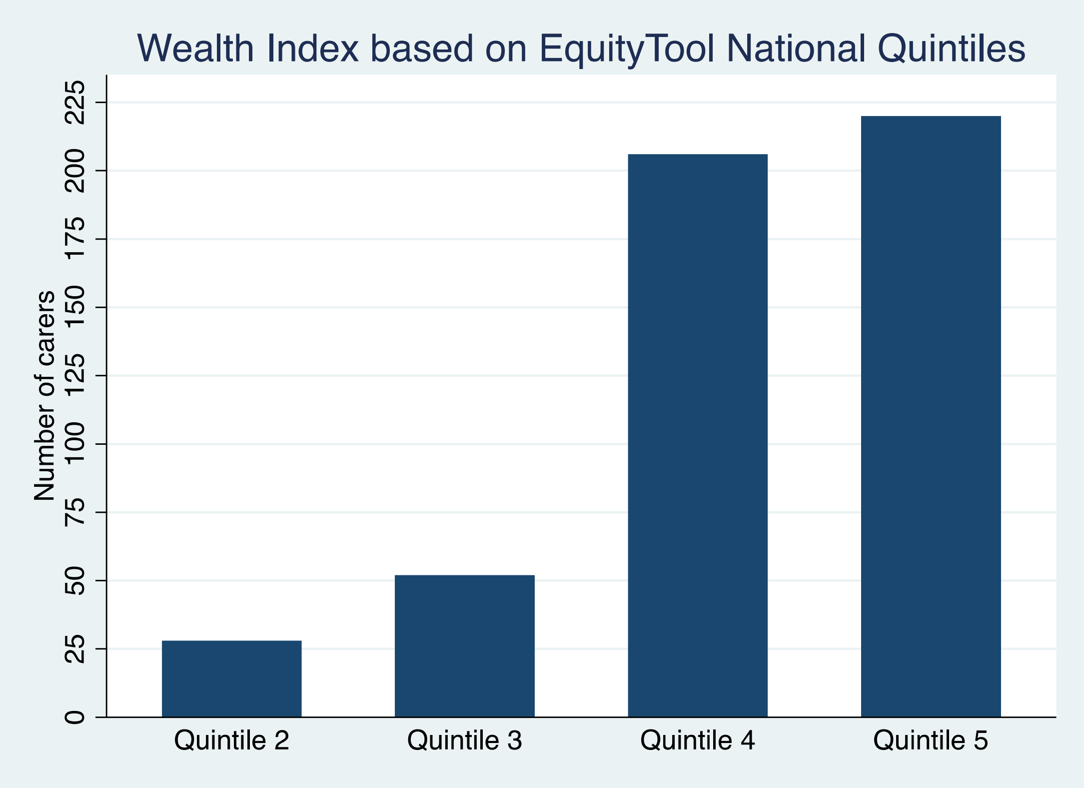


Figure 9. Wealth distribution of the carers in the sample relative to national wealth

Profile of the care-recipients

Gender. The care-recipients were in majority male (n=313, 61.86%), with 38.14% of care-recipients being female (n=193).

Age and condition. The care-recipients were in majority younger people (mean age≈25.14 std≈0.85) and seemed to be living with varied illnesses and disabilities, with the most common condition being physical disabilities (n=217, 42.89%), followed by cerebral palsy (n=74, 14.62%), and intellectual/learning disabilities (n=66, 13.04%). Only 59 care-recipients (11.66%) used assistance disability devices, with 55 stating they needed a new device. In slightly more than half of the cases (n=266, 52.57%), carers deemed the care-recipient could not be left alone (i.e., someone needed to be with them at all times), with 169 (33.40%) of carers stating they could leave the care-recipient alone, but not for more than an hour. 71 carers (14.03%) felt they could leave their care-recipients for more than one hour.

Age category	Frequency	Percentage
0-14	196	38.74
15-24	95	18.77
25-34	71	14.03
35-44	49	9.68
45-54	42	8.30
55-64	25	4.94
65-74	21	4.15
75-105	7	1.38
Total	**506**	**100.00**

Table 9. Distribution of care-recipients' age

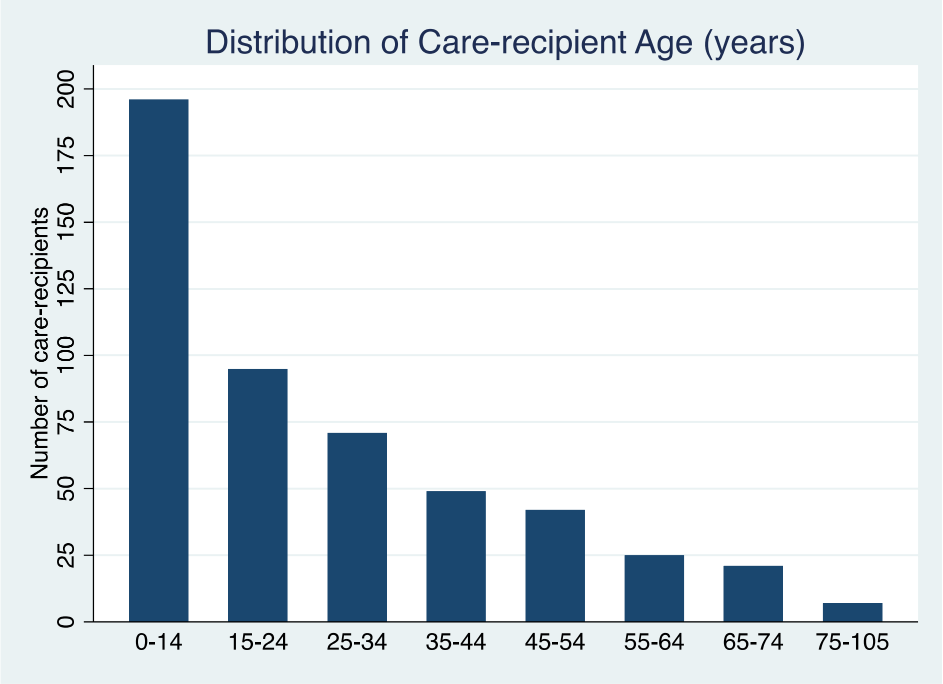


Figure 10. Distribution of care-recipient age in years.

Care-recipient condition	**Number of care-recipients**	**Percent**
Autism spectrum	5	0.99
Down’s syndrome	9	1.78
Communication or speech disability	38	7.51
Visual disability	23	4.55
Hearing disability	14	2.77
Intellectual/learning disability	66	13.04
Mental illness	29	5.73
Physical disability	217	42.89
Cerebral palsy	74	14.62
Dementia/Alzheimer’s Disease	2	0.40
Multiple disabilities	29	5.73
Total	**506**	**100.00**

Table 10. Care-recipient conditions

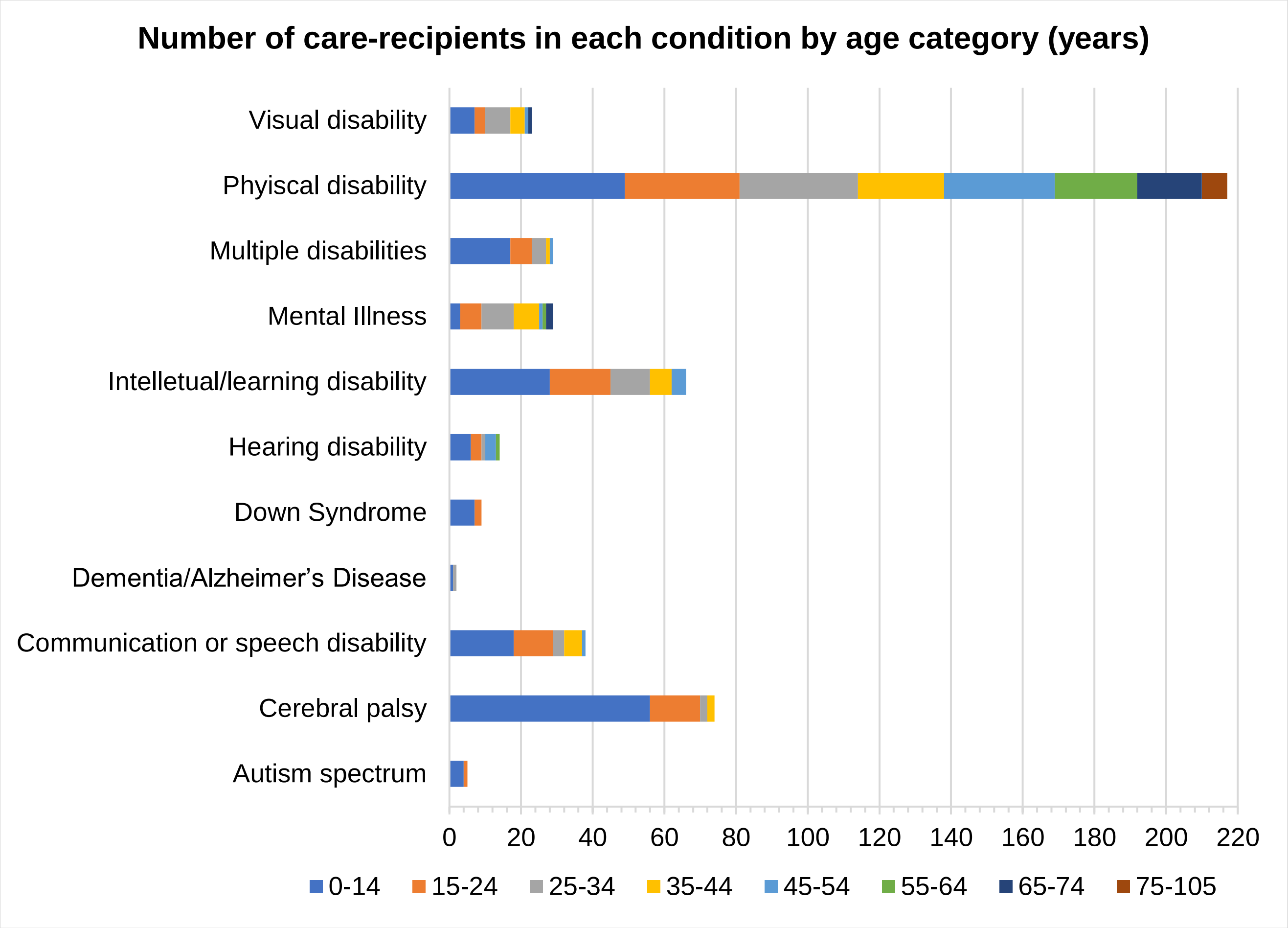


Figure 11. Distribution of care-recipient conditions per age category (years)

Work status and annual income. Most care-recipients (n=489, 96.64%) were not working with only 17 care-recipients (3.36%) working. Of those in some form of paid employment, their individual annual income ranged from ৳1,500 to ৳1,44,000 (equivalent to ~£12.81 to ~£1,237).

Carer health and wellbeing

Presence of disability and/or health issues. Most carers did not consider themselves to have a disability (n=480, 94.86%), but seven of those carers shared they were suffering from chronic body pains and lower back pains. The carers considering themselves to have a disability (n=26, 5.14%) were living with a range of conditions, including back pain (n=1), lower back pain (n=6), body pains (n=1), body and back pains (n=3), mental illness (n=1), disability linked to old age (n=2), physical problem (n=2), and visual disability (n=2).

When asked: “Do you consider yourself to have a health issue?”, 337 said they did not (66.60%), six carers shared they had a mental health issue (1.19%), 158 carers were living with a physical health issue (31.23%), and five carers were living with both a physical and mental health issue (0.99%). Carers stating they had a health issue were asked whether they considered to have a disability, to which 157 individuals stated not having a disability (Table 11).

Do you consider yourself to have a disability? **Do you have a health issue?**	**No**	**Yes**
Mental health issue	6	0
No health issue	323	14
Physical health issue	146	12
Physical and mental health issue	5	0
Total	**480**	**26**

Table 11. Carers' perceptions of their disability and health issues

Seeking support. Of the 169 carers stating they had a health issue, 54 carers sought out support, and 110 carers did not (5 chose to not answer this question). Reasons for not attending included: Not knowing where to get treatment (n=1), Not needing or wanting treatment (n=36), Not having enough money to pay for the treatment (n=78), and Not having anyone to take care of the care-recipient while the carer seeks treatment (n=2) (52 carers chose not to answer this question). Finances are therefore a significant barrier in carers accessing support.

Below are the graphed distributions of carers' responses to Likert-type questions about their perceptions of support (Figure 12); perceived emotional, mental, and physical wellbeing and feelings of loneliness and isolation (Figure 13); respite and control over their life (Figure 14); and feeling valued as a carer (Figure 15).

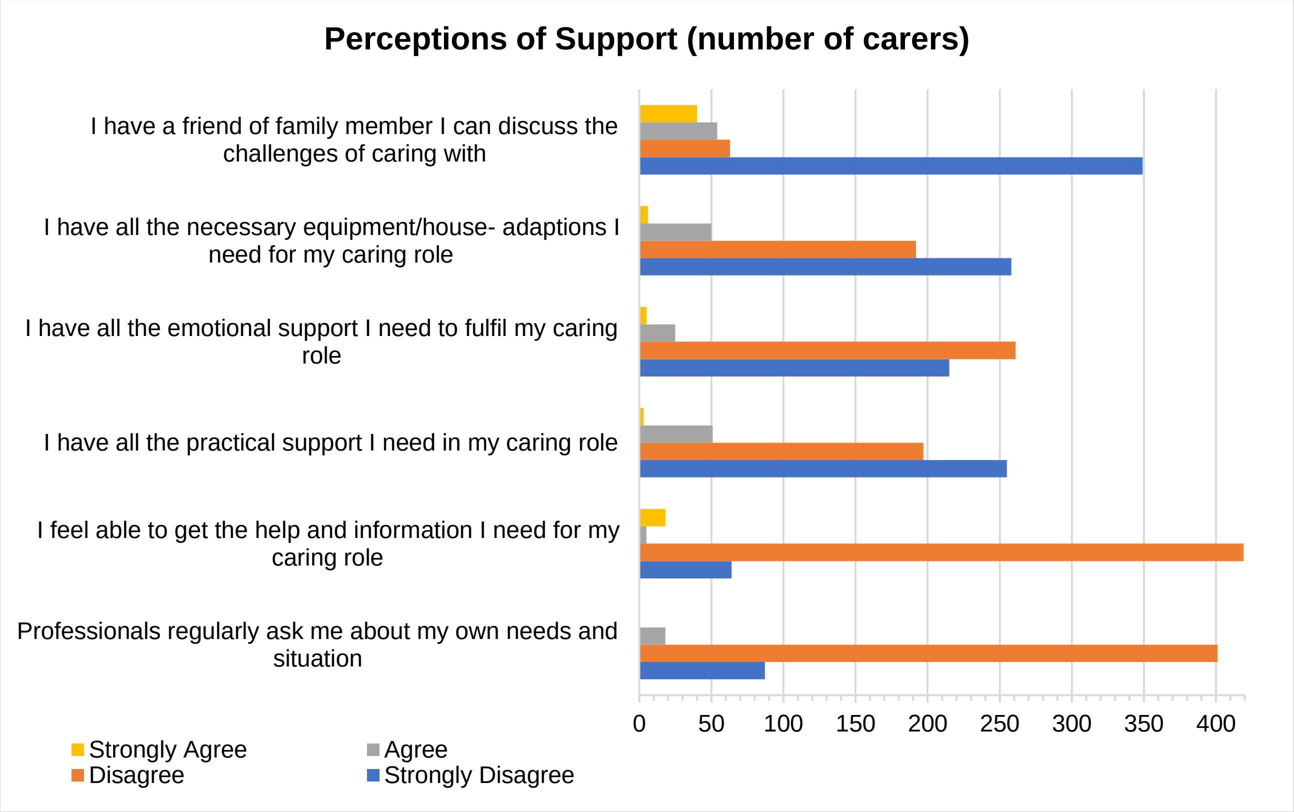


Figure 12. Carers' responses to Likert-type questions about their perceptions of support

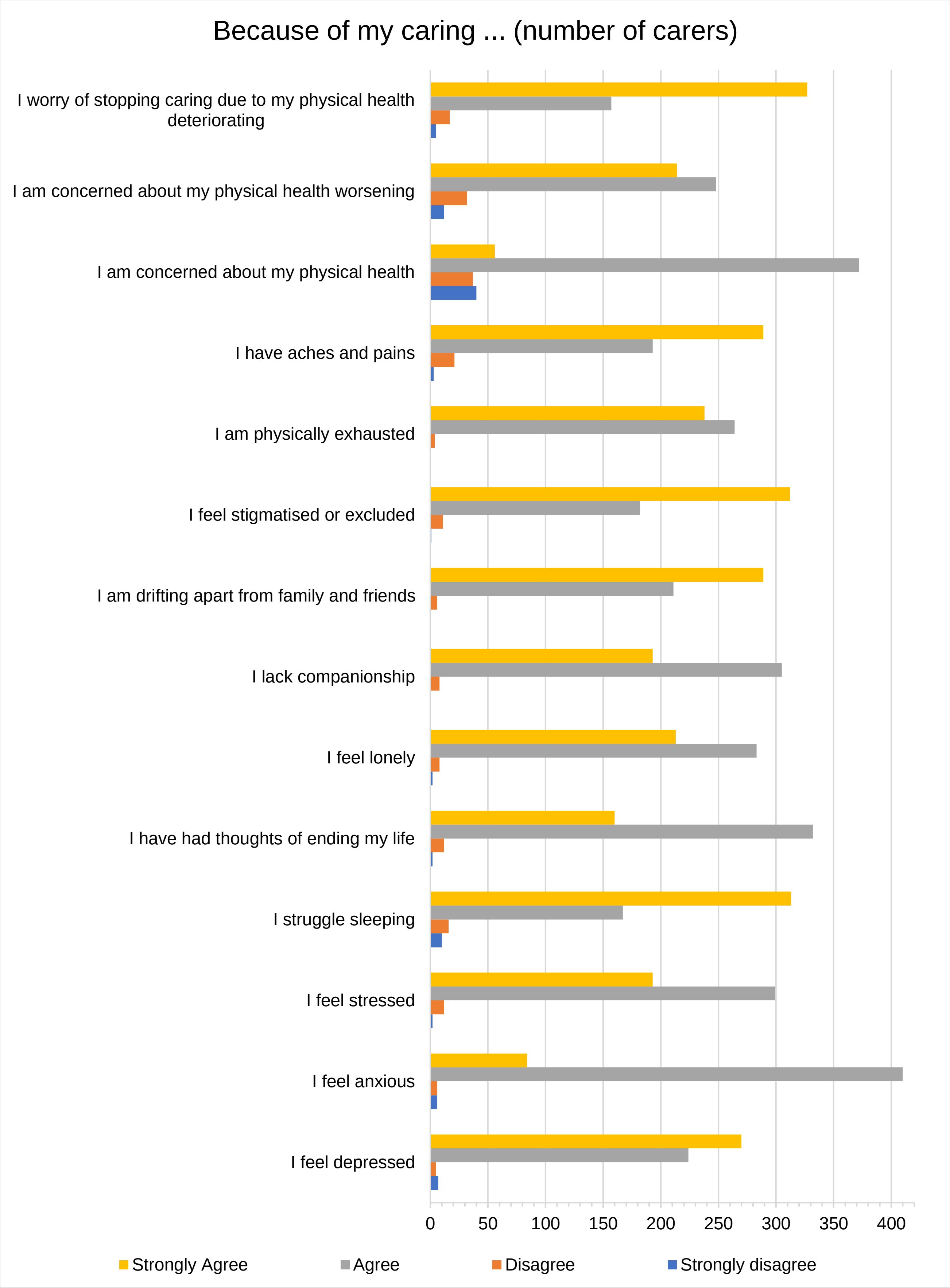


Figure 13. Carers' responses to Likert-type questions about their emotional and mental wellbeing, their physical wellbeing, and their feelings of loneliness and isolation.

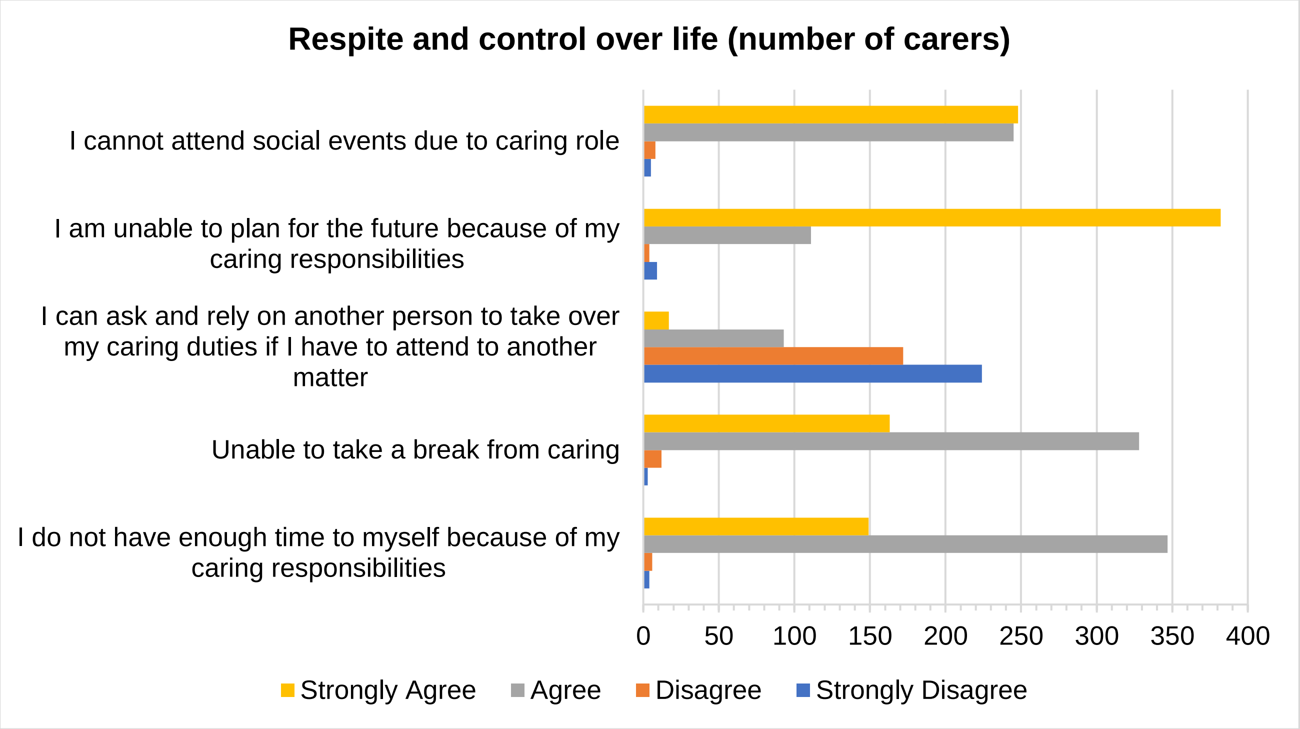


Figure 14. Carers' responses to Likert-type questions about how they perceive their time and control over their life

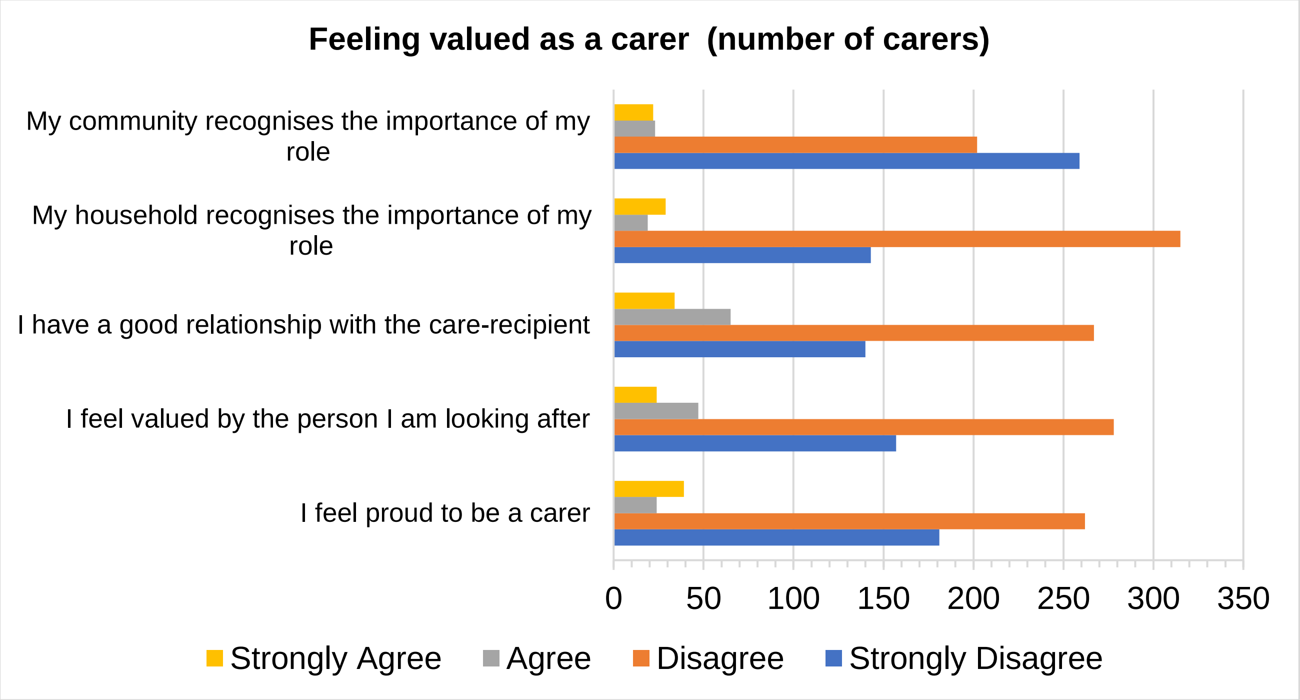


Figure 15. Carers' responses to Likert-type questions about how valued they feel as a carer

Carer overall concerns

Most pressing issues. When asked to list the three most pressing issues that made caring more difficult, carers listed economic and financial problems as the first most pressing issue/need. This coincides with carers' answers to Likert-type questions about their financial concerns (Figure 16). The second most pressing issue was physical health problems, and the third social problems.

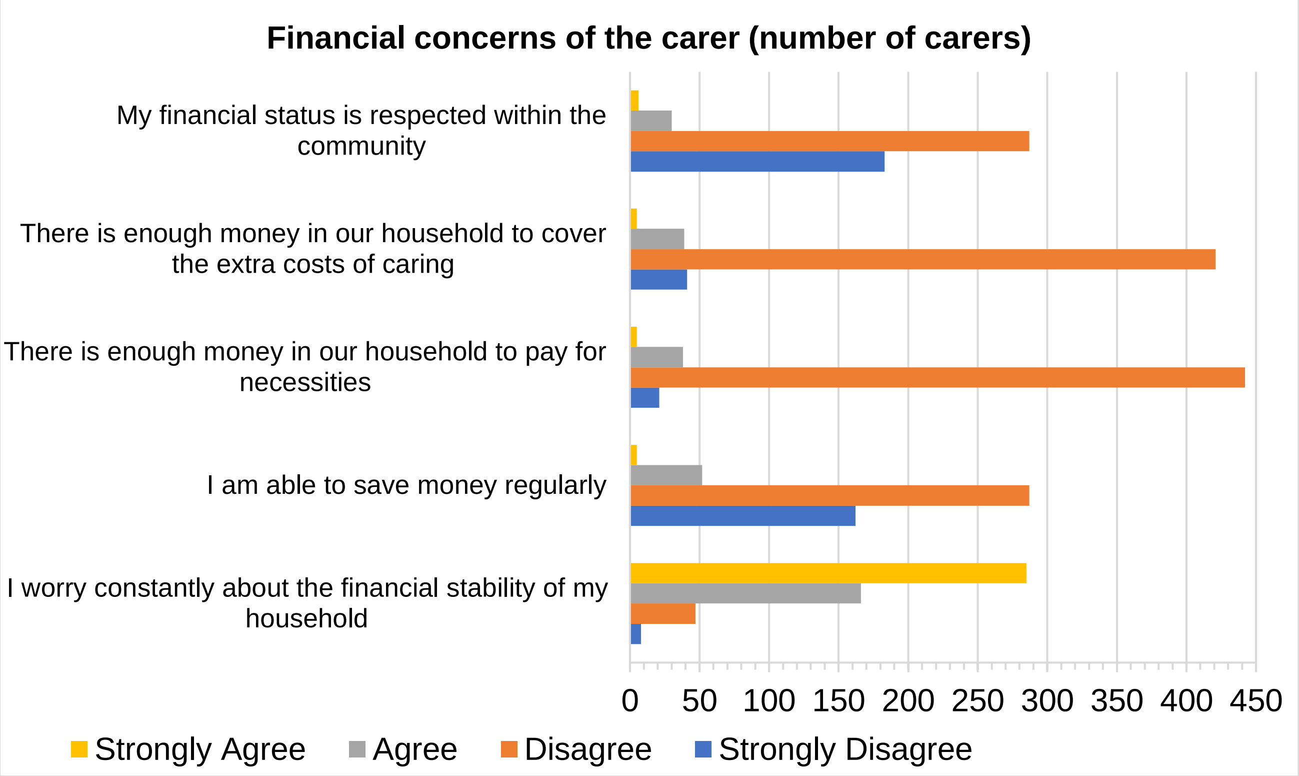


Figure 16. Carers' responses to Likert-type questions about their financial concerns

Confidence in advocacy. When asked to respond yes or no to the statements "I have approached a public official to request support for myself and/or my family", "I have approached a public official to request support for groups of carers and their families", and "I have been part of a group which has taken advocacy action for carers and their families", all carers (n=506, 100%) responded no. When asked Likert-type questions about their confidence in advocacy processes (Figure 17), responses were generally negative.

Yet, when carers were asked to list three ways in which they believed their most pressing issues could be resolved, their responses included support and training, counselling, extra income and economic support, treatments for their health needs, and social awareness of their caring roles. These solutions suggest a real potential for advocacy to create positive change in carers' lives.

Figure 17. Carers' responses to Likert-type questions about their confidence in advocacy processes

Baseline Comparison Carer Group 1 and Carer Group 2

The table below presents the characteristics at baseline of Carer Group 1 and Carer Group 2. We can observe some similarities in the dispersion of socio-demographic factors between the two samples. For instance, both samples have a majority of female carers than males, the mean age of the carers are similar, most carers possess an ID, and most are married. However, the carers Group 2 seem to be less educated and have better health. Care-recipient characteristics were also similar, particularly relating to the sex, work status, condition of the care-recipient (although there was a slight difference in that Group 2 had more mental health carers), and whether the care-recipient was a member of a support group. When comparing answers to survey questions through the chi2 test, Group 1 and Group 2 were found to significantly differ in their answers at baseline.

Measure	**Group 1 (n=504)**	**Group 2 (n=506)**
Carer Gender		
Male	56 (11.11%)	31 (6.13%)
Female	448 (88.89%)	475 (93.87%)
Carer Age (mean, sd)	38.83 (0.49)	38.89 (0.61)
Carer ID possession		
Yes	469 (93.06%)	486 (96.05%)
No	35 (6.94%)	20 (3.95%)
Carer Marital status		

Married	461 (91.47%)	443 (87.55%)
Single	42 (8.33%)	63 (12.45%)
Missing	1 (0.20%)	0 (0.00%)
Carer Highest qualification		
No education	17 (3.37%)	160 (31.62%)
Primary ed or less	309 (61.31%)	164 (32.41%)
Junior Sec to Sec ed	161 (31.94%)	141 (27.87%)
HSC	9 (1.79%)	22 (4.35%)
University level	8 (1.59%)	19 (3.75%)
Whether the carer is in paid employment		
Yes	94 (18.65%)	39 (7.71%)
No	410 (81.35%)	467 (92.29%)
Carer Health issue/disability		
Yes	488 (96.83%)	185 (36.56%)
No	8 (1.59%)	321 (63.44%)
Missing	8 (1.59%)	0 (0.00%)
Carer Type of health issue		
No health issue/disability	5 (0.99%)	323 (63.83%)
Physical issue/disability	36 (7.14%)	171 (33.79%)
Mental issue	23 (4.56%)	6 (1.19%)
Physical and Mental issue/disability	440 (87.30%)	6 (1.19%)
Carer received treatment		
Yes	185 (36.71%)	55 (10.87%)
No	319 (63.29%)	444 (87.75%)
Missing	0 (0.00%)	7 (1.38%)
Carer is part of support group		
Yes	5 (0.99%)	32 (6.32%)
No	499 (99.01%)	474 (93.68%)
Care-recipient characteristics		
Care-recipient Gender		
Male	299 (59.33%)	313 (61.86%)
Female	205 (40.67%)	193 (38.14%)
Care-recipient Age (mean, sd)	23.07 (0.71)	25.14 (0.85)
Care-recipient condition		
Cerebral palsy	71 (14.09%)	74 (14.62%)
Autism	4 (0.79%)	5 (0.99%)
Deaf blindness	4 (0.79%)	1 (0.20%)
Down's syndrome	8 (1.59%)	9 (1.78%)
Visual	18 (3.57%)	23 (4.55%)
Hearing	23 (4.56%)	14 (2.77%)
ID	66 (13.10%)	66 (13.04%)
Multiple	49 (9.72%)	28 (5.53%)
Physical	225 (44.64%)	217 (42.89%)
Speech disorder	36 (7.14%)	38 (7.51%)
Mental Illness	0 (0.00%)	29 (5.73%)
Alzheimer's Disease	0 (0.00%)	2 (0.40%)
Whether the care-recipient is in paid employment		
Yes	37 (7.34%)	17 (3.36%)
No	467 (92.66%)	489 (96.64%)

Care-recipient is part of support group			
Yes	16 (3.17%)	0 (0.00%)	
No	488 (96.83%)	506 (100.00%)	
Carer survey questions			**Chi2**
I do not have enough time to myself because of my caring responsibilities			917.7528 <0.001
Strongly Agree	410 (81.35%)	149 (29.45%)	
Agree	79 (15.67%)	347 (68.58%)	
Disagree	13 (2.58%)	6 (1.19%)	
Strongly Disagree	1 (0.20%)	4 (0.79%)	
Missing	1 (0.20%)	0 (0.00%)	
I am unable to take a break from caring			905.0832 <0.001
Strongly Agree	386 (76.59%)	163 (32.21%)	
Agree	103 (20.44%)	328 (64.82%)	
Disagree	13 (2.58%)	12 (2.37%)	
Strongly Disagree	0 (0.00%)	3 (0.59%)	
Missing	2 (0.40%)	0 (0.00%)	
I am unable to plan for the future because of my caring responsibilities			921.3645 <0.001
Strongly Agree	419 (83.13%)	382 (75.49%)	
Agree	71 (14.09%)	111 (21.94%)	
Disagree	7 (1.39%)	4 (0.79%)	
Strongly Disagree	3 (0.60%)	9 (1.78%)	
Missing	4 (0.79%)	0 (0.00%)	
I worry that one day I will have to stop caring due to my physical health deteriorating			906.5718 <0.001
Strongly Agree	436 (86.51%)	327 (64.62%)	
Agree	58 (11.51%)	157 (31.03%)	
Disagree	6 (1.19%)	17 (3.36%)	
Strongly Disagree	2 (0.40%)	5 (0.99%)	
Missing	2 (0.40%)	0 (0.00%)	
I am concerned about my caring role making my physical health worse			835.5652 <0.001
Strongly Agree	447 (88.69%)	214 (42.29%)	
Agree	40 (7.94%)	248 (49.01%)	
Disagree	15 (2.98%)	32 (6.32%)	
Strongly Disagree	0 (0.00%)	12 (2.37%)	
Missing	2 (0.40%)	0 (0.00%)	
I am concerned about my own physical health			702.5783 <0.001
Strongly Agree	458 (90.87%)	56 (11.07%)	
Agree	36 (7.14%)	372 (73.52%)	
Disagree	8 (1.59%)	37 (7.31%)	
Strongly Disagree	0 (0.00%)	40 (7.91%)	
Missing	2 (0.40%)	1 (0.20%)	
I am physically exhausted by caring			987.4823 <0.001
Strongly Agree	457 (90.67%)	238 (47.04%)	
Agree	41 (8.13%)	264 (52.17%)	
Disagree	2 (0.40%)	4 (0.79%)	

Strongly Disagree	0 (0.00%)	0 (0.00%)	
Missing	4 (0.79%)	0 (0.00%)	
I am drifting apart from friends and family because of my caring responsibilities			937.9010 <0.001
Strongly Agree	330 (65.48%)	289 (57.11%)	
Agree	157 (31.15%)	211 (41.70%)	
Disagree	13 (2.58%)	6 (1.19%)	
Strongly Disagree	0 (0.00%)	0 (0.00%)	
Missing	4 (0.79%)	0 (0.00%)	
I feel lonely			953.6504
Strongly Agree	430 (85.31%)	213 (42.09%)	<0.001
Agree	67 (13.29%)	283 (55.93%)	
Disagree	3 (0.60%)	8 (1.58%)	
Strongly Disagree	2 (0.40%)	2 (0.40%)	
Missing	2 (0.40%)	0 (0.00%)	
I feel excluded or stigmatised by others due to caring for a sick or disabled loved one			935.7176 <0.001
Strongly Agree	394 (78.17%)	312 (61.66%)	
Agree	100 (19.84%)	182 (35.97%)	
Disagree	8 (1.59%)	11 (2.17%)	
Strongly Disagree	0 (0.00%)	1 (0.20%)	
Missing	2 (0.40%)	0 (0.00%)	
I have a friend of family member I can discuss the challenges of caring with			93.4733 <0.001
Strongly Agree	378 (75.00%)	40 (7.91%)	
Agree	115 (22.82%)	54 (10.67%)	
Disagree	8 (1.59%)	63 (12.45%)	
Strongly Disagree	0 (0.00%)	349 (68.97%)	
Missing	3 (0.60%)	0 (0.00%)	
I feel depressed due to caring			914.6300
Strongly Agree	417 (82.74%)	270 (53.36%)	<0.001
Agree	71 (14.09%)	224 (44.27%)	
Disagree	13 (2.58%)	5 (0.99%)	
Strongly Disagree	0 (0.00%)	7 (1.38%)	
Missing	3 (0.60%)	0 (0.00%)	
My caring role makes me feel anxious			905.7539
Strongly Agree	396 (78.57%)	84 (16.60%)	<0.001
Agree	90 (17.86%)	410 (81.03%)	
Disagree	14 (2.78%)	6 (1.19%)	
Strongly Disagree	1 (0.20%)	6 (1.19%)	
Missing	3 (0.60%)	0 (0.00%)	
I struggle to sleep because of the worry of caring			898.9946 <0.001
Strongly Agree	445 (88.29%)	313 (61.86%)	
Agree	51 (10.12%)	167 (33.00%)	
Disagree	6 (1.19%)	16 (3.16%)	
Strongly Disagree	0 (0.00%)	10 (1.98%)	
Missing	2 (0.40%)	0 (0.00%)	

I have had thoughts of ending my life due to my caring role			919.9369 <0.001
Strongly Agree	389 (77.18%)	160 (31.62%)	
Agree	101 (20.04%)	332 (65.61%)	
Disagree	7 (1.39%)	12 (2.37%)	
Strongly Disagree	3 (0.60%)	2 (0.40%)	
Missing	4 (0.79%)	0 (0.00%)	
I have enough money to cover the extra costs of caring (e.g., trips to the hospital)			699.2847 <0.001
Strongly Agree	0 (0.00%)	5 (0.99%)	
Agree	6 (1.19%)	39 (7.71%)	
Disagree	38 (7.54%)	421 (83.20%)	
Strongly Disagree	457 (90.67%)	41 (8.10%)	
Missing	3 (0.60%)	0 (0.00%)	
I constantly worry about the financial stability of my household			922.1610 <0.001
Strongly Agree	486 (96.43%)	285 (56.32%)	
Agree	13 (2.58%)	166 (32.81%)	
Disagree	4 (0.79%)	47 (9.29%)	
Strongly Disagree	0 (0.00%)	8 (1.58%)	
Missing	1 (0.20%)	0 (0.00%)	

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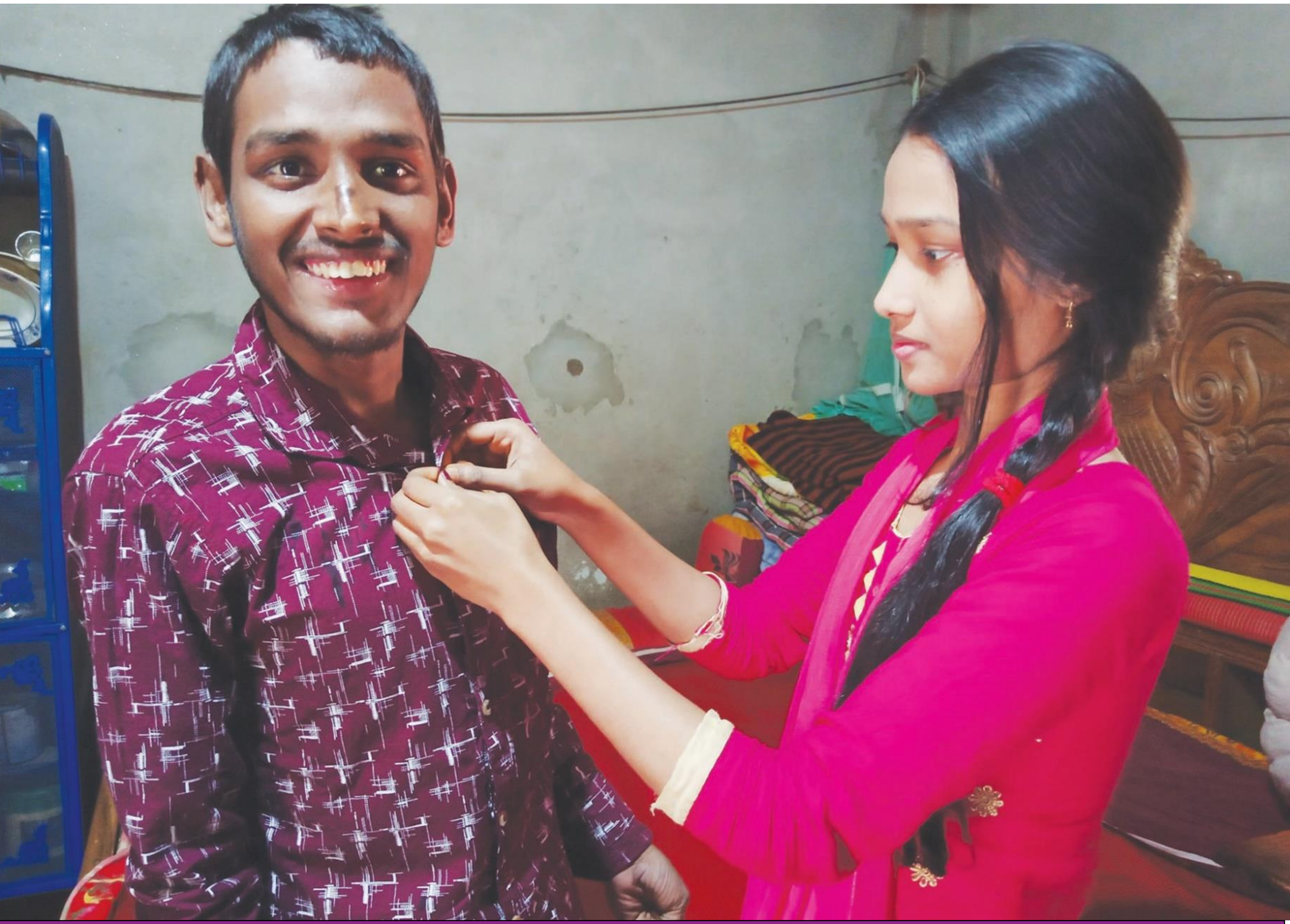

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