

CARERS: CHOICE AND CONTROL



Title: An investigation in to what extent Self-Help Groups, Carers Associations and Carers Cooperatives empower informal, female carers within the Baglung and Myagdi regions of Nepal

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FOREWORD

This study does a great job of showing us clearly the perspectives of carers in two different districts in the very hilly remote part of Western Nepal, where there is a 5-part community intervention designed to support them run by Carers Worldwide with their partner LEADS. The study has been carefully planned and carried out with thought and sensitivity and the data brings to life the real challenges and dilemmas faced by people caring for those with disabilities or chronic illness in a low income setting like Nepal, where the family do not have the resources to buy extra help, nor does the state provide much to help them.

Supported by a review of the previous literature and evidence, the study demonstrates what many of us know anecdotally, that being an informal unpaid carer (usually for a family member), takes a massive toll on the carers' physical and psychological wellbeing, as well as having social and economic consequences for the whole family. Their caring responsibilities and the negative effects on them such as stress, depression, exhaustion, social isolation are often hidden from the community around them. The stigma that often surrounds disability and mental illness means that the family do not publicise their difficulties or ask for help from others, but the whole household may be stigmatised and negatively affected. The rather scant existing evidence suggests that the number of unpaid carers is increasing in all cultural contexts, as people live longer and both noncommunicable/chronic diseases and mental health difficulties which can have disabling effects are on the increase. The majority of carers are women, this tendency driven by long held patriarchal structures and traditional expectations about gendered work roles in many settings, although men and children are also involved in caring responsibilities and experience similar negative impacts

The study shows (using interviews and focus group discussions as the main method of data collection) clearly how helpful women-led self-help groups, carers' associations and cooperatives, and additionally cooperative microfinance initiatives, can be in tackling some of these impacts of being a carer, and investigates whether such activities are seen as empowering by their members. The aim is for these organisations to provide mutual support for the carers and also for them to develop the confidence and skills to advocate for themselves at local government and community levels, so that their needs are recognised and stigma is reduced. The evidence does suggest however that these initiatives may not be equally accessible to all and that the most vulnerable and marginalised may not be participating in the programmes as much as others. The study presents some nice examples of the positive impacts of the self-help groups and the microfinancing element on carers' wellbeing: financial, emotional and physical and on their social and political participation, although this is mixed.

The study provides us with useful evidence about carers' lives and the kinds of interventions that can be effective in improving their wellbeing and those of the people they care for and the whole family. Communities as a whole will benefit if the most vulnerable in their midst are well cared for and the responsibility for caring for them is recognised and shared.

Carers Worldwide's work is contributing greatly to this important aim through the work of its partners working at community level to change individual lives and structural systems. Although this study is located specifically in Nepal, many of the principles of this kind of supportive may well be applicable in many settings globally.

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I wish to thank all the carers who took time out of their busy lives to participate in the data-gathering activities that I held in Nepal. Without their willingness to share their personal stories with me, this research would not have been possible. I feel privileged to have met those who spoke to me and believe that they are all an inspiration to other carers out there.

Finally, on behalf Carers Worldwide, I would like to thank UK Aid Direct for funding our latest project that is strengthening the existing Carers Associations and Carers Cooperatives that are operating in Baglung and Myagdi. As this research shows, these groups are making a real difference to the lives of carers and by increasing their capacities, more carers will hopefully benefit from their expertise.

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SUMMARY

The topic of unpaid family caring is one of the biggest social challenges facing the world today. As populations continue to grow and live longer, and as the number of persons living with non-communicable diseases and mental health conditions continues to increase, so too will the demand for informal carers. Informal carers, most of whom are women and girls, play a vital role in the provision of care, filling the gap that governments currently do not, and often cannot, provide.

Caring can have a detrimental effect on the wellbeing of carers. The challenges associated with caring often impact on the social, economic, physical and mental wellbeing of carers. Carers commonly find themselves having little or no time for respite and become socially isolated as a result of their caring role. In several instances, caring duties prevent carers from participating in income-generating activities which puts financial strain on the carer and their family.

Since 2012, Carers Worldwide have been working on projects in India, Nepal and Bangladesh that support the wellbeing of carers and which advocate for carers to be formally recognised. A key aspect of this work has been the creation of self-help groups, Carers Associations and Carer Cooperatives which bring carers together so that they can take action to promote and protect their own social, economic, physical and mental wellbeing.

The research presented in this text is an investigation in to how effective the self-help groups, Carers Associations and Carers Cooperatives, which were established by Carers Worldwide, have been in empowering informal, female carers within the Baglung and Myagdi regions of Nepal.

A qualitative investigation involving the use of semi-structured interviews and focus group discussions took place in both the regions of Baglung and Myagdi in June 2019. The findings of the research supported existing evidence that carers face a variety of personal challenges as a result of their caring role including social, mental and financial challenges.

The research then explored whether being a member of a carers group, association and/or cooperative has changed the lives of those carers and whether or not this change can be deemed as empowering. The research found a general shift in the wellbeing of carers who participated in the groups, with all carers noting at least one improvement to their lives. Many carers had seen an improvement in their economic position and noted a positive change in their standing within their households and the wider community through their participation in carers groups.

Overall, the investigation provided evidence that self-help groups, Carers Associations and Carers Cooperatives are powerful tools that can be utilized to transform the lives and empower, predominately female, carers.

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- Figure 1 Map of Nepal showing Baglung and Myagdi regions
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CHAPTER 1 | INTRODUCTION

1.1. Introduction

This research is an investigation in to what extent Self-Help Groups (SHGs), Carers Associations (CAs) and Carers Cooperatives (CCs) empower informal, predominately female, carers in the regions of Baglung and Myagdi, Nepal. It first assesses the impact that informal caring has on the wellbeing of carers in Baglung and Myagdi. Then it investigates how, if at all, the SHGs, CAs and CCs empowers female carers in Baglung and Myagdi.

1.2. Key Definition

To begin with, it is necessary to outline what the term ‘informal carer’ means for the purpose of this research. An informal carer is:

... someone who spends a significant proportion of their life providing unpaid support to family or potentially friends. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems (UK Government, 2008).

It should be noted that the definition of informal caring is not concerned with the standard caring role of raising a healthy child and is concerned with persons of ill health or disability.

1.3. Setting of the Research

Nepal is the second poorest country in Asia and the 16th poorest nation in the world in terms of its per capita income (UK Government, 2018). This research looks at two districts called Myagdi and Baglung (see Figure 1) which are hilly, remote and located in Western Nepal (Carers Worldwide, 2018; Baglung District Coordination Committee Office, n.d.; Myagdi District Coordination Committee Office, n.d.). The villages are mostly inaccessible by road, with distances between villages measured in the number of days to walk (LEADS Nepal, n.d.).



Figure 1: Location of Baglung and Myagdi, Nepal

In 2014, a three-year project called “Improving the Physical and Mental Health, Promoting Social Inclusion and Increasing the Household Income of 1,500 Carers of Mentally Ill Individuals in Nepal” was launched in the regions of Myagdi and Baglung by Carers Worldwide (Carers Worldwide, 2018). Before this project, there was no support

or projects in these regions that worked with carers of people with epilepsy and mental illness (Carers Worldwide, 2018).

Carers Worldwide implemented the three-year project with local NGO 'LEADS Nepal'. LEADS Nepal were an established organisation who worked with persons living with mental illness and epilepsy in Western Nepal (Carers Worldwide, n.d.2). Carers were identified by LEADS Nepal to become beneficiaries of the three-year project (Carers Worldwide, n.d.2). Throughout the duration of the project, Carers Worldwide implemented their 5-part model (see Figure 2) that focuses on the holistic wellbeing of carers.

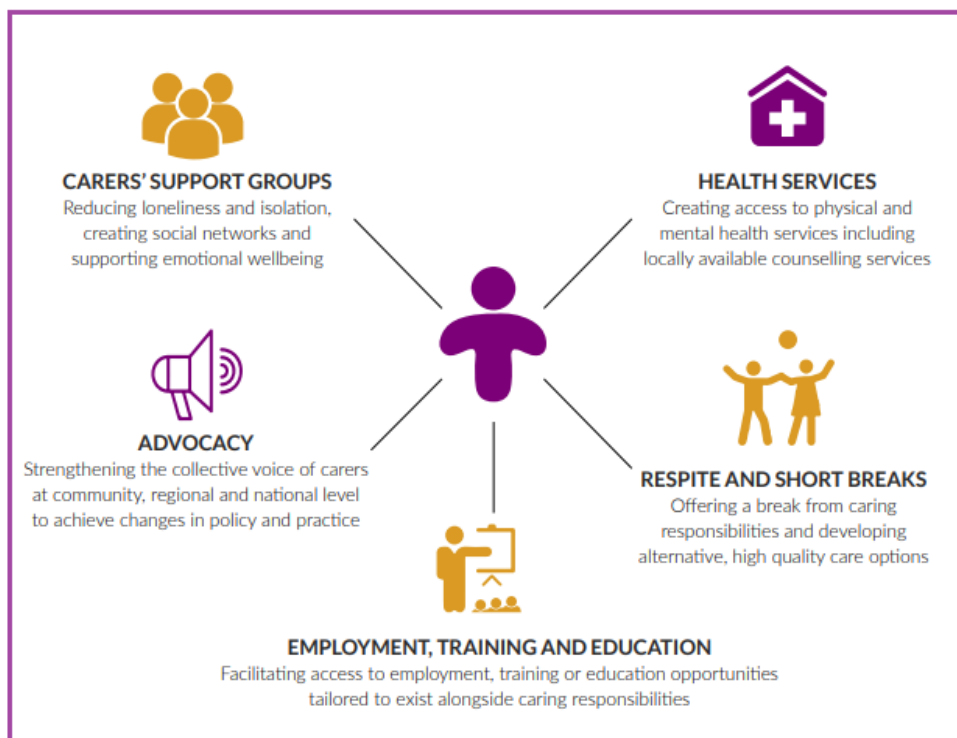


Figure 2: Carers Worldwide, 2019

One key aspect of the three-year project, which is the focus this research, was the establishment of village-Level SHGs, Cluster-Level Committees (CLCs), district-level CAs and district-level CCs. The following information, which has been taken from Focus Group Discussion (FGDs) that were conducted as part of this research, explains how these groups work:

Between 2014 - 2017, a total of 57 SHGs were established across Baglung and Myagdi which brought together 870 carers. 9 CLCs were established in Baglung and 8 CLCs were established in Myagdi. There is one CA and one CC in each of the two regions. Typically, each of the SHGs, CLCs, CAs, and CCs meet once a month.

The SHGs provide emotional support to carers and also encourage carers to deposit personal savings which are held in an account that provides interest on those savings. The savings are collected and passed to the CLCs and then to the CC who deposits the money in a bank account held with the government. Carers can access their own savings at any time. The CAs focus on the social empowerment of carers and discuss how to collectively advocate for the rights of carers. The CCs focus on economic inclusion of carers and offer loans to shareholders of the CC which can be used for income-generating activities or for emergency purposes. There is a 1% admin charge for loans and 12% interest is charged. Other cooperatives in the region typically charge a 2% admin fee and 17% interest.

All carers who are members of the SHGs are members of the CA. However, not all members of the SHGs are members of the CC. To be a member of the CC, the carer must purchase a share. In Baglung there are 219 shareholders and in Myagdi there are 207 shareholders.

The CAs and CCs both have an executive board, each with 9 executive members. Each board has a Chairperson, Vice-Chairperson, Secretary, Treasurer and 5 other executive members. The executive boards are elected by general members every three years. Sometimes, a person is an executive member of both the CA and CC in their region. In total, Baglung had 15 unique executive members across the CA and CC whilst Myagdi had 13 unique executive members. In regards to gender, Baglung CA consists of 5 males and 4 females and the CC consists of 3 males and 6 females. In Myagdi, the CA composition is 9 females and 0 males and the CC is composed of 8 females and 1 male.

The following research analyses whether these district-level CAs and CCs (which also includes the SHGs and CLCs) empowers informal, predominately female carers.

1.4. Current UK Direct Project

In April 2019 Carers Worldwide and LEADS Nepal launched a new, two-year project titled “Promoting social and economic empowerment of carers by strengthening women-led Carers Associations” which is being funded by UK Aid Direct. The purpose of the project is to further extend and consolidate the work of CAs and CCs in Baglung and Myagdi which were established in the 2014 project discussed above. It aims to raise awareness of carers’ existence, role and needs; lobby for practical support; and advocate with local government for policy changes and recognition. The project has a specific focus on advocacy and economic inclusion of carers with the aim of strengthening and empowering predominately female carers in both the civil society space and in their immediate communities. The ultimate outcome, by the end of the project, will be strong, fully fledged CAs who can independently advocate for the rights of carers, and CCs who facilitate opportunities and economic security for carers. The CAs will be recognised as the collective voice of a hitherto vulnerable group, bringing carers onto the local government and community agenda and ensuring this neglected group of predominantly women can come out of their homes, be socially and economically empowered, continue to provide the quality care their ill relatives require, and together bring their families and communities out of poverty.

1.5. About Carers Worldwide

Carers Worldwide, established in 2012, is the only organisation working exclusively and strategically with unpaid family carers in the developing world (Carers Worldwide, n.d.1). Carers Worldwide currently works with ten partner organisations across India, Nepal and Bangladesh, taking a holistic approach to impact the lives of carers and the individuals for whom they care (Carers Worldwide, n.d.2) They work with existing local NGOs, encouraging them to incorporate carers into their existing programmes and to initiate carer-specific activities that meet the emotional, social, physical and economic needs of carers (Carers Worldwide, n.d.).

1.6. About LEADS Nepal

Established in 2009, LEADS Nepal is committed to improving the lives of persons with mental illness and, as of 2014, their carers in the Baglung and Myagdi districts of Nepal (LEADS Nepal, n.d.). Their work is based on the philosophy of building inclusive communities, where mentally ill people – through development – realise their own rights (LEADS Nepal, n.d.).

CHAPTER 2 | BACKGROUND INFORMATION

2.1. Introduction

This chapter presents background information on the relevant themes discussed in this research.

2.2. Current Prevalence of Informal Caring

As caring is *informal*, by its nature it tends to be unrecorded and as a result there is negligible data on the number of people caring for family and friends and on the frequency of their caregiving (OECD, 2017). Data that is available tends to come from developed countries with there being no easily accessible data in developing countries on the scale of the issue (Patil, 2012). Data from the European Quality of Life Survey indicates the number of caregivers in Europe to be 100 million which is 20% of EU population (Embracing Carers, 2017). In the UK, estimates suggest that 12.5% of adults are carers (Carers UK, 2015).

A search for data on the number of carers in Nepal and other developing countries in the region was performed but no figures were available. However, literature suggests that the demand for informal caregiving may be higher in developing countries than in developed countries (Thrush and Hyder, 2014). Most recent figures show the population of Nepal to be 28,087,871 in 2018 (World Bank, n.d.) and if 20% of the population were carers, as in Europe, then this would mean over 5.6. million people in Nepal are carers.

2.3. Growing Prevalence of Informal Caring

Whilst the role of unpaid caregiving is already in high demand, the demand is likely to continue to increase in the future, for several reasons. Life expectancy across the globe is increasing which means there are more elderly people who require care as whilst people are living longer, they are typically spending more of their elder years living with disabilities than previously (Kassebaum et al., 2016). Another reason is that the number of persons living with chronic diseases continues to increase (World Health Organization, 2005). Developing countries feel the burden of chronic diseases strongly as they are dealing with these conditions alongside several long-established infectious diseases that also affect them (World Health Organization, 2002). A final key reason is that it is currently estimated that there are nearly 1 billion people living with a mental health disorder globally (Global Burden of Disease Collaborative Network, 2016) yet the number of people at risk of having a mental health condition is forecasted to continue to increase (Patel et al., 2018).

2.4. Challenges of Informal Caring

Whilst many carers are proud of their role and find it rewarding to care for a loved one (Cavaye, 2016), caring can also have negative effects the wellbeing of carers (Thrush and Hyder, 2014). In developing countries, limited research is available on the challenges experienced by carers (Yakubu and Schutte, 2018). This lack of research is concerning due to the potentially higher prevalence of carers in developing countries.

From the data that is available, meta-analysis of 51 studies across 33 low-and-middle income countries (LMICs) found a negative impact on the social, mental, physical and financial wellbeing of carers with 64% - 68% of carers reporting financial difficulties and 88% of carers reporting concerns of exhaustion and fatigue. (Thrush and Hyder, 2014). Koyanagi et al. did a cross-sectional analysis of 58 low, middle and high-income countries and found that in all countries, caregiving can lead to significantly worse stress, depression and poor sleep patterns (2018). The same study found that carers had very limited free time in which they could socialize or have any respite. Although carers in both low and high income countries feel negative effects of caring, it is possible those in lower-income settings face greater challenges. Research focusing on carers in low-income settings in Cape Town, South

Africa found that caring caused greater pressure on the financial resources of a lower-income household which created greater stress to carers in comparison to carers in higher-income settings (Yakubu and Schutte, 2018).

Another challenge is that stigmatization, which is commonly faced by people living with medical conditions, disability and mental illness (Duran and Ergün, 2018), is also acquired by those closely related to such individuals (Goffman, 1963). This is known as 'courtesy stigma' and such stigma can negatively affect the social standing and social life of affected individuals (Goffman, 1963).

In research specifically from Nepal, a survey of 334 carers of children with Cerebral Palsy and other neurological conditions in Kathmandu found 70% of those carers reported not being in receipt of any income; 76% were concerned about feeling anxious; 71% were struggling with depression and 55% had a chronic lack of sleep (Waddell, 2017). Another study that investigated 31 carers of persons living with a mental health condition in rural areas found that due to an absence of government mental health services and inadequate social security provisions, carers found it socially and financially challenging to manage the complex situation of caring (Robertson, 2016).

2.5. Informal Caring as Predominately a Female Issue

Across the globe women and girls perform 76.2% of unpaid household work, with this figure rising to 80% across Asia and the Pacific (International Labour Organization, 2018). Included within the definition of unpaid household work is caring for persons with medical conditions (UNIFEM, 2000) i.e. informal carers. In Nepal, research has found that the main informal carer is female in 84% of cases (Embracing Carers, 2017) which can rise to as high as 97% in instances when caring for a child with a disability (Waddell, 2017). Gender stereotypes and discriminatory social institutions contribute to the unequal distribution of caring responsibilities between the genders (Ferrant et al., 2014).

2.6. Empowerment

This study focuses on whether SHGs, CAs and CCs empower female carers. Empowerment is concerned with choice meaning those who are empowered have the ability to shape the choices that are available to them and also have the capacity to analyse and reflect on the choices available to them (Mosedale, 2003; Reeves and Baden, 2000).

Empowerment is multi-dimensional and can be found in the family/interpersonal, legal, economic, socio-cultural, psychological and political spheres (Malhotra et al., 2002). Currently, it is held that economic empowerment is the most important tool for gender equality and sustainable development (DAC Network on Gender Equality, 2011; World Bank, 2012; United Nations Women, 2018) as once economic empowerment is achieved it can pave the way to empowerment in other spheres (Mason, 2005) such as social and political empowerment (Stromquist, 1995). Once economic empowerment is attained, it can lead to increased bargaining power in other spheres, which is why economic empowerment is seen as a 'magic potion' in development and gender equality (Blumberg, 2005).

CHAPTER 3 | METHODOLOGY

This research was conducted using a qualitative approach and used two data-gathering tools: SSIs and FGDs. SSIs and FGDs were conducted through the aid of a translator. 4 females from each of the regions, who were members of the CA and/or CC, participated in an SSI (8 SSIs in total). For the FGDs, a total of 9 CA/CC members took part in Baglung and a total of 12 CA/CC members took part in Myagdi.

The data gathered from the SSIs and FGDs has been analysed and the findings are presented in the following chapter.

CHAPTER 4 | RESEARCH FINDINGS AND ANALYSIS

4.1. What impact does informal caring have on the wellbeing of female carers in Baglung and Myagdi?

In the SSIs, carers were asked about the impact caring had on their lives prior to their involvement in SHGS, CAs and CCs. Every carer reported at least one negative consequence in their lives because of their caring role. These impacts have been categorized in to three separate sections, each of which will now be discussed.

Economic Challenges and Household Dynamics

In the literature review, a meta-analysis study of caregivers in LMICs found 64-68% of carers reported financial difficulties (Thrush and Hyder, 2014) and research in Kathmandu found 70% of carers lived below the poverty line (Waddell, 2017). From the SSIs I conducted, 7 out of 8 carers reported financial difficulties (87.5%) which is higher than the number who reported financial concerns in the previous literature. However, even for the 1 SSI participant who did not report financial hardship, she too was financially worse off as she had to opt for a lower-paid employment position to fit around her caring duties:

I passed an exam to work for the government, but I was required to relocate to another region for work, which was impractical due to caring for my daughter and my father-in-law. I was then offered a senior role within a private insurance firm but that role would have required travel which again I could not do due to caring. I currently work within that insurance firm but in a lower position for less pay. (Participant 3)

Literature finds that carers are often unable to work due to their caring responsibilities, or are in precarious, unprotected employment (United Nations Special Rapporteur on Extreme Poverty and Human Rights, 2013). Again, answers from the SSIs corroborate this:

My husband had severe epilepsy and he was unable to go to work. I too was unable to go to work as I couldn't leave him in the house unattended. We struggled to afford food and we relied on a little financial help from my parents to survive. (Participant 4)

My husband was an alcoholic and did not work. We lived with his parents who also did not work. I had to care for my husband and look after the small field we owned so that we had food to eat. I also had to look for daily labour work in the village but it was never guaranteed. I was under a lot of pressure. (Participant 7)

In some instances, the answers provided in the SSIs reflected the patriarchal nature of Nepali families, show how caring is predominately a female role, and how there is an inequity in the division of this labour (Bhadra, 2001; Chopra et al., 2014). In the two examples below, even though the SSI respondents were not biologically related to the person they cared for, being the women of the households, the caring duties were adopted by them whilst the biological sons of the person being cared for did not provide care:

My mother-in-law and I care for my father-in-law. My husband does not care for his father. (Participant 5)

My husband and I lived and worked in Kathmandu. My husband's father became unwell so we had to relocate to his village and I was to care for him. My husband went out to work and I had to remain at home to care. (Participant 8)

In the SSIs, examples could be found of female carers who were unable to work, or who had very limited income, of having tense relations within their households and having no power within their family:

I cannot go anywhere as I have to care for my son. My husband, and his children from a previous marriage, are completely unsupportive about the situation. The sons of my husband work abroad but refuse to send money to support us. My husband works and controls all the finances, he only allocates me money for essentials and gives me no money to spend freely. (Participant 2)

I care for my sister as our parents are both dead. She has a mental illness and is unable to be left unattended. I cannot work and have to care for her at all time. I set up a very small shop at home to try to generate my own income but it made very little profit. My husband sometimes worked in Saudi Arabia and sent money for the purpose of sending our two sons to school, but he refused to financially support my sister. It is hard to afford the medicine my sister needs. I also get shouted at by my husband and sons for bringing my sister into our home. (Participant 1)

Even though I was the only person caring for my husband, and the only person looking for labour work, I was completely dominated by my mother-in-law who we lived with. (Participant 7)

For these women carers, they had no or very limited income and were dependent on controlling male family members or dominating mother-in-laws. This aligns with literature that women carers often are restricted in economic resources (Bhadra, 2001; Furuta and Salway, 2006; Oxfam International and HAMI, 2019) and that rural women have their households dominated by males or mother-in-laws even though they play a huge role supporting the household (Pant and Standing, 2011).

Social and Political Challenges

The background information introduced the concept of 'courtesy stigmatization' which is stigma affecting the close family of a person who is ill (Goffman, 1963) and which can lead to emotional distress and social isolation (Duran and Ergün, 2018). From 33 LMIC countries, it was found that the social wellbeing of carers was adversely impacted through their caring role (Thrush and Hyder, 2014). Also, a lack of free time available to carers means women have limited time to be able to participate on an equal footing in public life (Chopra et al., 2014).

In this research, every single SSI participant (100%) and both FGDs referred to adverse social implications of caring which were either: exclusion from community, stigma or not having time to participate in community life. Five examples that highlight this point have been selected:

My husband has epilepsy and the villagers believed it to be contagious. Society completely excluded my family. There is one shared water tap in our village but the others did not let me use it. I had to walk further afield to access water. No-one in society ever visited me and I was not welcome to visit others. (Participant 6)

People mocked my husband because my sister is unwell and lives with us. This made him more frustrated about our family situation. (Participant 1)

Even though I live in a bigger town and I am well educated, I still faced stigma and have experienced negative social effects of caring. (Participant 3)

I am from a very low caste and my community life was difficult enough. I faced even more social challenges due to caring. (Participant 4)

At community events, female carers wouldn't be able to participate or would be made to sit very far back. They played no active role in village life and had no say in local politics. (Focus Group 2)

Taken together, these comments all show the ways in which stigma excludes not only the person who requires care but also the person and the family of those requiring care. In SSI 1, the family was excluded from society, and this caused further tension at home for the female carer as her husband did not like being mocked by the local community because of his sister-in-law's condition. SSIs 3 and 4 show that all carers face stigma, yet those from lower classes and castes may face even more stigma as the stigma of caring is on top of stigma that they face due to their position in society (Atteraya et al., 2016). Therefore, attempts at improving the wellbeing of carers need to realise that not all female carers are on an equal footing and that there are differences in how caring affects women individually (Mohanty, 1988).

Emotional and Mental Challenges

The background information provided evidence that shows carers can experience depression, anxiety, disturbance to sleep and exhaustion (Carretero, 2009; Waddell, 2017). In one example, 77% of carers surveyed reported being depressed or anxious (Carers Worldwide, 2018). This can be due to numerous reasons e.g. the substantial use of time, effort and financial resources that caring uses (Carretero, 2009) or from having limited free time for respite or socializing (Brinda et al., 2018).

In the SSIs of this research, 100% of participants reported negative emotions or negative affects to their mental health. The most common complaints were of anxiety, stress, worry and depression. As well as this, there was also mention of carers stating they felt a lack of confidence. The following comments show this:

I constantly had to care for my son and do everything which lead me to feel ill with anxiety and stress. I felt negative all the time and as a result I was unable to feel any love for my son. I was responsible for caring for him but I always questioned why he was born. (Participant 2)

I was unable to reach my potential in life and could not pursue my career goals because of caring. The burden from caring has affected me mentally. I feel a pain inside because of my situation. (Participant 3)

I never socialised due to caring duties and I used to be anxious whenever I did end up in a social situation. (Participant 5)

I couldn't cope and I cried every day. I felt in the dark. I believe I was on the verge mental illness myself. (Participant 4)

Concluding section 4.1.

In this section, evidence has been presented that suggests that caring has had a negative impact on the economic, family, social, mental and emotional wellbeing of carers in Myagdi and Baglung.

4.2. How, if at all, do SHGs, CAs and CCs empower female carers in Baglung and Myagdi?

The previous section presented the challenges that carers faced. In the following section, findings are presented to show, how, if at all, being part of the SHGs, CAs and CCs empowers female carers.

Economic Wellbeing and Household Dynamics

In this research there were three ways identified which could change the economic situation of carers:

Carers could change their economic situation in three ways. The first was through income-generating activities that were provided by project funds from Carers Worldwide; the second was through personal savings; and the third was through purchasing shares in the CC and then applying for loans. Loans are predominately used for income-generation but are also used for emergencies such as needing to pay for medical care for the care recipient. (Focus Group 2)

Many carers have improved their financial wellbeing. The following examples show how using microfinance obtained via the CC has greatly improved the financial situation of carers and enabled them to feel more financially secure. It has allowed them to generate income by participating in income-earning activities, as seen in other research (Adhikari and Shrestha, 2013), and also reduced their vulnerability to emergency situations (Karnani, 2007) e.g. by being able to afford treatment for care recipients:

Using money from my home I purchased shares in the CC. I borrowed from the CC to buy a goat. I now sell 4 goats per year for an average of 10,000 NPR per goat. I have now purchased a buffalo and sell the milk it produces. I use the manure from the animals as fertilizer for our field which has increased our vegetable production. I am now financially secure. (Participant 8)

I have borrowed 10,000 NPR on four separate occasions (total 40,000 NPR) from the CC. I have invested some of the money to expand my shop at home which now generates a good income, and I have also spent some of the loans on accessing treatment for my sister. (Participant 1)

One problem is that out of the three ways participants have changed their financial position, one of the methods was receiving income-generating activities through project funds of Carers Worldwide. Participant 7, the woman who cared for her alcoholic and was dominated by her mother-in-law, said the following:

In 2014, I was provided with chickens for free through the project enacted by LEADS Nepal and Carers Worldwide. I now sell 1200 chickens per year and make 120,000 NPR from the sales. After the first year, I invested in a tunnel for my family's field which has significantly increased the amount of vegetables we grown. I then purchased goats which I sell for around 60,000NPR per year. Most recently, I have purchased a buffalo and expect sell milk soon. My financial situation makes me happy now and has changed my life. I am no longer dominated by my mother-in-law and my husband respects me (Participant 7)

Although there has been a remarkable shift in the circumstances of Participant 7, it is unlikely this change would have occurred through SHG participation alone and it is unlikely she would have been in a position to buy shares in the CC to purchase the initial chickens that she received for free through project funds. On this basis, this would suggest the current SHG, CA and CC system could possibly exclude the most vulnerable carers as they now operate independently from project funds and only allocate finances to carers who buy shares. However, the CC in Baglung is conscious of this and is trying to find ways to resolve this issue:

What is the most ethical way to increase capital? The current share value is 5000 NPR whereas it used to be 1000 NPR. Some want to increase it to 10000 NPR yet some cannot even afford the 1000 NPR so it would become a “rich carers association” if we increased share value again. We have an idea to offer money for income-generating purposes to the poorest carers who cannot afford shares and once they start to earn a profit, the profit will be used to purchase shares (Focus Group 1)

This line of thinking shows how the CC's are addressing a general weakness of cooperatives and are giving special focus on how they can assist the most vulnerable carers.

Another identified way of changing economic wellbeing was through personal savings. Personal savings are an issue for carers who commonly have an inability to accumulate savings and retirement income (United Nations Special Rapporteur on Extreme Poverty and Human Rights, 2013). Becoming part of the SHG in these regions has changed the saving habits of many carers:

Many carers previously had no savings but since joining SHG they have become educated about savings and now try to personally save between 200 NPR to 300 NPR per month. Carers are really concerned with saving and the importance of it when they previously weren't. For those who have accessed income-ventures they use this money for savings but for those without, they try to raise funds for savings via other means e.g. family members (FGD 1)

I have started personal savings for the first time. I save income I make from my shop. As my husband does not wish to financially support me and my sister, this gives me confidence that I have financial support should I need it. (Participant 1)

I learned about savings and managing finances through the SHG and now I make monthly savings of 400 NPR per month. I obtain the money to save through relatives which is given to me during festival times. (Participant 2)

I received a goat through project funds which had several kids. From the sale of the goats, I was able to start saving money. I feel secure knowing there are available funds if I ever need them. (Interview 5)

Following on from the improvement in their economic position, many SSI participants and the FGDs held that SHG participation and access to credit increased the bargaining power that women have within their households (Swain and Wallentin, 2009). Examples of positive changes to the position of women within their families include:

Attitudes of husbands are changing. They realise women participating in the groups is good and are cooperating as the women are bringing in money. There are now stories of women controlling all the

household finance sent from sons working abroad, when previously it was the husband's domain (Focus Group 1).

We estimate that 80% of women carers are now in charge of decisions in the household because of income-generating opportunities they receive. They decide what to do with loans and savings. Husbands and mother-in-laws respect them more because of this. (Focus Group 2)

I used to be completely dominated by my mother-in-law and my husband did not have respect for me. As before, I am still the only person in the household working. However, I am now more respected because of the level of income I bring in and I am fully satisfied now. My husband is cooperative, my children now go to school and I have savings for the first time (Participant 7)

This corroborates that now that the SHG members are earning an income, they are appreciated and respected by the family members, including their in-laws, which is important in Nepal's patriarchal society (Dhungana and Kusakabe, 2010). Interestingly, in one instance even without economic power, one woman's participation in the SHG alone has given her more control within her family:

I have not been able to change my personal financial situation through my SHG participation. My husband has a pension so I was not eligible for income-generating materials funded by the project and I have no funds myself to invest in the cooperative. However, even just being part of the SHG has given me more control within my home. If I feel my child needs to go to Kathmandu to access hospital treatment, I will gather other SHG members and we will all visit my husband at home to put pressure on him to agree to this. I feel more powerful now. (Participants 2)

The above findings support the idea that economic contributions can cause a shift in power dynamics in the home, but in addition to this, also finds that simply being a member of an SHG without a change in financial circumstances can also positively impact power dynamics within the home.

Overall, group membership plays a role in the economic empowerment of women as it is giving them more control in regards to household spending and how they are viewed by other persons living in their households.

Emotional and Mental

Existing literature suggests that SHG participation can improve emotional and mental health and increase confidence (Mohindra et al., 2008; Sarumathi and Mohan, 2011). The same was found in this research:

My life has been changed. I was on the verge of mental illness myself because of my situation. Now I run my own pot-making business and my life is transformed. I do not worry anymore. I now want to motivate other carers because of the positive changes to my life (Participant 4).

Before the project I did not know how to cope but now I feel relief knowing other people are in my situation and I have more confidence in being able to support my sister (Participant 1).

The SHG provides an opportunity to share problems and stories. Sharing does not change my situation but it does help bring some relief to the pain of caring. It can also be a forum for change which brings peace of mind to carers. (Participant 3)

I used to be isolated and when I first joined the SHG I had no confidence and was anxious at the thought of talking. Now I am an active group member and enjoy participating in discussions and trying to find solutions to improve the lives of carers (Participant 6)

SHGs gives its members the chance to share experiences and receive support (Rappaport, 1993) and in the instance of this research, it appears SHGs have given carers a chance to unite to discuss their problems, realise they are not alone, and has in many cases increased the confidence of the members. Increasing confidence is empowering as it gives female carers the necessary tools to be able to take control of their lives and make demands for their rights.

Social and Political

Previous literature has found that women were able to participate more freely in community life, and no longer be solely just housewives due to their involvement in SHGs (Dahal, 2014) and that participation enabled women to become and feel respected by their peers (Dahal, 2014). Other research has found that women who previously had no standing within their communities now had some influence over decisions in local political life through their membership in an SHG and were speaking to government officials (Sundaram, 2012). Starting from a respect point of view, there was changes to the social lives of carers in this research:

The SHGs have provided information and awareness campaigns which has helped change community attitudes towards carers. I feel my status has changed in the community. I am from a low caste and used to do what the community ordered without challenging it but now I challenge what I do not like and I am more respected for this as a result. (Participant 4)

Carers used to hide away and if they ever attended community events they would sit very far back. Now there is more respect for carers and the role they play which has come about from carers gathering family members and community members and discussing the important the role they play within society. (Focus Group 1)

Society used to make me use another water tap. Now there is a big change in my standing in the community. Everyone knows who I am now. I am invited to events and people in the community value my opinion. My son has been able to join the police force and is becoming a national folk singer too. This, for my son, would not have been conceivable under my previous status before I joined the carers group (Participant 6).

There is significantly less stigma than before. Carers are now welcome and happy to participate in community life and events (Focus Group 2).

However, there was an anomaly in the findings that suggest the improvement to social wellbeing has not been unanimous:

If a female carer wants to attend a SHG, CA or CC meeting it means the husband has to clean dishes, wash clothes or cook and the husband would be teased by the community about this. (Focus Group 1)

Therefore, while the overall consensus of female carers participating in SHGs, CAs and CCs has been generally positive, there are still some attitudes that suggest there is still room for society to more accepting of female carers participating in the groups.

In regards to changes in political standing, carer's have attempted to bring the issue of caring to the attention of government through the CAs and have plans for further action to be taken:

Last year, we held an awareness day about caring in which the chair of the Municipality and a Member of Parliament attended. We have raised the issue of caring with government for the first time and are continuing to make proposals to the government offices in how they can recognise and promote the rights of carers (Focus Group 1).

Myself and the CA want to guide government policy. People with disabilities are issued an ID card and receive a small financial allowance from the government so we are going to advocate for the same for carers (Participant 3).

We have attracted government attention. Government has provided training opportunities exclusively for carers which included such things that carers demanded e.g. women-leadership, making potato chips, making incense sticks etc. All the expenses were covered by the government.

However, there is evidence to suggest further support could be provided to strengthen the capacity of the groups:

We want to have more of an effect and make greater progress with the Government than what we are currently doing, but feel that we do not have the skills to do this. We feel we need training in how to achieve our goals (Focus Group 2).

Therefore, whilst at a personal and community level SHGs and CAs may improve the wellbeing of carers, they may need further external support to achieve empowerment at a formal. political level. For the SHGs, CAs and CCs to become politically empowered, they may require external assistance from other bodies e.g. NGOs, who could help strengthen their skills and their capacity to be able to take action to empower themselves (Reddy and Manak, 2005), hence the need for this current UK Aid Direct funded project being implemented by Carers Worldwide and LEADS Nepal.

Concluding section 4.2.

In this section, evidence has been presented that suggests self-help groups, Carers Associations and Carer Cooperatives can empower carers in an economic, social and political capacity.

CHAPTER 5 | CONCLUSION

This study investigated the burden of caring on, predominately female, carers in the Baglung and Myagdi districts in Western Nepal and assessed whether self-help groups, Carers Associations and Carers Cooperatives can improve the wellbeing of those carers and, in turn, empower them.

The findings in this study regarding the burden of caring supports existing evidence which finds that caring negatively effects the social, economic and mental wellbeing of carers. Common challenges presented in this research were carers being unable to work due to their caring responsibilities (which often contributed to a power imbalance within their households); carers not being respected within their communities and being excluded from the public sphere; not having free time for themselves and having feelings of anxiety and/or depression.

This study also found that microfinance and participation in SHGs, CAs and CCs can improve the wellbeing carers and empower carers. Several of the carers discussed how their economic positions had changed since becoming members of the groups and how the change in their economic situation has increased the control they have within their households. Carers also noted that they are more respected within their communities since joining the carers groups and that they are able to participate in other aspects of community life that they previously were unable to. The groups are also making connections with local Government officials who are starting to pay attention to the needs of carers, and who are implementing projects specifically for carers for the first time.

Challenges raised by the carers include how to allocate finances to ensure that the most vulnerable carers aren't excluded and to consider how to make groups more effective in politically increasing the rights of carers. The purpose of this new project being funded by UK Aid Direct is to strengthen the capacity and capabilities of the CAs and CCs so that these current challenges can be resolved.

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