

Article

Disabled Families: The Impacts of Disability and Care on Family Labour and Poverty in Rural Guatemala

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Abstract: An increasing body of literature has started to look at how disability impacts and shifts poverty in the global South in and through a range of areas, including health, education, and livelihoods. However, much of this research is limited to disabled individuals, while qualitative research focusing on and articulating the circumstances, needs and demands of rural families remains scarce, especially research focusing on Latin America. This paper reports on a qualitative study looking at how disability affects family labouring patterns in rural Guatemala, with a special focus on women carers of people with acquired physical impairments, in the bid to contribute to a more inclusive understanding of the disability and poverty relationship and its gendered dimensions. Findings highlight how in rural communities already living in dire poverty, the fragmentation of labour input of the disabled person, costs (notably health care) and intensified collective poverty, push fragile families with no safety nets into a set of dynamic responses in the bid to ensure survival of the family unit. These include harder and longer work patterns, interruption of paid labour, and/or induction into exploitative and perilous labour, not only for women, but also children. These responses are erosive and have severe personal, social, cultural and economic consequences, strengthening a deep, multidimensional, chronic and intergenerational impoverishment, transforming these families into ‘disabled families’, among the poorest of the poor. This paper concludes that research, policy and services need to move beyond the disabled individual to understand and address the needs and demands of whole families, notably women, and safeguard their livelihoods, because ultimately, these are the units that singlehandedly care for and ensure the well-being and survival of disabled people. It is also within these units that disability is constructed, shaped, and can ultimately be understood.

Keywords: disabled families; rurality; Guatemala; livelihoods; labouring

1. Introduction

The past two decades have seen an increase in research and literature focused on disability in the global South, often in a micro field called ‘global disability’ or ‘disability and development’ (see for example [1–3]). Much of this focus on disability, including in recent development and humanitarian work, has been and continues to be propelled by the discursive turn towards an assumed disability and poverty relationship, one often depicted as a cycle [4,5]. The dominant narrative is one where disability supposedly exacerbates, feeds into and intensifies poverty, and how poverty in turn opens a set of conditions or rather makes people vulnerable to impairment and disability (see for example [6]). Research also continues to emerge looking at a range of dimensions including education and livelihoods, and how problems in access impact well-being and poverty for disabled people. This relationship, though, is too often simplified or generalised, empirical research (notably qualitative studies) into the dynamics operating within remains scarce, and even more broadly, theoretical interdisciplinary work on this relationship remains lacking [7]. Research into disability and poverty in Latin America in

particular remains sparse, and rural areas are too often relegated to a space that is either excluded, assumed or generalised through hearsays and myths propagated by dominant urban voices, including Disabled People's Organisations (DPOs) in the global South. Nevertheless, the increased mentioning of this supposed relationship by international bodies, International NGOs and major donors (see for example [8,9]) has, alongside broader shifts towards a rights-based approach in development, the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and the recent inclusion of a disability component in the Sustainable Development Goals (SDGs), encouraged and supported disability advocacy efforts, in particular those pushing for disability mainstreaming and/or disability-inclusive development. It has also encouraged research looking at individual areas such as education, livelihoods, and health among others.

The experiences and impacts of disability and care on families have been reasonably explored and documented in global North settings [10–13], and family dimensions are also increasingly addressed in global studies, documents and policies (disability and non-disability specific) (e.g., the UNCRPD, the SDGs, the WHO/World Bank World Report, etc.) alongside a growing body of research. However, there remains a dearth of qualitative research focused specifically on families in rural areas in specific regions of the global South, notably Latin America. This includes the personal, social, economic, political, cultural and other impacts of disability on family members and the contextual, ideological, gendered and other dimensions of care. This is more than a cursory concern in rural areas in countries such as Guatemala marked by high rates of poverty and inequality. More than half of the population lives in poverty and almost 25% in extreme poverty, with indigenous populations (over 40% of the total population) disproportionately disadvantaged—almost 80% live in poverty and 40% in extreme poverty [14]. Inequality is rife and wealth is concentrated—and the richest 20% account for 51% of the country's overall consumption. What marks these lives is dramatic hardship, compounded by the fact that the country's social protection system flagrantly excludes poor people, especially those in rural areas. The country does not have universal social protection, and the social security system offered by the Guatemalan Social Security Institute (Instituto Guatemalteco de Seguridad Social (IGSS)) is a contributory one, limited to those engaged in the formal sector, generally those better off and in urban areas. The services offered by these, though, are limited in quantity and quality, and many (the wealthier ones) choose to opt for private insurance and services to compensate this. Overall, the poor, notably those in rural areas, are totally excluded—they work in the informal sector (approximately 75% of the total population) [15], are not registered, do not pay contributions, and are hence not entitled to any benefits. Poor people are left to their own devices, livelihoods are precarious, and survival and well-being are compromised by perpetual insecurity. More basically, fragile families are the only source of support and even survival when illness, disability and other crises (e.g., drought and food scarcity) strike, with the implication that not only poverty, but also disability are lived and survived as a family [7]. Many of these impacts are weathered by women, as mothers, wives, siblings and caregivers who shoulder a disproportionate portion of care [16] and whose livelihoods, well-being and poverty among others are critically shifted as a result of the care they provide [17].

This gap in contextualised research is perhaps compounded by a disability studies that remains largely global North centric and focused [7,18], and where the disability experience is too often filtered through global North hegemonic notions of nation state, citizenship, some or other social protection and rights, formal waged labour and so on, and predominantly through an urban lens. This may contrast sharply with rural contexts in countries such as Guatemala, where labour is largely in the informal sector, where formal social protection is fragmented or inexistent, and where geographical dispersion combines with racism, ethnic discrimination, rights violations, violence, and institutionalised corruption and impunity to shape a complex web of oppression [7]. This is, though, once again hardly surprising given that global North disability studies has not done a great job in even engaging with the experiences of Southern subjects such as disabled refugees in the global North and that of their families [19].

This lack of focus on rural families is no marginal issue, given that families, for better or for worse, often remain the lifeline for disabled people, especially in poor rural contexts. Yet these are also families and communities that are often weak (especially economically and politically) and insecure in the face of crises, including ill health and disability [7]. There is even less engagement with the intergenerational relationship between disability and poverty [20], to include the impacts of disability and care on children and their own children in the future, reflecting how this relatively young field (disability and development) has yet to grapple with the familial, spatial and temporal dimensions of disability.

Overall, this has serious implications not only for theory on disability and poverty, but also on development and disability-specific policy and practice, in particular in how these engage with (or otherwise) and can support the needs and demands of families—especially women carers in contexts of extreme poverty in informed, contextualised and responsive ways, particularly when these have critical impacts on the well-being and even survival of disabled people. Even more basically, it leaves these voices unheard and excluded from the disability narrative, hence relegating the needs of families to the peripheries, while individualising and isolating disability as a personal ‘condition’ and experience, and reinforcing the exclusive need for ‘interventions’ on the disabled body.

This article responds to some of these concerns and looks specifically at the impacts of disability and related caregiving on rural families in Guatemala, notably women carers of people with acquired physical impairments, with a special focus on labouring patterns and how these in turn affect and shift their poverty situation. The objective is not only to render these experiences and perspectives visible, but also to contribute to an exploration of the disability experience and the disability and poverty relationship that are not only complex, heterogeneous and multifaceted, but that also have familial, gendered and intergenerational dimensions.

2. Methodology

This qualitative study forms part of a broader ongoing ethnographic research looking at the dynamics between poverty and disability in rural Guatemala (2008 to date). Qualitative methods were deemed suitable for this study, given the priority of listening to, exploring in-depth and articulating the voices and perceptions of family members on their own terms.

This study, looking at families specifically, employed in-depth unstructured interviews as the main tool of investigation in the bid to allow sufficient space and freedom for family members to articulate their main concerns around disability, care and labouring with minimal restrictions. A total of 20 families that include a person with acquired disability were interviewed in 3 departments (regions that are divided into municipalities) of the country (1 indigenous; 2 non-indigenous), comprising 47 adults (over 18) and 20 adolescents, all immediate family members and caring for a disabled adult. These were purposively selected from a sampling frame provided by key gatekeepers, including NGOs and DPOs and other local contacts. All families hailed from and were living in their native rural areas. They all defined themselves as families having one or more disabled family members, and also to be living in poverty, and hence a subjective definition of poverty was adopted (see [21]). Interviews were held in participants’ homes and other places deemed safe and chosen by participants themselves. The bulk of the interviews were conducted directly in Spanish, while a translator/cultural mediator was present with 7 participants who exclusively spoke an indigenous Mayan language.

Following permission by participants, interviews were audio recorded using a digital voice recorder and then transcribed by the author. These were accompanied by field notes. Thematic analysis, defined as a method ‘for identifying, analysing, and reporting patterns (themes) within data’ [22] (p. 6), was employed. This involved an inductive and iterative process of rereading transcripts and field notes, where patterns emerged from the data, and progressively organising these into themes and categories.

The findings below present these key emerging themes and sub-themes, supported by direct quotes from the participants. All names have been changed to protect their identity.

All ethical procedures were carefully followed. Informed consent was provided by all participants, following a clear and an accessible explanation of the scope of the study, the process, and their rights including anonymity and confidentiality and the right to withdraw at any time with no explanation expected. Oral recorded consent was provided by participants who were illiterate, and in the case of adolescents (under 18), provided orally by them and in written format by their legal guardian (parents), present during the interviews.

3. Findings and Discussion

The following sections and subsections present the key findings from the study and will prioritise the narratives of families, in particular women carers. I will also be discussing key thematic points in the bid to flesh out, substantiate and analyse key emerging points and arguments directly.

Findings from the study highlight how the presence of disability rocks the whole family living in poverty, pushing family members to respond to the needs of the disabled person while trying to ensure survival of the whole household. These responses in the midst of poverty are, however, erosive and impoverish them even further, casting these families among the poorest of the poor entrapped in a chronic poverty difficult to shift. For women carers in the study, the presence of disability shifted their labouring patterns, pushing some to labour harder, while others were forced out of the labour market, and others still cast into exploitative labour for the first time, and often prematurely. These dynamics had serious social, cultural, economic and personal impacts on these women. These key findings will be fleshed out before. However, and before discussing these range of responses, participants were quick to note that it is important to first understand the factors and processes, or rather the situations, confronting these families and the contexts they inhabit, which in turn propel such responses and position disability as a crisis within these fragile families. These are discussed in the section below, followed by a discussion on why these responses turn out to be erosive and impoverishing.

3.1. Disability as Crisis in Spaces of Poverty

The first key factor is dependence on informal labour and absence of formal safety nets. In poor rural areas in Guatemala, people are largely dependent on informal casual labouring, frequently in the agricultural sector and, to a lesser extent, construction. Overall, their own labour is more often than not the only asset they possess. Choices of labouring activities are limited, including on the basis of geographical isolation and distance from main thoroughfares. Agricultural and other paid work is often temporal and more often than not, scarce, erratic and exploitative. Arrangements such as sharecropping are also present, whereby labourers tend to the land, and payment is in the form of a share of the crop, which is rarely enough to cover the basic food basket. Importantly, such informal work is unregistered, which means that workers do not have any rights, are not entitled to leave or benefits or insurance, including unemployment or disability benefits or access to medical services offered by the Guatemalan Institute for Social Security (IGSS). Overall, this contributes to dramatic household and income insecurity as well as unpreparedness when shocks such as disability jolt the family.

You are on your own and they (employers) owe you nothing, and something happens, they then don't know you. And we have no IGSS, no nothing to protect you ... like invisible workers and people (Alfonso).

The second key issue is the loss or fragmentation of labour input by the disabled family member. In this case, much of the work performed by rural people is arduous and requires physical strength. Loss of strength and ability to perform and withstand these tasks has catastrophic economic, social and even cultural dimensions, especially when the disabled person is the household head (main income earner) [7]. The implications, as documented by participants, are loss of income, alongside the reduced production of food (especially when farming on own small plots) and ability to cover the basic food basket, constrained ability to obtain consistent, safe and quality health care for all, and to sustain education and other costs of children among others.

Like a boat that sinks, because you are like a work horse, you depend on your body ... and when this goes, everything drowns ... you cannot work the land, you lose the few cents, and your children suffer (Maria Elena).

Thirdly, the costs of disability are both direct and indirect in such poverty contexts, are substantial and often prohibitive, and importantly, are invariably out-of-pocket. These include the costs of health care and medication (when these are sought), assistive devices and supplies, specialised food, transportation costs (e.g., to seek medical care) among many others. Evidence from this study highlights how these costs and their impacts vary based on the severity of the disability, level of household poverty and composition (e.g., ratio of labourers to dependents such as small children), and type and extent of health care required among others. The major cost, though, and as amply supported by participants, is often that on health care, when this is sought. Public health care in Guatemala (the only one available to poor people) is stretched, fragmented and under-resourced, and more often than not does not cater for specialised health conditions. Instead, people are generally referred to private clinics and hospitals, charging exorbitant prices, and which poor people cannot afford (including purchasing medication). Paired with remoteness, expenses in travel and few or no savings, access to adequate and sustained health care is frequently an impossibility and also results in debt traps—small loans taken from informal money lenders at extremely high interest rates (also known as shark loans), which then cannot be repaid (see [7] for more on health care and disability in Guatemala). The following extract sums up the breadth and intensity of these costs that weigh in on weakly positioned families.

The public hospital, 7 hours to get there, we need to find a person with a car, we pay him, fuel, then lodging to stay in city, then pay for some of his (disabled person) medicine only when we can, many times no, just a prescription and then we cannot buy it ... so we just go back home with a paper ... the doctor's fees, sent to private clinics of the rich ... they tell you buy this and buy that ... we can't ... so we are poorer and full of debt, because we have nothing ... and now the moneylender is threatening us (Maria, spouse).

Within such contexts, findings from the study indicate clear and severe impacts of disability on immediate families related by blood, including women and children, setting them off on a trail of intensified, multidimensional and chronic impoverishment. This supports literature looking at a range of crises and responses to these in families, including ill health, job loss, accidents and financial stressors among others (see [23]), marking disability as a major shock, defined in development literature as an 'adverse event' propelling loss of financial and productive assets, fragmentation or loss of income and/or productive assets [24]. Disability, within such contexts, more specifically, constitutes an 'idiosyncratic shock', which though experienced by the individual, envelopes and impacts the whole family (see [25]).

It (disability) broke us, every single one us (Mario, son).

3.2. *Reacting to Disability: Erosive Responses and Entrapment in Chronic Poverty*

Participants reflected on how the presence of disability within their fragile, vulnerable and insecure families meant that attempting to respond to and survive disability and its impacts contributed to a complex dynamic of reduced consumption (food, education, and health care); shifts in labouring patterns; occasional borrowing from informal money lenders (and debt traps); disposal of assets; and requests for money and handouts among others. Overall, it strengthened the grip of chronic poverty for these families, casting them into what are called 'poverty traps' [26] multidimensional, enduring and intergenerational—and out of which it was difficult if not impossible to pull out. Sandra, the wife of a disabled man with spinal injury from a gunshot wound, documents this trail of impoverishment and how these families find themselves among the poorest of the poor within their communities, more vulnerable to shocks, and likely to never recover.

He (husband) was shot ... to rob him of Q20 ... from then on, he couldn't work anymore, because there is nothing here but the land, all suffering and struggle ... dry, no money, then I have to buy his medication, but only when I can ... the (colostomy) bags ... then we don't have enough food, we go hungry, we borrowed some money, but we can't pay it ... we are in trouble with the

moneylender ... we sold even our bed and machete ... sometimes I have to go and beg for money, but it is not enough ... school, that's all gone for my children ... my husband just cries because he can't feed them anymore ... they are still young but they have to work, but there's little here ... we are the poorest here, no one like us ... we will never recover again ... it can only get worse ... because it always does when there is illness and we are not prepared (Sandra).

The greatest shifts, it was clear, were among families with one or more members with a serious and/or chronic impairment requiring substantial medical care (and hence incurring costs), those living in more remote areas (e.g., on account of distances and costs to reach service providers), those living in areas characterised by profound institutional and infrastructural barriers, those living in volatile environments (e.g., vulnerable to environmental disasters such as mudslides and drought and climate change), those with other disabled or ill family members, and those with a weaker asset base and less resilience to deal with a crisis.

Overall, in their attempts to respond to disability, family members explained how they could not simply give in, but were instead pushed into a set of reactive and often panicked responses, which were often neither planned nor strategic, and importantly could not be sustained over time. This defies the logic of 'coping strategies' dominant in development literature (see [27]), since this implies not only some or other strategic thinking, but also that as a result these families cope and may ultimately recover following a stress or shock such as disability. Instead, these responses, as participants elaborated, were often adopted on the spot and reactively to a new 'crisis' as it emerged (e.g., lack of food and price hikes pre-harvest, need to purchase medication, transportation in emergency situations, etc.). These were often propelled by the urgent need to survive and enable the survival of the disabled family member in the face of intensified impoverishment as a result (directly or indirectly) of disability and the structural and other barriers it confronted (see below). These barriers, it was evident, were framed, constructed, lived and intensified in and through rural contexts, to some or other extent, typified by: fragmented or no formal safety nets (e.g., access to adequate and specialised health care, social protection, etc.); poor infrastructure (e.g., dirt roads which increase distance, travel costs and impact mobility); constrained livelihood options (lack of paid work options, limited or no investment potential, etc.); and importantly few or no savings and assets (including those with potential to be used as collateral for loans). These and other aspects, characterise these families as highly vulnerable in the face of any stresses and shocks such as disability, trapped in perpetual insecurity, and in turn possessing limited ability to prepare for, cope with and adapt to an event that shakes their asset and consumption base (e.g., maintaining consumption and production levels). This dynamic is well documented in poverty, development, and other literature [28,29]. The following quote clearly maps out this spiralling path.

My son fell working, and broke his spine, and he became like this ... he can't move, and then everything came to eat us all ... we are so poor here, not enough for food, no money, and then we lose the few cents he brought in through his work on Don Chilo's farm, then money to buy him some pills ... only once in a while ... and then we don't have enough food for the family ... so this condition of his is a tragedy, because we are already poor, we are weak ... look at how we live, so far away ... we try and do our best, but we are not strong ... weak ... it is a dive to the bottom for us until we die of all this (Emilio, father).

These responses to disability, as documented in development literature [30], turned out to be 'erosive coping strategies', because they were: unsustainable; undermined further resilience; weakened defence against future shocks; led to reductions in consumption and assets; and intensified the breadth and trap of poverty for all and likely across generations to come. Overall, these responses and the respective impacts transform these families into what are best described as 'disabled families'.

That's it ... we, our children, our grandchildren, even others to come, will never recover from this, because we have nothing else to give ... we are all screwed (Adolfo, brother).

Attempting to deal with this situation and emerging crises roped in family members, stretched to the limit, and one major area was that of labouring, posing a direct and critical link between disability, care and shifting family labouring patterns, in particular for women. I will discuss this further below.

3.3. Shifting Family Labour

Participants recounted how disability, especially when it reduced or removed the labouring input of the disabled family member, notably that of the household head, meant that loss of labouring capacity and earnings had to be compensated for by other family members. This is significant in rural areas, where household economies, consumption and survival often depend on labour and income pooling and sharing [31]¹. Participants explained how it is common for all family members, including children, to contribute labour power during key stages of the agricultural cycle in rural Guatemala. However, disability intensifies these pressures with a sense of urgency and impending collapse of the household economy and well-being. Family members documented in detail how they had to step in and contribute towards the direct costs (in particular health care), even if partially and erratically, compensate for lost or reduced labour power and income, provide caregiving duties, and most critically, ensure that crucial basic needs, notably food, were satisfied, even if partially.

When one falls, the other has to pick up the rest, because it is only your family and God ... the government gives you nothing ... so we all have to work, maybe to buy him (disabled person) a pill or two sometimes, maybe just for the pain, to buy some food ... all we can afford (Cristian, son).

These shifts in family labour patterns appeared to be more common in contexts where families lived and worked together in reasonable proximity. However, those families with a member residing and working in the US (often irregularly) noted how disability and its financial demands led to stepping up of pressure on the migrant family member to work harder and send some money, intensifying dependence on the small remittances sent. These, as they emphasised, could not always be sustained, and were growing more irregular in the face of intensified border policies, fragmented work, and the hunt for irregular migrants in the US.

We have a son working in construction in the US, he has his own family, sometimes sends us some money ... since his father had his accident, we are always asking for more money to help us eat and he can't ... he has mouths to feed, and work is becoming more difficult for him ... he wants to do more, but ... he is scared they will catch him too, and that will ruin us all (Manuela, mother).

In some cases, disability and its severe impacts led to increased pressure on family members, in particular young adults to consider trying to cross the border into the US, if it meant the ability to work and send back some money. More recently, they also started contemplating taking a child with them believing that this placed them in a better position to apply for asylum, a dynamic supported by coyotes who are paid and accompany migrants in the irregular crossing. In line with other literature, disability, alongside poverty, and lack or absence of remunerated labour, therefore, become push factors in forced migration [32]. However, and in practice, disability drained most if not all financial resources, and reduced the possibilities of informal loans, paradoxically making it even tougher for these families to migrate irregularly. The following quote by Jose, the 17-year-old son of a disabled father lays out this scenario.

I tell my father and mother I have to go to the US because there is nothing here, no work, no money ... nothing ... just misery ... maybe we all die soon ... the coyote tells us it is easier when you are young or a child ... maybe the gringos let you stay like that ... but we cannot save the money for me to go, and no one will lend us because we already borrowed too much money and they are after us.

The most dramatic changes in work patterns, as the evidence from the study suggests, though, occurred among family members who remained in the village and were in direct contact with and cared for the disabled person, especially women. Three key family labouring dynamics were notable in response to disability:

1. Some family members were forced to withdraw from work, reduce their hours, or faced problems in entering paid productive work, largely on account of caregiving;
2. Existing labourers were pushed to labour harder and for longer hours;

¹ This does not mean that income and assets are distributed equally between family members.

3. Others were prematurely cast into the exploitative world of paid labour, including women and children.

I expand on each of these below, focusing in particular on the impacts on women.

3.3.1. Caregiving, Fissures in Labouring and the Gender Effect

It was clearly apparent that caregiving had serious impacts on labouring patterns, in particular for women and girls already struggling to juggle their multiple tasks, specifically through the imposition of serious time constraints for productive labour, in particular remunerated work. In rural Guatemala, just like many other places, caregiving (of children, those who are sick and/or disabled) is frequently provided by women (see [33,34]). The bulk of this work is unpaid. Opportunities for paid work are scarce in rural areas, also propelled by a lack of opportunities alongside well documented gender-based discrimination and machismo. Overall, women work longer hours, have less time for paid work on account of caregiving and, when they do, are more often than not paid less, intensifying inequity and power differentials within the household [35,36].

Women participants in the study documented a number of responses/changes in the area of labouring following the onset of disability in the family and notably the caregiving duties that followed. These included reduction in paid labour and, on occasion, being forced to pull out altogether, translating into loss of income for them and for the household. This sustains literature highlighting the burden of care vis-a-vis time for productive labour [37]. It also demonstrates how the costs of disability, and indeed an analysis of the disability and poverty relationship, need to factor in so-called opportunity costs (alongside direct and indirect costs—see above), defined as the value of the resource given up (in this case labour) when put in its best alternative use [7,38]. These are substantial when paired with the opportunity costs of the lost labour of the disabled person. Fragmented labouring for some of these women was also compounded by their own ill health, limiting their ability to engage in paid labour, such as housekeeping or childcare for marginally wealthier households, or temporal agricultural labour. The following extract from the wife of a disabled man maps out this scenario.

I need to wash him (disabled husband), feed him, take care of my grandchildren ... I used to clean a house for a few cents, but I had to stop that too ... and I do not have the strength to tend to the fields, because I have severe arthritis ... I have time for nothing ... God help us ... (Marilena).

The findings suggest that the impacts on time and labour were more severe for those women providing care to a disabled family member requiring substantial and sustained care during the day (e.g., toileting and feeding), who had limited or no mobility and could no longer contribute any labour power, and when there were no other family members (especially daughters, sisters or women in the extended family) to support with these tasks. The key analytical point here is that labouring power and the capacity to earn an income by these women is impacted just when direct and indirect costs (notably health care of disabled member) are at their highest. Marcela, a single mother, explains the hardships that come with singlehandedly supporting her disabled daughter and taking care of her elderly mother.

We bleed money we do not have, we need more ... she (daughter) needs me to move her, feed her, bathe her, and I have no help ... only my mother who is 85, she is sick ... I live in her house so I can't say anything ... the more money we need, the less I can work to earn something ... stuck always here and no one to give me a break ... I am falling ill myself.

While, for women previously engaged in labouring, disability often meant interruption in their paid labour, for some younger family members, in particular daughters, the need to provide care and attend to households tasks meant the inability to even start labouring, while deepening barriers in starting or continuing their education. This is clearly laid out in the following quote.

All I do is clean the house, help my father to the toilet, feed him, take care of my brothers ... school is something I was forced to stop ... my father cries about it, but he tells me 'my daughter I can no longer send you to school ... you now have to take care of us' (Anabela, daughter).

Findings highlight, though, how not all female remunerated labour was given up. Instead, responses were complex and dynamic, changing as opportunities (notably small casual paid work) and setbacks (e.g., crop failure, food shortages and price hikes) cropped up. These included women substituting labour, worked around economic (earning potential) among other factors. This demonstrates the agency of the poor and also ability to strategise when afforded some or other opportunity (see also [39]). Daughters, for example, on occasion assumed caregiving duties (of the disabled family member and younger siblings) alongside household tasks, when this enabled mothers to engage in paid labour or micro-trade, for example to sell agricultural produce on the market. This meant the shift of the mother and wife into the household head, while contemporaneously positioning and entrapping daughters in the caregiver role.

My life was effectively stopped to take care of my father while my mother tries to go earn some money selling some onions and garlic on Sunday at the market in town ... she has to travel for hours and back ... and I don't have time to go to school, or maybe one day find a man and get married ... everything stopped ... so like my mother I am now (Ana, daughter).

The impacts of caregiving and those of fragmented or interrupted labouring had serious effects and constraints, not only on the financial inflows and assets of women, but also on their time. These included time and opportunities for socialising and to build some or other social capital, affecting the benefits often reaped through reciprocity, including the sharing of food, small loans, connections for paid work and work experience, support in times of crises, and help with child care and during illness among others. Daughters commented how being cast into caregiving, interrupted education (and often to never be picked up again) and importantly shrunk their chances of finding a partner and eventually having their own families, because they were confined to the house—out of sight, out of mind. Marriage in such contexts, as participants confirmed, is a critical source of future economic support as well as social and cultural valuation for many rural women, and hence a core part of personhood. The following quote documents these constraints on time, socialisation and impacts on marriage potential for these daughters.

My dream is to find a husband, have children ... a family ... someone who will support me ... to be a normal woman here, but I am not out, only washing, bathing, feeding (disabled father), so I do not know who will take care of me ... and locked up ... like I do not exist, just a carer (Yancy, daughter).

Caregiving and removal from work, often reinforce existing gender roles, expectations and possibly discrimination when this exists, while negatively impinging on women's bargaining power within the household, especially when much of this power may be bound to productivity and economic contribution to the household economy [40,41]. Less access to money, as some of these mothers, wives and daughters insisted, on occasion meant lower status and say within the family, less ability to negotiate better terms for themselves, and a weaker fall-back position if and when problems cropped up.

If I don't have money, it is less respect for me and what I contribute ... and if I do not have any money to eat and take care of myself, what will happen to me, if I get sick or something else like this, or I end up on my own (Connie, daughter).

Overall, and reflecting back on these findings, the responsibilities shouldered by these women caregivers, confirms the emphasis in global North disability literature on the love and care of family (see [42–45]), but contemporaneously highlights how this caregiving, within these rural poverty contexts, is not without consequences for those providing it. More precisely, it highlights the complexity of care across space, time and circumstances and its dynamic nature see (see also [46]). Findings demonstrate how, for these women, the extreme rural poverty they live in and the virtual absence of formal safety nets and services, and lack or no social protection and limited rights (part and parcel of life in rural poverty), mean that the responsibilities they shoulder are concretely tough, without respite, and do have profound physical, social, economic, cultural and psychological implications. Psychoemotional dimensions documented in disability studies [47] clearly extend to supporting family members too. The women in the study frequently mentioned anxiety and depression, withdrawal from social contact

and spheres, less money, and less ability to cater for their own health care needs as a result of the care they provided and its ramifications. A number also reported severe ill health because caring for the disabled family member's health needs left no financial assets or time to cater for their own. As a result, these women persistently framed disability and the care that came along with it as 'a weight' and an unforgiving burden in these fragile families, because they came at a cost to their chances, opportunities and well-being. But they had no choice: not providing this care not only had serious implications for survival of the disabled person, but also went against social and familial expectations. This echoes Fryers' [48] (p. 356) observation that 'how oppressive caring is felt to be, must vary with the relationship to the person cared for, the opportunities for alternate lifestyles' and 'the culture', and one would add, the economic, spatial, temporal and situational context. Elena, the daughter of a disabled mother neatly captures this.

This disability she (disabled mother) has is a weight I cannot handle ... a major trouble for us ... because I cannot handle it, I cannot have my own life, I have constant anxiety, fear for her, that she will just die ... and fear for us all. I wish this problem never came to hit us ... I was in school before, I wanted to get married. Instead, now I am locked at home 24 hours, so that my father and brothers can work.

3.3.2. Working Harder: Desperate Attempts at Making Ends Meet

While some family members were forced to pull out of work or cut down on labour input, those who continued to work following the onset of impairment within the family were too often forced to work harder. Similar patterns have been observed during or after other crises, including drought, floods, crop failure, and HIV among others (see for example [49]). These responses were not necessarily either/or, and at times complemented each other over time, and as needs and demands unfolded and changed. As participants explained, labouring remained the pivotal concern because they had to: compensate for the lost income of the disabled person and that of the caregiver; try and maintain food production; help to cover some of the direct costs (notably health care for the disabled person and food costs); and support young dependents, especially small children too young to work. Shifts in labouring were reported by spouses, children and siblings who explained how the demands associated with disability meant they were now forced to work harder and for longer hours and were constantly searching for any paid casual work. The pressure to labour was overall more intense for those families with a higher number of dependents, and/or fewer labourers contributing economically and productively. Some, such as sons who had their own families, also explained how they had to tend to the disabled person's (e.g., the father) plot of land, after or alongside farming their own land in the bid to maintain some or other crop production (exclusively for subsistence) or to minimise crop failure. They explained how this, on occasion, affected their own crop production and hence food output, impacting consumption and pushing up food expenses for their own immediate families. Consequently, these labour inputs on the disabled person's plot were often erratic, and could not be sustained over time, leading the crop to wither and the land to eventually dry up.

I can barely farm my own plot, and the work I do is killing me, because my father doesn't work, just spending on him, so I have to intervene ... money, just money, and my family is starving too ... I fear one of these days I will die working where I am ... and then ... his (father) field is now gone, because I couldn't work that and mine (Oscar).

The pressure to work harder and longer, had various consequences, including stress and also heightened and prolonged exposure to perilous work and consequently risk of accidents, ill health and even impairment. Indeed, while poor rural people do not have much choice as to the work they do, the demands imposed by disability, reduce this choice even further, pushing family members to take up the first hazardous work that comes along, including seasonal migratory labour for months on end. Domingo, an 18-year-old, had taken off to work on a plantation many miles away from home to try and support the family after a stroke which left his father paralysed. His family were worried sick at the time of interviewing, explaining how accidents, brutal working conditions, and even violent crime

and assault were common, stating that all they could wish for was for him to return safe and sound. Nevertheless, and while they tried to dissuade him from going, the family was already going hungry, and his decision, like that of other forced migrants, was propelled by the desperate need to survive despite all odds. His mother, Ermelinda, explains.

Many go and they have not returned, you can die because you do not have equipment, they can rob you and kill you when they pay you ... you can fall or get hurt, and no one will take care of you ... so far away ... I pray to god every day he returns safe ... he would say 'we are dying here and if I do not go and do something, we will'.

3.3.3. Forced Inductions into Perilous Labour

Findings from the study suggest that while some are forced to work harder, other family members, in particular wives and children, are sometimes pushed into the world of paid labour for the first time. These inductions into poor labour are discussed in the following two subsections.

Exploitable Bodies

The narratives of partners and spouses, wives in particular, were fraught with dramatic changes following the loss or fragmentation in their husband's labour input and contribution to the household economy. They recounted in detail how disability meant dramatic pressure to find paid work, wherever and whatever it was, especially work that was sufficiently close to the homestead to allow them to provide some or other care for the disabled family member, care for small children and attend to household tasks. Indigenous women in the mountain areas also explained how they were consistently pushed by the need to grow some of the subsistence food crop for consumption, and indeed many picked up the machetes and took to the fields to continue working the land previously tended by their husbands (unpaid). Overall, this demonstrates the substitutability of traditionally male and female work (see [50]) during times of crises within contexts of dramatic market imperfections, dire unemployment, input constraints (e.g., water and agricultural inputs such as fertilizer), environmental factors (e.g., drought) and climate change, lack of financial assets (for consumption and/or investment), and overall poverty. In this study, and supporting other studies (see [51]), this was particularly the case among rural indigenous families, highlighting a greater fluidity and less rigidity in gender roles than among non-indigenous people.

I had to take to the fields, to maybe save something, my husband's suffering is mine, because he can't do it anymore ... I work with the machete, sometimes the neighbours help me ... because if not, we do not eat ... it didn't rain, dryness, and we do not have enough water, so most of the crop will die again ... it is desperate (Esmeralda).

These family members narrated how entry into the paid informal labour market, though, was far from smooth or harmless, often marred by exposure to its extreme negative forces, including abuse and exploitation, and critically, hazardous and unsafe working conditions, and where accidents are common, e.g., exposure to harmful chemicals and falls. They recounted how employers rarely provide any protective equipment (e.g., in construction or in farming) and how informal labouring means they have no obligations towards workers when something happens (e.g., compensation in the case of accidents). However, what marks and distinguishes the situation of these families as particular is that their dire financial situation and critical need to labour translates into a form of slavery or bonded labour when employers (e.g., landowners) know how desperate their situation is, the knowledge that they will work for anything, and how they in turn capitalise on their misery as a default response. Participants told how providers of temporal work knew they were in no position to negotiate in the face of impending hunger, debt and severe impoverishment, initiating a cycle of seriously abusive and even violent work.

I work as a *muchacha* (maid/housekeeper) for this wealthy family from the city, I wash, take care of the house, take care of their children, cook, buy, everything ... they just relax and the wife just shouts at me, accuses me of doing things that aren't true ... she said I stole money and she hit me ... she

knows my husband is in a wheelchair, and instead of helping me, she treats me like a dog and pays me almost nothing, saying my husband is useless (Mirna).

While the situation offered some leverage for these women within their households, the chances of shifting broader gender-based discrimination and machismo, though, it appeared, remained small. This is because the notion of what a 'real' man should be and do is embraced by and frequently also maintained by women, highlighted on occasion in participants' claims that their husband had stopped 'being a man', or was no longer 'man enough'. As Stobbe [52] succinctly notes, while machismo oppresses women, it is also women who reinforce this through their expectations of what a man should deliver. Furthermore, many women were in large part induced into work considered female, but on even more exploitative terms, while others (especially daughters) were trapped even further in the caregiving role, reinforcing existing female positions. Also, while women, especially those in agriculture, took on work considered traditionally male, men rarely performed tasks considered female, notably cleaning, cooking and child rearing.

From Child to Labourer

In this study, it was not only adults who saw working patterns shift. Indeed, the impoverishing impacts of disability and the struggle to keep afloat, it was clear, did not spare anyone. In these families, even children were quickly pushed into the world of labouring, marking 'a premature entrance to burdens of adulthood, all without the ... strengths ... associated with adult status' [53]. Barely adolescents, these children were on occasion driven to find some or other remunerated work, not so much by their parents, but by bare necessity, including food shortages as supplies and money waned. Indeed, an inverse relationship seemed to exist whereby as the demands and costs of disability rise and shift fragile families towards destitution, the age at which children are forced to take up work appears to dramatically drop (in this study as young as 9). Conversations with these children in the presence of their families exposed an intense pressure to intervene, a decision they reiterated was their own, motivated by the desire and need to help their families. This drive was particularly intense when: the mother could no longer work, e.g., on account of ill health, or was not earning enough to cover the basic needs; the household had a high dependency ratio (infants or other ill members or ones with a disability); parents were no longer able to pay for education and these children had to pull out (on account of the draining of financial resources and loss of labour); the disabled person faced high direct costs of disability; and/or debts had been incurred and needed to be repaid.

My family is buried into the ground, hungry and my father is bent over with pain in his chair and my mother is getting sick. I cannot let them starve, so maybe I can get some medicine for both of them (Antonia, 14 years old).

The induction of children into work, though, is a decision that these families did not take lightly. It is important, though, to contextualise this situation. Child labour is customary in Guatemala, especially among the poor and extreme poor. Guatemala's legal working age is as low as 14, but it is estimated that some 42% of working children are below this legal working age, especially in agricultural and rural areas, motivated by extreme poverty [54]. This work is on occasion temporal, for example contributing some labour input at key stages of the agricultural cycle, meaning that children often go back to school. In this case, work is gradual and involves the sharing of tasks, work that is also meant to teach these children the skills to eventually have their own trade. The impoverishing urgency created by disability, the narratives confirm, though, accelerate this process, driving children into rough, hazardous and exploitative labour prematurely, with no preparedness, opening extraordinary channels for accidents, disease and impairments.

A child here helps the family, it is customary, but one should not have to see his son or daughter shouldering the weight of the family, scarred, bruised, working with the machete, not knowing whether he is going to make it back home every day ... he is only 12, but he (son) says he is the man of the house, but he's already gotten hurt..I fear next time it will be worse (Angela, mother).

While sons were often pushed to work in agriculture, daughters were induced into a range of productive activities (remunerated or not) alongside, or instead of caregiving, many in the home, such as food processing and its sale, but also outside, for example housekeeping for marginally wealthier families in return for a small (often exploitative) payment or selling food.

While there is substantial literature addressing child labour and linkages with education and other aspects (see [55]), there is a gap in the literature connecting this labour (which may not always be forced or exploitative) with parental or familial disability. Longitudinal research is also needed to look at the connections with potential impairments among these same children, and how they feed back into and connect with the disability experience of the parent and the interactions with poverty for the disabled family.

4. Conclusions

The findings from the study highlight a complex and dynamic set of responses and impacts on families and can hardly be captured in this small study. However, it is clear that disability has severe impoverishing impacts on the whole family, reinforcing the notion that disability extends beyond the individual, transforming these units into what are best described as ‘disabled families’ [7], those among the poorest of the poor, weakened by association and care, increasingly vulnerable to stresses and shocks. More basically, understanding the disability experience, livelihoods, and indeed the disability and poverty relationship requires us to transcend the individual to understand disability as a family affair alongside the gendered dimensions of care, not least because these units are solely responsible for survival in the absence of any safety nets. It is also within these units that disability is constructed, shaped, and can ultimately be understood. Any other narrative will remain partial and individualized, and clearly disability is neither of these. Longitudinal familial and intergenerational research is needed to understand how these shifts in labouring and poverty and their impacts transcend space and time. Furthermore, the impacts of caregiving and the impositions on time, money, autonomy and well-being, especially for women, are critical subjects of research in their own right and need to be explored diligently over time. Only then can we speak about genuinely inclusive and gender-sensitive development and research.

The findings also have serious policy and practice implications. The first is perhaps the most obvious—the need to address the needs of the family. Measures including social protection, protection of livelihoods, and education are perhaps best targeted at these disabled families, and not be limited to the disabled individual. A stronger family is in a better position to weather shocks, provide care and ultimately benefit the disabled person, without having to sacrifice opportunities and well-being of other family members. While policies such as job quotas for disabled people are important in urban areas and cities, they are limited in scope and reach in contexts where unemployment is rampant for all, where work is temporal and fragmented, where policies and rights are hardly known and implemented at a local level (including by local government), and where poor disabled people rarely have the means to seek legal redress [7]. Indeed, and perhaps, this pushes us to question and challenge the fate in international rights, treaties and conventions such as the UNCRPD and their ability to have any impact on the ground, when rights violations are the order of the day, known too well by people in extreme rural poverty. Importantly, much of the work available is premised on and requires strong productive bodies. Policies and practice would do well to target, protect and facilitate paid labouring opportunities for family members, because ultimately the benefits of such labour are shared, including by the disabled person.

Secondly, protecting the livelihoods of family members and ensuring their basic needs are attended to (especially food) has serious implications for their own well-being, their own families and once again the disabled family member. Exposure to exploitative and hazardous work by family members, including women and children, opens serious avenues for ill health, injuries, accidents and impairment—all of which will ultimately impinge on the care they can provide for the disabled family member.

Findings point to the need for cross-sectoral services to compensate and support the caregiving efforts of family members, especially women, not least because this care has dire effects on their own well-being, health and opportunities. Indeed, as Fryers contends, ‘there needs to be a balance between the needs of the disabled person and the needs of the caregiver’ [48]. Efforts are needed not only at protecting their labouring opportunities, but also to provide financial assistance to cover the costs of the disabled person, at the very least to reduce the financial strain on families and minimise collateral impacts of disability such as interruptions in their own education. This requires nuanced, contextualised research to understand how this caregiving is shaped and lived on the ground in different spaces and places, and what the needs and demands are.

Finally, addressing these needs and investing in women, including their livelihoods and earning potential, is critical, because, as research has amply demonstrated, the benefits transcend these women and reach the whole family given their instrumental roles in food production, child care, caregiving and education [37]. Overall, adopting a family approach in research, policy and practice is not only what genuine inclusive development should be about, but also ensures that interventions in the lives of disabled people do have impacts and extend over space and time.

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