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CHAPTER 5

How Poverty Shapes Caring for a Disabled Child:
A Narrative Literature Review

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5.1 ABSTRACT

Despite ample research on the relationship between disability and poverty, the experiences of parents of disabled children are herein generally overlooked. We argue that an understanding of how poverty shapes caring for a disabled child is crucial for disability inclusive development. Therefore, this paper narratively reviews literature on carers of disabled children from various contexts published between 1990 and 2015. It uncovers a significant knowledge-gap on the impact of poverty despite slowly emerging evidence on how political, cultural, and socio-economic exclusion stifles parents to enhance their families' wellbeing and possibly reap the benefits of development policies. Implications for future research are addressed.

5.2 INTRODUCTION

Parents of disabled children face myriads of practical and emotional challenges. On a daily basis they juggle between the child's physical, medical and emotional needs; personal and social obligations and responsibilities; expectations and requirements of the outside world; and their own physical and mental wellbeing (Kuhlthau 2012). In order to support these parents and to understand the challenges they face, parents' lives have been and still are a growing subject of research (Kimura and Yamazaki 2013; McConnell et al. 2015; Yagmurlu et al. 2015).

As other authors have pointed out before (Huiracocha et al. 2015; McConkey et al. 2008; Park and Chung 2015; Wijesinghe et al. 2015), the majority of the disability and care research¹ has been conducted in affluent settings, mostly Western countries. Yet, poor socio-economic conditions and a lack of resources (a resource-poor context) are likely to influence the experiences of carers² of a disabled child³, as caregiving takes place in a societal context which influences the family and their possibilities to attain wellbeing (Bronfenbrenner 1986; Chambers 1995; Deneulin and Shahani 2009; Pouw and Gilmore 2012). Other studies on carers of orphans of the HIV pandemic and of people living with HIV/AIDS provide evidence on the influence of a resource-poor context on caring (Evans and Atim 2011; Hunter 2012; Ice et al. 2010; Lindsey et al. 2003). Based on a Kenyan study, for example, Ice et al. (2010) suggest "the effect of caregiving as a stressor may be small relative to the stressor of low socioeconomic status, general lack of access to care, a lifetime exposure to numerous infectious diseases, and generally poor nutrition" (17). This may be similarly true for carers of a disabled child living in a resource-poor context.

Understanding this impact of poverty on parenting a disabled child, we argue, is essential for disability mainstreaming in development. Disability mainstreaming or disability-inclusive development is based on the premise that disability justice should be an integral part of socio-economic development efforts and should not be seen as peripheral to society (see for example MacLachlan and Swartz 2009; Power 2001; UN 2003). The well-documented bidirectional link between disability and poverty (Eide and Ingstad 2011; Elwan 1999; Loeb et al. 2008; Mitra et al. 2013; Yeo and Moore 2003) lies at the foundation of this argument. Disability and poverty issues are seen as intertwined and need to be handled accordingly. Instead of addressing the needs of children and people with disabilities only through social welfare structures, it is suggested they need to be included in all poverty reduction and (social) development strategies (UN 2007; World Bank 2015). "Disability issues are in fact core to the reaching of development goals" (Swartz 2009: 99). For example, accomplishing the Sustainable

Development Goals on access to education requires specific strategies for children with disabilities. Research on the relationship between disability and poverty has been vitally important in the understanding and implementation of such disability-inclusive strategies (e.g. Mitra et al. 2013; Palmer 2011). However, it generally does not include the experiences of parents of disabled children.

We argue that for full disability-inclusive development, the realities of children and people with disabilities need to be understood; but also, the experiences and practices of the carers living in poverty. For one, children with disabilities (as all children) depend on their carers for their wellbeing (Kuhlthau 2012). Two, for many children the family is the “principal context in which human development takes place” (Bronfenbrenner 1986: 723). A disabled child influences a carer and her capabilities, both positively and negatively. Vice versa, a carer impacts a child’s development, which can similarly be positive or negative. Three, focusing on the child in formulating development policies omits carers’ personal or socio-economic constraints for care. For example, a public policy on inclusive education for disabled children ignores the financial or public transport constraints carers face to access schools. In line with this argument, this (exploratory) narrative literature review⁴ aims at gaining a theoretical understanding of how living in a resource-poor context shapes parents’ experiences of caring for a disabled child.

5.3 METHODOLOGY

No other literature review, to our knowledge, has attempted to analyze and synthesize current knowledge on how poverty influences carers of disabled children specifically. As this article thus serves as a first of its kind, a qualitative narrative review was chosen as methodology as it provides for a preliminary broad perspective on the topic (Green et al. 2006).

Studies on disability and care were included if they provided either original research or a literature review on specifically the practices and/or experiences of parents of disabled children. To identify studies from a resource-poor context, we subscribed to the notion of poverty being multidimensional (Alkire 2011; Sen 1992). Nevertheless, we also included studies using unidimensional measurements of poverty, as they shed light on at least one aspect of the multidimensional complexity of poverty. Studies were thus considered as ‘resource-poor’ if they had a sample of which at least 50 per cent were carers with a low SES, explicitly discussed the role of poverty on carers, or described the study setting as impoverished or disadvantaged. A very

limited availability of disability and care studies from a resource-poor context made us broaden our search towards disability and care literature from any context in order to make comparisons between settings. As there is an abundance of studies on parents of disabled children in general, we narrowed inclusion of these studies down to a set number which would be sufficient for comparison. Inclusion was based on obtaining a wide representation of literature regarding country of research, methodology (qualitative or quantitative) and sampling (fathers and/or mothers, and medical disability type). Intervention-impact and effectiveness studies were not included; neither were studies pertaining to theory and methodology.

Our search focused on electronically available English literature from 1990 up until August 2015. Searches were performed in online bibliographic databases and in university library search engines (see Table 3). Grey literature and web reports were retrieved using Google and international institutions websites. Hand searches of reference lists were executed. In addition, due to the research question involving the concept of poverty, manual searching was performed in ten influential development journals (see Table 3). A variety of search words were used related to care, disabled children and poverty including: care, caring, caregiv*, carer*, mother*, parent*, child*, experience*, wellbeing, disabled, disabilit*, poverty, poor, resource-poor, disadvantage*, low-income, developing countr*, culture*, context*. Using the computer software program Atlas.ti, data was extracted, compared and analyzed pertaining to the study particulars including conceptual framework, methodology, sampling and results.

Table 3. Literature Search Sources

Source	Particulars
Online Bibliographic Databases	<ol style="list-style-type: none"> 1 Google Scholar 2 Science Direct 3 JSTOR 4 Taylor and Francis Online 5 Wiley Online Library 6 PubMed
University Library Search Engines	<ol style="list-style-type: none"> 1 University of the Western Cape, South Africa 2 VU University, Netherlands 3 University of Amsterdam, Netherlands
International Institutions Websites	<ol style="list-style-type: none"> 1 United Nations 2 World Bank 3 UNICEF 4 World Health Organization
Influential Development Journals	<ol style="list-style-type: none"> 1 Economic Development and Cultural Change 2 Journal of Development Studies 3 World Development 4 Development and Change 5 Third World Quarterly 6 Journal of International Development 7 Development Policy Review 8 Canadian Journal of Development Studies 9 European Journal of Development Research 10 Progress in Development Studies

To answer our research question, we firstly review disability and care literature and what it reveals on the impact of poverty. Then, we highlight three studies which specifically focus on the impact of poverty on carers of disabled children and thus examine the dynamics between all three concepts: disability, care and poverty. We conclude with identifying knowledge gaps and providing directions for future research.

5.4 DISABILITY AND CARE

As mentioned earlier, studies on parents of a disabled child are abundant, yet mostly conducted in affluent settings. By contrast, our literature search resulted in only 20 articles from a resource-poor setting which suggests a lack of understanding of experiences of parents living in poverty. For comparison purposes 40 articles from other settings were included. The resulting 60 studies under review represent 32 countries in total⁵.

Most of the disability and care literature has a disability, family and child care, nursing or health background. Other studies have appeared in rehabilitation or special education journals. By analyzing the research questions of the studies, a few conceptual lenses used to study the parents' experiences are found to be common (see Table 4 on next page). Most concepts relate to the negative impact of childhood disability on parents (burden, stress, wellbeing, challenges/unmet needs) (e.g. McConnell et al. 2015; Neely-Barnes and Dia 2008; Ryan and Runswick-Cole 2008). This focus on adverse effects "has underpinned much of the research of the past three decades" (Neely-Barnes and Dia 2008: 94). The underlying assumption is that caring for a disabled child is considered a burden by their carers, poses tremendous challenges and has a negative effect on multiple life domains (Ryan and Runswick-Cole 2008). The concepts of coping and positive effects or (re)interpretation counterbalance this negative presumption in literature (Seltzer et al. 2001). These conceptual lenses try to capture how parents find ways to cope, and attach positive meaning to parenting a disabled child (Gona et al. 2011; McConnell et al. 2015). They have however received less attention in literature.

To review this body of literature, the distinction made between the negative impact of childhood disability and the positive effects and coping mechanisms is useful. Rather than presenting literature following all employed concepts, this division provides an opportunity to assess how poverty forms both the negative and positive experiences and caring practices. Therefore, the next paragraphs follow this division. Moreover, we examine what each section of this body of literature can teach us on the influence of poverty.

Table 4. Common concepts in literature

Concepts	Analysis of	Levels of measurement (one or more)	Examples literature
Burden	Burden of childhood disability on parental lives.	Emotional Psychological Physical health Social Financial Time Family Functioning Parental Employment	(Datta <i>et al.</i> , 2002; S. E. Green, 2007; Oh and Lee, 2009; Wijesinghe <i>et al.</i> , 2015)
Stress	Impact of childhood disability on parental stress levels, and influential variables (such as child's gender)	Parental distress, depression, anxiety Pessimism Parental perceptions of child Social Isolation Child-Parent Interaction Difficult behavior child Family problems	(John, 2012; Shapiro and Tittle, 1990; Shin <i>et al.</i> , 2006; Wang <i>et al.</i> , 2011)
Wellbeing	Impact of childhood disability on parental wellbeing, and influential variables (such as receiving support)	Emotional Psychological Pessimism Stress Physical Family Functioning Parental Education Level Parental Employment	(McConkey <i>et al.</i> , 2008; Samadi <i>et al.</i> , 2014; Seltzer <i>et al.</i> , 2001; Yagmurlu <i>et al.</i> , 2015)
Challenges/ Unmet Needs	Challenges or unmet needs in caring for a disabled child	<i>Measurements unspecified, outcomes usually related to:</i> Emotional Physical health Child behavior Obtaining support (social, medical, information) Financial Time	(Gona <i>et al.</i> , 2011; McNally and Mannan, 2013; Resch <i>et al.</i> , 2010; Sandy <i>et al.</i> , 2013)
Coping	Coping efforts to manage external or internal stressors faced by parents with a disabled child	Emotional focused (such as acceptance, express feelings, keeping active with hobbies) Problem-focused (such as seeking cure, learning new skills)	(Hartley <i>et al.</i> , 2005; Hauser-Cram <i>et al.</i> , 2001; Kishore, 2011; Taanila <i>et al.</i> , 2002)
Positive effects	Positive effects and adaptation to childhood disability of parents	Emotional Spiritual Social Family Functioning Parental Employment	(Kayfitz <i>et al.</i> , 2010; McConnell <i>et al.</i> , 2015; H. J. Park and Chung, 2015; Ylvén <i>et al.</i> , 2006)

5.4.1 Adverse Impact of Childhood Disability

Research on the negative impact of childhood disability generally encompasses the psychological and the physical effects of care on parents, as well as effects on a parent's environment, that is the socio-structural impact (which will be explained later in this paragraph) (e.g. Hauser-Cram et al. 2001 on wellbeing and stress; Oh and Lee 2009 on burden; Resch et al. 2010 on challenges). After describing these effects of childhood disability on carers, we discuss factors found to aggravate the adverse effects.

Psychological impact

Research indicates parents of disabled children are more likely to portray poor mental and physical health than other parents (Gona et al. 2011; Oelofsen and Richardson 2006; Seltzer et al. 2001; Taanila et al. 2002; Wallander and Marullo 1997). Due to the demands of care, parents experience negative psychological and emotional effects. Kermanshahi et al. (2008) report in an Iranian study: "All mothers identified degrees of painful emotions. These emotions ranged from, feeling burdened and 'finding the child a burden', 'being agitated', to feeling 'hopeless and depressed'" (320). Studies in Pakistan, Uganda, Hong Kong, Taiwan, Ireland, Jordan and China uncover feelings of guilt, being overwhelmed, sadness, anxiety and tremendous stress (Azeem et al. 2013; Hartley et al. 2005; Lam and Mackenzie 2002; McConkey et al. 2008; Wang et al. 2011).

Studies conducted in resource-poor settings however suggest the reported negative emotions are not merely related to the child and the strain of care. Stigma and the consequential isolation are similarly pointed out as a source of painful emotions (e.g. in Uganda, Hartley et al. 2005; in Zimbabwe, Van der Mark and Verrest 2014). Furthermore, poor living conditions and lack of access to services are reported to cause additional worry and concern (e.g. in South Africa, Hemming and Akhurst 2009; Saloojee et al. 2007; and in Turkey, Yagmurlu et al. 2015). As Emerson (2004) states: "The 'daily grind' of living in poverty is often a source of chronic and pervasive strain" (325). In fact, in a phenomenological study with a small sample in Tanzania, McNally and Mannan (2013) assert: "The parents do not see the child as the problem. It is the inability to provide for the child that creates the most stress" (8). Research from Kenya, Pakistan and South Africa supports the notion of stress due to carers' constrained ability to satisfy their child's basic needs (respectively Gona et al. 2011; Qayyum et al. 2013; Sandy et al. 2013).

Physical impact

Chang and McConkey (2008) describe how Taiwanese "parents also spoke of the physical effort and strain in taking care of their child, especially if their child had a

profound disability. Some mothers had suffered long-term physical illness and physical change, mentioning constant fatigue, and sprains" (35). In particular when a child grows older and therefore heavier, parents start to experience physical ailments (Park and Chung 2015). This physical burden of care is acknowledged in other parts of the world, such as Uganda, Israel, Japan, and Canada (respectively Hartley et al. 2005; Heiman 2002; Kimura and Yamazaki 2013; Raina et al. 2005).

However, in a Kenyan study, Geere et al. (2013) hypothesize the physical burden to be more severe due to poverty. With limited provision of for example wheelchairs, specialized transport and personal hoists and in the context of poor housing, an extra burden is placed on parents' physical efforts. Though Geere et al. do not positively establish this link, the physical demand of carrying a child due to transport and assistive technologies shortages occurs frequently in literature from resource-poor settings (e.g. in Uganda, Hartley et al. 2005; in South Africa, Hemming and Akhurst 2009; Masasa et al. 2005; and in Tanzania, McNally and Mannan 2013). In other literature the constrained supply of assistive equipment and technologies in resource-poor areas is confirmed (Eide and Øderud 2009).

Socio-structural impact

In her US-based research, Green (2007) protests the narrow focus on "individual, and emotional burdens" (151) such as psychological and physical stresses in academic literature on carers of disabled children. She claims it fails to capture the objective socio-structural effects. These include "items related to the impact of the child's disability on the mother's financial, work, family, social and recreational activities" (ibid.: 154). She therefore conceptualizes caregiving burden as an interplay between the subjective (emotional) and the objective (socio-structural) burden. Green's conceptualization of the socio-structural impact of caring is useful to explore disability and care literature, as research examining the impact of care on carers' circumstances is growing. Though other studies use concepts such as challenges, (impact on) wellbeing, or a specific descriptive concept (such as impact on finances), they all relate to the socio-structural impact (e.g. Hauser-Cram et al. 2001 on wellbeing and stress; Leonard et al. 1992 on financial and time costs; Resch et al. 2010 on challenges).

Concerning the socio-structural impact, several issues are studied such as the effects of caring on finances in the US (McConnell et al. 2015), on social relationships in Canada (Watt and Wagner 2013) or on family functioning in Israel (Al-Krenawi et al. 2011). Caring for a disabled child is found to be a time-consuming, expensive and isolating experience in addition to the physical and psychological effects (e.g. in Israel,

Heiman 2002; in South Africa, Hemming and Akhurst 2009; in Canada, McConnell et al. 2015; and in Zimbabwe, Van der Mark and Verrest 2014). Engaging with a wide range of services for medical care, assistive devices, and information is often cited as a time and cost intensive process (Leonard et al. 1992; Raina et al. 2005; Yagmurlu et al. 2015). Particularly attaining information on both the practical and emotional side of having a disabled child is perceived as a struggle, for example in Russia, Iran and Canada (respectively Kaplan 2010; Kermanshahi et al. 2008; Stainton and Besser 1998). It reduces parents' so-called health-literacy. "Health literacy refers to an individual's achievement of a level of knowledge, personal skills and confidence to take action to improve his or her life" (Sandy et al. 2013: 349).

In an impoverished area though, research suggests the main burden is not simply the time needed to deal with these services due to childhood disability. Rather, a shortage of financial resources, a serious lack of existing services, limited knowledge on available services, and transport constraints to access them are experienced as the major struggle. Affordability, availability and accessibility of services, which we in short refer to as the *Triple A's*, are thus significant in a resource-poor context (e.g. in South Africa, Jones et al. 2000; in Pakistan, Qayyum et al. 2013; and in Sri Lanka, Wijesinghe et al. 2015). The Triple A conundrum also exacerbates the difficulty to attain information from services (Hartley et al. 2005; Philpott and McLaren 2011), and thus further diminishes health literacy.

Seltzer et al. (2001) report on the strenuous balance experienced by American parents between employment and the demands of care. Frequently, carers have to reduce their working hours or quit a job to be able to provide care for their child, which can lead to financial instability (e.g. Daudji et al. 2011). Neely-Barnes and Dia (2008) show similar results in their cross-cultural literature review. Furthermore, problematic family functioning is reported due to a disabled child in the household (McConkey et al. 2008). Personal and social relationships come under pressure because of the lack of time to invest in social and recreational activities by carers (Chiang and Hadadian 2007; Gona et al. 2011; Seltzer et al. 2001). Some studies suggest disability stigma aggravates social isolation. Due to negative responses, parents are more likely to stay at home and reduce their social activities (e.g. in Nigeria, Hamzat and Mordi 2007; in Israel, Heiman 2002; and in India, Kishore 2011).

Particularly parents from resource-poor areas refer to disability stigma as a reason for a limited social life. For example, McNally and Mannan (2013) and Hartley et al. (2005) make note of Tanzanian and Ugandan carers wanting to hide their child out of shame

and therefore not engaging in social events themselves. Furthermore, in Uganda and South Africa reports are made of fathers abandoning their family once a disabled child is born (Hartley et al. 2005; Hemming and Akhurst 2009). Traditional and/or religious ideas surrounding disability (known as the moral model in disability studies⁶) (ACPF 2014; Ingstad 1995; Yekple 2014), which likely influence disability stigma, are among others reported in Kenya by Gona et al. (2011), in Nicaragua by Matt (2014) and in Vietnam by Shin et al. (2006). According to Ssebunnya et al. (2009), poverty can be a catalyst for stigma, as it can worsen one's disability and therefore, in combination with prevailing belief systems, increase stigma. Furthermore, they suggest access to "material resources [for example proper clothing] can offer protection against stigma" (2009: 5). Foley and Chowdhury conclude that:

Regardless of disability, poverty can be a morally and socially devastating ordeal. However, [...] the added loss of social solidarity and equitable access, due to the social exclusion and stigma of disability for the families concerned, make it statistically far less likely that they will [...] be able to escape poverty (2007: 372).

A legitimate question to ask though is whether social isolation is more severe due to poverty and stigma, or whether other factors are at play as well. Gona et al. referencing Nduati (1995) state for example that in Africa in particular "the collapse of traditional systems coupled with social inequality" (2011: 176) compromises family and community cohesion, which in turn diminishes available social support.

Influential variables for adverse impact

Evidently the psychological, physical and socio-cultural impact of caring for a disabled child varies amongst parents. A vast number of quantitative studies focus on measuring these risk variables for caregiving burden of parents. These studies examine how specific child- and mother-related variables predict caregiving burden (Aldosari and Pufpaff 2014). Child-related factors include sex, level of disruptive behavior, age, and severity of disability (e.g. John 2012; Samadi et al. 2014). Maternal-related variables take account of variables such as education level, age, and marital status (e.g. Green 2007; Oh and Lee 2009).

Two other risk factors occasionally analyzed are carers' socio-economic status and urban or rural residency. These variables in particular might shed some light on the influence of poverty on caring. For example, in Lebanon, India and Hong Kong, higher perceived burden is associated with a low income (respectively Azar and Badr 2006; Datta et al. 2002; Mak et al. 2007). Several articles from a resource-poor context

confirm these findings. In a 52 per cent low and 48 per cent middle income sample in Vietnam, Shin et al. (2006) find that low average monthly income increases parenting stress and perceived stigma. Geok, Abdullah and Kee (2013) report that poor and rural Malaysian parents experience lower quality of life than middle-income or urban parents. In addition, in a resource-poor Sri Lankan setting, rural residency results in higher perceived caregiver burden (Wijesinghe et al. 2015). Income poverty and rural residency can thus aggravate experienced burden and stigma, yet the whys and wherefores remain unexplored in these studies.

5.4.2 Positive Impact of and Coping with Childhood Disability

A growing body of research is available on coping mechanisms of parents of children with disabilities. Coping strategies are generally divided into problem-focused strategies and emotional-focused strategies (Lazarus and Folkman 1984). However, not all studies make this division and merely show coping strategies from a phenomenological standpoint. Common coping strategies are seeking peer and social support (in Australia, Plant and Sanders 2007; in Finland, Taanila et al. 2002), seeking medical or formal care (in Kenya, Gona et al. 2011; in Spain, Shapiro and Tittle 1990), seeking information and advice (in Israel, Heiman 2002; in the US, Resch et al. 2010), acceptance and positive reinterpretation (in China, Wang et al. 2011; in 7 countries, Ylvén et al. 2006), and learning new skills (in the US, Green 2007; in Uganda, Hartley et al. 2005). Religious coping or otherwise named spiritual intervention is reported to be connected to acceptance. Huang, Chen, and Tsai (2012) state that for Chinese fathers: “Chinese religion sustained their hope of improving the child’s disability and strengthened their belief in their child’s future wellbeing” (3290). Norizan and Shamsuddin (2010) find religious coping to be linked to positive adaptation in Malaysia, and Iranian parents believe God has given them a special gift and thus accept their child fully (Kermanshahi et al. 2008).

Data from resource-poor contexts reveals differences in importance and usage of certain coping strategies. Van der Mark and Verrest (2014) suggest poverty impedes coping through informal and formal support in Zimbabwe. In their study, mothers describe how friends, family and neighbors’ capabilities to be of assistance are constrained by poverty. Even if people would want to help, their own lack of financial and material resources prevents them from doing so. Seeking formal and medical support from services is reported to be unfeasible due to the Triple A conundrum (e.g. in Pakistan, Qayyum et al. 2013; in South Africa, Saloojee et al. 2007; and in Zimbabwe, Van der Mark and Verrest 2014). Instead, parents’ self-reliance is revealed as an important strategy. Carers tend to resort more to learning skills themselves, such

as giving physiotherapy, making assistive devices or administering medication (e.g. in Kenya, Gona et al. 2011; and in Uganda, Hartley et al. 2005).

Religious coping is most frequently described in resource-poor settings, which suggests greater importance. Faith enhances carers' ability to accept their child and be positive and confident about the future, as for example reported in South Africa, Nicaragua, Tanzania and Sri Lanka (respectively Masasa et al. 2005; Matt 2014; McNally and Mannan 2013; Wijesinghe et al. 2015). Religious coping is widely acknowledged in coping and care literature on, for example, caring for elder relatives (Hebert et al. 2006; Herrera et al. 2009; Pearce 2005). It has, however, a small presence in disability and care research from resource-rich settings. Perhaps this is influenced by the larger prominence of religiosity in developing countries (Crabtree 2010), or the possible increased use of religious coping in the context of poverty (Black 1999; Puffer et al. 2012; Wadsworth 2012).

In addition to the focus on coping mechanisms, some authors incorporate and assess the positive effects and meanings attributed to parenting a disabled child. Green (2007) reveals that American mothers value the peace and joy their child brings into the family. Interestingly, Green notes becoming an expert in the medical system is perceived as a benefit, despite it being costly and time consuming. Extensive knowledge of the medical system and being comfortable in it helps parents in other times of crisis, unrelated to their child. Also, in their Korean study, Park and Chung (2015) state:

All mothers in this study shared that the changes their child's disability brought to their own lives helped them grow over time as a person. Many agreed that they have become more open-minded and have new expectations for life as a person apart from life as a mother (925).

Stainton and Besser (1998) demonstrate in a Canadian study that having a disabled child in the family increases family cohesion and parental relations, which is confirmed by Kayfitz, Gragg and Orr (2010). Tanzanian carers are reported by McNally and Mannan (2013) to experience happiness by interacting with their child and seeing their progress. This positive impact is described for both resource rich and poor settings.

In sum, disability and care literature provides an understanding of the adverse and positive impact of childhood disability on carers, and coping strategies. Moreover, it preliminarily points towards the influence of poverty. The question is not *whether*

a resource-poor context will influence parenting a disabled child, but rather *how* it affects parents. The discussed literature shows that Triple A challenges hinder caring strategies; increased stigma diminishes social support; the inability to provide for basic needs intensifies stress; transport and assistive devices shortages exacerbate physical impact; and faith functions as a buffer. Nevertheless, these contextual dynamics merely shine through in the descriptions of parents' perceived adverse and positive effects, and are not assessed conceptually.

5.5 HIGHLIGHTING POVERTY AS A CONTEXTUAL FACTOR

In our literature search, we only found three articles in disability and care literature specifically analyzing the three concepts simultaneously, i.e. the impact of poverty on carers of children with disabilities. These articles are highlighted below to examine what an explicit focus on poverty reveals.

In a qualitative Ecuadorian study, Huiracocha et al. (2015) examine the role of the so-called 'social situation' on the experiences of parents with a deaf child. They argue parents' responses to the diagnosis and their coping mechanisms "are shaped by the situations in which they live, rather than being inherent in the impairment itself" (2015: 11). In line with a study by Beazley and Moore (1995), they choose to include health care availability, social organization and culture, and individual resources and structures into their analysis. Based on interviews with parents, Huiracocha et al. show that limited financial and social resources, either due to poverty or disability stigma, shape the character of their experiences. Since their sample also includes Ecuadorian parents from a more advantaged background, their research demonstrates how the individual and societal context affects the possibilities for seeking and receiving informal and formal support. This supports previously discussed data on the limited presence of coping by seeking support in resource-poor contexts.

Contrary to most literature on carers of disabled children, Barratt and Penn (2009) choose not to apply a burden or coping framework to their study in a South African rural setting. Instead, they focus on the relationship between contextual factors, childhood disability and care. Their research confirms the Triple A challenges, the severe disability stigma and related discrimination and exclusion, and the supportive role of faith and peer support as previously described. Yet, due to their focus on the impact of poverty, their research brings two important factors to the table, namely the HIV/AIDS pandemic and government policies. On the one hand, in the South African context, HIV/AIDS has crippled the personal and social support networks

available. Loss of income, disrupted families, stigma and exclusion due to HIV/AIDS cause an intensification of poverty. On the other hand, “this disease provides family members with access to disability grants, which were acknowledged to be helpful in addressing the needs of disabled children” (Barratt and Penn 2009: 199). This is similar for government policies that saw installment of a care dependency grant (specifically for carers of disabled children) and a child support grant (for carers in need). HIV/AIDS and government policies are thus relevant factors for carers in a resource-poor context, as they can exacerbate or reduce poverty by offering new opportunities.

An interesting literature review worth noting is Park, Turnbull and Turnbull (2002) in which the impact of poverty on American families with a disabled child is examined. Using a Family Quality of Life framework, the authors review the consequences of living in poverty on five life domains, namely “a) health, (b) productivity, (c) physical environment, (d) emotional wellbeing, and (e) family interaction” (2002: 155). They establish that poverty adds an additional strain to the families and alters caring practices as a consequence of limited resources and lesser available coping strategies. Poverty in the context of disability increases stress, hampers child learning and development, heightens the risk of alcohol and drug abuse by parents, reduces the quality of home and neighboring environment, and limits recreational activities and play. However, Park, Turnbull and Turnbull use an income-based definition of poverty which provides a narrow view on the impact of poverty (Hall and Midgley 2004). They demonstrate for example that having limited financial resources reduces possibilities for recreational activities at sports clubs, camps and music schools. In a resource-poor context however, institutional provisions such as recreational activities, professional child care, and stimulating toys and books are commonly unavailable which reduces the applicability of Park’s research to such a context.

These three articles confirm most features of the impact of poverty found previously such as the Triple A challenges, the influence of stigma, limited social support, religious coping and increased stress. In addition, Huiracocha et al. (2015) provide an invaluable comparison between two groups which highlights the resource-poor context as a determining factor. Barratt and Penn (2009) point towards the importance of taking HIV/AIDS (thus possibly also other poverty-related ‘neglected’ diseases (Stevens 2004)) and government policies into account. Lastly, Park, Turnbull and Turnbull (2002) show how poverty increases drug and alcohol abuse amongst parents and offer a useful conceptualization of the impact of poverty.

5.6 DISCUSSION

This article set out to gain a preliminary theoretical understanding of how living in a resource-poor context shapes parents' experiences of caring for a disabled child, i.e. the interplay between disability, care and poverty. We argued at the beginning of this article this knowledge is essential for enhancing disability mainstreaming in development. The core concern in disability mainstreaming is universal poverty reduction or eradication, and human and social development for all. This review could be used as a stepping stone for further research and herewith inform poverty reduction strategies, reach full inclusive development and improve the wellbeing of parents and disabled children from resource-poor contexts in the long-term.

We do acknowledge this review's limitations. First of all, it does not offer a full picture of the dynamics between disability, care and poverty. Its narrative nature and the small number of studies from a resource-poor setting provide for a preliminary understanding only. We therefore believe development policy recommendations cannot be made as they would be insufficiently substantiated. This review aims primarily at synthesizing an important topic and informing further research. In addition, a narrative literature review comes with a risk of author bias. This has been reduced as much as possible by applying sound research procedures, such as explicit criteria for inclusion, clear research questions and discussions of findings with the project team. Last of all, we recognize the vast complexity of the lived realities of parents of disabled children. Poverty is just one of many factors of the interconnected context encompassing parents and children. However, we chose to focus solely on poverty and its specific impact as portrayed in literature in order to make targeted research recommendations. Notwithstanding the limitations, our review does a) provide a preliminary theoretical understanding, b) disclose existing knowledge-gaps and c) offer a direction for future research.

Disability and care literature shows parenting a disabled child can be a time-consuming, stressful, physically challenging, isolating and expensive process. Yet, parents find various mechanisms to cope with the situation. This creates room for positive experiences and perceived benefits. Studies on carers living in a resource-poor context, however, suggest poverty influences both the perceived negative impact and the coping strategies. Our review shows that limited affordability, availability and accessibility (Triple As) of services impedes caring strategies; increased stigma reduces social support; the inability to satisfy basic needs increases stress; transport and assistive devices shortages aggravate physical impact, and faith can act as a buffer. The three highlighted disability and care articles indicate a higher risk for drug

and alcohol abuse by parents, and the role of HIV/AIDS and government policies in resource-poor contexts. The literature uncovers the context-dependency of caring for a disabled child; political, cultural, and social exclusion issues surface as part of the disability, care, and poverty nexus. The above therefore provides an initial answer to our research question on how poverty shapes caring experiences and practices in the context of childhood disability.

Nevertheless, substantial knowledge gaps remain in the current literature. Disability and care research from impoverished settings is scant; only 20 articles were found. The majority focuses on the impact of childhood disability on parents. The conceptual lenses used to analyze parents' experiences do not specifically address a notion of poverty or other restricting structures. Contextual factors merely arise in the parents' descriptions of perceived adverse and positive effects of childhood disability. Just three studies have been found with a more contextual focus explicitly examining the impact of poverty on carers of disabled children. This sample of evidence (20 articles) can hardly be called representative for resource-poor regions worldwide, as personal and contextual conditions vary. For example, are experiences of Triple A challenges in caring similar for parents with a high and low education level alike? Does family composition (for example nuclear family, single-mother family, high number of children) alter poverty experiences and therefore giving care? How does poverty relate to care and the different types of childhood disability? Also, a lack of clarity remains on which effects are caused by childhood disability, by poverty, or by other contextual factors such as HIV/AIDS. How does the burden of disease affect poverty conditions and thus providing care? What are the dynamics between government policies, poverty and caring for a disabled child? Is social support for carers limited due to poverty or is it related more to urban migration? Furthermore, as the interplay between disability, poverty and care relates to multiple academic disciplines, no universal conceptual framework exists for researching the impact of poverty on parents of disabled children. Evidence remains fragmented and difficult to appraise, due to the plethora of employed concepts.

In light of the various knowledge-gaps, we argue future research should particularly target parents of disabled children living in poverty, and their experiences, practices and needs. Studies should a) increase focus on impoverished settings, b) analyze variations along demographic and contextual variables in resource-poor settings, and preferably c) have a multidisciplinary character, d) have parents participate in research to assure practical relevance and e) aim at developing a conceptual framework for analysis.

With reference to the latter, we suggest a conceptual framework in which the adverse and positive impact of childhood disability on parents and coping strategies are combined with a conceptual framework which recognizes a context of poverty. Such a framework gives room to both the influential factors such as stigma, HIV/AIDS, and the Triple As, and to the more personal attributes such as faith, physical impact and self-reliance. It would recognize carers and their individual agency whilst acknowledging structural influences, and includes important concepts and factors derived from reviewed literature. Empirical testing, ongoing adjustment and input from various disciplines can help establish such a robust conceptual framework, which can provide a holistic encompassing understanding of parents of children with disabilities living in poverty. Scientific research will be then able to play a larger role in both informing social welfare policies, and disability inclusive poverty reduction and development policies. This can potentially empower thousands of carers and disabled children and enhance their opportunities to escape poverty.

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- ¹ The phrase disability and care literature or research refers only to studies focusing specifically on the experiences and practices of carers of children with disabilities.
 - ² The words 'parent' and 'carer' are used interchangeably in this article. They both refer to either the biological parent, or the primary carer of a disabled child. In addition, as research indicates the vast majority of carers of disabled children are women, and most research respondents in the presented literature are female, this article will use feminine pronouns throughout for readability purposes.
 - ³ Many terms have been used in history to describe disabled people, and not without controversy (see, for example, Dajani 2001; and Mackelprang 2010). This literature review on the impact of poverty supports the social model of disability which views disability as a result of societal factors rather than of impairment. Therefore, we choose to use the social model terminology ('disabled person/child') throughout this article.
 - ⁴ This literature review is part of a cross-sectional study with mothers of disabled children in a township in South Africa.
 - ⁵ Though Hong Kong and Taiwan are not officially recognized as countries, they are counted as such as they represent different cultural and socio-economic backgrounds.
 - ⁶ The moral model harbors traditional ideas on the causes of disability which include witchcraft, God's punishment, maternal promiscuity and ancestral wrath.