

# VU Research Portal

## **Against All Odds**

van der Mark, E.J.

2019

### **document version**

Publisher's PDF, also known as Version of record

[Link to publication in VU Research Portal](#)

### **citation for published version (APA)**

van der Mark, E. J. (2019). *Against All Odds: Exploring wellbeing transformation with mothers of disabled children from poor urban settlements in Southern Africa*.

### **General rights**

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal ?

### **Take down policy**

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

### **E-mail address:**

[vuresearchportal.ub@vu.nl](mailto:vuresearchportal.ub@vu.nl)

# CHAPTER 1

---

Introduction

Parents of children with disabilities around the world face numerous challenges in caring for their child. They fight uphill battles on a daily basis in order to ensure their child's special care needs relating to, for example, education, healthcare or assistive devices such as wheelchairs. The care for a disabled child is often reported to be a time-consuming, financially draining and mentally challenging task. As a result, parents can experience various emotional and physical wellbeing issues, such as depression and severe fatigue (Green 2007; Kimura and Yamazaki 2013; Landsman 2005; Raina et al. 2005; Resch et al. 2010). While much has been written on the experiences of carers of children with disabilities in high income countries, few studies are conducted with carers living in poor socio-economic contexts in low- and middle-income countries (LMICs) (Gona et al. 2011; Hartley et al. 2005; Matt 2014; Norizan and Shamsuddin 2010; Sandy et al. 2013). Yet, LMICs are estimated to be home to 80% of all the disabled children in the world (UN 2019) (see Box 1). Moreover, care practices can be assumed to be highly context dependent. For instance, the quality of healthcare services, availability of assistive devices, gender norms, and transport and infrastructure are likely to be influential factors in caregiving. Southern Africa, the focus of this thesis, is particularly exemplary for some of these issues:

Firstly, several studies have recognized a bidirectional relationship between poverty and disability that complicates caregiving practices (Filmer 2008; Graham et al. 2014; Mitra et al. 2013; Yeo and Moore 2003). People and children with disabilities are believed to be more prone to live in poverty

### Box 1. Facts & Figures on Childhood Disability

Data on childhood disability are scarce, particularly from LMICs, and hugely unreliable due to differences in definitions, methodologies and analysis (UNICEF 2013). The data below must therefore be interpreted with caution.

#### Children with Disabilities

Worldwide:	between 93 and 150 million
LMICs:	between 74 and 120 million
South Africa:	between 500,000 and 1,1 million
Zimbabwe:	between 50,000 and 150,000

#### Main Causes for Childhood Disability in Southern Africa:

- Early Childhood Disease
- Pre- and peri-natal problems
- Accidents
- Violence/War

Particularly the first two causes for childhood disability often result in mother-blaming in Southern Africa.

#### Basic Rights Coverage of Children with Disabilities in Southern Africa:

- Primary Education: < 10 %
- Under-five Mortality: up to 80%
- Basic Healthcare: Limited access
- Rehabilitation: Limited access to services, for example 1 physiotherapist on 45000 people in South Africa
- Assistive Devices: between 0,4-33%

Sources: (ACPF 2011; ACPF 2014; Choruma 2007; HC-IDC 2014; UNICEF 2013; WHO and UNICEF 2012)

because “poverty is both a cause and consequence of disability” (Choruma 2007: 12). Loss of income, additional costs due to medical needs and social and economic exclusion faced in society are just a few reasons why “disabled people are often the poorest of the poor” (HC-IDC 2014: 3).

Vice-versa, poverty is one of the leading causes for childhood disability in Southern Africa (see Box 1) when for example poor treatment of infectious diseases or substandard pre- and post-natal care cause permanent impairments.

Second, stigma surrounding disability is understood to be prevalent and severe in Southern Africa. People living with disabilities are reported to suffer oppression and discrimination on a daily basis. Disability is often seen as a curse, as a result of witchcraft or of maternal promiscuity. Social acceptance of and support for disabled people and their carers is therefore limited. Consequently, disabled children remain to be among the most marginalized and ill-treated groups in many Southern African countries (ACPF 2014).

Lastly, Southern African countries are commonly characterized by poor provision of basic medical and disability services, poor living conditions and a weak, underperforming state (UNDP 2018). Fulfilling a disabled child’s special needs, receiving external support and coping psychologically with the task at hand can be assumed to be more problematic in this context.

The detrimental influence of a poor social, economic and institutional context on the scope of caregiving is expected to be particularly true for female carers. Many studies reveal that in Southern Africa the responsibilities of care often predominantly lie with mothers and other female household members such as daughters, sisters, grandmothers, and aunts (Akintola 2008; Evans 2010; Núñez Carrasco et al. 2011; Thomas 2006). Also, persistent gender inequality, in terms of control over resources and the double workload of being the main carer and breadwinner, is likely to exacerbate women’s burden specifically (Lorber 2010; Tamale 2004).

## 1.1 CARING FOR A DISABLED CHILD IN A GLOBAL CONTEXT

As mentioned above, limited knowledge is available on carers of disabled children living in contexts of poverty. At the start of this PhD-research in 2014, a scoping literature review revealed less than a dozen articles conducted in resource-poor settings specifically addressing the experiences of carers, as compared to hundreds, possibly thousands from resource-affluent settings, mostly Western countries. A thorough review of this literature will be provided in Chapter 5. However, in order to understand and identify gaps in knowledge, an overview is necessary here.

Studies from resource-rich contexts show that parenting a disabled child impacts a mother's physical and psychological health. In comparison with mothers of abled children, mothers with disabled children are found to have poorer psychological health in terms of stress and anxiety, and more physical ailments such as back pain, sleeping problems and headaches (Kimura and Yamazaki 2013; Resch et al. 2010). In addition, their social relationships, financial situation and careers are commonly negatively affected. Caring for a disabled child is reported to be a time-consuming, socially isolating and expensive experience (Green 2007; Watt and Wagner 2013). Caring strategies revolve around pursuing a cure or treatment, income generation and seeking support. The kinds of support sought to fulfill the child's and carer's needs could be formal, informal and/or medical (McConkey et al. 2008; Plant and Sanders 2007; Resch et al. 2010).

The few studies from resource-poor contexts hint at the substantial impact the socio-economic environment can have. Carers in disadvantaged regions often face severe deprivation in terms of housing, food, clothing and electricity, which precludes the fulfillment of basic needs (Gona et al. 2011; Qayyum et al. 2013; Sandy et al. 2013). Likewise, access to essential services such as healthcare, education, information and can be very limited, further hampering possibilities for care (Barratt and Penn 2009; Philpott and McLaren 2011; Qayyum et al. 2013; Saloojee et al. 2007). In disadvantaged regions, the lack of assistive devices and transport is often identified as placing an additional strain on carers' physique, resulting from carrying and transporting their child by themselves. Furthermore, studies reveal that the paucity of financial resources is a particular stressor in the lives of disabled children and their carers in deprived areas (Barratt and Penn 2009; Kaplan 2010; McNally and Mannan 2013). Basic financial coverage of costs as well as access to loans, credit schemes and other financial resources are pointed out as being tremendously challenging to obtain.

Lastly, some authors emphasize that informal support systems are often weakened or non-existent in deprived areas, due mainly to disability stigma (ACPF 2014; Gona et al. 2011; Matt 2014).

## 1.2 FOCUS AND AIM OF THESIS

A multi layered social problem has been presented: the high numbers of children with disabilities, and the myriad of socio-economic, political and institutional barriers that can affect caregiving practices; specifically, against a background of unequal gender relations which places the burden of care exclusively on female carers. The paucity of research on this topic is therefore especially conspicuous when it comes to the experiences and needs of these women. How do they experience and value their everyday lives? Which context-specific challenges do they face and find the most exigent? How does this influence their caregiving opportunities? To what extent are they able to maintain their child's wellbeing? How does their caregiving responsibility in such a context affect their own wellbeing?

However, many governmental and civil society services in Southern Africa lack resources to conduct context-specific research and are thus unable to incorporate local knowledge in their support programs. Professionals and policy makers commonly resort to adopting support program-models based on research from high-income countries (ACPF 2014). As a result, targeted services, policies and programming remain insufficient, while poverty-reduction policies largely fail to reach disabled children and their families (DSD 2012; UN 2010; UNICEF 2013). Additional questions that arise are thus: In which areas do these carers require support? How can their challenges be successfully addressed? Which interventions can be feasible and effective in such a context?

The aim of this thesis is therefore to:

- 1) gain insight into the daily realities of women and their disabled children living in poor urban settlements in Southern African countries, and to
- 2) investigate successful mechanisms of change.

In view of the limited evidence base from resource-poor contexts and the complexity of the issues prevailing in these contexts, this thesis combines a thorough review of literature with empirical research involving experiential experts, namely the female carers. To foster both academic and social relevance and contribute to epistemic

justice, this thesis used a Participatory Action Research (PAR) approach in one of the research phases to ignite a process of change in which female carers were the principal agents of change. It empowered female carers by actively involving them in scientific research and facilitating interventions that corresponded with their daily realities and needs.

Thus, on a theoretical level, this thesis tests the assumptions and solutions for carers proposed in existing literature from mostly resource-rich contexts. Additionally, it contributes to the scientific knowledge on the relationship between disability, care and poverty. Methodologically, this thesis sheds light on the usage of PAR in such a context in comparison to a traditional research design in understanding the experiences of female carers. Ultimately, this thesis has relevance for future policy-making and intervention practices for the benefit of children with disabilities and their carers from resource-poor settings.

### 1.3 THESIS OUTLINE

The first three chapters of this thesis set the scene by introducing the research problem and current knowledge on the topic (Chapter 1), explaining relevant concepts and theories (Chapter 2), and discussing the research questions and design (Chapter 3). The subsequent five chapters present the results and conclusions of the three studies conducted for this thesis; one case-study in Zimbabwe, a literature-study, and one case-study in South Africa.

First, an exploratory study on the daily realities of female carers from resource-poor urban settlements in Mutare, Zimbabwe, is discussed (Chapter 4). Then, a more in-depth narrative review of literature on how poverty specifically shapes caring for a disabled child is presented (Chapter 5). An account of the daily realities of female carers from the resource-poor urban settlement Khayelitsha in Cape Town, South Africa, follows (Chapter 6), along with a discussion on how they adapt, act and react to their specific context (Chapter 7). The final empirical chapter captures mechanisms of social change found to be most relevant in a resource-poor urban settlement (Chapter 8). Lastly, Chapter 9 will bring all preceding conclusions together and critically discuss their theoretical, methodological and practical implications.

