

SUMMARY

Background

208 — 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. As a result, parents often experience various issues relating to their own wellbeing, such as depression and severe fatigue. 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). Yet, the majority of the world's disabled children are estimated to live in low- and middle-income countries. Moreover, contextual factors such as 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 from Southern Africa have recognized the bidirectional relationship between poverty and disability that complicates caregiving practices. Loss of income, additional costs due to medical needs and economic exclusion faced in society are just a few reasons why "disabled people are often the poorest of the poor". Secondly, stigma surrounding disability is understood to be prevalent and severe in Southern Africa. Consequently, disabled children and their carers remain to be among the most marginalized and ill-treated groups in society. Lastly, Southern African countries are commonly characterized by poor provision of basic medical and disability services, poor living conditions and a weak, underperforming state. 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. In Southern Africa, the responsibilities of care predominantly lie with mothers and other female household members such as daughters, sisters, grandmothers, and aunts. 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. The paucity of research on caring for a disabled child in a poverty context is therefore especially conspicuous when it comes to the experiences and needs of these women.

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. As a result, targeted disability programs, services and policies remain insufficient, while poverty-reduction policies largely fail to reach disabled children and their carers.

Research Questions

In light of the above, this thesis aims to gain a better understanding of the lives and experiences of female carers in the particular context of resource-poor urban settlements in Southern Africa. Moreover, in order to enhance women's wellbeing, it aims to understand their challenges and to identify interventions based on their needs and daily realities. The main research question thus addressed in this thesis is:

How do female carers of disabled children from Southern African resource-poor urban settlements experience and practice everyday life and care, and how can they successfully enhance their wellbeing?

The first two sub-questions are:

1. How do female carers describe and assess their daily realities?
2. How do female carers provide care in their particular contexts?

The results of exploring the above two questions highlighted the need for a bottom-up, participatory and action-oriented approach. Thus, the third sub-question addressed in this thesis is:

3. How can female carers enhance their wellbeing through participatory action research?

A conceptualization of wellbeing is applied based on the University of Bath's wellbeing framework which aims to assess an individual's level of multidimensional poverty. It recognizes a person's objective circumstances, his/her subjective experiences, and the influential societal and institutional processes.

Methodology

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. Four phases of inquiry were pursued in an iterative way, namely the exploratory, theoretical, empirical and interventional phases.

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The first phase consisted of a mixed methods exploratory research in the low-income urban settlements of Mutare, the fourth largest town of Zimbabwe. This exploratory phase with 61 female carers incorporated various qualitative and quantitative methods: a survey, participatory creative workshops and semi-structured interviews. This mixed-methods approach aimed to shed light on the well-being outcomes, processes and structures that are at play in caring for disabled children in a resource-poor context.

The results of the Zimbabwean exploratory study emphasized the importance of context, in particular poverty, in understanding disability and care. A theoretical exploration of this field was warranted to inform and adapt the study design for the planned empirical phase. The theoretical phase therefore applied a qualitative narrative literature review to analyze 20 articles which focused on parents with disabled children from a resource-poor setting and 40 disability and care studies from other contexts. This analysis aimed at gaining a theoretical understanding of how living in a resource-poor context shapes parents' experiences of caring for a disabled child.

The empirical and interventional phases intended to gain a deeper and more contextualized understanding of how mothers experience daily life and care in a resource-poor setting whilst simultaneously fostering social change. For this purpose, a Participatory Action Research (PAR) approach was chosen, executed with 30 mothers from the resource-poor settlement Khayelitsha in Cape Town, South Africa. A project called Mothers in Action (MIA) was conducted in this setting. Following the nature of PAR, the empirical and interventional phases were mostly qualitative, and more importantly iterative in both gaining knowledge and achieving transformation through the PAR-cycles of analysis, planning, action and reflection. They included a questionnaire, semi-structured interviews, numerous participatory group sessions and two-year-long participant observation.

Caring Strategies of Zimbabwean Female Carers

The exploratory study (Chapter 4) examines the resources and strategies that Zimbabwean female caregivers employ to realize the well-being of their disabled child. Moreover, it discusses how these are shaped by societal structures, specifically the conditions of a weak state and stigma.

It is found that Zimbabwean female caregivers operate largely without external support. As formal state and non-governmental organization facilities have deteriorated and social support networks are limited in Zimbabwe, women deploy three strategies to provide care and comfort to their child: *reducing the effects of poverty* by deploying basic household activities and providing health/hygiene to their child; *learning skills* to provide the necessary medical care; and *training* the child for independence. The lack of external support causes stress, pain and feelings of neglect among women. A fourth developed strategy, *acceptance*, addresses this and supports women in finding peace with their situation. Faith is the base for this acceptance and plays an important role in realizing well-being. Strikingly, income generating activities play a minor role, mainly because of high caring demands and poor economic conditions in Zimbabwe. Women are thus mostly self-reliant and their strategies focus on enabling themselves to take care of their child.

The results of the study demand a more central role of faith, and in particular religious coping, in disability and care studies, and emphasize the importance of context in understanding disability and care. In Zimbabwe, where 'external' financial, social, medical and educational resources are limited, caregivers rely on and subsequently attach a higher value to self-provided 'embodied' and human resources. This stresses the importance of interventions that address the realities, resources and strategies of caregivers in a poverty context, thus developing strategies that address poverty conditions at least as much as the actual disability of the children itself.

How Poverty Shapes Care in a Global Context

The theoretical phase (Chapter 5) presents a preliminary 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. Moreover, it discloses existing knowledge-gaps and offers 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. The literature review shows that limited affordability, availability and accessibility (Triple As) of services impede caring strategies; increased stigma reduces social support; the inability to satisfy basic needs increases stress; and transport and assistive devices shortages aggravate physical impact. At the same time, faith can act as a buffer. Three highlighted disability and care articles indicate a higher risk for drug and alcohol abuse by parents, the dual role of HIV/AIDS, and the influence of government policies in resource-poor contexts. The literature thus 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.

Nevertheless, the review reveals substantial remaining knowledge gaps in the current literature. Disability and care research from impoverished settings is scant; only 20 articles were found. Also, the majority focuses on the impact of childhood disability on parents whereas a notion of poverty or other restricting structures are not specifically addressed. 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.

The theoretical phase underwrites the need for more research on parents of children with disabilities living in poverty, and the development of a framework in which the adverse and positive impact of childhood disability on parents and coping strategies are combined with one 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 individual faith, physical impact and self-reliance. It would recognize carers and their individual agency whilst acknowledging structural influences.

Daily Realities of South-African Female Carers

The first part of the empirical phase (Chapter 6) presents the daily experiences and perspectives of mothers with a disabled child from Khayelitsha, a poor resource urban settlement in South Africa. It aims to understand how mothers assess, value and experience their life in all its complexity.

Mothers in Khayelitsha often bear the responsibility of care on their own, engage minimally with others and with services, and become rather isolated in their own small world; in other words, they carry a 'solitary care' responsibility. Several factors are influential herein. A profound lack of professional, community, and family support

renders women the main individuals responsible for meeting their child's basic needs. Most mothers argue that the main cause for '*andinyamezeli*' (not enduring) is being unable to provide for basic needs and the accompanying sense of failure. Also, an important socio-contextual factor underreported in the literature, namely the omnipresence of violence, crime and abuse, leaves mothers in Khayelitsha in constant fear for the safety of their children, especially for a disabled child. The consequential mistrust has a substantial impact on mothers' choice to live an isolated life. Lastly, mothers' sense of resignation, thus 'choosing' to accept and not expecting any change, fuels their solitary responsibility of care. At the same time, it fosters a sense of power and being in control. Mothers tend to accept whatever life throws at them, no matter how painful; they create their own small world and aim to maintain a quiet but decent life.

The results suggest that in order to substantially improve the living conditions and well-being of disabled children and their families, one must focus on systematically supporting these women and thus sharing the responsibility of care between peers, family, civil society and the state while taking into account the notions of trust, resignation, and the impacts of poverty. Such measures can reach their full potential in a wider context of poverty-reduction and macroeconomic policies fostering job opportunities and education, and lowering crime levels.

Agency and Adaptation of South African Female Carers

The second part of the empirical phase (Chapter 7) highlights adaptation and agency of Khayelitsha mothers by showing how they manoeuvre, adapt, act and react within their daily constraints, and how they maintain or improve their own and their family's wellbeing.

A conceptualization of Adapted Preferences (APs) is adopted to be able to assess mothers' (sometimes deprivation-perpetuating) adaptation to a disadvantaged context, while simultaneously acknowledging their underlying values, reasoning and ultimately their agency. Mothers in Khayelitsha have two major preferences, namely *keeping their child at home* and *minimizing their search for external support*. The study shows how these are based on forced trade-offs. Discrimination, violence and abuse in the home and in the wider society turn out to be the driving *external forces* behind mothers' adaptive preferences. Mothers have a strong desire to keep themselves and their child safe from any form of abuse or harm which leads them to limit their social relations and focus on their household and care. Both the high value they place on 'good motherhood' and their religious belief are the main *internal motivators*. Women take great pride in being a good mother who raises a clean, well-fed, and safe child

and in fulfilling their God-given duties, even if achieving this requires sacrifices to be made in the domains of income, basic needs and personal wellbeing. Self-respect and social recognition are indeed the benefits mothers gain in return from these forced trade-offs, apart from the most important, namely freedom from (all kinds of) violence.

The problematic consequences of their agency and adaptation and the resulting isolation are however that it reinforces patriarchal standards of care and renders the women and their children invisible to policymakers and society at large. For interventions to be successful, priority should be given to eradicating the forces behind these adaptive preferences, which are discrimination, violence and abuse. Changing these conditions while taking into account mothers' personal values and preferences might provide room for these mothers to adapt and act in more self-beneficial ways, and so improve their own and their child's wellbeing. Yet, considering the fact that altering structural conditions is easier said than done, it is vital to simultaneously explore how women themselves can employ their agency to positively transform their daily realities and wellbeing.

Unlikely Transformation towards Wellbeing

The interventional phase (Chapter 8) explores how women from Khayelitsha caring for a child with a disability can effectively increase their own and their child's wellbeing by implementing a Participatory Action Research (PAR) case-study called Mothers in Action.

At the start of the project, while trying to operationalize the conscientization phase of PAR, mothers' severe psychological stress and the strong intersectionality of their daily life challenges come to the fore. Most mothers are so emotionally overcome that they cannot see any possibilities for change and are overtly acquiescent and apathetic towards life. Furthermore, mothers prove unable or unwilling to prioritize and distinguish between daily issues such as accessing medical assistance, facing discrimination, and having limited income.

Both factors appear to render the project 'inactionable' at first while shedding light on the severity of marginalization these women experience. As they try to grapple with the general stressors of living in poverty, the birth of a disabled child proves to be a shock which can hardly be absorbed. Reflecting on the initial 'inactionability' at the start of the project, it becomes clear that the cognitive, sublinear (although reflexive), learning cycle of PAR, wherein people engage to analyze collective issues and develop initiatives to tackle those issues, does not immediately fit the context and experiences of the women in this study.

Yet, quickly, many women start expressing significant individual transformations in their wellbeing. Moreover, several women become a collective of passionate change makers. They take business, finances and sewing classes to register their own non-governmental organization (NGO) under which name they eventually generate income from offering sewing services to the public, and publish their first children's book catering to the needs of their children with disabilities. The main driver of these unlikely changes proves to be the sharing of stories between the women and the resulting collective emotional labor. Indeed, collective action, as per PAR theory, could only be imagined and developed *after* this process had occurred. Improved (emotional) wellbeing, which is commonly positioned as the envisioned impact of PAR, here became both a requirement for change and a driver for more wellbeing.

The Mothers in Action-project illustrates how wellbeing enhancement can be achieved with particularly vulnerable, marginalized groups. It however highlights the need to rethink the PAR learning cycle, include a phase for collective emotional healing, and sensitize researchers and practitioners alike to the level of emotional wellbeing of participants at the start of a project. One should be critically aware of their isolated way of life, their emotional state, and therefore the potential impact of breaking their isolation. This approach can, as it did in the Mother in Action-project, turn the tables surprisingly quickly and foster a substantial upward wellbeing spiral.

Discussion

This thesis has gained an in-depth understanding of the daily realities of women from poor urban settlements in Southern Africa who are caring for disabled children, and identified interventions that ameliorate their wellbeing based on these realities.

Many mothers caring for a disabled child in Zimbabwe and South Africa tend to care for their child completely on their own, are overwhelmingly pressured by contextual factors which inhibit many forms of coping and caring strategies reported in the literature from different settings, and experience a mountain of physical and psychological distress. Even their adaptive strategies, although informed by their personal values and intended to keep one from harm, cause further wellbeing diminutions.

This thesis shows that applying PAR in this particular context with such a severely marginalized group can aid in enhancing wellbeing, but in a different way than expected. At the start of the project, wellbeing was conceptualized as being an asset held by a person which can be enhanced as an end-goal through a cognitive, collective, and reflexive process of analysis and action. However, in the Mothers in Action-project, the sharing of stories was an important process, yet as an affective, rather than a cognitive analytic one; collective emotional labor occurred and needed to occur which was unanticipated in this form; and the improvement of wellbeing turned out not to be an end result but was generated throughout the project. The findings thereby emphasized the processual role wellbeing can play; wellbeing as a driver for wellbeing.

These findings imply a need to re-shift our conceptualization of participatory action research for wellbeing. A more processual, collective notion of wellbeing should be applied. The concept of 'relational wellbeing' enables a different reading of how wellbeing transformation could take place in spite of a seemingly 'inactionable' setting. This concept views wellbeing as a process rather than an asset, occurring in the midst of shifting relations between people (mothers, researchers, and others), materials and places. This could also be conceptualized as a web of *caring* relations, with both multiple positive forms of 'taking care of', e.g. supportive siblings, material grants or spiritual guidance, and negative forms, e.g. disengaged medical professionals, prevalent stigma and a lack of policies, producing an ever-changing landscape of wellbeing.

This thesis proposes to employ relational wellbeing as an overarching ontological awareness in participatory action research with marginalized groups. Particularly during the reconnaissance and conscientization phase of PAR, one should be acutely aware of, or conceptually sensitive to how wellbeing is *produced* through the web of relations surrounding the participants, including the research project. It is thus suggested to employ relational wellbeing in PAR as a way of viewing, understanding and explaining existent marginalization and processes of social change. Hereby ultimately contributing to insights on which conditions, relations and interventions are beneficial for producing wellbeing, this being relevant for policy and practice.

Recommendations for Research and Practice

Given the significant lack of studies on mothers of disabled children from resource-poor settings, more empirical research is required to determine whether the concepts of solitary care, adaptive preferences and severe psychological stress can be maintained and incorporated into policy and practice. Furthermore, a new conceptual framework is required to guide future research. In order to draw such a framework, given that this thesis only hypothesizes the application of relational wellbeing in PAR, empirical evidence is firstly needed to provide insights into how consciously adopting a relational wellbeing perspective into PAR will affect processes and outcomes. Finally, future research will have to play a role in establishing modes of monitoring the *production* of wellbeing and its effect on collective action for social change.

Considering the solitary nature of care, government institutions and civil society organizations should make a conscious effort to try to establish contact with mothers *outside* of mainstream services. Also, they should not underestimate the severity of psychological stress many mothers experience when succeeding in reaching out to them. Institutions and organizations should therefore make provision for qualified professionals whom mothers can trust to facilitate a process of *collective* and shared emotional labor, before attempting to integrate them into existing or newly developed programs. Lastly, institutions and organizations should focus on eradicating the main forces driving mothers' solitary care, namely (disability) discrimination, violence and abuse.

Conclusion

The combined research questions 'How do female carers of disabled children from Southern African resource-poor urban settlements experience and practice everyday life and care, and how can they successfully enhance their wellbeing through Participatory Action Research?' can in conclusion be summarily answered as follows:

Poor female carers of a disabled child from Southern Africa practice solitary care on a daily basis in which they view their socio-economic context as the most challenging and constraining aspect of their lives. In order for wellbeing changes to occur through PAR, emphasis must be put on collectivity and connection-making which would establish spaces of healing and wellbeing.