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van der Mark, E.J.

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CHAPTER 9

Discussion

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

For this purpose, three sub-questions were formulated:

1. How do female carers describe and assess their daily realities?
2. How do female carers provide care in their particular contexts?
3. How can female carers enhance their wellbeing through participatory action research?

The mothers' daily realities including their caring strategies, the influence of context, solitary care and adaptation were explored in the exploratory, theoretical and empirical phases respectively (Chapter 4-7). The results of the exploratory and theoretical phase revealed a need to shift the attention more to participatory modes of inquiry, and provided a necessary framework to build on in order to answer the third sub-question, which was specifically addressed in the interventional phase (Chapter 8).

This discussion will, firstly, expand on the concluding remarks of each chapter to answer the sub-questions. Sub-questions 1 and 2 will be addressed simultaneously since women's daily realities are so intertwined with providing care. Then theoretical implications will be elaborated upon, followed by implications for PAR research for wellbeing, and for practice. This thesis is concluded with some methodological reflections and recommendations for future research.

9.1 PRACTICING LIFE AND CARE AS A MOTHER OF A DISABLED CHILD

Findings from the first three phases, namely the exploratory, theoretical and empirical, uncovered the strong context-dependency of care for a disabled child, and revealed how disability might not be the main challenge impeding mothers' wellbeing. First of all, a profound lack of basic necessities and the limited availability, affordability and accessibility of (para) medical and educational services significantly add to the daily burden of providing care. Whereas in much literature the stress of dealing with a plethora of people, services and organizations in order to care for a disabled child is indicated (Raina et al. 2005; Yagmurlu et al. 2015), in a resource-poor context the mere task of reaching and accessing these is the main reason for stress. Being unable to provide for these basic needs and the accompanying sense of failure are exceptionally demanding (Chapter 4,5,6).

Secondly, disability stigma is experienced to be so severe, it significantly hampers mothers' caring strategies and wellbeing. As suggested in previous studies in resource-poor contexts (Gona et al. 2011; Matt 2014), cultural and religious beliefs around disability intensify the discrimination and abuse children with disabilities and their carers face in both Zimbabwe and South Africa (Chapter 4 and 6). This not only psychologically drains mothers; it also greatly affects their mobility as they tend to minimize their external relations (Chapter 4-7).

In connection with this lies a third contextual factor which has received little attention in disability & care literature, namely the omnipresence of violence, abuse and crime, and their impact on the closely allied notion of trust (Chapter 6 and 7). The imminent and constant threat of robbery, assault, rape and even murder permeate all areas of Khayelitsha mothers' lives (Nleya and Thompson 2009; Seekings 2013). As a result, mothers constantly fear for the safety of their children, especially for their disabled child, and their own safety. (Dis)trust runs as a thread through their narratives on the (im)possibilities of sharing the responsibility of care. As established in caregiving literature, trust is a significant indicator for the use of supportive networks by (informal) carers (Ray and Street 2011). This form of trust however often relates about trusting others' knowledge and ability to provide appropriate care (e.g. Whetten et al. 2006), rather than about trusting to keep (their child) safe from bodily harm, as is the case in Mutare and Khayelitsha.

This is not to suggest violence, abuse and crime, particularly abuse instigated by disability stigma, do not occur in resource-affluent areas (see for example Krnjacki et al. 2016 on Australia). Nor are, of course, all resource-poor settings more unsafe than elsewhere. Findings do however suggest that it can be such an influential factor that it needs to be taken into account when aiming to understand and enhance mothers' wellbeing.

In response to these highly inhibiting contextual factors, both Zimbabwean and South African mothers tend to focus on home-based activities and, what I called, 'solitary care'. Where the exploratory phase zoomed in on the particulars of these home-based caring strategies such as enforcing hygienic standards (Chapter 4), the empirical phase fully revealed the motivations behind these and the extent to which mothers care for their child on their own (Chapter 6 and 7). The adaptive preferences discussed in Chapter 7 emphasized mothers' agency in dealing with safety and trust concerns by 'creating a small world of their own', even though it greatly disadvantages other endeavors in their lives. Mothers' personal values about their 'female care

responsibility', and their religious duties motivate them additionally to keep their child mainly indoors, provide 24/7 care on their own, and resort to learning care and medical skills themselves. Their faith also informs a sense of resignation towards life's challenges (Chapter 4 and 6).

However, despite this form of acceptance, one main (and previously underreported) finding of this research is the severity of the psychological burden these mothers carry. In Zimbabwe, *kurwadza* ('being in pain') permeates all narratives (Chapter 4), and in South Africa *andinyamezeli* ('I do not endure') is expressed repeatedly (Chapter 6). The theoretical phase (Chapter 5) furthermore revealed how experienced stress is often very much related to the contextual difficulties such as discrimination, grinding poverty and a lack of institutional support. The empirical and interventional phases particularly, lay bare the intense level of distress that many mothers experienced. There were times when they were hardly able to speak about their child and their lives in the first phase of the PAR project. They appeared and confessed to feel completely overwhelmed.

In sum, many mothers caring for a disabled child whilst living in poverty 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. As one reads through the first four consecutive chapters, and begins to attain an understanding of these mothers' daily realities, a sense of unease may be hard to shake off. Gradually the question might arise whether enhancing wellbeing is a feasible aim, which I will address in the following section.

9.2 MOTHERS OF DISABLED CHILDREN INCREASING THEIR WELLBEING

One critical finding of the research is the fact that the joint problem analysis (or conscientization) phase proved impossible and therefore irrelevant at first in the above described context. Sub-question 3 on enhancing wellbeing through PAR was formulated based on theoretical and empirical assumptions underlying PAR. The underlying overall goal of participatory action research consistent across disciplines, is, as Lake and Wendland (2018: 15) identify, "the improvement of human life", or as Nicolaidis and Raymaker (2015: 168) phrase it, the improvement of "health and

wellbeing through action". In most cases, this commitment to human wellbeing is implicit rather than explicit in program and research design, with some exceptions (e.g. Tsey et al. 2007). Generally, it is thought that through iterative phases of analysis, action and reflection (McNiff 2002), a collective of co-researchers will establish some form of project targeting a specific local problem, for example income-poverty (Seferiadis et al. 2017), women's political participation (Hammad et al. 2018) or home-based care for people dying of AIDS (Campbell et al. 2009), ultimately contributing to improved overall wellbeing.

Considering these PAR and wellbeing assumptions, sub-question 3 was a logically phrased question expecting the Mothers in Action (MIA)-project in Khayelitsha to provide opportunities for participatory action projects for mothers' wellbeing. However, the MIA-project initially demonstrated primarily how 'inactionable' mothers' realities seemed to be, and how assessing a status-quo level of wellbeing, let alone enhancing it, proved to be too impossible a task. The perceived 'inactionability' and high level of psychological stress, both of which altered the process of the project, lay bare the lack of consideration within PAR-theory for the emotional suffering of severely marginalized people. Furthermore, it is generally assumed in PAR that people are capable of analyzing and pursuing their own interests, and will inevitably be empowered through participation (Golooba-Mutebi 2005). However, at first, the mothers in the MIA-project were not keen to make collective efforts for change, felt unable to dissect and analyze daily challenges, and were feeling completely overwhelmed.

The profound intersectionality of issues, reluctance towards change, and high level of psychological stress thus cast doubt on the applicability of the PAR learning cycle, that consists of the phases of conscientization, action, and reflection. Therefore, the encountered 'inactionability' questioned the possibilities for participatory action towards wellbeing with a highly marginalized group (Aldridge 2015).

Nevertheless, as the interventional phase revealed, findings did point towards successful changes in wellbeing. Most mothers reported to feel, act and think differently because of their involvement in the MIA-project. A more pertinent question to explore therefore is *how* PAR aided the enhancement of wellbeing for female carers of disabled children from resource-poor urban settlements. First of all, bringing the mothers together and inviting them center stage as PAR requires (White and Jha 2014), opened up the possibilities for the mothers to share their stories with each other. In fact, the nature of PAR, being participatory and highly qualitative, enforced a deep

and long narrative process into the complexities of their daily lives. The sharing of stories between these mothers was however more a highly affective, intuitive and healing process, than a typical PAR conscientization phase, which is a collective but rather cognitive, semi-structured process of discussing and understanding resources, processes and structures influential in people's lives and wellbeing (Israel et al. 2012).

Secondly, the emotional healing which occurred as a result of particularly their story-sharing demonstrated to be an important instigator of positive changes in wellbeing. In Chapter 8, I suggested, borrowing a phrase from Hochschild's seminal work, that the formation of supportive relations with each other fostered a form of collective emotional labor (Hochschild 1983). That is, through collectivity, recognition and mutual support, the women turned their isolated modes of care into a 'community of coping' (Korczyński 2003), herewith directly enhancing their (sense of) wellbeing.

Though not discussed previously due to word-limits in the article-based chapters, it is important to note that a similar 'community of coping' arose during the exploratory phase in Zimbabwe. This small study was not aimed at establishing change and did not have a participatory character. Nevertheless, during the personal interviews at the end of the project and during informal meetings, most mothers expressed to have gained a profound shift in their outlook towards life and in emotional resilience. The main reason stated was to be able to share their stories with other mothers, and through this, establish connections and obtain support.

Lastly, in the South African PAR project, the early improvements in mothers' wellbeing through their collective emotional labor, enabled and triggered subsequent individual and collective wellbeing changes in the typical PAR sense. That meant among others, on an individual level, adjusting family relations, and establishing income-generation projects, and on the level of collective action, publishing a children's book. The knowledge and skills building through expert-training workshops functioned as drivers in these processes, as suggested in PAR literature (Reason and Radbury 2008). However, their improved (emotional) wellbeing stood out as the main trigger which was unexpected, considering the linearity that underlies the common idea of applying PAR for improved wellbeing as an end-result.

In answer to the newly posed sub-question above, applying PAR in such a particular context with a severely marginalized group can thus aid in enhancing wellbeing, but in a different way than expected. The sharing of stories was indeed 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. Looking for ways to understand, capture and build on the described daily realities and the seen transformations, a more processual, collective notion of wellbeing is essential. In the following paragraphs I discuss in greater detail the implications of the findings for the conceptualization of wellbeing and its enhancement through PAR.

9.3 THEORETICAL IMPLICATIONS: NEW WAYS TO LOOK AT WELLBEING THROUGH PAR

In recent years, a formulation of wellbeing has arisen called ‘relational wellbeing’, which, though “still emergent as a construct” (White 2015: 18), seems capable of deepening our understanding of the above described daily realities of mothers, and the unexpected transformations in wellbeing.

9.3.1 Relational Wellbeing

Human wellbeing as a concept has received more and more attention over the past two decades, particularly as an alternative to mainstream income-poverty measurements of human flourishing. Consequently, conceptualizations have changed, merged and expanded. One such conceptualization is relational wellbeing. This is commonly theorized as an element of human wellbeing namely the quantity and quality of an individual’s social relations, just like material and physical wellbeing concern the quantity of the material resources and the quality of physical health respectively (Huovinen and Blackmore 2016). In this sense, relational wellbeing is similar to the concept of social capital; i.e. relationships and networks are an asset to an individual (Woolcock and Narayan 2000).

In recent years, however, relational wellbeing has been developed as a construct of wellbeing based on a relational ontology. Whereas most wellbeing approaches are grounded in an individual ontology, which suggests wellbeing is an individual’s possession, a relational wellbeing approach understands wellbeing as a *process*

continuously constructed by material, social and environmental relationships. Through relationality, wellbeing is viewed as something that *happens* and not as something that can be acquired, or be an asset (White 2015). Specific contexts can therefore be understood as either conducive or adverse to *producing* wellbeing, that is being “spaces of wellbeing” (Atkinson 2013: 142). Relationality is regarded as prior to individuals, and wellbeing a set of relations in which individuals are rooted.

Instead of social relations as something to acquire, a network of connections, the focus here is on the relationality itself. Moreover, wellbeing here comprises complex assemblages of relations not only between people, but also between people and places, material objects and less material constituents of places, including atmosphere, histories and values. Wellbeing is thus conceptualized as in constant production and reproduction (Atkinson 2013: 142).

Thus, when applying the evaluative, asset-based concept of wellbeing, the objective circumstances, subjective experiences and structural factors are assessed to measure an individual’s wellbeing. From a relational wellbeing perspective, however, these elements should be regarded as part of the substantive relationality which *is* wellbeing. In sum,

wellbeing is emergent, the outcome of accommodation and interaction that happens in and over time through the dynamic interplay of personal, societal and environmental structures and processes, interacting at a range of scales, in ways that are both reinforcing and in tension (White 2017: 133).

This relational and processual understanding of wellbeing enables a different reading of how wellbeing transformation could take place in spite of a seemingly ‘inactionable’ setting in which conscientization was hardly achievable.

9.3.2 Relational Wellbeing and Understanding Mothers’ Daily Realities

The relational, processual nature of wellbeing became, in hindsight, quite apparent in the consecutive phases of this research. First of all, in its most basic form, the interdependent relation between the mother and the child hints at the illusion of wellbeing as an individual’s possession. Everything most mothers reported to experience, choose and do is through, with and/or for the child. It can be argued that this level of intimate care between mothers and their children creates an interrelatedness beyond individual wellbeing; that is their children’s wellbeing is their wellbeing.

Secondly, the exploratory phase in Zimbabwe (Chapter 4) drew attention to the significance of relations, whether social, religious, economic or political, in women *describing* their (sense of) wellbeing. Similar to White's findings (2018), mothers in Zimbabwe, when "asked about wellbeing – or what makes life good – . . . invariably talked first of 'having enough', not just as individuals, but rather to *care*. . . and to *share* with others in need" (9). The wider relationships with family, community, economic spheres and political structures were seen as formative of being able to *care and share*.

Furthermore, the theoretical phase (Chapter 5) amplified how political, cultural and socioeconomic exclusion shape mothers' strategies and experiences. It became clear that the child's disability is indeed a major stressor; however, as Brangan (2016) argues, as for non-communicable diseases in South Africa, it is "set amidst, and contributes to, other challenges and priorities" (114), such as material exclusion, and is affected by the numerous social challenges afflicting the urban settlements. These findings do not yet steer towards a processual understanding of wellbeing, as wellbeing is still viewed as a possession of an individual, but do point at the construction and experience of wellbeing in *relatedness* to people and places.

Then, the empirical phase (Chapter 6 and 7) zoomed in and provided a detailed account on how mothers act and react as *relational subjects* (Donati and Archer 2015), in response to personal values, societal belief systems, communal tensions and government policies and structures (Held 2006), rather than as objects of inquiry holding a certain level of wellbeing, separated from the world that surrounds them. One can argue that mothers stand in relation to for example gender politics in the wider South African society (Gordon et al. 2013) and respond by internalizing the 'female responsibility of care'. Likewise, the relation of, arguably, 'non-care' between mothers and the South African government, as a product of the social policies emphasizing the need for family care rather than state-care for disabled children (SALS 2007), hinders the *production* of wellbeing. Finally, during the interventional phase it became clear how processual wellbeing functions, which I will discuss below.

9.3.3 Relational Wellbeing and Understanding the Project Process and Outcomes

Transformation aimed for at the start of the MIA project in South Africa was, as discussed earlier, thought to be a process throughout the study with enhanced wellbeing as an end result. Wellbeing was conceptualized as something that could be evaluatively measured at the start of the project and eventually be individually enhanced through collective effort. Because of this conceptualization, the wellbeing

changes, e.g. emotional healing or leaving an abusive husband, which occurred relatively quickly at the start of the project could only be viewed as 'unlikely'. However, when approaching it from a relational ontology standpoint, these changes come as less of a surprise.

At the very least, the intersectionality of daily life challenges becomes legible when viewed as a web of relations that continuously changes, in which the individual is merely one link in the chain. Approaching the intersectionality from a relational wellbeing perspective allows us to understand why women were struggling with disentangling and analyzing their daily challenges. Most, if not all, issues in their lives are connected, fluctuant and entwined in a complex web of relations.

In fact, this web of relations *produces* wellbeing (White 2015). That is, the relatedness between for example, social prejudices, modes of transport, geographical location, and social policies lies within the production of wellbeing for mothers of disabled children. This is not to suggest wellbeing is an independent entity. It is indeed experienced by individuals. It cannot however generally be measured at and reduced to the individual level (Atkinson 2013), as it is fluctuant and in process, depending on changing relations.

This web of relations indeed shifted the moment the mothers decided to join the project. Not only did they form new relations with each other, but also with knowledge structures, services, and the researcher. In other words, new "spaces of wellbeing" emerged (Atkinson 2013: 142). Additionally, existing relations were questioned by virtue of new relations. For example, through sharing their stories some mothers started critically challenging their gender and family values. The 'unlikely' changes suddenly become more 'likely' when adopting the processual nature of wellbeing and acknowledging how any effort to bring people together will alter relations and therefore the production of wellbeing.

The way how wellbeing thus *happened* through collectivity, without aiming for wellbeing enhancement, demonstrates how it is not a state which can be acquired. Wellbeing occurred in and as a process, in the midst of shifting relations between people (mothers, researchers, and others), materials and places (White 2015).

A helpful way to look at this web of relations with respect to mothers of disabled children, hereby understanding the importance of conceptualizing wellbeing as relationally constructed, is as a web of *caring* relations. It could be argued that if care is ultimately always aimed at maintaining or increasing human wellbeing (Held

2006), a web of caring relations, with both multiple positive forms of ‘taking care of’ (Tironi and Rodríguez-Giralt 2017), e.g. supportive siblings, material grants or spiritual guidance, and negative forms, e.g. disengaged medical professionals, prevalent stigma and a lack of policies, produces an ever-changing landscape of wellbeing. In other words, following Tronto and Fisher’s (1990) classification of care explained in the Introduction, a changing web of *caring for*, *caring about* and *care giving* relations shapes the production of wellbeing. The sharing of stories at the early stages of the project can then be imagined as producing new modes of care, or care relations, that is both self-care and attentive, supportive care (Tironi and Rodríguez-Giralt 2017), hereby altering the production of wellbeing.

On the one hand, this is a hopeful message, as wellbeing enhancement could thus be triggered in a relatively easy way in such dire circumstances. On the other hand, it greatly emphasizes the role of the researcher as a facilitator of these ‘spaces of wellbeing’. It requires a critical and ethical awareness on the process of doing research. Fortunately, in PAR, the role of the researcher is broadly acknowledged and critically reflected upon (Dillon 2014; Lake and Wendland 2018). There exists a fundamental understanding of how the researcher and his/her methods shape, influence and, arguably, partly determine the process and outcomes of a study.

What the concept of relational wellbeing underlines, however, is how PAR researchers who aim to contribute to wellbeing, form *part* of the web of relations which produces wellbeing, and are thus part of a social change process themselves. “It means locating accounts of wellbeing in relation to the identities of researchers, the disciplines and the methods used to produce them” (White 2015: 13). This conceptualization helps explain the narrative of the South African women on how the researcher was the ‘main pillar’ of change (Chapter 8). By establishing a new mode of care by guiding, teaching, affirming, and listening, the researcher became part of the web of relations and hereby helped constitute new forms and spaces of wellbeing.

9.4 PAR RESEARCH IMPLICATIONS: SENSITIZING PAR

The relational wellbeing concept, together with the conceptualization of a web of caring relations, have aided in understanding Zimbabwean and South-African mothers' accounts of their daily realities, and the processes and outcomes of the interventional phase with Khayelitsha mothers. The question remains however, how the initial adoption of the concept at the start of the MIA-project, would or could have changed in terms of developing and executing the study? In other words, how can we, in future, operationalize relational wellbeing in participatory action research with severely marginalized groups?

By adopting a wellbeing concept rooted in a relational ontology, one cannot operationalize wellbeing as a starting point or an end result of a PAR project. Wellbeing will *occur* throughout and *due to* the research process. The relational wellbeing concept therefore runs a risk of being elusive and remaining fuzzy (White 2015). As placing wellbeing in a relational ontology is a fairly recent effort, limited advice is available on its operationalization, let alone its use in PAR. Without referring specifically to relational wellbeing, Brangan (2016) suggests, in order to improve a typical element of wellbeing, i.e. physical health, one needs to "create conditions conducive to the broader wellbeing" (115), which would be the web of relations. Atkinson (2013) phrases it more explicitly:

A shift is demanded away from how to enhance the resources for wellbeing centered on individual acquisition and towards attending to the social, material and spatially situated relationships through which individual and collective wellbeing are effected. (Atkinson 2013: 142)

White (2018) asserts that "taking a relational approach to wellbeing means looking for interventions with multiplier effects, the potential to generate further positive outcomes" (15) - which links to what I call wellbeing as a driver for wellbeing (Chapter 8). It however remains unclear *how* to create these conditions, attend to situated relationships, or develop multiplier interventions.

I would like to contribute to this debate by proposing a notion of conceptual sensitivity; that is employing 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. Rather than

operationalizing relational wellbeing into measurable, evaluative elements, looking to determine a level of relational wellbeing (if this is even expedient or feasible), or aiming to improve a web of relations, I thus suggest 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 practice and policy.

The reason I suggest this approach is two-fold. For one, approaching a PAR project with vulnerable groups from an ontological perspective of relational wellbeing will open up possibilities for (collective) emotional labor. PAR theory has, as discussed in Chapter 8, given little attention to dealing with severe psychological stress among participants. However, PAR would be very suitable to foster broad, open-ended discussions on the web of relations in daily life because of its qualitative, participatory nature. A substantive relational wellbeing approach (rather than evaluative) will provide the time and space to explore all relational influences, and herewith create healing spaces of wellbeing. It will nurture and amplify the sensitivity to (caring) relations, among participants, researchers and stakeholders alike. Through this process, not only knowledge will be created and shared, but collective emotional labor can occur. This will ultimately benefit the analytic and interventional cycles of PAR.

Secondly, a relational wellbeing perspective in PAR greatly reduces the focus and onus on the individual to increase his/her wellbeing. Both development and feminist theorists have critiqued the mainstream tendency to put the onus on individuals, and in particular women, to uplift themselves and their families out of poverty (e.g. Chant and Sweetman 2012). Relational wellbeing, however, assumes that wellbeing is produced through relations and not acquired by an individual. PAR can benefit from this conceptualization of wellbeing as it helps both participants and researchers to understand how not people's possessions and behavior determine their sense of wellbeing, but rather the web of relations they are in. It inspires to look more for, better understand, and further acknowledge *all* influential relations in people's lives which produce wellbeing. The onus on the individual to better his/her life hereby fades, and a shared responsibility to foster (caring) relations emerges. In this way, as the findings from Khayelitsha reveal, PAR and its collective character can realize quite some change on a local level, without denying the myriad of political, cultural or even global factors underlying mother's daily realities.

9.5 IMPLICATIONS FOR PRACTICE

The findings of this thesis have implications beyond conducting Participatory Action Research with severely marginalized groups. They also show a way for government institutions and civil society actors who have an important role to play in reaching out to and supporting in particular these mothers and their children. Three key lessons based on the findings are discussed below.

Firstly, the solitary nature of care as found in this thesis of mothers with a disabled child living in poverty, hampers the possibilities for governmental and civil society actors to reach out to them. Moreover, vice versa, it reduces mothers' inclination to reach out for support and services themselves. Therefore, in practice, institutions and organizations should make a conscious effort to try to establish contact with mothers *outside* of mainstream services. As many programs, if available, rely on for example medical center waiting rooms and day-care center attendance lists to connect with mothers and include them in their services, mothers who opt to live solitary lives remain to be excluded.

In the MIA-project, connection was established mostly through word-of-mouth with a day-care center as a starting point. Moreover, the prospect for mothers in the wider community to be able to connect with other mothers turned out to be one of their main reasons to join the project at first. This could be intentionally aimed for by institutions and organizations. Whilst mainstream services can provide a first entry-point, the snowballing search for other mothers must be part of the inclusion process to avoid leaving out this highly vulnerable group of 'invisible' mothers and children, preferably by bringing them together.

This leads to the second lesson for practice, which is the provision for collective emotional healing. Government institutions and civil society actors should not underestimate the severity of psychological stress many mothers experience when succeeding in reaching out to them. The often time and cost sensitive character of programs and services leaves little room for a gradual and timely approach towards change as proposed in Chapter 8. Yet, it is precisely this approach which is required for collective emotional healing, in order for motivation, participation, and change to occur. 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, as this thesis has shown that the main force driving mothers' solitary care is the omnipresence of discrimination, violence and abuse, government institutions and civil society actors not only need to acknowledge and recognize this in their efforts to include mothers in their programs, but also focus on eradicating it. Awareness raising on disability and care with families, community members, public transport drivers and (para) medical professionals could be a first step. Similarly, public education campaigns on the rights of disabled people and the need for social equality, unity and respect are vital to alter the highly constraining context for mothers. Moreover, more interventional and intensive practices, such as providing for high quality (abuse-free) day-care and education facilities, and inclusive public transport are equally important.

9.6 METHODOLOGICAL REFLECTIONS

When reflecting on the use of methods in this thesis, two issues are worth highlighting, namely the role of the researcher and the issue of generalization and transferability.

9.6.1 Role of the Researcher

All participatory action research requires a researcher to be creative, flexible, and reflexive throughout the process. This was anticipated at the start of the Mothers in Action-project, as well as during the exploratory phase (notwithstanding that this particular phase was not a PAR project). Three issues in particular are important in terms of creativity, flexibility, and the need for reflexivity: namely a PhD/PAR tension, preconceived ideas on care, and becoming a part of the web of relations.

Both the empirical and interventional phases laid bare the tension between the academic requirements for my PhD and the participatory research process (Lake and Wendland 2018). Relinquishing control of the methods, objects of study and change objectives proved to be harder than expected. Combining the need for a certain level of methodological rigor, and quantity and quality of data with a desire to honor the voices of the mothers turned out to be a challenging task. As briefly touched upon in Chapter 8, this may have influenced mothers' initial reluctance to commit to the process, since I initially forced certain requirements, methods and standards on the process under the rubric of planned creative methods, possibly for too long a period.

This PhD-PAR tension was coupled with unavoidable preconceived (academic, white, Western) notions, theories and ideas on how these women were living their life, what they would need and how I could assist them in this. Despite being fully aware of my own limitations in this regard and 'going in' with an open mind, there is no denying

I had a certain idea on how to 'care' for them (Groot et al. 2019), namely with a PAR project focused on improved wellbeing as its ultimate aim. This thesis reveals, however, how my idea of providing care did not match their care needs. I was focused on assessing and enhancing aspects of their wellbeing through PAR, while they needed connection, recognition, empathy and collective emotional labor. In my view, it was only after I 'dared' to let go of control and follow the pace and directions of the women, the project could effectively start. For instance, I needed to ban ranking exercises and give time and space for general discussions. Moreover, it highlighted the need to have certain capabilities as a researcher working with such vulnerable individuals to facilitate a process of collective emotional labor.

The last important matter concerning the role of the researcher is intrinsically connected to the relational wellbeing perspective, namely the realization that I – without being fully aware of it at the time – became part of the mothers' web of caring relations. Understanding how my presence and my bringing these women together *in and of itself* produced wellbeing in both Zimbabwe and South Africa was a humbling experience. For example, my efforts to always bring a surplus of food to both the formal and informal meetings so that mothers could take it home to their families were, in hindsight, attempts to increase their physical wellbeing and my own psychological wellbeing. Yet, viewed from a relational wellbeing framework, it was not the food, as a resource, that produced wellbeing for us, but rather the fact that we were "sharing an occasion which itself generates a sense of wellbeing" (White 2018:10). The above thus strongly underlines the crucial role a PAR researcher plays in the processes and outputs of any study.

9.6.2 Generalization and Transferability

One of the reasons to carry out this research was because so little was known about the experiences of mothers of disabled children from resource-poor settings. The idea was to make a first attempt to fill this gap by qualitatively exploring this topic, without aiming for generalization or transferability necessarily. In fact, some sociologists have previously argued that external validity is impossible in socio-qualitative research (e.g. Denzin and Lincoln 1995), as in the social world no invariant universal laws exist on how individuals act and react. However, following Payne and Williams (2005), from this thesis "an intermediate type of limited generalization, 'moderatum generalizations'" (296) can be drawn. These are generalizations which are moderate and hypothetical in character, but explicitly voiced and supported by evidence.

The obvious limitations in drawing generalizations from this thesis are that 1) only two case-studies have been conducted, 2) both studies, particularly in South Africa, have small sample sizes based on probability sampling, and 3) limited literature is available on this specific topic (disability, care and poverty) for triangulation. On the other hand, not only does the theoretical approach towards relational wellbeing for PAR support generalization, the case-studies and literature review revealed similarities in findings, particularly on the context-dependency of care; all findings were cross-checked with participants, local experts and academics; and other academic and grey literature confirmed many contextual findings.

This means that three findings on mothers' daily realities have the potential to be comparable in similar contexts in different locations. One, a lack of basic necessities and services in other resource-poor settlements can be assumed (Thrush and Hyder 2014), which would suggest a similar detrimental physical and psychological influence on mothers with disabled children. Two, disability stigma is confirmed to be pervasive in resource-poor settings, leading in all probability to a lack of support for mothers (ACPF 2014; Lauber and Rössler 2007; Thrush and Hyder 2014). Three, a female responsibility for care is shown to be particularly relevant in low- and middle-income countries (Budlender 2008; Chopra and Sweetman 2014), which could, in combination with the above, lead to mothers assuming a 24/7 caring role on their own, i.e. solitary care. The latter in particular, however, needs to be hypothesized cautiously. Even though similar contextual influences can be expected in other settings and this thesis' empirical and theoretical findings are suggestive, the responses of mothers towards their child's disability, care and context could be highly variable. In other words, the concept of solitary care, their specific adaptive preferences and the severe psychological stress are indeed *likely* but not *necessarily* to be found in other resource-poor settings.

With regards to the PAR outcomes, external validity is confounded. First of all, due to the chapters being published or submitted as journal articles, word limitations have restricted "to represent PAR practices more fully and share the outcomes from all perspectives" (Lake and Wendland 2018: 20). This reduces the options for transferability. Also, the actions of mothers in Khayelitsha are set in a local space and time, and cannot be assumed to occur in the same way with other mothers, despite similarities in experiences and contextual influences.

9.7 SUGGESTIONS FOR FUTURE RESEARCH

This research has answered some topical questions on mothers' experiences and their options for improved wellbeing. Simultaneously, it has raised several new ones of which three are worth highlighting.

Firstly, the conceptual findings in this thesis, i.e. solitary care, adaptive preferences and severe psychological stress, are a significant contribution to the understanding of the experiences of women of disabled children specifically in a resource-poor context. However, as discussed above (Section 9.6.2), they cannot be blindly extrapolated to other settings despite expected similarities in context. A lack of basic necessities, (disability) services, and informal support can be assumed in other resource-poor settings. Still, this does not *necessarily* mean that most women will act, react, and adapt in ways similar to women from Mutare and Khayelitsha, by, for instance, focusing on home-based care, limiting the search for external support, and feeling psychologically overwhelmed. Given the significant lack of studies on mothers of disabled children from resource-poor settings, more empirical research is required to determine whether these concepts of solitary care, adaptive preferences and severe psychological stress can be maintained and incorporated into policy and practice.

Second, the evaluative perspective on wellbeing as an asset, conceptually framed in the beginning of this thesis, proved to be inapplicable in the particular research context (see Figure 9, as presented in Chapter 2). The adoption of a relational wellbeing perspective as an overarching ontological awareness in participatory action research with marginalized groups will, I theorize, benefit the applicability and adoptability of the PAR-cycles, provide room for healing spaces of wellbeing, and take the responsibility for wellbeing of the shoulders of individuals. A new conceptual framework is therefore 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. Will more women participate, remain

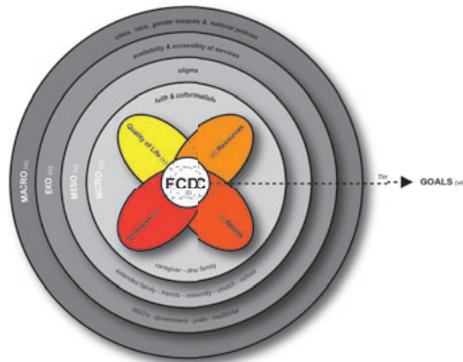


Figure 9. Adaptation of the Wellbeing Framework: Disability, Care and Poverty Model

in the project, and be active, assuming such a perspective does more justice to their (care) needs and experiences? Will the creation of spaces of wellbeing have the desired multiplier effect, and if so, work quicker, better and more efficient than in this research? Which relations can be confirmed to be influential in producing wellbeing? And, are there other factors inhibiting participatory action which were not recognized in this thesis?

Lastly, in line with the above, this thesis argues that adopting a relational wellbeing perspective into PAR with marginalized groups is crucial to overcome 'inactionability' by creating spaces of healing and wellbeing. This can open up possibilities for successful PAR-cycles and collective efforts for social change. Yet, since relational wellbeing is a new concept, and has hitherto not been integrated conceptually into PAR with marginalized groups, it is unclear how one can recognize and appraise wellbeing transformations that occur due to the spaces of wellbeing. In Khayelitsha, the transformations came to the fore in the narratives and actions of participating women which triggered both the researcher and other women to take further steps towards collective action. This however happened rather unintentionally. 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.

9.8 CONCLUDING REMARKS

This thesis has revealed significant theoretical, conceptual and practical insights into how women caring for disabled children living in urban poor settlements in Southern Africa practice everyday life and care, and how participatory action research can enhance wellbeing. By means of two case-studies, in Zimbabwe and South Africa, combined with an extensive narrative literature review, the findings unveil the context-dependency of care for a disabled child, the detrimental consequences for and responses of female carers, and the significance of collective emotional labor for social change.

Southern African women caring for a disabled child face challenging contextual difficulties with regards to meeting their family's basic needs, accessing social services, coping with severe disability stigma, and ever-present violence and abuse. This thesis finds that the disability of the child is seen merely as an additional challenge in life, on top of the existing disadvantageous contextual factors.

This particular context inhibits many forms of ‘common’ coping and caring strategies such as searching for information, advice and care from professional services, and relying on informal support. Instead, female carers from resource-poor urban settlements tend to care for their child completely on their own – i.e. solitary care – and herewith experience a mountain of physical and mainly psychological distress. Their focus on home-based caring strategies and limiting external support is forced by the detrimental, unsafe context while simultaneously informed by their religious and gender beliefs. These adaptive preferences are however in their turn further decreasing mothers’ quality of life in terms of income, basic needs provision and personal health, and rendering the women and their children invisible to policymakers.

As the mothers’ daily realities and context presented a seemingly ‘inactionable’ situation, this thesis established that the rather cognitive, analytical PAR-cycle did not initially fit. Rather, to achieve social change, collective emotional labor had to occur by providing room for recognition, connection, and collectivity. Through diving deep into the shared narratives, wellbeing changes started to take place fairly quickly, in spite of it being operationalized as an end-goal in this research. The findings therefore amplified a more continual, processual role of wellbeing, subsequently theorized by the use of the relational wellbeing approach. The findings of this thesis support this notion of wellbeing which conceptualizes it not as an asset of an individual carer which can be attained or further increased. Instead, it sees wellbeing as a process continuously constructed by material, social and environmental relationships, that is a web of (caring) relations producing wellbeing. A relational understanding of wellbeing explains both the perceived ‘inactionability’ and the ‘unlikely’ wellbeing transformations. This thesis therefore argues that in participatory action research with female carers of disabled children, and other severely marginalized groups, relational wellbeing should be employed as an ontological awareness to view, understand and explain existent marginalization and processes of social change.

The research questions 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.

