CHAPTER 3

Research Design
3.1 QUESTIONS AND OBJECTIVES

As discussed in the previous chapters, a better understanding of the lives and experiences of female carers in the particular context of a resource-poor urban settlement is warranted. Moreover, in order to enhance their wellbeing, it is essential 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?*

Since there is little knowledge available on the experiences of female carers living in poverty, the first part of the main question requires ample attention. There is need to explore their realities holistically and in-depth, prior to understanding how their everyday living can be enhanced. Therefore, the following sub-questions are posed:

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 that will be addressed in this thesis is:

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

3.2 ONTOLOGICAL AND EPISTEMOLOGICAL APPROACHES

In research it is important to identify what epistemological and ontological assumptions underlie the study, since this will influence and frame the research and the choice of research methods. Considering the qualitative and participatory action nature of this thesis, a constructivist ontological position is maintained (Langhout and Thomas 2010). This “asserts that social phenomena and meanings are continually being accomplished by social actors. It implies that social phenomena are not only produced through social interaction but are in a constant state of revision” (Bryman 2016: 29). In this thesis emphasis is put on the interpretation of behavior, action and structures, i.e. the social reality, by the respondents.
The epistemological view that follows is one of interpretivism. PAR-theory in particular asserts that knowledge about a socially constructed reality cannot be gained through standardized methods. Rather the focus lies on subjective meanings of social action and its interpretation (Bryman 2016). The only ‘true’ knowledge that exists, is local and requires local interpretation. The researcher is seen as a facilitator bringing to light existing local knowledge among participants. PAR therefore requires a conscious acceptance by researchers of shifting power to participants (Ozanne and Saatcioglu 2008; Snoeren et al. 2012).

To sum up, this thesis assumes that reality is a social construct and dependent on local context and interpretation. In addition, it recognizes that

the thought objects constructed by the social scientist, in order to grasp this social reality, have to be founded upon the thought objects constructed by the common-sense thinking of men [and women!], living their daily life within the social world (Schutz 1962: 59).

However, it is also assumed that since we are all human beings, similarities in experiences, behavior and meaning will occur. Therefore, without aiming to generalize, this thesis plays an informative role for similar contexts by pointing towards a direction to study caregiving in a resource-poor context, and therefore develop possible policies and programs.

### 3.3 METHODOLOGY

In order to answer the main research question, four phases of inquiry were pursued in an iterative way namely the exploratory, theoretical, empirical and interventional phases. The empirical and the interventional phases occurred simultaneously, however, for reading and clarification purposes these two phases have been separated in this thesis. Below, the four phases will be briefly explained with short introductions on context and rationales for modes of inquiry. Further elaboration on these topics can be found in the relevant chapters, to avoid unnecessary overlap. Table 1 provides a visual overview of the Methodology.
Table 1. Thesis Structure and Methodology

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3.3.1 Exploratory Phase

Considering the limited knowledge available on mothers of disabled children living in poverty, the first phase set out to *explore* this topic in more detail.

*The Zimbabwean context*

The first phase consisted of a mixed methods exploratory research in the low-income urban settlements of Mutare, the fourth largest town of Zimbabwe. Zimbabwe is considered to have a high prevalence of disability among children (Lang and Chadowa 2007; Mutepa et al. 2007). Taking into account the gravely insecure and poor social and economic situation in Zimbabwe, carers are expected to face numerous challenges in providing basic needs for their children. Moreover, disabled children are one of the most marginalized groups in Zimbabwean society, due to the stigma of disabled people that is still prevalent in Zimbabwe (Choruma 2007; Lang and Chadowa 2007). People living with disabilities are reported to suffer oppression and discrimination on a daily basis. Disability is seen as a curse, as witchcraft, or as a result of maternal promiscuity, and tolerance and social acceptance of disabled people is limited.

Paradoxically, Zimbabwe used to be mentioned as “one of the most disability-accessible countries in Africa” (Devlieger 1995; cited in Mpofu and Harley 2002). The Zimbabwean government enacted the Disabled Persons Act (DPA) in 1992, a legislation on disability which aimed at providing welfare and rehabilitation to people living with disabilities (Choruma 2007). However, many disabled people in Zimbabwe are disappointed in the implementation of the DPA (Spink 2010). It is reported to show
serious shortfalls, particularly because the economic and political crisis resulted in a profound lack of basic, medical and educational services (Choruma 2007; SIDA 2014; UN 2010).

Mixed-methods approach
The exploratory phase with 61 female carers from Mutare, Zimbabwe incorporated various qualitative and quantitative methods: a survey, participatory creative workshops and in-depth semi-structured interviews. This mixed-methods approach aimed to shed light on the wellbeing outcomes, processes and structures that are at play in caregiving of disabled children in a resource-poor context. Since the ontological emphasis in this thesis is put on the perspectives and interpretations of the female carers, qualitative methods received maximum attention. The mixed-methods approach has resulted in a holistic understanding of carers’ experiences, hereby partly addressing sub-question 1 and 2. It provided the opportunity to triangulate the data extensively and to combine data on objective circumstances and subjective meanings (Chapter 4).

3.3.2 Theoretical Phase
The results of the Zimbabwean exploratory study emphasized the importance of context in understanding disability and care. In particular, they pointed towards the significant influence of poverty on caring for a disabled child. A theoretical exploration of this field was warranted to inform and adapt the study design for the planned empirical phase.

Qualitative narrative review
No synthesis of knowledge on parents caring for a disabled child living in poverty existed in academic literature. It was therefore decided to conduct a qualitative narrative literature review, rather than a systematic one, in order to get a first, broad understanding of the topic. Systematic reviews are commonly used in development studies to assess the impact of policies and programs, whereas a more narrative review is better suited to synthesize all research on a particular social topic. Moreover, as terminology in the social sciences and development research in particular, is not uniform, as in the medical sciences in which the systematic review was used initially, formulating inclusion criteria which would provide a solid overview of all relevant research is complicated. A narrative review offers a “less rigid and more reflexive form” (Hagen-Zanker and Mallett 2013) of review, thereby reducing the risk of partial and misleading conclusions.
The review consisted of an analysis of 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 to partly address sub-question 1 and 2 (Chapter 5).

3.3.3 Empirical and Interventional Phases
After the exploratory and theoretical phases, the empirical and interventional phases aimed at gaining a deeper and more contextualized understanding of how mothers experience daily life and care in a resource-poor setting whilst simultaneously aiming at fostering social change. For this purpose, a Participatory Action Research (PAR) approach was chosen, executed in the resource-poor settlement Khayelitsha in South Africa, to conduct a project called Mothers in Action (MIA).

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. The aims of the PAR project were to enable mothers to reflect on their daily realities, categorize their main challenges, and identify and execute interventions to enhance wellbeing. Thirty women, that is mothers, grandmothers and sisters, caring for a disabled child participated. At the start of the project, one questionnaire on basic socio-demographic information and ‘status-quo’ semi-structured interviews were conducted to get a first understanding of their level of wellbeing. Simultaneously, participatory group sessions were started every other week throughout a two-year period. These sessions included several introductory sessions, 24 creative data collection sessions, four training workshops facilitated by field experts, and numerous goal setting sessions and intervention planning and execution sessions.

Chapters 6 and 7 deal with results from the qualitative and ethnographic methods employed during this case-study (empirical phase), whilst Chapter 8 is more concerned with the process of participatory analysis-action-intervention (interventional phase).

The South African context
The third phase of inquiry consisted of two qualitative, ethnographic studies, while the fourth phase comprised an interventional study, all three nested in a two-year-long PAR project with mothers of disabled children in the urban settlement of Khayelitsha near Cape Town in South Africa. In South Africa, people and children living with disabilities face stigma, oppression and discrimination on a daily basis (ACPF 2011;
Lansdown 2002; Marumoagae 2012; Rohleder 2010; Saloojee et al. 2007). Many South Africans “do not understand the nature of disability or are frightened by it. They see the disability as limiting the child’s ability to do anything, and thus view the child as a ‘burden’” (ACPF 2011: 43). As a result, carers of disabled children experience severe affiliate stigma and are subject to scorn and social exclusion (Barratt and Penn 2009; Sandy et al. 2013).

However, based on the progressive and rights-based constitution adopted after the end of apartheid, the South African state is required to “respect, protect, promote and fulfill the rights of all people in the Bill of Rights” (SAHRC 2002: 19). Discrimination on the basis of disability is specifically prohibited in the Constitution. As a result, South Africa is, in theory, one of the more progressive African countries in terms of laws and policies concerning disability issues (Lansdown 2002; SALS 2007; Sandy et al. 2013). However, studies show that the implementation and execution of these policies has had limited effect on the daily realities of disabled children and their carers (ACPF 2011; DSD et al. 2012; Saloojee et al. 2007; SALS 2007).

Additionally, a legacy of inequality created under apartheid still echoes in South African society. Class, race and gender inequalities still permeate South African society (FFP 2014; Seekings 2010; World Bank 2018), despite government efforts to establish a multi-racial, inclusive ‘rainbow’ nation (Muyeba and Seekings 2010; STATS SA 2014; World Bank 2014). Recent statistics show that “64.2 percent of black South Africans were poor in 2015, compared with 41.3 percent of colored, 5.9 percent of Indian, and 1.0 percent of white South Africans” (World Bank 2018: 22). Though a strong upward mobility of black people has been seen since the end of apartheid (Nattrass and Seekings 2005), an underclass comprised of mainly black individuals and families, in particular women, children and people with disabilities still exists (Kane 2009; Seekings 2014; World Bank 2018). Despite major investment in social development after 1994, these people have limited access to social services. Moreover, as observed by the African Child Policy Forum (ACPF) (2011) “the public health system (…) is overburdened and understaffed; social development safety nets are overstretched; and the education system is struggling to provide quality education for the majority of learners” (5).

Khayelitsha in particular is a resource-poor urban settlement with high levels of violent crime and poverty (Cluver and Orkin 2009; Super 2015). It “is an overcrowded mix of formal housing and informal (shack type) houses, but most residents are poor and live in corrugated iron shacks without running water. Unemployment rates in the area lie around 51%” (Venkataramani et al. 2009: 3). Khayelitsha is known to be an economically
and spatially segregated area. This segregation vastly influences the social, economic and political possibilities for Khayelitsha residents (Du Toit and Neves 2007; Seekings 2013; Thompson et al. 2014).

**Qualitative, ethnographic approach**

As part of the PAR project, several qualitative and ethnographic methods were used throughout the study with 30 participants. In the first phase of the project, 15 semi-structured interviews and 24 (creative) group sessions were conducted to explore mothers’ daily activities, challenges and contexts. Shared analysis and further discussions shed light on the highly complex nature of caring for a disabled child in a resource-poor urban settlement (Chapter 6).

As the PAR project progressed, more creative group and action sessions were held and additionally, extensive participant observation during all sessions and during informal time spent with the mothers occurred. Through this PAR process based on interviews (n=15), group sessions (n=30), and participant observation, the women and myself collaboratively came to an understanding of their agency, that is how they adapt, react and act within their context. This is discussed in Chapter 7.

**Participant observation**

To reflect on the question of how change for wellbeing does and does not occur, the interventional phase draws mainly on extensive participant observation, including, but not limited to, informal interviews, direct observation, and collective discussions. Both during the more formal gatherings of the PAR process and the numerous informal occasions I shared with the women, participant observation proved invaluable for this study, helping provide detailed and in-depth data on the mechanisms working against and for social change. In addition, as the famous pioneer in participant observation William Whyte (1943) stated, it yielded “answers to questions that I would not even had the sense to ask if I had been getting my information solely on an interviewing basis” (808). This rich set of observation data was supplemented by data from eight interviews and one group session conducted close to the end of the project. These qualitative methods gave room to (collectively) reflect on the processes and outcomes of the participatory action research project, and to validate the observations made (Chapter 8).
3.4 STUDY RESPONDENTS AND SAMPLING

In both case-studies, in Zimbabwe and South Africa, respondents were sampled through the help of one local disability organization. These organizations were chosen and contacted after intensive scoping of the local disability and care landscape by means of internet searches, reviewing academic and grey literature, and informal interviews with academics and professionals from the field. The fact that I had been living in both countries prior to the start of the studies provided ample time to familiarize myself with and approach relevant stakeholders in the field.

Both organizations were more than willing to assist with the studies as they recognized the general lack of support for parents with children with disabilities. They provided me with contact lists of parents of disabled children living in the area which would otherwise have been unavailable due to the lack of data on children with disabilities in Southern Africa. Moreover, they were able to assist with practical matters such as recruiting local translators, providing transport, and securing study locations. Working in collaboration with these organizations however also meant limitations in terms of flexibility in time schedules, available resources and sampling. In an attempt to counter the sampling limitations, in South Africa, snowball sampling was initiated to also recruit carers from the wider community who had no links to a disability organization.

In both countries, a variety of female carers participated. Most carers were the biological mother to the child; others included stepmothers, grandmothers, aunts and sisters. The majority of female carers were under 40 years old, had not been educated beyond secondary school, and had an average income of only €100, = per month. Among the children, the gender ratio was skewed towards boys, particularly in Zimbabwe. This might be related to the ‘strong gender dimension to the stigma and discrimination experienced by children with disabilities’ (ACPF 2014: 36). Girls with disabilities often receive less support, are more prone to neglect, abuse and violence, and are generally treated unequally. Female carers of boys might have been more eager to participate in order to support him than carers of girls with a disability. The children presented with various types of disabilities with physical disabilities being the most prevalent (either or not caused by cerebral palsy). The majority of children were between the ages of 6 and 15 years old. Further specificities are presented in the relevant chapters.
3.5 SCIENTIFIC VALIDITY

There is a close and mutually dependent relation between ethics and scientific validity; this is especially so in order to ensure that no exploitations are taking place under the aegis of research (Khanlou and Peter 2005; SRA 2003). However, systematic and rigorous methodological processes in qualitative research and action research are confounded by their in-depth, close-up and participatory nature respectively. Rather, validity in these types of research “is based on checks to ensure that the outcomes of research are trustworthy” (Stringer 2007: 57, italics in original). Therefore, this study has ensured trustworthiness by establishing credibility, transferability, dependability and confirmability (Thomas and Magilvy 2011).

In Zimbabwe, preliminary results of the qualitative methods were validated through a feedback meeting with the involved NGO. Moreover, the use of a mixed methods approach, through which sub-questions were addressed in several methods with a wide variety of stakeholders, provided for extensive data triangulation and herewith enhanced the validity of the responses. One local research assistant was qualified in conducting scientific research; the other had extensive practical experience with disability on the ground. The questionnaire was developed by breaking down wellbeing concepts based on disability and care literature. It was pre-tested by two program managers of the involved NGO and two mothers, and adapted accordingly.

In South Africa, the PAR project presented its own validity concerns. PAR intrinsically embeds a researcher in the research context. This form of research provides crucial in-depth knowledge. At the same time, it questions researchers’ capacity to observe and analyze this context. However, the nature of PAR, being participatory and reflexive, ensured a continual process of data gathering, shared analysis, and collective reflection with the participants, hereby strengthening validity of all responses. In essence, without internal validation a PAR project can hardly be successful (Melrose 2001). In addition, several informal meetings with other stakeholders such as NGOs, local academic researchers and non-Khayelitsha mothers supported data triangulation and strengthened the credibility of the study. Prolonged observation and extensive informal time spent with the mothers established deep levels of trust and respect through which I could engage first-hand with the daily realities they reported on during the formal sessions. This helped confirm the accuracy of their reflections on their experiences.
In both countries, detailed descriptions of the context(s), activities, and procedures of the research process, and a systematic research administration further increased transferability, dependability and confirmability (Stringer 2007; Thomas and Magilvy 2011). Moreover, I kept a personal diary throughout this study which provided me with ample opportunity to reflect and adjust, together with my academic supervisors. Lastly, as a comparable conceptual framework was used in both countries to address issues concerning wellbeing, similarities and differences between countries could be discovered which further validates the results.

### 3.6 ETHICS

Ethical approval for the study in Zimbabwe was granted by the University of Amsterdam, the Netherlands (2011). The South African part of the study was ethically approved by the Senate Research Ethics Committee of the University of the Western Cape, South Africa (2015) (No. 15/2/15). Informative for this thesis were ethical guidelines on conducting social science research, research with human participants, and participatory action research, such as the British Social Research Association Ethical Guidelines (SRA 2003), the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (CIHR et al. 2010) and the Sheffield University SREGP Ethical Considerations in Participatory Research/Participatory Action Research (TUS 2012). Specific ethical considerations pertaining the empirical and action phases in South Africa are described in each relevant chapter.

In general, one of the most important ethical issues faced by development studies and PAR is what Minkler et al. (2002) refer to as, “insider/outsider tension”. Researchers should “realize the extent of the power imbued by their own, often multiple, sources of privilege and how it can adversely affect interactions and outcomes” (2002: 24). As a white female with a Western privileged background, issues of power and powerlessness were an overarching theme throughout the study (Chambers 1997; Tembo 2003). These issues were not overlooked, rather reflected upon, either with the participants or the promotors, and acted upon accordingly. In addition, the following ethical guidelines were observed.

**Informed consent and confidentiality:**

Prior to each method, written informed consent was obtained from the participants and the right to withdraw (without giving reason) and to remain silent were explained and protected (Minkler et al. 2002). Anonymity and confidentiality were guaranteed by the researcher in any physical output of the study, such as presentations and articles.
Also, all participants were asked to promise to keep the information shared in group sessions confidential. In the South African PAR-study, so-called informed process consent through a mutual negotiation process was established (Khanlou and Peter 2005; Rambaldi et al. 2006; Tembo 2003).

Fair subject selection:
The participant’s vulnerability has not determined her acceptance into the study (Khanlou and Peter 2005). This means that no exclusion based on type of disability or level of income occurred. Barriers to participation were reduced by using multiple sources for sampling, flexibility in scheduling, close proximity of research venues and provision of childcare (Minkler et al. 2002).

Compensation for participants:
Following local guidelines, participants received no compensation. However, transportation costs were reimbursed and refreshments were provided. Additionally, during particularly long group sessions, lunch was covered.

Favourable risk-benefit ratio:
At all times, this study adhered to the ethical guideline that research and its outcomes should never surpass the human rights of the participants or put them in jeopardy (De Koning and Martin 1996; Khanlou and Peter 2005; Rambaldi et al. 2006). Besides by emphasizing cultural sensitivity throughout, this was further ensured by involving DPOs and other relevant NGOs prior to the start of both empirical studies for further counseling or assistance if needed.
The state of affairs in Zimbabwe prior to the start of this research (2014) is described here. Significant events have taken place since then in Zimbabwe. They are however not discussed as they have not notably altered the situation for women with disabled children.