



Connecting relational wellbeing and participatory action research: reflections on 'unlikely' transformations among women caring for disabled children in South Africa

Elise J. van der Mark, Teun Zuiderent-Jerak, Christine W. M. Dedding, Ina M. Conradie & Jacqueline E. W. Broerse

To cite this article: Elise J. van der Mark, Teun Zuiderent-Jerak, Christine W. M. Dedding, Ina M. Conradie & Jacqueline E. W. Broerse (2023) Connecting relational wellbeing and participatory action research: reflections on 'unlikely' transformations among women caring for disabled children in South Africa, *Journal of Global Ethics*, 19:1, 80-104, DOI: [10.1080/17449626.2023.2186468](https://doi.org/10.1080/17449626.2023.2186468)

To link to this article: <https://doi.org/10.1080/17449626.2023.2186468>



© 2023 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group



Published online: 22 Mar 2023.



[Submit your article to this journal](#)



Article views: 719



[View related articles](#)








[View Crossmark data](#)

RESEARCH ARTICLE



Connecting relational wellbeing and participatory action research: reflections on ‘unlikely’ transformations among women caring for disabled children in South Africa

Elise J. van der Mark ^{a*}, Teun Zuiderent-Jerak ^a, Christine W. M. Dedding ^{a**}, Ina M. Conradie ^b and Jacqueline E. W. Broerse ^a

^aVU University Amsterdam, Athena Institute, Amsterdam, The Netherlands; ^bUniversity of the Western Cape, Institute for Social Development, Bellville, Cape Town, South Africa

ABSTRACT

Participatory action research (PAR) is a form of community-driven qualitative research which aims to collaboratively take action to improve participants’ lives. This is generally achieved through cognitive, reflexive learning cycles, whereby people ultimately enhance their wellbeing. This approach builds on two assumptions: (1) participants are able to reflect on and prioritize difficulties they face; (2) collective impetus and action are progressively achieved, ultimately leading to increased wellbeing. This article complicates these assumptions by analyzing a two-year PAR project with mothers of disabled children from a South African urban settlement. Participant observation notes, interviews, and a group discussion served as primary data. We found that mothers’ severe psychological stress and the strong intersectionality of their daily challenges hampered participation. Consequently, mothers considered the project ‘inactionable’. Yet, many women quickly started expressing important individual and collective wellbeing transformations. To understand these ‘unlikely’ transformations, a feminist relational account, in particular, that of relational wellbeing, proves essential. We reflect on the consequences of these findings for the dominant PAR methodology and operationalization, and propose to sensitize future PAR with marginalized women by employing relational wellbeing as an overarching ontological awareness.

ARTICLE HISTORY



Received 28 September 2021
Accepted 20 February 2023

KEYWORDS

Relational wellbeing;
participatory action research;
mothers; disabled children;
resource-poor; South Africa

1. Introduction

Participatory action research (PAR) is a form of community-driven qualitative research aiming to collaboratively take action to improve participants’ lives and foster social change. It does so by incorporating people and communities throughout the research process. PAR has many origins and has been influenced by various theories and initiatives,

CONTACT Elise J. van der Mark  elise.vandermark@gmail.com  VU University Amsterdam, Athena Institute, Amsterdam, The Netherlands

*Present Affiliation: Researcher I&O Research, The Netherlands.

**Present Affiliation: VU Medical Centre, The Netherlands.

© 2023 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group

This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (<http://creativecommons.org/licenses/by-nc-nd/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way. The terms on which this article has been published allow the posting of the Accepted Manuscript in a repository by the author(s) or with their consent.

therefore no universal PAR definition exists (Chambers 1997; Darroch and Giles 2014; MacDonald 2012). The underlying overall goal of PAR however, consistent across disciplines, is as Lake and Wendland identify, ‘the improvement of human life’ (2018, 15), or as Nicolaidis and Raymaker phrase it, the improvement of ‘health and wellbeing through action’ (2015, 168).

For this reason, PAR is generally designed as cognitive, reflexive learning cycles, wherein people collectively generate local and relevant knowledge on pertinent issues, design interventions reflecting their daily realities to tackle chosen issues, and subsequently act to ultimately enhance wellbeing (Abma et al. 2019). This approach builds on two assumptions: (1) participants are able to reflect on and prioritize difficulties they face; and (2) collective impetus and action is progressively acquired and achieved, ultimately leading to increased wellbeing. This article complicates these assumptions by analyzing a two-year PAR project with mothers of disabled children from a poor urban settlement in South Africa, who face numerous daily challenges which affect their wellbeing. It reflects on the consequences of these findings for the dominant PAR methodology and operationalization often adopted by the novice PAR researcher and offers an alternative, through an account of relational wellbeing.

2. Central concepts

2.1 Disability, care and poverty

While mothers of disabled children globally experience multiple difficulties in their lives affecting their wellbeing, those living in resource-poor areas face even greater challenges. Women are faced with an intersecting dearth of social, medical and human resources, and problematic gender and care notions, all of which affect their psychological and physical wellbeing (Van der Mark et al. 2017).

As literature is scarce on this topic, professionals and policy makers in low- and middle-income countries often resort to adopting support program-models based on research from high-income countries (ACPF 2014). Given that experiences of mothers of disabled children worldwide are not similar, at best, this approach might ameliorate the situation for women with disabled children in poorer areas despite the lack of applicable studies. At worst, it may entrench neo-colonialist or orientalist perceptions, amount to intellectual laziness and/or cause sticking-plaster politics, and thus be ineffective. For example, the African Child Policy Forum (ACPF) showed that implemented programs such as community-based rehabilitation services for children with disabilities reach a minority of targeted families, as these programs often do not take into account local circumstances such as poor health literacy, lack of access to transport and severe stigma (2011). For good reason, United Nations Children’s Fund (UNICEF) calls for more research on children with disabilities and their families in low- and middle-income countries, and in particular for involving caregivers and their children in research and program design to avoid this pitfall (2013).

2.2 Feminist participatory action research

Participatory action research (PAR) can be a promising avenue for responding to this call. PAR emerged as a response to positivist epistemologies by emphasizing local knowledge production and ‘the explicit goal of research for anti-oppressive social change’ (Nygren

2009, 16). It seeks to expose underlying social, political and ideological processes of inequality by giving voice to the multiply marginalized. ‘Feminist-infused participatory and action research’ in particular seeks to ‘foreground women who live at the intersections of oppressions and social inequalities – or privileges – due to gender, race, class, sexualities, abilities, ethnicities, languages, and other systems of oppression’ (Brinton Lykes and Hershberg 2012, 335). It herewith aims to transform these sources of oppression through empowerment, collective interventions and action.

These interventions come to fruition in PAR through shared cycles of cognitive analysis-action-reflection (see Figure 1). The diagnostic phase entails the process of becoming aware (*conscientização* (Port.) = consciousness raising) or to achieve an in-depth understanding of the world, in particular of unequal political and social conditions, by collectively analyzing daily challenges and prioritizing issues. The planning phase focuses on designing projects to challenge these conditions, whilst the action phase puts these into practice. The reflection phase assesses processes and outcomes of the action projects and thereby informs the subsequent phase. In other words, ‘PAR involves all the relevant parties coming together to study a common problem, devise plans to deal with it and implement these plans’ (Ngwenya 2018, 96). It is a local, participatory, contextual and situated approach set on reducing the researcher’s role and increasing the role of the ‘researched’ (Khanlou and Peter 2005). *Their* voices and stories become significant and guide the social change process.

As a novice PhD researcher, this article’s main researcher (EvdM, Western, white, female) was triggered by the promises and processes of these feminist-infused PAR characteristics. Having worked as a development official and researcher in Zimbabwe (with mothers of disabled children from Mutare’s townships), she was a proponent of decolonizing research, amplifying local female voices, and social empowerment. From the outset, we acknowledged the general consensus on the ultimate goal of emancipatory PAR being ‘the improvement of health and wellbeing’. Moreover, we aimed to

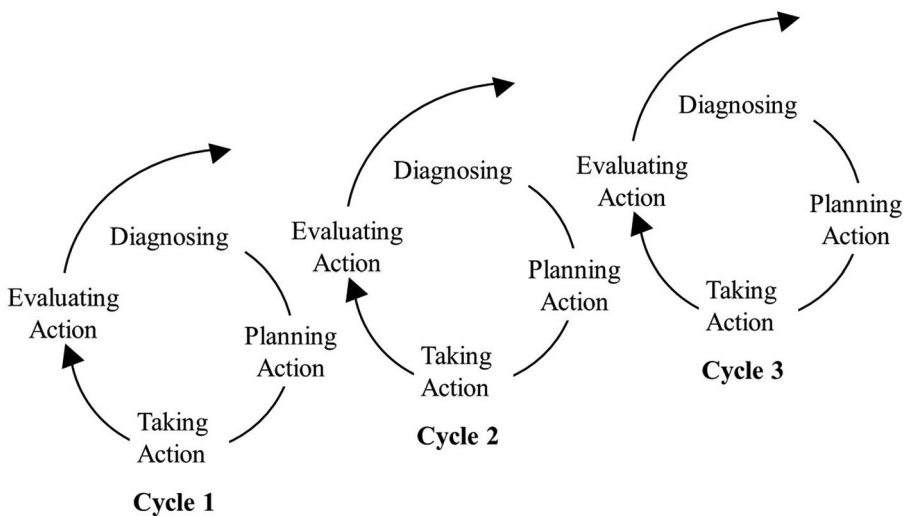


Figure 1. Cycles of PAR.

leave as much of the decision-making on research topic, process, analysis and action plans with the participants. To counterbalance the fact that the researcher(s) initiated the project, we entered the research site respectfully and with care by collaborating with important parties drawing on decades of research experience in the community by the South African co-author (IC). We discussed needs and possibilities with the country's largest NGO for parents of children with disabilities. We conducted a pilot workshop with mothers connected to the NGO to refine needs and co-design techniques and methods. These mothers referred us to two day-care organizations in Khayelitsha. One organization invited us to share our research ideas with parents during a yearly event. Many were enthusiastic, therefore we decided to start recruiting via this day-care organization.

To structure and plan the PhD research accordingly, we formulated two central, yet still very broad, PAR research goals: gaining contextualized knowledge about intersectional oppression of poor mothers with disabled children, and investigating situated mechanisms for wellbeing transformation. Following dominant PAR theory (Israel et al. 2012), we aimed to establish learning cycles of: (1) analysis of their social realities, challenges and influential factors, (2) designing and planning action to tackle these challenges towards a higher wellbeing level, (3) putting these action plans into practice, and (4) analysis and reflection on results and re-planning accordingly. Trust building, an important PAR element, was designed to be fostered during the first phase as the heterogeneity and isolated lifestyles of mothers in Khayelitsha restricted relation building and immersion in the community prior to the project.

2.3 Initial wellbeing conceptualization

With wellbeing as an end-goal in mind, we adopted the wellbeing conceptualization by Gough and McGregor (2007). Their team at the University of Bath designed this conceptualization to understand 'the social and cultural construction of wellbeing in developing countries' (2007, 316). Their wellbeing concept emerged as a response to conventional development frameworks that tend to focus on money-metric poverty measurement. It attempts to integrate poverty notions, such as income poverty, basic needs and capabilities deprivation, into a wider, and methodologically sound concept.

Placing 'people at the center of the picture' (White and Jha 2014, 63), wellbeing is conceptualized as the result of the interaction between available resources, a person's needs and goals, and the value a person attaches to the goals they achieve (McGregor 2006). These components are shaped by societal and contextual relations. We hypothesized that the change objectives women would choose would likely fall under three main wellbeing elements: *resources*, *strategies* and *quality of life*. All three were deemed extraordinarily limited at the project's start (discussed below).

2.4 Mothers in Action project

Two research projects can be distinguished in our PAR-research in South Africa. In this section we introduce the broader two-year Mothers in Action project (MIA) and its methods for the reader to understand the context. Research results from this broader PAR project are presented in previous publications (Van der Mark et al. 2018, 2019).

The additional reflexive study to understand project processes and outcomes informing the current article is discussed in the Methods section.

Our broader participatory MIA-project was executed between February 2015 and February 2017 in a resource-poor part of the urban settlement Khayelitsha in South Africa. Khayelitsha lies at an isolated 25 kilometers from Cape Town. Most of the 400,000 primarily black African residents migrated to Khayelitsha from the rural areas after the apartheid's 'influx control' law was abolished. Khayelitsha is reported to be overcrowded, and scourged with crime, gang violence, and drug abuse (Brunn and Wilson 2013; Terreblanche 2002). 'Poverty is widespread, with the majority of Khayelitsha's residents living cheek by jowl in overcrowded shack settlements, accessing electricity illegally, sharing communal water taps, and relying on grossly inadequate sanitation arrangements (such as outdoor portable toilets)' (Super 2015, 1). Social and medical services are often overstrained, ineffective and inaccessible for most (Vaaltein and Schiller 2017).

Disability prevalence data is scarce. Estimates suggest five to 10.7 per cent of South African children have a disability (ACPF 2011), which would mean 7,500–16,000 in Khayelitsha (City of Cape Town 2013). Stigma and abuse of these children and their mothers are widespread (DSD, DWCPD, and UNICEF 2012). The above characteristics have contributed to most Khayelitsha women bearing the brunt of the family's social and economic survival, thus being both the main caregiver and breadwinner (Budlender and Lund 2011).

For the MIA project, we recruited via a reputable day-care center for disabled children (<https://www.sibongile.org>) and viva voce with carers from the wider community. Thirty isiXhosa-speaking women caring for a disabled child participated (see Table 1 for characteristics), out of 53 carers invited to join. The project included five training sessions (disability types and causes, care in the Khayelitsha context, performing therapy at home, preventing and finding support for sexual abuse), 24 creative participatory group sessions, and numerous intervention sessions (see Appendix 1 for an overview). Where relevant, group sessions were complemented with individual semi-structured interviews. Lastly, extensive participant observation was executed during informal gatherings in Khayelitsha like shared lunches and home visits. This helped to build trust and aided a deeper understanding of mothers' lives.

2.5 Unanticipated turn of events

Although we had substantial reconnaissance prior to the project, and planned flexibly, we had not foreseen the project's start as it turned out. As early as the introductory session, the theory-derived PAR phases proved not to match the reality on the ground. Almost all mothers were overcome with emotion when introducing themselves and their child. It took one mother three sessions before she could speak about herself and her child, and even then, she was constantly in tears. During following interviews and group sessions many mothers continuously struggled to answer questions and participate in creative methods because of their overwhelming emotions. They viewed their whole lives as agonizing and the idea of prioritizing one issue over the other did not do justice to their experience. Moreover, they felt powerless and not inclined to exert any action in their lives which could foster positive change. Consequently, as researchers we feared our PAR-inspired aim to disentangle issues these women faced would not work out. A 'mutual powerlessness' emerged (Broer, Nieboer, and Bal 2014) essentially rendering

Table 1. Characteristics of participating carers and their children of the MIA project.

Carer	#	Child	#	
<u>Age</u>	21–30	<u>Age</u>	0–5	8
	31–40		6–10	8
	41–50		11–15	8
	51–60		16–20	2
	> 61		21–25	4
	Missing	2		
<u>Relation to child</u>	Mother	<u>Gender</u>	Boy	17
	Grandmother		Girl	13
	Sister			
<u>Marital status</u>	Single	<u>Type of disability</u> <i>(in carers words)</i>	Cerebral Palsy	16
	Relationship, Not living with partner		Cannot walk, talk, sit	5
	Relationship, Living with partner		Cannot walk	1
	Divorced		Down Syndrome	1
	Widowed		Blind	1
			Slow learner	1
			Special need	1
<u>Highest level of education</u>	Primary		Spinal cord injuries	1
	Secondary		Left side doesn't work	1
	Vocational Training		Prader-Willi syndrome	1
	College		Mental disability and seizures	1
	Missing			
<u>Number of Householdmembers</u>	Mean			5,1
	Median			5
<u>Average monthly income (ZAR)</u>	< 2000 (± £98,=)			17
	2001–4000			6
	> 4000 (± £195,=)			1
	Missing			6
<u>Most important source of income</u>	Own job			5
	Own income generating activities			2
	Other householdmember's job			4
	Learnership			1
	Social grant			18

the whole situation *inactionable*, a term we coined as a linguistic opposite of Mothers in Action.

However, after three months, many women started expressing changes in their well-being, aptly phrased by Funeka, a mother of a four-year-old girl, during her reflective interview: 'Because of this project, I am a brand new Funeka!' Moreover, after two years, several women became a collective of passionate change makers who registered their own non-governmental organization (NGO) and published a book for disabled children. How could a seemingly 'inactionable' project, a 'failing' initiative, result in such

tangible positive outcomes? Which change mechanisms were underlying this ‘unlikely’ shift? In other words, how did women manage to overcome their individual emotional states, engage with the PAR project and collaborate towards improved wellbeing in their chosen form; and how could such changes take place before we thought the (collective) action element of the first PAR-cycle was taking place?

We explore answers to the questions above by first discussing our reflexive study methods. Then we take a closer look at the ‘inactionable’ circumstances and the manifestations of change towards wellbeing. Finally, we indicate which mechanisms were drivers for change, reflect on our role as researchers in this process, and discuss what these imply for PAR theory and for using PAR to enhance wellbeing in vulnerable circumstances.

3. Methods

3.1 Reflexive study data collection

To assess change processes within the Mothers in Action (MIA)-project, we studied three data sets in our reflexive inquiry: fieldnotes, a group interview and individual interviews. This provided for both data and methodological triangulation. For two years, participant observation fieldnotes were written during and after all PAR-sessions and informal meetings (for example, group lunches and house-visits). To supplement fieldnotes, qualitative data collection on project activities, mechanisms and outcomes occurred between October 2016 and February 2017. The main researcher conducted eight semi-structured interviews and a group interview with five core group participants (see sampling below). Interviews and the group interview were executed in both English and isiXhosa, with one English-speaking participant functioning as translator where necessary. All interviews and the group interview were recorded.

3.2 Reflexive study sampling

Five core participants (board members of the established NGO) were asked and agreed to participate in this reflexive inquiry. Other (previous) participants were recruited based on voluntary response (purposive sampling). Aiming explicitly to understand the positive shift mothers made, we included only participants who attended a minimum of eight of 24 data collection sessions. Six participants matched this inclusion criterion. Three responded positively and were interviewed. All three had left the project; two left Khayelitsha and one took maternity leave during the project (see [Table 2](#) for characteristics).

3.3 Reflexive study data analysis

Ethnographic content analysis was applied to synthesize ‘insider’ participants, and ‘outsider’ researchers insights (Geertz 1973; Morse 1994) to understand context-specific experiences. Two native isiXhosa language scholars translated the data from isiXhosa into English whilst transcribing verbatim in English. An independent third scholar assessed transcriptions at random for correctness, accuracy and quality. The field notes, reflective interviews and group interview were inductively coded using Atlas.ti. Selective thematic coding was applied to understand negative and positive effects, occurred changes,

Table 2. Characteristics of participating women (n = 8) of additional inquiry, out of 30 participants of the MIA project.

	Age	Age child	Type of disability (<i>in carer's words</i>)	Marital Status	Highest level of education	Average monthly income (ZAR)	€ equiv.
Mother	36	5	Cerebral Palsy	Single	College	Missing	
Grandmother	55	15	Cerebral Palsy	Widowed	Secondary	Missing	
Mother	25	5	Cerebral Palsy	Living with partner	Primary	1410	82
Mother	45	9	Prader Willi syndrome	Living with partner	Secondary	1500	87
Mother	51	11	Cannot walk, talk, sit.	Single	Secondary	2700	157
Mother	36	3	Left side doesn't work	Living with partner	Secondary	3500	203
Mother	24	4	Cerebral Palsy	Single	Secondary	2000	116
Mother	30	8	Cerebral Palsy	Living with partner	Secondary	1410	82

reasons for change, project processes and reasons for inaction. Changes and processes witnessed during the wider PAR project (field notes) were triangulated with changes and explanations mentioned in the interviews and group interview. Similarly, individual interpretations discussed during interviews were triangulated with the group interview data. Then, code-cooccurrence and query analysis was used to examine relations between themes to analyze underlying assumptions and change mechanisms. Throughout, all four supervisors (TZJ, IC, CD, JB) engaged in auditing the analysis by reflexive discussions with the main researcher and critical appraisal based on their own expertise.

3.4 Ethics

The University of the Western Cape's ethics committee granted ethical approval (No. 15/2/15). As is common in PAR, informed consent was a bi-directional process; an ongoing negotiation process between researchers and participants (Khanlou and Peter 2005). In addition, participants signed informed consent letters which emphasized anonymity and confidentiality and their rights to remain silent or withdraw. To reduce participation barriers we guaranteed proximate research venues, flexibility in scheduling and childcare provision (Minkler et al. 2002). We relied upon mental health, sexual and domestic violence and disability professionals for referral purposes.

4. Results

First, we briefly discuss mothers' living conditions and experiences to set the stage. Then, we describe the two entwined challenges rendering the project 'inactionable', followed by the 'unlikely' individual and group transformations. Lastly, we show which drivers for change enticed mothers to move beyond their challenges and focus on action.

4.1 Status quo

Most mothers in Khayelitsha face numerous personal, communal and societal challenges on a daily basis. They experience a profound lack of community and family support,

tremendous difficulty to afford and access (para-) medical services, and limited financial stability. This results in poor basic needs provision. Persistent (disability-related) discrimination and (domestic) abuse force the majority to choose an isolated life at home, with minimal external contacts (motivated by their notion of good motherhood and faith). Consequently, mothers' psychological and physical wellbeing are affected; many experience high stress levels, emotional pain, worry, continuous fatigue, headaches, muscular pain and more severe stress-related diseases such as high-blood pressure. Lastly, many mothers portray a sense of resignation to this complex reality. They tend to accept life's struggle and do not expect anything to change in their life (for a detailed description of women's experiences and their context, see Van der Mark et al. 2018). From this starting point we initiated the MIA project and invited women to participate.

4.2 Encountering the 'inactionable'

Initially, when the project took off, women did not respond to the idea of working towards action for change as a group. They stated it was not clear what sort of action the researcher meant and how *the researcher* thought *she* was going to achieve any change. Most mothers emphasized nothing could change in their life because 'people don't care', for example neighbors, public transport drivers, teachers and government. Their resignation towards life and expecting precious little from the future ran as common threads through their narratives. When asked in one of the first group sessions what they would like to change in the future, Aphiwe said: 'We just don't think about it anymore. It is painful. This is what it is' (Session).¹

Two factors influenced mothers' particular outlook on life and their reluctance to engage in an action project. First the profound intersectionality of daily life challenges became apparent during some creative methods introduced during the PAR diagnostic phase. The applied methods to incite conversation, debate and reflection included ranking basic needs by assigning dots, ranking caring strategies by pyramid, photo voice and peer interviews. For example, when ranking daily resources, mothers were asked to select five pictures representing resources such as education, transport and medical assistance they felt were most important to them and their child (see Figure 2). They were invited to divide ten dots among the five pictures, ranking them from their most needed resource to the least needed. In a final column they indicated their ability to fulfil the need in their current life, using the terms 'Yes', 'No', and 'A Little'.

We then invited mothers to ask each other questions about their sheets. However, most mothers assigned two dots to each category, not prioritizing one need over the other. Some women divided the dots in uneven numbers, for example Noluthando in Figure 2. Yet when asked why she had given five dots to medical assistance, she replied: 'Because I had five dots left, after giving the others a few dots' (Session). At first, we assumed we explained the method unclearly. However, as we probed further into the matter, mothers stated their whole life is troubled. Distinguishing between one issue or the other was impossible. Nceba explains:

It is sort of like a circle, things we are doing on a daily basis. For example, going to R. (hospital) and having to take a taxi, having to meet grumpy people on the road who are not able to help you [...]. Because those are the things we get to live in our daily lives. (Session)

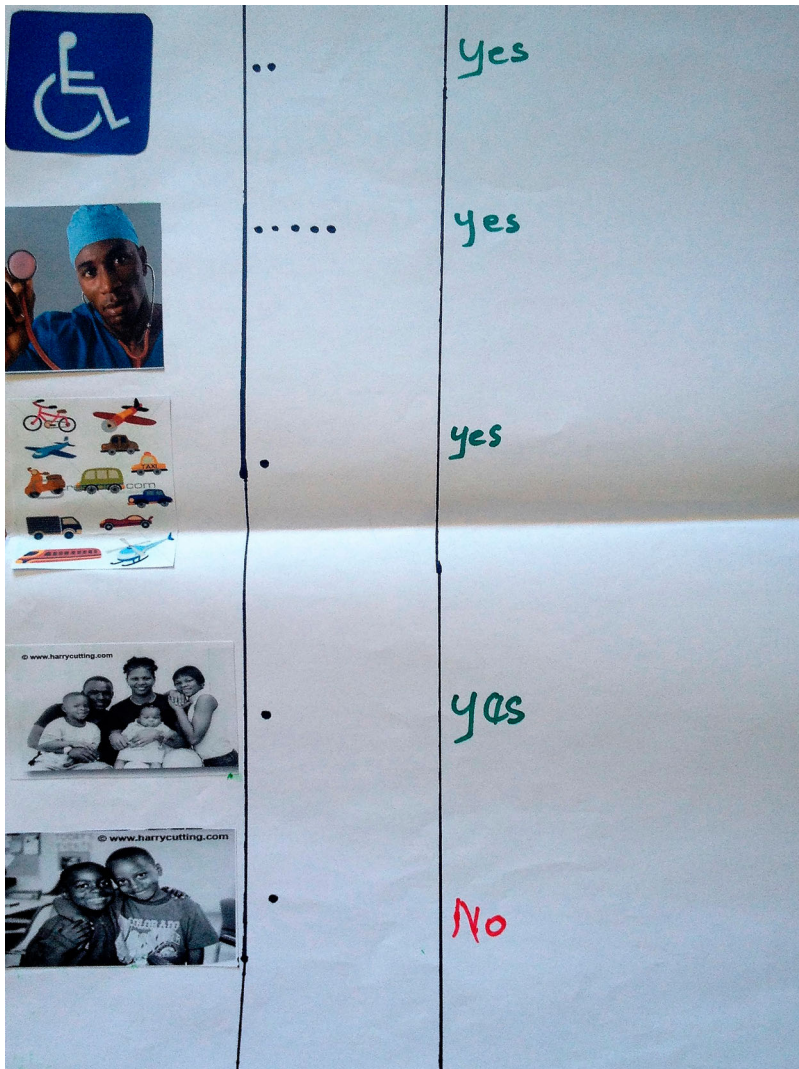


Figure 2. Ranking resources and needs example.

How could they argue the quality of medical assistance is troubling them the most, when they cannot access transport to get to a hospital in the first place? For example, some cannot get to the taxi stands with their child’s wheelchair through the sandy roads in front of their house, while others who can reach the taxi stand, are often scolded at and not accepted into the taxi bus by the drivers. Similarly, how could accessing transport be assigned to be the most troublesome, when going outside to access transport also means dealing with severe discrimination from neighbors and passersby? The intersectionality of their challenges thus came into full view and incited feelings of powerlessness. As researchers we felt they had a real point in treating their troubles as interrelated while we also struggled with the problems this provided for going through the four PAR phases.

Our proposal to conduct peer interviews brought a second influential factor forward, namely mothers' intense, negative emotions as discussed in the Introduction. We invited mothers to participate in data collection to enact the PAR ideal of working with co-researchers rather than treating them as mere research participants. We suggested that interviewing other women with a disabled child could provide a more comprehensive overview of daily challenges as well as an opportunity for others to become involved in the project. Yet most mothers reacted reluctantly. Their reluctance was explained by Anathi during an informal lunch: 'I really don't know what to ask such a person. I am not an interviewer. And I have enough problems of my own. How can I help her, I can't even help myself' (Fieldnotes)? Even though we planned to equip mothers with interviewing skills, their emotional state of mind seemed to be the biggest barrier as most were overcome with emotion while discussing their lives. Experiencing life as one giant cluster of problems, life for them became emotionally overwhelming, and overwhelmingly emotional. As three women stated while reflecting on the project's start:

- Lulama: I used to feel lonely and didn't know what to do with my life (Interview).
Funeka: At first, I didn't really have a life. I didn't even think about looking for a job because I have this child. I was just very troubled (Interview).
Nceba: I mean, at first [before the project], I used to cry. I used to cry a lot (Interview).

Due to this 'inactionable' situation of intersectionality and severe stress, the foreseen first two PAR-phases to disentangle and prioritize challenges, and design action plans did not work out. Mothers emphasized their more important need to just talk with each other and share and receive information (including from experts). It forced us all to critically reflect on and adjust our approach and methods.

4.3 Individual transformations towards wellbeing

Despite the 'inactionable' circumstances, mothers wanted to continue with the group sessions to talk, share and learn, yet without a specific focus on analyzing issues or individual and/or collective change. However, gradually, signs of individual transformation and wellbeing enhancement came to the fore, even though no diagnosing or action planning had yet taken place. Two striking examples were Funeka and Fundiswa's stories. Funeka had talked about how abusive her husband was. She indicated the group sessions were, apart from informative, a temporary relief from her family situation. She always came half an hour early and was the last to leave together with her four-year-old daughter. She mostly kept quiet, and only spoke when addressed directly. One day, she did not show up to a group session and instead phoned during the session. She explained she had left her husband and moved in with her cousin living far from Khayelitsha. She would not be able to attend the sessions anymore, but at least, she said, 'my children and myself will be safe' (Fieldnotes). This came as a massive surprise to the other mothers. They burst out laughing and into applause to celebrate Funeka's unexpected 'victory'.

Similarly, grandmother Fundiswa had shared her story on how her adult daughter made her 'life a pain' (Fieldnotes). The daughter refused to care for her disabled child, a 15-year-old with severe cerebral palsy, whilst using his social grant money for going out and drinking. The daughter verbally and physically abused both her mother and her child when drunk. Fundiswa's demeanor was timid and shy, and during her interview

and the first group sessions, she cried continuously. The shock was thus all the greater a few months later when the group learned Fundiswa had gone out on her own to the South African Social Security Agency (SASSA), the social grants distributor. She had demanded the social grant to be put in her name, on her bank account, as she was the child's sole caregiver. Once arranged, Fundiswa felt less dependent on her daughter and her daughter could no longer access the money for alcohol.

Funeka and Fundiswa were just two of the many (grand)mothers who shared similar stories of changes they made in their personal or family spheres during the PAR-project. Anathi managed to apply for a state wheelchair, Bhabalwa started babysitting other children for additional income, and Ndiliswa sent her 'leeching' adult son back to South Africa's Eastern Cape. All this occurred while the group felt like the project had not taken off yet as we had not moved towards any planned action. Similarly, we as researchers felt we struggled to even begin the PAR diagnostic and planning phases (Phase 1 and 2), and therefore, we were far removed from action and ultimately achieving wellbeing enhancement.

4.4 Collective transformations towards wellbeing

Simultaneously, most mothers not only made changes at home, they also became more positive, talkative, active and involved. The idea of collective change began to grow on them. Comments about opening a bakery together or protesting at city hall for better transport were made, resulting in lots of laughter. Women became eager to focus on analyzing and prioritizing their challenges together (Phase 1) to be able to inform intervention planning.

After about seven months, the mothers decided upon a first collective intervention. They agreed to start an income-generating sewing project, as they felt increasing their income would benefit their own and their child's wellbeing the most. Also, a sewing project would yield 'quick results' as two members knew how to sew and were willing to transfer their skills. To achieve this goal, nine active mothers set up several intervention activities, assisted by the main researcher. Four women enrolled in an eight-week sewing course, taught by a local female community leader. Three other women received financial training (four workshops) from a local business woman. Then, the group sought legal counsel to be able to institutionalize their sewing endeavors by setting up a non-profit organization. Furthermore, the mothers invited the main researcher to teach business, project management and administration basics.

As a result of these activities, several months later, the mothers registered their own NGO named Lithemba Organization (meaning 'hope'), aiming to support and empower mothers with disabled children in the wider Khayelitsha community. Under the organization's project wing, they established two independent projects. The first was the sewing business, which received its first order close to the end of the MIA project. Secondly, they created a children's learning book, catered to their disabled children's needs. Their decision to create this book was based on their self-confessed realization, due to gained knowledge on disability, that their children could still learn and grow. Even though this book was not going to change or challenge the injustices they faced, they felt an immense need to take matters into their own hands as none of the children attended special schooling and educational materials for them were scarce. The

mothers focused on the book's content creation and contracting a printing house, whilst the main researcher recruited an illustrator. In January 2017, their children's book was published (100 copies) and distributed amongst all members (see [Figure 3](#) and [4](#)).

So, what triggered the process of change from 'inactionable' to transformative regarding wellbeing enhancement? From feeling emotionally overwhelmed and seeing no possibilities for change to feeling empowered to make individual life-changing decisions? How did Funeka come to leave her husband? And what caused mothers to become a strong collective of change makers?

4.5 How relationality mattered

The most important driver for change mothers reported, a change in and of itself, was emotional transformation: a shift from intense, negative emotions such as grief, anger and despair towards more positive emotions and feelings such as joy, pride and hope. Throughout the process and during interviews, all mothers showed and indicated that emotional transformation occurred and *needed* to occur prior to even thinking about life's issues and targeted individual and group action, and that such transformation only became possible through forming this group. Unanimously mothers attributed their emotional transformation to two processes; their increased

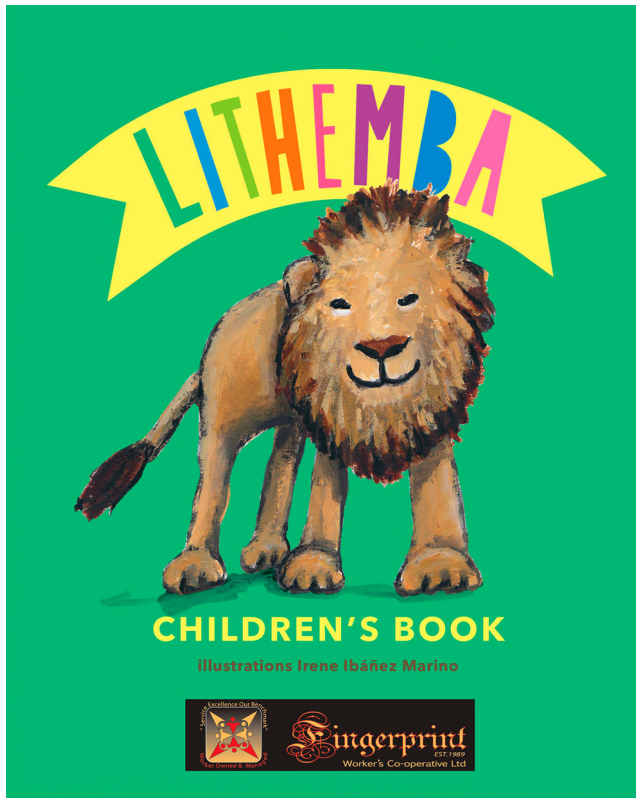


Figure 3. Cover Lithemba book.

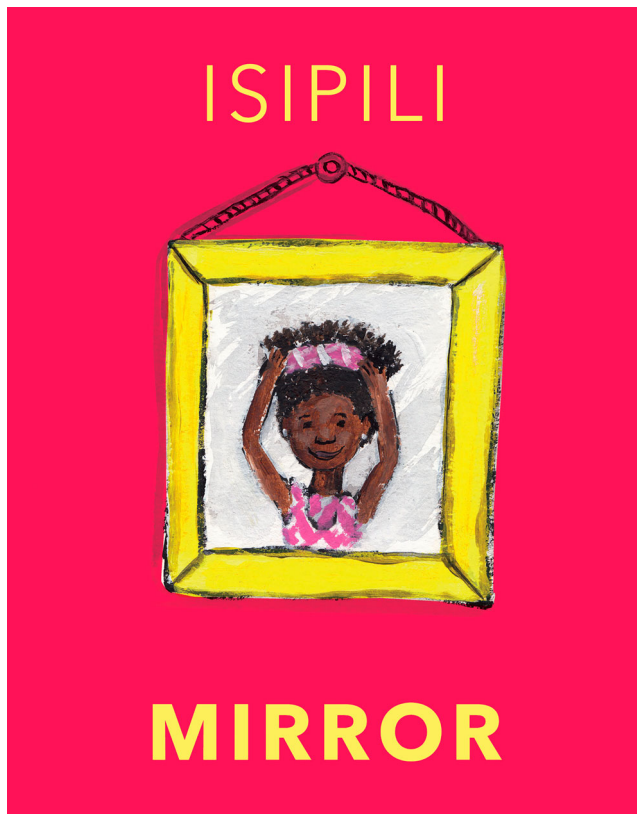


Figure 4. Page Lithemba book.

disability knowledge, and the relationality that evolved through sharing their stories with other women.

In PAR, collective knowledge generation is known to bring people closer, build group confidence, and provide a clearer vision. What is less well-known is the capacity of knowledge generation to contribute to individual emotional transformation and thereby to enhanced wellbeing itself. Women cultivated personal strength and a more hopeful and positive outlook on life and slowly shifted their thinking on disability through the knowledge gained during our expert training and creative method workshops and by sharing their own experiential insights with each other.

- Lulama: What can I say? Oh, I used to cry a lot but I'm fine now. I used to cry to the point when I couldn't even speak. So, I'm stronger now, because of the knowledge I gained (Interview).
- Ndiliswa: It [the training workshops] was very necessary because all those opened our eyes and mind. We didn't know about most of the stuff they told us about. [...] As we get those, we gain strength (Group Interview).
- Funeka: I never thought I'd be this strong and confident while I have this disabled child. I always thought there was nothing I could do with my life (Interview).

Similarly, sharing stories with other people facing the same life challenges, forming new affective relationships, and the resulting trust and peer support are well-known in PAR.

This commonly occurs during the diagnostic phase and brings about positive change. The mothers, however, did not want to engage in analysis and prioritization activities. The intense, psychological stress was so significant, it demanded an emotional transformation process *prior* to any formalized PAR activities. Emotional transformation therefore became arguably the project's most important aspect. As shown above, these emotional changes would not have occurred if the women had not acquired more information and knowledge about disability, thus facilitating a thinking-feeling transformation. Additionally, through new relations, mothers realized they were not the only one with a disabled child and they could share their experiences, thoughts and feelings without being judged. This fostered a process of healing and acceptance which sparked a journey of changing perspectives, shifting emotions and personal growth.

- Nceba: [What helped was] basically talking to strangers. Now they are sort of part of my family because they are people I can speak to comfortably and not fearing anything and not fearing any judgements (Group Interview).
- Thozoma: The reason why I kept on coming back was because we kept on talking and I realized I'm not the only one with a child like this. It made me stronger. I had already given up hope but it made me really realize other people actually go through worse than myself (Interview).
- Zimkhita: When I came and met you, I just found people who have the same problem as mine. So, I felt that I've got a lot of support because sometimes having that baby gets stressful and you don't know how to treat her sometimes; you become angry. When I met with the group, I gained confidence and I love my daughter too much now (Interview).

With vigorous passion, all interviewed mothers expressed hope, positivity, and greater love towards their child after the project. They argued this deeper positive shift within themselves created a foundation for their confidence and mental strength to grow and act. Fundiswa and Funeka attributed their individual actions and decisions to this emotional transformation process. Consequently, mothers identified emotional transformation brought about by changed disability perceptions and the formation of affective relations as a necessary enabler of being willing to critically assess challenges, seeing possibilities for change, awareness of their level of control and a belief in the future.

- Nceba: I think basically being with people that are going through the same challenges that you are going through helps in a way. I won't say it was the first step but basically, it has helped me also towards taking control (Interview).
- Funeka: The project has showed me I still have a future. It made me realize that this is not all there is to my life. I do not have to just stay with my child and be lonely. There's more I can do with my life, you understand? (Group Interview)
- Ndiliswa: At first, I used to question God about why He gave me this child in the first place because He knows I have a lot to do; how was I to do all that with this child? Why didn't He give this child to someone with nothing to do? After the counselling, I realized I'm not the only one and God didn't make a mistake, because I am able to take care of her (Interview).

So, by temporarily forgoing the diagnostic and planning phase (Phase 1 and 2) and letting the process unfold, knowledge generation and sharing stories cultivated emotional transformation. This turned out to be an important wellbeing change in its own right. Indeed, it became the main facilitator for further individual wellbeing transformations, group confidence and a clear vision for the future – the last two being prerequisites for targeted

participatory interventions. Without this emotional shift through relationality, mothers asserted they would not have been willing or able to ‘transform wellbeing’.

5. Discussion and conclusions

In this article, we reflexively assessed our two-year PAR-study called Mothers in Action (MIA) in resource-poor area in South Africa. We explored how women caring for a disabled child were able to increase their own and their child’s wellbeing. The women and researchers encountered a ‘mutual powerlessness’ and an ‘inactionable’ situation at first. Yet, a puzzling mix of individual life changes started soon after the preparation, and a group of women ultimately became a strong collective of change makers. Our main interest lay in understanding how this remarkable shift could occur.

5.1 Limitations

One limitation of our methods is that we only investigated change dynamics with women who responded to our invitation, and secondly, attended many sessions. This selection of women means we cannot assess whether the project fostered these positive changes with women who attended less often, and/or women who left the project without notice. Moreover, we can only speculate about their reasons for leaving. Khayelitsha is an area with high migration patterns, meaning residents move in and out of the area as well as within the 38km² area. This might explain the great difficulty we had contacting women who left the group without notice. Our results should therefore not be interpreted as relevant to all South African mothers of disabled children living in poverty. However, bearing in mind the considerable time invested in this research and the extensive participant observation, we believe it provides a credible view of caring for a disabled child in Khayelitsha and the (im)possibilities for change.

5.2 Reflections

Reflecting on our two-year PAR project, mothers’ severe psychological stress and the strong intersectionality of their daily life challenges stand out. Both factors appeared to render the project ‘inactionable’, while shedding light on the severity of marginalization these women experience. Initiating a PAR project with participants experiencing such severe marginalization and stress is insufficiently problematized within PAR theory. As PAR is focused on collaboratively tackling challenges and fostering social change, a certain degree of emotional story-telling is expected during the diagnostic phase (Johnson and Johnson 2003). Yet, the level of distress the Khayelitsha women experienced at the start, which even prevented some from introducing themselves, and therefore the required emotional transformation, is not something one prepares for in PAR. The initial ‘inactionability’ highlights how the cognitive, sublinear (although reflexive), PAR learning cycles (Israel et al. 2012), wherein people engage to analyze collective challenges and formulate action plans to tackle those challenges, did not immediately fit the context and the women’s experiences.

The unavoidable PhD/PAR tension, i.e. adhering to academic requirements vs honoring women’s voices, might have, as Sutton and Kemp (2006) suggest, influenced

mothers' reluctance, for example introducing certain questions and methods too soon. We focused on assessing and enhancing wellbeing aspects through the four PAR phases, while the women needed affection, connection, recognition, empathy and collective emotional labor. Therefore, we argue that in this PAR project first and foremost a process of what we would like to call relational healing needed to take place prior to any cognitive diagnostic process. Drawing on Hamber's definition of healing, we view relational healing as 'any strategy, process or activity that improves the psychological health of individuals' through relationality (2003, 77). A PAR-principle, namely placing people center stage, provided a starting mechanism for this relational healing. It forced us all, despite feelings of 'mutual powerlessness', to remain flexible by firstly diving into mothers' deeply personal and emotional narratives about life with a disabled child and focusing on increasing their understanding of disability. These helped trigger a process by which women healed individually; but what made healing possible at all was the affective relationality with each other and the researchers through the stories they shared. Realizing they were not alone and being able to share without being judged facilitated a process of changing perspectives, shifting emotions and personal growth.

The story-sharing between these mothers was thus more a highly affective, intuitive and relational healing process than a typical PAR diagnostic 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). Moreover, relational healing turned out to be a *prerequisite* for the subsequent individual and collective wellbeing changes the women established. Their enhanced emotional wellbeing increased their sense of self-efficacy and collective efficacy (Bandura 2000). This in turn fostered agency and motivated them to improve their social, material, and/or physical wellbeing. Indeed, only after this process could collective action interventions in the typical sense be developed. In other words, relational healing had to become a prelude to the PAR cycles as presented in literature.

5.3 Implications

Our MIA-project shows how applying PAR in such a challenging context can aid in enhancing wellbeing, yet in a different way than expected. The sharing of stories was an affective process, rather than cognitive; relational healing occurred and needed to occur; and wellbeing improvement was generated throughout the project rather than an end-result. These findings emphasize the processual nature of wellbeing and the importance of relationality. This implies a need to re-shift our conceptualization of PAR and 'intervening' as a sequential process for improved wellbeing, particularly with traumatized, isolated and/or vulnerable women (see also Kidd et al. 2018). In recent years, a wellbeing formulation has arisen called 'relational wellbeing'. This concept speaks to feminist debates on fostering relationality, also through participatory research practices (Koggel 2013; Madhok 2019). Even though relational wellbeing is 'still emergent as a construct' (White 2015, 18), it seems capable of deepening our understanding of the daily realities and the unexpected transformations in wellbeing.

5.4 Relational wellbeing

Relational wellbeing is commonly theorized as an element of human wellbeing based on human beings' need for connections (see for example Gough and McGregor 2007; Schuhmann 2016, in development studies and psychology respectively). From this perspective, relational wellbeing constitutes the quantity and quality of an individual's social relations. This is similar to how material and physical wellbeing concern the quantity of material resources and the quality of physical health respectively (Huovinen and Blackmore 2016). In this sense, relational wellbeing is derived from the social capital concept, i.e. relationships and networks are assets to an individual (Woolcock and Narayan 2000).

In recent years, however, relational wellbeing has been developed as a wellbeing construct 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 not only human, but by all material, social and environmental relationships.² Through relationality, wellbeing is viewed as something that *happens* and not as something that can be acquired, for example as a PAR-project's final outcome; nor can it be an individual's asset (White 2015). Specific contexts can therefore be understood as either adverse or conducive to producing wellbeing – as 'spaces of wellbeing' (Atkinson 2013, 142). Relationality is regarded as prior to individuals, and wellbeing is, thus, a set of inter-relations in which individuals are embedded:

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 despite a seemingly 'inactionable' setting in which a diagnostic process was hardly achievable.

5.5 Relational wellbeing and the MIA project

Transformation aimed for at the MIA project's start was thought to be a process throughout the study with enhanced wellbeing as an end result based on PAR theory. Because of this conceptualization, the wellbeing changes, e.g. emotional transformation or leaving an abusive husband, which occurred relatively quickly after initiation 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. It helps us to understand why women struggled with disentangling and analyzing their challenges during the eventual diagnostic phase. 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).

A helpful way to look at this web of relations with respect to mothers of disabled children, thereby understanding the importance of conceptualizing wellbeing as relationally constructed, is as a web of *caring* relations. It could be argued that such a web of *caring*

relations with both multiple positive forms of ‘taking care of’ (Tironi and Rodríguez-Giralt 2017), e.g. supportive siblings or financial grants, and negative forms, e.g. disengaged medical professionals and a lack of policies, produces an everchanging landscape of well-being. Mothers thus act and react as relational subjects (Donati and Archer 2015), rather than as objects of inquiry holding a certain wellbeing level. This understanding of wellbeing resonates with feminist relational theory and the ethics of care that positions relationality as emergent and accomplished in practice (Held 2006; Kittay 2011; Koggel 1998; Mackenzie and Stoljar 2000; Tronto 2010). Mothers stand in relation to, for example, gender structures in the wider South African society and respond by internalizing a ‘female responsibility for care’. Likewise, the relation of, arguably, ‘non-care’ between mothers and the South African government, as a product of social policies emphasizing family care rather than state-care for disabled children, hinders wellbeing *production* (Budlender and Lund 2011).

In other words, following Tronto and Fisher’s (1990) care classification and ethical care qualities (Tronto 2010), a changing web of caring *about* (attentiveness), caring *for* (responsibility) and care *giving* (competence) relations shapes wellbeing production. This web of relations shifted the moment mothers decided to join the project. The story-sharing during the project’s early stages can then be imagined as producing new modes of relationality through both self-care and attentive, supportive care (Tironi and Rodríguez-Giralt 2017). Moreover, they did not only form new relations with each other, but also with knowledge structures, disability services, and the researcher, thereby altering wellbeing *production*. The ‘unlikely’ changes thus suddenly become more ‘likely’ when adopting the relational wellbeing conceptualization.

This begs the question why we as researchers did not initially acknowledge the relational wellbeing conceptualization rather than the individual one. This is where we believe the PhD/PAR tension is influential again. Our example shows how when a (novice) researcher designs a PAR project based on PAR theory, methodology and operationalization in literature, which many (Western) novice researchers tend to do, this can turn out to be a very structured, phased and sometimes ‘extractive’ project with wellbeing as its ultimate aim. Even though we anticipated time to build trust, form new relationships and establish collective rapport, there is no denying the four-phase design did not match the reality on the ground.

This PhD-PAR tension was coupled with unavoidable preconceived (academic, white, Western) notions, theories and ideas on how these women were living their lives, what they would need and how the main researcher (EvdM) could assist them in this. Despite being aware of her own limitations in this regard and ‘going in’ with an open mind, there is no denying she had a certain idea on how to ‘care’ for them, namely with a PAR project focused on improving wellbeing as an end-goal. We reveal, however, how her idea of providing care did not match women’s care needs. The main researcher’s focus came to rely on ‘performing’ the four PAR phases and working ‘towards’ action, based on PAR literature. The *relationality* of wellbeing and research largely remains absent in the dominant discourse on PAR and was therefore unexpected.

5.6 Sensitizing participatory action research

The above reveals how a relational ontology viewpoint on wellbeing explains why wellbeing transformations occurred during all project phases, and how the adoption of a

rather theoretical and structured conceptualization of PAR by a novice researcher explains the ‘unlikelihood’ of the transformations. These findings demand a substantial shift in ‘intervening’ for wellbeing through PAR, with intervention becoming a profoundly ‘layered concept and a continuous activity’ (Zuiderent 2002, 59).

The evaluative wellbeing notion which we adopted initially derives from a male-centered, neoliberal (and oppressive) ideology of the free, atomized and independent individual (Sointu 2005). This ‘obscures the innumerable ways persons and groups are interdependent in the modern world’ (Held 2006, 14). Indeed, for long, relational feminists have been arguing for a more socially and politically embedded notion of an individual, and an ethic of care (eg. Held 2006; Mackenzie and Stoljar 2000; Tronto 2017). Relational wellbeing follows this line of thought by pushing towards a notion of care, interconnectiveness and shared responsibility. As Atkinson states:

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 affected. (2013, 142)

This shift has implications for operationalizing wellbeing in PAR. We hereby propose a notion of conceptual sensitivity in future PAR with marginalized women, one that employs relational wellbeing as an overarching ontological awareness. Rather than looking to determine a level of relational wellbeing (if this is even expedient or feasible), or to improve a web of relations, we argue that, particularly during the PAR diagnostic phase, one should be acutely aware of, and conceptually sensitive to how wellbeing is produced through the web of relations surrounding participants, including the research project itself.

The reason we suggest this approach is three-fold. For one, approaching a PAR project with vulnerable women from an ontological perspective of relational wellbeing will aid in viewing, understanding and explaining existent intersectional marginalization and social change processes. This ultimately contributes to insights on which conditions, relations and interventions are beneficial for producing wellbeing, as a way to strive for social justice and reduce marginalization.

Second, acknowledging and ‘following’ relationality can function as a source to address power disparities between researchers and participants. The project shows how despite diversity in backgrounds (geographical, SES, race and age among others), wellbeing was constructed and transformed for both respondents and researchers once the web of relations (material, social, human and environmental) altered. In addition, acknowledging and ‘following’ relationality can break through feelings of mutual powerlessness. By anticipating and trusting the transformative power of relationality, powerlessness can shift towards powerful.

Finally, a relational wellbeing perspective in PAR abates the focus and onus on women to increase their and their family’s wellbeing. Both development and feminist theorists have critiqued the mainstream tendency, including in PAR, 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). A relational wellbeing conceptualization in PAR helps both participants and researchers understand how people’s individual possessions and behavior do not determine 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 women to better their lives hereby fades, and a shared responsibility to foster (caring) relations emerges. In this way, as our MIA-project reveals, PAR can realize considerable change on a local (and individual) level, without denying the myriad of political, cultural or even global factors underlying mother's daily realities (Brinton Lykes and Hershberg 2012). Moving the relational to center stage in participatory action projects with a wellbeing focus can help transform the 'inactionable' into the transformative by fostering a relationally embedded understanding of research and care.

Notes

1. Quotes indicated with Fieldnotes are derived from the wider PAR project. Quotes used from the wider PAR sessions for illustration purposes are designated with Session. Quotes indicated with Interview or Group Interview are stemming from the Reflective Inquiry.
2. We acknowledge the various fields in which relational wellbeing is an important element of the academic discourse, analysis and practice such as community psychology (Sonn et al. 2022), development studies (White 2017) and public health (Von Heimburg and Ness 2021). Each field has its own conceptualization, all on a continuum between an individual and a radical relational ontology. We purposefully use a radical relational standpoint to understand the shifts and transformations which occurred.

Acknowledgements

This work was supported by the European Commission under Grant number 2013-2717/001-001. This publication reflects the view only of the authors, and the Commission cannot be held responsible for any use which may be made of the information contained therein.

Funding

This work was supported by the European Commission: [Grant Number 2013-2717/001-001].

Notes on contributors

Dr Elise J van der Mark is a senior researcher focusing on wellbeing at I&O Research; a company researching governmental and societal issues. She obtained her PhD in a joint trajectory at the University of the Western Cape, South Africa and VU University Amsterdam, the Netherlands. Her research interests lie in PAR, civil participation, relationality, wellbeing, disability, vulnerability and women's empowerment.

Dr Teun Zuiderent-Jerak is Associate Professor of Transdisciplinary Science & Technology Studies at the Athena Institute, VU University Amsterdam. His research focuses on transdisciplinary social studies of health care and medicine. It includes evidence appraisal in relation to different knowledges, knowledge standardization and health care improvement, and technology development for inclusive health and employment.

Dr Ina M. Conradie is a senior researcher and lecturer at the Institute of Social Development at the University of the Western Cape. Her research interests include capabilities and agency; women's organisations; poverty alleviation; action research and social policy.

Dr Christine W.M. Dedding is Associate Professor of Ethics, Law and Medicine at the VU University Medical Centre. Her research interests include participation and co-creation with children and

young people in healthcare, welfare and research; e-health for vulnerable populations; healthcare and agency among the elderly.

Prof Dr Jacqueline E.W. Broerse is Professor of Innovation and Communication in the Health and Life sciences and Director of the Athena Institute, VU University Amsterdam. Her research focuses on public engagement and multi-stakeholder involvement, patient participation and sustainability system innovations; all in the (global) health, food and sustainable development domain.

ORCID

Elise J. van der Mark  <http://orcid.org/0000-0002-2318-7061>
 Teun Zuiderent-Jerak  <http://orcid.org/0000-0003-3008-1297>
 Christine W. M. Dedding  <http://orcid.org/0000-0003-3296-4245>
 Ina M. Conradie  <http://orcid.org/0000-0002-5374-7410>
 Jacqueline E. W. Broerse  <http://orcid.org/0000-0002-8478-3422>

References

- Abma, Tineke, Sarah Banks, Tina Cook, Sónia Dias, Wendy Madsen, Jane Springett, and Michael T Wright. 2019. *Participatory Research for Health and Social Well-Being*. Cham, Switzerland: Springer.
- ACPF. 2011. "Children with Disabilities in South Africa: The Hidden Reality." In: Addis Abeba: The African Child Policy Forum.
- ACPF. 2014. "The African Report on Children with Disabilities: Promising Starts and Persisting Challenges." In: Addis Abeba: The African Child Policy Forum.
- Atkinson, Sarah. 2013. "Beyond Components of Wellbeing: The Effects of Relational and Situated Assemblage." *Topoi* 32 (2): 137–44. doi:10.1007/s11245-013-9164-0.
- Bandura, A. 2000. "Exercise of Human Agency Through Collective Efficacy." *Current Directions in Psychological Science* 9 (3): 75–8. doi:10.1111/1467-8721.00064.
- Brinton Lykes, M., and Rachel M Hershberg. 2012. "Participatory Action Research and Feminisms: Social Inequalities and Transformative Praxis." *Handbook of Feminist Research II: Theory and Praxis*, 331–67.
- Broer, Tineke, Anna P Nieboer, and Roland Bal. 2014. "Mutual Powerlessness in Client Participation Practices in Mental Health Care." *Health Expectations* 17 (2): 208–19. doi:10.1111/j.1369-7625.2011.00748.x.
- Brunn, Stanley D., and Matthew W. Wilson. 2013. "Cape Town's Million Plus Black Township of Khayelitsha: Terrae Incognitae and the Geographies and Cartographies of Silence." *Habitat International* 39: 284–94. doi:10.1016/j.habitatint.2012.10.017.
- Budlender, Debbie, and Francie Lund. 2011. "South Africa: A Legacy of Family Disruption." In *Global Variations in the Political and Social Economy of Care: Worlds Apart*, edited by S. Razavi, and S. Staab, 141–59. United Kingdom: Routledge and UNRISD.
- Chambers, Robert. 1997. *Whose Reality Counts?: Putting the First Last*. London: ITDG Publishing.
- Chant, Sylvia, and Caroline Sweetman. 2012. "Fixing Women or Fixing the World? 'Smart Economics', Efficiency Approaches, and Gender Equality in Development." *Gender & Development* 20 (3): 517–29. doi:10.1080/13552074.2012.731812.
- City of Cape Town. 2013. "Population Profile for Khayelitsha." In. Online: http://resource.capetown.gov.za/documentcentre/Documents/Maps%20and%20statistics/2011_Census_CT_Suburb_Khayelitsha_Profile.pdf: City of Cape Town.
- Darroch, Francine, and Audrey Giles. 2014. "Decolonizing Health Research: Community-Based Participatory Research and Postcolonial Feminist Theory." *The Canadian Journal of Action Research* 15 (3): 22–36. doi:10.33524/cjar.v15i3.155.
- Donati, Pierpaolo, and Margaret S Archer. 2015. *The Relational Subject*. Cambridge: Cambridge University Press.

- DSD, DWCPD, and UNICEF. 2012. "Children with Disabilities in South Africa: A Situation Analysis: 2001-2011." In: Pretoria: Department of Social Development/ Department of Women, Children and People with Disabilities, Republic of South Africa/ UNICEF.
- Geertz, C. 1973. *The Interpretation of Cultures: Selected Essays*. New York: Basic Books.
- Gough, Ian, and J. Allister McGregor. 2007. *Wellbeing in Developing Countries: From Theory to Research*. Cambridge University Press.
- Held, Virginia. 2006. *The Ethics of Care: Personal, Political, and Global*. Oxford University Press.
- Huovinen, R., and C. Blackmore. 2016. "The Dynamics of Relational Wellbeing in the Context of Mobility in Peru." In *Cultures of Wellbeing: Method, Place, Policy*, edited by S. C. White and C. Blackmore, 175–97. London: Palgrave Macmillan.
- Israel, Barbara, Eugenia Eng, A. J. Schulz, and Edith Parker. 2012. "Introduction to Methods for CBPR for Health." In *Methods for Community-Based Participatory Research for Health*, edited by Barbara Israel, Eugenia Eng, A. J. Schulz, and Edith Parker, 3–37. San Francisco: Wiley.
- Johnson, D. W., and F. P. Johnson. 2003. *Joining Together: Group Theory and Group Skills*. 8th ed. Boston: Allyn and Bacon.
- Khanlou, Nazilla, and Elizabeth Peter. 2005. "Participatory Action Research: Considerations for Ethical Review." *Social Science & Medicine* 60 (10): 2333–40. doi:10.1016/j.socscimed.2004.10.004.
- Kidd, Sean, Larry Davidson, Tyler Frederick, and Michael J. Kral. 2018. "Reflecting on Participatory, Action-Oriented Research Methods in Community Psychology: Progress, Problems, and Paths Forward." *American Journal of Community Psychology* 61 (1-2): 76–87. doi:10.1002/ajcp.12214.
- Kittay, Eva Feder. 2011. "The Ethics of Care, Dependence, and Disability*." *Ratio Juris* 24 (1): 49–58. doi:10.1111/j.1467-9337.2010.00473.x.
- Koggel, Christine M. 1998. *Perspectives on Equality: Constructing a Relational Theory*. MD: Rowman & Littlefield.
- Koggel, Christine M. 2013. "A Critical Analysis of Recent Work on Empowerment: Implications for Gender." *Journal of Global Ethics* 9 (3): 263–75. doi:10.1080/17449626.2013.818383.
- Lake, Danielle, and Joel Wendland. 2018. "Practical, Epistemological, and Ethical Challenges of Participatory Action Research: A Cross-Disciplinary Review of the Literature." *Journal of Higher Education Outreach and Engagement* 22 (3): 11–42.
- MacDonald, Cathy. 2012. "Understanding Participatory Action Research: A Qualitative Research Methodology Option." *The Canadian Journal of Action Research* 13 (2): 34–50. doi:10.33524/cjar.v13i2.37.
- Mackenzie, Catriona, and Natalie Stoljar. 2000. *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self*. Oxford University Press.
- Madhok, Bindu. 2019. "The Theory-Practice Nexus of Care Ethics and Global Development: A Case Study from India." *Journal of Global Ethics* 15 (1): 21–31. doi:10.1080/17449626.2019.1582552.
- McGregor, J. A. 2006. *Researching Human Wellbeing: From Concepts to Methodology*. Bath: Economic and Social Research Council.
- Minkler, Meredith, Pamela Fadem, Martha Perry, Klaus Blum, Leroy Moore, and Judith Rogers. 2002. "Ethical Dilemmas in Participatory Action Research: A Case Study from the Disability Community." *Health Education & Behavior* 29 (1): 14–29. doi:10.1177/109019810202900104.
- Morse, J. M. 1994. "Emerging from the Data: The Cognitive Processes of Analysis in Qualitative Inquiry." *Critical Issues in Qualitative Research Methods* 346: 350–1.
- Ngwenya, Dumisani. 2018. "Participatory Action Research." In *Healing the Wounds of Gukurahundi in Zimbabwe*, edited by Dumisani Ngwenya, 95–116. New York: Springer.
- Nicolaidis, Christina, and D. M. Raymaker. 2015. "Community Based Participatory Research with Communities Defined by Race, Ethnicity, and Disability: Translating Theory to Practice." In *The SAGE Handbook of Action Research*, edited by Hilary Bradbury, 167–79. Thousand Oaks, CA: Sage Publications.
- Nygreen, Kysa. 2009. "Critical Dilemmas in PAR: Toward a new Theory of Engaged Research for Social Change." *Social Justice* 36 (4 (118)): 14–35.
- Schuhmann, Carmen. 2016. "Counseling in a Complex World: Advancing Relational Well-Being." *Journal of Constructivist Psychology* 29 (3): 318–30. doi:10.1080/10720537.2015.1102109.

- Sointu, Eeva. 2005. "The Rise of an Ideal: Tracing Changing Discourses of Wellbeing." *The Sociological Review* 53 (2): 255–74. doi:[10.1111/j.1467-954X.2005.00513.x](https://doi.org/10.1111/j.1467-954X.2005.00513.x).
- Sonn, Christopher C., Rachael Fox, Samuel Keast, and Mohi Rua. 2022. "Fostering and Sustaining Transnational Solidarities for Transformative Social Change: Advancing Community Psychology Research and Action." *American Journal of Community Psychology* 69 (3-4): 269–82. doi:<https://doi.org/10.1002/ajcp.12602>.
- Super, G. 2015. "Violence and Democracy in Khayelitsha, Governing Crime Through the 'Community'." *Stability: International Journal of Security & Development* 4 (1): 1–20. doi:[10.5334/sta.ft](https://doi.org/10.5334/sta.ft).
- Sutton, Sharon E., and Susan P. Kemp. 2006. "Integrating Social Science and Design Inquiry Through Interdisciplinary Design Charrettes: An Approach to Participatory Community Problem Solving." *American Journal of Community Psychology* 38 (1-2): 51–62. doi:[10.1007/s10464-006-9065-0](https://doi.org/10.1007/s10464-006-9065-0).
- Terreblanche, Sampie. 2002. *A History of Inequality in South Africa, 1652–2002*. Scottsville: University of Kwazulu Natal Press.
- Tironi, Manuel, and Israel Rodríguez-Giralto. 2017. "Healing, Knowing, Enduring: Care and Politics in Damaged Worlds." *The Sociological Review* 65 (2_suppl): 89–109. doi:[10.1177/0081176917712874](https://doi.org/10.1177/0081176917712874).
- Tronto, Joan C. 2010. "Creating Caring Institutions: Politics, Plurality, and Purpose." *Ethics and Social Welfare* 4 (2): 158–71. doi:[10.1080/17496535.2010.484259](https://doi.org/10.1080/17496535.2010.484259).
- Tronto, Joan. 2017. "There is an Alternative: Homines Curans and the Limits of Neoliberalism." *International Journal of Care and Caring* 1 (1): 27–43. doi:[10.1332/239788217X14866281687583](https://doi.org/10.1332/239788217X14866281687583).
- Tronto, Joan C, and Berenice Fisher. 1990. "Toward a Feminist Theory of Caring." In *Circles of Care*, edited by E. Abel, and M. Nelson, 36–54. Albany NY: SUNY Press.
- UNICEF. 2013. *The State of the World's Children 2013. Children with Disabilities*. New York: United Nations Children's Fund.
- Vaalteijn, Sive, and Ulene Schiller. 2017. "Addressing Multi-Dimensional Child Poverty: The Experiences of Caregivers in the Eastern Cape, South Africa." *Children and Youth Services Review* 76: 227–36. doi:[10.1016/j.childyouth.2017.03.008](https://doi.org/10.1016/j.childyouth.2017.03.008).
- Van der Mark, E. J., I. Conradie, C. W. M. Dedding, and J. E. W. Broerse. 2017. "How Poverty Shapes Caring for a Disabled Child: A Narrative Literature Review." *Journal of International Development* 29 (8): 1187–206. doi:[10.1002/jid.3308](https://doi.org/10.1002/jid.3308).
- Van der Mark, Elise J., Ina Conradie, Christine WM Dedding, and Jacqueline EW Broerse. 2018. "Exploring Adaptation and Agency of Mothers Caring for Disabled Children in an Urban Settlement in South Africa: A Qualitative Study." *Women's Studies International Forum* 76: 102271. doi:[10.1016/j.wsif.2019.102271](https://doi.org/10.1016/j.wsif.2019.102271).
- Van der Mark, Elise J., Ina Conradie, Christine WM Dedding, and Jacqueline EW Broerse. 2019. "We Create our own Small World': Daily Realities of Mothers of Disabled Children in a South African Urban Settlement." *Disability & Society* 34 (1): 95–120. doi:[10.1080/09687599.2018.1511415](https://doi.org/10.1080/09687599.2018.1511415).
- Von Heimbürg, Dina, and Ottar Ness. 2021. "Relational Welfare: A Socially Just Response to co-Creating Health and Wellbeing for all." *Scandinavian Journal of Public Health* 49 (6): 639–52. doi:[10.1177/1403494820970815](https://doi.org/10.1177/1403494820970815).
- White, Sarah C. 2015. "Relational Wellbeing: A Theoretical and Operational Approach." In *Bath Papers in International Development and Wellbeing*, edited by Susan Johnson, and Althea-Maria Rivas. Bath: The Centre for Development Studies, University of Bath.
- White, Sarah C. 2017. "Relational Wellbeing: Re-Centring the Politics of Happiness, Policy and the Self." *Policy & Politics* 45 (2): 121–36. doi:[10.1332/030557317X14866576265970](https://doi.org/10.1332/030557317X14866576265970).
- White, Sarah, and Shreya Jha. 2014. "Inner Wellbeing: The Wellbeing and Poverty Pathways Approach." In *Wellbeing and Quality of Life Assessment. A Practical Guide*, edited by Sarah White, and Asha Abeyasekera, 55–76. Warwickshire: Practical Action Publishing.
- Woolcock, M., and D. Narayan. 2000. "Social Capital: Implications for Development Theory, Research, and Policy." *The World Bank Research Observer* 15 (2): 225–49.
- Zuiderent, T. 2002. "Blurring the Center: On the Politics of Ethnography." *Scandinavian Journal of Information Systems* 14 (2): Article 9.

Appendix 1

Table A1. PAR-sessions how they occurred (not how they were planned).

Session	Content	Techniques (e.g.)	Moderator/Trainer
Training (n = 5)	Parenting a Disabled Child	-	DICAG (NGO for Parents of Disabled Children)
	Causes and Types of Disability	-	DICAG (NGO for Parents of Disabled Children)
	Living in Khayelitsha with a Disabled Child	-	ILISO Care Society (NGO for vulnerable people in Khayelitsha)
	Performing Physiotherapy, Occupational therapy and Speech therapy at Home	-	SENECIO (NGO by therapists to assist disabled people)
	Identifying, Preventing and Finding Support for (sexual) abuse of Disabled Children	-	Thuthuzela Care Centre (NGO for integrated approach to rape care)
Data Collection (n = 12)	Daily activities and contexts	Drawing daily pie-chart Ranking daily activities Drawing social atoms Photovoice Etc.	Participants and researcher
Data Collection (n = 12)	Emerging topics and shared analysis like resignation, domestic abuse, knowledge	Shared discussion and analysis	Participants and researcher
Intervention Design (n = 6)	Planning and designing two action projects	-	Participants and researcher
Implementing Interventions (numerous)	Implementing and executing two action projects including training on relevant topics	-	Local sewing expert, local financial expert, local legal expert, and main researcher